THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS

By

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This thesis is submitted in accordance with the requirements for the partial fulfilment of the requirements in the degree

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Declaration

I, Sharon Anne Aitken, *2012147761,* hereby declare that the dissertation titled *The psychosocial experiences of adolescents with juvenile idiopathic arthritis* that I herewith submit for the Doctoral Degree Child Psychology at the University of the Free State is my own independent work and that I have not previously submitted it for a qualification at another institution of higher education.

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DATE: 12 January 2019

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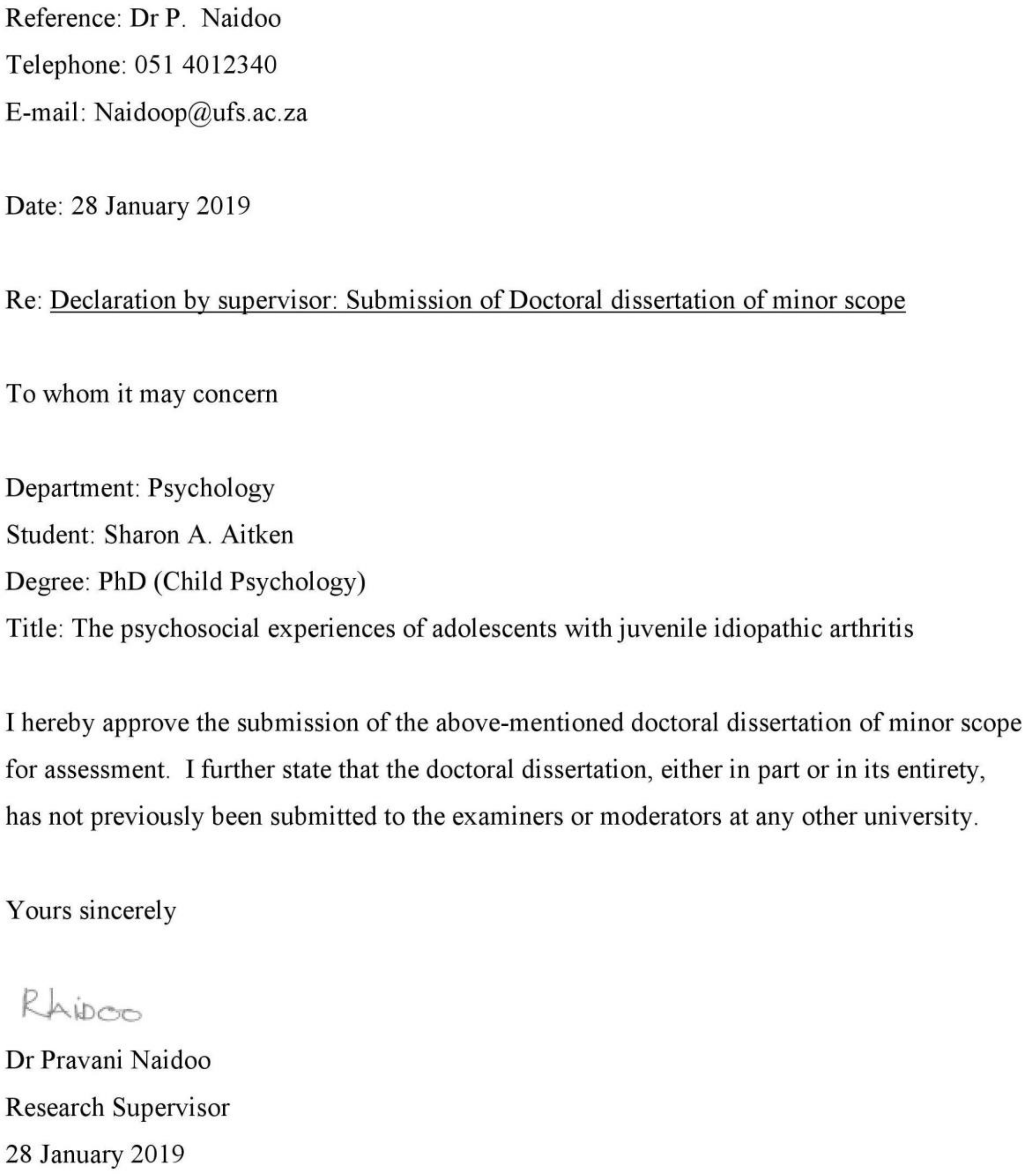

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To whom it may concern

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I hereby approve the submission of the above-mentioned doctoral dissertation of minor scope for assessment. I further state that the doctoral dissertation, either in part or in its entirety, has not previously been submitted to the examiners or moderators at any other university.

Yours sincerely

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To whom it may concern,

It is hereby confirmed that the dissertation document outlined below has undergone language editing by myself, Esley van der Berg. I am a language editor employed by Melody M Consulting.

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Kind regards,
Esley van der Berg

Signed: EvdBerg

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I would encourage readers of this doctoral dissertation who are not familiar with the debilitating nature of chronic fatigue to first read Christine Miserandino's "The Spoon Theory"[1] *before commencing the reading of the dissertation. "The Spoon Theory" has enabled many people to describe their experiences of chronic fatigue to significant others in a manner that facilitates empathy.*

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[1] Available from: https://butyoudontlooksick.com/category/the-spoon-theory/
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Abstract

The aim of this study was to explore and describe the psychosocial experiences of South African adolescents with juvenile idiopathic arthritis (JIA). Consequently, rich, thick descriptions of their experiences and understandings of living with JIA were sought from seven individuals with JIA and their parents and situated within developmental psychopathology and resilience theory.

JIA is one of the most common chronic inflammatory diseases in childhood and adolescence. Notably, it is a debilitating auto-immune disease which has an adverse effect on the biopsychosocial functioning of children and adolescents as it causes high levels of chronic pain and fatigue. Despite an estimated prevalence of 18,700 cases in South Africa, only medical research has been conducted in the field of JIA in this country. Moreover, international psychology studies are mainly pathogenic in stance with only a few studies exploring resilience processes and well-being. In addition, most studies do not differentiate between child and adolescent participants. Hence, there is a need for both international and specifically South African qualitative psychological research that explores both the risk and the resilience processes that impact on adolescents with JIA. More specifically, an exploration of adolescents' understandings of their adaptive processes and the possibility of experiencing well-being in illness is needed.

A multiple case study approach was chosen for this research. The participants were selected from the Western Cape and Gauteng provinces by using purposive and snowball sampling. Each case study consisted of an adolescent participant with JIA whose age ranged between 15 and 18 years of age and a parent participant. Two semi-structured interviews were conducted with the adolescent participants, while the parent participants were interviewed once. Thereafter, the data was analysed in a twofold, iterative process that made use of multilevel and thematic analyses. The final stages of analysis were guided by a developmental psychopathology framework and resilience theory. Three main themes were identified – namely, multisystem risk processes, multisystem resilience processes, and adapting positively to living with JIA. In this regard, the findings indicated that the symptoms generated by the disease resulted in a cascade of transactions within and between the biopsychosocial systems, resulting in cumulative risk processes. However, over time, resilience processes developed in the biopsychosocial systems, which seemed to enable the adolescent participants' positive adaptation to JIA.

This study has provided an initial foundation for further research in South Africa and has attempted to present the complexity of the multisystemic transactions that are involved in living with JIA. It has made valuable contributions to psychological research in the fields of JIA, developmental psychopathology, adolescent development, and adolescent resilience and well-being.

Keywords: Adolescent development, developmental psychopathology, juvenile idiopathic arthritis, multilevel analysis, thematic analysis, resilience, universal theory of development, well-being

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List of Abbreviations

APA	American Psychological Association
DMARD	disease-modifying anti-rheumatic drugs
ILAR	International League of Associations of Rheumatology
JIA	juvenile idiopathic arthritis
NGO	non-governmental organisation
NREPP	National Registry of Evidence-Based Programs and Practices
PE	physical education
PEWTER	prepare, evaluate, warning, telling, emotional response, and regrouping preparation
PMTS	paediatric medical traumatic stress
PTSD	post-traumatic stress disorder
SPIKES	setting, perception, invitation/information, knowledge, empathy, and summarise/strategise
TB	tuberculosis
TEARS	The Emma Animal Rescue Society

CHAPTER 1: INTRODUCTION

1.1 Introduction

The objective of this chapter is to provide a preview of this study that orients the reader by contextualising and explaining the motivation for the research. As the study is situated within a constructivist-interpretivist paradigm, it is essential to explicate my role in selecting the area of study, as well as the choices made regarding the research design and analysis. Thus, from the outset, it is important to note that this dissertation has value to me on personal, professional, and academic levels. Thereafter, the chapter provides research question and clarifies the central concepts. Finally, the subsequent chapters are introduced, and an outline of their content is provided.

1.2 Motivation for the Research Topic

My interest in the field of chronic illness and inflammatory arthritis began when I was diagnosed with inflammatory arthritis in my forties, after over 20 years of illness. Thus, initially, my interest in this field was a personal one. My professional interest, as an educational psychologist, was stimulated by working with children and adolescents who experienced chronic pain and illness. Some of these referrals included children and adolescents with juvenile idiopathic arthritis (JIA).

JIA is one of the most common chronic inflammatory diseases in childhood and adolescence (Beukelman et al., 2017). This genetic auto-immune disease causes high levels of chronic pain and fatigue, and is characterised by unpredictable flare-ups (Armbrust, Siers et al., 2016). Consequently, JIA is a debilitating disease that may result in mortality due to disease complications and treatments (Davies, Southwood, Kearsley-Fleet, Lunt, & Hyrich, 2015). Of specific relevance to this study, is that JIA has a deleterious effect on the biopsychosocial functioning of children and adolescents (Unal et al., 2018). It also has no known cure (Giancane et al., 2016).

In my professional capacity, I noticed that there was scant psychosocial support available in South Africa for individuals with JIA and their families in comparison to that available for individuals diagnosed with other diseases that occur in childhood, such as cancer, diabetes, epilepsy, and HIV. It also became apparent that these clients and their families required interventions that were tailored to meet the specific biopsychosocial stressors that arise as a consequence of living with JIA. Certainly, the existing body of literature indicated that JIA places multiple stressors on individuals with the disease and their families (Modica et al., 2016; Saetes, Hynes, McGuire, & Caes, 2017; Turner-Cobb & Cheetham, 2016; Unal et al., 2018). Notwithstanding the serious biological symptoms of chronic pain and chronic fatigue, individuals with JIA also experience high levels of negative affect and a sense of social isolation (Cartwright, Fraser, Edmunds, Wilkinson, & Jacobs, 2014; Moverley, Vinall-Collier, & Helliwell, 2015; Tong, Jones, Craig, & Singh-Grewal, 2012; Unal et al., 2018). Equally important is that JIA has a deleterious effect on family functioning (A. Cox, Ostring, Piper, Munro, & Singh-Grewal, 2014; Chausset et al., 2016; Gómez-Ramírez et al., 2016b; Saetes et al., 2017). However, despite there being extensive literature regarding the inherent psychosocial risks associated with developing JIA, there was scant literature providing recommendations regarding the support of individuals with JIA based on their psychosocial experiences. Thus, when the opportunity arose to pursue my doctoral studies in the field of child and adolescent psychology, my personal and professional interest in the experiences of individuals with JIA translated into a focal point for my academic pursuits.

My reading of the existing body of literature, as well as correspondence with a leading South African paediatric rheumatologist, revealed that JIA is a neglected area of research in South Africa, despite a conservative estimate of 18,700 children in this country being affected by this disease (personal communication, C. Scott, January 15, 2019; Weakley & Scott, 2012). Thus, the field of JIA was deemed to be an appropriate area of research for a doctoral dissertation. Furthermore, I postulated that, given the significant biopsychosocial changes that occur during adolescence, individuals with JIA may be particularly vulnerable during this developmental stage. Indeed, Pinquart and Pfeiffer's (2015) meta-analysis of 447 quantitative studies found that having a chronic illness may impact negatively on an adolescent's ability to negotiate developmental tasks successfully. In contrast, other researchers have reported that the presence of resilience factors and processes can promote the successful management of chronic illness and the negotiation of adolescent tasks (Cartwright et al., 2014; Lennon, Psihogios, Murray, Holbein, & Holmbeck, 2016; Livermore, Eleftheriou, & Wedderburn, 2016; McKeever & Kelly, 2015; Saetes et al., 2017; Turner-Cobb & Cheetham, 2016). These conflicting findings suggested that adolescence would be a rich developmental stage during which to explore the processes of risk and resilience in individuals with JIA. A final consideration during topic development was that the increase in the complexity of cognitive functioning during adolescence, as compared to childhood, would be more likely to yield rich data. Therefore, I chose to conduct research on the psychosocial experiences of South African adolescents with JIA.

Minimal South African research has been conducted in the field of JIA and the five published articles which were identified focused on quantitative medical research. This research either investigated the incidence and prevalence of JIA and its subtypes, or delineated current medical treatment (Haffejee, Raga, & Coovadia, 1984; Scott & Brice, 2015; Scott & Webb, 2014;

Weakley, Esser, Pope, & Scott, 2011; Weakley & Scott, 2012). Notably, the South African research indicated that the time to diagnosis in South Africa tends to be longer than that in other countries, as the diagnosis is further complicated by the presence of comorbid illnesses, insufficient resources, and a lack of medical knowledge (Scott & Brice, 2015; Weakley et al., 2011). These factors not only delay diagnosis, but also restrict access to appropriate medical services; this is problematic, as sub-optimal treatment may lead to the increased likelihood of complications (Aoust, Rossi-Semerano, Koné-Paut, & Dusser, 2017) such as joint deformity and blindness (Mosley, 2015).

A literature search produced approximately 70 journal articles discussing the biopsychosocial factors of JIA, most of which assumed a largely pathogenic stance (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & National Registry of Evidence-Based Programs and Practices [NREPP] databases, 24 January 2019). It became apparent that few articles focused on the developmental period of adolescence. Indeed, most articles conflated the developmental stages of childhood, adolescence, and even, at times, early adulthood. Moreover, the majority of articles identified risk factors and processes in normative development, neglecting to address resilience factors and processes. None of the articles explored the participants' understandings of well-being within illness, although some referred to well-being as an outcome. Hence, there is a need for international, and specifically South African, qualitative psychological research that explores both the risk and the resilience factors that impact on adolescent experiences of JIA. More specifically, an exploration of adolescents' understandings of their adaptive processes and the possibility of well-being within illness is needed.

In summary, qualitative research that explores the psychosocial experiences of South African adolescents with JIA is required. This research may contribute to a deepened understanding of adolescents' everyday experiences of living with JIA, as well as their management of the resilience resources available to them. Such insights may provide the basis for the development of appropriate, timeous medical and psychosocial interventions in the future.

1.3 The Aim of the Research

This exploratory study aimed to explore and describe the psychosocial experiences of South African adolescents with JIA. A rich description of their experiences and understandings of living with JIA was sought from seven adolescents with JIA and their parents and situated within developmental psychopathology and resilience theory.

Developmental psychopathology was used as the conceptualising model for this study, as it is an integrative framework that can be defined most simply as “the study of behavioural health and adaptation in a developmental context” (Masten, 2006, p. 47). This framework is multisystemic, multidisciplinary, and acknowledges the complexities of both normal and abnormal development (Davis & Suveg, 2014; Marshall, 2013; Masten, 2014). Notably, the interaction between risk and protective factors are conceptualised as causing developmental cascades that are cumulative in nature and that alter the trajectory of development (Masten & Cicchetti, 2010; Rutter & Sroufe, 2000). The developmental psychopathology framework thus accommodates the concept of resilience, which represents the possibility of successful adaptation in the context of adversity to ultimately optimise well-being (Davis & Suveg, 2014; Masten & Tellegen, 2012; Shiner & Masten, 2012). Accordingly, within this framework, JIA can be conceptualised as a risk factor that, given multiple interacting systems, leads to unique, multiple pathways of illness and well-being. Furthermore, the developmental psychopathology framework takes into account that adolescents with JIA may also actively engage in resilience processes which may contribute to their well-being despite the adverse context of chronic illness.

The value of this study lies in its facilitation of a deepened understanding of the psychosocial experiences of South African adolescents with JIA. Areas of risk and resilience, which may provide the foundation for future research in this field, both in South Africa and internationally, have been identified. Furthermore, recommendations which may minimise risk processes and enhance resilience processes within and between multiple systems are made. These recommendations should facilitate the design of developmentally appropriate psychosocial interventions, specific to JIA, which may enhance the resilience processes and well-being of adolescents with JIA.

1.4 Concept Clarification

The key concepts of this study are clarified below.

Adversity: Adversity refers to the conditions that threaten positive adaptation or normative development. It incorporates a wide range of acute and chronic risk factors which may occur within and between multiple systems (Shiner & Masten, 2012; Wright, Masten, & Narayan, 2013). Examples of adversity in this study would be experiencing chronic childhood illness or living with JIA.

Resilience: Resilience is a process of positive adaptation in the face of adversity. It is the ability of an individual to endure and recover from adverse conditions that threaten his or her normative development and biopsychosocial well-being (Masten, 2014; Wright et al., 2013). In this study, an example of resilience processes would be an adolescent with JIA who implements coping strategies to optimise his or her emotional regulation and social interactions.

Resilience in medical contexts: Medical resilience involves negotiations between individuals, families, and institutions in order to meet needs in a meaningful manner, and enhance and sustain well-being (DeMichelis, 2016; Ungar, 2016). Thus, it refers to a process of transactions that occur within and between multiple systems (interpersonal, institutional, and political). It is important to note that medical resilience is not equated with recovery and that well-being is considered to be relational in nature. In this study, examples of medical resilience would be the processes of receiving an accurate diagnosis, adhering to treatment plans, and experiencing well-being despite chronic illness.

Risk: Risk includes a broad range of factors or conditions that increase the likelihood of an undesired outcome (Shiner & Masten, 2012). In the current study, an example of risk would include having a genetic predisposition to developing JIA.

Risk Factor: Risk factors include measurable individual or contextual characteristics that usually give rise to a negative outcome. These characteristics may be proximal (experienced directly by the adolescent) or distal (occurring in the ecological context of the adolescent) (Wright et al., 2013). In this study, examples of risk factors would include contracting a virus or bacterial infection, high levels of stress, or a lack of knowledge of JIA in medical and social systems.

Cumulative risk: Cumulative risk refers to increased levels of risk as a result of the occurrence of numerous risk factors, each one serving as a trigger for the next (Wright et al., 2013). In this study, examples of cumulative risk are single-parent families, poverty that prevents access to medical care, and the existence of comorbid disorders with JIA.

Protective factors: Protective factors are factors that change responses to adverse conditions or events in a way that prevents or mitigates possible negative outcomes. These factors can occur in the individual or within the ecology in which the individual is situated (Cousins, Kalapurakkel, Cohen, & Simons, 2015; Wright et al., 2013; Zolkoski & Bullock, 2012). In this study, examples of protective factors include problem-solving skills, access to medical care, and having effective social support systems.

Cumulative protection: Cumulative protection refers to a process where existing protective factors pave the way for additional protective factors to arise in the person's life (Wright et al., 2013). As with cumulative risk, cumulative protection is seen to be multiplicative, rather than additive. Examples of cumulative protection in this study might include an adolescent with JIA who has attentive parents, prosocial peers, and access to medical care.

Developmental tasks: Developmental tasks refer to age-based expectations for behaviour that are specific to the context, culture, and historical period. These expectations change according to the age, context, culture, and historical period of the person as well as new challenges that are faced (Shiner & Masten, 2012). Examples of developmental tasks during adolescence would be forming a coherent identity and becoming autonomous.

Resilience processes: Resilience is not an unchanging characteristic trait, but rather the interaction of multiple processes. Resilience processes refer to multilevel, dynamic, potentially active processes which may result in positive adaptation to adversity (Cousins et al., 2015; Feinstein et al., 2018; Masten, 2014). Examples of resilience processes in this study would include pain acceptance, pain self-efficacy, and stress regulation.

Subjective well-being: Subjective well-being refers to the degree to which an individual cognitively or affectively appraises his or her life to be positive and desirable. It is characterised by high levels of positive affect, low levels of negative affect, and high levels of life satisfaction (Diener et al., 2017; Diener, Oishi, & Tay, 2018). In the current study, examples of subjective well-being would include having higher levels of positive affect such as happiness and gratitude; lower levels of negative affect such as sadness and anger; and experiencing satisfaction with aspects such as one's health status or academic performance.

Disease: The term “disease” refers to a specific abnormal disorder that negatively affects part or all of the individual’s structure and functioning. It is the objective, biological occurrence of pathology that medical practitioners are trained to identify and manage (Gatchel, 2015; Peteet, 2015; Ventriglio, Torales, & Bhugra, 2017). Thus, in this study, the term “disease” is used when referring to JIA within a medical context.

Illness: Illness is different to disease in that it refers to the individual’s subjective experience of a disease or condition. It is concerned with the impact of the disease on the patient’s functioning, relationships, and social interactions. The term “illness” incorporates aspects such as psychosocial functioning, emotional distress, physical limitations, and discomfort (Gatchel, 2015; Peteet, 2015; Ventriglio et al., 2017). Therefore, in this study, illness refers to the biopsychosocial experiences of the adolescent participants.

Sign: A sign is any objective evidence of disease. It is a phenomenon that can be detected by someone other than the individual affected by the disease (Maturo, 2007). In this study, examples of signs of a disease would include swollen joints, a rash, and an elevated temperature.

Symptom: A symptom is any subjective evidence of disease. It refers to a phenomenon that is experienced by the individual affected by the disease and cannot be observed (Maturo, 2007). In the current study, examples of symptoms would include pain, weakness, fatigue, and headaches.

Paediatric medical traumatic stress (PMTS): PMTS refers to psychological and physiological reactions of children to pain, serious illness, medical procedures, and emotionally distressing treatment (National Child Traumatic Stress Network, 2003). This concept identifies post-traumatic stress symptoms that do not necessarily qualify for a diagnosis of post-traumatic stress disorder (PTSD). These symptoms hamper medical recovery, impair daily functioning, and affect treatment compliance (Holley, Wilson, Noel, & Palermo, 2016; Hoysted et al., 2018; Kassam-Adams, 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016). In this study, examples of symptoms of PMTS include heightened arousal, avoiding reminders of the traumatic experience, re-experiencing the trauma, and continued intrusive and distressing thoughts.

Activity limitations: Activity limitations refer to limitations in mobility or self-care (Dunn & Andrews, 2015). In this study, examples would include the inability to walk, not being able to brush one's hair, or not being able to take part in strenuous activities.

Participation restrictions: Participation restrictions refer to difficulty in engaging with the activities of daily living (Dunn & Andrews, 2015). Examples of participation restrictions would include absenteeism from school and not being able to socialise with peers.

1.5 Structure of the Thesis

This thesis is divided into seven chapters which are outlined below.

Chapter 1 aims to introduce and provide the motivation for the study. It affords a brief explanation of the nature of JIA, its pervasive impact on adolescent health, and the potential disruption it may have on the achievement of developmental tasks during adolescence. Furthermore, the need for resilience research in this field, both internationally and in South Africa, is highlighted. An overview of the developmental psychopathology framework is presented, wherein JIA is positioned as a risk factor, and resilience processes are viewed as pathways to optimise levels of subjective well-being. In addition, the research question addressed in this study is expounded. Finally, the structure of the thesis is outlined.

Chapter 2 serves to delineate the conceptualisation underpinning the study. The overarching conceptual framework of the study is that of developmental psychopathology, as this provides a multisystemic, developmental understanding of risk factors and resilience processes during adolescence (Cicchetti & Rogosch, 2002). Sameroff's (2010; 2014) unified theory of development is presented as a means to integrate the multiple levels of analysis. Thereafter, current research regarding risk and resilience processes in the field of adolescent chronic illness and chronic pain is delineated. In addition, subjective well-being is discussed as an outcome of resilience processes. Finally, the chapter presents research regarding resilience in the field of child and adolescent chronic illness in the South African context.

Chapter 3 focuses on understanding normative adolescent development as well as the maladaptive trajectories that may occur as a consequence of developing JIA. Firstly, the term "adolescence" is defined, and a broad overview of the biopsychosocial changes that occur in adolescence is provided. Thereafter, a summary of the aetiology, pathogenesis, diagnosis, and treatment of JIA is outlined. Also, the biopsychosocial challenges of living with JIA and the effect that these challenges may have on the successful negotiation of the developmental tasks of adolescence are described. The latter presents literature in the fields of chronic illness and chronic pain, given the dearth of literature on JIA. The last section provides an overview of South African research in the field of JIA.

Chapter 4 provides an in-depth explanation of the research design and the methodology used in this qualitative study. It includes the details of the participants, the data gathering procedure, and the steps that were engaged in to analyse the data. The participants' contexts and illness experiences are briefly described in order to contextualise the findings presented in Chapter 5. Moreover, the ethical considerations involved in working with vulnerable human subjects, the ethical approval process, and the collation of data in an ethical manner are delineated. Finally, the trustworthiness of this study is discussed.

Chapter 5 documents the findings obtained in this study. The main themes of multisystemic risk processes, multisystemic resilience processes, and adapting positively to living with JIA are presented and substantiated by providing rich, thick quotations from the participants. Care was taken to provide sufficient contextualisation to support my interpretations of the subjective experiences of the participants.

Chapter 6 interprets the findings from the previous chapter with reference to relevant literature. The chapter concludes with a reflexive analysis of my role as researcher within the research process.

In Chapter 7, the concluding chapter, the research aim of this study is revisited and the strengths and limitations of the study are critically reviewed. Thereafter, the significant contributions of the research are presented, and recommendations for future research and practice are made.

1.6 Conclusion

In this chapter, the motivation for the research topic was presented. In addition, an overview of the research question was provided, the major concepts were clarified, and the layout of the subsequent chapters was provided. In the following chapter, the conceptual framework of this study – developmental psychopathology – and the concepts of risk, resilience, and subjective well-being are discussed.

CHAPTER 2: CONCEPTUALISATION

2.1 Introduction

JIA affects the biopsychosocial functioning of an adolescent; therefore, selecting a research framework that accounts for individual and contextual factors would be most appropriate. Current approaches to development have embraced an integrative, multidisciplinary approach that emphasises the multisystemic, transactional processes involved (Beauchaine, Constantino, & Hayden, 2018; Hadfield & Ungar, 2018; Masten, 2018; Masten & Barnes, 2018). Furthermore, recent trends direct attention towards resilience processes that mitigate developmental risk processes, enable prevention and intervention, and enhance subjective well-being (Hadfield & Ungar, 2018; Masten & Barnes, 2018). Thus, developmental psychopathology, which is situated within the relational developmental systems meta-theory (Marshall, 2013), provides an appropriate theoretical approach to explore the complex developmental processes involved in the psychosocial experiences of adolescents with JIA.

In this chapter, the overarching framework of relational developmental systems theory will be presented as the grounding meta-theory for developmental psychopathology. The developmental psychopathology framework will then be explored using Sameroff's (2010, 2014) unified theory of development to explicate the complexity of multisystemic, transactional developmental processes. Thereafter, risk, resilience, and subjective well-being theory is presented with reference to JIA. Finally, research methods used in the fields of developmental psychopathology and resilience are discussed.

2.2 Developmental Psychopathology

2.2.1 Origins and Definition of Developmental Psychopathology

Developmental Psychopathology is a theoretical model that falls under the meta-theory of relational developmental systems theory (Marshall, 2013; Masten, 2006; M. Cox, Mills-Koonce, Propper, & Gariépy, 2010). This meta-theory rejects the reductionist dualism of early developmental theories, and is holistic, integrative, and multidisciplinary in approach (Lerner, Johnson, & Buckingham, 2015). It is concerned with the processes involved in human development at all levels of ecological organisation, from biological to cultural and historical levels (Bergman, 2015; Lerner et al., 2015; Overton & Lerner, 2014). The basic units of analysis are the mutually influential transactions, also known as coactions, which regulate development at multiple levels (Lerner et al., 2015; Overton & Lerner, 2014).

Situated within relational developmental systems theory is the integrative framework of developmental psychopathology, which arose partly in response to the limitations of psychiatry and developmental psychology in the 1970s (Beauchaine et al., 2018; Rutter & Sroufe, 2000). During this period, developmental psychology was focused on universals and tended to ignore individual differences, but as Rutter (2013b) notes, development is complex and cannot be explained by one mechanism. Although psychiatry concentrated on the individual, it was overly concerned with narrow diagnostic criteria and conceptualisations (Rutter, 2013a). The fusion of the disciplines of psychopathology and development was fuelled by studies in several areas that generated a solid empirical base regarding fundamental developmental processes in psychological and biological systems (Masten, 2006; Rutter & Sroufe, 2000; Toth & Cicchetti, 2010). Over the past 40 years, developmental psychopathology has evolved into a broad, integrative framework (Eme, 2017; Masten, 2016, 2018; Toth & Cicchetti, 2010). The core principles of developmental psychopathology as outlined by Masten (2006) will be explored in the following section.

2.2.2 The Defining Principles of Developmental Psychopathology

2.2.2.1 The developmental principle.

Developmental psychopathology views individual development as relational, transactional, reciprocal, and consisting of multiple levels within both the individual and the context (Marshall, 2013; Masten, 2016; M. Cox et al., 2010). As a result of the complexity of multilevel coactions that take place, it is inevitable that multiple pathways of development to health and to illness are created (Eme, 2017; Hinshaw, 2013). These diverse pathways are encapsulated by the terms “equifinality” and “multifinality” (Sroufe, 2013). Equifinality denotes that different pathways can lead to the same outcome, whereas multifinality indicates that the same starting point can result in different outcomes (Sroufe, 2013). Thus, an individual who begins life with normal development may be pushed into abnormal development because of multiple factors, one of which might be illness (Masten, 2006). Furthermore, development moves in the direction of increasing adaptability with the intent of attaining cultural goals, reproducing, or surviving (Masten, 2006). This development occurs in an orderly manner with predictable patterns of change which establish coherence (Cicchetti & Rogosch, 2002; Masten, 2006; Rutter & Sroufe, 2000). Masten (2006) observes that changes in the individual, the environment, or in the interaction between these can result in intense transformations that lead to times of growth, vulnerability, or opportunity. Adolescence is such a time (Cicchetti, 2006; Masten & Barnes, 2018; Shiner, Allen, & Masten, 2017; Shulman & Scharf, 2018). Although there is considerable individual variation during adolescence, the overall pattern of development is normative.

2.2.2.2 The normative principle.

An understanding of normative development is required to identify when and how development diverges and becomes abnormal (Cicchetti, 2006). Divergence from the norm occurs on a continuum, with some individuals demonstrating maladaptive behaviours and others not (Cichetti, 2006). However, Masten (2006) cautions that normal development is a social expectation of what is appropriate behaviour for an individual of a specific age and gender. Thus, while expectations may differ according to the historical period, culture, and context, some behaviours remain universal (Luthar, 2015). The term “developmental tasks” is used to encapsulate these social expectations which are benchmarks for positive adaptation and normative development (Shiner et al., 2017; Shiner & Masten, 2012). Developmental tasks present in a variety of domains and they change in nature as individuals age and experience new challenges. Thus, a task that is important in one stage has less relevance in another (Shiner & Masten, 2012). Moreover, the achievement of developmental tasks lays the foundation for the successful negotiation of tasks in future developmental stages (Masten & Cicchetti, 2010). Therefore, failure or success in achieving an important developmental task during adolescence can impact on future well-being. Furthermore, the multiple interactive systems that make up the individual and the context influence normative development.

2.2.2.3 The systems principle.

Relational developmental systems theory accounts for systemic processes that occur within the individual, as well as between the individual and the environment (Marshall, 2013). Each system derives meaning from the entire context, and no system is given priority over another (Marshall, 2013; Masten, 2016). However, M. Cox et al. (2010) point out that systems change at different rates and certain systems may become deterministic at certain times of development – the onset of puberty being an example of this. Furthermore, systems are characterised by the ability to self-regulate and self-organise their functioning from the molecular to the societal level (Marshall, 2013; Masten & Monn, 2015). Therefore, human development occurs as a result of continuous adaptation to the interaction of systems both within the individual and between the individual and the environmental systems (Masten & Monn, 2015). The presence of multiple systems requires a multilevel analysis to fully comprehend the complexity involved.

2.2.2.4 The multilevel principle.

Developmental psychopathology researches a phenomenon through a multilevel analysis that examines the reciprocal nature of the coactions within and across the levels (Marshall, 2013). Cichetti (2006) notes that this complexity necessitates that research becomes a multidisciplinary project, with researchers adjusting their methods and focus depending on the phenomenon or level in question. A phenomenon can only be understood when all levels have been investigated and integrated, as each level constrains and informs the other levels (Cicchetti, 2006; Marshall, 2013; Masten, 2016). Thus, Cichetti (2006) argues that working in isolation, rather than in a multidisciplinary manner, tends to produce theories that are reductionist and incorrect, as crucial information from other disciplines is not included. All the systems which constitute the individual, as well as the systems in which the individual is embedded, need to be analysed (Sameroff, 2014). An individual's sense of agency plays a significant role in determining the influence of multilevel systems on developmental trajectories.

2.2.2.5 The agency principle.

Individuals are active agents in determining their own development as they make choices about their lives which in turn affect future experiences and choices (Masten, 2006). Personal agency is a central component of resilience as it enables positive transitions and changes in negative trajectories (Masten & Barnes, 2018). Bandura (2006) contends that although individual agency increases during development as a result of neurological and physiological changes, it is socially embedded and does not occur in isolation (Bandura, 2006). Consequently, individual agency is also promoted through psychosocial and learning experiences and can be a critical factor in determining normal or abnormal development (Masten, 2006).

2.2.2.6 The mutually informative principle.

Developmental psychopathology models stress that abnormal behaviour deviates from normal developmental pathways; therefore, unless normal development is understood, abnormal development will be decontextualised (Hinshaw, 2013). In turn, abnormal development sheds light on normal development (Cichetti, 2006). Consequently, Toth and Cichetti (2010) assert that individuals who are at risk for pathology, but who do not develop pathology, are as important for research as those individuals who do develop pathology. Accordingly, investigating the continuities and discontinuities between normal and abnormal behaviour can enable an understanding of development across a range of variations (Cichetti, 2006). Therefore, according to Masten (2006), comprehending the processes of continuity and discontinuity is crucial when investigating individuals who are at risk. The processes of continuity and discontinuity are best studied through a lifespan approach to development.

2.2.2.7 The longitudinal principle.

Developmental psychopathology embraces a lifespan approach which aims to understand the developmental transformations and reorganisations that take place over time (Toth & Cichetti, 2010). Masten (2006) emphasises that longitudinal studies are required to ascertain the pathways of development that occur from multiple interactions within and between organisms situated in larger systems. Furthermore, M. Cox et al. (2010) assert that a lifespan and intergenerational approach is required to understand developmental cascades fully. Essentially, developmental cascades are adaptive or maladaptive developmental pathways that affect functioning at higher system levels or competency in later periods of development (Masten & Monn, 2015; Shiner & Masten, 2012). Developmental cascades are also present at the community or social level, and they can permeate multiple generations (Masten & Cicchetti, 2010). These cascades can run downwards, whereby experience affects genetic expression, or upwards, whereby problematic systems affect personal interactions (Masten & Cicchetti, 2010). According to M. Cox et al. (2010), understanding developmental cascades raises the possibility of preventing or intervening in negative cascades and creating or improving positive cascades.

2.2.2.8 Summary of the principles of developmental psychopathology.

Developmental psychopathology is a useful model to explore the experiences of adolescents with JIA as it emphasises development across the lifespan. Moreover, an understanding of normative development is needed to ascertain whether these adolescents' developmental trajectories deviate from the norm and if the developmental tasks are being negotiated successfully. The mutually informative interplay between adaptive and maladaptive trajectories is considered critical when investigating individuals in high-risk situations (Masten, 2006) such as chronic illness. In addition, developmental psychopathology views adolescents as being active agents in their own development (Masten et al., 2004). Personal agency can foster resilience in chronic illness, as positive choices can change negative trajectories in risk situations (Ferguson & Walker, 2014). Furthermore, developmental concepts such as equifinality and multifinality may be useful in explaining differences and commonalities across adolescents with the same disease. The focus on mutually interactive systems and multilevel analysis will facilitate a broader exploration that may more fully account for their experiences. Finally, risk and resilience processes that may enable optimised development and well-being in the face of chronic illness can be identified. However, the developmental psychopathology model is complex and requires multilevel analysis. Integrating the researcher's understanding of the psychological and social experiences of adolescents with JIA requires a framework to structure the analysis. The following section delineates Sameroff's multilevel analysis.

2.2.3 Multiple-Level Analysis: Sameroff's Unified Theory of Development

Sameroff (2010; 2014) proposed the unified theory of development as a means to integrate multiple levels of analysis. His model incorporates the principles of developmental psychopathology into a cohesive framework that scaffolds the exploration and understanding of human development within the ecological context. Sameroff's model will be used to frame the exploration of psychosocial experiences within this study.

2.2.3.1 Five models.

Initially, Sameroff (2010) posited that four models were needed to understand human development, but later a fifth model was incorporated (Sameroff, 2014). The five models he postulated were a model of personal change, a contextual model, a regulation model, a representational model, and an evolutionary model (Sameroff, 2014). A model of personal change is required to understand the biological and psychological changes that occur during growth and development. As the individual is situated within an environment, the contextual model enables an understanding of the multiple sources of environmental experience that facilitate or hinder individual development. This complexity is integrated through the regulation model, which integrates the dynamic systems of the individual, the context, and the relations between them. Furthermore, the representational model accounts for how individual experiences are encoded at abstract levels that create structures to interpret new experiences and develop a sense of self. Finally, the evolutionary model explains the codevelopment of genes and psychological and social functioning (Sameroff, 2014). Sameroff (2010, 2014) integrates these five models into a comprehensive unified theory of development that takes into account most of the known factors that influence life trajectories. This theory consists of a structural formulation and a process formulation. The structural formulation, which Sameroff (2014) terms the biopsychosocial ecological model, integrates the personal and contextual models of human development.

2.2.3.2 Structural formulation of Sameroff's unified theory of development.

2.2.3.2.1 The biopsychological self-system.

The biological and psychological domains comprise what Sameroff refers to as the *biopsychological self-system*. This self-regulating system interacts with other self-regulating systems in the environment. The biological system explains how behaviour can have biological roots as a result of variables such as physiology, genetics, and neurotransmitter and hormonal activity (Ensink, Biberdzic, Normandin, & Clarkin, 2015; Marshall, 2013; Masten, Herbers, Cutuli, & Lafavor, 2018). Biological changes cascade into behavioural changes in response to stressors in the environment, which may result in the potential for negative health outcomes in adverse situations and positive health outcomes in supportive environments (Ellis & Boyce, 2008).

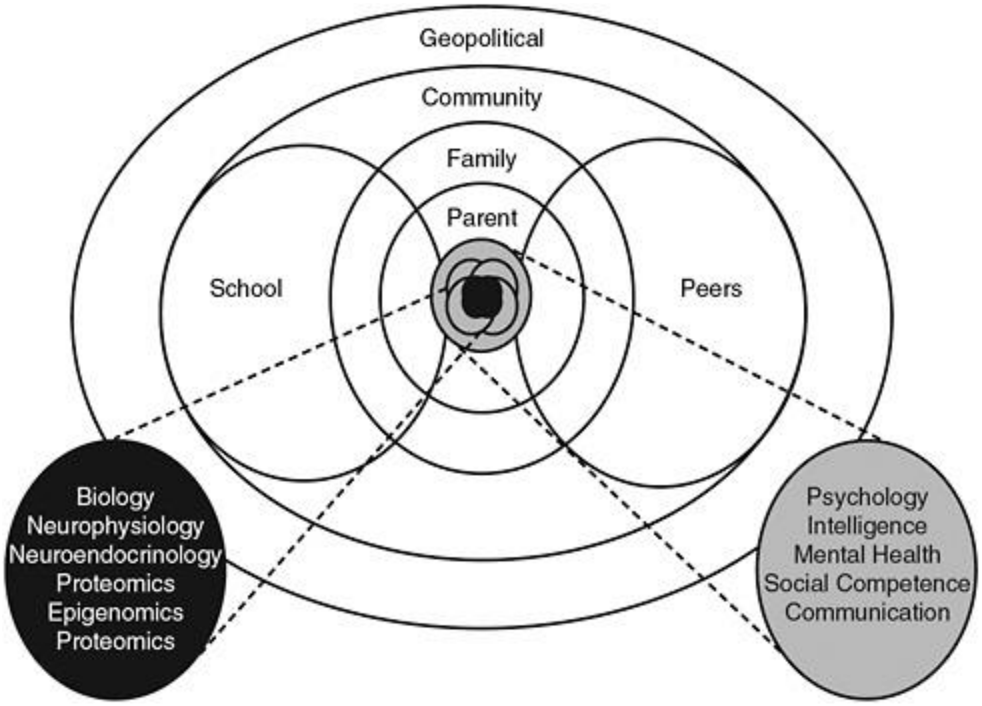

Figure 2.1. **Sameroff's biopsychosocial ecological model**
Source: Sameroff, 2010, p. 18

Similarly, the psychological system is not isolated but is an embedded system that develops in concert with the biological and contextual systems (M. Cox et al., 2010). Bronfenbrenner and

Morris (2006) observe that the psychological domain is comprised of coactions between the cognitive, emotional, and behavioural systems. Sameroff refers to the combination of the *biopsychological self-system* and the social context as the *biopsychosocial ecological model* (see Figure 2.1 above). This model will be described in the following section.

2.2.3.2.2 The biopsychosocial ecological model.

Sameroff's (2014) biopsychosocial ecological model situates individual development within multiple contexts that engage in bi-directional transactions. Sameroff (2010) incorporated Bronfenbrenner's (1979) ecological model into his unified theory to fully explicate the multiple social contexts that impact on individual development. The ecological model will be outlined below. Thereafter, Sameroff's explanation of the process of development will be presented.

The ecological model of Urie Bronfenbrenner is often integrated into theories of developmental psychopathology (Cicchetti, 2006; Masten & Monn, 2015; Sameroff, 2010). Bronfenbrenner's theory evolved through three phases, between 1973 and 2006, from an ecological to a bioecological theory (Rosa & Tudge, 2013). However, it is his earlier ecological model that is incorporated into Sameroff's work. Initially, Bronfenbrenner (1979) viewed development as occurring because of reciprocal interactions between the individual and the multiple systems of the individual's context. Four nested tiers were conceptualised – namely, the microsystem, the mesosystem, the exosystem, and the macrosystem (Tudge, Mokrova, Hatfield, & Karnik, 2009). The proximal environments, such as the microsystem, were thought to directly influence the individual, whereas distal environments, such as the macrosystem, affect the individual indirectly (Bronfenbrenner, 1979).

The microsystem is the most proximal situation in which the individual interacts face to face with other individuals (Bronfenbrenner, 1979). These settings have physical characteristics and include environments such as the family, the school, and peers (Bronfenbrenner, 1994). In this system, the individual engages in activities, interpersonal roles, and relations (Rosa & Tudge, 2013). Links between two or more microsystems create a mesosystem, which is essentially a system of microsystems (Bronfenbrenner, 1994). For example, the interaction between the family and the school may take place in the mesosystem. However, the exosystem differs from the micro- and mesosystems in that one of the settings does not include the individual, but rather indirectly affects the individual (Bronfenbrenner, 1979). An example of this would be how the parental workplace affects the parent and, in turn, may affect the child. Finally, the macrosystem is concerned with the institutional systems that exist within a culture or subculture (Bronfenbrenner, 1994). These include economic, political, social, educational, and legal systems that affect the opportunities, hazards, and life course options of the individual (Bronfenbrenner, 1994). Sameroff's process formulation explicates the processes through which an individual situated within multiple contexts develops.

2.2.3.3 Process formulation of Sameroff's unified theory of development.

The process formulation encapsulates how the individual changes over time as a result of regulatory and representational processes. Sameroff (2014) posits that developmental periods occur because of changes in the individual or in the environment that result in developmental shifts. Such changes in organisation are indicated by upward and downward arrows in Figure 2.2 (page 26). According to Sameroff (2014), these can be simple changes such as learning to walk, or more complicated ones, such as the advent of adolescence. These processes do not lead to a uniform and consistent increase in development (Sameroff, 2010). Rather, development is characterised by periods of stability interspersed with periods of change that lead to a new equilibrium. Periods of change can be generated by or within the individual, such as puberty, or from the environment, such as transitioning to secondary school (Sameroff, 2014).

2.2.3.3.1 Regulatory processes.

Sameroff's (2010) unified theory of development emphasises that regulation is a dynamic process which occurs within multiple systems. Individuals develop psychological self-regulation because of the regulation of others, such as parents and teachers, in their environments (Sameroff, 2010). Initially, infants are regulated by others, but as the individual becomes more independent, self-regulation increases. The individual's development is the product of continuous coactions between the individual and the objects or others in the environment, which can alter developmental trajectories for better or worse. These continuous coactions are an important concept in adolescent chronic illness, given that the individual's illness is managed initially by the adults in the environment. However, self-regulation must occur as the adolescent transitions into adulthood (Lansing & Berg, 2014). Furthermore, adolescents' perceptions of their experiences influence their development.

2.2.3.3.2 Representational processes.

Representations are encoded experiences or internal summaries of the external world (Sameroff, 2010). These representations include cognitive, social, and cultural representations. They fulfil an adaptive function by organising perceptions of the world into a set of expectations (Sameroff, 2014). Representations are not an accurate internalisation of what they represent, as certain characteristics are included, while others are not. For example, children tend to internalise positive characteristics in their representations of their parents (Sameroff, 2014). Understanding representational processes may provide more insight into the experiences of, and meanings attributed to, these processes by adolescents with JIA.

2.2.3.4 Summary of multilevel analysis.

Multilevel analysis is a complex form of research that incorporates coactions within the individual, within the context, and between the individual and the context (Sameroff, 2014). Sameroff's (2010; 2014) unified theory of human development provides a coherent integration of these multiple levels, which includes the internal representations of the individual. Such an analysis is of particular relevance when exploring the experiences of chronically ill adolescents, given the complex interaction of risk and promotive factors. However, such complex research is not without its difficulties.

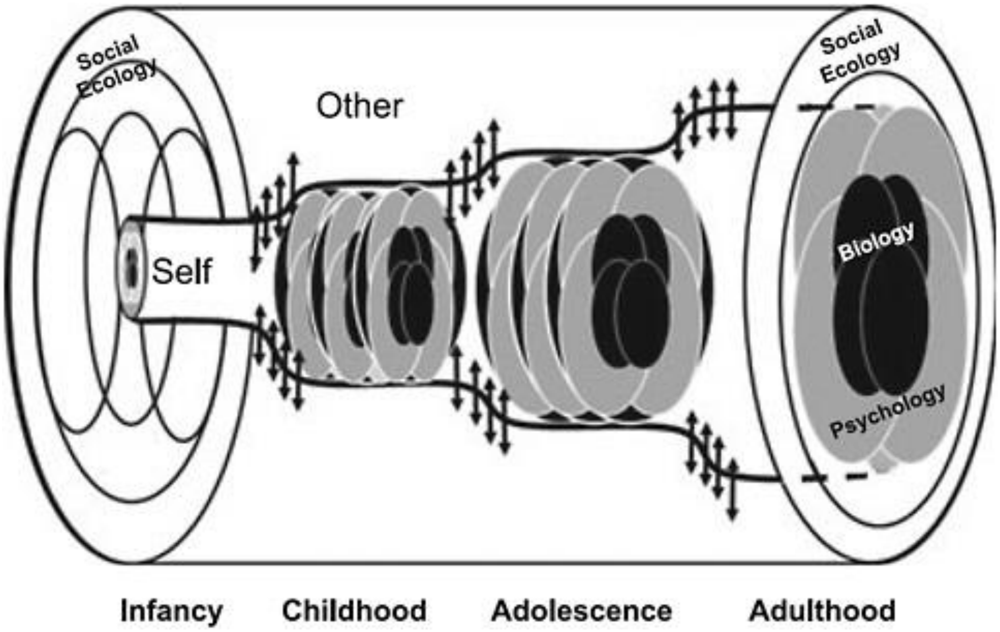

Figure 2.2. **Sameroff's unified theory of development**
Source: Sameroff, 2010, p. 19

2.2.4 Critique of Developmental Psychopathology

Using a developmental psychopathology perspective enables the articulation of the complexities of human development. However, the approach has some inherent difficulties, particularly with the use of the multilevel perspective and longitudinal studies.

Engaging in multilevel analysis presents certain challenges. Firstly, given the interdisciplinary nature of multilevel research, communication channels between disciplines need to be established to facilitate knowledge transference (Cicchetti, 2006; Masten, 2016). Secondly, given the complex nature of development, research designs and strategies need to be developed to cope with this complexity (Marshall, 2013; Masten, 2016). Sameroff (2014) notes that it is not possible for one study to analyse all the levels; rather, the developmental psychopathology framework allows for multiple studies from multiple disciplines to be integrated at a later stage. Given that this study is restricted to only one researcher, communication between disciplines will not be a concern. Furthermore, by situating the research within a developmental psychopathology framework, the researcher has allowed for the findings to be incorporated into future studies.

While longitudinal studies are clearly needed to understand the interactions between systems, as well as the adaptive and maladaptive developmental cascades, longitudinal research is difficult to implement (Cichetti & Curtis, 2007). Such research requires significant funding as well as the investment of the participants' time (M. Cox et al., 2010). Furthermore, data quality and subject retention, as well as establishing a causal link by using control groups, are all issues that need to be overcome in longitudinal studies (M. Cox et al., 2010). Given the scope and time constraints of this study, longitudinal research was not feasible. Rather, this study involves retrospective longitudinal and cross-sectional research. Retrospective longitudinal research involves the participants' recollections and can link early factors with later consequences.

Vernberg and Dill (2003) warn that the accuracy of these retrospective reports can be questionable; however, they also note that the triangulation of sources of data, as well as theoretical triangulation, can rectify this issue. In this study, the use of multiple interviews per case aims to improve the accuracy of the retrospective research. Furthermore, cross-sectional studies are needed to provide a basis for longitudinal studies (Masten & Tellegen, 2012; Vernberg & Dill, 2003). As this research is exploratory in nature, it would be premature to conduct prospective longitudinal studies; nonetheless, this study may inform such future research.

Although developmental psychopathology has its limitations, this study has addressed them through the use of multiple data sources, as well as cross-sectional and retrospective longitudinal research. Furthermore, by using the developmental psychopathology approach and Sameroff's multilevel analysis, this study can be incorporated into future analyses.

2.2.5 Summary of Developmental Psychopathology

Developmental psychopathology provides a model for the complex processes that occur both within and between the systems involved in human development. Such complexity is challenging to research and requires multidisciplinary interaction, varied research designs, and both cross-sectional and longitudinal studies. Sameroff's (2010; 2014) unified theory of development provides a framework that guides multilevel analysis and that enables the integration of many smaller studies. Despite the seemingly negative orientation implied by the name, developmental psychopathology embraces the concept of resilience, which is thought to play a crucial role in development. The concept of resilience will be explored in the following section.

2.3 Developmental Psychopathology and Resilience Theory

The history of research in the field of resilience is closely associated with that of developmental psychopathology, and resilience has been incorporated into the broader framework of developmental psychopathology since the 1970s (Masten & Obradovic, 2006). Studies of resilience investigate why some children and adolescents can adapt positively in the face of adversity (Cousins, Cohen, & Venable, 2014; Cousins et al., 2015; Ferguson & Walker, 2014; Kalapurakkel, Carpino, Lebel, & Simons, 2014; Lee, Cheung, & Kwong, 2012; Masten, 2014). In light of this, resilience is thought to be particularly relevant to understanding the experiences of adolescents with JIA (Cartwright et al., 2014; Eyckmans, Hilderson, Westhovens, Wouters, & Moons, 2011; Livermore, Eleftheriou, & Wedderburn, 2016; McKeever & Kelly, 2015). In the following section, risk and resilience theory will be presented in relation to chronic illness and juvenile arthritis.

2.3.1 Risk as a Concept

While it is not possible to provide a detailed description of the research undertaken in the field of risk and chronic illness owing to the limited scope of this thesis, a brief understanding of the concept of risk is necessary for conceptualising resilience theory.

Developmental psychopathology views risk as a broad term that refers to an increased probability of an adverse outcome in a population, but maintains that it is possible for this outcome to be averted (Cicchetti & Toth, 2009; Shiner & Masten, 2012). An adverse outcome occurs when disturbances threaten the viability of a system, or experiences threaten development and adaptation (Wright et al., 2013). Initially, adverse outcomes were seen as the result of risk factors inherent in the individual or the context (Masten, 2018; Shiner & Masten, 2012; Zolkoski & Bullock, 2012). However, by the 1960s, longitudinal studies and the inclusion of relational developmental systems theory shifted attention from factors to processes (Wright et al., 2013). Thus, risk factors can be viewed as stable individual traits or familial and social factors, whereas risk processes are active and modifiable. Furthermore, cumulative risk refers to the presence of multiple risk factors and processes which increase the probability of adverse outcomes, either additively or exponentially (Compas & Andreotti, 2013). Therefore, in this study, JIA is a risk factor that challenges adolescent development and well-being.

Chronic pain is a clinically significant symptom of JIA, with individuals experiencing pain on 70% of days (Bromberg, Connelly, Anthony, Gil, & Schanberg, 2014). The term "chronic pain" refers to continuous pain lasting more than three months that is not alleviated by current medical treatments (Yeung, Arewasikporn, & Zautra, 2012). Whereas acute pain is a crucial process that directs attention to parts of the body that need care during injury or illness, chronic pain becomes detrimental to the adolescent's physical, cognitive, and emotional equilibrium and is correlated with decreased quality of life (E. Fisher, Heathcote, Eccleston, Simons, & Palermo, 2017; Forgeron et al., 2010; Forgeron, Evans, McGrath, Stevens, & Finley, 2013; Russo et al., 2012; Sturgeon & Zautra, 2013).

Individual risk factors for chronic illness and pain in adolescents include depression, anxiety, anger, and conduct disorder (Bennett, Shafran, Coughtrey, Walker, & Heyman, 2015; Kaushansky et al., 2017; McKillop & Banez, 2016; Sansom-Daly et al., 2012; Sinclair et al., 2016). One of the most studied risk factors is the fear of pain, which results in the avoidance of activities (Cousins et al., 2015; McKillop & Banez, 2016; Sinclair et al., 2016). Individual risk processes might include cognitive processes such as catastrophising or avoiding pain (Cousins et al., 2015; Dick & Riddell, 2010; E. Fisher et al., 2017; Sinclair et al., 2016). Furthermore, individual risk factors can be exacerbated by contextual risk factors.

Family and social risk factors are thought to include parental psychopathology, parent health, parent-child attachment, and family environment (Cousins et al., 2015; McKillop & Banez, 2016; Palermo, Valrie, & Karlson, 2014; Sentenac et al., 2011). Research regarding family and social risk processes focuses mainly on parental behaviour, affect, and cognitions (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010; Sinclair et al., 2016). In addition, parental catastrophising, parent modelling of pain, protective parenting, and solicitous reactions towards a child's pain behaviours, are seen as reinforcing of maladaptive coping styles (McKillop & Banez, 2016; Palermo et al., 2014). Within the social systems, St Leger (2014) reports that neither the education system nor the medical system supported families and children adequately. Moreover, Haase, Kintner, Monahan, and Robb (2014) advise that further research is needed to improve the communication and relationships between health practitioners and adolescents and their families. Furthermore, research indicates that health practitioners frequently dismiss reports of pain by adolescents and their families (Defenderfer, Bauer, Igler, Uihlein, & Davies, 2018; Igler et al., 2017). In addition, Siembida and Bellizzi's (2015) research on adolescents with cancer indicated that medical practitioners' communication with adolescents is often developmentally inappropriate.

Risk factors and processes seldom operate in isolation and adolescents are often faced with multiple risk factors at different levels; consequently, examining cumulative risk factors becomes crucial (Wright et al., 2013). Adolescents with chronic illness are considered to be at significant risk, as they need to manage their illness and cope with the impact this has on multiple levels within their lives (Ferguson & Walker, 2014). Despite this risk, many adolescents who are exposed to adversity – including chronic pain and illness – cope well and are seen as being resilient (Cartwright et al., 2014; Eyckmans et al., 2011; Ferguson & Walker, 2014; Goldstein, 2016; Humphreys & LeBlanc, 2016; Lennon et al., 2016; Turner-Cobb & Cheetham, 2016). The following section explores the concept of resilience in relation to chronic illness and chronic pain.

2.3.2 Resilience as a Concept

2.3.2.1 The history of resilience.

During the 1970s, the focus of developmental psychopathology began to shift from risk to resilience factors when it became apparent that some children adapted well despite being at risk (Masten, 2011). Research in the field of resilience, emerging simultaneously in various fields such as ecology and psychology, was strongly influenced by general systems theory (Masten, 2014). Moreover, resilience theory has features in common with related fields such as positive psychology, risk research, and prevention science, while remaining distinct from them (Luthar, 2015). Indeed, Weems (2009) argues that interweaving developmental psychopathology with positive psychology could provide significant “knowledge development in child and adolescent care” (p. 2). More recently, Wright et al. (2013) compiled a list of protective factors that included child characteristics which overlap with positive psychology constructs. These protective factors include: having a positive outlook on life, or hopefulness; having faith and a sense of meaning in life; and characteristics valued by society, such as humour. This overlap of knowledge may provide a more nuanced understanding of the resilience processes described by the participants in this study.

Wright et al. (2013) identified four waves of resilience research. In the first wave, scientists realised that psychopathology models did not provide an understanding of how positive adaptations were achieved in the face of adversity (Wright et al., 2013; Zolkoski & Bullock, 2012). The significant contribution of these researchers was that they advocated for the understanding of adaptive developmental trajectories in adversity being crucial for the prevention and treatment of children at risk (Wright et al., 2013). In the second wave of resilience research, a more dynamic understanding of resilience was presented through the adoption of a developmental systems approach (Zolkoski & Bullock, 2012). The dynamic and reciprocal patterns through which development is shaped were thought to be best understood through transactional models (Sameroff, 2000). Furthermore, the importance of children's perceptions of, and the meanings they ascribed to, experiences was seen to partly mediate adverse conditions (Wright et al., 2013). The driving force of the third wave was that of fostering resilience by implementing prevention, intervention, and policy strategies (Wright et al., 2013). This wave was characterised by a sense of urgency to assist vulnerable children in the present without waiting for a complete clarification of the concept of resilience (Masten & Obradovic, 2006; Zolkoski & Bullock, 2012). The current fourth wave is concerned with integrating research across multiple levels of analysis, with a focus on epigenetics, neurobiology, brain development, behaviour, and context (Wright et al., 2013). This wave has been facilitated by technological advances and the need to integrate research from various disciplines in order to respond to national and global threats (Masten & Obradovic, 2006; Wright et al., 2013). These technological advances reveal the interaction that occurs between genes and the environment, which may in turn assist in the development of early preventative measures in JIA (Bruck, Schnabel, & Hedrich, 2015; Cobb, Hinks, & Thomson, 2014; Gilbert & Punaro, 2014; Hinks et al., 2013; Van Dijkhuizen & Wulffraat, 2015). In line with current conceptualisations regarding resilience, DeMichelis (2016) argues that adopting a relational understanding of resilience within the medical context of child and adolescent chronic disease is essential. Thus, given the current emphasis on integrating multiple systems research in the field of resilience, it is essential that this study make use of a multilevel analysis framework that enables integration with other studies.

2.3.2.2 Defining resilience.

Since the 1970s, numerous definitions of resilience have been posited, all of which require an identified risk succeeded by a defined adaptive outcome (Zolkoski & Bullock, 2012). Thus, two characteristics are needed to infer resilience – namely, the presence of adversity and positive adaptation (Masten, 2014). With the incorporation of the developmental systems approach, definitions have become broader and more dynamic to reflect multiple levels of transactions (Carey DeMichelis, 2016; Wright et al., 2013). Moreover, Rutter (2012) notes that resilience is an interactive concept whereby the presence of resilience is implied as a result of differences in individual adaptation when faced with adversity. Indeed, Masten and Barnes (2018) provide a systems-based and interactive definition in which resilience is "the capacity of a system to adapt successfully to challenges that threaten the function, survival, or future development of the system" (p. 2). This definition means that a person's resilience is constantly changing, and the individual's capacity for adapting is spread across interacting systems (Masten, 2014). However, DeMichelis (2016) emphasises that, for researchers in the child and adolescent medical context, it is essential to acknowledge that resilience is relational in nature – it is not equated with recovery – and that well-being can take many forms. In DeMichelis' (2016) proposed definition of relational resilience within medical contexts, "resilience is shown to be a process of complex interpersonal, institutional and political interactions, which together make it more or less possible for people to do well in the face of adversity" (p. 1). This definition is more appropriate for the current study, as she elaborates that, by supporting children and families "through close personal relationships, through institutional partnerships, and through equitable political process, they are better able to sustain well-being" (DeMichelis, 2016, p. 1). Ungar (2016) also highlights the importance of institutional partnerships and advocates that, in the medical context,

> the resilience of individuals is their capacity to navigate to the resources they need to do well, along with the capacity of systems to negotiate with individuals and their caregivers to decide how resources will be provided to ensure they meet people's needs in ways that makes sense to them. (p. 215)

Thus, resilience is a multifaceted concept that requires a relational, multisystemic approach to understand the intricacies involved.

2.3.2.3 Resilience factors and processes.

Resilience is a complex term that can be used to denote factors and processes (Zautra, Arewasikporn, & Davis, 2010). Resilience factors, also known as promotive factors or assets, are measurable characteristics of individuals or groups across all levels of risk that predict a desirable outcome (Masten & Tellegen, 2012; Rutter, 2012). As with risk theory, the focus has shifted from factors to processes that function at multiple levels (Feinstein et al., 2018; Hadfield & Ungar, 2018; Infurna & Luthar, 2018; Masten, 2018). Ungar (2012) asserts that resilience refers to "the processes that individuals, families and communities use to cope, adapt and take advantage of assets when facing significant acute or chronic stress, or the compounding effect of both together" (p. 387). Similarly, R. Brown and Kupst (2016) emphasise the social-ecological nature of resilience processes within chronic illness, which they note are multiplicative rather than additive.

Individuals develop processes such as coping strategies to manage unfavourable conditions. Coping strategies are specific cognitive and behavioural processes that individuals use to manage adverse situations (Lazarus & Folkman, 1984). These processes can be both adaptive and maladaptive, and are therefore not synonymous with resilience, but they can be a source of resilience (Compas & Andreotti, 2013). Compas et al. (2012) conducted a literature review of child and adolescent coping strategies in dealing with chronic illness and posited a control-based model of coping consisting of three levels of strategies – namely, primary, secondary, and disengagement. Primary coping strategies are active in that the individual attempts to act on the cause of the stress or the emotions being experienced by using strategies such as problem solving or emotional expression. Secondary coping strategies are accommodative, seek to adapt to the source of stress, and include strategies such as positive thinking, distraction, and cognitive reappraisal (Compas et al., 2012). Finally, disengagement or passive coping strategies involve avoiding or denying the stressor. The authors found that disengagement strategies correlated with lower levels of adaptation and emotional regulation and may prevent the use of active coping strategies. Haase (2004) reported, however, that in the early stages of cancer, adolescent use of avoidant strategies can be adaptive, but in the long term this becomes maladaptive. Moreover, Compas et al. (2012) found that active coping strategies were not as effective as secondary coping strategies, possibly owing to the uncontrollable nature of chronic illness. They concluded that the efficacy of the coping strategy depended on the individual's ability to control the stressor – where this was not possible, secondary coping strategies were more successful. Resilience processes and successful coping strategies lead to positive adaptation and outcomes.

2.3.2.4 Outcomes of resilience processes.

Resilience processes lead to positive or adaptive outcomes (Davis & Suveg, 2014; Masten & Monn, 2015). Certainly, Wright et al. (2013, p. 18) report that "a variety of criteria have been utilized to judge positive adaptation in the literature, including criteria focused on the absence of pathology, successes in age-salient developmental tasks, subjective well-being, or all of these". Although the absence of pathology is an important indicator of positive adaptation, this criterion does not fall within the parameters of the current study. However, the attainment of developmental tasks (see section 2.2.2.1, p. 14) and subjective well-being may be valuable indicators of the adolescent participant's positive adaptation to JIA.

Well-being is a complex construct that has resisted simple definition and has given rise to intense debate (Jayawickreme, Forgeard, & Seligman, 2012; Kern, Benson, Steinberg, & Steinberg, 2016; La Placa, McNaught, & Knight, 2013). Subjective well-being can be defined as "a person's cognitive and affective evaluations of his or her life as a whole" (Diener, Oishis, & Lucas, 2009, p. 187). In other words, well-being relates to the degree to which an individual views their life as good and desirable (Diener, Pressman, Hunter, & Delgadillo-Chase, 2017). It is a broad construct that encompasses high levels of positive affect, low levels of negative affect, as well as high levels of life satisfaction (Ronen, Hamama, Rosenbaum, & Mishley-Yarlap, 2016). Although individuals are seen as actively creating and interpreting their well-being, their perceptions are influenced by cultural expectations (La Placa et al., 2013). Furthermore, subjective well-being and health are considered to be mutually influential. There is much debate as to how well-being is measured – subjectively, objectively, or through a combination of both subjective and objective measures (Masten, 2014). For the purposes of this qualitative study, narrative accounts of subjective well-being will be focused on in order to elicit the participants' unique perspectives.

Although Zautra et al.'s (2010) work in the field of chronic pain refers to well-being, rather than subjective well-being, their resilience outcomes enable a more nuanced understanding of subjective well-being. They identified three main classes of resilience outcomes that lead to well-being – namely, recovery, sustainability, and growth. "Recovery" refers to the physiological, cognitive, and affective changes that occur in an individual after an adverse event; "sustainability" is concerned with continued perseverance in activities that lead to positive self-esteem and emotions. "Growth" refers to a greater awareness of one's capabilities and new learning that occurs as a result of an adverse experience and coping efforts (Sturgeon & Zautra, 2010; Zautra et al., 2010). Cousins et al. (2015) have adapted Zautra et al.'s model to the field of paediatric chronic pain, which may prove useful in exploring the adolescent participants' experiences of subjective well-being in this study.

The following section presents resilience research findings that are relevant to the study of adolescents with JIA, chronic illness, and chronic pain.

2.3.3 Adolescent Resilience During Chronic Illness and Pain

It is necessary to clarify the terms "illness" and "disease" before progressing further. These terms are often used interchangeably in psychological research and journal articles. However, Ventriglio et al. (2017) contend that Eisenberg's (1977) clarification of these terms is still applicable. Eisenberg (1977) posited that "disease" refers to pathology, which is in the domain of medical practitioners to identify and manage; whereas, "illness" is the patient's subjective perspective of how the disease impacts on his or her physical and psychosocial functioning. In this study, Eisenberg's conceptualisation of these terms will be used. Thus, the term "disease" will be used in sections explaining the medical aspects of JIA, whereas "illness" will be used when discussing psychosocial aspects.

Understanding adolescent resilience during chronic illness requires a developmental perspective that acknowledges that the manner in which the transition to adolescence is managed affects disease and illness outcomes for the balance of the lifespan (Lennon et al., 2016). It is thus important to identify multisystemic factors and processes that enable resilience in adolescents with chronic illness (Lennon et al., 2016).

A database search revealed two published studies within the field of resilience development amongst children or adolescents with JIA (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & NREPP databases, 24 January 2019). One article discusses the protocols for a systematic review of family resilience and adaptive coping in children (Saetes et al., 2017). The second article discusses resilience processes in adolescents with JIA (Cartwright et al., 2014). Turner-Cobb and Cheetham (2016) also report that research regarding resilience interventions in children and adolescents with JIA is scarce, and that they were unable to find studies in this regard. Thus, it was necessary to refer to literature concerning child and adolescent chronic illness.

Childhood chronic illness has been defined by Van Cleave, Gortmaker, and Perrin (2010) as all physical, emotional, or mental conditions that prevent children and adolescents "from attending school regularly, doing regular school work, or doing usual childhood activities or that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment" (p. 625). A limited number of studies regarding resilience in adolescents with chronic illness and immune-related illness were found, and only one study on mindfulness that focused on adolescents with chronic pain was found (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & NREPP databases, 24 January 2019). Moreover, studies regarding resilience in chronic illness and pain often group children and adolescents together (Asmundson, Noel, Petter, & Parkerson, 2012; Cousins et al., 2014, 2015; E. Fisher et al., 2017; Guite, Logan, Simons, Blood, & Kerns, 2011; Kalapurakkel et al., 2014; McKillop & Banez, 2016; Palermo et al., 2014; Sinclair et al., 2016; Vervoort, Logan, Goubert, De Clercq, & Hublet, 2014). Studies that include adolescents as participants have been used to gain an understanding of resilience factors and processes in this field of study.

2.3.3.1 Resilience factors.

Positive character traits such as optimism, hope, mindfulness, positive self-concept, and high self-esteem have been linked to improved resilience in adolescents with chronic illness and pain (Cousins et al., 2015; Ferguson & Walker, 2014; Lennon et al., 2016). A key resource is thought to be dispositional optimism, which can be defined as a broad, generalised confidence that future outcomes will be favourable (Carver, Scheier, & Segerstrom, 2010; Cousins et al., 2014). Optimism has been found to improve coping strategies in the face of adverse events (Carver et al., 2010; Cousins et al., 2014) and to improve subjective well-being (Foregard & Seligman, 2012). Optimism was found to minimise pain-related fear and improve health-related quality of life (Cousins et al., 2014; Saetes et al., 2017). Also, optimism enables individuals to persevere in the face of adversity and to reach long-term goals, which in turn further bolsters optimism in chronically ill adolescents (Ferguson & Walker, 2014). In addition, optimism has been linked to improved immune functioning (Cousins et al., 2014).

A similar construct, hope, has been linked to resilience (Griggs & Walker, 2016; Lennon et al., 2016). Hope can be defined as “the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways” (Snyder, 2002, p. 249). During illness, hope is an important factor in coping with the illness itself and also with pain (Rand & Cheavens, 2009). Hope enables adolescents to find meaning in chronic illness, and it improves emotional well-being, quality of life, and self-esteem (Griggs & Walker, 2016). Moreover, hope improves health and increases treatment adherence (Griggs & Walker, 2016; Rand & Cheavens, 2009). Cousins et al. (2015) also identified self-concept and self-esteem as being correlated with pain adaptation. In addition, positive self-concept and high self-esteem have been linked to improved resilience in adolescents with chronic illnesses (Lennon et al., 2016; Saetes et al., 2017; Turner-Cobb & Cheetham, 2016).

Similarly, mindfulness – which refers to a state of consciousness in which attention is paid to present-moment experience in an accepting and non-judgemental manner – has also been found to be an important resilience trait (Petter, Chambers, McGrath, & Dick, 2013). Petters et al. (2013) found that mindfulness predicted decreased pain intensity, pain interference, and pain catastrophising in adolescents. Furthermore, having a growth mindset – that is, the perception that a personal attribute is malleable – has been linked to improved coping in the face of adversity (Dweck, Walton, & Cohen, 2014; Haimovitz & Dweck, 2016; Schroder et al., 2017). Indeed, studies have shown that adolescents who believe in their potential to change and adapt are more resilient than those with a fixed mindset (Jach, Sun, Loton, Chin, & Waters, 2017; Schleider & Weisz, 2016; Yeager & Dweck, 2012). These individual resilience factors can be engendered and facilitated by contextual resources.

Typically, family and social resilience resources would incorporate aspects such as adaptive family functioning, social support, supportive school environment, and teacher support (Cousins et al., 2015; Lennon et al., 2016; R. Brown & Kupst, 2016). Although there is considerable research on the deleterious effect of adolescent pain on parent and family functioning, there has been little focus on parents and family as resilience resources (Cousins et al., 2015; Saetes et al., 2017). Palermo et al. (2014) stress the importance of understanding the bi-directional relationship between the child and the family. Through this relationship, parent and family factors shape the individual's perception of and response to pain; however, the adolescent's responses can also shape those of the parents (Palermo et al., 2014; Sinclair et al., 2016). Adaptive family functioning and secure attachment are protective factors in adolescent chronic pain and illness (Lennon et al., 2016; Sansom-Daly et al., 2012; Sinclair et al., 2016; Turner-Cobb & Cheetham, 2016). Pain adaptation is enhanced when parents utilise acceptance strategies, practise emotional regulation, and communicate effectively (Palermo, 2014). Hoehn, Foxen-Craft, Pinder, and Dahlquist (2016) assert that parents can promote resilience by minimising physical health risks, facilitating emotional adjustment, and enabling the continuation of daily living. More specifically, they discuss helping adolescents to adapt to medical procedures, augmenting adolescent competence in managing and adhering to treatment, and cultivating the development of autonomy and social competence (Hoehn et al., 2016). Moreover, clearly defined roles, effective problem solving, and good cohesion within families facilitate improved outcomes (Cousins et al., 2015; Sansom-Daly et al., 2012).

Outside of the nuclear family, social experiences are often limited because chronic pain interferes with an individual’s ability to engage in social activities. Some research has shown that supportive peer relationships enable improved coping with pain (Ferguson & Walker, 2014; Forgeron et al., 2010, 2013). Although supportive teacher relationships and connectedness with the school have been shown to be protective factors in adolescent development, these have received little attention in relation to adolescent chronic illness (Sinclair et al., 2016). However, one study by Vervoort et al. (2014) found that teacher support enhanced competence and autonomy, as well as serving a buffering role for pain severity, bullying, and school absenteeism. St Leger (2014) reported that school support was beneficial. Nevertheless, optimising school support is an ongoing process, as knowledge and experience are gained over time by schools. Ungar (2016) argues that the resilience of chronically ill individuals is greatly enhanced when social or community institutions ensure that resources are available and accessible, when interventions by multiple service providers are coordinated, and when interventions are contextually and culturally relevant.

Cultural resources usually encompass aspects such as religiosity or spirituality, community support, neighbourhood safety, climate, and socio-economic status (Cousins et al., 2015; N. Reynolds, Mrug, & Guion, 2013). Cultural or community context may influence the choice of coping strategies employed by adolescents (C. Campbell & Edwards, 2012; Ferguson & Walker, 2014); furthermore, religious and spiritual social support has been linked to improved resilience (Reynolds et al., 2013). Such resilience factors have been found to combine with resilience processes to foster well-being.

2.3.3.2 Resilience processes.

Several resilience processes have been highlighted in chronically ill adolescents. Individual processes, such as having life goals (Ferguson & Walker, 2014); maintaining relationships with friends and school (Ferguson & Walker, 2014); and the self-regulation of behaviour, emotion, and cognition were identified (Bhana et al., 2016; Lansing & Berg, 2014; Saetes et al., 2017). Furthermore, according to McCracken and Morley (2014), pain acceptance – an individual's preparedness to live a life of pain while embracing a lifestyle that has personal meaning, but without trying to avoid or control the pain – also bolsters resilience. In Wicksell, Olsson, and Hayes's (2011) Swedish study with 32 adolescents, an Acceptance and Commitment Therapy intervention was implemented. Findings indicated that pain acceptance led to improvements in pain impairment beliefs and decreased pain reactivity, which in turn resulted in improved emotional and physical functioning despite a lack of symptom alleviation.

Committed action – another resilience process – refers to value- and goal-driven behaviour that is persistent but flexible (McCracken, 2013). Individuals that engage in committed action can manage failure and discomfort as well as abandon behaviours that are unsuccessful. These self-regulatory behaviours are particularly important in relation to lifestyle management in which both exercise avoidance and over-exercising can increase chronic pain. Furthermore, pain self-efficacy – the belief that one can function adequately despite experiencing pain – has been related to improved functioning in chronic illness and chronic pain (Griggs & Walker, 2016; Kalapurakkel et al., 2014). In this regard, a study of 199 adolescents with chronic headaches found that pain self-efficacy was a protective factor that partially mediated pain-related fear, disability, and school functioning (Carpino, Segal, Logan, Lebel, & Simons, 2014). Similarly, Kalapurakkel et al.'s (2014) study of 209 adolescents with chronic headaches indicated that the combination of pain self-efficacy and pain acceptance was linked to decreased disability, reduced levels of depression, and improved school functioning.

Another resilience process is active coping, which refers to directed action to control pain (Cousins et al., 2015; Saetes et al., 2017). Active coping styles encompass problem-solving strategies and seeking social support, and have been found to be significantly correlated with a decrease in functional disability in adolescents (Sinclair et al., 2016). In this regard, positive spiritual coping was found to decrease levels of anxiety, depression, and acting-out behaviours in adolescents (Reynolds et al., 2013). These resilience processes are forms of self-regulation, and self-regulation during development is mediated by the context (Sameroff, 2014). Moreover, some adolescents have described a process of self-growth, character development, and increased sense of responsibility as a result of JIA (Cartwright et al., 2014).

Resilience processes also function within adolescents' contexts. Palerma et al. (2014) report that substantial evidence has been compiled to support the importance of parent emotions, behaviours, and cognitions in the functioning and pain management of the child. Indeed, parent pain acceptance may impact positively on child functioning, as parents are role models of how to cope effectively (A. M. Smith, Sieberg, Odell, Randall, & Simons, 2015). As noted earlier, the interplay between child and parent variables is dynamic and complex (A. M. Smith et al., 2015). Child pain acceptance appears to be tied to parental pain acceptance and both impact on the child's functional disability (A. M. Smith et al., 2015). Similarly, D. Wallace, McCracken, Weiss, and Harber-Weber (2015) found that parent psychological flexibility, including pain acceptance, is associated with higher levels of pain acceptance and functioning, and lower levels of depression in adolescents. Interestingly, there is scant reference to resilience processes between the medical system and adolescents or children. Indeed, DeMichelis (2016) emphasises the need to identify the range of adversities within the medical system that families need to overcome so that opportunities for resilience processes can be implemented. Moreover, he notes the need for practitioners to assume an interdisciplinary stance. However, St Leger (2014) reports that some participants shared how health practitioners have fostered hope.

2.3.3.3 Subjective well-being during chronic illness.

Subjective well-being has been found to contribute to improved health and longevity in two ways (Diener et al., 2017; Tay, Kuykendall, & Diener, 2015). Firstly, positive emotions can improve physiological functioning in the cardiovascular, immune, and endocrine systems, and can increase resilience (Diener et al., 2017; Diener et al., 2018; Tay et al., 2015). Similarly, negative emotions cause regulatory dysfunction and increase vulnerability. Secondly, elevated levels of subjective well-being result in health-promoting behaviours such as following a healthy diet and engaging in physical exercise (Tay et al., 2015). In turn, chronic illness that impacts on daily living can influence subjective well-being (Mukuria & Brazier, 2013). Graham, Higuera, and Lora (2011) report that the health conditions most likely to be related to lower levels of subjective well-being are pain, anxiety, and difficulty engaging in usual activities. Similarly, Mukuria and Brazier (2013) found that subjective well-being was correlated with engagement in normal daily activities, the ability to care for oneself, and the level of pain experienced. Pain, anxiety, and difficulty engaging in daily activities and self-care are prominent features of JIA and are thus important aspects to investigate in this study.

An extensive review of literature in the field of the well-being of adolescents with chronic illness, chronic pain, or JIA (Barlow & Ellard, 2006; Barlow, Wright, Shaw, Luqmani, & Wyness, 2002; Cavallo, April, Grandpierre, Majnemer, & Feldman, 2014; Kaushansky et al., 2017; Lal et al., 2011; Lomholt, Thastum, Christensen, Leegaard, & Herlin, 2015; Sällfors, Hallberg, & Fasth, 2004; Sinclair et al., 2016; Tarakci, Yeldan, Kaya Mutlu, Baydogan, & Kasapcopur, 2011) reveals that the term “well-being” has not been operationalised in international articles. Rather, this term is used as a broad and vague outcome. Furthermore, terms such as “well-being”, “wellness”, and “quality of life” are used loosely and interchangeably. Despite the lack of conceptual clarity, the findings from these studies indicate that JIA has a deleterious effect on the psychosocial functioning of adolescents. Interestingly, adolescents with JIA tend to disagree with their parents’ ratings of disability, well-being, and pain (Lal et al., 2011). Moreover, some adolescents with JIA have described an increased sense of responsibility, as well as a process of self-growth and character development as a result of JIA (Cartwright et al., 2014).

A database search found two articles that focused on well-being in adolescents with JIA (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & NREPP databases, 24 January 2019). Barlow et al. (2002) explored the influence of maternal stressors and well-being on the well-being of children with JIA. Their study consisted of 30 children and their mothers. The researchers did not provide the age range of the children nor did they define well-being. A variety of self-report measures were used and analysed through Pearson correlations. The study had originally intended to study both parents, but only one father accompanied his child. The researchers found that children's physical functioning was linked to maternal distress; however, there was no association between maternal well-being and the children's self-reported ratings of anxiety, depression, pain, and self-esteem.

A later study by Sällfors et al. (2004) aimed to describe a model for predicting well-being in children with juvenile chronic arthritis. This quantitative study involved 125 Swedish adolescents and used self-report questionnaires – specifically the Childhood Health Assessment Questionnaire and the Visual Analogue Scale. Sällfors et al. (2004) conceptualised well-being as consisting of the adolescents' own affective and cognitive evaluations of their lives. Findings indicated that pain was a robust predictor for well-being, with the number of pain-free days and attendance of physical education classes correlating with higher levels of well-being. Furthermore, protective factors included a good school environment, being physically active, having good intimate relationships, and feedback from peers. Nevertheless, Sällfors et al. (2004) also indicated that almost 50% of the variation in adolescents' well-being was explained by factors not included in their regression model, and they emphasised the value of using qualitative studies to explore this further. Accordingly, the research design of this study takes into account the multiple systems in which the adolescent is situated, and uses qualitative methodology to explore the adolescents' psychosocial experiences as broadly as possible. This approach should allow for new data to come to the fore.

The limited number of studies that have investigated the subjective well-being of adolescents with JIA indicates the necessity of further exploratory research in this area. A focus of this study is the psychosocial factors that influence the subjective well-being of adolescents with JIA. It is critical that research methods used in this study be appropriate.

2.3.3.4 Resilience during chronic illness within the South African context.

The South African context places many adolescents at risk for maladaptive developmental trajectories. Factors such as poverty, low levels of education, and violence make the negotiation of adolescence very difficult and place youth at risk (Mosavel, Ahmed, Ports, & Simon, 2015). With regard to child and adolescent health in South Africa, there are more than 55,000 children suffering from chronic illness, but only 14.9 % of children have access to medical aid, while 72.6% rely on medical care from public clinics (Statistics South Africa, 2017). Estimates of the prevalence of juvenile idiopathic arthritis vary, with a conservative estimate being 18,700 (Weakley & Scott, 2012); however, international studies suggest that the prevalence of JIA may be as high as four in 1000 (Scott & Brice, 2015). Given that current statistics estimate the number of children in South Africa to be 18,566,000 (Statistics South Africa, 2017), it is possible that the prevalence of JIA in South Africa may be over 70,000. The need for South African studies that focus on adolescent resilience in chronic illness is clear.

Despite the range of South African studies that have investigated resilience and wellness processes in the field of medicine (Heath, Donald, Theron, & Lyon, 2014; Hills, Meyer-Weitz, & Asante, 2016; Meda, 2016; S. Edwards, 2015; Van Rensburg, Theron, & Rothmann, 2015), only a small number of studies have been conducted within the field of physical health. One study researched resilience within the health care system in general (Eyles, Harris, Fried, Govender, & Munyewende, 2015). Moreover, in the field of chronic illness, AIDS seems to be the primary focus of resilience studies (Bhana et al., 2016; Heath et al., 2014; Pienaar, Swanepoel, Van Rensburg, & Heunis, 2011; Visser et al., 2012; Wadley, Mitchell, & Kamerman, 2016).

One mixed-methods study explored resilience in 16 families living with a child diagnosed with type 1 diabetes (O. Brown, Fouché, & Coetzee, 2010). The researchers found that the family system provides crucial support for children with chronic illness. Specific variables that would enable practitioners to facilitate resilience were identified – namely, working together as a family unit to manage the diabetes, communication, family time and family routines, acceptance of the diabetes, adherence to a treatment regimen, hardiness, and gaining skills and knowledge. Furthermore, it was found that the role played by medical practitioners extended beyond physical treatment regimens and that spiritual or religious affiliations can be used as a resource.

Consequently, O. Brown et al. (2010) recommended that more studies that explore resilience in families over a wider range of chronic illnesses should be conducted. Clearly, there is a need for further research in South Africa regarding adolescent resilience in chronic illness, specifically JIA. Research that is qualitative in nature will enable a more nuanced, contextualised understanding of the resilience processes involved. The following section situates subjective well-being as the resilience outcome that will be explored in this study.

2.4 Developmental Psychopathology and Resilience Research Methods

It is necessary for the research methodology to fit the conceptual framework and the research problem in order to generate meaningful answers and ensure credibility (Bloomberg & Volpe, 2012). Current developmental psychopathology and resilience approaches incorporate relational developmental systems theory, which advocates that research should be developmentally appropriate, take into account multilevel transactions, and be translational (Cicchetti, 2006; Lerner & Overton, 2008; Marshall, 2013; Masten & Monn, 2015; Sameroff, 2014). Furthermore, qualitative studies are valued as they contribute depth and expand on quantitative research (Kang, Mellins, Ng, Robinson, & Abrams, 2008; F. Reynolds, 2017; Rutter, 2006; Sterba & Bauer, 2010; Sullivan, 1998; Ungar, 2012). Indeed, F. Reynolds (2017) argues that qualitative research strategies are well suited to exploring the complexity of psychosocial experiences in disability and serious illness. Thus, the research methodology used in this study is supported by current trends in the fields of developmental psychopathology and resilience.

Cicchetti and Rogosh (2002) proposed that developmental psychopathology is an appropriate framework for informing the design of studies investigating adolescent phenomena. Moreover, a significant number of studies regarding adolescents that use a developmental psychopathology framework have taken place, which supports the use of this approach in the present study (Ensink et al., 2015; Fairchild, 2011; L. Brown & Wright, 2001; Séguin, Arseneault & Tremblay, 2007; Steinhausen, 2006). Similarly, there has been considerable research in the area of adolescent resilience (Brownlee et al., 2013; Coleman & Hagell, 2007; Compas & Andreotti, 2013; Ferguson & Walker, 2014; Martel et al., 2007; Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003; Scoloveno, 2015). Thus, using a developmental psychopathology framework for the current study is well-substantiated.

Traditionally, research in the fields of developmental psychology and resilience has been dominated by studies that utilise a quantitative approach to methodology. However, as early as the 1990s, it has been argued that a qualitative approach is needed in order to incorporate contextual factors into the understanding of developmental processes (Rutter, 2013a; Sullivan, 1998). Rutter (2013a) contends that some of the best research began with rigorous quantitative analyses, but thereafter detailed qualitative studies were undertaken to gain a more nuanced understanding of the processes involved. In contrast, F. Reynolds (2017) argues that in many cases, beginning with quantitative methods is premature, as there is insufficient evidence on which to base appropriate questions and response choices.

Masten, Cutuli, Herbers, and Reed (2009) identified four types of research models used in the fields of developmental psychopathology and resilience – namely, variable-focused, person-focused, pathways models, and transactional models. Transactional models are based on the latest relational developmental systems theory, and they account for the complexity of development pathways and the need to integrate research across disciplines and levels of analysis (Cicchetti & Curtis, 2007). Sameroff's (2010; 2014) unified theory of development is a transactional, multilevel analysis model that will be used in this study to integrate understandings of risk and resilience factors in the development of adolescents with JIA.

Ethically, the principle of beneficence indicates that research should be of benefit in some way either to the participants, or to the broader research domain (Hammersley, 2015). Toth and Cichetti (2010) note that developmental psychopathology is well suited to facilitate translational research – which applies findings from research to improve health and well-being – as well as basic and applied research.

Thus, developmental psychopathology is an appropriate conceptual framework to underpin this qualitative research study, as it incorporates the constructs of resilience and subjective well-being. Furthermore, this framework assumes a developmental approach, which makes it well suited to researching the adolescent stage. Also, developmental psychopathology supports the use of qualitative methods to deepen the understanding of individual experiences and of bi-directional transactions that occur between and within multiple systems. Finally, developmental psychopathology embraces the translation of research to informed practice, which hopefully will result from this study.

2.5 Conclusion

This chapter aimed to provide an overview of the conceptualisation underpinning the present study. The argument was made that developmental psychopathology is an appropriate framework for this research topic. The importance of multilevel analysis was highlighted, and Sameroff’s unified theory of development was presented as a suitable multilevel analysis model. Furthermore, risk and resilience theory was situated within the developmental psychopathology framework and linked to research regarding JIA, chronic illness, and pain. JIA was thus positioned as a risk factor in adolescent development, with resilience processes leading to possible subjective well-being. Moreover, the need for qualitative research in this area was made apparent by the dearth of existing literature. The following chapter will discuss relevant research in the areas of adolescent development and JIA.

CHAPTER 3: THE ADOLESCENT LIVING WITH JIA – A DEVELOPMENTAL PSYCHOPATHOLOGY PERSPECTIVE

3.1 Introduction

Adolescence was traditionally thought to be a stormy period marked by stress, vulnerability, and risk (Hall, 1904; Hollenstein & Lougheed, 2013). The fact that most adolescents successfully negotiate this period challenges this perspective. Furthermore, in recent times, adolescence has been claimed to be an age of opportunity (Steinberg, 2014). Indeed, by adopting a developmental systems perspective that integrates risk and resilience processes, a more balanced stance is promoted (Lerner & Castellino, 2002). Such a stance acknowledges that puberty is universal, but individual and contextual variance means that adolescent development is not uniform and can result in adaptive and maladaptive trajectories (Steinberg, 2017). Hence, adolescents with a chronic illness such as JIA experience the same developmental issues as healthy adolescents, but their developmental pathways are often disrupted (Turner-Cobb & Cheetham, 2016). This chapter defines adolescent development and delineates current research on adolescents' physical and psychosocial development. Thereafter, the nature of JIA and its effects on the physical and psychosocial development of adolescents will be presented.

3.2 Adolescent Development

3.2.1 Defining Adolescence

The term "adolescence" originates from the Latin word *adolescere*, meaning to "grow into adulthood" (Steinberg, 2017, p. 3). Accordingly, adolescence is a critical developmental period that can be defined as the transitional stage that occurs between the onset of puberty and the establishment of social independence (Steinberg, 2014). Despite this seemingly simple definition, there is much inconsistency in the existing literature regarding the age boundaries of adolescence

(Curtis, 2015; Gutman, Peck, Malanchuk, Sameroff, & Eccles, 2017; Steinberg, 2017) as even the onset of puberty can vary significantly (Susman & Dorn, 2012). Moreover, the duration of adolescence also differs according to cultural groups, with adolescents in some cultures transitioning quickly to adulthood, while in industrialised cultures further education results in a prolonged transition (Steinberg, 2016). Nevertheless, Curtis (2015) argues that there is a need for conceptual clarity around adolescent age boundaries in order to facilitate research.

The span of 10 to 18 years is the most commonly cited chronological definition of adolescence (American Psychological Association [APA], 2002). The World Health Organization and the South African Department of Social Development define adolescence as the age range between 10 to 19 years (Department of Social Development, 2015; World Health Organization, 2018). Similarly, the International Association for Child and Adolescent Psychiatry and Associated Professions cites the span of 11 to 18 years (Guerra, Williamson, & Lucas-Molina, 2012). Western societies tend to divide adolescence into three overlapping phases: early adolescence from 10 to 13 years, middle adolescence from 14 to 17 years, and late adolescence from 18 to 21 years (Steinberg, 2017). However, in South Africa, the Children’s Act of 2005 (Republic of South Africa, 2006) lowered the legal acquisition of adult status to 18 years of age (Louw & Louw, 2014).

Defining adolescence becomes more problematic in the field of medicine. Some paediatric studies have used the normative Western categories for adolescence – namely, early, middle, and late adolescence (F. Campbell et al., 2016; McDonagh, Southwood, & Shaw, 2007), whereas others make no distinction between children and adolescents (Bomba et al., 2013). Matters are further complicated by the South African Children’s Act, which has legislated that children from the age of 12 years may make decisions regarding their health independent of their parents

(Republic of South Africa, 2006). Furthermore, in sub-Saharan Africa, there are no national guidelines providing an age for transition from paediatric to adult medical care (Dahourou et al., 2017). However, Stefan and Van der Merwe (2008) reported that in South Africa, transition at 13 years was common in the public sector, but they acknowledged that this may not be the case in private health care. The focus of this study will be on research participants who are in the phase of middle adolescence, which ranges between 15 and 18 years in Western society and overlaps with both early and late adolescence (Steinberg, 2017).

The use of Western norms in this study is relevant given that the participants are from white, middle-class communities. This age group is of particular significance as JIA often worsens during adolescence (Mannion et al., 2016). Furthermore, adolescence is the period of transition from paediatric to adult care, which places adolescents at high risk for psychological distress and disease complications (Cartwright et al., 2014; Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014; Mannion et al., 2016; Sauer et al., 2011; Stefan & Van der Merwe, 2008; Wilson, 2017). Adolescence is also a time of increased turmoil as a result of rapid changes in physical and psychosocial development (Dahl, Allen, Wilbrecht, & Suleiman, 2018), which may place individuals with JIA at greater risk than their healthy peers.

3.2.2 Revisiting Storm and Stress

Hall (1904) described adolescence as a period of development characterised by behavioural difficulties and emotional storminess. Despite the acceptance of the "storm and stress" theory in popular psychology, its validity has been challenged (B. Casey, 2015; Payne, 2012; Van Duijvenvoorde, Peters, Braams, & Crone, 2016). Contemporary research indicates that the majority of adolescents do not experience maladjustment (Hadiwijaya, Klimstra, Vermunt, Branje, & Meeus, 2017; Louw & Louw, 2014; Meeus, 2016), with most individuals negotiating the developmental tasks of adolescence successfully (Cicchetti & Rogosch, 2002). Nonetheless, adolescence does engender more turbulence than childhood or adulthood (Hadiwijaya et al., 2017; Meeus, 2016; Steinberg et al., 2017).

Recent neurological research has indicated that the asynchronous brain development between the prefrontal cortex and limbic system during adolescence results in heightened emotional sensitivity without sufficient ability to regulate the arousal (Dahl et al., 2018; Duckworth & Steinberg, 2015; Griffin, 2017; Steinberg et al., 2017). However, past research has been criticised for mostly focusing on negative outcomes, which leads to an unbalanced view of adolescence (Curtis, 2015; O’Connor, Sanson, Toumbourou, Norrish, & Olsson, 2017). Consequently, there has been an increase in international studies that explore the positive aspects associated with adolescence and ways of optimising adolescent well-being (Bach & Guse, 2015; Kern et al., 2016; O’Connor et al., 2017; Ronen et al., 2016; Salam, Das, Lassi, & Bhutta, 2016; Steinberg, 2016). In this vein, Hollenstein and Lougheed (2013) argue that the complexities of adolescence require a multisystemic approach that provides a more balanced and comprehensive understanding of adolescent development. As discussed in Chapter 2, systems-based approaches often use the attainment of developmental tasks to assess normative development (Wright et al., 2013).

3.2.3 Normative Adolescent Development

The term “developmental tasks”, which was first introduced by Havighurst (1948), encompasses normative or socially expected activities or goals during certain periods of the lifespan. In adolescence, these developmental tasks are concerned with establishing identity, autonomy, peer relationships, intimacy, sexuality, achievement, and with exploring career options (Pinquart & Pfeiffer, 2015; Steinberg, 2017). The extent to which these tasks are successfully negotiated depends on the competence attained in earlier years (Masten & Tellegen, 2012). For individuals who have not successfully negotiated earlier stages, adolescence is an opportunity to intervene and promote more competent adaptation, resulting in positive developmental trajectories (Cicchetti & Rogosch, 2002).

Adolescents with chronic illnesses such as JIA have higher levels of difficulty in negotiating developmental tasks than their healthy peers (Behle & Pinquart, 2015; Pinquart & Pfeiffer, 2015). Despite the challenges faced, many adolescents with chronic illness are as successful as their healthy peers in negotiating developmental tasks (Pinquart & Pfeiffer, 2015). Thus, Pinquart and Pfeiffer (2015) stress the need for research on factors that facilitate the attainment of these tasks amongst adolescents with chronic illness. The latter requires an understanding of normative adolescent development in order to interpret the research findings. The following section will present research on adolescent development within the physical and psychosocial systems. Although these systems have been separated for the reader's convenience, their transactional nature is a key philosophical stance of this dissertation.

3.2.3.1 Physical development.

Despite puberty being a universal aspect of adolescence, it is significantly affected by the context of the individual (Griffin, 2017). Steinberg (2017) contends that context affects not only the age of onset, but also the psychological and social consequences of going through puberty.

Puberty is a biological process that is the consequence of a series of neuroendocrine changes which cause internal and external physical changes resulting in reproductive competence (Dorn & Biro, 2011; Susman & Dorn, 2012). Steinberg (2017) reports that these physical changes are manifested in three main ways – namely, a rapid acceleration in growth, the development of primary sex characteristics, and the development of secondary sex characteristics. Consequently, noticeable physiological changes occur in adolescence as the body changes from that of a child to that of an adult within approximately four years (Guyer, Silk, & Nelson, 2016). In addition, Susman and Dorn (2012) note that puberty sparks a rapid and uneven skeletal growth spurt in which the hands, legs, and feet grow first, followed by the body. Furthermore, sexual maturation takes place, with the majority of girls achieving menarche between 10 and 16 years (Dorn & Biro, 2011; Hollenstein & Lougheed, 2013). In boys, sexual maturity is marked by semenarche, which can occur between 11 and 15 years (Hollenstein & Lougheed, 2013).

Given the rapid physiological changes that occur during adolescence, it is the most challenging developmental period during which to have a chronic illness, as continuous adjustments to medication, diets, treatments, and assistive devices are required (Hauser-Cram, Nugent, Thies, & Travers, 2014). Moreover, Susman and Dorn (2012) note that the most important factor in determining the onset of puberty is physical well-being. Thus, chronic illness in general, and JIA in particular, has been linked to delayed puberty (Pozo & Argente, 2002; Umławska & Prusek-Dudkiewicz, 2010).

Hormonal changes during puberty have been found to affect the brain, leading to asynchronous development between the socio-emotional subsystems and the cognitive control subsystems (Hollenstein & Loghleed, 2013). In early adolescence, individuals demonstrate heightened responsivity to socio-emotional signals, resulting in increased emotional arousal and a tendency towards sensation-seeking behaviours (Caballero, Granberg, & Tseng, 2016; Duckworth & Steinberg, 2015). The prefrontal cortex is immature by comparison, and this asynchronous development results in bottom-up emotional responses that are relatively ungoverned by top-down regulatory processes (Duckworth & Steinberg, 2015; Hollenstein & Lougheed, 2013; Selemon, 2013). During mid-adolescence, individuals are more able to control their emotional reactivity, but self-regulation is not consistent until the early to mid-20s (Duckworth & Steinberg, 2015). Consequently, the level of cognitive development will affect self-regulation and the coping strategies that adolescents with JIA can implement.

The adolescent brain is also undergoing its final growth spurt of increased plasticity that enables the brain to change in response to environmental factors and experience (Andersen, 2016; Holder & Blaustein, 2014; Selemon, 2013; Tottenham & Galván, 2016; Whittle et al., 2014). Therefore, adolescence is a period of great opportunity during which immense learning can take place. However, it is also a period of great vulnerability to environmental stressors which can change the neurobiology of the brain, resulting in maladaptive pathways (Holder & Blaustein, 2014; Tottenham & Galván, 2016). Given the sensitivity of the brain to environmental influences during adolescence (Andersen, 2016; Schulz & Sisk, 2016), the effects of JIA may have serious implications for the physical and psychosocial development of adolescents.

3.2.3.2 Psychosocial development.

In the developmental psychopathology model, the psychological domain is not an isolated system but rather an embedded system that develops in concert with the physiological and contextual systems (M. Cox et al., 2010; Sameroff, 2014). The psychological domain is comprised of reciprocal coactions between the cognitive, affective, and behavioural systems (Bronfenbrenner & Morris, 2006).

3.2.3.2.1 Cognitive development.

The neural development that occurs during adolescence results in improved cognitive skills such as problem solving, logical reasoning, language skills, perspective taking, and academic achievement (Caballero et al., 2016; Eccles & Roeser, 2012). Thinking becomes more abstract, multidimensional, and hypothetical (Duckworth & Steinberg, 2015; Steinberg et al., 2017). In addition, information processing, memory retention, and problem-solving skills improve, enabling more sophisticated social and ethical understanding (Steinberg et al., 2017). Adolescents also acquire logical thinking, which improves independent decision making and judgement. By late adolescence, although their cognitive self-regulation is improved, adolescents do not always have the experience or self-awareness to make effective decisions (Duckworth & Steinberg, 2015; Steinberg, 2015).

During adolescence there is an increase in introspection and self-awareness which enables the establishment of a coherent sense of identity, but also results in adolescent egocentrism (Steinberg, 2017). A heightened sense of self-consciousness results in the belief that their appearance and behaviour are the focus of everyone’s attention (Hanna, 2017). Thus, adolescents perceive themselves to be judged by an imaginary audience (Elkind, 1967), causing them to fluctuate between self-criticism and self-admiration (Hanna, 2017). Simultaneously, adolescents believe that they are unique and that no-one can understand them (Lin, 2016). This personal fable (Elkind, 1967) can lead to a sense of invulnerability which may result in increased risk-taking behaviours (Lin, 2016). Adolescents who have experienced direct threats to their survival may, however, overestimate their vulnerability and be concerned about their well-being (Fischhoff, Bruine de Bruin, Parker, Millstein, & Halpern-Felsher, 2010; Griffin, 2017). Furthermore, adolescents who are experiencing adverse situations, such as chronic illness, may be less likely to seek social support because they feel that no-one will understand them (Lin, 2016). They also may assume that they are the only people to have experienced this adverse event and may feel socially isolated (Hanna, 2017). However, Johnson, Blum, and Cheng (2014) argue that an orientation to the future – the ability to view a future self – is correlated with positive outcomes in adverse situations. Thus, chronic illness places the adolescent at risk of maladaptive pathways, but resilience processes may enable adaptive development.

Social cognition skills that are necessary for appropriate social behaviours continue to develop during adolescence (Chiasson, Vera-Estay, Lalonde, Dooley, & Beauchamp, 2017). Adolescents learn to apply critical thinking to social and interpersonal issues and make sense of these matters from their perspectives, leading to the maturation of cognitive autonomy and moral reasoning (Steinberg, 2017). While Kohlberg, Levine, and Hewer (1983) viewed morality as consisting of rational, intentional choices made through conscious processing, this is not the contemporary view (Decety & Cowell, 2014; Decety, Michalska, & Kinzler, 2012). Rather, moral decisions are thought to be influenced by internal and external processes that operate in parallel, often without conscious awareness (Decety & Cowell, 2014; Decety & Howard, 2013; Narvaez & Vaydich, 2008). Neurobiological studies indicate that moral decisions are often affected by unconscious emotional processes, thus underscoring the multisystemic and transactional nature of development (Decety & Cowell, 2014; Decety et al., 2012; Narvaez & Vaydich, 2008; Steinberg, 2017). With maturity, the ability to make moral decisions evolves and there is a shift from a focus on personal consequences towards integrating the perspectives of others (Chiasson et al., 2017; Decety et al., 2012).

The development of abstract thinking, perspective taking, and logical reasoning enables the adolescent to make choices regarding their developing identity. Furthermore, improved cognitive abilities facilitate the development of emotional regulation and emotional autonomy.

3.2.3.2.2 Emotional development.

Adolescence is characterised by the development of identity, emotional regulation, and autonomy (Steinberg, 2017). This section will present recent findings in these areas.

Identity formation. The formation of a new, unique, and individual identity is possibly the most important task for adolescents (Dahl et al., 2018; Erikson, 1968; Marcia, 1966; Ragelienė, 2016). The advent of abstract, multidimensional cognitive skills enables adolescents to imagine what the future could be like and to consider potential identities (Johnson et al., 2014; Schwartz, Donellan, Ravert, Luyckx, & Zamboanga, 2012; Steinberg, 2017). Such visualisations are challenging for adolescents with JIA, as they have to incorporate living with a chronic and possibly lifelong illness into their identities (McDonagh et al., 2016). Furthermore, peers form an important facet of identity development by providing opportunities for new experiences, new activities, and the exploration of different values (Ragelienė, 2016). Scholars have increasingly focused on the idea that multiple, situation-dependent identities are formed during adolescence (Abes, Jones, & McEwen, 2007; S. Jones & Mcewen, 2000; Steinberg, 2017). Therefore, the concepts of health identity (Grabowski & Rasmussen, 2014), illness identity (Leen Oris et al., 2016, 2018; Luyckx et al., 2018), and disability identity (Forber-Pratt, Lyew, Mueller, & Samples, 2017) may have relevance for studies related to adolescent chronic illness. Such research in the field of identity development may have implications for chronically ill adolescents, especially given that marginalised groups may develop greater differences between their public identity and their personal or private identity (McDonagh et al., 2016). Moreover, successful identity formation is a process of exploration and self-reflection that can take several years. Kroger, Martinussen, and Marcia (2010) conducted a meta-analysis of 124 studies published in English and found that only half of the participants had realised identity achievement by the age of 36. Similarly, a study of 172 Finnish participants indicated changes in adult identity across all domains, even during middle adulthood (Fadjukoff, Pulkkinen, & Kokko, 2016). Thus, chronic illness in adolescence may influence identity formation over the lifespan. However, identity formation does not occur in isolation and is inextricably linked to changes in self-concept and self-esteem.

Self-concept – the attributes that individuals see in themselves – becomes differentiated during adolescence (Gecas, 1982; Rosenberg, 1989). Adolescents come to realise that their personality is expressed differently in different situations. Similarly, they not only differentiate between their own opinions of themselves and those of others, but they recognise that they present differently to different people (Sebastian, Burnett, & Blakemore, 2008). Furthermore, adolescents recognise the discrepancy between their real and ideal selves (Frant, 2017; Pfeifer et al., 2009). Too large a discrepancy between the real and ideal self can be maladaptive, causing a sense of failure, self-criticism, and depression (Frant, 2017; Zentner & Renaud, 2007). However, the characteristics of the future ideal self may also provide the motivation to engage in positive behaviours (Santrock, 2014). Early adolescents may feel confused or conflicted about discrepancies in their self-concept, but by late adolescence there is increased clarity of self-concept as different facets of the self are integrated into a coherent and logical whole (Van Dijk et al., 2014). Higher self-concept clarity is related to improved self-esteem.

According to extant literature, adolescent self-esteem – how they subjectively evaluate their worth as a person – increases during late adolescence, although there can be considerable differences in the level of self-esteem amongst individuals in the same age group (Birkeland, Melkevik, Holsen, & Wold, 2012; Luciano & Orth, 2017; Morin, Maïano, Marsh, Nagengast, & Janosz, 2013). Self-esteem may be lower during early adolescence, partly due to biological changes that increase self-consciousness and awareness of body image, as well as due to the stressors that accompany the transition to secondary school (Birkeland et al., 2012; Liu & Xin, 2015; Steinberg, 2017). However, the validity of measuring global self-esteem has been questioned, as adolescents compare themselves variably within and across domains such as academic and athletic ability, appearance, morality, and social relationships (Steinberg, 2017). Indeed, perception of body image has been found to be one of the strongest contributors to self-esteem in adolescence and has a stronger influence on girls than on boys (Birkeland et al., 2012; Donnellan, Trzesniewski, Conger, & Conger, 2007; Leen Oris et al., 2016; Van den Berg, Mond, Eisenberg, Ackard, & Neumark-Sztainer, 2010). Similarly, Pinquart and Pfeiffer (2015) found that girls with chronic illness are less accepting of their bodies than boys. This finding is corroborated in studies regarding adolescents with JIA (McKeever & Kelly, 2015; Tong et al., 2012). Furthermore, research indicates that physical activity and healthy social relations are also important sources of self-esteem (Ahola Kohut et al., 2018; Birkeland et al., 2012; Donnellan et al., 2007; Leen Oris et al., 2016, 2018). Adolescents with JIA have restricted physical activities and social relationships which may result in lower levels of self-esteem.

Another component of identity formation is that of spiritual development. Spiritual development is an integral part of identity formation, as adolescents attempt to find meaning in the world (Apostolides, 2017; Erikson, 1968; Roeser, Issac, Abo-Zena, Brittian, & Peck, 2008; Weaver & Wratchford, 2017). Adolescence is a time of spiritual exploration and questioning that contributes to the establishment of a worldview and to identity formation (Apostolides, 2017; Weaver & Wratchford, 2017). Furthermore, like moral beliefs, spiritual beliefs become more abstract, principled, and autonomous throughout adolescence, moving from the symbolism of early adolescence to the personal experiences of late adolescence (Steinberg, 2017).

Research indicates that, amongst chronically ill adolescents, spiritual well-being has been associated with fewer internalising and externalising problems (N. Reynolds et al., 2013, 2014; Zehnder, Prchal, Vollrath, & Landolt, 2006), fewer occurences of post-traumatic stress (Zehnder et al., 2006), and improved long-term health (N. Reynolds et al., 2014; Turner-Cobb & Cheetham, 2016). According to Weaver and Wratchford (2017), for adolescents with chronic or life-limiting illnesses, exploring identity and meaning has increased significance. The authors reviewed clinical and research findings pertinent to integrating adolescent spiritual health as part of comprehensive palliative support. They concluded that adolescents with chronic or life-limiting illnesses often asked questions regarding "meaning, purpose, fairness, potential for higher power, nature of suffering, etiology of pain or illness, and the afterlife" (Weaver & Wratchford, 2017, p. 276). Such questions necessitate a comprehensive understanding of spirituality that is multisystemic and relational. In this regard, J. Fisher, Francis, and Johnson (2000) posited a broad and interactive model of spiritual well-being which consisted of four domains of well-being – namely, personal, communal, environmental, and transcendental. Spiritual well-being is viewed as the quality of relations that individuals have in these four domains (Gomez & Fisher, 2003; J. Fisher, 2011). The systemic and transactional nature of the model is apparent, as within the personal domain the person intra-relates with self; within the communal domain relations are interpersonal; the environmental domain is where the individual connects with nature; and the transcendental domain is the individual's relation to something beyond the human level (Gomez & Fisher, 2003; J. Fisher, 2011; J. Fisher et al., 2000). Thus, chronic illness during adolescence may influence several domains of spiritual identity.

Emotional regulation and autonomy are closely connected to identity formation and self-esteem (Birkeland et al., 2012; Santrock, 2014). During adolescence, individuals are exposed to new emotional experiences that contribute to their developing identity (Guyer et al., 2016).

Emotional regulation and emotional autonomy. High emotional response and emotional reactivity are characteristics of adolescence which result from changes in the biological, psychological, and social systems (Guyer et al., 2016). Due to this reactivity, adolescence is a vulnerable period for the development of maladaptive patterns of emotional response, but it is also an opportunity for emotional growth via the improvement of strategies to manage emotional reactivity (Guyer et al., 2016; Holder & Blaustein, 2014). The development of emotional regulation strengthens as cognitive abilities mature (Guyer et al., 2016). Developing strategies such as cognitive reappraisal and expressive suppression is critical to minimise negative emotions when managing social interactions (Gross & John, 2003). Moreover, Wu et al. (2013) found that using cognitive reappraisal strategies – changing how one thinks about a situation to change the associated emotion – improves adaptation to adverse events and reduces stress-related psychopathology.

Such emotional regulation does not develop in isolation but within social contexts and as a result of close relationships (Lougheed et al., 2016). In this regard, Klimes-Dougan et al. (2014) contend that parents are the fundamental socialising agents responsible for explicitly and implicitly teaching children the necessary skills for expressing and managing their emotions. Even though parents play a significant role during adolescence, relationships with peers become increasingly important, and the relationship between adolescents and their parents transforms as adolescents become increasingly emotionally autonomous (Dahl et al., 2018; Pace & Zappulla, 2009; Steinberg, 2017) . Similarly, peer relationships have an increasing influence on risk-taking, reward-seeking, and prosocial behaviours (A. R. Smith, Rosenbaum, Botdorf, Steinberg, & Chein, 2018; Dahl et al., 2018; Guyer et al., 2016; Klimes-Dougan et al., 2014). As adolescents relinquish their dependency on their parents, they assume responsibility for regulating their own emotions (Shifflet-Chila, Harold, Fitton, & Ahmedani, 2016; Steinberg, 2017). The development of emotional regulation is especially important in developing appropriate self-management behaviours in chronically ill adolescents and those with JIA (Garnefski, Koopman, Kraaij, & Ten Cate, 2009; Lansing & Berg, 2014; Saetes et al., 2017; Turner-Cobb & Cheetham, 2016). Increased cognitive and emotional regulation leads to improved behavioural autonomy and regulation.

3.2.3.2.3 Behavioural development.

While adolescence has been seen predominantly as a period of risk taking, current findings indicate that positive and prosocial behaviours also develop (Andersen, 2016; Gestsdottir & Lerner, 2008; Guyer et al., 2016; Telzer, 2016; Telzer, Ichien, & Qu, 2015). Furthermore, international research increasingly supports neurobiological asynchronous development as an explanation for adolescents being prone to risk-taking behaviours (A. R. Smith et al., 2018; Crone & Dahl, 2012; Steinberg, 2017; Steinberg et al., 2017; Van Duijvenvoorde et al., 2016). One study revealed that adolescents of approximately 15 years old can self-regulate their behaviour at adult levels in emotionally calm environments (B. Casey, 2015), while other studies indicated that in more negative emotional situations, self-regulation is only fully developed by early adulthood (Cohen et al., 2016; Steinberg et al., 2017). Also, Steinberg et al. (2017) contend that adolescent risk-taking behaviour presents differently – both in degree and manner – in various cultural contexts, which suggests that social context has a strong influence on adolescent behavioural development.

Within the social context, parents and peers have the strongest effect on adolescent behaviour (A. R. Smith et al., 2018; Steinberg, 2017), with the type of peer group that adolescents associate with having a direct influence on their behaviours. If their peers engage in safe behaviour, there is an increased likelihood of the adolescent engaging in safe behaviour; however, the same is true regarding risky behaviour (A. R. Smith et al., 2018; Guyer et al., 2016; Lin, 2016;

Paternoster, McGloin, Nguyen, & Thomas, 2013; Van Duijvenvoorde et al., 2016). In addition, the combination of emotional arousal and risk taking can also facilitate prosocial behaviours such as academic or sporting achievement, and engagement in family and community activities (E. Smith, Faulk, & Sizer, 2016; Guyer et al., 2016; Telzer, 2016). When peers provide positive feedback for prosocial behaviour, this tendency is reinforced (Guyer et al., 2016; Van Duijvenvoorde et al., 2016). Likewise, certain family management practices, such as good communication, appropriate discipline, and nonaggressive conflict resolution, engender prosocial behaviour (Meeus, 2016). Engaging in risky or prosocial behaviours also facilitates the process of identity formation.

Behavioural, cognitive, and emotional development are strongly influenced by the expectations of other individuals in social systems (Sameroff, 2010). The following section explores the different social contexts of the adolescent.

3.2.3.2.4 Social development.

Adolescence is a period of significant social development resulting in more sophisticated social competence and social behaviour (Blakemore, 2012). In this regard, research is increasingly examining how familial and extra-familial relationships facilitate adolescent development (Collins & Steinberg, 2008; Steinberg, 2017).

Family system. During adolescence, family relationships remain important, even though peer relationships become more influential and mature. The focus of adolescent family research has primarily been on parenting and the parent-child dyad, although recently researchers have begun to explore sibling and grandparent relationships (Attar-Schwartz, 2015; Attar-Schwartz & Khoury-Kassabri, 2016; Attar-Schwartz, Tan, Buchanan, Flouri, & Griggs, 2009; Gavazzi, 2013; Steinberg, 2017). Parent-adolescent relationships are seen to be an important facet of development and have been found to be more positive than previously thought (Bush, Peterson, & Chung, 2013; Santrock, 2014).

Traditionally, the socialisation process between parents and adolescents was seen to be one-way, but more recently, the socialisation process has been seen as being reciprocal (Hadiwijaya et al., 2017; Moed et al., 2015; Qin & Pomerantz, 2013). Positive or negative patterns of reciprocated emotional exchange between parents and adolescents can develop, whereby positive emotions in adolescents foster positive emotions in the parents and vice versa (Meeus, 2016; Moed et al., 2015). Although the closeness between parents and adolescents diminishes, parents who continue to be nurturing and supportive foster the development of psychologically well-adjusted, socially competent adolescents who engage in fewer risk-taking behaviours, have improved coping skills, and adjust better to high school (Attar-Schwartz, 2015; Steinberg, 2017).

Adolescent-parent relationships are commonly seen as being high in conflict, but this is not the norm. Low-level conflict and disagreements are common (Bush et al., 2013; Moed et al., 2015), and recent studies suggest that conflict may have positive outcomes contingent on how it is managed (Bush et al., 2013; Moed et al., 2015). Moderate levels of conflict are increasingly viewed as normative and as facilitating better overall adjustment. As such, conflict is thought to enable reasoning, mature decision making, personal insight, an understanding of values, and adaptive development (Hadiwijaya et al., 2017; Meeus, 2016). The role of nurturing and supportive parenting is important for chronically ill adolescents, as are supportive sibling relationships (Turner-Cobb & Cheetham, 2016).

Sibling relationships have a significant influence on adolescent behaviours, attitudes, and achievements (East, 2009). Siblings may be a source of emotional support and communication (Buist, Deković, & Prinzie, 2013), although, in comparison to childhood, adolescent sibling relationships may be less close, not as intense, and result in more equitable relationships (East, 2009). Research indicates that there are fewer behavioural and emotional problems if healthy sibling relationships are maintained (Buist et al., 2013; Campione-Barr, Greer, & Kruse, 2013; McHale, Updegraff, & Whiteman, 2012). Furthermore, siblings are often more influential than parents in relation to navigating peer interactions, dealing with difficult teachers, and discussing taboo subjects (McHale et al., 2012; Santrock, 2014). Close and supportive sibling relationships have been found to ameliorate the effects of adverse experiences (East, 2009).

Increasing attention is also being paid to the supportive role played by grandparents as part of the family system (Attar-Schwartz & Khoury-Kassabri, 2016; Wild & Gaibie, 2014). Studies indicate that although there is less contact with grandparents during adolescence, grandparents still play a beneficial role – albeit more in some cultures than in others (Attar-Schwartz, 2015; Attar-Schwartz & Khoury-Kassabri, 2016; Attar-Schwartz et al., 2009; Wild & Gaibie, 2014). Positive relationships with grandparents appear to improve adolescent psychological, physical, and academic well-being, particularly when families are under stress (Attar-Schwartz, 2015). According to Wild and Swartz (2012), in South Africa, grandparents can play a vital role in supporting adolescents practically, financially, and emotionally. In addition, Wild and Gaibie (2014) report that relationships with grandparents promote prosocial behaviour and improve psychological health. Furthermore, adolescent relationships with grandparents have been found to foster resilience in adversity (Flouri, Buchanan, Tan, Griggs, & Attar-Schwartz, 2010). Thus, supportive familial relationships are key in promoting adaptive adolescent development, particularly in adverse situations such as chronic illness. Peer relationships are also a central feature of adolescent development.

Peer relationships. Peer relationships become a focal point during adolescence, and most adolescents want to belong to a group with shared interests and values (Veenstra & Dijkstra, 2011). There has been a tendency for research in the field of adolescent development to focus on the negative aspects of peer relationships. However, adolescents have been found to influence one another in both positive and negative ways (Steinberg, 2017).

Adolescent friendships are thought to be beneficial in that they may help individuals to cope with stressors, enable the development of self-concept, diminish feelings of loneliness and isolation, contribute to the development of identity and empathy, and increase well-being (Marion, Laursen, Zettergren, & Bergman, 2013; Meter & Card, 2016). Moreover, close friendships have been found to enable perspective taking, insight into others, and the provision of emotional support (Meter & Card, 2016). However, research shows that not all adolescents are accepted by their peer group, and unpopular individuals are more likely to experience a variety of emotional and mental health problems (Griffin, 2017; Guyer et al., 2016; Marion et al., 2013). Indeed, chronic illness and being visibly different are risk factors for peer victimisation (Behle & Pinquart, 2015; Griffin, 2017). Although victimisation can lead to poor self-concept, having one good friend, family support systems, and a specific talent have been found to ameliorate the negative effects of victimisation during adolescence (Griffin, 2017). Steinberg (2017) asserts that early rejection is not necessarily fixed, and as adolescent thinking becomes less rigid and more tolerant, unpopular adolescents become more accepted during late adolescence.

The increased need to conform during middle adolescence can have both a positive and a negative effect on adolescents. While peer pressure is thought to be coercive, research suggests that most adolescents are influenced by individuals that they respect and admire (Ragelienė, 2016). For some adolescents, peer pressure undermines core values and may result in delinquent behaviours and depression (Paternoster et al., 2013; Rageliené, 2016). For others, peer pressure increases prosocial behaviours and success in avoiding risky behaviours (Kilford, Garrett, & Blakemore, 2016). Peer relationships have been found to be particularly problematic for adolescents with chronic illness, as they are often marginalised (Griffin, 2017; Tong et al., 2012), and this may in turn lead to maladaptive trajectories.

Along with increased peer interaction, there is decreased adult supervision during adolescence, which allows for more intimate relationships to develop (Veenstra & Dijkstra, 2011). In addition, Luciano and Orth (2017) posit that the increased capacity for intimacy that is characteristic of adolescence leads to the development of romantic relationships which also influence well-being. This important social transition may benefit adolescents by further developing independence and identity; allowing for companionship; improving communication, interactional skills, and social skills; and increasing levels of well-being and self-esteem (Connolly et al., 2014; Luciano & Orth, 2017). However, given that some chronically ill adolescents are hesitant to disclose their illness for fear of how it may affect relationships (Kaushansky et al., 2017), they may not achieve the same level of intimacy in romantic relationships as their normative peers.

Social interaction with peers and intimate partners also takes place through digital media. Research has emphasised the negative effects of the use of digital media on adolescent development (Benowitz-Fredericks, Garcia, Massey, Vasagar, & Borzekowski, 2012; King, Delfabbro, & Griffiths, 2010; Tam & Walter, 2013; Van Rooij, Schoenmakers, Vermulst, Van den Eijnden, & Van de Mheen, 2011). In contrast, Choudhury and McKinney (2013) caution that the evidence suggesting negative effects of digital media use on brain plasticity and behaviour is not conclusive. In fact, studies have shown that digital media can aid adolescents in negotiating developmental tasks (Ahola Kohut et al., 2018; Borca, Bina, Keller, Gilbert, & Begotti, 2015; Louw & Louw, 2014; Uhls, Ellison, & Subrahmanyam, 2017). In particular, digital media facilitates identity development, personal autonomy, peer and romantic relationships, and future aspirations (Borca et al., 2015; Louw & Louw, 2014; Uhls et al., 2017). Access to the internet may also allow adolescents to engage in health-seeking behaviours (Ahola Kohut et al., 2018; Edwards-Hart & Chester, 2010; Haverman et al., 2012; Henderson, Keogh, & Eccleston, 2014; Henderson, Keogh, Rosser, & Eccleston, 2013). For adolescents with chronic illness and pain, digital media can provide information and social support during periods of limited activity (Ahola Kohut et al., 2018; Henderson et al., 2013; Henderson et al., 2014; Stinson, Feldman et al., 2012). The importance of this is increased amongst adolescents with JIA, as they may experience high levels of school absenteeism.

School system. Adolescents spend more time at school than in any other context (Verhoeven, Poorthuis, & Volman, 2018). School shapes adolescent identity through friendships, engagement in extra-curricular activities, and exposure to culturally based knowledge (Eccles & Roeser, 2012). Furthermore, school is the environment which enables adolescents to prepare for the future. Govender et al. (2013) report that the school context can provide a protective environment that supports the psychosocial well-being of learners. In addition, gaining peer acceptance in high school may be more important to adolescents than academic results (Schall, Wallace, & Chhuon, 2016). Indeed, friendships are seen as being crucial for adolescent development, although school friendships can be social impediments as well as resources (Crosnoe, Cavanagh, & Elder, 2003; Meter & Card, 2016). Research suggests that friendships can foster academic performance and offer resources to negotiate the school system; conversely, school friendships can lead to risk-taking behaviours such as substance abuse, truancy, and delinquency (Crosnoe et al., 2003; Meter & Card, 2016). As a result of physical limitations, high absenteeism, and marginalisation, the school context can be physically and psychologically challenging for adolescents with chronic illness and pain (Cartwright et al., 2014; Kaushansky et al., 2017).

3.2.4 Summary of Adolescent Development

Current research tends to challenge the traditional negative view of adolescence with a more balanced perspective. Adolescence is still acknowledged to be a time of vulnerability owing to the significant development that occurs in the physical and psychosocial domains (Steinberg, 2017). However, most adolescents traverse this period successfully, achieving the relevant developmental tasks. Although past research has focused more on the challenges associated with adolescence, recent research suggests that adolescence can be a period of positive growth and optimised well-being (B. Wallace, 2016; Dahl et al., 2018; Steinberg, 2014). This section has attempted to provide a balanced view of adolescent development that recognises the inherent vulnerability and risk, but also emphasises the positive growth that can occur. When contextual factors are not conducive to optimised well-being, then adolescents are at greater risk of following maladaptive trajectories. A chronic illness such as JIA impacts on all the systems in which an adolescent is embedded, which can disrupt developmental pathways. In line with the developmental psychopathology perspective, the normative development outlined in this section provides the counterpoint for exploring the abnormal development that can occur in adolescents with JIA in the following section.

3.3 JIA

JIA is one of the most common chronic diseases in childhood, and it has no known cure (Beukelman et al., 2017). It is a heterogeneous, polygenic auto-immune disease that causes inflammation of joints and organs and may cause death (Kelly, 2012). JIA can be a serious disease that impacts on physical, emotional, academic, and social well-being, and may persist into adulthood (Beukelman et al., 2017; Hersh & Prahalad, 2015).

3.3.1 Defining JIA

JIA is defined by the International League of Associations of Rheumatology (ILAR) as "arthritis of unknown aetiology that begins before the sixteenth birthday and persists for at least six weeks; other known conditions are excluded" (R. Petty, Southwood, & Manners, 2004, p. 390). Arthritis occurs when the joint is swollen or has limited movement and there is joint warmth, pain, or tenderness (Mosley, 2015). The term "JIA" includes all forms of juvenile arthritis and covers a range of inflammatory auto-immune diseases of varying severity (Bruck et al., 2015). It can be difficult to diagnose because the presenting symptoms vary greatly. However, according to Eisenstein and Berkun (2014), the most recent classification system aims to improve the understanding of the pathophysiology of each disease type, thus optimising the development of more specific treatment interventions.

3.3.2 Classification and Incidence of JIA

In 2004, the ILAR provided a comprehensive classification of the subtypes of JIA, based on clinical laboratory features, to standardise future research (R. Petty et al., 2004). According to this system, JIA is divided into eight subtypes with classification typically occurring six months after onset (Rigante, Bosco, & Esposito, 2015). The subtypes are systemic arthritis, persistent oligoarthritis, extended oligoarthritis, rheumatoid factor negative polyarthritis, rheumatoid factor positive polyarthritis, psoriatic arthritis, enthesitis-related arthritis, and undifferentiated arthritis. Currently, the incidence and prevalence of these subtypes are not well known.

A comprehensive literature review of 43 journal articles of European and North American cases conducted by Thierry, Fautrel, Lemelle, and Guillemin (2014) reported that statistics regarding the incidence and prevalence of JIA vary widely as a result of differences in geographic origin, source population, classification systems, and acquisition of cases. Internationally, the incidence rate – the risk of developing the disease – varies between 2 and 20 cases per 100,000 children, and the prevalence rate – the proportion of cases in the population at a given time – varies between 16 and 150 cases per 100,000 children (Rigante et al., 2015; Thierry et al., 2014). Nevertheless, the most cited prevalence statistic is one in 1000 children, with twice as many girls being affected as boys (Armon, 2013; Beukelman et al., 2017; Mosley, 2015; Prakken, Albani, & Martini, 2011). As with the incidence and prevalence of JIA, further research regarding the aetiology and pathogenesis is required.

3.3.3 Aetiology and Pathogenesis

Aetiology refers to the causes that lead directly to the onset of a disease and involves the interplay of factors that are necessary to trigger the disease process; pathogenesis refers to the factors that maintain the disease (Witthöft, 2013). The aetiology and pathogenesis of JIA are not well understood, and to date research has not been able to provide clear, irrefutable evidence in this regard (Barut, Adrovic, Şahin, & Kasapçopu, 2017; Rigante et al., 2015; S. Bell, Shenoi, Nelson, Bhatti, & Mueller, 2017). The most widely supported theory is that JIA results from the combination of genetic predisposition and an atypical response to environmental factors (Giancane et al., 2016; Hersh & Prahalad, 2015; Neufeld, Karunanayake, & Maenz, 2010; Prahalad, 2006; Rigante et al., 2015; S. Bell et al., 2017). Certain genes appear to be more common in certain subtypes; for example, one study found that HLA-B27 was present in 60 to 90% of individuals with enthesitis-related arthritis (Hersh & Prahalad, 2015). However, it is relevant to note that the inflammatory process in JIA is exceptionally complex, and genetics alone cannot sufficiently explain auto-immune disorders (Hersh & Prahalad, 2015; Rigante et al., 2015; S. Bell et al., 2017)

Prakken and Albani (2009) posit that JIA is caused by multiple factors, including epigenetics and environmental factors. Epigenetics is the term used to denote the reversible, but heritable, changes made in gene regulation as a result of environmental factors (Dieudé, 2009; Woo & Colbert, 2009). During cell replication, these changes are passed on from parent cells to daughter cells, resulting in the development of auto-immune disorders such as JIA (Brooks, Le Dantec, Pers, Youinou, & Renaudineau, 2010). Therefore, in individuals with a genetic predisposition to auto-immune disorders, an atypical response to environmental factors is thought to result in the occurrence and maintenance of JIA (Rigante et al., 2015). According to Rigante et al. (2015), JIA can be caused by infectious diseases such as Epstein-Barr virus, parvovirus B19, cytomegalovirus, and rubella. Similarly, bacterial infections such as streptococcus, salmonella, and mycoplasma pneumonia have also been linked to the pathogenesis of JIA (Rigante et al., 2015). Given the lack of clarity regarding aetiology and pathogenesis, researchers emphasise the importance of continued investigation in these areas in order to aid diagnosis and treatment (Cobb et al., 2014; Rigante et al., 2015; Woo & Colbert, 2009).

3.3.4 Diagnosis

Internationally, the diagnosis of JIA is often delayed; however, if the disease is severe and presents with swollen joints, the diagnosis can be rapid (Foster, Rapley, & May, 2010). A delayed diagnosis has been found to result in a greater risk of functional disability and psychological difficulties (Barut et al., 2017; Foster et al., 2010). Depending on the country, the median interval between experiencing symptoms of JIA and being correctly diagnosed can range from 2.5 months to 10 months, with more extreme delays ranging from 33 months to 163 months (Foster et al., 2010). Furthermore, research indicates that parental concerns are often discounted and that parents can be labelled as being anxious, overly protective, or can even be suspected of child abuse (Foster et al., 2010; Gómez-Ramírez et al., 2016). Despite being dismissed by many medical professionals, parents continue to act as advocates for their ill children (Foster et al., 2010). Research has also shown that children have been diagnosed as having psychosomatic pain owing to the invisible nature of their symptoms (Chausset et al., 2016). There are also no specific laboratory tests for the diagnosis of JIA (B. Wallace, 2016); thus, the diagnosis is one of exclusion (Consolaro et al., 2016), in which all other medical conditions that could cause similar symptoms must be investigated and eliminated.

The diagnosis of JIA is made based on three dimensions – namely, clinical evaluation; family and individual history; and recent pathology tests, including blood and radiology (Kelly & Beresford, 2012). However, laboratory tests for inflammation correspond poorly with disease activity (Gilbert & Punaro, 2014; Rowan, Wyllie, & Foster, 2014). Similarly, Armon (2013) cautions that blood tests are often negative. Therefore, a systematic examination that assesses all joints, respiratory and cardiology systems, rashes, ulcers, muscle weakness, and hair loss should be conducted (Armon, 2013). Consolaro et al. (2016) emphasise that the use of patient- and parent-reported outcomes (PROs) is thought to be crucial in assessing the health state of individuals with JIA. These tools allow the medical practitioner to monitor the disease state and to identify and treat the most pertinent clinical issues. Furthermore, PROs have been found to improve treatment compliance through shared decision making (Consolaro et al., 2016; Giancane et al., 2016).

3.3.5 Treatment

The treatment of JIA requires a multisystemic and multidisciplinary approach that focuses on inducing disease remission and improving the psychosocial well-being of the individual and family (Mosley, 2015). Individuals with JIA should be under the supervision of a paediatric rheumatologist, but a broad range of medical professionals – including specialist nurses, orthopaedic surgeons, orthodontists, dermatologists, ophthalmologists, podiatrists, psychiatrists, psychologists, and physiotherapists – may be involved in various aspects of treatment (Giancane et al., 2016; Kelly, 2012; Mosley, 2015). Thus, treatment is holistic, individualised, and usually involves a combination of pharmacological and non-pharmacological interventions (Davies et al., 2016; Giancane et al., 2016).

Initial treatment tends to be aggressive, as pharmacological treatment aims to achieve total disease control and remission within 3–6 months (Barut et al., 2017; Bos et al., 2016). According to Giancane et al. (2016), non-steroidal anti-inflammatory drugs (NSAIDs) or cortisone are used as the initial treatment modality. If the disease remains active after two months, then disease-modifying anti-rheumatic drugs (DMARDs) are advised. DMARDs are slow acting and aim to change the underlying disease, thus decreasing disease activity (Davies et al., 2016; Falvey, Shipman, Ilowite, & Beukelman, 2017). This category of drugs is divided into non-biologic or conventional DMARDs and biologic DMARDs (Davies et al., 2016). Internationally, methotrexate is the non-biologic drug of choice because it is effective in approximately 70% of cases, has fewer toxic effects than other medications, its long-term safety has been established, and it is inexpensive (Falvey et al., 2017; Giancane et al., 2016; Mosley, 2015; Van Dijkhuizen & Wulffraat, 2015). However, methotrexate is not always well tolerated, and leflunomide is sometimes prescribed as it has similar efficacy and safety ratings to methotrexate (Giancane et al., 2016). Biologic DMARDs such as etanercept and adalimumab have been developed recently and are used if conventional DMARDs prove ineffective. Giancane et al. (2016) note that the management of JIA has advanced significantly over the last 15 years, and the advent of biologic agents has improved the prognosis of individuals with JIA. However, despite the benefits of pharmacological treatment, this intervention may have negative side effects.

The side effects of treatment vary according to the medication used and the individual’s response to the medication. NSAIDs and cortisone have been found to cause gastrointestinal discomfort and ulcers (Jennings, Hennessy, & Hendry, 2014). Furthermore, research shows that the effects of methotrexate and biologics are unpredictable and they may cause bone marrow failure, pulmonary fibrosis, and liver toxicity (Mosley, 2015). Mouth ulcers, nausea, vomiting, and anticipatory nausea are also reported to be common side effects (Falvey et al., 2017). In addition, DMARDs suppress the immune system, which places individuals at greater risk for infections (Kelly & Beresford, 2012; McKeever & Kelly, 2015; Mosley, 2015). Due to these side effects and risks, complementary alternative medicine is increasingly being used in place of, or as an adjunct to, traditional pharmacological treatment (Seburg et al., 2012). Whereas pharmacological treatment focuses on the disease, non-pharmacological interventions attend to physical and psychological symptoms.

The aims of non-pharmacological treatment are to promote the psychosocial development of the individual, support the family, and alleviate disease symptoms (Giancane et al., 2016; Uziel, 2017). According to Giancane et al. (2016), psychosocial development is improved when the individual engages in age-appropriate activities such as attending school and interacting with peers. Similarly, supporting parents and family members has been found to improve overall well-being in individuals with JIA (Gómez-Ramírez et al., 2016). Moreover, recent research suggests that appropriate exercise improves the quality of life and physical capacities of the individual (Coda et al., 2017; Rochette, Duché, & Merlin, 2015). Exercise can also result in decreased inflammation, but further research is needed to determine the most efficient exercise regimes

(Rochette et al., 2015). Non-pharmacological treatments such as physiotherapy, occupational therapy, and surgical procedures have been found to aid in restoring joint function (Giancane et al., 2016). Furthermore, complementary alternative medicine interventions are wide-ranging and include supplements, herbal remedies, massage, aromatherapy, meditation, and prayer. These methods are often chosen because of concerns regarding side effects of medical treatments (McKeever & Kelly, 2015). However, many individuals with JIA do not reveal their use of alternative interventions to their rheumatologists for fear of disapproval (McKeever & Kelly, 2015; Seburg et al., 2012). Thus, the treatment for JIA is holistic, multidisciplinary, and based on the specific needs of the individual and on their disease state.

3.3.6 Disease States and Remission

Consolaro et al. (2016) advise that, when managing the treatment of JIA, it is important that disease activity states can be defined according to reliable criteria. These disease states are inactive disease, clinical remission on medication, and clinical remission off medication (C. Wallace, Giannini, Huang, Itert, & Ruperto, 2011). The disease is deemed inactive when the individual “has no joints with active disease, no systemic manifestations attributable to JIA, no active uveitis, normal values of acute phase reactants and a global physician assessment of disease activity indicating no disease activity” (Consolaro et al., 2016, p. 4). Once the inactive disease state has been achieved for no less than six months while on anti-rheumatic medication, then the requirements for a disease state of clinical remission with medication have been met (C. Wallace et al., 2011). Clinical remission is only achieved when the individual’s disease state has been inactive for a minimum of 12 months after the medication has been discontinued (Consolaro et al., 2016). In order to define the disease state and provide appropriate treatment, a detailed understanding of the physical manifestations of the disease is required. Furthermore, knowledge of how the disease affects the adolescent physically allows for a deepened understanding of the psychosocial experiences of the individual.

3.3.7 The Physical Challenges Associated with JIA

The symptoms and severity of JIA are quite diverse, varying between subtypes and individuals within subtypes. Furthermore, the disease course of JIA is complicated by unpredictable flare-ups, during which symptoms are exacerbated (Cartwright et al., 2014). The long-term prognosis is that 30–50% of individuals will experience continued inflammatory or arthritic disorders into adulthood (Cartwright et al., 2014). According to Bruck et al. (2015), mortality rates have been estimated at 1% in Europe and 0.5% in the USA. JIA is usually typified by chronic pain from inflammation and damage to the joints which can result in both short- and long-term impairment that limits participation in daily activities (Rigante et al., 2015). Furthermore, chronic fatigue is a pervasive condition amongst 60–76% of individuals with JIA (Armbrust, Siers et al., 2016; Stinson et al., 2014). This type of fatigue can be defined as a "persistent, overwhelming sense of tiredness, weakness or exhaustion, resulting in a decreased capacity for physical and/or mental work and is unrelieved by sleep or rest" (Armbrust, Siers et al., 2016, p. 587). Other symptoms can include delayed growth, uneven limb length, sleep disorders, fevers, and stiffness (Angeles-Han et al., 2015; Consolaro et al., 2016; Rigante et al., 2015; Rochette et al., 2015). In addition, organs can also be affected, resulting in serositis, psoriasis, and uveitis (Angeles-Han et al., 2015; Consolaro et al., 2016; Rigante et al., 2015). Further complications such as anorexia, anaemia, and insulin resistance can arise as a result of the chronic inflammation (Rochette et al., 2015). Moreover, as pharmacological treatment aims to suppress the immune system, these individuals are more at risk of contracting infectious illnesses such as tuberculosis (TB) (Mosley, 2015).

This section demonstrated the transactional nature of JIA in the physical systems of the body, as well as its possible epigenetic aetiology. Furthermore, the diagnosis of JIA (Chausset et al., 2016), the physical symptoms, and the treatment regimen each present challenges to adolescents' psychosocial functioning (Cartwright et al., 2014; Chausset et al., 2016; Livermore et al., 2016; McDonagh et al., 2016; McKeever & Kelly, 2015; Turner-Cobb & Cheetham, 2016).

3.3.8 The Psychosocial Challenges Experienced by Adolescents with JIA

3.3.8.1 Developmental tasks amongst individuals with JIA.

Adolescents with JIA have to negotiate the developmental tasks of adolescence while contending with the debilitating effects of the diagnosis. Taylor, Gibson, and Franck (2008) note that adolescent development can be impaired by chronic illness as a result of health issues, hospitalisation, and changes in appearance. Furthermore, research has indicated that chronically ill adolescents face challenges related to achieving autonomy (Pinquart & Shen, 2011; Wicks, Berger, & Camic, 2019), developing peer relationships (Pinquart & Shen, 2011; Wicks et al., 2019), planning for the future (Parslow et al., 2017; Taylor et al., 2008), vocational success (Maslow, Haydon, McRee, Ford, & Halpern, 2011; Schlichtiger et al., 2017), body image (Pinquart, 2013), self-esteem (Pinquart, 2012), and identity formation (McDonagh et al., 2016; Snelgrove, 2015).

A meta-analysis of 447 quantitative empirical studies highlighted the variability in the achievement of developmental tasks by adolescents with different chronic physical illnesses or physical/sensory disabilities (Pinquart & Pfeiffer, 2015). The authors found that the adolescents who encountered the most difficulty in achieving developmental tasks were those with highly visible diseases or disabilities, as this impacted on body image, autonomy, and relationships with friends and peers. A further finding was that those adolescents with invisible diseases or disabilities had greater difficulty developing intimate relationships (Pinquart & Pfeiffer, 2015). These findings suggest that, while adolescents with chronic illness or disability were generally less successful in negotiating developmental tasks than their healthy peers, many chronically ill or disabled adolescents were as successful as their peers, particularly in the area of identity formation (Pinquart & Pfeiffer, 2015). Despite the challenges faced, some chronically ill adolescents are resilient, are able to adapt to their illness, and can successfully negotiate developmental tasks. The following section presents research regarding the psychological challenges associated with JIA and resilience in the face of those challenges.

3.3.8.2 Psychological challenges.

JIA affects the cognitive, emotional, and behavioural development of adolescents. Given that these systems are relational and not isolated, transactions between the systems are seen to have a cumulative effect on developmental risks and resilience. Although the different components of JIA have been addressed separately in this section, pain, fatigue, medication, and visibility of the disease are all interrelated (Armbrust, Lelieveld et al., 2016). However, for ease of reading, these systems are presented independently.

3.3.8.2.1 Cognitive development.

Research indicates that the cognitive development of adolescents with JIA is compromised by both the disease and medication (Armbrust, Siers et al., 2016; Russo et al., 2012; Sansom-Daly et al., 2012; Tong et al., 2012). Chronic pain has been found to cause changes in attentional processes and reduce working memory (Dick & Riddell, 2010; Pinquart & Shen, 2011). Increased attentiveness towards the pain itself may result in further cognitive impairment (Dick & Riddell, 2010; Pinquart & Shen, 2011). In addition, frequent pain-related absences from school can lead to reduced exposure to cognitive and skills training (Dick & Riddell, 2010). A systematic review of literature conducted by Armbrust and Siers et al. (2016) reported that fatigue negatively impacted on the cognition of individuals with JIA. Although chronic illness may affect cognitive development negatively, research suggests that adolescents can learn adaptive coping strategies (Garnefski et al., 2009; Holley et al., 2016; Lomholt et al., 2015; Sawyer et al., 2004). Cognitive and emotional functioning are mutually interactive and influence each other (Steinberg, 2017; Sameroff, 2010); hence, the cognitions of ill adolescents may also affect their emotional development.

3.3.8.2.2 Emotional development.

Since the early 1970s, studies have shown that individuals with chronic illness and chronic pain tend to experience higher levels of psychological difficulty than their healthy peers, especially those individuals whose illness was not visible (LeBovidge, Lavigne, Donenberg, & Miller, 2003; Margetić, Aukst-Margetić, Bilić, Jelušić, & Bukovac, 2005; McAnarney, Pless, Satterwhite, & Friedman, 1974; Tong et al., 2012). Similarly, Tong et al. (2012) reported that adolescents with JIA struggled with feelings of uncertainty, powerlessness, and disappointment. Furthermore, research indicates that the invisible nature of the pain and symptoms causes high levels of frustration and isolation, especially when individuals are accused of malingering or do not receive validation from their physicians (Cartwright et al., 2014; Forgeron et al., 2013; Stinson, Feldman et al., 2012; Tong et al., 2012a). Research has also indicated that individuals with arthritis are at higher risk of developing anxiety and depression (Bomba et al., 2013). Furthermore, a qualitative study by Cartwright et al. (2014) highlighted that adolescents with JIA had to cope with the uncertainty of their illness and usually felt shock and disbelief at the physical difficulties that they were experiencing. Adolescents also expressed concerns about career prospects, worsening symptoms, and the adverse effects of medication on their health and lifestyle (Cartwright et al., 2014).

Research indicates that adolescents with JIA are dependent on their parents and significant others, which undermines their emotional autonomy, individuation, and self-concept (Margetić et al., 2005; Moverley et al., 2015; Stinson, Feldman et al., 2012; Tong et al., 2012; Vuorimaa et al., 2011). Bomba et al. (2013) reported that JIA compromised adolescents' ability to reach adult independence. Furthermore, adolescents with JIA often feel different to their healthy peers because they experience continuous pain and physical disability (Tong et al., 2012). Consequently, they strive for normality through preserving their social identity, developing resourcefulness and a sense of community, and mastering their bodies and the pain (Tong et al., 2012). An additional challenge is the need to create an identity that is separate from JIA (Cartwright et al., 2014), but fits into the teenage culture (McDonagh et al., 2016; Sällfors & Hallberg, 2009). Indeed, chronically ill adolescents have been found to refer to their identities before and after the diagnosis, as well as the changes the disease has made to their plans for the future (McDonagh et al., 2016). Although taking medication enabled them to maintain a sense of self as it reduced symptoms, it was also a daily reminder of the illness (McDonagh et al., 2016). Such difficulties and challenges related to the self-concept of adolescents with JIA have not been reported on uniformly, as some contradictory research findings have emerged. LeBovidge et al. (2003) found that individuals with JIA were not at increased risk for poor self-concept, whereas Pinquart (2012) reported that adolescents with chronic illness have lower self-esteem than their healthy peers. Similarly, Pinquart's (2013) meta-analysis of body image in individuals with chronic illness found that concerns regarding body image were strongest in those with visible physical illnesses.

Thus far this review has highlighted the mutual interactions between the physical, cognitive, and emotional systems of adolescents. These, in turn, may lead to challenges in behavioural development.

3.3.8.2.3 Behavioural development.

JIA presents both challenges and opportunities for behavioural autonomy. On the one hand, behavioural autonomy is at times decreased in these adolescents owing to their dependence on their parents for their basic needs, especially in severe cases (F. Jones, Rodger, Broderick, & De Monte, 2009). On the other hand, being able to make decisions regarding disease management and illness disclosure can foster behavioural autonomy and personal agency (Cartwright et al., 2015).

Disease management is often challenging as it requires adhering to treatment regimens, acquiring knowledge, making decisions about medicine, and managing relationships with health care professionals (Seburg et al., 2012; Secor-Turner, Scal, Garwick, Horvath, & Wells, 2011; Stinson et al., 2008; Stinson, Feldman et al., 2012; Tong et al., 2012). Furthermore, adolescents are not always successful at negotiating these challenges. Indeed, Secor-Turner et al. (2011) noted that 20% of adolescents were not successful in managing their medication by 17 years of age. In addition, research indicates that regulating physical activity is difficult, as the high levels of pain experienced result in many individuals becoming sedentary (Cavallo et al., 2014; Rochette et al., 2015). According to Rochette et al. (2015), regulating physical activity is an important behaviour, as inactivity leads to a vicious cycle in which decreased activity causes muscle loss and worsens muscle fatigue and metabolic disorders. Conversely, increased physical activity, if managed appropriately, has been found to promote muscle strength, range of motion, short- and long-term anti-inflammatory responses, and psychosocial well-being (Bos et al., 2016; Rochette et al., 2015).

While it has been found that adolescents engaged in alternative activities to compensate for physical restrictions, individuals also reported that they felt physical activity was important for joint mobility (Tong et al., 2012). Another challenge faced by adolescents with JIA is that of optimising their levels of physical activity. Some individuals refuse to accept the physical limitations of JIA and over-exert themselves physically, which can be harmful (Cartwright et al., 2015). However, the decision to over-exert oneself also displays a strong sense of personal agency (Cartwright et al., 2015). This sense of personal agency or behavioural autonomy is also demonstrated in the individual's decision regarding whether or not to disclose their illness to others.

Adolescents have been found to gain a sense of control by deciding whether to disclose or conceal their illness (Cartwright et al., 2014). Studies have shown that adolescents' disclosure of chronic illness is influenced by the visibility of the disease, how the other person would respond, whether there were practical needs to disclose, and whether the disclosure was justified (Cartwright et al., 2014; Kaushansky et al., 2017; McDonagh et al., 2016). Furthermore, adolescents with a visible illness prefer to disclose their illness as soon as possible to increase social comfort, reduce stigma, and lessen psychological distress. Those with invisible illnesses are more selective about disclosure (Cartwright et al., 2014; Kaushansky et al., 2017; McDonagh et al., 2016).

The cognitive, behavioural, and emotional systems are mutually interactive facets of the psychological system, which in turn interact with the physical and environmental systems. Of particular relevance to this study are the effects of the social systems within the environment on adolescent development.

3.3.8.3 Social challenges.

JIA has a pervasive impact on the social lives of adolescents, affecting the family, peer, and school systems. In addition, adolescents with JIA need to interact with medical professionals on a regular basis. Interactions with the social system may be lead to either adaptive or maladaptive trajectories.

3.3.8.3.1 Family.

Having a chronically ill child within a household has been found to impair the psychological well-being of the whole family (Incledon et al., 2015; Russo et al., 2012; Taylor et al., 2008). Gómez-Ramírez et al. (2016) reported that the unpredictable nature of JIA, with its periods of quiet followed by flare-ups, has been referred to by parents as a recurring roller coaster ride. Research indicates that parents are overwhelmed by the initial diagnosis (Chausset et al., 2016), bear the burden of managing the disease (Gómez-Ramírez et al., 2016; Stinson, Feldman et al., 2012), express concerns about the effects of medication, and experience negative emotions (A. Cox et al., 2014; Chausset et al., 2016; Gómez-Ramírez et al., 2016; Stinson, Feldman et al., 2012). Parents also need to cope with the financial costs and the time required to take care of their children; consequently, some parents resign from their jobs (Russo et al., 2012; Stinson, Feldman et al., 2012). Also, Russo et al. (2012) found that the time and financial constraints of treating the physical symptoms of JIA reduce family activities and well-being. In addition, Christin, Akre, Berchtold, and Suris (2016) reported a poor relationship in the parent-adolescent dyad as a result of psychosocial and behavioural difficulties, as well as parental difficulty in distinguishing between problems associated with the chronic illness and normal adolescent issues. Furthermore, parents may be overprotective and may not provide sufficient opportunities for independence (Gómez-Ramírez et al., 2016). Healthy siblings are also affected by chronic illness, as they may take on a caregiver role towards their ill sibling (Sharpe, 2002) and may be at risk of developing internalising behaviours such as anxiety and depression (Incledon et al., 2015; Sharpe, 2002). Waite-Jones and Madill (2008) found that sibling power dynamics are affected because the ill sibling has more parental protection, yet at the same time they need to ensure their well siblings are not upset, as this might jeopardise their caregiving role (Waite-Jones & Madill, 2008). Moreover, well siblings experience “amplified ambivalence” – on the one hand, they feel love and concern for their ill sibling, but on the other hand, they are competing for parents’ time and acknowledgement (Waite-Jones & Madill, 2008).

Studies indicate that mothers generally take on the role of primary caregiver for the chronically ill child, while the father’s role appears to be to support the mother (A. Cox et al., 2014; Barlow et al., 2002; Christin et al., 2016). Thus, the well-being of the mother constitutes an important facet of supporting adolescents with JIA (Barlow et al., 2002; Christin et al., 2016). Furthermore, family patterns have been found to have both a negative and positive impact on individuals’ development, as parental attitudes towards the illness inform the individual’s attitude (Lennon et al., 2016; Taylor et al., 2008; Vuorimaa et al., 2011). Indeed, parents play a crucial role in managing the complex treatment regime, as well as improving the self-efficacy and coping strategies of their child (F. Jones et al., 2009; Lennon et al., 2016; Stinson, Luca, & Jibb, 2012). Yet, according to Vuorimaa et al. (2009, 2011), the focus of medical practitioners is mainly on the individual with JIA. Families that are becoming overwhelmed are thus often not identified.

Parental, sibling, and family systems interact with those of the individual to facilitate or impede normative development. Similarly, peer interactions can challenge the development of adolescents with JIA.

3.3.8.3.2 Peers.

Studies have shown that adolescents with JIA have restricted social activities, fewer friends, and experience feelings of isolation (Bomba et al., 2013; Cartwright et al., 2014; Cavallo et al., 2014; Eyckmans et al., 2011; McDonagh et al., 2016; McKeever & Kelly, 2015; Tong et al., 2012). Furthermore, research suggests that individuals with JIA may feel stigmatised and misunderstood by their peers as a result of their disease being trivialised (Eyckmans et al., 2011; Gómez-Ramírez et al., 2016; Tong et al., 2012). Although Tong et al. (2012) report that individuals with JIA value engaging in activities with their peers, Cavallo et al. (2014) found that the range of activities that they engage in is restricted by their illness. Moreover, having to be responsible for self-care reduces spontaneity in social interactions, especially with regard to experimentation that conflicted with medical restrictions (Cartwright et al., 2014). Peer support was noted as an important coping resource, as it helps the adolescents to feel accepted (Cartwright et al., 2014). Also, Cartwright et al. reported that talking to other individuals with JIA is seen as desirable and helpful, as it reduces the sense of isolation.

Along with the peer and family systems, transactions within the school system affect adolescent development. Relationships with teachers and peers within the school system may affect the psychological development of adolescents.

3.3.8.3.3 School.

Adolescents with JIA encounter both physical and psychological challenges within the school system. Physical difficulties include factors such as school absenteeism, fatigue, carrying heavy bags, walking long distances, reduced involvement in activities, and the need for dispensations and accommodations (Eyckmans et al., 2011; Gómez-Ramírez et al., 2016; Kelly & Beresford, 2012; McDonagh et al., 2016). Moreover, psychological difficulties have been reported because of victimisation by peers and social isolation (Lum et al., 2017; Taylor et al., 2008)). Studies have also indicated that teachers are viewed as uncaring, unknowledgeable, discriminatory, and imposing unnecessary restrictions (Dick & Riddell, 2010; Lum et al., 2017; Taylor et al., 2008; Tong et al., 2012). Nonetheless, further studies have indicated that teachers may be caring and supportive of adolescents with chronic illness (Lum et al., 2017). Indeed, Lum et al. (2017) caution that managing learners with chronic illness is not usually included in the training of most teachers. In addition, Livermore et al. (2016) reported that the transition from primary to secondary school provokes anxiety. Also, research has shown that individuals experience academic difficulties as a result of prolonged absences (Bouaddi et al., 2013; Dick & Riddell, 2010; Taylor et al., 2008). The research discussed above suggests that adolescents with JIA face many challenges in school that may cause them to feel marginalised and isolated. Their relationships with medical practitioners invoke similar responses.

3.3.8.3.4 Relationship with medical practitioners and the transition to adult care.

A database search revealed minimal research in the area of paediatric practitioner-patient relationships in JIA and chronic illness (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & NREPP databases, 24 January 2019). Only seven articles looking at the relationship between adolescents and medical doctors were found (Beresford & Sloper, 2003; Britto, 2004; Han, Whitehouse, Tsai, Hwang, & Thorne, 2018; J. Brown & Wissow, 2009; Klostermann, Slap, Nebrig, Tivorsak, & Britto, 2005; Siembida & Bellizzi, 2015; Van Staa, Jedeloo, & Van der Stege, 2011). Of these articles, only five focused on adolescents with chronic illness (Beresford & Sloper, 2003; Britto, 2004; Dickinson, Smythe, & Spence, 2006; Han et al., 2018; Van Staa et al., 2011). Moreover, there is scant research in the field of JIA, although one meta-analysis regarding the experiences of children with JIA reported that they wanted to be involved in decision-making processes and wanted emotionally supportive medical practitioners who understood their illness and emotional pain (Tong et al., 2012).

Research indicates that adolescents with chronic illness and JIA want good relationships with medical practitioners and value personal agency. They prefer medical practitioners who understand their illness and who can provide support regarding emotional experiences and pain (Eyckmans et al., 2011; Han et al., 2018; Taylor et al., 2008; Tong et al., 2012). Furthermore, they value familiar practitioners with whom they have trusting relationships and good rapport (Beresford & Sloper, 2003; Han et al., 2018). Studies have shown that adolescents want to actively participate in clinical decision making about treatment options and lifestyle management (Han et al., 2018; Siembida & Bellizzi, 2015; Taylor et al., 2008; Tong et al., 2012). Such decision making requires being apprised of how procedures work, as well as being given information on how the medications work, the potential side effects, and recent medical advances.

Improved health outcomes are facilitated by good communication between patient and practitioner (Turner-Cobb & Cheetham, 2016; Van Dijkhuizen et al., 2018). Turner-Cobb and Cheetham (2016) emphasised the need for age-appropriate communication between practitioner and patient. Earlier research by Beresford and Sloper (2003) reported that communication is problematic when other personnel, such as interns, are present in consultations, but good communication with practitioners facilitates treatment compliance (Beresford & Sloper, 2003). In addition, the authors found that when parents dominate the appointments, communication is inhibited, but supportive parents give adolescents the confidence to talk to the medical practitioner. Furthermore, Taylor et al. (2008) emphasised that adolescents need the focus to be on them as individuals rather than on the illness. They also found that if adolescents do not feel respected, this results in noncompliance. Good communication and relationships within the health care system are essential when adolescents transition to adult health care.

Research regarding transitional care indicates that this process is often fraught with problems (American Academy of Pediatrics, 2011; McKeever & Kelly, 2015; Pai & Ostendorf, 2011). Indeed, the American Academy of Pediatrics (2011) emphasises the importance of high-quality transition processes to support well-being, and recommends that this occurs between 18 and 21 years of age. Furthermore, this process should ensure the readiness of the patient, the family, and the service provider (American Academy of Pediatrics, 2011). Studies have shown that badly conducted transitions have negative consequences for morbidity and long-term outcomes (Blamires & Dickinson, 2013), thus transitional care should begin in early adolescence and continue into adulthood (Mazur, Dembinski, Schrier, Hadjipanayis, & Michaud, 2017; McKeever & Kelly, 2015). Furthermore, researchers argue that the transition process should be holistic, multidisciplinary, and attentive to the medical, psychosocial, and educational needs of the adolescent (McDonagh et al., 2007). More specifically, McKeever and Kelly (2015) advocate for improving adolescent and parental preparation, as well as enhancing communication between the paediatric and adult rheumatologist. The environment in which the adolescent is situated does not always allow for a smooth transition, however. Indeed, in comparison to those of other countries, the South African health care system generally has ineffective procedures for transitioning adolescents to adult care (C. Scott, personal communication, January 15, 2019). Similarly, a recent study regarding the transition of adolescents with HIV noted that transition services are increasingly overtaxed and do not have sufficient human resources to be effective (Dahourou et al., 2017).

The research on the psychosocial effects of JIA indicates the importance of the context in facilitating positive adaptation to JIA. In the next section, research pertaining to the South African context will be presented.

3.3.9 JIA in South Africa

Research regarding JIA in South Africa is largely restricted to medical articles describing incidence, prevalence, treatment, and access to services (Haffejee et al., 1984; Scott & Brice, 2015; Scott & Webb, 2014; Usenbo, Kramer, Young, & Musekiwa, 2015; Weakley et al., 2011; Weakley & Scott, 2012). A database search revealed that no psychological studies regarding South African adolescents with JIA have been conducted to date (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & NREPP databases, 24 January 2019). According to Usenbo et al. (2015), there are no data regarding the prevalence of JIA in sub-Saharan Africa. Weakley and Scott (2012) report that, if the conservative estimate of one child per 1000 is used, then South Africa has at least 18,700 children with JIA. Furthermore, Weakley et al. (2011) found that the prevalence of enthesitis-related arthritis and polyarthritis subtypes appeared to be higher than that reported internationally, although they cautioned that this data might be skewed given the restricted geographical area used. A further difficulty is that the diagnosis of JIA in South Africa usually occurs later than it does internationally as a result of comorbid diseases such as TB and HIV, socio-economic factors, low awareness of the disease, and insufficient resources (Weakley et al., 2011). Understandably, national resources are directed towards combating diseases and illnesses with high mortality rates; nevertheless, this results in insufficient health care planning and budgeting for JIA at a national level (Scott & Webb, 2014). This focus on high-mortality diseases has resulted in doctors, both undergraduate and postgraduate, receiving minimal training regarding JIA. Thus, JIA is often misdiagnosed or overlooked, and patients often do not receive appropriate treatment (Scott & Webb, 2014). Clearly, there is a great need for research on the psychosocial effects of JIA in South Africa. Given the lack of research in this area, an exploratory study is advisable.

3.4 Conclusion

Adolescence is a particularly vulnerable developmental stage during which individual and contextual factors can lead to adaptive or maladaptive trajectories. Although research indicates that most adolescents negotiate this phase successfully, a chronic illness such as JIA can have significant deleterious effects on adolescent development. This chapter endeavoured to present typical adolescent development, against which the development of adolescents with JIA was compared. It was evident that JIA affects all facets of adolescents' psychosocial development, placing them at high risk for maladaptive pathways. Nonetheless, research indicates that individual and contextual resilience mechanisms can lead to positive adaptation, improved well-being, and the successful negotiation of adolescence, despite the presence of JIA. The lack of South African research regarding the psychosocial effects of JIA suggests that this is a critical area of study, especially considering that a conservative estimate places nearly 19,000 individuals at risk of following maladaptive trajectories of development. The following chapter presents the research methodology that was used to explore the psychosocial experiences of adolescents with JIA.

CHAPTER 4: METHODOLOGY

4.1 Introduction

The choice of research approach is pivotal in ensuring compatibility with the research problem so that meaningful findings are generated (Bloomberg & Volpe, 2012) and the merits of the study can be judged by appropriate criteria (N. Petty, Thomson, & Stew, 2012b). Qualitative research is well suited to gaining a deep understanding of the complexity of human phenomena, as well as gaining new knowledge and insights within poorly understood areas (Bloomberg & Volpe, 2012; Crowe, Inder, & Porter, 2015; Gough & Lyons, 2016; Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017). Although not new to the field of paediatric psychology, a qualitative research approach is increasingly used as it is well suited to describing the psychological experiences of medical populations (Alderfer & Sood, 2016; Forman, Creswell, Damschroder, Kowalski, & Krein, 2008; Rich & Ginsburg, 1999). Indeed, the focus of qualitative research on the subjective experiences of individuals makes this approach inherently valuable in both the field of psychology (Crowe et al., 2015) and the field of medicine (Alderfer & Sood, 2016). This chapter seeks to explicate the congruity of the research paradigm, methodology and methods used in the design of this research.

4.2 Purpose of the Research

This exploratory study aims to explore and describe the psychosocial experiences of South African adolescents with JIA. A rich description of their experiences and understandings of JIA will be sought and situated within resilience theory.

4.3 Methodology

4.3.1 Constructivist-Interpretivist Paradigm

For the purposes of this study, qualitative methodology is positioned within the constructivist-interpretivist paradigm (Guba & Lincoln, 1994; Ponterotto, 2005, 2010). It is necessary to clarify this point as social constructivist philosophy has been viewed as an overarching term for interpretivism (Malterud, 2016; O'Neil & Koekemoer, 2016; Ponterotto, 2005), as an extension of the interpretive paradigm (Malterud, 2016), and as a separate paradigm (O'Neil & Koekemoer, 2016). Within the constructivist-interpretivist paradigm, knowledge is viewed as being fluid and dependent on the subjective interpretations of the individual (Malterud, 2016). Therefore, the truth is a relative concept and multiple, socially co-constructed, equally valid realities can exist (O'Neil & Koekemoer, 2016; Ponterotto, 2010). In addition, the aim of constructivist-interpretivist research is to explicate perceived realities while retaining their complexity (O'Neil & Koekemoer, 2016). This aim is achieved through the active agency of the researcher (Malterud, 2016), who elicits hidden meanings and the expression of experience through interactive dialogue with the participants (Ponterotto, 2005, 2010). Thus, the research process is a subjective one in which research findings are co-constructed by the researcher and the participants in a process of methodical hermeneutics (Levitt et al., 2017; Ponterotto, 2010). Such active agency by the researcher necessitates reflexivity, as it contributes to rigour and trustworthiness by enabling researchers to acknowledge their role and the embedded nature of the research (Guba, 1981; Malterud, 2016). Therefore, situating this study within a constructivist-interpretivist paradigm will facilitate a deeper understanding of the psychosocial experiences of adolescents with JIA as well as the complex interactions between and within the individual and social context.

4.3.2 The Characteristics of Qualitative Research

A practical definition of qualitative research is that it "points to methods that use language, rather than numbers, and an interpretivist, naturalistic approach" (Biggerstaff, 2012, p. 177). However, Gough and Lyons (2016) caution that given the methodological diversity within qualitative research, providing a coherent definition is challenging. Thus, an overview of the characteristics of qualitative research may be more useful.

Although qualitative research is an umbrella term for a variety of research methodologies based on different epistemological principles (N. Petty et al., 2012b), the key characteristic of qualitative research is that it seeks to capture and interpret subjective experience within contextual meaning (Brannen, 2004). Thus, it is well suited to studies that assume a developmental systems approach, as the inclusion of contextual factors facilitates the understanding of developmental and resilience processes (F. Reynolds, 2017; Rutter, 2013a; Sullivan, 1998). Qualitative research is rooted in the ontological assumption that reality is socially constructed, and therefore the social world cannot be researched in the same manner as the natural world (N. Petty, Thomson, & Stew, 2012a). Consequently, knowledge of a phenomenon is gained by understanding the multiple perspectives of individuals within their contexts (Cresswell, 2013) and is seen to be co-constructed by the participants and the researcher (Biggerstaff, 2012; N. Petty et al., 2012b). Qualitative research is preferable when understanding the participants' experiences and the meanings they attribute to them, as the focus on language, rather than numbers, enables a much deeper understanding of the complexity of individuals' experiences (Braun & Clarke, 2013; N. Petty et al., 2012a; Silverman, 2013). Such research produces narrow, but rich, data with thick descriptions (Geertz, 1973) from a few participants; it searches for patterns but embraces divergence within the data (Braun & Clarke, 2013; N. Petty et al., 2012a; Silverman, 2013).

Furthermore, because the person's own framing is used rather than that of the researcher, new insights or knowledge can arise that may not have been uncovered if the researcher had pre-framed the research (Gough & Lyons, 2016). While qualitative research can be used for more than initial studies, its exploratory, flexible, and open-ended nature is well suited to traversing new areas of study (Yin, 2014, 2018). Its flexibility, in particular, allows for the inclusion of vital but unexpected occurrences (Hanson, Balmer, & Giardino, 2011).

According to Braun and Clarke (2013), there are two broad approaches to analysing qualitative data – namely, critical and experiential. The current study assumes the experiential approach, in which data is taken at face value and the focus is on understanding the participants' own perspectives and the meanings they ascribe to experiences (Silverman, 2013). The participants' language is used to make sense of their inner world (Braun & Clarke, 2013). Given the exploratory nature of this study, the experiential approach was deemed to be a better fit than the critical approach, as it will generate a base of knowledge on which future studies can elaborate. The research process in experiential qualitative research involves collecting participant information and situating it in an organising and interpretive framework (Silverman, 2013). A case study design was selected as it generates thick descriptions from multiple perspectives.

4.3.3 Qualitative Methodology: A Case Study Approach

Methodology is a "strategy of enquiry that guides a set of procedures" (N. Petty et al., 2012b, p. 378) which should be grounded in a philosophical viewpoint. There is a broad range of methodologies within qualitative research, one of which is the case study (Bloomberg & Volpe, 2012; N. Petty et al., 2012b; Saldaña, 2011; Silverman, 2013). According to Yin (2014), case study methodology is preferred when needing to understand a complex social phenomenon and explore contemporary events in which the behaviours cannot be manipulated. Furthermore, case study methodology ensures that the research issue is explored through a variety of perspectives, enabling multiple facets of the phenomenon to be identified and understood (Baxter & Jack, 2008). This methodology also allows close collaboration between researcher and participants while their stories are told (Baxter & Jack, 2008).

One widely used approach to case study methodology is that of Robert Yin (1981). There are various definitions of the case study method, but Yin (2014) provides a twofold operational definition that encompasses the scope and features of the method. Firstly, the scope of a case study is an empirical enquiry that “investigates a contemporary phenomenon (the “case”) in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident” (Yin, 2014, p. 974). Yin (2014) argues that the phenomenon and the context are often difficult to differentiate in real-world situations, and therefore understanding the features of case studies is essential. Secondly, “a case study inquiry copes with the technically distinctive situation in which there will be many more variables of interest than data points”. It relies on “multiple sources of evidence, with data needing to converge in a triangulating fashion” and benefits “from the prior development of theoretical propositions to guide data collection and analysis” (Yin, 2014, pp. 974–975).

Multiple case studies have the advantage of exploring differences between and within cases, with the aim being to reproduce findings across cases (Baxter & Jack, 2008; Liebenberg, 2016). The assumption is that similar phenomena occur in the same contexts and will change if the context differs (Hancock & Algozzine, 2006). In this study, the use of multiple case studies will allow for similarities and differences in the adolescents’ psychosocial experiences to be explored. Moreover, multiple cases may lead to a broader understanding of the pathways that lead to resilience and well-being in adolescents with JIA. In addition, Yin (2014, 2018) also distinguishes between explanatory, explorative, and descriptive case study research designs. Explorative designs are often conducted as preliminary research on which later research can be based; descriptive designs endeavour to provide a thorough description of phenomena in their context (Yin, 2014, 2018). Given that this is the first study in South Africa that investigates the psychosocial experiences of adolescents with JIA, a broad exploration of the adolescents' experiences should be undertaken. Moreover, thick, rich descriptions are necessary to provide the groundwork for future studies. Therefore, this study will use a multiple case study approach that is exploratory and descriptive in design to understand the psychosocial experiences of adolescents with JIA.

While the case study methodology has many advantages, it also has limitations. Yin (2014) cautions that the rigour of the research can be compromised if the researcher does not follow a systematic procedure. Similarly, Hyett, Kenny, and Dickson-Swift (2014) emphasise the need to ensure rigour by providing sufficient detail to comprehend the research design. The latter includes explicating the paradigm and theoretical perspectives underpinning the research, as well as substantiating the reasons for significant methodological decisions. In this study, the paradigm, theoretical perspectives, and decision-making process have been clearly delineated to enable the reader to understand the study design. Furthermore, although the ability to generalise from case studies has been questioned, analytic generalisation is well supported (Flyvbjerg, 2007; Hyett et al., 2014; Levitt et al., 2017; Yin, 2013). In the process of analytic generalisation, cases are selected based on replication logic, whereby the results are generalised to theoretical propositions, not to populations (Levitt et al., 2017; Yin, 2014). Therefore, this study provides sufficient detail of the sample, method, and data to ensure that it can be replicated. Moreover, case studies can generate massive amounts of information and may be time consuming to implement (Yin, 2014).

Realistic time constraints were established through careful research design which placed boundaries on the cases studied (Baxter & Jack, 2008). To prevent an over-abundance of data, the current study selected the cases that typified the phenomenon under study. In addition, the interview questions were carefully formulated to allow for flexibility, but also to ensure that the discussion remained relevant to the research topic. To maintain relevance, the parent participant interviews focused on the adolescent participants' psychosocial experiences, rather than those of the parents. Thus, strategies have been implemented to overcome the limitations of case study methodology.

4.3.4 Qualitative Research in Paediatric Chronic Illness and JIA

Using qualitative approaches to research individual experiences of paediatric illness is not a recent occurrence. Indeed, in a seminal work in this field, Rich and Ginsburg (1999) argued that qualitative methods see beyond diagnostic outcomes and explain the context and motivation behind adolescent health behaviours. They advocated that understanding human factors, such as context and patient perspective, would enable improved interventions and treatment. Moreover, Alderfer and Sood (2016) emphasised that capturing the subjective experiences of individuals can improve a variety of aspects of paediatric clinical care. Certainly, the benefit of qualitative methods has been recognised to such a degree that *Clinical Practice in Pediatric Psychology* – a quarterly peer-reviewed academic journal published by the APA – released a special issue showcasing qualitative articles in 2017. Furthermore, several qualitative studies regarding the experiences of children and adolescents with JIA have been conducted internationally (Cartwright et al., 2014; Chausset et al., 2016; Gómez-Ramírez et al., 2016; Kaushansky et al., 2017; Livermore et al., 2016; McDonagh, Shaw, & Southwood, 2006; Moverley et al., 2015). Although none of these studies reported using a case study approach, they did use small groups of participants who were interviewed either individually (Cartwright et al., 2014; Livermore et al., 2016; Moverley et al., 2015) or in focus groups (Gómez-Ramírez et al., 2016). Such studies provide a precedent for the use of case study methodology and semi-structured interviews when exploring the psychosocial experiences of adolescents with JIA. The current study's point of departure is that the findings are informed by Sameroff's (2014) unified theory of development, in which the individual's experiences are the result of transactions that take place within and between the biopsychosocial systems. The data has been situated in a multilevel model of analysis, in order to ensure a broad, yet in-depth analysis of the transactions between the systems.

4.4 Research Design

As outlined in the previous section, an exploratory, descriptive multiple case study approach was suitable for this study. Unlike other methodologies, there are no standardised research designs for case study research. For this reason, Yin's (2014) approach to research design was selected as it allows for in-depth investigation of a case within its real-world context. Multiple sources of evidence are used to triangulate the data. In addition, in this approach, the existing body of literature is viewed as beneficial in that it guides data collection and analysis.

4.4.1 Sampling

4.4.1.1 Sampling procedures and participants.

The number of participants, or units of analysis, in a multiple case study design can vary in size, but typically a small number of cases are studied in great detail (Saldaña, 2011; Silverman, 2013; Yin, 2014). A homogenous group of participants was chosen to facilitate generalisability and comparison to previous studies (Braun & Clarke, 2013). However, sufficient diversity was included to ensure the richness of the data (N. Petty et al., 2012b).

Participants were selected because they met the criteria for the study (Saldaña, 2011) and were likely to be able to provide rich descriptions of their experiences (Devers & Frankel, 2000; Fugard & Potts, 2015; Stangor, 2015). Initially, purposive sampling was used to recruit individuals with the necessary characteristics (Silverman, 2013; Stangor, 2015). However, snowball sampling (Braun & Clarke, 2013; Hanson et al., 2011) occurred when some of the potential parent participants contacted other parents of adolescents with JIA and discussed the research with them. Although the sample was originally intended to include participants from three provinces, difficulties were experienced in accessing individuals within this vulnerable group. Consequently, 11 sets of volunteers came from Gauteng and two sets from the Western Cape. The inclusion criteria outlined below were used to select the 11 adolescent participants aged between 15 and18 years.

1. The disease must have been controlled for six months or longer, thus ensuring that there was a depth of experience to reflect upon as well as providing sufficient time for possible resilience processes to develop.
2. The parents must be willing to participate in the study, as their perspectives of the psychosocial experiences of the adolescent participants enhance credibility.
3. The adolescents must be in high school, as their increased capacity for self-reflection should result in rich thick descriptions of their experiences.
4. The adolescents must consent to participate and have parental consent to participate in the research.
5. Participants needed to be able to communicate fluently in English owing to the researcher's language limitations. Moreover, working with a translator may have impacted negatively

on the development of rapport and prevented the sharing of information of a sensitive nature, thus compromising the data collected.

Exclusion criteria included a comorbid, complicating illness not related to JIA, being recently diagnosed with JIA, and being in full remission.

The group of participants were fairly homogenous with regard to context, as they are all from white, middle-class communities with English being their mother tongue. All of the adolescent participants' disease statuses were active. Differences in disease progression, schooling, and religious background were considered to add diversity and richness to their experiences.

4.4.1.2 Methods of participant recruitment.

A research advertisement, which aimed to recruit adolescent participants with JIA, was placed on the website and Facebook page of the Arthritis Foundation of South Africa and was sent to specialist doctors in the Free State, Western Cape, and Gauteng (see Appendix H). However, the Free State clinic did not service adolescents older than 13 years, and the clinics in the other major cities required that the researcher be registered with the respective academic institutions. The parents of the adolescents who were interested contacted the researcher, and once parental permission to contact the adolescent had been received, the adolescent participants were contacted by the researcher directly. Once contact was established, participants were provided with information sheets (see Appendices C and D) regarding the research which outlined the research process and the participant's role and rights. Furthermore, telephonic conversations and e-mail correspondence were undertaken to ensure that the participants and their parents understood the research process and their rights. The individuals were informed that their participation was voluntary and that confidentiality would be maintained.

During the first round of interviews, one mother was present with her child, as she preferred that they were interviewed together. Ultimately, this case was not part of the dissertation as, firstly, the mother was not interviewed separately and, secondly, I felt that her views had dominated the joint interview. At the end of the first interview, the adolescent participants were informed that they would be contacted to ascertain if they were willing to take part in a second interview. One participant chose not to be interviewed the second time. Consequently, her case could not be included in the dissertation as there were no data regarding resilience processes and her understanding of well-being in illness. Another participant requested that both interviews take place at the same time. Upon later reflection, I decided not to include this case, as there had not been an opportunity to confirm my understanding of certain aspects that she had raised. The remaining eight adolescent participants were interviewed twice. Parent participants were interviewed once, usually on the same day as the first adolescent interviews. One mother requested to be interviewed before her daughter on a separate day. One participant’s parents were not available for interviews; accordingly, I decided that this case was not strong enough to be included in the dissertation. The data from the four cases that were excluded will, however, be incorporated into research articles of limited scope arising out of this dissertation. The remaining seven cases served as the basis for this dissertation and are presented in Table 4.1 (page 109).

Table 4.1

Biographical information of adolescent and adult participants

Pseudonym	Age	Grade	Area	Age diagnosed	Disease status	Gender	Parent Pseudonym
Ursula	16	10	Gauteng	11	Active	Female	Adele
Rochelle	14	9	Gauteng	11	Active	Female	Adele
Micaela	15	10	Gauteng	10	Active	Female	Ceri
Rayne	16	11	Gauteng	8	Active	Female	Ann
Leigh-Ann	16	AS1	Gauteng	12	Active	Female	Samantha
Charlotte	14	9	Gauteng	12	Active	Female	Julie
Jessica	18	12	W. Cape	15	Active	Female	Judith

4.4.1.3 The adolescent participants' context and illness history.

A brief overview of the adolescent participants' context and illness history is provided to deepen the reader's understanding of their experiences, as well as to contextualise the findings which will be presented later.

Rayne: Rayne is 16 years old and is in Grade 11 at a private school. Rayne's mother, Ann, was also interviewed. Rayne enjoys tap dancing, and she works part-time as a shop assistant. Rayne is one of the presidents of her school's Interact Club, which partners with a non-governmental organisation (NGO) to raise funds and provide material goods for children with JIA at a local hospital. Rayne experienced joint pains, throat problems, vertigo, and stomach pains for most of her childhood. Her earliest recollection of being ill was in Grade 3, when she experienced joint pains in her hands that required splinting. Rayne went to multiple orthopaedic specialists who made different diagnoses. When Rayne was eight years old, she was referred to a paediatric rheumatologist who diagnosed undifferentiated JIA, but this diagnosis was later changed to enthesitis-related JIA. The diagnostic process took approximately nine years. Rayne experiences periodic flare-ups that are virus- and stress related.

Ursula: Ursula is 16 years old and is in Grade 10 at a private school. Ursula described herself as being very active in sports before she developed JIA. As a result of her physical symptoms, Ursula concentrates on her academic studies, but also takes part in dramatic productions and debating. She intends to qualify as a medical doctor. Ursula is an atypical case in this study as she experienced the rapid onset of a severe case of JIA. Her mother, Adele, is a school administrative officer and plays an active role in supporting families whose children have been diagnosed with JIA. Ursula has been ill since she was 10 years old. Her sister, Rochelle, was diagnosed with JIA approximately two years after Ursula, and her case is discussed next. In 2010, Ursula experienced extreme fatigue, which progressed to intense pain by the beginning of 2011. During the following six to seven months, she saw numerous specialists and underwent many tests, including magnetic resonance imaging and computed tomography scans, but the results were inconclusive. By this stage, she was experiencing excruciating joint pain and was using a wheelchair. When she contracted pneumonia, she was hospitalised, but the subsequent blood tests were inconclusive, and no diagnosis could be made. Fortuitously, while in hospital, Ursula was treated by a paediatric rheumatologist who tested for the HLA-B27 gene. The result was positive. Consequently, at 11 years of age and after 18 months of being ill, Ursula was diagnosed with JIA, subtype systemic arthritis. Ursula spent four years using a wheelchair owing to joint pain. By Grade 9 she was able to walk, although movement was still painful. She is currently able to move and take care of herself, but her engagement in physical activities is limited.

Rochelle: Rochelle is 15 years old, in Grade 9, and attends the same private school as her sister, Ursula. Rochelle enjoys playing hockey and taking part in dramatic productions. She was elected to be the mayor of the city's Mini Council which involved managing several committees and organising charity events. Rochelle is invested in her academic studies and intends to achieve well. She would like to pursue a career as a medical doctor. Rochelle is also an atypical case in this study; having a sister with severe JIA impacted significantly on her own experiences of adapting to JIA, as the severity of Ursula's very visible illness contrasted starkly with Rochelle's "invisible" illness. At 11 years of age, Rochelle began to experience pain and swelling in her ankles and her back. She tested positive for the gene HLA-B27 and was diagnosed with enthesitis-related JIA by a paediatric rheumatologist. Owing to the severity of her sister's illness, Rochelle was immediately placed on methotrexate and anti-inflammatories. Rochelle's illness is characterised by pain, high levels of fatigue, and regular flare-ups. Rochelle's disease status is active.

Jessica: Jessica is 18 years old and in Grade 12 at a government school. Jessica used to enjoy playing water polo. Nowadays, she administers first aid at sports meetings and volunteers at a local animal shelter. Jessica's mother, Judith, is a pharmacist. Jessica's symptoms began when she was approximately six years old. Consultation with a range of specialists resulted in Jessica undergoing an ankle operation. When Jessica was in Grade 8, her mother requested a referral to a rheumatologist, who diagnosed Jessica as having hip bursitis. This diagnosis resulted in a referral to a paediatric rheumatologist who diagnosed enthesitis-related JIA when Jessica was 15 years old. It took approximately nine years for Jessica to receive this diagnosis. She was initially treated with methotrexate, but she experienced severe nausea. Her medication was changed to leflunomide (Arava) and Enbrel (a biologic DMARD). In addition to pain, Jessica also experiences high levels of fatigue.

Micaela: Micaela is 15 years old and in Grade 10 at a private school. Micaela reported that, before she developed JIA, she used to be active in many sports and was a talented swimmer. She enjoys spending time with her companion animals. Her parents were divorced when she was an infant. Her mother, Ceri, is a single parent with a background in nursing who takes care of Micaela and her older sister. Micaela has experienced sinusitis and frequent infections since she was an infant. She experienced joint pains since she was two years of age, but these were thought to be growing pains. It took nine years for her to be diagnosed with JIA, as her blood tests were negative and she had few visible indicators of arthritis. In 2009 she contracted the H1N1 virus (swine flu) as well as the Coxsackie B virus. Micaela tested positive for the HLA-B27 gene, and she was referred to a paediatric rheumatologist who diagnosed polyarticular and enthesitis-related JIA when she was 10 years old. She experiences significant joint pain and is under the care of a maxillofacial specialist for jaw erosion.

Leigh-Ann: Leigh-Ann is 16 years old and in AS 1 (equivalent to Grade 11) at a homeschool. She enjoys photography and researching medicine on the internet. Leigh-Ann is very attached to her dogs and guinea pigs. When Leigh-Ann was nine years old, she developed pain in her neck and shoulders. After many consultations with different medical professionals, Leigh-Ann's mother, Samantha, contacted the Arthritis Foundation and was referred to a paediatric rheumatologist. In February 2013, at 12 years of age, Leigh-Ann was diagnosed with enthesitis-related JIA and TB. The diagnostic process lasted 4 years. She experienced an anaphylactic reaction to the biologic DMARD, Revelex, and spent a week in the hospital. Thereafter, she was placed on a different biologic DMARD, Humira, which she injects herself. In 2016 she developed a rash, and she was diagnosed with psoriatic arthritis. Her disease status is active.

Charlotte: Charlotte is 14 years old and is in Grade 9 at a private school. She loves dancing but was unable to continue with lessons because of the pain. Nevertheless, she still sings, bakes, and loves doing her friends' make-up. Her mother, Julia, who is a medical doctor, was also interviewed. Approximately five years ago, Charlotte contracted the Coxsackie virus, but she continued to experience chronic fatigue after the virus had passed. Her levels of fatigue improved slowly, but then she began to experience joint pains. Both her paediatrician and her mother thought that she was experiencing post-viral fatigue and reactive arthritis. These symptoms continued for two years, after which she began to develop swollen joints. After consulting with a paediatric rheumatologist, Charlotte was diagnosed with polyarticular JIA when she was 12 years old. She experienced severe flare-ups and was placed on Humira (a biologic DMARD).

4.4.2 Data Collection Method and Procedure

Exploratory and descriptive case studies aim to provide thick descriptions of a phenomenon which can be obtained by using semi-structured interviews (Braun & Clarke, 2013). The semi-structured interview has the purpose of garnering descriptions of the life world of the participant (Kvale, 2007; Kvale & Brinkmann, 2009). There are two main objectives of the semi-structured interview: firstly, to understand the participant's perspective and experiences, and secondly, to confirm insights or information that the researcher already has (Kvale, 2007; Kvale & Brinkmann, 2009). Therefore, the interviews are based on a list of open-ended questions that have been predetermined (Kallio, Pietilä, Johnson, & Kangasniemi, 2016; Whiting, 2008).

In accordance with Kallio et al.'s (2016) five-phase process of developing a semi-structured interview guide, the first phase entailed ensuring the suitability of this method for addressing the research problem. As discussed previously, the usefulness of interviews in exploring the experiences of children and adolescents with chronic illness has been established

(Carter, Kronenberger, Threlkeld, Townsend, & Pruitt, 2013; Livermore et al., 2016; Moverley et al., 2015). Moreover, the face-to-face nature of interviewing allows for the development of rapport between the participant and the researcher (Kornbluh, 2015; Kvale & Brinkmann, 2009; Shaw, 2010). Additionally, interview method enables the researcher to attend to nuances of emotion and facilitates the sharing of information at a deeper level. Subsequent interviews also allow the researcher to verify her understanding of the participant's meaning. The second phase required a thorough, critical literature review to create a conceptual basis for the interview (Kallio et al., 2016). Thereafter, the third phase entailed generating a list of open-ended questions for the first interview. The questions were intended to guide the discussion towards the research topic but also incorporated the flexibility to change the order of questions and include other questions that emerged from the dialogue (DiCicco-Bloom & Crabtree, 2006). Such flexibility is essential, as it is the participants who are the experts and thus shape the course of dialogue, whereas the interviewer's role is to prompt the dialogue and clarify experiences (Doody & Noonan, 2013; Kvale & Brinkmann, 2009). During the fourth phase, the aim was to assess the relevance of the content, reformulate questions to generate rich data, and test the implementation of the interview (Kallio et al., 2016). The interview guide was critically assessed by the research supervisors, who suggested reformulating some of the questions, as well as changing the order of certain questions. In addition, the interview guides (Refer to Appendices E and F) were submitted to, and approved by, the Research and Ethics Committee of the Humanities Faculty at the University of the Free State. Subsequently, internal testing was undertaken (Doody & Noonan, 2013; Kallio et al., 2016) to improve research integrity, research ethics, and the researcher's ability to collate data (Chenail, 2011). Accordingly, a pilot interview was conducted with a volunteer in order to assess the effectiveness of the questions, ensure that the questions were understood, and improve the researcher's interview skills (Kvale, 2007; Kvale & Brinkmann, 2009). The data generated from the pilot interview was not included in the study. In the course of the fifth phase, a final revision of the questions took place in order to create a logically structured, but flexible interview guide that would generate rich data (Kallio et al., 2016).

This five-phase process of developing the semi-structured interview guide highlighted the sensitive nature of this research and the importance of being aware of the emotional effects of the interview process on the participants and of any changes that might occur in their self-understanding (Kvale, 2007). Furthermore, it was crucial to take into account the length of the interview and the comfort of the adolescent participants. Sitting still for long periods can result in pain from stiffened joints, so the adolescent participants needed to be comfortably seated and able to shift their position or move around. Consequently, interviews were conducted in the homes of the participants to provide emotional security and physical comfort. It became clear that some of the interview questions had the potential to evoke strong emotions in the participants and the researcher, and the importance of having a psychologist to refer to was accentuated. However, none of the participants needed to make use of the referral service. Only one participant was identified who may have been in need of counselling. With her permission, her parents were contacted in this regard, but she preferred to use her own therapist. The researcher also arranged debriefing for herself with a fellow psychologist.

Care was taken to ensure that the participants' rights to privacy were upheld and that the interview data remained confidential (Donner, VandeCreek, Gonsiorek, & Fisher, 2008). The second interviews with the adolescent participants were scheduled approximately two months after their initial interviews, and as good rapport had been established, the interviews progressed smoothly. The interviews were audio recorded and transcribed verbatim. Owing to time constraints, the transcription of the interviews was outsourced to a reputable, confidential transcription service provider (refer to Appendix G for the confidentiality contract), as interviews can take up to 10 times longer than the duration of the interview itself to transcribe (N. Petty et al., 2012b). Each transcription was checked by the researcher against the audio recording and errors were corrected, but only minor changes that did not affect the meaning of the interview were identified (Toms, Quinn, Anderson, & Clare, 2014). These changes included correcting the spelling of medical and religious terminology. The transcripts were then shared with the participants for participant verification to ensure that they accurately reflected each participant's experiences and perspectives and were thus credible (Houghton, Casey, Shaw, & Murphy, 2013; Kornbluh, 2015; Kvale & Brinkmann, 2009). Furthermore, the verification process gave participants the opportunity to contact the researcher regarding any concerns they may have had about the content (Houghton et al., 2013). In addition, participants were able to reflect on their first interview before the second interview. None of the participants expressed concerns, but two mothers requested that certain details, such as the name of a participant's friend, be deleted. The second interview served to clarify and confirm points of interest previously raised. Moreover, it allowed for further exploration of areas of interest and sharing of new insights (Morrow, 2005). Thus, the second interview was individualised, as it was based on the first interview. The interviews provided rich, thick descriptions of the adolescent and parent participants' experiences. The analysis of this data will be discussed in the following section.

4.4.3 Data Analysis: Sameroff's Unified Theory of Development and Braun and Clarke's Six-Phase Process of Thematic Analysis

Research fidelity is improved by limiting the researcher's perspective in data analysis. Levitt et al. (2017) suggest two strategies for achieving this. Firstly, the researcher could use self-awareness to challenge prior conceptions, which might bring to the fore understandings that would otherwise have been obscured. Alternatively, they suggest using a theoretical framework, such as critical psychology, for the unit of analysis in order to view marginalised dynamics that may be hidden by prevailing discourses (Levitt et al., 2017). I chose the latter option to ensure that the data was viewed broadly, thus limiting the influence of my prior knowledge and preventing an overly narrow analysis of the data. The hallmark of a developmental psychopathology framework is the multilevel analysis, in which the unit of data is the transactions that occur between and within the systems (Marshall, 2013; Sameroff, 2014). Exploring the data set within such a broad vehicle of analysis helped to ensure that new findings were not obscured by my preconceptions and knowledge. Consequently, the data analysis phase consisted of two processes. Firstly, in line with the developmental psychopathology framework utilised in this study, Sameroff's (2014) multisystemic analysis model was used to situate the data within multiple systems. Secondly, Braun and Clarke's (2006) six-phase process of thematic analysis was used to discover hidden meanings within each system.

Sameroff's *unified theory of development* is both a developmental psychopathology theory and an analysis model (Sameroff, 2014). The use of a multilevel analysis process not only ensures that factors are not overlooked because of an overly narrow focus, but it also enables an understanding of how transactions between the systems impact on the phenomenon. Once the coding was completed, all the codes and emerging themes were placed into the different systems so that the interactions between the systems could be analysed. Firstly, each participant's experiences were mapped individually into the multilevel systems. Next, in order to understand the dynamic processes involved as well as the commonalities and differences, the data across all the participants were integrated into one multilevel analysis. After the codes had been situated within an analytic framework, Braun and Clark's thematic analysis was used within each system to explore the emerging themes. As Sameroff's unified model of development is presented in depth in Chapter 2, the following paragraphs will describe Braun and Clarke's (2006) six-phase process of thematic analysis.

Braun and Clarke's (2006) six-phase process of thematic analysis was used in this study, as it is well suited to exploring participants' perspectives and experiences (Braun & Clarke, 2014) of illness and well-being. Clarke and Braun (2014, p. 1) define thematic analysis as "a method for identifying and interpreting patterns of meaning across qualitative data". It is a method that enables the researcher to make sense of collective experiences by focusing on the meaning and commonalities across a dataset (Braun & Clarke, 2012). Thematic analysis is similar to other pattern-based qualitative analysis methods, but its advantage lies in the fact that, as it is not tied to any theoretical framework, it can be applied to different types of research questions and data forms (Clarke & Braun, 2014). Moreover, this method is used to analyse experiences, perspectives, behaviours, and practices (Braun & Clarke, 2012), as well as the data yielded from semi-structured interviews (Clarke & Braun, 2014). The final advantage of this method is that it can be applied to small data sets.

In this study, thematic analysis entailed the iterative process of the hermeneutic circle employed by interpretive researchers (Levitt et al., 2017). The codes and themes were obtained from the data and gave voice to the participants' experiences and perspectives (Braun & Clarke, 2012). The rich descriptions derived from the dataset enabled the identification of central themes and patterns of meaning (Braun & Clarke, 2012). The process is seen as being recursive rather than linear, with the analysis moving back and forth between phases (Clarke & Braun, 2013). Inherent meanings were formulated through the interpretivist cycle, which entailed moving from conceptualisations to theory to make sense of the findings. As meanings were generated, further analysis was undertaken to provide contextualised evidence. Finally, after further data was incorporated, commonalities were sought using the interpretive cycle. Through this process of methodical hermeneutics, the meanings generated were refined into stable conceptualisations.

Braun and Clarke do not include transcription as part of their six-phase process and advise that once transcription has taken place, the researcher is ready to begin with the analysis (Braun & Clarke, 2012; Braun, Clarke, & Rance, 2014; Clarke & Braun, 2013). An overview of Braun and Clarke's (2006) phases of analysis is presented in Table 4.2 (page 120).

Table 4.2

Overview of steps taken in Braun & Clarke's six-phase analysis

	Phase	Description
1	Familiarisation with data	Deep immersion with the data through repeated readings with some noting of observations.
2	Coding	Coding data that is relevant to the research process.
3	Searching for themes	Analysing the codes for overarching themes and collating all codes into relevant themes.
4	Reviewing themes	A recursive process in which the themes are checked against the codes and the full data set.
5	Defining and naming themes	A written analysis of each theme is conducted, the essence of each theme is identified, and informative names are given.
6	Writing up	This step involves integrating the analytic narrative with data extracts to provide the reader with a coherent story that is situated within the relevant literature.

Source: Adapted from Braun & Clark, 2006

4.4.3.1 Phase 1: Familiarisation with the data.

The aim of Phase 1 is to become immersed in the content and to start noting aspects that might be pertinent to the research. Braun and Clarke advise reading through the whole data set at least once, preferably twice, until the researcher is deeply familiar with the content (Braun & Clarke, 2012; Clarke & Braun, 2013). Furthermore, they suggest that note-making at this stage be observational and casual – more stream of consciousness than well-written prose. Consequently, the audio recordings were listened to for a second time while reading the transcripts, so that the emotional tone of the content, as well as any initial ideas regarding codes and themes, could be noted.

4.4.3.2 Phase 2: Coding.

Phase 2 is the start of the systematic coding of the data. A third reading was undertaken to identify any data that might be relevant to the research question. As advised by Braun and Clarke (2012), at this stage any data that might be relevant was coded to ensure inclusivity and thoroughness. The first and second interviews were combined and coded together. The parent interviews were coded separately. The interviews that appeared to be the richest in data were coded first. Initial codes were modified as coding progressed and the process endeavoured to identify patterns and diversity within the data (Clarke & Braun, 2013). The codes were recorded on the digital copies of the interviews by highlighting excerpts and typing in the codes using the "Review" functions of Microsoft Word. To limit researcher bias, an external auditor, who was not involved in the study but who has experience in qualitative research, coded the data separately. Moreover, a database was created that listed the codes according to the participants, which allowed for the relevance of different codes across cases to be analysed.

4.4.3.3 Phase 3: Searching for themes.

During this phase, the analysis focused on themes which encapsulated significant topics connected to the research question (Braun & Clarke, 2006). This involved re-reading the coded data to identify the broad topics overarching the codes that reflected a meaningful pattern (Braun & Clarke, 2012). At the same time, the relationships between themes were explored to ascertain how they worked together to convey meaning about the data (Clarke & Braun, 2013). These themes were loosely situated within a multiple-system framework to allow for broad, flexible exploration of themes and interactions, and to limit the effects of my perspective on the data.

Codes that did not appear to answer the research question were grouped together (Braun & Clarke, 2012).

4.4.3.4 Phase 4: Reviewing themes.

Clarke and Braun (2013) describe this phase as a recursive process during which the themes are reviewed for quality checking. The themes were first checked against data extracts to ascertain whether the theme fit the data (Braun & Clarke, 2012). If it did not fit, then it was either discarded or grouped under another theme. When I had compiled a coherent set of themes, the second phase of the thematic review was undertaken. This involved reviewing the themes by re-reading all of the data (Clarke & Braun, 2013), with the aim of deciding if the themes represented the most important and relevant aspects of the entire data set. The research supervisors were an integral part of this review process, during which additional themes were created and weak themes were discarded. At the end of the second phase of the thematic review, new themes which extend the current body of literature were retained.

4.4.3.5 Phase 5: Defining and naming themes.

According to Braun and Clarke (2012), themes should fulfil three purposes. Firstly, they should have a singular focus. Secondly, they are related but should not overlap. Thirdly, they must directly address the research question. Moreover, the themes should provide a coherent overview of the data and may contain sub-themes. In this study, the themes were named in a manner that attempted to be informative and concise. The names of themes and sub-themes were reviewed by the supervisors and underwent many changes until they epitomised the content being discussed.

4.4.3.6 Phase 6: Writing up.

This phase underlay the entire data analysis process, as it included the informal writing and notes from the earlier phases. During this phase, I attempted to situate the themes within the conceptual framework and provide a coherent representation of the data. Thick descriptions were selected from the participant interviews to represent the themes in an expressive manner. These extracts provided the foundation of the analysis to follow. The data were interpreted, linked to the research question, and situated within the existing research findings. As discussed previously, this was a recursive process which moved back and forth between phases (Clarke & Braun, 2013). Engagement in the interpretivist cycle facilitated meaning making through moving between themes and theory. Again, the supervisors were an integral part of this process as they identified bias and encouraged deepened reflexivity.

4.5 Rigour and Trustworthiness

Research quality, or rigour, necessitates a systematic approach that ensures that the research components are coherent and congruent with the research paradigm (Levitt et al., 2017; Ryan, Coughlan, & Cronin, 2007). Several authors have provided research measures that establish credibility and trustworthiness in qualitative research (Guba, 1981; Krefting, 1991; Lincoln & Guba, 1985; Shenton, 2004; Silverman, 2013). In accordance with these guidelines, rigour and trustworthiness were established in this study by delineating the conceptual framework, the research paradigm, the research question, and the methods of data collection and analysis. Furthermore, detailed descriptions of the researcher and contextual characteristics are provided.

Trustworthiness refers to the degree of confidence that is instilled in the reader about the methods used, data obtained, and interpretations made (Connelly, 2016; Levitt et al., 2017; Lincoln & Guba, 1985). Over the last four decades, the parallel approach (Guba & Lincoln, 2001) has been accepted by most researchers. This approach entails using parallel concepts to those used in the positivist paradigm – namely, credibility, reliability, transferability, and dependability. Critical analysis has determined this approach to be appropriate for ensuring trustworthiness (Connelly, 2016; Morse, 2015; Ryan et al., 2007; Silverman, 2013). However, some researchers still advocate including the component of authenticity (Connelly, 2016; Cope, 2014; D. Casey & Murphy, 2009; Lamb, 2013a, 2013b; Tracy, 2010). Therefore, for this study, trustworthiness was achieved by applying the principles of credibility, transferability, dependability, confirmability, and authenticity (Amankwaa, 2016; Connelly, 2016; Cope, 2014; Ryan et al., 2007; Silverman, 2013).

4.5.1 Credibility

The credibility of a study and its findings is considered to be the most important criterion of trustworthiness (Connelly, 2016). Credibility refers to the level of confidence the reader has that the research represents an accurate reflection of the experiences of the participants (Amankwaa, 2016; Cope, 2014; Levitt et al., 2017). Given that in the constructivist-interpretivist paradigm knowledge is viewed as being subjective, credibility is enhanced by the researcher acknowledging her experiences and checking the research findings with the participants (Cope, 2014; Kornbluh, 2015). In this study, I was able to use my own experiences of having chronic, inflammatory arthritis as a resource to make sense of the participants' experiences. However, my understanding of their comments was reflected back to the participants within the interviews to enhance clarity. Moreover, the interview transcripts were made available to the participants to ensure that my understanding of the participants' experiences reflected their intended meanings (Kornbluh, 2015). Respondent verification also helped to limit researcher bias.

Triangulation may also increase credibility (Amankwaa, 2016; Lincoln & Guba, 1985). Two purposes of triangulation have been identified – namely, confirmation of data and completeness of data (D. Casey & Murphy, 2009). Confirmation involves analysing data from multiple sources to ascertain the extent of convergence (D. Casey & Murphy, 2009). If findings are consistent across multiple sources, then credibility is increased. Furthermore, triangulation may increase the completeness of data as multiple perspectives are gained from a variety of sources, which again strengthens credibility (D. Casey & Murphy, 2009). Two methods of triangulation were used in this study to enhance credibility. Firstly, data source triangulation (Braun & Clarke, 2013; Silverman, 2013) was implemented through the use of multiple participants, as both the adolescent and their parent were interviewed in each case. As the adolescent and parent dyads were situated in the same family, their unique views of the psychosocial experiences of the adolescent participants enhance credibility. Moreover, the two phases of the adolescent participants' interviews were separated by a few months. Given the inherent unpredictability of JIA, this separation of phases may have increased the comprehensiveness and variability of the data acquired. In addition, participants were selected from different provinces, which may have provided variations in experiences that were context specific. Furthermore, the audio recording of the interviews preserved the original data and enabled the researcher to reflexively re-engage with the emotional content of the interviews and check the accuracy of the transcription. In addition, the audio recordings facilitated prolonged and repeated immersion in the data and allowed the researcher to check developing constructions against the original data (Guba & Lincoln, 2001; Hays, Wood, Dahl, & Kirk-Jenkins, 2016).

As a second method of triangulation, I selected multiple theoretical perspectives to interpret the data; this is referred to as theoretical triangulation (Silverman, 2013). Sameroff's (2014) universal theory of development provides a multilevel analysis model which ensured a broad analysis of the data. Moreover, the emphasis on regulatory and representational processes enabled a nuanced understanding of the effects of transactions between the systems on adolescent experiences and development. I also made use of adolescent developmental theories to interpret and find meaning in the experiences described by the participants. In addition, resilience theory was used to understand the adolescent participants' processes of positive adaptation to JIA and experiences of subjective well-being. The use of multiple theories provided multiple lenses through which to interpret and make sense of the data.

4.5.2 Confirmability

Confirmability places emphasis on whether the findings represent the participants' beliefs and experiences and are not affected by the researcher's own biases (Connelly, 2016; Guba & Lincoln, 2001). Confirmability was enhanced by using the strategies of an audit trail and triangulation (Morse, 2015). Through maintaining a detailed audit trail (see section 4.5.3 on page 127 for an in-depth explanation of this strategy), I could demonstrate how the interpretations and conclusions were made and that they were derived directly from the data, rather than from my preconceptions. This process was enriched by providing direct quotes when reporting the findings, thus ensuring that the participants' voices were heard (Cope, 2014). Moreover, the data was audited by the research supervisors to prevent further personal bias and thereby strengthen confirmability.

Confirmability is also strengthened by the use of multiple analysts. Analyst triangulation makes use of multiple analysts or auditors to review the interpretations and findings made by the researcher (Amankwaa, 2016). Consequently, analyst triangulation generates multiple ways of interpreting the data. In this study, two sets of coding were undertaken. I created an initial set of codes which I then critically compared to a second set of codes from an external auditor. Furthermore, the two supervisorsupervisors reflected on their interpretation of the data and provided critical feedback on my findings; this facilitated deeper insight into the nuances of the data. Moreover, their comments assisted me in identifying blind spots and helped to prevent a limited perception of the data. In addition, they encouraged increased levels of reflexivity by alerting me to possible areas of bias. Finally, a professor of paediatric rheumatology was asked to critically reflect on the interpretations and findings that pertained to the medical system in order to ascertain whether my interpretation of the data represented his experiences in the field of JIA. The professor confirmed that my interpretations did indeed correspond with his professional experience, which further contributed to increasing the confirmability and dependability of the research.

4.5.3 Dependability

Dependability is concerned with ensuring that the research findings are consistent and replicable (Amankwaa, 2016; Lincoln & Guba, 1985). Yardley (2000) argues that, as qualitative research is subjective, the interpretations of the data may differ. Thus, dependability is achieved when other researchers agree with the decisions made at different points in the research (Cope, 2014). To facilitate dependability, Lincoln and Guba (1985) recommend using an audit trail which involves creating a detailed account of each step of the research process. In the current study, detailed notes that outlined all the decisions that were made about access, settings, experiences, participants, and problems were kept (Koch, 1994; Lamb, 2013a, 2013b). These notes enabled me to remain aware of the different aspects of the research process and my role therein. The audit trail included recording the interviews verbatim to allow for re-checking, documenting any problems that arose during the research process, and taking note of the manner in which these problems were resolved. Moreover, I engaged in a continuous process of reflexivity in which I recorded any personal experiences that may have affected the way the research evolved. I attempted to ensure that the participants' voices took priority by questioning my thoughts and interpretations during the research process. Questions such as "Is this what the participant is saying, or is this my voice?" and "Is this a balanced interpretation of the data?" assisted in highlighting the participants' voices, rather than my own. In this regard, critical feedback from the research supervisors was helpful in identifying and reducing possible bias. This feedback was filed for later reference. Thus, the rigour of this research was optimised through being critically aware of my own role during the research process, as well as adhering to the principle of transferability.

4.5.4 Transferability

Transferability is supported by providing rich, detailed descriptions of the participants and context (Levitt et al., 2017; Ryan et al., 2007). Even though transferability is seen to be a parallel concept to that of generalisation, it is significantly different, as the aim of qualitative studies is not generalisation (Connelly, 2016). Thus, transferability does not claim that the findings are the same for everyone (Connelly, 2016). Instead, rich descriptions are provided so that the readers can decide the extent to which the conclusions drawn from this study are transferable to other situations (Amankwaa, 2016; Lincoln & Guba, 1985). This study aimed to provide thick descriptions of the psychosocial experiences of seven sets of adolescent and parent participants. In order to enhance transferability, I attempted to provide an accurate account of the seven cases by providing rich descriptions and verbatim quotes of their experiences in context. Moreover, the detailed account of the research context combined with the in-depth literature review may allow for generalisation in similar cases.

4.5.5 Authenticity

The concept of authenticity was first proposed by Guba and Lincoln (1994). Authenticity refers to the degree to which researchers realistically present participants' lives by including a range of different realities (Connelly, 2016). It allows qualitative researchers to present the deep meaning of a phenomenon to enrich understanding (Connelly, 2016). In the current study, authenticity was addressed by selecting appropriate participants and providing rich, thick descriptions of their experiences through the use of verbatim quotes. In addition, the adolescent participants' descriptions were contextualised to facilitate the reader's understanding of the deeper meanings underlying the quotes. These descriptions were supplemented by the experiences of participants' parents, which serves to further enhance the authenticity of the research. The reflexive processes I engaged in as researcher were documented in my research journal, which also strengthens authenticity (Lamb, 2013a, 2013b).

4.6 Ethical Considerations

Although qualitative health studies regarding psychological phenomena seldom entail physical risk, there is the potential for emotional risk during the research process (Huang, O'Connor, Ke, & Lee, 2016; Wassenaar & Slack, 2016). Certainly, when conducting research with minors, it is essential to minimise risk and safeguard their emotional well-being (Davidson & O'Brien, 2009; Huang et al., 2016). In order to ensure the well-being of the participants, this study adhered to the ethical guidelines proposed by the APA (2016) and the Health Professions Council of South Africa (HPCSA, 2008). Ethical clearance (UFS-HSD2016/0337) was obtained from the Research and Ethics Committee of the Humanities Faculty at the University of the Free State (see Appendix A). Furthermore, this study adhered to the principles of non-maleficence and beneficence, which respectively state that the researcher should take care to do no harm and that the research should benefit the research participants (APA, 2016; HPCSA, 2008). The additional measures that I took to ensure the ethical treatment of the participants are described in the following sections.

4.6.1 Evaluating Potential Risks and Benefits

In line with the principles of non-maleficence and beneficence, it is essential that the potential risks to, and benefits for, the participants be carefully evaluated (Hammersley, 2015). In this study, the recalling of painful or traumatic events during individuals' journey with JIA could give rise to anxiety or emotional distress and was thus identified as a possible source of emotional risk to participants. To ameliorate this possibility, the interviews were conducted in the participants' homes when one parent would be at home to provide a sense of security and emotional containment should it be necessary. Although great care was taken not to conflate my distinct roles as researcher and psychologist, my professional experience as a registered educational psychologist ensured that any immediate emotional distress could be safely managed. In addition, the interviews were conducted in an age-appropriate, sensitive, and accepting manner. I often work with adolescents, thus I am skilled at using developmentally appropriate language and responding in a non-judgemental way. Moreover, I paid close attention to body language and other cues that might indicate that a participant was becoming distressed. Given the possibility that the interviews might have triggered emotional distress, registered psychologists were available to address the emotional needs of the participants free of charge, as indicated in the information sheet (See Appendix C). Although some strong emotions were evoked during the interviews, only one adolescent participant needed follow-up counselling. With the participant's permission, her parents were informed of the need, and she chose to see her own therapist.

In line with the principles of caring and reciprocity when working with vulnerable groups (N. Bell, 2008), I have undertaken to provide the participants and their families with a pamphlet that delineates the research findings and provides individualised guidelines that might be beneficial to the adolescents, their parents, and their treatment team. Furthermore, the adolescent and parent participants were unanimous in voicing the need for greater awareness of JIA and access to support for newly diagnosed children and their families. In this regard, and with participants' endorsement, I have undertaken to provide useful information regarding JIA on my professional website which is accessible to the public. In addition, I am in the process of establishing a parent support group which links families with a recent diagnosis to families with greater experience in managing JIA. The intention is to provide information and social support after a recent diagnosis, which should facilitate the process of positive adaptation to JIA. While therapeutic intervention had not been undertaken during the interviews, the adolescent and parent participants indicated to me that the interviews had been an uplifting experience and that they felt empowered through their involvement in research that they viewed as meaningful.

4.6.2 Obtaining Informed Consent and Assent

Ethical guidelines indicate that research cannot be carried out on children, but rather with or by them (Hammersley, 2015). Moreover, when working with vulnerable groups or children, it is essential to continuously confirm with the participants, throughout the data collection process, that they are still willing to be involved or if they would prefer to withdraw (Ryan et al., 2007). Informed consent is a legal term that refers to the interactive process that ensures that participants have been fully informed of the proposed research activity and can freely decide to participate in the study (Huang et al., 2016). Similarly, informed assent is an ethical term which refers to participants who are minors and who are unable to legally consent to be part of the research (Huang et al., 2016). Instead, they assent to being part of the research process, in addition to their parents or guardians providing informed consent (Hammersley, 2015; Lambert & Glacken, 2011). Not obtaining informed assent from children and only accepting parental or guardian consent is seen to infringe upon the rights of children (Hammersley, 2015). Moreover, obtaining informed consent or assent requires more than reading and signing a form.

Indeed, Lambert and Glacken (2011) argue that for informed assent to be valid, six steps need to be followed. In this study, I engaged with the adolescents, built rapport, and assessed their capacity and readiness to provide assent. In addition, the oral and written information provided to the adolescents was presented in age-appropriate language. I emphasised that their participation was voluntary and that they could withdraw at any time during the research process without repercussions. Moreover, I carefully observed the adolescent participants for of any signs of refusal or external pressure from their parents. Furthermore, I entered into discussion with the adolescents to assess their level of understanding of what might be required of them and their rights in the research process. I provided the adolescents with time to reflect on what was required and to voluntarily decide whether or not they would like to participate. Finally, informed assent was revisited continuously throughout the data collection process to ensure that the adolescents were still willing to be involved (Lambert & Glacken, 2011).

In this study, the parents made initial contact with the researcher either telephonically or via e-mail. During the initial communication, they were provided with an overview of the research project. Given that the adolescent participants were between 15 and 18 years of age, informed consent was first obtained from their parents. The parents were provided with a letter containing an information sheet that explained the aims and nature of the research and what would be expected during the research process (see Appendix B). The letter clearly expressed the participants' right to confidentiality and to withdraw at any time during the research process without repercussion or explanation (Allmark, 2002). Moreover, telephonic or e-mail discussions were held to answer any queries raised by the parents. When the parents had read the consent form and decided to given permission for their child to participate in the study, they completed the consent form (see Appendix B). Following this, the adolescent participants were provided with a letter written in developmentally appropriate language (Huang et al., 2016) that described the purpose of the research and what would be expected of them (see Appendix C). This letter also emphasised their right to confidentiality and to withdraw from the research process at any time without any explanation or repercussions. Again, telephonic or e-mail discussions were held in order to address concerns raised by the adolescent participants. Also, adolescent participants were requested to read, and upon understanding, to sign an assent form (see Appendix C). Finally, the parent participants were also provided with a letter describing their role in the research and were requested to sign a consent form (see Appendix D).

At the beginning of the first interview, time was taken to establish rapport with the participants and to check whether they would like to continue. Also, they were reminded that they could withdraw at any time. Moreover, during the interviews, I carefully monitored for emotional distress, physical discomfort, or fatigue and discontinued the interviews as soon as the participants indicated that they wished to stop.

4.6.3 Confidentiality and Anonymity

As with adults, children have the right to confidentiality and anonymity during the research process (N. Bell, 2008). Before the initial interview, adolescent participants' rights to confidentiality and anonymity were explained in an age-appropriate manner, and they were invited to raise any concerns or queries. Both adolescent and parent participants were asked for permission for their interviews to be recorded and transcribed. They were informed that their responses might be reviewed by people responsible for making sure that this research is conducted properly, including the transcriber, external coder, and research supervisors. Furthermore, they were advised that the records would be available only to people working on the study. In addition, this written report of the research study uses pseudonyms and does not contain any identifying information. The participants were made aware that the results of this research project may be published in a scientific journal and presented at child and adolescent psychology conferences. They were assured that, should this happen, their identities and personal information would remain strictly confidential, and their participation would not be identifiable. With regard to the research data, I will store the hard copies of the interviews in a locked filing cabinet for five years for future research or academic purposes, and the electronic information will be stored on a password-protected computer. Moreover, future use of the stored data will be subject to further review and approval by a research and ethics committee, if applicable. After five years have passed, the hard copies will be shredded by hand, and the electronic information will be deleted.

4.7 Conclusion

This chapter demonstrated the appropriateness of the constructivist-interpretivist paradigm and case study methodology for researching the psychosocial experiences of adolescents with JIA. Furthermore, the coherence and congruence of paradigm, methodology, and method were presented. The research design was critically discussed in depth with specific reference to case study methodology, semi-structured interviews, and thematic analysis. Care was taken to provide sufficient information regarding each adolescent participant in order to contextualise the findings. The importance of trustworthiness and rigour, and the steps taken to achieve this, were addressed in detail. Finally, the ethical considerations needed to protect the well-being of the adolescent and adult participants were elucidated. This chapter provided the methodological framework for the subsequent chapter in which the research findings are discussed.

CHAPTER 5: THEMATIC ANALYSIS

5.1 Introduction

Developing a rich understanding of the psychosocial experiences of adolescents living with JIA required investigating and integrating their experiences within multiple systems. The interviews provided a wealth of data regarding risk and resilience processes. However, given the limited scope of this dissertation, it is not possible to present all the themes that arose. Instead, this chapter presents the themes that extend the body of psychological knowledge regarding adolescents with JIA. It is essential to emphasise that, although the themes are presented separately, they are embedded within dynamic, interactive biopsychosocial ecological systems (Sameroff, 2014).

To facilitate the reader's processing of the data, an overview of the themes and sub-themes is presented in Table 5.1 (page 137). The verbatim interviews of the adolescent and parent participants are provided in Appendices K to Q, and each quotation can be found by using the appendix letter, the interview number, and the paragraph number. Accordingly, K[1p22] indicates the source as Appendix K (Rayne), Transcript 1, paragraph 22. Where necessary, clarification of comments may be inserted within brackets () into the quotations. The focus of this chapter is to present the data with minimal interpretation.

Table 5.1:

Overview of the themes and sub-themes

Theme	Sub-theme
Multisystemic risk processes	Limited social awareness of JIA Illness invalidation and the dismissal of pain Time taken to diagnosis Delivering the diagnosis Anxiety-provoking medical experiences Dis/Empowering relationships with medical practitioners
Multisystemic resilience processes	Passivity evolves into a sense of agency Monitoring physical and social activities Monitoring emotions and thoughts
Adapting positively to living with JIA	Negotiating identity formation in the context of living with JIA Qualitatively different opportunities for becoming autonomous Experiences of well-being in living with JIA

The first theme presents findings regarding the risk processes that may affect adaptation to JIA. In the second theme, rich descriptions of multisystemic resilience processes elicit an increased understanding of how the adolescent participants adapted to JIA. The final theme explores the positive adaptive outcomes that may have been attained by the adolescent participants, with specific reference to developmental tasks and subjective well-being.

5.2 Multisystemic Risk Processes

The consensus in international research is that JIA presents risks to normative development, both within and between multiple systems (Cartwright et al., 2014; Tong et al., 2012). The adolescent and parent participants recounted very similar risk experiences to those portrayed in the literature to date, specifically regarding individual, family, and school systems. While these multisystemic experiences were meaningful for the adolescent participants and worthy of exploration, they did not extend the current body of literature. Hence, as this is a doctoral dissertation of limited scope, it was decided to focus on data that extended the current body of knowledge with regards to risk processes associated with JIA.

5.2.1 Limited Social Awareness of JIA

The level of social awareness of a chronic illness may be either a risk or protection factor in the process of adaptation. In this study, both adolescent and parent participants seemed to express frustration with the lack of social awareness regarding JIA in comparison to other serious childhood diseases, such as cancer. This limited understanding seems to give rise to misconceptions about the nature of JIA which, in turn, seem to have led to reduced levels of empathy from significant others. In addition, the participants reported that, unlike other serious childhood illnesses, there are minimal psychosocial support systems for individuals with JIA or their families. Limited social awareness, misconceptions, and insufficient social support systems seem to have led to participants experiencing a sense of social isolation.

The adolescent and parent participants were frustrated with the lack of social awareness regarding JIA, particularly in contrast with the substantial awareness regarding other serious childhood illnesses. Micaela reflected on the different level of social awareness regarding cancer treatment in comparison to that of JIA: "*It's well known, you know. People know the treatment is chemo or radiation, and it's sort of well known that there's a lot of treatment out there and support and stuff . . .*[2] *We didn't know like where to start with medication, what to do with school, what*

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[2] The use of an expanded ellipsis (. . .) indicates that a section of the interview has been excluded.

to do, I don't, just with everything" O[2p86]. The previous quote highlights that JIA requires management within multiple systems; consequently, the limited information and support systems available make this a daunting prospect.

The adolescent and parent participants stated that the lack of awareness regarding JIA leads to several misconceptions, one of which is the idea that arthritis is a disease associated with old age. Rayne was particularly emphatic about the need to raise awareness that children and adolescents also develop arthritis: "*I think, I feel like when people think of arthritis they think of like some old granny like walking around with a wooden stick and having like arthritis in her knees and everything. And I just don't want people to. I want people to like realise it happens to people my age and people younger. And it's like a thing that really impacts your life. Ja. Because I don't think they really understand*" K[2p436]. Leigh-Ann also commented on this misconception amongst her peers: "*Well, I guess firstly no-one's ever heard of juvenile arthritis there* (at school). *I think once someone asked me if I have old lady disease, something like that"* P[1p238]. These comments suggest that arthritis is viewed as a disease associated with old age and that there is minimal social awareness that children and adolescents can develop inflammatory arthritis. As a result, the adolescent participants did not seem to receive much support or empathy when disclosing that they have been diagnosed with JIA.

A second misconception identified by the adolescent and parent participants is that other individuals do not understand the serious nature of the disease, especially when the debilitating physical symptoms are not visibly noticeable. In particular, Rochelle, Jessica, Micaela, and Leigh-Ann developed enthesitis-related JIA, in which there are high levels of pain, but no visible signs such as swollen joints. Daisy, Micaela's mother, explained that the invisible nature of JIA meant that people could not see evidence of ill-health: "*It's because it's so so different to cancer because* *with the cancer it doesn't seem to be so isolating because everybody understands cancer and they rally round but with the JIA I think because it's so invisible that: 'but what's wrong, you look fine, what's wrong with you*?'" O[3p129]. Similarly, Samantha, Leigh-Ann's mother, reflected: "*You know, it's so difficult when you're dealing with something that is essentially invisible. You know there's, there's a great deal of sympathy, and I'm not saying that there shouldn't be, for people. For children who have cancer, for example*" P[3p44]. The question *"what's wrong with you?"* highlights how the adolescent and parent participants had to continually explain what JIA was and how it affected them. Moreover, unlike cancer patients, they often needed to defend or justify their ill-health. These comments are interesting in that, while cancer symptoms may also be invisible, the participants were of the view that because the latter is a well-known childhood disease, high levels of empathy and support are elicited. In contrast, they felt that the lack of social awareness regarding JIA appears to limit the social support offered to them.

The adolescent participants also discussed how the invisible symptoms of JIA can mask the severity of the disease; consequently, it is difficult for their friends and peers to empathise with their high levels of pain. Charlotte believed that her friends are not able to understand her level of pain: "*So it's a bit difficult, because they don't really understand like what really, what the condition really is. Like what it like really means to experience that kind of pain and whatever*" Q[1p375]. Furthermore, Ursula expressed frustration that, since her physical symptoms are no longer highly visible, her peers seem to forget that she has JIA: "*I guess I get annoyed that I just wish they would understand. And that, realise that, you know, just because I'm not in a wheelchair anymore doesn't mean that the disease is gone. And that if I come to school one day and I'm fine, the next day doesn't mean I'm going to be fine either"* L[2p74]. These comments emphasise that it is difficult for other individuals to understand the high levels of pain and fatigue experienced by the adolescent participants, which seems to reduce the amount of social support offered. Similarly, Ursula noted that the unpredictability of JIA flare-ups is confusing for her friends. In addition, it is not only the invisible nature of the pain, but also of the fatigue, that tends to cause misunderstanding. The adolescent participants recounted experiencing high levels of fatigue despite apparent health, which is one of the hallmarks of JIA. Leigh-Ann described her peers' reactions when she mentions her fatigue: "*And we just got talking about how tired I am. And of course everyone says: 'Oh, you seem fine, you look healthy, you don't seem that tired, you cope so well'*" P[2p14]. The invisible nature of pain and fatigue experienced by some of the adolescent participants seemed to contribute to diminished levels of understanding and empathy from peers and friends.

The adolescent and parent participants explained how the low level of social awareness meant that the adolescent participants' illness experiences had to be explained and justified, which contrasted with the high level of awareness and social support that a childhood illness such as cancer seems to elicit. This lack of social awareness yields misconceptions about JIA – namely, that arthritis is a disease associated with old age and that the visibility of physical symptoms correlates with the degree of pain and fatigue experienced. In particular, it seemed as if other individuals were unable to comprehend the severity of the adolescent participants' pain and fatigue if there were no visible physical signs of illness and the adolescent participants appeared to be healthy. Thus, low levels of social awareness place the adolescent participants at risk of maladaptive trajectories. As a result, it seems possible that increasing the level of social awareness of JIA may facilitate positive adaptation to JIA.

5.2.2 Illness Invalidation and the Dismissal of Pain

The levels of illness and pain validation, or lack thereof, experienced by the adolescent participants affected their trajectories of adaptation to JIA. Certainly, there appeared to be a relationship between the degree of visibility of the illness and the level of illness or pain validation elicited from significant others. Rayne, Ursula, and Charlotte presented with visible signs of physical illness which seemed to garner medical and social support, despite inconclusive medical test results. In contrast, the remaining adolescent participants with enthesitis-related arthritis had invisible symptoms, which seemed to result in pain dismissal and the invalidation of their illness experiences by significant others, both before and after their diagnosis. Their comments suggest that they were critical of themselves, as they seemed to view a psychogenic illness as not being "real". As a result of having their illnesses invalidated and their pain dismissed, they adopted maladaptive strategies to cope with the emotional pain that they experienced.

Jessica, Micaela, and Leigh-Ann experienced illness invalidation and pain dismissal from medical practitioners as a result of inconclusive medical tests and showing no visible signs of pain. Consequently, they began to experience self-doubt. The extent of Jessica's self-doubt is illustrated in her reaction to being diagnosed with JIA: "*You not going crazy because there's no markers or anything, so that was nice, and the psychologists I'd seen at the time also said it could be emotional pain so that made me think that it was still in my mind*" N[1p49]. It seems that when a physical cause for Jessica's pain had been dismissed, she had interpreted psychogenic pain to mean that she was "*crazy*". Moreover, Jessica reflected that she began to doubt that her physical symptoms were "real": "*Then you think: 'Am I faking this for psychological attention?'*" N[2p48]. The term "*faking*" suggests that she did not consider psychogenic pain to be "real" pain. In a similar manner, Micaela explained how a delayed diagnosis caused her to question whether her physical symptoms had a psychogenic basis: "*I also sort of started to question myself, because once enough people tell you: 'No, you're just acting up'. You start to think: 'Well, am I actually feeling this or is it in my head?'"* O[2p214]. Although Micaela could not recall any specific interactions in this regard, her comment, "*No, you're just acting up"*, intimates allegations of malingering. As a result of feedback from medical practitioners, Leigh-Ann also became concerned that her illness was psychogenic, as some medical practitioners who were consulted had alluded to the fact that her pain was psychogenic: "*No doctor actually told me outright that it was in my head, but you know there were doctors that told me there was nothing wrong*" P[1p96]. She recounted how this uncertainty affected her: "*It made me question how I saw things and how I felt emotionally as well. It made me wonder if there was, you know, something wrong with me*" P[1p112]. These quotes illustrate that the comments made by the medical practitioners caused her to doubt her illness experiences. In addition, the comment, "*It made me wonder if there was, you know, something wrong with me?*", suggests that she did not view psychogenic pain as being real. Thus, it was as a result of interactions with the medical system that these adolescent participants became concerned that their illness was psychogenic in origin. Furthermore, these quotes imply that Jessica, Micaela, and Leigh-Ann were exposed to a sceptical view of psychogenic pain, in which the psychological causes of pain are not viewed as being "real" and the individual is considered to be malingering.

Rochelle and Micaela both reported illness invalidation and dismissal of pain by certain family members, despite having a diagnosis of JIA. Rochelle's illness was overlooked by members of her extended family as they focused their support on Ursula – her visibly and severely ill sister. She described the comments that she received as follows: "*Ursula's your responsibility now, you know, you really have to take care of her . . . And then also a lot of times I was told:*

'Your pain isn't nearly as bad as Ursula's, suck it up'" M[1Bp121]. By contrasting Rochelle's levels of pain with that of her sister, her pain was dismissed, and her illness experiences were invalidated by family members. Similarly, Micaela shared that not even her father believed that she was ill: "*So my dad didn't believe the diagnosis*" O[2p62]. In addition, this disbelief was reinforced by other family members: "*At the time that people, a lot of people were not believing me, I was very self-conscious and I became very withdrawn*" O[2p270]. Not having her illness validated by family members seems to have led to Micaela experiencing increased levels of negative affect.

Such pain dismissal and illness invalidation by significant others resulted in increased levels of negative affect amongst other participants as well. Leigh-Ann described her feeling towards the doctors who suggested that her pain was psychogenic in origin as follows: "*Well, it made me very frustrated. Because a part of me was, was angry at the doctors rather than upset with myself, you know*" P[1p142]. Although Rochelle understood that her family was trying to be empathetic towards Ursula, she still experienced an increase in negative emotions when they dismissed her levels of pain: "*(I felt) very frustrated and very angry. But I think out of their ignorance they were just trying to help and be sympathetic towards Ursula, but empathy was lacking. But I felt invisible, you know*" M[1Bp123]. The previous quote highlights the depth of Rochelle's emotional pain as a consequence of having her illness experience minimised by her extended family. In a similar manner, Micaela related how she felt when her father did not regard the diagnosis of JIA as credible: "*But it's frustration because it's almost like you can't get through to them. But back then it was just loneliness and sad. Because I felt if you're not going to believe me, and you're not going to believe me, then who's going to believe me? And who have, who have I got there to talk to?"* O[2p272]. Micaela's sense of sadness and frustration with her father's lack of emotional support is evident. These adolescent participants appear to have experienced increased levels of negative emotions as a consequence of the sceptical attitude that they received from significant others.

In order to protect themselves from the sceptical attitude of significant others, Micaela, Rochelle, and Leigh-Ann began to adopt maladaptive coping strategies. Micaela began to hide her levels of pain by pretending that she was healthy and pain-free: "*And I often wouldn't tell people if I was feeling sick that day or what. And I sort of almost began to just put on a mask and because I was afraid of just so many people just saying they don't believe me. And still to this day I won't. If I'm in pain I won't voice it*" O[2p270]. The comment, "*And still to this day I won't. If I'm in pain I won't voice it*", implies that the dismissal of her illness experience may have led to maladaptive coping mechanisms over the long term. Similarly, Rochelle appears to have been made to feel guilty about speaking of her pain to extended family members, because of the severity of her sister's symptoms: "*Ursula's pain was bad, but what about mine? Does that mean that because mine isn't as bad it doesn't exist? So, ja, I just started questioning whether I could talk about it, whether it was right. Whether I was a bad person for feeling pain and then talking about it*" M[1Bp124]. In addition, because she had been told to "*suck it up*" by extended family members, Rochelle began to ignore the pain that she was experiencing: "*But for a really long time I just kept pushing myself. I was like, oh, it's nothing, I've got to keep going*" M[1Bp63]. In a similar manner, Leigh-Ann's fear that the pain was not "real" resulted in her denying her high levels of pain and fatigue: "*I have to push through and do the things that other people are doing, even though I feel physically that way. Because it made me think that actually I don't feel physically that way, it's just in my head. So I need to push myself to do things that hurt*" P[1p124]. It seems that having the reality of the pain questioned resulted in Leigh-Ann doubting her illness experience and over-exerting herself physically. It may be inferred that the lack of validation of these participants' illness and pain led to them adopting maladaptive coping strategies.

The adolescents with visible physical symptoms were able to garner support and empathy from significant others and medical practitioners, even without a conclusive diagnosis. In contrast, the adolescent participants whose physical symptoms were not visible seemed to experience pain dismissal and a lack of validation of their illness experiences. There also seems to have been suggestions by significant others and medical practitioners that these participants were malingering or that their pain was psychogenic in origin. Consequently, Jessica, Micaela, and Leigh-Ann feared that their illness had a psychogenic cause rather than a physical one. The perceived lack of legitimacy seems to have caused them to become self-critical. However, despite receiving a diagnosis of JIA, both Rochelle and Micaela's illness experiences were minimised by members of their family. Leigh-Ann, Micaela, and Rochelle seemed to utilise maladaptive coping strategies largely because of the lack of compassion and judgemental attitudes that was characteristic in their social interactions. This sub-theme – illness invalidation and the dismissal of pain – highlights the complex nature of the illness and pain invalidation experienced by the adolescent participants. Not only did the adolescent participants experience different degrees of illness and pain invalidation, but at times they experienced simultaneous validation and invalidation from significant others in their environment. However, it seems that the invalidation of their illness and pain experiences may have led to negative developmental trajectories and maladaptation to having JIA.

5.2.3 Time Taken to Diagnosis

The time taken to correctly diagnose JIA in the adolescent participants in this study ranged from several months to nine years. The adolescent participants with delayed diagnoses appeared to be at increased risk for negative physical and psychosocial trajectories. Certainly, the adolescent participants who received relatively quick diagnoses did not seem to experience the same degree of emotional distress and physical symptoms as those whose diagnostic period – the period of time between the onset of symptoms and the making of an accurate diagnosis – was prolonged.

For both Rochelle and Charlotte, the diagnostic period was fairly rapid and did not appear to be emotionally distressing. Rochelle's sister, Ursula, had been diagnosed with JIA and was under the supervision of a paediatric rheumatologist. Rochelle also presented with swollen joints: "*But with me it was immediate. So I was put on medication immediately, which meant that it probably couldn't get worse*" M[1Bp47]. Rochelle did not report adverse emotional experiences during the diagnostic period, possibly because it was fairly quick. Charlotte's mother, Julie, is a medical practitioner who works with children who have JIA. Consequently, although it took almost two years for signs of swelling to develop, once Charlotte developed pain and swollen joints, diagnosis was rapid. Julie noticed that Charlotte was having difficulty walking: "*I noticed that there was some swelling of one of the knees and she actually was struggling to go up the stairs in the hotel where we were staying. And I pretty much realised that this reactive arthritis ...*[3] *wasn't actually going away and we're going to have to actually treat it*" Q[3p8]. It appears that the diagnostic period was shorter due to a family history of JIA and visibly swollen joints. In addition, having a family member as an attentive practitioner seemed to have implications for the duration of the diagnostic process.

For most of the adolescent participants, the diagnostic period was prolonged. What is striking about the following quotes is the level of advocacy required of the parent participants in order to drive the process of diagnosis over prolonged periods of time ranging from 18 months to almost a decade. The diagnostic process appears to have been arduous and expensive, with

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[3] The use of a standard ellipsis indicates that a word or words in the interview could not be heard clearly by the transcriber.

numerous consultations with medical practitioners. Certainly, these adolescent and parent participants conveyed that they had experienced high levels of emotional distress before the diagnosis of JIA was made. A further area of concern is the suggestion that the adolescent participants' physical symptoms seemed to increase in severity over time.

Making a diagnosis of JIA appears to be complicated, as medical tests can be inconclusive and not all individuals with JIA present with swollen joints. It is problematic that medical practitioner awareness of JIA appears to be limited. Indeed, in response to the observation that Charlotte's diagnosis had been quite quick, her mother, Julie, asserted: "*I've only become aware of it because (the paediatric rheumatologist) showed me what to look out for. It's certainly not something that a GP would notice, or even sometimes a paediatrician that's inexperienced may not be aware of it*" Q[3p40]. Julie's comments suggest that even with a working knowledge of JIA, the disease can be difficult to diagnose until it has progressed sufficiently for the physical symptoms to be identified.

Several parent participants described how it was through their own advocacy and initiative that the diagnosis of JIA was finally made. Both Judith and Samantha used their social resources to access the services of paediatric rheumatologists. After having consulted with an adult rheumatologist, Judith made contact with a friend who was a paediatrician: "*And the only thing that the rheumatologist said was she's got bursitis in both hips. So I picked up on that and I was, said to (my paediatrician friend) 'What do I do? Something, something's not right. What, what?' So he said: 'E-mail me'. So I emailed him all the information. He said: 'Look, I don't know, I'm just going to pass it straight on to (the paediatric rheumatologist)'*" N[3p16]. It took approximately nine years for Jessica to receive an accurate diagnosis, which was achieved as a consequence of Judith's initiative and social resources. In a similar manner, after three years with no conclusive diagnosis, Samantha demonstrated resourcefulness in accessing a paediatric rheumatologist through a website support group: "*So I contacted the Arthritis Foundation and they said, oh, well what about Dr (paediatric rheumatologist)? So we went to (that doctor)*" P[3p10]. Consulting with the paediatric rheumatologist enabled an accurate diagnosis to be made.

Ceri and Ann used their own knowledge and experiences to facilitate an accurate diagnosis. Ceri had to suggest that Micaela be tested for immune diseases: "*I think that year that she turned 10, within the first six months, she was on about 10 antibiotics and eventually I actually said to the paed, isn't there something wrong with this child's immune system? ... So then she did an auto-immune profile and it came up that she's HLA-B27 positive and she sent us off to (the paediatric rheumatologist)*" O[3p10]. This quote implies that it took Ceri's own medical knowledge and advocacy to facilitate an accurate diagnosis, which only occurred after Micaela had been experiencing symptoms for nine years. In a similar manner, Ann kept querying the diagnoses and drawing the medical practitioners' attention to Rayne's other physical symptoms: "*And I kept saying to them, you know, not only is it sore, but just look at her. Oh she looked terrible . . . She had sores in her mouth and he just said, no, no, she's just in pain*" K[3Bp34]. Ann's refusal to accept that Rayne's symptoms were caused solely by pain resulted in Rayne undergoing a nuclear scan which identified areas of inflammation: "*The next minute there was a doctor on the phone from (another suburb), miles away . . . He said, 'I want to know exactly what's going on and I want you to get this orthopaedic surgeon to phone me straight away, there's something terribly wrong here'*" K[3Ap32]. The previous quote implies that accessing a medical practitioner who was more knowledgeable regarding inflammatory responses possibly aided in Rayne's diagnosis.

Their delayed diagnoses meant that the adolescent participants may not have received optimal interventions and may have undergone unnecessary procedures. Certainly, the long period of time preceding diagnosis may have compromised Ursula's physical health, as the disease progressed rapidly without effective treatment: "*I couldn't go to the toilet by myself, I couldn't bath myself. At night I would lie down um then I'd have to call my parents to come and turn me over, so two to three times a night*" L[1p60]. Furthermore, Jessica expressed frustration at what she perceived, in retrospect, to have been unnecessary medical procedures: "*They gave me a steroid injection; that worked maybe for a little while but then it came back and we went in for surgery. Then they took out the extra tendon that probably wasn't doing much harm anyway, and all the built-up nonsense and that. Then that did nothing. It did absolutely (nothing)*" D2p34]. Similarly, Samantha related that Leigh-Ann underwent many different treatments for her pain symptoms, but none of them were successful: "*And we started going to physio, we went to a biokineticist, we went to obviously the GP. We went to a GP who had subsequently trained in Chinese medicine, and she did acupressure, acupuncture. None of it helped*" P[3p6]. These experiences suggest that the delayed diagnoses may have resulted in sub-optimal treatment.

Furthermore, the prolonged diagnostic period seemed to result in higher levels of negative affect. Ann was visibly angry when she recollected the process of consulting with many medical practitioners to no avail: "*And it just went on and on to various other orthopaedic surgeons and neurologists*" K[3Ap33]. Moreover, in the following quote, Adele's sense of helplessness and fear at Ursula's rapidly declining health is apparent: *"Um, so the diagnosis was a long process, and I think that was terrifying. As parents, we were petrified because we didn't know what we were doing"* L[3p8]. Also, Leigh-Ann's comment alludes to a sense of despondency that the medical practitioners appeared to lose interest when their treatments were unsuccessful: "*It seems to me that, that doctors either say: 'Oh we can help you, try this, whatever'. And then it doesn't work, and then they lose interest. Well I don't know if they lose interest, but they're not willing to, I* *guess, explain or go further, look at more things ... And I guess after you've tried like one or two medications, they kind of say: 'Okay well, we've done all we can do, now go home and deal with it'*" P[2p52-56]. These comments suggest that Leigh-Ann lost faith in the medical practitioners consulted as she did not perceive them to be committed to helping her.

JIA seems to be difficult to diagnose even when medical practitioners are aware of the disease. One reason for this seems to be that the disease needs to progress sufficiently before physical symptoms manifest. Nevertheless, a lack of awareness of JIA amongst some of the medical practitioners who were consulted seems to have contributed to delays in diagnosis. Furthermore, the extent to which some parent participants needed to drive the diagnostic process, often for years, may have contributed to increased levels of negative affect in both the adolescent and parent participants. Certainly, for those with delayed diagnoses, the diagnostic process seems to have been an arduous and anxiety-provoking period.

5.2.4 Delivering the Diagnosis

This sub-theme describes adolescent participants' immediate and delayed emotional reactions to receiving a diagnosis of JIA. Notably, there did not seem to be guidelines in place for delivering the diagnosis of JIA, nor did there seem to be any post-diagnosis follow up of psychological functioning. Rayne was the only adolescent participant who could not recollect being diagnosed: "*I honestly can't remember, I've just, I've had this for like my whole life so I can't remember exactly when I was diagnosed*" K[1p28]. In contrast, the other adolescent participants expressed a range of emotional responses to receiving a diagnosis, including acceptance, affirmation, validation, anger, and anxiety.

The range of emotions expressed by the adolescent participants when they heard of their diagnoses strongly indicates that psychological containment is needed at the time and after a diagnosis is made. Rochelle had anticipated being diagnosed with JIA because of her sister's diagnosis. Indeed, Rochelle reflected: "*I mean one of my most vivid memories is I was walking in the shopping centres, and I just thought and I was pushing my sister I was like 'This is gonna be me one day' and I really knew it like, I knew I have it*" M[1Bp12]. Rochelle's initial comments suggested that she had adjusted well to the diagnosis: "*It was one of those things that I genuinely knew. I just knew. And so when they did tell me, I was, it was fine*" M[1Bp51]. Conversely, Ursula and Micaela recalled experiencing strong negative emotions upon hearing they were diagnosed with JIA. Ursula recollected her thoughts upon hearing the diagnosis: "*To be honest, I think as well because this disease is not known about, the first question I asked my mom was*: '*Am I going to die*?'" L[1p28]. It is noteworthy that Ursula and her mother, Adele, were informed of the diagnosis telephonically. Thus, Ursula and Adele's fears and questions could not be addressed as the diagnosis was not given in the doctor's presence where time could be taken to contain their reactions. Similarly, Micaela also related experiencing strong negative emotions upon receiving the diagnosis of JIA: "*I was scared and angry about having to, you know. Because I no longer saw myself as what you call a normal kid. And I'd, I had to stop, so I was quite angry. And I was quite sad as well*" O[2p94]. Micaela's description of her experiences suggests that she felt different to her peers because of the diagnosis of JIA. These strong negative reactions to being diagnosed with JIA indicate that there is a need for psychological intervention during the delivery of such a diagnosis.

It was notable that both Leigh-Ann and Jessica remembered receiving the diagnosis as an affirming experiencing. Leigh-Ann and Jessica had had their illness experiences invalidated and felt stigmatised by the suggestions that their pain symptoms were psychogenic. Leigh-Ann confided that she had wanted a diagnosis that would explain why she had been ill for three years:

"*I think I was quite confused. And it felt like. I just wanted a diagnosis; even if was a bad diagnosis, I just wanted a reason for what I was feeling*" P[1p80]. Moreover, she reflected that not being able to provide a medical reason to exempt her from school activities, such as physical education and sport, was difficult to negotiate: "*Well, it was difficult to not do those things without having a reason. It felt like I was just, you know, making excuses. Because no-one knew actually what was wrong*" P[1p92]. So, for Leigh-Ann, the diagnosis provided a legitimate reason for her physical symptoms and not being able to engage in certain school activities. In a similar manner, Jessica asserted that her diagnosis was an affirming experience in that it confirmed that she had a physical disease and that her pain was not psychogenic in origin: "*You not going crazy because there's no markers or anything, so that was nice, and the psychologists I'd seen at the time also said it could be emotional pain so that made me think that it was still in my mind, so that was nice to know*" N[1p49]. Her mother, Judith, also explained that being diagnosed was a positive experience for Jessica: "*But after years and years and years of having to defend yourself against things, it's actually nice to know that it wasn't. Because she was starting to believe that it was made (up). You know, I didn't, but she was. So for her, it was a happy moment*" N[3p56]. Of note is that both Leigh-Ann and Jessica felt stigmatised by the suggestion that their pain might be psychogenic, whereas they felt vindicated when their pain was found to have a physical cause. Moreover, the comments imply that this stigmatisation was reinforced socially, as Jessica had to "*defend*" herself against such allegations. Although Leigh-Ann and Jessica welcomed the diagnosis, these comments indicate that the diagnostic process was emotionally draining and difficult. This suggests the need for psychological intervention during this process.

All the adolescent and parent participants recalled feeling confused about the prognosis, the medical treatment, and the home management of the disease, which implies the need for psychoeducational interventions. Rochelle, who initially reported no emotional distress, revealed that as she had time to reflect on the diagnosis, she experienced fear and anxiety about the prognosis of the disease: "*What is going on? What is going to happen? And then I did get a bit scared and a bit down about it. I think watching Ursula suffer like she did, I think I was a bit scared of, you know, not being able to walk or being in that much pain. Like watching her scream and stuff like that I think that was quite scary for me, you know. What if that happens to me?*" M[1Bp41]. Having been exposed to the severity of Ursula's physical symptoms, it is not surprising that Rochelle was anxious about how the disease might progress. In addition, Micaela appears to have viewed the diagnosis as being irrevocable and life-changing: "*My life would sort of never be the same again. So I think it was a lot of like uncertainty*" O[2p96]. Micaela seemed to lose her sense of self as a result of the diagnosis, which created uncertainty about how the disease would impact on her future. Certainly, Ursula reflected that the time between receiving the telephonic diagnosis and the consultation was anxiety provoking for both her and her mother: "*The in between it's difficult. And then if you look on the internet, there's that's not a great thing to do at all. So eventually my mom and I just stopped, and this is not gonna happen*" L[1p36]. Ursula declared that even after the consultation, the diagnosis and prognosis did not prepare her to cope with the realities of an unpredictable, chronic pain disease. In the following quote she shared her belief that being diagnosed would result in being cured: "*I didn't know, I don't know what to expect, I didn't know yeah. So that was quite harsh. And to be honest I didn't really understand the journey that was ahead. So you know in my mind I expected, 'Okay, medicine ... Fixed, that's done'*" L[1p30-32]. Indeed, it was only as the treatment and disease progressed that Ursula became aware that *"the journey that was ahead"* would entail a four-year recovery process during which she would endure high levels of pain.

It is significant that, although the adolescent participants seemed to have experienced significant emotional distress in the periods before, during, and/or after the delivery of the diagnosis, they did not receive any form of counselling. Indeed, Ursula's diagnosis was delivered telephonically rather than in the consultation room, and it was followed by a week-long waiting period before the next appointment. Moreover, the relief that was experienced by some adolescent and parent participants indicates that they may have experienced significant emotional distress during the prolonged diagnostic process. Developing guidelines for the delivery of diagnoses and post-diagnostic care seems important.

5.2.5 Anxiety-Provoking Medical Experiences

The adolescent participants seemed to experience different levels of anxiety regarding the medical treatments or their anticipation of the side effects. Also, several adolescent participants remembered emotionally distressing experiences that occurred in the hospital environment. Certainly, the data suggest that some of the adolescent participants may have experienced chronic symptoms of anxiety as a consequence of their experiences.

Some of the adolescent participants required weekly or fortnightly injections of DMARDs to modify their responses to the disease. These injections appear to have caused significant emotional distress. Judith recounted that Jessica had developed high levels of anxiety as a result of the severe nausea caused by the methotrexate injections: "*Four days out of seven she was nauseous ... She's got, she's got literally PTSD from, from methotrexate*" N[3p90]. Moreover, Judith described the severity of Jessica's anxiety: "*She has flashbacks . . . She wakes up in the middle of the night freaking out that she has to have her methotrexate. Freaking out from nausea because she was dreaming about methotrexate. It's quite, quite severe*" N[3p92-94]. Similarly, Rochelle discussed her psychological reaction to the side effects of the injections: "*But the nausea* *was still very bad. And I think, I think more now, oddly enough, is the psychological effect, is whenever I smell anything like it, or Dettol, because we always used to use Dettol just before we use it, before we inject ourselves. Whenever I smell something like that, I get this rush of nausea"* M[1Bp191]. This quote implies that the smell of Dettol still triggers flashbacks of nausea, which suggests that she experienced high levels of emotional distress. These descriptions of Jessica and Rochelle's psychological reaction suggest that the side effects from the medication may have caused negative, chronic psychological responses.

The adolescent participants recollected experiencing high levels of anxiety before treatments such as injections and infusions were administered. Judith noted that Jessica becomes very distressed before the Enbrel injection is administered because it is very painful: "*And even the Enbrel, she knows she has to take it, we just. It's just her meltdown point, you know*" N[3p372]. Indeed, Jessica described how she engages in avoidant behaviours: "*I think the biggest problem for my mom was trying to get me to do Enbrel on Friday. And I'd just refuse and be super childish and like lying under tables. A complete brat*" N[2p322]. Jessica's comments imply that they she and her mother find administering the Enbrel injection to be an anxiety-provoking experience. In a similar manner, Rochelle recounted feeling anxious before injecting herself: "*I would inject my stomach, so I can remember just clenching onto my stomach and just doing it quickly or getting it over and done with . . . I was scared and I was always nervous before each one*" M[1Bp195]. Samantha also explained that it was emotionally distressing for Leigh-Ann to inject herself: "*It was just horrible for Leigh-Ann to have to inject (Humira), because she found it really really painful*" P[3p20]. These quotes suggest that the pain arising from the injections seemed to cause high levels of anxiety before they were administered.

Ursula and Leigh-Ann received in-hospital infusions. Ursula explained that she experienced severe nausea after the infusions: "*So there was, it was an entire day infusion. Um and then afterwards, for about a week afterwards, I was completely out of it, I was nauseous, I was even more tired. It was just harsh, horrible*" L[1p46-48]. Ursula's comments suggest that the side effects to the medication were severe and caused emotional distress. In addition, Ceri related that Leigh-Ann went into anaphylactic shock after Revelex had been administered intravenously: "*We raced through (to the hospital), and Leigh-Ann was having a, a mild anaphylactic reaction to the Revelex, which was really horrible. She spent a couple of nights in the hospital . . . Obviously feeling quite anxious about whether the reaction was going to be similar*" P[3p20]. Clearly, this was an emotionally distressing experience for Leigh-Ann, and consequently she experiences anxiety when new medication is introduced. These quotes suggest that the side effects of the medication may cause emotional distress and may result in chronic symptoms of anxiety even after the medication has been discontinued.

Rayne and Ursula remembered medical procedures that they had found emotionally distressing. Rayne related being particularly anxious about having a brain tumour operation: "*It was actually very scary thinking about it now. Like, I was very scared*" K[2p240]. Rayne conveyed her alarm when she found that a catheter had been inserted after a medical procedure: "*I didn't even know. I just saw this tube one day and I was like, what? What even -- What is this? I didn't even know . . . Ja, no-one told me that. No. So it was very shocking, honestly*" K[2p266-268]. It is clear from Rayne's comments that the discovery of the catheter added to her emotional distress. In addition, Ursula described one procedure which seemed to be particularly anxiety provoking: "*So they sit you down on a table and you, you lie on your stomach. And then they inject your spine. It's a horrendous procedure; it's not a very nice thing to go through at all*" L[2p18].

The previous quote indicates that Ursula and Rayne found their procedures to be emotionally distressing.

Furthermore, Ursula, Rochelle, and Micaela reported experiencing anxiety-provoking events in the hospital environment. Ursula described her placement in an adult psychiatric ward for individuals addicted to pain medication as being particularly distressing: "*It was the darkest time of my life. I was at an absolute low. It was it was awful. Yeah, and it was three weeks"* L[1p156]. Later in the interview she recalled this time in hospital as characterised by experiences of high levels of negative affect: "*Firstly I'd had TB, so I was feeling the worst I'd ever felt before, um I wasn't in a familiar space, my family could only come between 4 and 8 in the afternoon, um and you know, and it's a mental institution, so you're surrounded by people that have very different issues*" L[1p138]. Ursula's comments indicate that her stay in the adult psychiatric ward was exceptionally distressing given that it was not an appropriate placement for her developmental stage and her medical condition. Rayne also reflected on experiences that she had during the time that she was hospitalised: "*Just like people in pain and people going through like, all these like. I mean not death. People like on the edge of death and everything. And everyone is just upset*" K[2p224]. It appears that her experience of hospitalisation was emotionally distressing, as she was only 12 years old but was placed in a ward with adults who were in pain and possibly terminally ill. The need for developmentally appropriate wards that meet the needs associated with adolescents' particular medical conditions is apparent. Placing adolescents in adult wards may place them at risk for inappropriate experiences.

Notably, both Rochelle and Micaela witnessed the death of a patient while in hospital. Rochelle recollected being alone when she saw a car crash victim: "*And I remember a woman being wheeled past me and ja, she had just been in a horrible car accident I think. And just, I just* *remember seeing these things and being alone*" M[1Bp275]. Rochelle communicated that seeing a dead body was an emotionally scarring experience: "*But moments like those are scarring ones, you know. I remember also in the ICU, a person had just died and their body was wheeled past and I was alone, but I didn't know what was going on. So it's that thing of being alone, not knowing what was going on, just seeing things that ja, are just hard to do by yourself I guess*" M[1Bp277]. It was evident that Rochelle was exposed to emotionally distressingexperiences without the mediating support of an adult. Similarly, Micaela received a 12-hour infusion of Polygam in an adult oncology ward when she was 14 years old. She noted that several emotionally distressing events took place during the time she was hospitalised: "*So like its wasn't only overwhelming, having to sleep over at the hospital, being in the oncology ward, like seeing like a lot of cancer patients and then having like a lady die next to me, so that was quite hectic*" O[1p230]. The following description highlights the emotionally distressing nature of the event: "*It was quite a small room so I was about meter maybe half a meter away from her bed, where the two beds were and so they all, all the nurses rushed to put her on the bed and then they got the little ... paddle things and they were like doing CPR and everything and then she died and so that was quite traumatic for me*" O[1p226-228]. Despite the emotionally distressing nature of these incidents, there was no indication in the data that Rochelle or Micaela received any debriefing. The lack of psychological intervention was later confirmed by their mothers.

The adolescent participants explained how they continued to experience what seems to be chronic emotional distress in relation to certain events. Indeed, Ursula noted that having had to use a wheelchair in the past still impacts negatively on her emotions: "*And you know at times I think, 'Okay, no, I've gotten over the wheelchair, I've gotten over' and then other times I'll just be like, 'Damn that wasn't cool'*" L[1p206]. These excerpts suggest that Ursula continues to grapple with the intense emotions experienced when she was using a wheelchair full time to aid in mobility. Similarly, Rayne recounted: "*Oh, I hate hospitals so much right now. Ja, I just. It just makes me very depressed, ja, to just go back there and think of the times like that when I was in there the whole time*" K[2p288]. It is evident that these medical procedures caused long-term psychological distress that is re-experienced whenever she attends consultations in a hospital environment. Also, Micaela seemed to experience high levels of anxiety as a result of witnessing the death when she was in hospital: "*And for I think about a month that was all I could think about. Like every, sort of, everything related back to that situation. Almost like, I'd see a flower, and I'd be like there were flowers next to that lady's bed. Or I'd go for a shower – that lady went to the bathroom, that's where she collapsed, next to the shower*" O[2p350]. Moreover, the incident made her particularly aware of her own mortality: "*So it, it sort of made it real to me that it could happen to me, that I could all of a sudden just die one day. And so that was also quite hectic*" O[2p342]. She also became anxious that her family members would die: "*I was more petrified, not personally of me dying, but more of like my family . . . And so I got very scared*" O[2p358-360]. These quotes suggest that Micaela continued to experience heightened levels of anxiety after returning home from the hospital, which seems to have affected her daily functioning. It appears that the adolescent participants were experiencing chronic anxiety as a result of events that they had witnessed or experienced.

In this sub-theme – anxiety-provoking medical experiences – the lack of protective factors highlights this as an area of potential intervention to prevent or mitigate the emotional distress experienced by the adolescent participants before, during, and after treatments. It appears that the medical practitioners may not have been cognisant of the psychological consequences that could result from the treatments, inappropriate placement in adult wards, and inadvertent exposure to emotionally distressing events. Notably, the participants did not report on the availability of psychological interventions for the adolescent participants before, or after, medical procedures and treatment.

5.2.6 Dis/Empowering Relationships with Medical Practitioners

The adolescent and parent participants' relationships with medical practitioners seem to have been influenced by the expectations of the participants and the way in which the medical practitioners interacted with them. Both adolescent and parent participants seemed to value medical practitioners who listened to their understandings of the illness, who were empathetic, and who had good communication skills. In addition, the adolescent participants appeared to value medical practitioners who engaged with them in a developmentally appropriate manner, spoke to them during consultations, and included them in the treatment decision-making process. While these medical practitioners' behaviours seemed to empower the participants, other medical practitioners who behaved in a disrespectful manner seemed to disempower the participants.

Both Judith and Ann communicated how they felt disempowered by having their knowledge of the illness dismissed by medical practitioners. Judith had shared her understanding that the inflammation had occurred where Jessica's ligaments attached to the bone. She recalled that the orthopaedic surgeon had responded in a dismissive manner. Judith's anger at having her knowledge seemingly disregarded by the surgeon is evident in the following quote: "*And that's exactly what enthesitis arthritis is. I was so cross when I got the diagnosis, that three years before I had said to him this is what, where I think the problem is and he dissed me you know*" N[3p22]. Moreover, the orthopaedic surgeon's disregard of Judith's opinion possibly resulted in the diagnosis of JIA being delayed by another three years. In a similar manner, Rayne's mother, Ann, was also visibly angry when she related how she had been marginalised during a consultation with a paediatric neurologist: "*I eventually took her to a specialist neurologist, paediatric neurologist . . . She actually treated me as though I was a mad, you know, Northern suburbs housewife type thing. She barely even looked at Rayne. She barely looked at her. I mean that's when I talk about anger. When I think about it now I still feel angry about that*" K[3b20]. Ann's comment that the paediatric neurologist treated her as though she were "*mad*" certainly implies that Ann felt disempowered and marginalised. It can be inferred from the experiences shared by these parent participants that when parental knowledge is disregarded by medical practitioners, not only are the parents disempowered, but medical practitioners may overlook significant medical information.

It is noteworthy that the parent participants also recounted supportive and empowering relationships with certain medical practitioners. Ann contrasted the thorough approach taken by the paediatric rheumatologist with that taken by other medical practitioners: "*You know as soon as I met her, I knew that this this was a totally different form of medicine. I mean none of these doctors had ever actually examined Rayne totally, as a whole. I mean (the paediatric rheumatologist) just sat there and I mean from the top of the head all of the way down, she went through everything and examined her totally*" K[3Ap42]. Similarly, Julie explained that Charlotte appears to have supportive relationships with the paediatric rheumatologist, biokineticist, and physiotherapist: "*She seems to have a really good relationship with (the paediatric rheumatologist). She's a lovely woman, and the kids seem to really like her, and I think parents do too. Oh she loves her biokineticist . . . She loves our physio and he's very good with her. And he's understood her condition from the beginning*" Q[p137-139]. These comments suggest that the medical practitioners have established supportive relationships with both Charlotte and Rayne. Moreover, it seems that understanding the chronic and inflammatory nature of JIA may facilitate optimal treatment.

It is significant that the adolescent participants also highlighted both negative and positive aspects of their interactions with medical practitioners. Jessica and Leigh-Ann communicated that their experiences and opinions were not acknowledged by certain medical practitioners. Jessica reflected that one of the medical practitioners seemed to be focused on her specialised knowledge: "*She wasn't listening to anything I was saying, but she had all these own theories of hers which is fine, I mean, that's what she's trained to do but sometimes you actually have to listen to the patient too*" N[1p335]. Similarly, Leigh-Ann felt that the certain medical practitioners that she had consulted did not seem to listen to her: "*I think a lot of doctors are very arrogant. [laughing] So I don't know. I think some of them need to just acknowledge that, you know, that there are nine-year-olds that should be listened to*" P[1p182]. Moreover, she noted: "*I think a lot of them were quite patronising. You know, acting like I was a drama queen*" P[1p152]. It seems that the medical practitioners did not establish rapport with Leigh-Ann and they gave her the impression that she was catastrophising. Jessica and Leigh-Ann's comments also imply that the medical practitioners were privileging their own expert knowledge, and in doing so, they invalidated Jessica and Leigh-Ann's illness experiences. Ursula also reflected on the lack of rapport: "*I've met so many doctors that only care for your physical and don't really understand the other side . . . So not only seeing the patient with the symptoms but also understand exactly what they're going through, because so many doctors haven't understood that*" L[2p383]. Ursula's quote intimates that some of the medical practitioners that she consulted with were not empathetic. From their comments, it may be inferred that Jessica's, Leigh-Ann's, and Ursula's moms felt marginalised and disempowered by certain medical practitioners, which seems to have impacted negatively on the patient-practitioner relationships. In addition, not taking into account the individual's illness experience may result in sub-optimal treatment, as significant symptoms may be neglected.

Furthermore, Jessica, Micaela, and Rayne felt that some of the medical practitioners behaved in a disrespectful manner. Jessica seemed particularly angry by what she perceived as disrespectful behaviour: "*I didn't like either of my surgeons, the orthopaedic surgeons . . . They just very arrogant, and they were late, the one was late for a surgery*" N[1p337-339]. In a similar manner, Micaela related that her paediatric rheumatologist was often late for procedures: "*And so my mom and I would get up at six that morning, be at the hospital by seven so we could get the medication up. And often she'd just sort of be late, and then I'd just have to go well on into the night, and then I'd get home at like 12*" O[2p298]. These quotes suggest that seemingly disrespectful behaviour, such as being late for medical procedures, impacts negatively on the relationship between the medical practitioner and the adolescent. Similarly, Rayne felt strongly that, while most medical practitioners communicated well, some were disrespectful: "*It depends on if the doctor actually helps or not, usually they are very helpful, but they can be really rude, like I had a neurologist before, he was very very rude, but he was brilliant*" K[1p172]. The latter comment also implies that Rayne perceived discourteous behaviour to be acceptable if the medical practitioner was able to treat her effectively. Rayne explained what she found disrespectful about the neurologist's behaviour as follows: "*He would just send me on 50 million tests and everything and do this, he wouldn't like take an interest in my life or anything he would just like, like he was very professional that's the thing ja but he was too professional*" K[1p176]. It appears that it was important to Rayne that medical practitioners take time to establish rapport with her. Micaela appeared to feel that the paediatric rheumatologist did not attempt to connect with her emotionally: "*Like I've said to my mom over and over again, if you're going to be a paediatrician and you're going to deal with this stuff, like of course you're going to have to sort of shield yourself almost cause it isn't easy, but having a bedside manner makes it a lot easier for the patient to like* *communicate*" O[1p140]. Moreover, Micaela indicated that an abrupt style of communication makes it difficult for her to discuss her health problems, as she feels intimidated and disempowered: "*Having someone talk directly to you and so abruptly, I think I got very scared. And to this day, I still sort of you know, I'm very polite, overly polite. And so I think that was also quite hard because I didn't like her as a person and I didn't like going to her*" O[2p248]. These comments suggest that abrupt communication and the lack of rapport may have hindered reciprocal communication in the patient-practitioner relationship. Also, it seems that these adolescent participants felt disempowered when they perceived to be subjected to discourteous behaviour and when the medical practitioner did not take time to establish rapport.

In addition, Jessica and Rayne raised the issue of developmentally inappropriate communication on the part of the medical practitioner. Jessica explained that she felt that the orthopaedic surgeon's communication with her was developmentally inappropriate: "*Ja and he spoke to me like a two-year-old, or he talked, spoke so he knew I wouldn't understand a word he was saying*" N[2p112]. The previous quote implies that communication between medical practitioner and adolescent participant may be less effective if it is not age-appropriate. In addition, it seems that Jessica felt alienated, as she perceived that he was purposefully communicating in this manner. Notably, Rayne emphasised the need for private consultations during which she could discuss personally sensitive aspects of her illness: "*Well I mean like different pains in like the weird places and everything, you're not sure of and everything and all those things*" K[1p208]. From the previous quote it may be inferred that individual consultations would have been appropriate given Rayne's developmental need for increased privacy and autonomy. Moreover, both Rayne and Rochelle noted that the doctors usually spoke to their parents. Rayne declared that she would prefer to answer questions about her experiences: "*I mean*

I guess my mom knows more about medication and everything so she does talk more but I mean I still don't get like, like she doesn't know what I'm going through, she can't really describe it for herself so like I do want to talk" K[1p186]. Rochelle also found it problematic that the paediatric rheumatologist directed questions to her mother instead of to her: "*She'd speak to my mom about, for example, asking my mom what symptoms I was having, asking my mom how my pain is. [laughing] I mean, I was right there, so silly stuff like that. And then, you know, talking to my mom about changing medication, if I would be fine with that*" M[1Bp159]. These comments suggest that certain medical practitioners may have prioritised communication with the parents and inadvertently marginalised the adolescent participants. It may be inferred that by excluding the adolescent participants from the discussions, they are essentially disempowering them.

At the same time, it is relevant to note that the adolescent participants seemed to feel empowered by empathetic, supportive medical practitioners. Micaela described her interactions with a maxillofacial surgeon: "*But then there's some doctors I've dealt with like um my, my maxillofacial surgeon, he's absolutely like, he's so amazing, he's so kind so like and he's made it so much easier to actually say what's on my mind than sort of just keeping it quiet*" O[1p148] . It seems that having an affirming relationship with the medical practitioner facilitated Micaela's ability to communicate how she was feeling, which empowered her to be an active part of the consultation process. Similarly, Rayne experienced supportive relationships with certain medical practitioners: "*I do have a close relationship with them like, I think it's quite good. (paediatric rheumatologist) especially I have a close relationship with her, my mom, they like work together or something like that ja. Then I have my neurologist as well, he's very nice to me and everything, but ja, I mean they all very nice and very helpful*" K[1p170]. Charlotte also related having predominantly supportive relationships with medical practitioners. She felt that she had a close relationship with a paediatric rheumatologist, which facilitated her ability to communicate during consultations: "*It's been good. Like I can ask her any questions and she's been very nice*" Q[1p481]. Charlotte's comments imply that she has supportive, trusting relationships with two medical practitioners and is empowered to communicate freely during consultations. Similarly, Ursula asserted that she had a supportive relationship with the physiotherapist: "*So she sent me to a lady, a physiotherapist who deals with chronic pain and I really liked her*" L[1p122]. It appears that having trust in a medical practitioner's knowledge facilitated stronger relationships and empowered adolescent participants to engage in consultation and decision-making processes.

The experiences shared by the adolescent and parent participants suggest that the manner in which the medical practitioners interacted them impacted on the participants' levels of empowerment during the processes of diagnosis and managing the illness. Medical practitioners whose communication style disregarded and marginalised the adolescent and parent participants' experiences and knowledge disempowered the participants and may have increased the likelihood of negative trajectories. Certainly, it seemed that significant information may have been overlooked due to disregard for patient input, leading to delayed diagnoses. In addition, at times the dismissal of the participants' knowledge resulted in inappropriate treatment. In contrast, medical practitioners who facilitated a relationship in which the participants felt comfortable to communicate with them served to empower the participants. These medical practitioners increased the likelihood of positive trajectories. By listening to the participants' knowledge and including them in the consultations and the decision-making processes, the medical practitioners were able to optimise the efficacy of treatment regimens. In particular, the adolescent participants' comments suggest that they felt valued and empowered when medical practitioners communicated in an empathetic and developmentally appropriate manner. It may be inferred that greater cognisance needed to be taken of the adolescents' increasing developmental need for private consultations. Providing adolescents with opportunities for private consultations may also be a significant factor in empowering them to make a successful transition to adult medical care.

5.3 Multisystemic Resilience Processes

This theme maps the adolescent participants' processes of adapting to the adversity caused by developing JIA. The process seems to have involved accepting the chronic nature of, and learning strategies to manage, the disease. A noteworthy sub-theme that arose from this study was that the adolescent participants shifted from an initial period during which they isolated themselves and refused to acknowledge the presence of the disease, to developing a sense of agency with regard to the biopsychosocial challenges presented by JIA. Indeed, the adolescent participants seemed to realise that the manner in which they were engaging with the disease was impacting negatively on their psychosocial functioning. In this regard, the second sub-theme presents how the adolescent participants set goal-directed behaviours to motivate themselves to be physically active and socially engaged. Particularly notable was the third sub-theme, which explores the adolescent participants' use of cognitive reappraisal strategies to increase their levels of positive emotions. Overall, this theme demonstrates how the adolescent participants seemed to engage in resilience processes that enabled positive adaptation to the challenges presented by the disease.

5.3.1 Passivity Evolves Into a Sense of Agency

The adolescent participants seemed to possess a strong sense of agency which enabled them to self-regulate and take purposeful actions to adapt to and manage the biopsychosocial aspects associated with JIA. The data suggest that the development of this sense of agency in relation to JIA had been a slow, unfolding process which was facilitated at times by a pivotal experience. The adolescent participants remembered an initial period during which they used avoidant and passive coping strategies. Thereafter, they described moving from a position of despair and hopelessness to one of hope and optimism.

With the onset of the disease, the adolescent participants either attempted to isolate themselves socially and emotionally, or refused to acknowledge that they had JIA. Ursula, Jessica, and Rayne recollected isolating themselves socially. Ursula confided: *"I mean, I don't know if I told you, but during that time especially I, I was just shutting people out*" L[2p130]. Also, Jessica related: "*I didn't (cope). I cut everyone out*" N[2p56]. In addition, the following quote suggests that Rayne initially coped with her illness in a manner that caused her to feel socially isolated: "*But I can remember just feeling like just so, like I said, lazy and just like lying in bed and feeling sick. And I'm like you know, I, I could be working hard, and I could be, be like my friends, and like having a goal set and like working towards my goal. But like you know, this, this illness has just made me miss out so much on everything.*" K[2p526]. Isolating themselves socially and disengaging emotionally were ways in which these adolescent participants seemed to cope with the initial onset of the disease. However, Leigh-Ann and Rochelle avoided acknowledging that they had JIA. Leigh-Ann explained how she denied her illness and forced herself to be physically active despite her symptoms of pain and fatigue: "*Because it made me think that actually I don't feel physically that way, it's just in my head. So I need to push myself to do things that hurt*" P[1p124]. In a similar manner, Rochelle compelled herself to be physically active: "*So I think the problem with me a bit was that I kept pushing myself. So when I would think that the pain was too bad and I want to go off (the hockey field), sometimes I just keep myself going. So that by the end of the game it would be, the pain would be so bad that I could barely walk*" M[1Bp57]. Moreover, Rochelle seems to have consciously avoided thinking or talking about the disease. Her approach was to: "*Just suppress it, don't talk about it, get through it*" M[1Bp97]. While these strategies may have initially enabled the adolescent participants to adjust to living with JIA, over time they appeared to be maladaptive.

The data suggest that over time the adolescent participants became aware of the need to make lifestyle changes. Ursula, Rayne, and Leigh-Ann reported this as a slow process which entailed accepting that JIA might be a permanent condition. Ursula depicted this process in the following manner: "*I kind of figured that then I had to come up with coping strategies. But before that, I was just saying: 'Okay, it's fine, it's fine, it's going to get better'. But I didn't have any coping strategies"* L[2p130]. Ursula's comment suggests that it took time to move from using passive coping strategies to making the decision to actively regulate her illness. Furthermore, her decision seems to have been prompted by the realisation of the chronic nature of JIA. Similarly, Rayne reflected that over time she became dissatisfied with the manner in which the illness dominated her lifestyle: "*Timing-wise I think that I just like got so sick of ja, being sick . . . My friends just like kind of losing contact with me. And I didn't really like -- Like, I wanted to be involved in everything. I just got so like tired of like the medication and the infusions and doctor visits, physio visits, and all those things. And I just, ja, I just wanted, needed it to stop. I needed to go back to how I was*" K[2p530]. It can be inferred from the previous quote that Rayne gradually became aware that she needed to change how she was managing the illness so that she could engage in a more fulfilling lifestyle. Initially, Leigh-Ann explained that the use of adaptive coping strategies was a gradual process: "*Honestly, I think just time. I don't. I mean I don't think there was any actual thing where I was like: 'Okay, now I'm going to accept it, you know'. It was gradual*" P[2p108]. Leigh-Ann also noted that being diagnosed with JIA changed her state of mind regarding the symptoms that she experiences: "*So now I feel that if I need to rest, I should rest. And I deserve to have a chance to rest*" P[2p226]. The previous quote suggests that once she had received the diagnosis of JIA, Leigh-Ann was able to alter her maladaptive behaviours because she believed that the illness was “real”.

Other adolescent participants, such as Rochelle and Micaela, identified a pivotal moment that prompted them to change the coping strategies that they use. When Rochelle collapsed while playing in a hockey match, she realised that, instead of denying the pain, she needed to regulate her physical activity more effectively: “*So I think a big part was for me learning where to know my body, where to stop and where not to stop. But for a really long time I just kept pushing myself. I was like, oh, it’s nothing, I’ve got to keep going”* M[1Bp63]. From the preceding quote it may be inferred that she was denying the negative effects that the disease was having on her physical health. For Rochelle, part of developing a sense of agency regarding JIA involved acknowledging that she cannot control the illness: “*We just have to go with the flow. We just go with it. And one step at a time, one day at a time*” M[1Bp271]. Instead, she seemed to realise that she had to learn to manage and accommodate the illness. Micaela recalled that her disappointment at receiving a school report with low marks created the awareness that ignoring the disease was detrimental to her psychosocial functioning: “*I think I just said, I need to get out of this slump. Yes, I’ve gone through this, but it’s now, life throws you curve balls and stuff, and you’ve just got to roll with it. So, I think I just said: yes, it’s horrible what happened. I can’t do that anymore and I’m sad about that, but you know what, let’s find something else*” O[2p156]. Moreover, Micaela’s comment: *“I can’t do that anymore and I’m sad about that but you know what, let’s find something else”* intimates that she realised that the disease might be permanent and she needed to adapt to living with JIA. From the preceding quotes, it may be inferred that when the disease impacted negatively on a valued aspect of their self-image, Rochelle and Micaela became aware that they needed to adjust the coping strategies that they were using.

The adolescent participants' acceptance of the chronic nature of JIA appeared to facilitate their sense of agency in self-regulating the disease. This sense of agency is reflected in the following quotes by Jessica, Rayne, and Ursula. Jessica emphasised that she needed to manage the disease as follows: "*And just trying to make it work. Like, it doesn't have to make sense*" N[2p571]. In addition, Ursula related that she chose to endure high levels of pain to engage in valued activities such as attending school and spending time with her friends: "*You know what, I forced myself to get up and move and stuff like that. I still felt well even though the pain was extreme. But I think I just forced myself to get through it, to try and move it to one side and just deal with everything else*" L[2p409]. In a similar manner, Rayne accentuated the fortitude required to manage the illness: "*It's hard to get through, but you just have to get through it, like you think you're going to struggle getting through it and everything but it does get better and everything. Medication does help . . . But it just it's a tough road, but you can get through it, there is an end*" K[1p138]. Moreover, Rayne's comment "*but it does get better and everything. Medication does help"* implies an optimistic stance towards the illness that may have helped her to adapt positively to living with JIA. Phrases such as "*trying to make it work", "I forced myself to get up",* and *"you just have to get through it"* highlight the strong sense of agency and grit displayed by the adolescent participants.

The descriptions shared by the adolescent participants suggest that initially they isolated themselves socially and avoided acknowledging that they had developed the disease. The use of avoidant and passive coping strategies may have provided a period of adjustment during which they began to come to terms with having the disease. Moreover, as they began to accept that having JIA was possibly a permanent condition, the adolescent participants seemed to develop a sense of agency which enabled them to utilise more effective strategies to regulate the biopsychosocial effects of the disease.

5.3.2. Monitoring Physical and Social Activities

Two accommodative coping strategies were used by all of the adolescent participants to manage the high levels of pain and fatigue that they experienced. Firstly, they communicated how each day entailed a balancing act between being socially and physically active while knowing when to rest so that they did not over-exert themselves. This engagement in social and physical activities was dependent on the extent to which the activity was valued by the participant. Secondly, they appeared to assume a step-by-step approach to managing daily activities. They emphasised the need to be sufficiently self-aware of their levels of pain and fatigue so that they could disengage from activities if necessary.

The unpredictable nature of JIA seems to necessitate the implementation of a self-regulated but flexible lifestyle in which the adolescent participants seem to constantly balance the costs and benefits of engaging in specific activities. They planned the activities of daily living to prevent over-exertion as well as to anticipate the possibility of having a flare-up of the disease. Ursula, Leigh-Ann, Rochelle, and Micaela conveyed how they balanced engaging in activities and rest so as to prevent or accommodate flare-ups. Ursula advised planning ahead but being flexible about participating in activities: "*I think now I've really learnt that you just need to manage it. You need to manage your time, and you must just go with the illness. So like you prepare in advance, because you don't know what tomorrow's going to be like*" L[2p331]. The comments "*you must just go with the illness*" and "*you don't know what tomorrow's going to be like*" also highlight the unpredictability of the disease and the possibility that plans may need to be changed. In the same fashion, Leigh-Ann emphasised the importance of planning in advance but being flexible about disengaging if she experienced high levels of pain and fatigue: "*So I've learnt my limits and, you know, what I can do on certain days and what I can't do. And I think I've learnt to plan accordingly"* P[2p88]. Moreover, Rochelle described how she achieves this balance when attending school: "*So in terms of school work sometimes it's just having to come home, rest for 30 minutes, do some school work, and then rest again, just to make sure I'm pacing myself*" M[1Bp215]. In a similar fashion, Micaela also related weighing up the costs and benefits of participating in a valued activity: "*I still want to do that, but I've learnt that if I go and do. Instead of being off for one day, if I go and do this thing that I wanted to do, I might be off for a week. And so I think realising that in my mind I've just got to sort of weigh up the benefits*" O[2p42]. These comments suggest that the adolescent participants are constantly engaged in a process of balancing activity and rest to ensure that they do not over-exert themselves. Over-exertion – physically, emotionally, or cognitively – may lead to a flare-up of JIA symptoms.

The adolescent participants also asserted that they might choose to engage in a valued activity, such as socialising with friends, even though it would exacerbate their physical symptoms. Jessica recounted that she may over-exert herself if she feels that the personal benefits associated with engaging in an activity are worthwhile: "*I have to decide am I going to go with the pain and have fun or am I going to just not go with the pain, sort of like*" N[1p277]. She elaborated on this by describing how valued but challenging activities require careful consideration: "*Last year for my Xhosa class we do this hike through Transkei and I was like in a six-month debate of whether I was going to go or not*" N[1p283]. Jessica chose to participate, despite knowing that she would experience high levels of pain. Similarly, Charlotte recounted that while she might choose to attend social activities, she has to limit the number of engagements: "*There has been some limitation, but I will. Like I'll go to a party and dance, like that kind of thing. Just not do it like* *every single week*" Q[1p459]. These descriptions highlight the complexity of the decisions that the adolescent participants make regarding their activities of daily living. They engage in a constant balance of curtailing their energy expenditure to prevent over-exerting themselves and causing a flare-up of the disease.

The second strategy that the adolescent participants appeared to use was a step-by-step approach to negotiating daily living. They conveyed the manner in which they divided their days into manageable sections, which seemed to prevent them from becoming overwhelmed by high levels of pain and fatigue. Indeed, Rayne's personal mantra illustrates that during a flare-up the high levels of pain and fatigue mean that she has to continuously motivate herself throughout the day: "*You just have to get through the next 10 minutes, and then another 10 minutes, and then another 10 minutes, until the day is over. And just repeat that. Like if I ever had a bad day, I would do that . . . Just repeat it the whole day*" K[2p74]. What is noteworthy is the amount of fortitude that is often required to accomplish the routine activities of a normal school day. This fortitude was particularly apparent during the most severe phase of Ursula's illness, when getting out of bed had become a major achievement. Initially, she was not independently mobile and required the help of her parents and sister. When she returned to school, she was using a wheelchair and needed her mother, who worked at the school, to assist her in going to the toilet. Ursula related that she divided the day into sections that seemed manageable: "S*o then it was, seeing my friends. Okay, and then that was fine. And then it was getting to first break, where I had to go to the loo. And then getting to second break, go to the loo. And then after school. And then you can go home. And then ja, then it's until tea*" L[2p220]. What is of consequence in the previous comment is that she mentioned "*to go to the loo"* twice. This seemingly basic self-care activity had become a significant challenge that needed to be planned for in her daily routine. In a similar manner, Rochelle explained that compartmentalising her day into small achievable goals helped to contain her anxiety: "*Sometimes all I'd have to do was isolate the day into bits of like, I'm just going to get through this morning and then we'll have this. And I'm going to get through this afternoon, and then we'll be fine. So just doing it step by step. Because it is scary, you know. And fatigue and pain, and that is scary*" M[1Bp287]. From the preceding quote it may be inferred that negotiating the activities of daily living during a flare-up can be overwhelming. As with balancing the cost and benefits of activities, a step-by-step approach to negotiating the activities of daily living is engaged in on a continuous basis.

The unpredictable nature of JIA seems to necessitate the implementation of a self-regulated but flexible lifestyle in which the adolescent participants constantly balance the costs and benefits of engaging in specific activities. The adolescent participants related that they take initiative in choosing their daily activities to compensate for their physical and psychological symptoms, as well as to make allowance for a possible flare-up. Nonetheless, they may choose to engage in a valued activity despite the likelihood of an increase in pain and fatigue. The adolescents also appeared to utilise a step-by-step approach to negotiating the activities of daily living. This approach enabled them to engage in the activities of daily living but to withdraw from activities if they needed to rest.

5.3.3 Monitoring Emotions and Thoughts

The adolescent participants used self-regulation strategies to change the way they felt and thought about the illness. What is particularly noteworthy is the extent of the cognitive self-talk that seems to be required for participants to endure a typical school day and increase their levels of positive emotions. The adolescent participants discussed incorporating a range of cognitive reappraisal strategies, such as challenging negative thoughts, minimising the illness, finding meaning and inspiration in their faith, using mindfulness, and having a sense of humour.

Rochelle and Ursula recollected challenging their negative thoughts regarding their self-concepts. During her interviews, Rochelle had frequently confided that the lack of validation of her illness experiences by her extended family members had resulted in very low levels of self-esteem. In order to improve her levels of self-worth, she consciously replaced her negative thoughts about herself with positive ones: "*I'd say something negative about myself, you just bring up back another positive. Which is incredibly hard at the beginning and it takes a while, but I made sure that I was doing it every single time*" M[2p28]. Furthermore, Ursula reframed the embarrassment of using a wheelchair so that she could find value in social activities in the following manner: "*Eventually I just made peace with it. Like, you know what, who cares really. So you just, you're not going to see those people again, or you're just going to have to try to make the most of it*" L[2p323]. The previous comment illustrates how Ursula consciously directed her attention to her enjoyment of an activity rather than her self-consciousness about using a wheelchair.

Some adolescent participants minimised their illness experiences by comparing JIA to other diseases or comparing themselves to other individuals with JIA. Rayne compares herself to a girl who has leukaemia: "*Because I always think, ja, like I would say you know what, then I'm not really going through that much. Can you imagine what she's going through? And I would be like, you know, you can. If she can get through that, then you can get through this*" K[2p482]. Rayne used the word "*imagine*" which suggests that part of her cognitive reappraisal involves empathising with the other individual. Moreover, Charlotte improves her levels of positive affect by reminding herself that she could be experiencing a more severe condition: "*It just like makes* *me feel better, if that makes sense? And like thinking that like, God forbid, it could be something so much worse. And that like, thank God, it's just juvenile arthritis*" Q[1p519]. By comparing themselves to individuals whom they perceived to have more severe symptoms or diseases, the adolescent participants were able to adopt a more positive attitude to their illness.

Ursula and Leigh-Ann appear to have developed pain self-efficacy through past experiences, and they seem to know that they can function adequately despite their levels of pain. Ursula declared that having negotiated previous negative experiences helps her to reappraise new challenges: "*And then I just think of when I was in Grade 8, I wasn't there for that whole term because I was sick and I had TB. And I came back a week before exams started and I was fine, and I studied and I. So it's ok; it will be ok, I know it will be*" L[2p339]. Similarly, Leigh-Ann explained that instead of becoming caught up in negative thought patterns, she reminds herself that the flare-up will pass: "*I think I get myself out of it much quicker than I would have in the past, because I know that after a week weeks it's going to go away*" P[2p216]. Furthermore, her efforts at cognitive reappraisal can be seen in the following comment: "*And maybe also like I'm entitled to rest when that happens, because after it's happened I'll be able to do the things that I can't do now*" O[2p224]. The previous quote also implies that prior to receiving the diagnosis of JIA, Leigh-Ann would force herself to be active despite the pain and fatigue. Nonetheless, now that she is cognisant of the physical nature of the illness, she is able to change her use of maladaptive strategies as she is aware that rest is important and will enable her to be more active. Ursula and Leigh-Ann are able to draw on successful experiences to boost optimism and hope when they are faced with difficult challenges.

In Rochelle and Jessica's interviews, reference was made to the use of another form of cognitive reappraisal – namely, humour. Rochelle clarified how humour helped to increase her levels of positive emotion: "*And I mean, making jokes that other people wouldn't think of us making about the disease or the wheelchair or having fun, you know, in a wheelchair. [laughing] Or, you know, making sure that we still had that important part of our lives, you know, of just being us, you know*" M[1Bp271]. Rochelle's comment "*of just being us*" implies that in those moments of shared light-heartedness, the relationship between her and her sister, Ursula, became the focus of their interaction rather than the illness. Similarly, Jessica conveyed that she often uses sarcasm and humour to cope with her illness: "*I think sarcasm is a coping mechanism*" N[2p364]. Certainly, humour appears to be a significant coping strategy for Jessica. Even when Jessica recalled incidents that had made her angry, she would put a humorous twist on the re-telling: "*This one mother came up to me and was like: you know, when I had cancer I spoke to my cells and it just, it went away. I was like 'Are you sure it's not the chemo that you were on?'*" N[2p392]. Although it is not apparent in the quotes, I observed that her demeanour became more positive when she shared these incidents. These comments illustrate how Jessica and Rochelle seemed to regulate their negative emotions through humour.

Furthermore, several adolescent participants reported finding meaning through religious faith, which seems to have provided a sense of hope. Through Christianity, Rochelle has faith that the future holds favourable outcomes, and this optimism and hope enables her to persevere through adversity: "*My Christianity is such an important part of my life. You know, just valuing the way that for me, what I believe is that there, there is a, a God you know, and He has a purpose for my life. So just trusting in Him and having that hope. And I think, having hope and having that somebody that I know has a plan for me, that, that just provides me hope every day, as much as possible . . . And I think that's important for me; it's a big part of my hope and what, how I continue*" M[2p161]. Moreover, developing a relationship with God had enabled Ursula to express her emotions and find personal meaning in relation to her illness: "*Sometimes if I'd be really angry, like sometimes I'd be really angry with God. And then I would just like ask Him why He would allow this. I don't know how to say, but like have a rant. Yes, just rant. Or, or I would just literally talk about anything that was going on*" L[2p281]. Both Rochelle and Ursula appear to derive hope from their religious faith, as well as a sense that their illness experiences hold personal meaning for them. In addition, it appears that Ursula's religious faith facilitates her expression of negative emotions in a safe space.

Although none of the adolescent participants used the term "mindfulness", several of them seemed to engage in mindfulness-based practices. Rochelle described living non-judgementally in the moment as follows: "*I think the most important thing is to allow yourself to feel whatever you're feeling, you know. Is, is to allow yourself to be down or to be happy, and that neither of them is wrong. Neither of them should give you less credibility or less support. And so allowing yourself to be where you are, but to make sure that you're going to keep moving forward from what you are"* M[2p158]. Rochelle's description suggests that she practices acceptance of both positive and negative emotions. Furthermore, the comment "*make sure that you're going to keep moving forward from what you are*" implies that she does not ruminate on negative emotions or cognitions. Rather, it appears that she may implement strategies to cope with negative emotions and thoughts. Ursula also explained how important it is for her to live in the present moment rather than focusing on the future: "*You have to live your life now and not wait um for things to get better because they're probably not going to get better that's just how things are . . . So I, that's what I would say is that you know what, live life now*" L[1p272]. Ursula seems to acknowledge and accept the chronic nature of her illness. By doing so, she can focus on engaging in activities in the present. Similarly, Rayne accentuated the importance of enjoying the present moment as follows:

"*You have to enjoy teenage years, ja because I mean you're only in high school for a few years and you only have these certain friends 'til you're out of school and everything, so you just have to you know enjoy your time*" K[1p146]. These quotes suggest that the adolescent participants came to accept the chronic nature of JIA and continued to mindfully engage in physical and social activities, notwithstanding the symptoms of pain and fatigue.

The adolescent participants appeared to use a variety of cognitive reappraisal strategies to produce a positive mindset and increase feelings of hope and optimism. These self-regulation strategies were used to change the way they felt and thought about the illness. Notably, the adolescent participants used a significant amount of sophisticated cognitive self-talk to manage their emotions and thoughts.

5.4 Adapting Positively to Living with JIA

This theme explores how the adolescent participants seem to be adapting positively to living with JIA. Positive adaptive outcomes can be assessed by the successful negotiation of developmental tasks. Despite the challenges presented by JIA, the adolescent participants' experiences seem to indicate that they were successfully negotiating the developmental tasks of identity formation and the development of autonomy. Moreover, increased levels of subjective well-being are thought to represent positive adaptation to adversity. In this regard, the adolescent participants communicated experiences of subjective well-being. In addition, they were able to articulate ways in which they could increase their sense of subjective well-being.

5.4.1 Negotiating Identity Formation in the Context of Living with JIA

The sub-theme of *negotiating identity formation in the context of living with JIA* describes the processes of identity formation that the adolescent participants engaged in. What was striking was that the adolescent participants seemed to be successfully negotiating the adolescent processes of identity formation despite living with a debilitating chronic illness. The adolescent participants seemed to be finding a balance between accepting the presence of the illness without being defined by it. Perhaps the main disparity in comparison to their healthy peers was that the adolescent participants seemed to be deciding how to integrate living with JIA into their developing identities. In this regard, the level of visibility of the physical symptoms seemed to affect identity development in nuanced ways, particularly the choice of whether to conceal or disclose their illness. While the adolescent participants whose physical symptoms were invisible could decide whether to disclose their illness or not, this choice was not available to those with visible physical symptoms.

Ursula, Micaela, and Rayne's physical symptoms were highly visible at times as they required devices to aid their mobility. During a period of approximately seven months, Ursula transitioned from being physically active to having to use a wheelchair full time for mobility purposes, which seemed to cause a profound and acute shift in her sense of identity: "*The disabled person, yeah. They don't put me and the wheelchair person together because I was that person, but they only saw the wheelchair*" L[1p196]. Ursula felt that she was viewed as "*the girl in the wheelchair*" and she exclaimed: "*That's not who I am and that's how people are perceiving me to be*" L[1p192]. Similarly, Micaela, who spent a few days using a wheelchair, also indicated that it caused her to feel socially isolated: "*I was just like on a showcase and everyone was just looking at me. And I felt very different again, because I was in a wheelchair, and there's a few number of people in a wheelchair. So I think I was very, I felt very isolated, and from that I got quite depressed because of feeling, like, alone*" O[2p376]. Rayne declared that the visibility of using crutches also caused her to feel isolated and marginalised: "*When I was in primary school, go on like, I had problems with my ankles and I would go on like crutches like every year, so I felt, I was* *like left out a lot in school ja, I couldn't do like PE (physical education) and everything*" K[1p260]. The physical limitations associated with JIA prevented Rayne from engaging in physical activities with her peers. As the preceding quotes indicate, Ursula, Micaela, and Rayne presented with visible physical limitations which affected the way in which other individuals interacted with them.

All of the adolescent participants were determined not to be defined by their illness as they felt that they were treated differently to their peers. Ursula provided a rich description of how her visible physical difficulties impacted on her sense of identity: "*So in that way I think as well I lost my identity because people, most people only saw me as as that (the girl in the wheelchair) . . . And I think that was really hard because you know I'm sick, I don't have my legs anymore that work as well as they should but you know what I'm still a person, I still have a personality, I still have everything*" L[1p200-202]. Ursula's comments illustrate that she grappled with the tensions and efforts of asserting her own sense of self in the face of social perceptions of being "*the disabled person*". In a similar manner, Micaela asserted that, while her peers tend to treat her differently once they know that she has JIA, she does not want to be defined by her illness: "*Like that's the girl who has juvenile arthritis, you know. We've got to be there for her and stuff. And then again the almost special treatment*" O[2p186]. Also, implicit in the term "*special treatment"* is that her peers viewed her as being "less capable" because of her illness. Rayne also emphasised that she is treated differently because of her illness: "*I don't think I've ever wanted people to feel that sympathetic for me, because it just makes me feel like people have pity on me and everything. Ja, and I don't really want that. I just want to be normal*" K[2p26]. From the preceding quote it may be inferred that receiving sympathy from other individuals makes Rayne feel as if she is "less capable" than her peers. Moreover, Rayne's comment "*I just want to be normal*" implies that she wants to be able to engage in physical activities with her peers and not be treated differently.

Ursula, Micaela, and Rayne’s comments suggest that the visual impact of their physical limitations affected the manner in which they were perceived, as well as the frequency of their social interactions. Despite not wanting to be defined by the illness, their visible physical differences appear to have resulted in them being marginalised and socially isolated by their peers and other individuals.

Remarkably, the adolescent participants whose physical symptoms were not as visible were just as determined not to be defined by JIA. Although Leigh-Ann had been relieved to receive the diagnosis of JIA as it validated her illness experience to an extent, she did not want it to be the defining feature of her identity. Leigh-Ann made the distinction that although she is often ill, this is only one aspect of her identity: “*Well I think, I mean I am (a sick person), but that’s not what defines me, even though it defines a lot of my life*” P[1p608]. Similarly, Rochelle balanced her need for acknowledgement of her illness against her desire not to be defined by it, as follows: “*And I think that all came from being defined by this illness, you know. This is what she has, so that’s who she is. And having to say that no, no that’s not. It’s not just that*” M[1Bp241]. Moreover, Charlotte seems to actively focus on defining herself through the positive aspects of her self-image: “*Like if I’m baking or singing or. I know like doing my make-up or doing someone else’s make-up, it like also acts as like a distraction and I can feel like I’m not defined by something that like I don’t want to be defined by. I’m defined by something that I'm good at or something that I love doing*” Q[2p143]. It appears that Charlotte consciously resists being defined by her illness. By highlighting the positive aspects of her self-image, she reinforces her own sense of self beyond that of being defined by her illness. Rochelle and Charlotte’s comments illustrate their multidimensional sense of self and their determination not to be labelled by JIA.

Even though they resisted being defined by JIA, the majority of the adolescent participants appeared to be engaged in the process of integrating JIA into their identities. Ursula seemed to accept that she would not be as physically active as she had previously been because of developing JIA: "*I'm not going to be that person again. And um you know as much as I want that to be, I'm not going to be that*" L[1p206]. Ursula's realisation implies that she was in the process of integrating JIA into her sense of identity. Likewise, after collapsing while playing a hockey match, Rochelle realised that instead of ignoring the physical symptoms of JIA, she needed to adjust her lifestyle to accommodate the physical limitations caused by her illness. She depicted the moment of realisation in the following manner: "*But when something like that happens, as you say, it does hit you. I realised that wow, what I used to do every single day of my life, I now can't do. And what my friends are doing right in front of me, I can't do. And I think that was the first example of me not being able to do everything. And I think that was hard for me to see wow, this, this is real, you know*" M[1Bp75]. Whereas previously Rochelle had denied her illness, this incident seems to have forced her to acknowledge that she was ill. Accepting that she was no longer able to be as physically active as she was before she developed JIA implies that she was in the process of integrating JIA into her identity.

While Micaela and Charlotte seem to be in the process of integrating JIA into their identities, they were reluctant to disclose that they have JIA for fear of being treated differently to their peers. Micaela also shared that she is reluctant to disclose her experiences to her friends because she does not want to have to explain her illness or how it affects her: "*It just leads to so many questions. And a lot of questions I almost don't want to answer because I'm afraid I'll get like pity*" O[2p178]. The term "*pity*" suggests that the diagnosis of JIA becomes the focal point of her public identity. Insightfully, she acknowledges that her peers are supportive, but she is not receptive to their support as she perceives it to be marginalising: "*Like, I'm so sorry. I'm here for you. Like very nice consoling words, but stuff I didn't want*" O[2p184]. Charlotte also prefers not to disclose that she has JIA and rather pretends that she has hurt herself: "*I like try like not tell people, like if that makes sense. Like I just say, oh, like something happened. Because I don't want people to be like, oh shame. Like I don't want them to pity me or like think less of me and like my abilities and what I can do. Because like it's not stopping me from doing anything*" Q[1p437]. Charlotte appears to be concerned that people will perceive her as being "less capable" and will pity her. Moreover, her assertion *"it's not stopping me from doing anything*" implies that she views herself as being able bodied and possessing the same abilities as her peers. Both Micaela and Charlotte's quotes imply that when they disclose their illness, the JIA becomes the focal point of their identity, rather than the traits and abilities that they value. Moreover, they feel that their peers view them as "less capable" and needing sympathy, which contrasts with their own perceptions of themselves as being capable.

In contrast, Rayne seems comfortable about disclosing that she has JIA to other individuals. She has chosen to raise awareness about JIA and assist children from disadvantaged backgrounds. Rayne described increased levels of positive emotions as a result of her volunteer work: "*It makes me feel happy to make people more aware, and like, especially to. I mean, I always feel happy when I'm helping out other people. And ja, just, it makes me feel happy that people are becoming more aware of this*" K[2p496]. It appears that Rayne may be in the process of integrating JIA as a positive aspect of her identity. In addition, this integration process implies that she has found a way to make her experiences of living with JIA add value and meaning to her life. Her comments suggest that she also seems to be integrating JIA into her identity in a manner that enriches her life, rather than detracts from it.

All of the adolescent participants appear to be engaged in similar processes of identity formation as their peer group. Indeed, the adolescent participants appear to be integrating JIA into their developing identities to different degrees. This process of integration seems to involve grappling with the complex process of accepting the disease but resisting being defined by it. Indeed, the adolescent participants appear to be engaged in the developmental task of establishing a coherent sense of identity notwithstanding the challenges associated with living with JIA.

5.4.2 Qualitatively Different Opportunities for Becoming Autonomous

This sub-theme describes how the adolescent participants seem to be developing autonomy despite the complex challenges of living with JIA. Moreover, it seems that the challenges associated with living with JIA provide new avenues for developing autonomy. Although the physical symptoms of JIA may often restrict physical independence, they also facilitate the development of behavioural autonomy. Indeed, as the adolescent participants matured, they became increasingly involved in making decisions regarding key aspects of their treatment and regarding their participation in social activities.

Several adolescent participants administered their own injections, which indicates that they are becoming autonomous with regard to managing their medication. As noted earlier in the chapter, administering the injections is a painful and anxiety-provoking experience. In order to administer the injection themselves, the participants seem to have learnt to regulate their emotions and thoughts. The following comment implies that Rochelle gains a sense of independence from injecting herself: "*I think it was more just because I wanted to be in control of it and I think. I don't know, I think it's easier to inflict pain upon yourself than have someone else do it. [laughing] If that makes sense? So I just ja, I, can do it faster in my own time, the way I want to do it*" M[1Bp189]. In addition, it appears that Rochelle is developing increased levels of emotional self-regulation and is less dependent on her mother for emotional support. Asserting control over administering the injection implies that she is developing a sense of self-efficacy and becoming autonomous. Jessica noted that she managed her medication when she went on a 10-day hike: "*Yes, yes I did and I took, even though I took all the preventative high-dose steroid pills on there, on the hike and I like strapped every joint up to stop it hurting, but I still, it was still sore even though*" N[1p293]. Deciding to accompany her peers on the hike implies independent decision making and confidence in her ability to self-regulate her emotions and manage her treatment guidelines. Furthermore, she made the decision knowing her parents would not be available for emotional support, which implies that she is developing a sense of individuation.

The data suggest that, as the adolescent participants moved through the stages of adolescence, they became increasingly involved in making decisions about treatment options. Rochelle communicated that initially the medical practitioners would talk to her mother, but now she voices her opinion during consultations: "*Just trying to direct the questions to me to be able to get the information coming to me. But eventually when I, now I'm starting to be fine with it. And she's a lovely doctor, so we can joke around a bit and have laughs and I can like sarcastically say: 'no it's fine, I, I'm going through it not my mom*'" M[1Bp177]. The comment "*I can like sarcastically say: no it's fine, I, I'm going through it not my mom*" suggests that Rochelle can regulate her emotions when the medical practitioner speaks to her mother rather than to her and that she can redirect the conversation appropriately. Similarly, Leigh-Ann asserted that her levels of engagement during medical consultations had increased: "*As I've gotten older I've, you know, done more of the talking (than my mother) because obviously I know more about what's going on*" P[1p560]. Indeed, her assertion that she knows more about her experiences suggests a high level of self-efficacy. She also takes a more active role in deciding on the choice of treatment: "*I'll tell* *them (medical practitioners) if I don't want to try something new. I'll tell them like the consequences of certain drugs. And just more about how I've been feeling. And maybe also what I think is the problem*" P[2p180]. These comments imply that Leigh-Ann has become more assertive in voicing her opinions regarding treatment options and her health, which suggests increasing levels of cognitive reasoning and decision making. Micaela also explained the significance of making her own decisions about her life: "*It's very important to me to be able to make my own choices, because a lot of, sort of control has been taken away . . . It's become very important to me. It's become sort of almost one of the main features in my life that like choice is probably one of my main priorities*" O[2p476]. From the previous comment, it may be inferred that the ability to make certain decisions about her life had been lost as a result of developing JIA. Despite the loss of autonomy in these areas of her life, Micaela appears determined to become autonomous in other areas of her life.

Consequently, Micaela asserts her own viewpoint when she disagrees with her mother about decisions: "*And I also went through a stage where I just wanted to come off all medication. So my mom and I had a few fights about that as well*" O[2p486]. Despite having lost a degree of autonomy in certain areas of her life, Micaela's comments suggest that she is becoming autonomous in other areas, particularly with regard to making decisions about her health.

Despite experiencing high levels of pain and fatigue, the adolescent participants described becoming autonomous in areas typical of adolescents. Rochelle was sufficiently independent and autonomous to be elected as a "mini mayor" of the city: *"(I was) pretty much head of that council group, so I was head of those 80 people, and then of another 80 Grade 11s*" M[2p95]. Rochelle was able to manage her responsibilities successfully, which suggests that her level of autonomy was not only developing appropriately, but may have been more developed than some of her healthy peers. Rochelle also noted that during middle adolescence she began to address her feelings of being marginalised with her extended family and friends: "*I remember having quite a long talk with my cousin about something and I pointed out to her that it hurt me a lot when people would push me aside and not notice me*" M[2p84]. Rochelle's ability to initiate these discussions with family members and friends, without conflict, implies that she is developing the ability to regulate her emotions as well as the ability to judge if other individuals' actions are appropriate.

Furthermore, the following excerpts from Jessica and her mother, Judith, highlight that becoming autonomous was a process during which Jessica successfully negotiated adverse experiences. In the following two quotes by Judith, the incremental nature of Jessica's growth in autonomy is illustrated: "*She just came back (from the 10-day hike) more, I suppose confident that she could actually do it and just more little like a group thing. She was just, ja. It was just a confidence thing . . . I think it just gave her more positivity . . . Although the licence has done that more than anything. Definitely. Now she can make her own plans. Like I mean before she'd never never phone TEARS (The Emma Animal Rescue Society) and ask herself if she could go. I mean, I didn't even know it was happening and she's organised it all"* N[3p230-236]. Judith reflected that taking part in the strenuous activity with her peers had improved Jessica's levels of confidence and possibly strengthened her peer relationships. Furthermore, passing her driver's licence test seems to have further increased Jessica's levels of confidence and facilitated her development of autonomy. Judith's comments imply that becoming autonomous was a process in which Jessica developed confidence in her ability to act independently as she successfully negotiated stressful situations.

Leigh-Ann appears to have become more autonomous about regulating her engagement with academic studies and hobbies: "*I don't need anyone to tell me to do school work, or to. Like,* *I'll do my own research into my photography and into things I want to do*" P[1p420]. Moreover, she seemed to describe high levels of self-efficacy and motivation about her academic studies: "*Well, I don't know. A lot of it's self-driven, most of it's self-*driven. *But I mean, my dad got good grades, my brother got good grades, my sister got good grades. So I can't. I don't know, I feel I now need to get good grades. But even though maybe that was at the beginning, now I feel like I want to get, get good grades for myself because of what I want to do in the future"* P[2p258]. From the preceding quote, it may be inferred that Leigh-Ann is involved in the process of individuation. Initially, she worked hard academically because it was a family trait, but she has embraced this work ethic and is working diligently because she values academic success.

Furthermore, Rayne shared two areas in which she appears to be developing autonomous behaviour. She sought out part-time employment, and she was one of the presidents of the school's Interact Club, which is involved in community outreach and development. Rayne sought out part-time employment to increase her sense of financial independence: "*Well not only the independence and that like feeling of like getting my own money so that I can pay for my own things*" K[2p368]. Certainly, the following excerpt implies that being employed has increased her levels of autonomous decision making: "*I also gain confidence just talking to them and helping them out and everything. And I just feel like very independent when I work there*" K[2p372]. In addition, Rayne described her leadership role as one of the presidents of the Interact Club: "*And then I'm part of an Interact Club at my school. I'm like one of the presidents or whatever. So I suggested that we do something in partnership with my mom's NGO and we can like, you know, collect clothes and then donate it to the school. So I want to make people aware like that, like fundraise and stuff*" K[1p494]. Being one of the presidents of the Interact Club is a leadership position which requires management skills and responsible, self-regulated behaviours. Rayne was able to establish a functional outreach programme to support children with JIA from disadvantaged communities. It appears that she was acquiring appropriate, if not advanced, levels of autonomy. Moreover, the following quote implies that Rayne engages in prosocial behaviours: "*It makes me feel happy that people are becoming more aware of this and especially people. If you go to (a government hospital), like the children there who have arthritis, like ja. I want people to see that it's not like, you know, it's not a sore pinkie, children with arthritis in* (a government hospital) *and everything*" K[2p496]. From the preceding quote, it may be inferred that Rayne's prosocial reasoning is maturing, as is her development of cognitive and behavioural autonomy. Indeed, despite experiencing physical challenges to her development of autonomy, Rayne appears to be meeting this developmental task appropriately.

The data presented suggest that, despite the complex challenges of living with JIA, the adolescent participants were engaged in the process of becoming autonomous. Indeed, it seemed that the challenges associated with JIA provided alternative pathways for the development of autonomy that would not necessarily be available to healthy adolescents. What was remarkable was that the adolescent participants were involved in becoming autonomous in a similar manner to that of their healthy peers. Despite the high levels of pain and fatigue, they held leadership positions, engaged in prosocial behaviours and strenuous activities, and successfully negotiated rites of passage such as acquiring a driver's licence. Thus, the adolescent participants seem to be successfully negotiating the developmental goal of becoming autonomous.

5.4.3 Experiences of Well-Being in Living with JIA

All the adolescent participants seem to be of the opinion that it is possible to experience well-being despite having an illness characterised by chronic pain and fatigue. Indeed, their comments suggest that their understanding of well-being has altered as a result of living with JIA.

Furthermore, the adolescent participants seemed to describe a complex understanding of well-being which involved reciprocal interactions between their physical symptoms, state of mind, and emotions. During flare-ups, the increased levels of fatigue and pain seem to impact negatively on their sense of well-being. Conversely, experiencing positive emotions during flare-ups appears to mitigate the extent to which pain affects their sense of well-being. In addition, experiencing high levels of stress or other negative emotions has the potential to trigger a flare-up of physical symptoms. Finally, the adolescent participants related how they were able to enhance their sense of well-being consciously.

The adolescent participants' descriptions suggest that their understanding of well-being has shifted since the onset of JIA. Charlotte and Ursula's explanations were particularly rich. Charlotte described how her understanding altered in the following manner: "*I suppose that when I wasn't ill, like after a cold or not having a like cold or flu or a stomach bug, and that was my definition of being well, whereas now it's I'm not in so much pain and nothing's very swollen and I can walk and I can run and I can do things*" Q[2p167]. Ursula contrasted her understanding of well-being prior to, and subsequent to, her development of JIA: "*It probably would have been you know, being completely physically fine, running around, no pain and whatever. I think that's what it would be. But now to me it's, I want to say managing, but not really. But it's, it's dealing with your pain. It doesn't necessarily mean being a hundred per cent, because I think I'm well and I'm not a hundred percent. And so just caring for your body . . . You know what, you have pain, you have fatigue, but it's just managing it. Not being a hundred per cent well, but just going on through it*" L[2p407]. Both Charlotte and Ursula's quotes imply that before they developed JIA, they did not think about what being well meant. Certainly, Ursula's comment, "*It probably would have been you know, being completely physically fine"* suggests that she had grappled with what well-being entailed. Nevertheless, she contended that, after developing JIA, well-being did not mean *"being a hundred per cent"*. Instead she felt that having a sense of well-being was related to reduced levels of pain and being able to manage her pain – *"just going on through it*". These sentiments were echoed by other adolescent participants.

The adolescent participants described a relationship between their physical symptoms and their experiences of well-being. In this regard, Leigh-Ann noted that her sense of well-being appears to be closely linked to her physical health: "*Sometimes when I have good days I feel great and like everything's fine. You know, life's good. And then on other days I have bad days and just everything will feel awful and you know, I feel like my life's going nowhere*" P[2p130]. Also, Rochelle reflected that well-being referred to her level of physical comfort: "*So in terms of comfort levels in my physical life, so not being in that much pain, you know*" M[2p154]. In addition, physical well-being included the ability to be active: "*Still being able to walk, still being able to do something that's active, you know. And for now, that's enough for me, you know"* M[2p154]. Leigh-Ann and Rochelle's comments suggest that their sense of well-being is enhanced when their physical symptoms, particularly their level of pain, are reduced.

It was remarkable that the adolescent participants depicted well-being as a state of mind. The following quotes suggest that accepting that they would experience days with increased symptoms seemed to enhance their sense of well-being. Ursula emphasised that well-being encompasses an acceptance of being ill: "*Not necessarily just about the pain level, but how you're doing emotionally, how you're actually dealing with what you're going through*" L[2p417]. She clarified this further: "*If I'm having a flare-up and I'll be in a lot, like a lot of pain. But sometimes I'm feeling fine inside. I'm actually at peace and I'm like: 'Okay, it's fine, is actually like okay well, you know what, I'm fine'*" L[2p417]. Similarly, Rochelle seemed to describe well-being as a state of mind and acceptance of the illness: "*Just knowing that not every day is going to be okay, but when the day is okay, is to value it, you know, and to take what I can from it. And I think that's what well-being for me is, is just knowing that it's not always going to be okay, but when it is, it's good you know*" M[2p154]. These comments suggest that acceptance may play a role in enhancing the adolescent participants' sense of well-being.

The adolescent participants also recounted that what they choose to focus on can affect their sense of well-being. Jessica clarified that her sense of well-being depends on where she focuses her attention: "*If you always focus on like: 'I'm so sick; I can't do that because I'm sick, I can't'. Then you're not going to have quality because you're making yourself miserable*" N[2p519]. During flare-ups, Rochelle seems to focus on her well-being in the future: "*And I think, I'm not happy in that moment, but working towards happiness at the end of that bad space, is important to me, in terms of well-being*" M[2p150]. Moreover, Rayne clarified that, if she is experiencing positive emotions, then her ability to cope with the pain is improved and her sense of well-being is enhanced: "*I'm not going to say the pain is totally gone, because it's still there. But I mean it's better than it would be if I was depressed and at home and sad and angry and everything. It's much better when I'm in a happy place and smiling and laughing and everything*" K[2p400]. In a similar manner, Charlotte emphasised actively choosing to create a positive environment and engaging with people who increased her levels of positive emotions: "*Surround yourself with things that make you happy, the people that make you happy. Positive energies . . . As opposed to like people that you hate and things that you hate; it's just going to make you feel worse when you're in pain and you're like uncomfortable. Like try make yourself happy and comfortable*" Q[1p571-573]. These comments indicate that the adolescent participants' sense of well-being can be enhanced by their state of mind towards the illness. An attitude of acceptance and choosing not to focus on the pain appears to improve their sense of well-being. Notably, experiencing positive emotions or a sense of agency seems to reduce the levels of pain experienced.

The adolescent participants identified aspects of their lives that increase their sense of well-being, one of which is choosing to focus on aspects of life that heighten their levels of positive emotions. Being mindful of positive or joyful moments appears to add to Rochelle's sense of well-being: "*I pick up the small things to just love about life, you know. It doesn't have to be a big thing, it can be while we're driving I see this like beautiful, beautiful view and I just think wow, it's a good life you know*" M[2p117]. These comments suggest that the adolescent participants' sense of well-being is optimised when they focus their attention on the positive aspects of their environments.

Gaining a sense of achievement improves the adolescent participants' sense of well-being. Rochelle's perception of well-being is bolstered when she has been engaged in philanthropic projects: "*I think those kind of big projects are very important to me. Those are also great to be able to give back to people*" M[2p136]. Photography also provides Leigh-Ann with a creative outlet that provides a sense fulfilment: *"(Photography) gives something else to my life, apart from school work and the illness*" P[1p432]. Moreover, Rayne has found that being physically active provides a sense of achievement and motivation: "*Just working out just makes me feel more active and I like. It just makes me feel young. I'm on a good road now, like I'm going to get better and everything. Ja. It makes me. It actually makes me. Contributes to the motivation and everything*" K[2p416]. Experiencing a sense of achievement seems to heighten levels of positive emotion and bolster a sense of well-being.

Family members and friends were also cited as resources that assist in the promotion of well-being. Rochelle conveyed that her family serves as an important source of well-being: "*Being* *surrounded by a loving family, you know, like that, that gives you motivation any day to do something, you know. To do anything that I need, now that, that's enough motivation for me. So I think that's really important to me, having a really loving home and a strong family*" M[2p138]. Moreover, Rayne felt that interacting with her friends increased her sense of well-being: "*When I go out to parties and everything, then I can just like you know, be with my friends and have fun and let loose. It makes me feel very like, you know, normal. And like fun, and, ja. Like I'm not one of those girls that just like lays at home in bed when all my friends are having fun outside and everything*" K[2p382]. From these quotes, it is apparent that the adolescent participants' sense of well-being is bolstered by positive relationships with family members and friends.

The adolescent participants' understanding of well-being seems to have evolved since developing JIA. Well-being no longer means being healthy but refers to times with reduced levels of pain and fatigue. In addition, the adolescent participants identified a complex, reciprocal relationship between their physical symptoms, their emotional state, and their state of mind. Furthermore, their sense of well-being in illness seems to be enhanced by several factors, one of which is accepting that that they would experience periods of increased pain and fatigue. Another factor contributing to a sense of well-being is actively choosing to focus their attention on aspects of their lives other than their illness. In addition, engaging in activities that provide personal meaning and a sense of achievement also seems to optimise their sense of well-being. Finally, having positive relationships with family members and friends appears to be a significant contributor to an enhanced sense of well-being.

5.5 Conclusion

The thematic analysis has presented a rich understanding of biopsychosocial transactions in the multiple systems of adolescents with JIA, which may extend the existing body of knowledge.

Although JIA is based primarily in the biological system, the symptoms caused by the disease created a cascade of transactions within and between the biopsychosocial systems resulting in cumulative risk processes. However, over time, resilience processes developed in the biopsychosocial systems, which seemed to enable the adolescent participants' positive adaptation to living with JIA. Their positive adaptation was apparent in that they appeared to be negotiating the developmental tasks of forming an identity and becoming autonomous. Notably, despite the chronic nature of JIA, the adolescent participants experienced periods of well-being in spite of their illness. In addition, they seemed have a sophisticated understanding of the transactional nature of their physical and psychological well-being. The following chapter discusses these findings with reference to the relevant existing literature.

CHAPTER 6: DISCUSSION OF FINDINGS

6.1 Introduction

This chapter presents new findings that arose from this exploratory study regarding the psychosocial experiences of adolescents with JIA and discusses them with regard to the relevant literature. The study corroborated the multisystemic risks discussed in the existing body of literature (Cartwright et al., 2014; Demirkaya et al., 2016; Jordan, Family, & Forgeron, 2017; Stinson et al., 2016; Tong et al., 2012; Unal et al., 2018). In addition, noteworthy findings are presented regarding risk processes, resilience processes, and positive adaptive outcomes that extend and contribute significantly to the current body of literature on JIA. The chapter concludes with a reflexive analysis of the researcher's role in the research process.

6.2 Multisystemic Risk Processes

This study has brought to light six noteworthy risk processes which have received scant attention in the existing body of literature. The finding that, at times, the adolescent participants experienced resilience processes in response to risk processes suggests that interventions may be designed to optimise resilience processes and positive adaptation to JIA. The first of these risk processes to be discussed is the sub-theme of limited social awareness of JIA and the resultant experiences of social isolation.

6.2.1 Limited Social Awareness of JIA

The adolescent and parent participants in this study described feeling socially isolated and marginalised at times owing to the lack of social awareness regarding JIA in South Africa. Furthermore, the participants contrasted this lack of awareness regarding JIA with the high level of awareness of other serious childhood illnesses such as paediatric cancer. Indeed, a Google search (2 January 2019) for South African support groups for individuals with juvenile arthritis yielded only two websites – the Arthritis Foundation and the South African Rheumatism Arthritis Association. Thereafter, the search results provided contact details for rheumatologists and links to journal articles. There were no websites for groups that serve children and/or adolescents in particular. In contrast, a Google search conducted at the same time for South African support groups for paediatric cancer provided a significant number of cancer support websites as well as several websites specifically for childhood cancer. These online search results suggest that the number of support sites for JIA in South Africa is minimal in comparison to that of paediatric cancer.

The lack of social awareness regarding JIA seems to have given rise to misconceptions about this form of arthritis. Two misconceptions that seemed to be particularly frustrating for the adolescent and parent participants were that arthritis is a disease associated with old age, and that the visibility of physical symptoms correlates with the levels of pain and fatigue experienced. Only the adolescent participants with visible physical symptoms reported having garnered significant social support. The adolescent participants with invisible physical symptoms noted having to explain or justify their illness in a manner that adolescents with familiar diseases, such as cancer, do not. This need to explain or justify may have been exacerbated because these adolescent participants appeared to be healthy, despite experiencing high levels of pain and fatigue. Reciprocally, the lack of social awareness and understanding of the adolescent participants' high levels of pain and fatigue caused the adolescent and parent participants to feel marginalised and socially isolated.

The finding that invisible symptoms did not elicit the same level of social support for the adolescent participants as visible symptoms raises questions about internal representations of what constitutes a serious disease. An individual's internal representations of pain and illness are socially and culturally informed and lead to a specific set of expectations (Sameroff, 2014). When these expectations of ill-health are not fulfilled, the individual who is ill may not receive empathy and support, which results in feelings of being socially isolated (Cartwright et al., 2014; Forgeron, Evans, McGrath, Stevens, & Finley, 2013; Stinson, Feldman et al., 2012; Tong et al., 2012). However, these internal representations can be altered. Cancer patients may have invisible symptoms; however, because this disease is well known, they still receive considerable social support. It is therefore posited that increasing the levels of social awareness regarding JIA may foster empathy and social support which could facilitate positive adaptation amongst adolescents with JIA.

Certainly, in this study it seemed that the degree of visibility of the physical symptoms and the lack of social awareness affected the levels of empathy and support provided to the adolescent participants. Consequently, the formation of support groups may assist individuals who have recently been diagnosed with JIA. Furthermore, support groups may create greater social awareness regarding JIA that engenders increased levels of social support for all individuals diagnosed with JIA. Moreover, creating greater social awareness may also decrease the occurrence of pain dismissal and illness invalidation.

6.2.2 Illness Invalidation and the Dismissal of Pain

The degree to which illness experiences and pain are validated seems to impact on the adolescent and parent participants' adaptation to living with JIA. What was notable in this regard was that social constructions of illness may have affected the extent to which illness experiences were validated. The internal illness representations held by other individuals seemed to inform their regulation of the adolescent participants' behaviours. If there were visible signs of physical illness then, despite inconclusive medical test results, the adolescent participants' illness experiences were validated, their pain was acknowledged, and they were able to elicit medical treatment. However, it needs to be noted that this medical treatment was not always optimal until a diagnosis of JIA had been made, as the treatment protocols for JIA must be early and aggressive in order to prevent disease progression (Demirkaya et al., 2016; Giancane et al., 2016). Furthermore, the visibility of the adolescent participants' swollen joints seemed to facilitate other individuals' belief in their pain, and thus they were able to garner support from family members, friends and school teachers.

Notably, the adolescent participants with invisible symptoms and negative test results had their illness experiences invalidated and their levels of pain dismissed. Thus, the lack of social awareness regarding JIA and the illness representations held by other individuals shaped the social regulation of the adolescent participants. In turn, these multifaceted social, emotional, and cognitive experiences influenced the self-regulation behaviours of the adolescent participants. The invalidation of certain adolescent participants' illness experiences led to the use of maladaptive coping strategies, such as not disclosing their pain and fatigue, which increased the risk of negative trajectories.

Regulation by other individuals seemed to play a greater role in contributing to positive or negative adaptation when it came from individuals in positions of power, such as medical practitioners. In some cases, medical practitioners either tacitly or overtly suggested that there was a psychogenic basis to the adolescent participants' illness. This response is in line with previous research which has noted the tendency for medical practitioners to default to psychogenic causes if no biomedical abnormality was found (Brennan & Creaven, 2016; Conrad & Barker, 2010; Dickson, Knussen, & Flowers, 2007; Newton-John, Mason, & Hunter, 2014). Similarly, recent studies (Defenderfer et al., 2018; Igler et al., 2017) have reported that 20% of pain in adolescence was thought by general practitioners to be psychogenic. In particular, higher rates of pain dismissal by medical practitioners were reported in relation to female adolescents in comparison to male adolescents as well as a greater likelihood of female adolescents' chronic pain being attributed to psychogenic factors (Igler et al., 2017).

In the current study, the suggestions made by significant others that the adolescent participants' pain might have a psychogenic cause appeared to impact negatively on their self-concept and sense of identity. Certainly, the adolescent participants seemed to view a psychogenic illness as not being a legitimate illness. This finding reflects that of research conducted by Newton, Southall, Raphael, Ashford, and LeMarchand (2013) which indicated that adult participants with invisible chronic pain were disbelieved by medical practitioners and significant others. Indeed, Parslow et al.'s (2017) study on childhood chronic fatigue syndrome reported that the lack of validation of the participants' experiences resulted in social isolation. The lack of validation also formed a barrier to the development of a coherent sense of identity. Parslow et al. (2017) noted that the disbelief by medical practitioners and significant others resulted in the participants' experiencing stigmatisation, social isolation, and emotional distress. In the current study, the adolescent participants with invisible symptoms seemed to experience strong negative emotions, such as anger, towards those who dismissed or minimalised their illness experiences. With no visible symptoms or diagnosis, withdrawal from activities such as physical education and sport became difficult to justify and resulted in these participants feeling stigmatised and socially isolated. This finding extends the earlier research undertaken by McDougall (2006) regarding the stereotypes associated with physical disability in South Africa. She noted a polarisation of views in which individuals with physical disabilities were viewed as either "pitiable" or as "heroic".

However, this study suggests that a third option, that of dismissal and invalidation, is possible when there are no visible signs of physical disability.

Notably, even after receiving the diagnosis of JIA, some of the adolescent participants' illness experiences continued to be invalidated by significant others who, in the absence of visible signs, seemed unable to comprehend their levels of fatigue and pain. Moreover, the adolescent participants with invisible symptoms seemed to have been accused of malingering or were misunderstood by significant others. These experiences in the current study corroborate the findings of two previous studies (Sällfors & Hallberg, 2009; Tong et al., 2012). The dismissal of the adolescent participants' pain and the invalidation of their illness experiences led these individuals to adopt coping strategies that were distinct from those used by adolescents with visible signs of illness. Coping strategies such as ignoring or denying the physical symptoms and participating in strenuous physical activity appeared to be maladaptive in that, ultimately, they led to flare-ups of the disease. Nevertheless, coping strategies such as not disclosing pain and fatigue may initially have been beneficial in protecting them from social criticism and thus played an adaptive role by enhancing levels of positive affect. However, these strategies were maladaptive with regard to disease progression as they prevented the adolescent participant from optimally managing the symptoms of the disease.

Further research regarding the complex role played by pain dismissal and illness invalidation in the process of adaptation to living with JIA is needed. Certainly, the extent to which medical practitioners and significant others validated the adolescent participants' illness experiences seemed to contribute to either positive or negative trajectories. Given that emotionally supportive relationships have been found to lead to positive adaptation in individuals with JIA (Cousins et al., 2015; Forgeron et al., 2013; Sansom-Daly et al., 2012; Sinclair et al., 2016), addressing the social misconceptions regarding invisible signs of JIA seems warranted. Moreover, increased social awareness regarding JIA may also assist in reducing the time taken to diagnosis.

6.2.3 Time Taken to Diagnosis

The length of the diagnostic period appears to be a risk process that can optimise or impede positive adaptation to living with JIA. The adolescent and parent participants whose diagnostic periods were fairly quick and relatively uneventful described experiencing lower levels of anxiety during this period in comparison to those whose diagnostic period was lengthy. Overall, the time taken to diagnosis was similar to that reported internationally (Aoust et al., 2017; Modica et al., 2016; Modica, Lomax, Batzel, & Cassanas, 2018) and ranged from a few months to almost a decade. The adolescent and parent participants' experiences corroborated findings that the limited awareness regarding JIA amongst South African medical practitioners may play a significant role in the delay of accurate diagnosis (Weakley et al., 2011; C. Scott, personal communication, January 15, 2019). Furthermore, there is a shortage of paediatric rheumatologists worldwide (Chausset et al., 2016), which appears to be particularly problematic in South Africa. In 2014, there were only five paediatric rheumatologists in South Africa (Scott & Webb, 2014); however, recent correspondence with Professor Chris Scott (personal communication, November 5, 2018), head of Paediatric Rheumatology at the University of Cape Town, revealed that this number has increased to eight paediatric rheumatologists.

Notably, the journey to diagnosis was often as complex as reported in the existing body of literature (Aoust et al., 2017; Hausmann, Lomax, Shapiro, & Durrant, 2018; Modica et al., 2016, 2018), with the adolescent participants experiencing many medical referrals, diagnostic procedures, and incorrect diagnoses – the latter being especially problematic when the symptoms were invisible. Adolescent participants who had invisible symptoms, as well as their parents, experienced the diagnostic process as being time consuming, expensive, and resulting in unnecessary medical procedures. These experiences corroborate recent research that describes the journey to diagnosis and treatment as a medical "merry go round" (Hausmann et al., 2018). Furthermore, the adolescent and parent participants who experienced a long delay in receiving an accurate diagnosis reported a loss of faith in the medical profession and becoming sceptical of medical practitioners in general.

A valuable finding was that higher levels of advocacy were required of the parent participants in order to drive the diagnostic process when the medical practitioners consulted had limited awareness regarding JIA. Indeed, the parent participants reported that they had to assume responsibility for the diagnostic process, and that it was through their initiative and determination that a diagnosis was eventually made. However, in the cases with a short diagnostic period, the parent participants indicated that the medical practitioners consulted were aware of the nature of inflammatory disorders or assumed responsibility for the diagnostic process.

These findings are consistent with those of a recent study by Hausman et al. (2018) regarding the journey to diagnosis and treatment of autoinflammatory diseases in the USA. Their study reported that parents had to assume an advocacy role for their children, although a proactive medical practitioner helped to make the final diagnosis. Furthermore, Hausman et al. (2018) reported a loss of faith in, and increased levels of distrust towards, medical practitioners. The authors recommended that health care providers should be cognisant of the effect of the lengthy diagnostic journey on families and should work to establish a setting of trust in which families and health care practitioners can work collaboratively. Indeed, another recent study has recommended that adolescent transition to adult chronic health care should be supervised by the family practitioner and the paediatric specialist, rather than the parent dyad (Han et al., 2018). This recommendation may lend support to the idea that managing the diagnostic process is the role of medical practitioners. Certainly, this study suggests that a valuable area of research would be to develop protocols to guide medical practitioners when the diagnostic process is prolonged, so that the risk of biopsychosocial complications is minimised.

Another important finding of this study was that delayed diagnoses seemed to increase the risk of biopsychosocial complications. Although research has investigated the biopsychosocial factors that predict a delayed diagnosis of JIA (Aoust et al., 2017; Tzaribachev, Benseler, Tyrrell, Meyer, & Kuemmerle-Deschner, 2009; Van Dijkhuizen & Wulffraat, 2015), only a few studies have begun to explore the biopsychosocial effects of a delayed diagnosis on the individual and the family (Chausset et al., 2016; Gómez-Ramírez et al., 2016; Hausmann et al., 2018; Modica et al., 2016; Tzaribachev et al., 2009). Given that the treatment protocol for JIA consists of early and aggressive intervention in order to limit disease progression (Demirkaya et al., 2016; Giancane et al., 2016), a delayed diagnosis may place individuals at risk for serious physical and psychological complications. In this regard, international studies have indicated that a lack of optimal treatment may lead to an increase in the severity of the disease which is linked to permanent abnormality in joints and organs as well as increased mortality rates (Coda et al., 2017; Davies, Southwood, Kearsley-Fleet, Lunt, & Hyrich, 2015; Mosley, 2015; Rowan et al., 2014). Thus, it is possible that the delays in diagnosis and resulting sub-optimal treatment experienced by the adolescent participants in this study may have had physical repercussions. Ursula’s severe symptoms, rapid degeneration, and subsequent use of a wheelchair for four years demonstrate the alarming repercussions of an individual not receiving a timeous, accurate diagnosis and appropriate treatment.

It was notable that the activity limitations and participation restrictions that the adolescent participants experienced were accompanied by psychological challenges. In this regard, a few studies have indicated that delayed diagnoses result in decreased levels of self-esteem, a negative self-concept, and increased levels of negative affect (Chausset et al., 2016; Hausmann et al., 2018; Tzaribachev et al., 2009). In line with the existing research, both adolescent and parent participants reported that the adolescent participants who were subject to delays in the diagnostic process experienced self-doubt, increased levels of negative affect, and stigmatisation. It may be inferred that diagnostic delays may place adolescents at risk for psychosocial complications which can prolong the process of adaptation to living with JIA.

From a developmental psychology perspective, further exploration of the effect that a delayed diagnosis has on identity development could possibly provide areas of intervention that may ameliorate some of the negative consequences of such a delay and increase levels of resilience and well-being. In addition, the biopsychosocial consequences of a delayed diagnosis and inconclusive medical tests suggest that protocols need to be devised to guide medical practitioners' support of individuals with chronic illnesses and their families. Furthermore, psychological interventions could be developed to bolster resilience and subjective well-being during, and after, lengthy diagnostic processes.

6.2.4 A Need for Guidelines when Delivering a Diagnosis

The adolescent and parent participants' varied responses to receiving a diagnosis of JIA suggest that there is a need for close monitoring and psychoeducational support during and after receiving a diagnosis. In particular, most of the participants noted that the period immediately following the diagnosis was one fraught with uncertainty and anxiety about the prognosis of the disease. These experiences resonate with previous South African and international research (Scott

& Webb, 2014; Chausset, 2016) which indicated that there appears to be minimal education or emotional support from medical practitioners once a diagnosis has been made. Indeed, there is an international move towards developing diagnosis delivery models, such as SPIKES (setting, perception, invitation/information, knowledge, empathy, and summarise/strategise) and PEWTER (prepare, evaluate, warning, telling, emotional response, and regrouping preparation) (Dean & Willis, 2016; Seifart et al., 2014). These models use a step-by-step process to deliver the diagnosis of serious or life-threatening conditions to patients and families. The process involves steps such as choosing appropriate settings, offering empathic responses and emotional containment, and providing information about the condition and proposed treatment strategies. Studies regarding diagnosis delivery have been conducted in the fields of ophthalmology (Hilkert et al., 2016), cancer (Bumb, Keefe, Miller, & Overcash, 2017; Konstantis & Exiara, 2015), HIV (Wiener, Mellins, Marhefka, & Battles, 2007), schizophrenia (Seeman, 2010), and autoinflammatory diseases (Hausmann et al., 2018). However, a literature search did not produce any studies discussing protocols for the delivery of a diagnosis of JIA (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & NREPP databases, 24 January 2019).

In this study, there were indications that there may not have been protocols in place for delivering the diagnosis of JIA. Most of the adolescent and parent participants reported feeling uncertain about the treatment protocols, the prognosis, and how to proceed with activities of daily living. They also expressed the desire to be able to access information about JIA that was accurate and helpful. Moreover, the majority of participants experienced negative emotional reactions immediately or shortly after receiving the diagnosis of JIA. The PEWTER and SPIKES protocols both include steps that would meet the post-diagnostic needs that were expressed by the adolescent and parent participants in this study. Certainly, based on the findings of this study, it seems that protocols need to be developed that support the parents and their children both during and after diagnosis delivery. This seems to be particularly necessary given the lack of JIA support groups in South Africa.

A key finding was that receiving the diagnosis of JIA was an affirming and vindicating experience for some participants – in particular, Leigh-Ann, Jessica, and Charlotte. In this regard, adolescent participants and their parents verbalised that the diagnosis confirmed that they were not imagining the illness experiences. Notably, the diagnosis appeared to improve the adolescent participants' levels of self-esteem. These findings corroborate Hausmann et al.'s (2018) research on the diagnostic process of autoinflammatory diseases, which also noted that patients felt vindicated and relieved to receive a diagnosis. The findings of their study suggest that a lengthy delay in diagnosis results in uncertainty and anxiety for both the individuals and their families. Consequently, the diagnosis brings an end to the uncertainty and allows for treatment plans to be established. The sense of relief experienced by participants in the current study, as well as the study conducted by Hausman et al. (2018), suggests that the long period of uncertainty before a diagnosis is made may be experienced as emotionally distressing. These expressions of relief may alert the medical practitioner to the fact that the patient has experienced emotional distress in the period leading up to diagnosis. It is likely that the protocols for delivering a diagnosis may need to be adjusted in such situations. Evidently, further research is needed to explore the psychosocial consequences of a lengthy diagnostic period. The findings of this research may better inform the development of future protocols for the delivery of a diagnosis and appropriate post-diagnostic care.

Establishing flexible protocols for the delivery of a diagnosis of JIA may enhance the individual and family's positive adaptation to the disease by decreasing levels of uncertainty and anxiety about the future. Furthermore, such protocols should include psychoeducational information on treatment options, the practical aspects of disease management, as well as referrals to appropriate mental health professionals and support groups. Previous studies have found that following protocols for delivering a diagnosis strengthens the relationship between the medical practitioner and the individual (Bumb et al., 2017; Wiener et al., 2007). In addition, the use of protocols has been found to empower the individual within the medical practitioner-patient relationship (Bumb et al., 2017).

6.2.5 Dis/Empowering Relationships with Medical Practitioners

An important finding was that their relationships with medical practitioners had the potential to either empower or disempower the adolescent and parent participants. The data suggest that medical practitioners whose approach was person-centred rather than condition-centred enabled the participants to share their own knowledge and experiences of the illness. This finding confirms those of previous studies which suggest that adolescents prefer a person-centred approach (Beresford & Sloper, 2003; Dickinson et al., 2006; Van Staa et al., 2011) which they find to be empowering (Beresford & Sloper, 2003). The adolescent participants reported that they felt marginalised when medical practitioners tended to address their parents rather than them. Moreover, they expressed the desire to be included in discussions and decision-making processes during consultations, as they felt that they could better explain their experiences to the medical practitioner. Even when they were included in the discussion, it was difficult to raise the issue of new symptoms in the presence of a family member, particularly if the information was of a sensitive nature. Not being able to privately discuss sensitive topics is problematic, as it may result in new symptoms being overlooked. It seems evident that greater cognisance needs to be taken of adolescents' increasing need for private consultations. The inclusion of private consultations may also be a significant factor in empowering the adolescents to make a successful transition to adult medical care. In addition, the adolescent participants indicated a preference for the use of developmentally appropriate language during consultations. This finding corroborates findings from earlier studies which explored adolescent preferences when engaging with medical practitioners (Beresford & Sloper, 2003; Britto, 2004; J. Brown & Wissow, 2009). When combined with a person-centred approach, the use of developmentally appropriate language appears to have facilitated the building of rapport and a supportive relationship between the medical practitioner and the adolescent participant.

Another critical finding in this study was that certain medical practitioners privileged their own expert knowledge over that of the adolescent patient and parents. This finding does not seem to have been explored in the existing body of literature. Moreover, it appeared that this privileging of expert knowledge may have resulted in negative physical and psychological trajectories of development. Three parent participants – namely, Judi, Jane, and Ann – reported that their understanding and knowledge of their child’s illness had been disregarded by medical practitioners, to the detriment of the adolescent’s well-being. In particular, Judi reported that the consequence of her insight being disregarded was that the accurate diagnosis of Jessica’s condition had been delayed by approximately three years. Both Jane and Ann reported what seemed to be sub-optimal treatment as a consequence of medical practitioners disregarding parental knowledge and experience. Certainly, these occurrences suggest that valuable diagnostic information may be overlooked when medical practitioners disregard the adolescent patients’ and parents’ own knowledge of the illness. This oversight may lead to delayed diagnoses, sub-optimal treatment, and negative psychological consequences for the adolescent patients and their parents. The adolescent and parent participants described feeling disempowered and marginalised, and experiencing high levels of anger towards the medical practitioner as a result of their knowledge and understanding being disregarded. In addition, they reported that, at times, this resulted in a loss of faith in that particular medical practitioner's ability to support them.

Of great import for this study was the finding that the adolescent and parent participants seemed to hold internal representations of the medical practitioner's role in the relationship and expected certain behaviours from the medical practitioner. These internal representations appeared to influence the relationship between medical practitioners and adolescent participants. It appeared that when medical practitioners conducted themselves in accordance with the adolescent and parent participants' expectations, the relationship was experienced as positive and empowering. Conversely, if their expectations were not met, then the relationship was not viewed as being supportive. For example, Jessica, Micaela, and Rayne expressed criticism towards the medical practitioners whom they felt conducted themselves in a disrespectful manner. A disrespectful manner entailed such behaviours as being late for appointments and procedures, as well as communicating in a manner that the adolescent participants felt was abrupt, condescending, or developmentally inappropriate. However, Rayne noted that this was acceptable behaviour if the medical practitioner was able to treat her effectively, which suggests that she holds different expectations in comparison to Jessica and Micaela. Her internal representations seemed to allow for medical practitioners who were "*rude*", but only if they were "*brilliant*".

The internal representations that existed regarding a medical practitioner's role were also apparent when different adolescent participants consulted with the same medical practitioner. The adolescent participants' descriptions of their relationship with a particular medical practitioner differed, and this seemed to be partly as a result of the expectations that they held. Whereas one participant might have described the medical practitioner as overly professional and abrupt, another found the same practitioner to be warm and supportive. Although the relationship between the medical practitioner and the patient is affected by a complex range of factors (Han et al., 2018), this study suggests that valuable findings may arise from further research that explores the expectations regarding the medical practitioner’s role and conduct held by the adolescent patients and their parents. Furthermore, research might be conducted to ascertain medical practitioners’ understandings of their own roles and the roles of their adolescent patients and parents. This suggestion is reflected in a recent study by Han et al. (2018), which also emphasised the need to clarify and clearly communicate the different roles of family practitioners and paediatric specialists to adolescents and their parents. Further research regarding the roles of the medical practitioner and the patient may enable medical practitioners to develop empowering relationships with chronically ill adolescents and their parents by clarifying roles and expectations for all parties.

It may be inferred from the data that when medical practitioners develop empowering relationships with adolescent patients and their parents, the likelihood of positive trajectories is increased. Indeed, Ungar (2016) emphasised that resilience processes within the medical context include facilitating a relationship between institutional partnerships, patients, and caregivers which ensures that the needs of the patients and caregivers are met in a meaningful way. This study reflected the finding that both the use of developmentally appropriate communication, as well as inclusion of the adolescent in the consultation process is experienced as empowering by the adolescent. It also highlighted the need for privacy to discuss issues of a sensitive nature. Importantly, in terms of the experiences of participants in this study, certain factors that contributed to the development of negative trajectories do not seem to have been highlighted in previous research findings. These factors included the medical practitioners’ privileging of their own knowledge over that of adolescent and parent participants, which may have resulted in negative physical and psychological consequences. Moreover, the internal representations held by participants regarding the medical practitioner's role may be an additional factor that influences the relationship between the medical practitioner, the adolescents, and the parents. Further research that explores developmentally appropriate consultations, the possible privileging of medical practitioners' knowledge, and the internal representations held regarding the roles of medical practitioners may facilitate stronger, more empowering relationships between medical practitioners, adolescent patients, and their parents. In addition, establishing strong relationships and effective communication with adolescent patients may increase the medical practitioner's awareness of the psychological well-being of the adolescent and enable them to ascertain if any medical experiences could be a source of emotional distress.

6.2.6 Anxiety-Provoking Medical Experiences

A key finding in the current study was that the adolescent participants experienced heightened levels of anxiety because of certain illness experiences, medical treatments and procedures, or events witnessed in the hospital environment. Certainly, the adolescent and parent participants' descriptions of the adolescents' symptoms of anxiety suggested that they may have experienced symptoms of post-traumatic stress.

Further exploration of this concept in the body of existing literature brought to light the concept of PMTS[4], which has been defined as "a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences" (National Child Traumatic Stress Network, 2003). Certainly, both adolescent and parent participants described psychological and physiological stress reactions

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[4] Acronym defined in Section 1.4 – "Concept Clarification" (page 10).

to emotionally distressing illness experiences. In addition, some adolescent and parent participants used the term "traumatic" to describe certain experiences in the medical context.

PMTS refers to the presence of post-traumatic stress symptoms that do not necessarily qualify for a diagnosis of PTSD, but that hamper medical recovery, impair daily functioning, and affect treatment compliance. Such symptoms can include heightened arousal, avoiding reminders of the traumatic experience, re-experiencing the trauma, and continued intrusive and distressing thoughts (Kassam-Adams, 2006; Price et al., 2016). Both adolescent and parent participants in the current study described possible post-traumatic stress symptoms such as high levels of distress, heightened anxiety, nightmares, intrusive thoughts, flash backs, and nausea induced by certain smells such as those of disinfectant solution or alcohol swabs.

These findings are significant as there is scant research regarding the presence of PMTS in individuals with JIA. A database search revealed no psychological studies of adolescents with JIA experiencing post-traumatic stress symptoms (Campbell Systematic Review, Cochrane Database of Systematic Reviews, EBSCOHost, & NREPP databases, 24 January, 2019). Indeed, there are only a limited number of international studies regarding PMTS. However, there is increasing research evidence that supports a traumatic stress model for understanding and addressing psychological reactions specific to paediatric illness and injury. These psychological reactions have been studied in relation to paediatric cancer survivors, diabetes, chronic pain, burns victims, and intensive care (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Holley et al., 2016; Kazak et al., 2006; Nelson & Gold, 2012; Neul, 2012; Price et al., 2016; Werba & Kazak, 2009).

Of great significance for this study was that, during periods of hospitalisation, both Rochelle and Michaela described witnessing the death of a person, and Ursula was asked to assist with a suicidal adolescent. All three participants described these events as traumatic. This is an important finding as the existing literature on PMTS focuses on patients' own medical experiences and does not include traumatic events that may have been witnessed in the medical environment. It was clear in this study that witnessing or being involved in traumatic events that were separate from their own illness condition caused heightened levels of anxiety for the adolescent participants.

These findings indicate that medical practitioners need to be cognisant that individuals with JIA may experience symptoms of acute and chronic anxiety. It is also possible that the levels of anxiety experienced may meet the criteria for a diagnosis of PMTS. Such awareness is necessary as heightened levels of anxiety regarding the administration or side effects of medication can reduce levels of treatment compliance. Also, as chronic anxiety symptoms may cause or exacerbate flare-ups of JIA, both chronic and acute anxiety may impact negatively on the individual's adaptation to living with JIA. In addition, medical practitioners should be aware that placement in medical facilities that are developmentally inappropriate may not be in the best interests of the patient. Moreover, they should be alert to possible traumatic events that may be witnessed by their patients, so that appropriate psychosocial interventions can be implemented. Further research in this area may enable the development of protocols to manage emotionally distressing events or medical procedures during hospitalisation.

6.3 Multisystemic Resilience Processes

This study has contributed significantly to the existing body of literature as it describes the multisystemic nature of the resilience processes engaged in by adolescents with JIA. As noted in Chapter 2, the body of literature regarding JIA has made scant reference to resilience processes. Other than one article which discusses the use of distraction as a coping mechanism when living with JIA (Cartwright et al., 2014), there appears to be no literature in the field of JIA that explores these mechanisms. The seven adolescent participants in this study described first-hand the resilience processes that they experienced as they adapted to living with JIA. A noteworthy finding was the extent to which the adolescents' sense of agency and grit enabled them to develop the strategies needed to cope with the challenges associated with their illness. Initially, the adolescents withdrew socially, but eventually they regained their personal agency. They developed self-regulation strategies to manage their physical and emotional functioning, which enabled them to cope adaptively to living with JIA. It may be inferred from the use of adaptive coping strategies that the adolescent participants seemed to be successfully negotiating the developmental goals of forming an identity and becoming autonomous. Furthermore, their positive adaptation is highlighted by their experiences of well-being despite living with chronic pain and fatigue.

6.3.1 Passivity Evolves into a Sense of Personal Agency

Disengagement and passive coping strategies are viewed as initially helpful in coming to terms with a serious illness but may become maladaptive in the long term (Compas, Jaser, Dunn, & Rodriguez, 2012). This finding is supported by research regarding adults with chronic pain who withdrew socially in order to avoid stigmatisation (Newton et al., 2013). Certainly, in this study, the adolescent participants reported periods at either the start of their illness journey or after diagnosis during which they withdrew socially and coped passively with their illness. It is noteworthy that the participants reported that social withdrawal and the use of passive coping strategies were not helpful in enabling them to adapt to the unpredictability of JIA. In fact, the descriptions given by the adolescent participants in the current study were consistent with the existing literature on effective coping strategies (Compas et al., 2012; Compas et al., 2014; Haase, 2004; Haase et al., 2014) and indicated that, while passive strategies became maladaptive over time, they found accommodative strategies to be more effective in managing the unpredictability, pain, and fatigue of JIA.

The process of moving from disengagement and the use of passive coping strategies to an increased sense of personal agency occurred over a period of time and seemed to entail a gradual acceptance of the chronic nature of their illness. However, Rochelle, Micaela, and Naomi identified pivotal moments that facilitated an increased sense of personal agency, such as collapsing while playing hockey and the deterioration of academic results. While having a sense of agency is a focal point of literature in the field of resilience (Masten, 2006; Rutter, 2012), it does not seem to feature in the body of literature regarding JIA. In this study, the adolescent participants developed a strong sense of agency which enabled them to actively make choices that transformed negative trajectories into positive ones. Their sense of agency was evident in their determination not to be defined by their illness, their acceptance of pain, their choice to participate in social activities, and the use of passive, accommodative, and active coping strategies to manage their illness.

6.3.2 Self-Regulating Physical and Psychological Activity

A valuable insight gained from this study was the extent to which the adolescent participants were continually engaged in regulating their physical and emotional states. The development of physical and psychological self-regulation is a key coping strategy in the positive adaptation to living with JIA. Indeed, Saetes et al. (2017) has recommended that further research be conducted regarding the self-regulation of pain in the field of JIA. The present study made a significant contribution by providing a detailed understanding of the degree of self-regulation that the adolescents engaged in to cope with the daily activities of living.

The development of strategies to self-regulate physical and social activities is essential because individuals who live with JIA have limited amounts of physical energy in comparison to their healthy peers. The characteristic symptoms of JIA – pain and fatigue – are exacerbated when individuals over-exert themselves (Coda et al., 2017; Rochette et al., 2015; Van Pelt et al., 2012). While a certain amount of physical activity is required for optimal physical functioning, this varies between individuals (Coda et al., 2017; Rochette et al., 2015; Van Pelt et al., 2012), and each individual needs to learn and manage their own parameters. In this study, the adolescent participants described the process of self-regulating their physical and social activities as a balancing act between being physically active and knowing when to rest so that they did not over-exert themselves. Moreover, they described a flexible, step-by-step approach to negotiating activities of daily living as well as recreational activities. Most of the adolescent participants described the need to be aware of their limitations and to be prepared for a flare-up of the disease which may prevent their engagement in anticipated activities.

The adolescent participants described how they needed to consistently balance the costs and benefits of activities, irrespective of whether they were related to daily living or recreation. Indeed, both parent and adolescent participants reflected on the consequent lack of social spontaneity as each action needed to be considered in terms of restricted energy levels and the possibility of exacerbating physical symptoms. At times, the psychosocial value of engaging in activities such as attending school, participating in hobbies, and socialising with families and friends outweighed the resultant costs of increased pain and fatigue.

Another significant finding was the extent to which the adolescent participants negotiated the daily activities of living through step-by-step approaches. Literature on chronic pain in adults refers to the resilience process of committed action in which individuals demonstrate goal-directed, flexible persistence in negotiating the activities of daily living (McCracken, 2013; McCracken & Morley, 2014). Although this resilience process has not received attention in the existing body of literature on JIA, it is noteworthy that it has been incorporated into Cousins et al.'s (2015) model of resilience in chronic paediatric pain. During flare-ups of physical symptoms, a simple action, such as getting out of bed in the morning, became a major achievement. The adolescent participants reported that it was emotionally overwhelming to consider the whole day that lay ahead of them. Instead, they split the day into achievable goals which needed to be reached. Furthermore, compartmentalising the day enabled the adolescent participants to engage in some of the activities of daily living, even if they were unable to manage the whole day.

Notably, the adolescent participants were aware of the reciprocal transactions between increased physical symptoms, negative cognitions, and negative affect. During flare-ups of physical symptoms, the adolescent participants used cognitive reappraisal to regulate their emotions and thoughts and to prevent themselves from experiencing a depressed mood. Conversely, they made use of cognitive reappraisal strategies to regulate their emotions and cognitions during periods of stress, as these could trigger a flare-up of physical symptoms. This reciprocal relationship between physical symptoms and psychological state has been described in research in the fields of adult chronic pain (Sturgeon & Zautra, 2013; Yeung et al., 2012) and childhood chronic pain (E. Fisher et al., 2017; Sinclair et al., 2016). Therefore, the present study extends the research regarding the reciprocal relationship between chronic pain and psychological state into the field of JIA.

Another important finding was the level and complexity of self-talk that was required for adolescent participants to regulate their emotions and cognitions while negotiating activities of daily living. The adolescent participants described using several forms of cognitive reappraisal such as challenging negative cognitions; pain self-efficacy; pain acceptance; minimising their illness; using humour; and engaging in spiritual reappraisal, such as mindfulness and finding meaning though their faith. While the use of cognitive reappraisal strategies has been described in the literature regarding adult chronic pain (Sturgeon & Zautra, 2013; Yeung et al., 2012) and, to some extent, childhood chronic pain (E. Fisher et al., 2017; Kalapurakkel et al., 2014; Sinclair et al., 2016), minimal research has been conducted on cognitive reappraisal and JIA. However, one study explored the relationship between pain intensity, psychological inflexibility, and pain acceptance in adolescents with JIA (Feinstein et al., 2011). Furthermore, the complex and unpredictable nature of JIA sets it apart from other chronic pain disorders, as it is characterised by high levels of fatigue as well as pain (Armbrust, Siers et al., 2016; Stinson et al., 2014). Moreover, the disease may cause sudden and unexpected inflammation of organs resulting in conditions such as uveitis, which causes partial or complete loss of vision (Angeles-Han et al., 2015; Consolaro et al., 2016; Rigante et al., 2015). Thus, the adolescent participants also had to learn to cope with unexpected, acute physical symptoms, which may explain the level of sophistication that they demonstrated when discussing their use of cognitive reappraisal strategies. Developing effective coping strategies enabled the adolescent participants to adapt positively to living with JIA.

6.4 Adapting Positively to JIA

Resilience processes may lead to positive or adaptive outcomes (Davis & Suveg, 2014; Masten & Monn, 2015) such as the attainment of developmental tasks and increased levels of subjective well-being (Wright et al., 2013). This study found that the adolescent participants seemed to be successfully negotiating the developmental tasks of forming an identity and developing autonomy. Furthermore, the adolescent participants described experiencing increased levels of subjective well-being as they adapted to living with JIA.

6.4.1 Negotiating Identity Formation in the Context of Living with JIA

Despite the challenges faced by the adolescent participants, the findings indicated that they were successfully negotiating the developmental task of forming a unique identity. The adolescent participants seemed to be grappling with finding a balance between accepting the illness while not being defined by it. The latter involved finding ways to integrate JIA into their developing identities. In this respect, the findings in this study are consistent with previous research findings that the degree of visibility of physical symptoms affects the way in which other members of society interact with an individual with a chronic illness and also affects the individual's choice to conceal or disclose their illness (Cartwright et al., 2014; Tong et al., 2012).

Recent research in the field of identity development in adolescents with a chronic illness has posited the concepts of health identity (Grabowski & Rasmussen, 2014) and illness identity (Luyckx et al., 2018; Oris et al., 2016, 2018). Health identity refers to the adolescent's observations, expectations, and knowledge of their own health, as well as the way in which their health compares to that of their peers. Illness identity refers to the degree to which a chronic illness is integrated into a coherent sense of identity (Luyckx et al., 2018; Oris et al., 2016, 2018). In this regard, recent research regarding young adults with epilepsy and adolescents with diabetes (Luyckx et al., 2018; Oris et al., 2016) supports a more nuanced understanding of adolescents' integration of JIA into their identity. In particular, four stages of integrating a chronic illness during the formation of identity have been theorised – namely, rejection, engulfment, acceptance, and enrichment (Luyckx et al., 2018; Oris et al., 2018).

To date, no research has been undertaken with regard to health identity and illness identity in the field of JIA. Although the concepts of health identity and illness identity were not specifically targeted in this research, the findings reflect these conceptualisations and suggest that health identity and illness identity are not mutually exclusive. The adolescent participants' use of self-regulatory strategies indicated that they were observing and monitoring their health throughout their daily activities. Moreover, they held expectations and knowledge about how their health was affected by JIA, and developed coping strategies to manage their levels of pain and fatigue. They also compared their health to that of peers and viewed themselves as less healthy. The data confirmed the findings of earlier studies (Luyckx et al., 2018; Leen Oris et al., 2016) as the adolescent participants seemed to be progressing through the four proposed stages of illness identity. Some participants initially described intense negative emotions when diagnosed with JIA, which suggests that they rejected the diagnosis. Furthermore, the period of disengagement and passive coping may indicate that, initially, their identities were overwhelmed by the diagnosis of JIA. Most of the participants appeared to be in the stage of accepting JIA as part of their identity, though to varying degrees. Finally, Rayne seemed to have incorporated JIA into her identity in a manner which provided enrichment. While the concept of illness identity was useful in assessing the degree to which the adolescent participants had integrated JIA into their identity, it does not take into account the differing levels of visibility or the severity of their physical limitations.

Even though the literature suggested that visible physical symptoms and restricted mobility would impact on the identity development of the adolescent participants, a surprising finding was that this was also the case when the symptoms were invisible. There are minimal studies (Brennan & Creaven, 2016; Dickson et al., 2007; Kool, Van Middendorp, Boeije, & Geenen, 2009; Masana, 2011; Nettleton, Watt, O'Malley, & Duffey, 2005; Parslow et al., 2017; Pederson, 2018) regarding the impact that invisible symptoms have on identity development in adolescents and children. In the present study, the adolescent participants with invisible physical symptoms described feeling marginalised and stigmatised by medical practitioners, family members, and peers. The lack of visible symptoms resulted, at best, in diagnoses of psychogenic illness and, at worst, in accusations of malingering. Furthermore, participants indicated that this marginalisation and stigmatisation resulted in low levels of self-esteem and negative self-concepts. Other than citing marginalisation as a result of invisible symptoms (Tong et al., 2012), there seems to be little research in the field of JIA on how the latter affects identity development.

Ursula was the only adolescent participant who referred to herself as disabled, and this was restricted to the four years that she spent using a wheelchair for mobility purposes. The other participants did not refer to physical disability, thus I was reluctant to incorporate disability identity theory into this discussion. My reasoning for not incorporating disability theory is discussed further in my reflections on the research process. However, Forber-Pratt et al. (2017) postulated that forming a disability identity requires the simultaneous negotiation of the physical disability and the social meaning of the disability. If one replaces the term “disability” with “illness”, then the same processes were identifiable in this study. The adolescent participants’ negotiation of the social meaning of their illness seemed to differ depending on the level of visibility of their physical symptoms. Individuals with visible physical symptoms seemed to receive increased levels of social support as their illness experiences were legitimised by the diagnosis of JIA and the visibility of their physical symptoms. They also received sympathy or pity, rather than empathy, which is in line with other research findings (McDougall, 2006; Tong et al., 2012). However, the adolescent participants with invisible physical symptoms endured long periods of time during which their illness experiences were not legitimised. While these adolescent participants did receive support and empathy from some individuals, they were often the recipients of disbelief and sceptical attitudes. Similar experiences are also reported in the literature regarding invisible illnesses (Dickson et al., 2007; Newton et al., 2013; Parslow et al., 2017).

All the adolescent participants appear to be engaged in similar processes of identity formation as their peer group. Indeed, the adolescent participants appear to be integrating JIA into their developing identities to differing degrees. This process of integration seems to involve balancing their acceptance of the disease with their resistance to being defined by it. Despite the challenges associated with JIA, the adolescent participants appear to be engaged in the developmental task of establishing a coherent sense of identity.

6.4.2 Qualitatively Different Opportunities for Becoming Autonomous

A key finding was that JIA may afford adolescents qualitatively different opportunities for becoming autonomous. Many studies regarding adolescents with JIA, chronic pain, or chronic illness, simply refer to autonomy as a developmental task to be negotiated or an outcome to be supported during adolescence (Leeman et al., 2016; McDonagh et al., 2016; Sällfors & Hallberg, 2009; Stinson et al., 2010; Turner-Cobb & Cheetham, 2016; Wilson, 2017). However, in their meta-analysis of research regarding adolescents with chronic illness, Pinquart and Pfeiffer (2015) reported that this group was less successful than their healthy peers in attaining developmental tasks, including becoming autonomous. In contrast, it seemed that the adolescent participants in the current study were becoming autonomous in qualitatively different areas, as well as in similar areas, to their peers.

Living with JIA may provide the adolescent participants with qualitatively different opportunities for becoming autonomous. The adolescent and parent participants described how the adolescents assumed control of their medication and treatment. They learnt to manage their medication, which in most cases required administering painful injections. Moreover, the adolescent participants demonstrated increased levels of emotional and behavioural autonomy as they overcame the negative affect associated with anticipation of the painful injection and the deleterious side effects of the medication. Similarly, some adolescent participants described being away from home for significant periods of time, which required them to manage their medication and treatments independently. It was noteworthy that the adolescent participants communicated that they became increasingly assertive with adults during medical consultations. In this regard, they began taking part in treatment decisions and redirecting the medical practitioners' queries away from their parents and to themselves. It should be emphasised that the adolescent participants' ability to learn to manage their emotional responses to continued pain and fatigue suggests a significant degree of emotional autonomy that may not necessarily be typical of the phase of adolescence. Furthermore, the adolescent participants learnt conflict management skills when misunderstandings arose regarding their illness experiences. In this regard, their decision to conceal or disclose their illness also suggests significant levels of independent decision making.

Furthermore, the adolescent participants were developing autonomy in areas typical of adolescence. In contrast to the findings by Pinquart and Pfeiffer (2015) that becoming autonomous was restricted by chronic illness, the adolescents described many areas of functioning in which they were indeed becoming autonomous. Certainly, they had to weigh up the consequences of attending social activities, and sometimes they made decisions in direct opposition to parental wishes. The adolescent participants chose which activities they wished to engage in, even if this meant accepting that they would experience pain and fatigue. Indeed, they continued to be involved in peer-related activities such as sport, drama, debating, and first aid. These participants also engaged in activities that might be regarded as typical of adolescence such as gaining part-time employment and learning to drive. Moreover, the adolescent participants were able to undertake strenuous but valued activities and manage the resultant pain and fatigue. The degree of autonomy displayed by the adolescent participants during typical adolescent activities may imply that earlier studies were overly focused on the deficits in the development of autonomy of adolescents with JIA. In this study, assuming a strengths-based approach has enabled a more balanced view of the risk and resilience processes involved.

This study has highlighted that living with JIA may facilitate the development of autonomy in different ways to those experienced by typically developing adolescents. However, it was also apparent that the adolescent participants expressed autonomy through similar activities as their peers. In sum, the data suggests that the adolescent participants are successfully negotiating the developmental tasks of independence and autonomy.

6.4.3 Experiences of Well-Being in Living with JIA

This study makes a valuable contribution to the existing body of literature in that it may be the first to explore how adolescents with JIA understand the concept of well-being in illness. A significant finding was that the adolescent participants felt that it was possible to experience well-being while living with JIA. The adolescent participants were able to reflect on how their understanding of well-being changed as a consequence of developing JIA. In addition, they were able to identify factors that increased their levels of subjective well-being; this may provide the basis for promoting the future use of strengths-based psychological interventions.

The data corroborated findings regarding well-being in adults (Diener et al., 2018), in that the adolescent participants described well-being in terms of increased levels of positive affect, decreased levels of negative affect, and a sense of satisfaction with life. The adolescent participants demonstrated a holistic understanding of well-being, and believed that it was possible for well-being to transcend illness, which reflects the findings of the study conducted by Ahanonu and Jooste (2016). Notably, the adolescent participants described how their understanding of well-being had changed since developing JIA. Well-being no longer meant being healthy but referred to times with lower levels of pain and fatigue and increased levels of positive affect. A significant finding was that most of the adolescent participants differentiated between physical and psychological well-being. This finding is also reflected in the study by Ahanonu and Jooste (2016), who found that the adolescent participants differentiated between physical, psychological, and spiritual well-being. The adolescent participants in this study reported that psychological well-being was a state of mind in which they were absorbed by the enjoyment of the present moment. Furthermore, the adolescent participants described a reciprocal relationship between psychological and physical well-being. They contended that they were able to reduce their levels of pain by engaging in activities that increased levels of positive affect. Further research regarding the process of this changing understanding of well-being during chronic illness may highlight factors that optimise resilience and well-being. In addition, future research that provides a more nuanced understanding of the reciprocal relationship between psychological and physical well-being in adolescents with JIA may enable the development of interventions specific to JIA.

A valuable insight was that the adolescent participants described feeling that a sense of well-being in illness was possible, especially when their focus was on pleasurable activities such as socialising with peers, rather than the symptoms of illness. This finding is consistent with that of Casier et al. (2013) who also reported that when chronically ill adolescents engaged in activities that provided personal meaning, their sense of well-being was optimised. However, in the current study the adolescent participants noted that the sense of well-being they gained may be dependent on their health status at the time. A further valuable insight communicated by the adolescent participants in this study was that positive relationships with family and friends promoted their sense of well-being. This confirms studies which have reported a strong correlation between social support and higher levels of positive affect during times of adolescent crisis (Ahanonu & Jooste, 2016; Casier et al., 2013; Ronen et al., 2016). Thus, the findings of this study have extended the current body of literature on JIA with regard to factors that may optimise a sense of well-being in adolescents with JIA. Given that individuals with JIA often feel socially isolated, these findings suggest that interventions that increase social engagement may facilitate positive adaptation to JIA.

The following section provides a reflexive analysis of how my role as researcher may have affected the research process.

6.5 Reflexive Analysis Regarding the Research Process

Reflexivity can be defined as the "the use of a critical, self-aware lens to interrogate both the research process and our interpretation or representation of participants' lives in our social world" (Finlay, 2017, p. 120). Essentially, it entails making the researcher visible in the research process (Braun & Clarke, 2013; Willig, 2013). Reflexivity is integral to experiential qualitative research as it provides a critical element of quality control by making explicit how the background and experiences of the researcher affect the research and vice versa (Braun & Clarke, 2013; Finlay, 2017; Shaw, 2010; Willig, 2013). Willig (2013) argues that reflexivity can be personal, whereby the researcher's identity and experiences are made evident in the research process, or epistemological, in that attention is given to the underlying assumptions that the researcher holds about knowledge. Similarly, Mao, Akram, Chovanec, and Underwood (2016) describe reflexivity as a spiral which starts with the positioning of personal identities and experiences, then making explicit how these underpin the research process from choosing methodologies and methods, to collecting data and analysing findings. Indeed, Yin (2014) warns that reflexivity is crucial when conducting case study interviews as the researcher's perspective can inadvertently influence the participant's responses, which in turn influences the line of inquiry. Likewise, Braun, Clarke, and Rance (2014) stress the importance of functional reflexivity when conducting thematic analysis, as the researcher makes active choices during the analysis of data and the generation of results. Furthermore, when the research involves sensitive topics that may affect the researcher's emotions and values, then reflexivity can protect the emotional well-being of the researcher (Malacrida, 2007). The following paragraphs will outline important facets of my reflexive processes.

Positioning myself as the researcher requires clarifying my identity, experiences, biases, and assumptions (Braun & Clarke, 2013; Finlay, 2017; Gemignani, 2017; Palaganas, Sanchez, & Molintas, 2017). However, Finlay (2017) emphasises the importance of explaining *how* my identity and experiences affected the research process. As described in Chapter 1, I am personally, professionally, and academically invested in this research. I developed an inflammatory, auto-immune, arthritic disorder which has resulted in me taking a professional interest, as an educational psychologist, in working with children and adolescents who have chronic illnesses and auto-immune disorders. Consequently, I have worked with individuals who have JIA, and it became apparent how health care professionals who work with children are not aware of the disease and its pervasive challenges to normative development. My initial readings on JIA as a psychologist, combined with knowing how difficult it was to come to terms with and manage my own illness, made me curious about how adolescents experienced and managed JIA. This curiosity fuelled my choice of research topic for my doctoral research.

My identity as a white, middle-class, English-speaking woman meant that I was able to identify with the participants from a broad cultural perspective, as all of the participants were white, middle-class, and English-speaking. Similarly, being of a Christian background, while having a sister who embraced Judaism, meant that I could relate to the participants on a religious and spiritual level. In particular, I found that my familiarity with Jewish culture facilitated discussion around the spiritual, religious, and cultural aspects of the Jewish participant's experiences. Furthermore, I was aware of the importance of certain social experiences that form part of Judaism, such as becoming Bat Mitzvah and attending the annual Bnei Akiva camp, which added depth to my understanding.

However, not having had children meant that I did not relate to the parent participants from a position of being a mother, but rather as a professional within the fields of education and psychology. Moreover, I have worked with adolescents for over 30 years, both as a teacher and as a psychologist, and I am used to assuming a more authoritative, knowledgeable role with parents and adolescents. Thus, it was essential to be aware of any underlying power dynamic (Anyan, 2013; Haverkamp, 2005; Kvale, 2007; Medico & Santiago-Delefosse, 2014) that may have occurred from being perceived as, and acting as, an “authority”. I took the time to position myself in the interviews as a “curious observer” rather than a “knowledgeable professional” (Haverkamp, 2005; Rhodes & Carlsen, 2018). By assuming this stance I became a “learner” in pursuit of understanding the experiences of the adolescent and parent participants (Rhodes & Carlsen, 2018). In order to become a learner, one of my earliest decisions was to dress informally for the interviews and to refer to myself as a student. In addition, I attempted to redirect comments and questions made to my “professional self” back to the experiences of the participant. Furthermore, the interviews took place in the participants’ homes, not only for physical and emotional comfort, but also to balance power inequities. I felt that I had succeeded in addressing the power dynamics during the interviews, as participants disclosed very personal and emotional experiences, and I was careful to treat these disclosures with respect. In order to balance the participants’ emotional vulnerability (Rhodes & Carlsen, 2018) with generous reciprocity, I ensured that I remained open to learning from the participants rather than privileging my own knowledge.

Functional reflexivity was undertaken by keeping a research journal to record decision making, internal dialogue, and critical reflections during the research process (Jootun, McGhee, & Marland, 2009; Lamb, 2013a, 2013b). In addition, the research supervisors provided feedback that engendered critical reflection on my choice of paradigm, methodology, and method, and also on the readings forming part of the literature review. While interviewing the participants, continual reflection ensured that the interviews were flexible and centred on what was important to the participant, as well as covering areas of focus identified during the literature review. My training and experience as a psychologist enabled me to conduct the interviews in a manner that engendered rapport. Consequently, in the second round of interviews, the adolescent participants shared very sensitive personal experiences. Indeed, following the participants' lead in the interviews gave rise to rich, unanticipated findings such as pain dismissal and witnessing traumatic events in hospital. Given the personal nature of the information shared, and the vulnerability of the adolescent participants, I remained aware that at any given moment it was possible that emotional harm might be done in the interview process (Haverkamp, 2005). Thus, I remained vigilant about monitoring the body language of the participants throughout the interview process. I also remained cognisant of my role as researcher, rather than psychologist, to ensure that I did not unintentionally become involved in therapeutic processes.

During the data analysis phase, I became aware of my biases and areas of emphasis as a result of my own illness, particularly regarding the lack of awareness of auto-immune disorders amongst medical professionals and the length of time it takes to be diagnosed. My increased awareness of my own agenda resulted in the decision to have the transcripts coded by an external auditor in order to balance my perceptions. Furthermore, during the writing up of the analysis and findings, I asked myself questions such as "How do I know this?" to ensure that the findings represented the experiences of the participants rather than my own biases. Finally, my research supervisors consistently queried areas that appeared unbalanced or lacking in substantiation.

As mentioned previously, during the analysis phase I grappled with my emotional responses to the participants' negative experiences with medical practitioners as well as the effect that this had on their psychological functioning. Certainly, my responses were grounded in my own experiences of being dismissed and disempowered and my perception that medical practitioners should hold themselves accountable for managing the diagnostic process. My research supervisors' critical feedback enabled me to re-engage with the data, which resulted in a more nuanced understanding of the participants' experiences. Furthermore, these findings were presented to a professor of paediatric rheumatology who served as a critical reader and deemed them a fair reflection of the experiences of individuals with JIA. Thus, the final analysis presented a balanced view of the participants' positive and negative experiences within the medical system, rather than privileging my voice.

I also grappled with using disability terminology when referring to the adolescent participants' physical limitations. Only one adolescent participant had referred to herself as being disabled, and this was only used in connection with a finite, four-year period. Thus, in the spirit of ethical vulnerability and generous reciprocity (Rhodes & Carlsen, 2018), I was reluctant to use this term as it seemed to prioritise my professional knowledge over participants' personal experiences. Moreover, I was concerned that a participant may read this dissertation and experience emotional distress when reading the term “disability”. Ultimately, I decided not to use the term “disability” and rather used the terms “activity limitations” and “participation restrictions”. In this manner, I felt that I had honoured the participants' own understanding of their experiences and adhered to the principle of non-maleficence.

The experiences shared by the adolescent and parent participants drained me emotionally as I maintained authentic engagement and rapport. I realised that, while it was necessary to remain authentic, I also needed to care for my emotional well-being (Bowtell, Sawyer, Aroni, Green, & Duncan, 2013). I shared my emotional stress with the main supervisor and it was decided that I would seek debriefing from a fellow psychologist without breaking the confidentiality of the research process. I also realised on the first day of interviews that it was necessary to limit the number of interviews per day, in order to prevent researcher saturation and burnout (Bowtell et al., 2013). These steps facilitated my authentic engagement with and continued openness to the experiences of the participants in an emotionally safe manner.

Engaging in personal and functional reflexivity throughout the research process ensured that my findings honoured the voices of the participants. Furthermore, I have attempted to delineate how my background and experiences may have affected the research process.

6.6 Conclusion

In summary, this chapter discussed the transactional nature of living with JIA. The biological symptoms generated by the disease resulted in a cascade of biopsychosocial transactions that affected the normative development of the adolescent participants and placed them at risk for maladaptive trajectories. However, over time, resilience processes which seemed to enable the adolescent participants to adapt positively to living with JIA developed. This chapter has made a substantial contribution to the body of literature by explicating the processes of risk and resilience in adolescents with JIA. Moreover, the findings suggest that, despite the multisystemic challenges presented by JIA, the adolescent participants were successfully negotiating the developmental goals of establishing a coherent identity and becoming autonomous. In addition, they experienced periods of well-being despite the chronic nature of JIA. Insights were provided regarding the adolescent participants’ understandings of well-being while living with JIA as well as factors that optimised their sense of well-being. Finally, through writing a reflexive analysis, my role as researcher was made visible in the research process of this study.

CHAPTER 7: CONCLUSION

7.1 Introduction

The value of a study lies in its rigorous research process (Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017; Morse, 2015; Trainor & Graue, 2014) as well as its contribution of original knowledge to the field (Levitt et al., 2017; Tracy, 2010; Trainor & Graue, 2014). Accordingly, this concluding chapter revisits the research aims of this study and critically reviews the strengths and limitations of the study by applying the eight criteria found in Tracy's (2010) model of excellent qualitative studies. Thereafter, the significant contributions of the research are presented, and recommendations for future research and practice are made.

7.2 The Research Aim Revisited

Producing an excellent study begins with the selection of a noteworthy topic that is relevant, timely, significant, interesting, and/or evocative (Tracy, 2010). This study pioneers psychological and developmental research in the field of JIA in South Africa, as it is the first non-medical research of its kind to be undertaken in the country. Despite a conservative estimate of 18,700 children being affected with JIA in South Africa (Weakley & Scott, 2012), JIA has been a neglected area of research. Given the debilitating nature of JIA and the possibility of early mortality as a result of complications and side effects, research in this field is clearly relevant to the needs of South African children with JIA. Moreover, the findings of this study will be of benefit to their families and the medical practitioners who support them. Thus, this exploratory study aimed to explore and describe the psychosocial experiences of South African adolescents with JIA. Rich, thick descriptions of their experiences and understandings of JIA were sought from seven adolescents with JIA and their parents. The transactions that occurred within and between the multiple systems were identified and processes of representation and regulation were examined. Consequently, new risk and resilience processes came to the fore. In addition, the processes involved in positive adaptation to living with JIA were explored in depth, which provided a nuanced understanding of the adolescent participants' evolving coping strategies. Finally, new insights regarding the adolescent participants' understanding of well-being while living with JIA were captured. The new insights that emerged from this study indicate that there is a need for both international and specifically South African qualitative psychological research that explores both the risk and resilience factors that impact on adolescent experiences of JIA. More specifically, an exploration of adolescents' understandings of their adaptive processes and the possibility of well-being in illness is needed.

7.3 Critical Review of this Study

7.3.1 Strengths of the Research Design

Establishing meaningful coherence and rich rigour is crucial for producing research of high quality (Tracy, 2010). One of the strengths of this study is its carefully constructed research design, which ensured that the choice of research approach was compatible with the research problem and would generate meaningful answers (Bloomberg & Volpe, 2012; Tracy, 2010). Moreover, the research paradigm, methodology, and methods used were meaningfully coherent. By choosing to situate the study within a constructivist-interpretivist paradigm, I facilitated the acquisition of multiple subjective interpretations (Malterud, 2016; O'Neil & Koekemoer, 2016) of the adolescent and parent participants' experiences while retaining the complexity thereof. Also, qualitative methodology strives to apprehend and interpret subjective experience within contextual meaning (Brannen, 2004) which means that it is well-matched to studies that explore developmental and resilience processes (Reynolds, 2017; Rutter, 2013a; Sullivan, 1998). By using a case study approach, I was able to elicit a variety of perspectives which facilitated my understanding of the complex social phenomenon of living with JIA. In addition, developmental psychopathology theory aims to understand the complexities of a phenomenon through the use of a multisystemic framework that incorporates the transactions within and between the biopsychosocial systems. Thus, utilising a developmental psychopathology framework enables the findings of this study to be integrated into the current body of knowledge regarding JIA in its totality in a conceptually effective manner.

Furthermore, the innovative use of a dynamic, twofold data analysis was valuable in the iterative process. The data analysis was comprised of a multisystemic analysis and a thematic analysis. The multisystemic analysis ensured that a holistic view of the data was taken, thus allowing for a broad understanding of the data. This understanding was complemented by the thematic analysis, which allowed themes within the data to come to the fore through a recursive process. Thus, the twofold, dynamic data analysis thwarted an overly-restricted view of the data and enabled me to retain and reflect the participants' unique experiences.

Credibility is another characteristic of excellent qualitative research identified by Tracy (2010). To enhance credibility, this study provided rich, thick descriptions from multiple data sources and used multiple theoretical lenses during the analysis process. The small sample of seven adolescent-parent participant dyads allowed for each case to be studied in great detail. Also, selecting adolescent participants in the developmental stage of middle adolescence, combined with the criterion that their illness had been controlled for six months or longer, enabled them to share rich descriptions of their experiences. By interviewing the parents of the adolescent participants, it was possible to confirm findings as well as gain a deeper, more nuanced understanding of the same experiences. Furthermore, the semi-structured nature of the interviews ensured that I remained focused on the parameters of the research topic, but simultaneously allowed for flexibility and openness to unanticipated data. Also, interviewing the adolescent participants twice allowed me to verify my understanding of the first interview and follow up on areas that required further clarification. Thereafter, the interview transcripts were checked by the participants to ensure that they reflected their experiences. Furthermore, the audio recording of the interviews enabled me to reflexively re-engage with the original data and verify the accuracy of the transcriptions.

The consideration of ethical factors is central to the research process and requires more than simply implementing procedural ethics (Levitt et al., 2017; Mitchell, Boettcher-Sheard, Duque, & Lashewicz, 2018; Tracy, 2010). In Chapter 4, I outlined in depth the ethical considerations that I grappled with while designing and preparing for this study; these included situational, relational, and exiting ethics. A further area of ethical consideration was that of ethical vulnerability as described by Rhodes and Carlsen (2018). The adolescent and parent participants expressed that they valued the research being undertaken. Consequently, the participants endeavoured to provide thick, rich descriptions of their experiences and were willing to share very personal thoughts and emotions. Moreover, the adolescent participants showed significant insight and self-reflection, which allowed for a rich, nuanced understanding of their experiences. In order to respect their vulnerability, I adopted the stance of "not knowing" rather than positioning myself as an expert. Assuming this stance allowed me to respect and honour their experiences as they were conveyed, rather than subsuming them with my own interpretations. Rhodes and Carlsen (2018) note that ethical vulnerability and the teaching of the other is not about generating knowledge per se, but rather about affective engagement whereby the researcher is susceptible to the uniqueness of the participant and can move beyond her own frame of reference. Indeed, generous reciprocity emphasises respecting the participants' uniqueness and ability to reflect on their own experiences. By engaging with the participants rather than viewing them as sources of data, I established rapport and honoured the distinctiveness of their individual journeys.

The characteristics of resonance and sincerity play a vital role in conducting a study of high quality (Tracy, 2010). With regard to resonance, the rich, thick descriptions contained in this study are likely to produce an empathetic response in the reader. Furthermore, my personal experience in having an inflammatory arthritis disorder meant that I understood the medical terminology used by the participants and that I could relate to certain aspects of the adolescent participants' accounts, particularly regarding their levels of fatigue and pain. This insight enabled me to build rapport with the participants, informed my follow-up questions, and assisted in interpreting the data. Consequently, I was able to garner evocative descriptions of their experiences that may promote empathy in the reader. Such empathy could, in turn, lead to improved medical and psychological practice. I strove to attain sincerity through engaging in self-reflexivity and being transparent about the methods used and challenges experienced. From the outset of this study, I portrayed my interest in this topic in an honest and transparent manner. Moreover, as described in Chapter 6, I took care to engage in reflexive processes when negotiating access to the participants and collecting and analysing the data. The challenges encountered in this study are presented in the following section.

7.3.2 Limitations of the Study

The strengths of a research design inevitably inform its limitations, as each methodology has inherent philosophical and methodological strengths and weaknesses. Although the research design of this study was carefully and rigorously planned to provide meaningful coherence and rigour, it is essential to demonstrate my awareness of the limitations of this study and their influence on my interpretation of the findings. In this study there were limitations in the lack of previous studies regarding JIA in South Africa, the broad research aim, and the sample.

In accordance with a case study design, the sample size of this exploratory study was deliberately small to facilitate detailed descriptions (Saldaña, 2011; Silverman, 2013; Yin, 2014). However, the challenges inherent in accessing this vulnerable population resulted in a homogenous sample of white, middle-class participants. This homogeneity was, however, counterbalanced by a certain level of cultural diversity that maintained richness of data. Furthermore, although a homogenous sample facilitates transferability to similar populations and is preferable when exploring the experiences of participants (Kornbluh, 2015b), this study is not representative of the South African population. Consequently, the inclusion of participants from diverse cultural groups and socio-economic backgrounds may have provided a greater variety of experiences and enhanced the richness of the study.

Furthermore, the data sources were limited to the adolescents and their parents. It was beyond the scope of this study to gain the perspectives of significant others who interacted with the adolescent participants. Nonetheless, gaining insight into the perspectives of the medical practitioners, peers, and other family members of the adolescent participants would have deepened my understanding of the complexities involved in living with JIA. However, including the parent participants in the study did provide an invaluable source of data that contributed to my depth of understanding of the psychosocial experiences of adolescents with JIA.

The scope of the literature review also presented challenges. A database search revealed that, to date, psychological studies regarding individuals with JIA have not been conducted in South Africa (NREPP, Cochrane Database of Systematic Reviews, Campbell Systematic Review, EBSCOHost and PsycInfo databases, 24 January, 2019). This being the first study in South Africa in this field, it was not possible to critically compare the findings to those of other studies. Similarly, there were minimal international studies regarding resilience processes and subjective well-being in the field of JIA. Furthermore, there was scant psychology literature that explored this topic from the perspective of adolescents, or that assumed a multisystemic approach. However, a critical discussion of the literature in the fields of child and adolescent chronic illness and chronic pain was engaged in. The review of literature was based on a limited number of studies, and consequently it was not possible to present a complete understanding of the psychosocial experiences of adolescents with JIA. Instead, this study provides a foundation on which future international and South African studies in this field can built.

The last of Tracy's (2010) eight criteria for excellent qualitative research is that of making significant contributions to the current body of knowledge in a particular field of research. The significant contributions made by this study will be summarised in the following section.

7.4 Significant Contributions of this Study

The coherent, rigorous research design has given rise to findings that contribute significantly to current bodies of international literature in the fields of JIA and developmental psychopathology theory. The use of a developmental psychopathology framework was an innovative conceptualisation that, heretofore, has neither been applied to the field of JIA nor has it featured substantially in the field of chronic illness. Furthermore, as researchers utilising the theory of developmental psychopathology have made little foray into the realm of physical illness, this study has extended the existing body of literature. Viewing transactions through the lens of representational and regulatory processes highlighted the critical role played by medical practitioners and significant adults in optimising the adolescent participants' adaptation to living with JIA. Indeed, using the developmental psychopathology framework brought to light new findings in the field of JIA, which will be presented according to the main themes.

The theme of *multisystemic risk processes* identified six areas of risk that were experienced by the adolescent and parent participants. These processes constitute significant findings as interventions in these areas may enhance positive adaptation to living with JIA. A notable finding was that the *limited social awareness of JIA* resulted in less social support than might be garnered by other serious childhood illnesses such as cancer. Consequently, the adolescent and parent participants felt marginalised and unsupported. Furthermore, there was a high degree of scepticism regarding the adolescents' illness experiences, particularly when there were no visible signs to indicate pain. The absence of visible symptoms led to the *lack of illness validation and dismissal of pain* by family members, friends, and medical practitioners. Illness invalidation and pain dismissal, in turn, regulated the adolescent participants' behaviours and at times resulted in maladaptive coping strategies.

It is noteworthy that the length of *time taken to diagnosis* varied as a result of the limited awareness regarding JIA within the medical system, with some adolescent participants experiencing symptoms for almost a decade prior to receiving the diagnosis of JIA. Moreover, it was apparent that a delayed diagnosis resulted in increased levels of negative affect, decreased levels of self-esteem, and maladaptive coping strategies. However, a valuable finding was that medical practitioners who were aware of inflammatory disorders facilitated earlier diagnoses and adaptive trajectories of development. Of great import was the need for guidelines when *delivering the diagnosis* so that individuals and their families are emotionally contained and receive psychoeducational support following the diagnosis.

A significant risk process that has not been previously identified in the body of literature in the field of JIA was *anxiety-provoking medical experiences*. The adolescent participants' inadvertent exposure to traumatic experiences during hospitalisation, the side effects of medication, and experiencing emotionally distressing treatments seemed to give rise to PMTS symptoms. It was apparent from the data that most of the adolescent participants were not receiving psychological support for their experiences. These important findings emphasise the need for medical practitioners and parents to be aware of the possibility of traumatic stress symptoms so that the necessary psychological support can be provided.

Furthermore, a valuable observation was the *dis/empowering relationships with medical practitioners*. Poor practitioner communication skills, prioritising practitioner knowledge over that of the adolescent and parent participants, and assuming that an illness was psychogenic in origin not only disempowered the participants but also resulted in inappropriate treatments, delayed diagnoses, and emotional distress. In addition, the need for developmentally appropriate consultations with scheduled private time with the medical practitioner was indicated.

The second theme, *resilience processes*, described how the participants moved from passive coping strategies, such as isolating themselves socially and denying their illness, to adopting accommodative and active coping strategies. A noteworthy finding was how the adolescent participants' initial *passivity evolved into a sense of agency* which enabled them to develop the strategies needed to cope with the challenges of their illness. The adolescent participants closely *monitored physical and social activity* through self-regulation strategies to manage their biopsychosocial functioning. A particularly surprising finding was the degree to which the adolescent participants continually *balanced the cost and benefit of activity*. Furthermore, the extent to which adolescent participants used *step-by-step approaches to negotiate* *daily living* with JIA was unanticipated. The latter seemed to be particularly necessary during flare-ups. Adolescent participants described compartmentalising the day into small sections that they could better manage during these times of increased symptom intensity. In this manner, the adolescent participants were able to engage in some activities of daily living even when they did not have the requisite levels of energy to participate throughout the day. Of great import was the sophisticated level of cognitive reappraisal techniques used to *monitor emotions and thoughts* during flare-ups and times of stress. Moreover, it was apparent that the adolescent participants understood the reciprocal transactions between their physical symptoms, cognitions, and affect.

The third theme, *adapting positively to JIA,* explored the outcomes of the resilience processes involved. Of great significance, and contrary to the majority of literature, was that the adolescent participants seemed to be successfully negotiating the developmental tasks of forming an identity and developing autonomy. Furthermore, they described experiencing increased levels of subjective well-being as they continued to adapt positively to living with JIA. Notably, the adolescent participants seemed to be successfully *negotiating identity formation in the context of living with JIA.* They seemed to be grappling with finding a balance between accepting the illness while not being defined by it, which involved integrating JIA into their developing identities. In this respect, the degree of visibility of the physical symptoms affected the way in which other individuals interacted with adolescent participants as well as their choices to disclose or conceal their illness. A noteworthy discovery was that JIA might provide *different opportunities for becoming autonomous* in comparison to those utilised by typically healthy peers. Also, although JIA does provide challenges to the development of autonomy, the adolescent participants in this study appeared to be developing autonomy in similar areas to that of their healthy peers. Another significant finding was that the adolescent participants were able to *experience well-being while* *living with JIA*. Moreover, this study may be the first to explore how adolescents with JIA understand the concept of well-being in illness. The adolescent participants reflected that their understanding of well-being had changed as a consequence of developing JIA. Well-being now referred to days with reduced levels of pain and fatigue and increased levels of positive affect and life satisfaction. Notably, they also identified factors that increased their levels of subjective well-being.

In the preceding discussion, important research findings that were identified in this study have been summarised. These significant contributions and a critical review of this study form the basis of the recommendations for future research and practice.

7.5 Recommendations for Future Research and Practice

Recommendations for future research and interventions need to be guided by the needs of the individuals with JIA as well as their carers and medical practitioners. Indeed, Schoemaker et al. (2018) are in the process of developing a Dutch research agenda for JIA in which patients, carers, and clinicians collaborate to ensure that future research addresses areas of need. Although the participants in this study were not specifically queried about their research priorities, they did emphasise certain areas that they considered to be particularly challenging when living with JIA. Consequently, I have attempted to prioritise these recommendations for future research and interventions in accordance with the needs expressed by the adolescent and adult participants. Thereafter, I reflect further on interventions that may be beneficial in supporting individuals with JIA and their families.

Perhaps the most pervasive challenge described by the adolescent and parent participants was the low level of social and medical awareness regarding JIA, which appeared to impact on the degree of support provided in multiple systems. Accordingly, increasing medical and social awareness may be a significant resilience process that improves the well-being of many individuals with JIA in South Africa. To achieve this, advocacy needs to take place at an institutional level to create more awareness within the medical system through undergraduate and postgraduate training. Providing continuous professional development courses may facilitate the development of awareness in South Africa regarding diagnosing and treating JIA. Paediatric rheumatologists situated in university clinics may be ideally placed to advocate for improved training in this regard. Increasing social awareness may be more challenging and may require intervention at a government level. However, it may be possible to mobilise greater awareness through organisations such as Arthritis Kids South Africa. Furthermore, awareness programmes could be conducted at a local level, such as at the schools where there are individuals with JIA.

A second critical area of significance raised by the participants was that of relationships with medical practitioners. Further research regarding the dynamic, reciprocal relationships that exist between medical practitioners, adolescents, and parents may facilitate a more nuanced understanding of the risk and protective factors involved. While medical practitioner-adolescent relationships have been researched in the fields of adolescence (Han et al., 2018; Klostermann et al., 2005) and adolescent chronic illness (Beresford & Sloper, 2003; Britto, 2004; Dickinson et al., 2006; Van Staa et al., 2011), little attention has been given to the field of JIA. Given the unpredictable nature of the disease, further psychological research may reveal factors in the relationships between medical practitioners, adolescents, and families that are specific to JIA. In addition, such research could be extended to children as well as adolescents in order to generate developmentally appropriate communication guidelines for medical practitioners. This recommendation is supported by international studies with regard to JIA (van Dijkhuizen et al.,

2018) and chronic illness (Han et al., 2018; Kim & White, 2018; Siembida & Bellizzi, 2015; Wilson, 2017).

Furthermore, communication guidelines for medical practitioners should also include protocols for the effective and compassionate communication of a diagnosis of JIA. Existing protocols such as SPIKES and PEWTER have been adapted to the fields of oncology, ophthalmology, and schizophrenia (Bumb et al., 2017; Dean & Willis, 2016; Hilkert et al., 2016; Konstantis & Exiara, 2015; Seeman, 2010; Seifart et al., 2014). Thus, it should be possible to adapt these protocols in a developmentally appropriate manner for use in the field of JIA. Indeed, Chausset et al. (2016) have called for protocols to guide the delivery of the diagnosis of JIA in order to improve the support provided to both parents and their children. Chausset et al.'s (2016) suggested process for breaking the news of a JIA diagnosis includes eight key points that cover providing information about the aetiology and trajectory of JIA, re-engaging local support such as general practitioners, providing ongoing education, and ensuring that there is psychological support for the parents, child, and sibling(s). Further research in South Africa could build on this preliminary study and provide a model that takes developmental and cultural factors into account.

Linked to the recommendation for developmentally appropriate communication, is the need for developmentally appropriate facilities and services for adolescents with JIA. Indeed, internationally there is growing recognition that developmentally appropriate health care is required to meet the biopsychosocial needs of adolescent patients (M. Edwards et al., 2016; Farre et al., 2015, 2016). It was evident that adolescent participants were placed in adult oncology and psychiatric wards, which is problematic because adolescent patients have different psychosocial needs to those of adult patients (M. Edwards et al., 2016). Ensuring quality care for adolescent patients may require the establishment of developmentally appropriate wards for adolescents, as well as staffing them with medical practitioners who understand this developmental stage (Farre et al., 2015). In South Africa, developmentally appropriate wards for adolescents are scarce. Certainly, South African research has indicated the need for developmentally appropriate wards for adolescent patients (P. Smith et al., 2018; Stefan & van der Merwe, 2008). Thus, further research is needed in South Africa regarding the implementation of health care services that meet the developmental needs of adolescents. Furthermore, in line with the recommendation made by P. Smith et al. (2018), it is advocated that medical practitioners who work with adolescents should receive further training regarding the psychosocial needs of adolescents.

While the recommendations presented in the preceding discussion have prioritised interventions that arose from the participant interviews, further areas for intervention were identified in the data. Recent international studies continue to focus on risk factors (Feinstein et al., 2018; E. Fisher et al., 2017; McKillop & Banez, 2016). While this study encountered similar risk factors to those reported internationally, it is possible, even likely, that research regarding lower socio-economic and previously disadvantaged groups in South Africa may identify new risk factors and processes. Certainly, Scott and Webb (2014) noted that in developing countries, such as South Africa, individuals with JIA also experience comorbid factors such as poverty, malnutrition, and exposure to infectious diseases. Future research and practice should ideally be informed by the values of critical community psychology, including that of promoting social justice, human rights, and empowerment amongst individuals with JIA. Such research may lead to interventions that could mitigate risk processes.

Of great concern is that children and adolescents with JIA appear to be marginalised and discriminated against by the South African health care system. South African studies have reported that national resources are focused on combating diseases with high mortality rates, such as cancer and HIV. This focus on high-mortality diseases has resulted in inadequate health care planning and budgeting for JIA at a national level (Scott & Webb, 2014; Weakley et al., 2011). Given that a conservative estimate of the prevalence of JIA in South Africa is 18,700 cases, a large portion of the children in South Africa do not have access to appropriate, affordable, efficient health care services and are most likely not receiving optimal treatment. Even the adolescent participants in this study, who were from a middle-class socio-economic background and had the resources to access private health care, experienced the diagnostic process as less than efficient and often delayed. Accordingly, future research and health care services targeting individuals with JIA would do well to be informed by the values of critical community psychology, including that of promoting social justice, human rights, and empowerment. Future research and interventions with individuals with JIA and their families at local and international levels would ideally be transformative, participatory, and critically reflexive in nature. As changes need to be implemented at a national level, further research will likely require a combination of quantitative research to provide statistical data, as well as qualitative research to ensure that the voices of individuals with JIA and their families are privileged.

A significant finding of this study which requires further research is the adolescent participants' reports of experiencing possible PMTS symptoms. Both qualitative and quantitative studies would be of value to the current body of knowledge. International studies have tended to explore PMTS symptoms (Holley et al., 2016; Nancy Kassam-Adams & Butler, 2017; National Child Traumatic Stress Network, 2017; Price et al., 2016) and the need for psychological interventions (Bergeron, 2017; Hoysted et al., 2018). Similar studies may contribute to our understanding of experiences within the South African medical system that may cause or exacerbate PMTS symptoms. In addition, such studies may develop interventions to prepare paediatric patients before potentially distressing interventions, as well as to provide trauma debriefing after traumatic incidents. The possibility and merits of psychologists, social workers, or counsellors being attached to South African paediatric and adolescent wards or units could also be explored. Furthermore, such research may inform the establishment of developmentally appropriate units or wards for adolescents, rather than placing them in adult wards.

Notably in this study, the adolescent participants described developing agency and coping strategies as they adapted to living with JIA. Further exploration of how individuals with JIA adapt positively may enable the development of strengths-based counselling programmes. An international review study that will investigate which resilience processes are linked to enhanced quality of life and well-being in multiple systems of children with JIA has been proposed (Saetes et al., 2017). Similar studies that may provide insight into culturally specific, as well as universal, resilience processes could be conducted in South Africa. In particular, Cousins et al. (2015) recommend including participants who experience pain but who do not suffer from pain as this line of inquiry might reveal novel coping strategies and resilience processes. By identifying specific resilience processes, it may be possible to design interventions that target these processes and optimise positive adaptation to JIA (Saetes et al., 2017). In particular, this study indicated that the adolescent participants developed high levels of self-regulation in comparison to their healthy peers in order to function optimally. The possibility of enhancing self-regulation as an approach to managing chronic illness was also raised by Lansing and Berg (2014), which suggests that this may be a promising avenue for future research and intervention.

One of the findings of this research was that the adolescent participants' understandings of well-being included increased levels of positive affect, decreased levels of negative affect, and a sense of satisfaction. Furthermore, they were cognisant of the relationship between their physical and emotional well-being, and they were able to use cognitive reappraisal strategies to optimise their well-being. Accordingly, therapeutic interventions which harness these findings may be effective in optimising well-being when living with JIA. In this regard, Neff's conceptual model of self-compassion (Neff, 2003; Neff & Germer, 2017) might be a worthwhile avenue to explore. Indeed, the findings of this study resonate with those of a recent study regarding adolescent perspectives on self-compassion (Klingle & Van Vliet, 2017). Strategies such as "putting oneself at the center, maintaining a positive outlook, engaging in pleasurable activities, connecting positively with others, working on self-improvement, making oneself attractive to others, accepting oneself, and experiencing emotional balance" (Klingle & Van Vliet, 2017, p. 1) are similar to the cognitive reappraisal strategies described by the adolescents in the current study. Moreover, self-compassion interventions have been found to reduce inflammatory responses in individuals after they have been exposed to psychosocial stress (Neff et al., 2018). This finding is significant given that the adolescent participants with JIA noted that stressful experiences increased the likelihood of a flare-up. Further research that investigates the application of self-compassion or other mindfulness-based interventions seems warranted.

7.6 Conclusion

This study has made valuable contributions to psychological research in the field of JIA both in South Africa and internationally. Not only has this study provided an initial foundation for further research in South Africa, but it has also attempted to present the complexity of the multisystemic transactions that are involved in living with JIA. Both of these aspects of this study make significant contributions to the current body of knowledge in the fields of psychology, JIA, adolescent development, and developmental psychopathology. Notably, this study also adds to the existing body of literature in the field of resilience theory, particularly with regard to the processes of resilience during adolescence. Finally, this study has also presented adolescents' understandings of subjective well-being when living with a chronic illness such as JIA, and thus contributes to the field of adolescent well-being.

Aside from the contributions to the existing literature, this study was found to be valuable to the adolescent and parent participants. The research process enabled the participants to reflect on their personal experiences in a manner that encouraged the realisation of their strengths and personal growth. As such, the research process benefitted the well-being of the participants. In addition, this study is valuable to me on personal, professional, and academic levels, and has encouraged me to work further in this field. Certainly, I hope that future research will build on these findings to optimise resilience processes and the subjective well-being of individuals with JIA.

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[5] The published article includes the incorrect placement of the apostrophe in "patient's" to indicate a plural possessive noun.

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APPENDICES

APPENDIX A: Ethical Approval from the University of the Free State

UNIVERSITEIT VAN DIE
VRYSTAAT
YUNIVESITHI YA
FREISTATA
HUMANITIES
GEESTESWETENSKAPPE

25 May 2016

Miss SA Aitken
Department of Psychology
UFS

Ethical Clearance Application: The psychosocial experiences of adolescents living with juvenile idiopathic arthritis (UFS-HSD2016/0337).

Dear Miss Aitken

I am pleased to inform you that your protocol has been successful in obtaining ethical clearance. However, please attend to the following before embarking on your research. No resubmission is required:

Concerning Third party data: Please attach a letter with the contact details of the Arthritis Foundation and medical doctors - after obtaining their permission to make their contact details available - that can be handed the prospective participants. Although it is mentioned that children will be referred to psychologists if they present with emotional distress it is not explained *how* they will get there, *who* will be responsible for the payment of the professional fees of the psychologists, and for how many sessions the psychologists will be available. Please add. [Typo on information sheet: "Freestate".]

Also, please check consistency between information sheets/consent forms where some documents provide the researcher's name and mentioning she is a psychologist - while other documents only reflect the researcher's name. As the (supervisor?) noted it may be best for the researcher not to announce her profession, particularly to the participants. On the advertising brochure are pictures of adolescents. Was permission obtained to use these images as there could be ramifications if one of the youngsters in the advertisement was not informed that her/his image is being associated with a chronic illness? If one purchases the images (usually from "stock photo" websites and for a small fee), then you are free to use them in any fashion.

Yours sincerely,

Prof Robert Peacock
Chairperson: Research Ethics Committee
Faculty of the Humanities
Copy: Charné Vercueil, Officer: Research Co-ordinator, Faculty of the Humanities

Kantoor van die Dekaan
Office of the Dean
Ofisa ya Dine

T: +27(0)514012240
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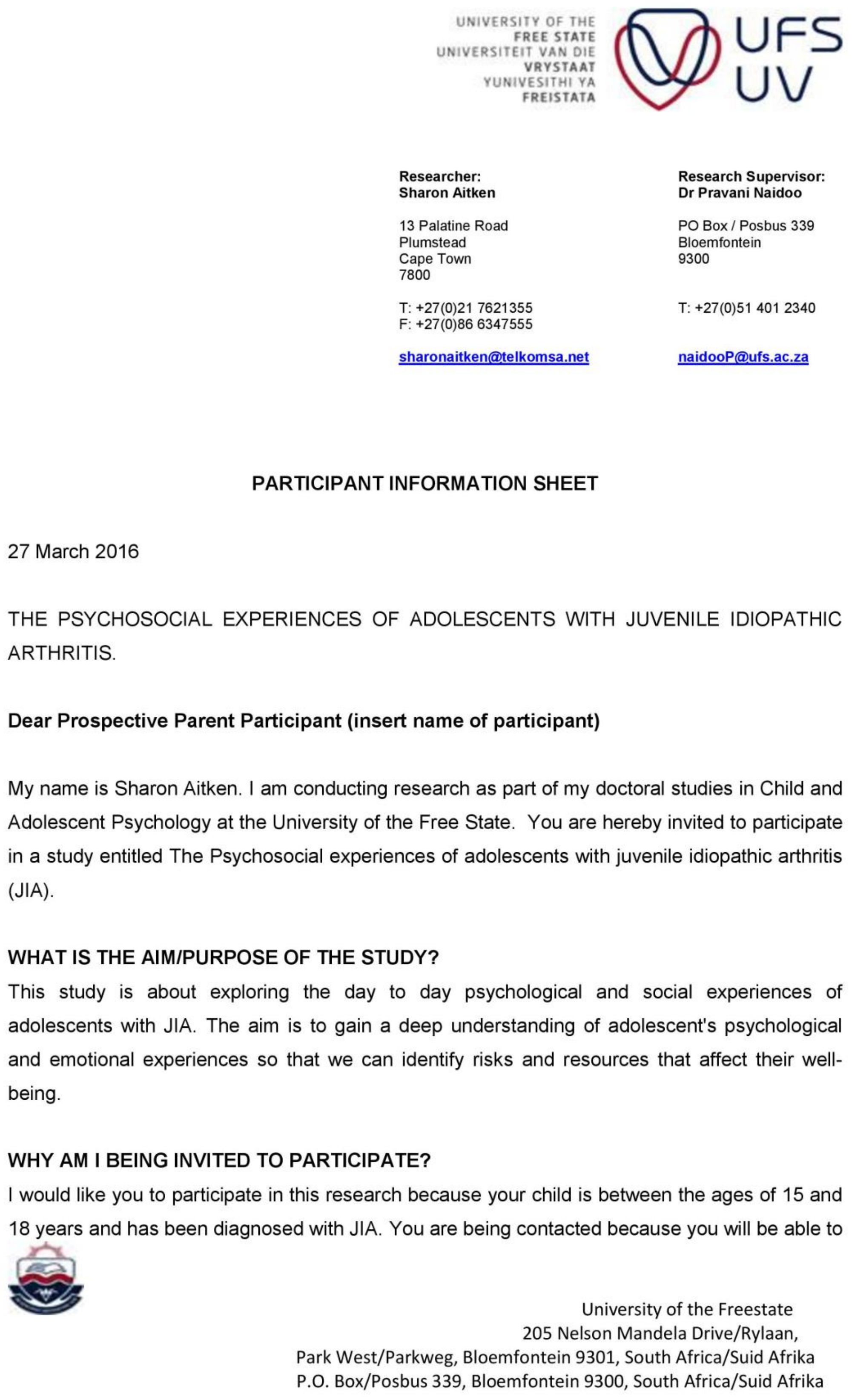
E: beukeshs@ufs.ac.za

P.O. Box/Posbus 339
Bloemfontein 9300
South Africa/Suid-Afrika
www.ufs.ac.za

APPENDIX B: Research Information Letter and Parental Consent Form



UNIVERSITY OF THE
FREE STATE
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Researcher:
Sharon Aitken

13 Palatine Road
Plumstead
Cape Town
7800

T: +27(0)21 7621355
F: +27(0)86 6347555

sharonaitken@telkomsa.net

Research Supervisor:
Dr Pravani Naidoo

PO Box / Posbus 339
Bloemfontein
9300

T: +27(0)51 401 2340

naidooP@ufs.ac.za

PARTICIPANT INFORMATION SHEET

27 March 2016

THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS.

Dear Prospective Parent Participant (insert name of participant)

My name is Sharon Aitken. I am conducting research as part of my doctoral studies in Child and Adolescent Psychology at the University of the Free State. You are hereby invited to participate in a study entitled The Psychosocial experiences of adolescents with juvenile idiopathic arthritis (JIA).

WHAT IS THE AIM/PURPOSE OF THE STUDY?

This study is about exploring the day to day psychological and social experiences of adolescents with JIA. The aim is to gain a deep understanding of adolescent's psychological and emotional experiences so that we can identify risks and resources that affect their well-being.

WHY AM I BEING INVITED TO PARTICIPATE?

I would like you to participate in this research because your child is between the ages of 15 and 18 years and has been diagnosed with JIA. You are being contacted because you will be able to provide valuable information regarding parenting an adolescent living with JIA. I will be interviewing approximately 8 to 12 adolescents with JIA and approximately 6 of their parents.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY / WHAT DOES THE RESEARCH INVOLVE?

If you decide to participate in the research, I will contact you in order to make an appointment for an initial interview. Your role will be to provide me with your experiences of being a parent of child who has been diagnosed with JIA. You will be asked to share your thoughts, feelings and experiences from when your child first fell ill until the present time through semi-structured interviews which will be digitally recorded. The interview will be conducted in private at a venue, date and time of your choice. There will be one interview of approximately 60-90 minutes duration three months apart. The transcript of your interview can either be e-mailed to you or I could provide you with a hard copy to read through so as to make sure that they accurately reflect the contents of the interviews. You may inform me of the option that you prefer when we meet for the interview.

CAN I WITHDRAW FROM THIS STUDY?

While I greatly appreciate your participation in this study and the valuable contribution that you can make, your participation is entirely voluntary and you are under no obligation to take part in this study. If you do choose to take part, and an issue arises which makes you uncomfortable, you may at any time stop your participation with no penalty or loss of benefit for non-participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason, or incurring any negative consequences.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

You will not benefit directly from this research. However, if you wish, you will be given the opportunity to discuss the results of the research once the project has been completed. An understanding of the risks and resources that adolescents encounter might better inform other families and medical practitioners in the future. In addition, this information may assist in developing support structures and interventions.

WHAT IS THE ANTICIPATED INCONVENIENCE OF TAKING PART IN THIS STUDY?

The only foreseeable inconvenience would be the time that it takes to be interviewed and to read the transcribed interviews. In addition, should you prefer that the interviews take place at the university rather than at home, then traveling might be an inconvenience. The possible risks to you in taking part in this study are that you may experience psychological distress as you will be sharing your experiences of parenting a child with JIA. However, please be assured that should you experience any psychological distress, a qualified professional will be made available to debrief you.

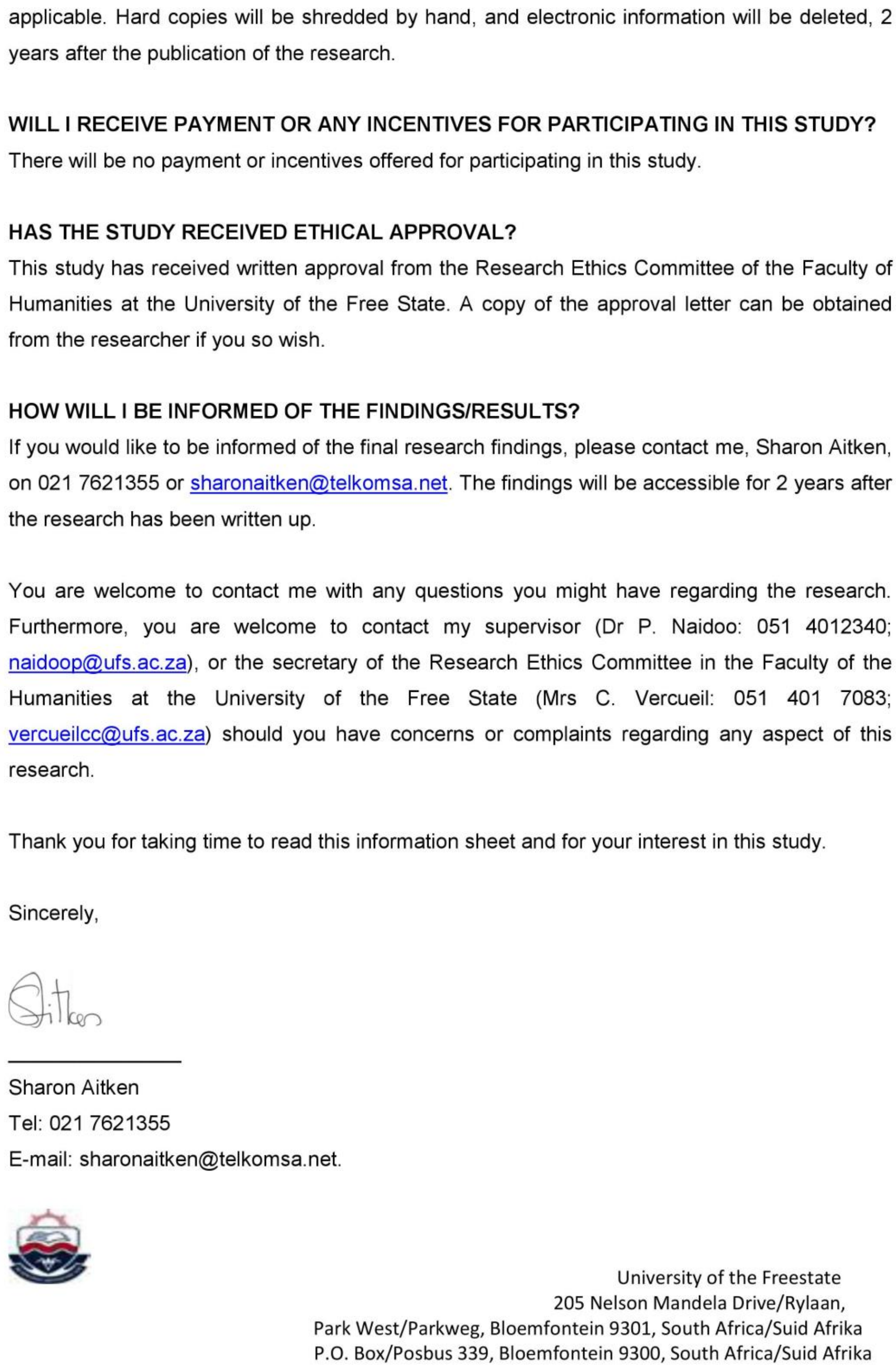
WILL WHAT I SAY BE KEPT CONFIDENTIAL?

All information obtained, including your and your child's identities and personal information, will be treated with the strictest confidentiality. When the results of this research project are documented, your and your child's anonymity will be protected as I will be changing your names. Your names will not be recorded anywhere and no one will be able to link you to the responses that you share. A pseudonym will be allocated to you and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is conducted in a sound manner, including the transcriber, and research supervisors. Otherwise, records that identify you will be available only to myself and my research supervisors. The results of this research will be used for my doctoral thesis, and may also be published in a scientific journal and presented at child and adolescent psychology conferences. Should this happen, your identity and personal information will remain strictly confidential and your participation will not be identifiable.

HOW WILL INFORMATION BE STORED AND ULTIMATELY DESTROYED?

Hard copies of your interviews will be stored by me, the researcher, for a period of two years after publication of the research in a locked filing cabinet in my home office for future research purposes. Electronic information will be stored on a password-protected computer. Future use of the stored data will be subject to further Research Ethics Committee review and approval if



applicable. Hard copies will be shredded by hand, and electronic information will be deleted, 2 years after the publication of the research.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

There will be no payment or incentives offered for participating in this study.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Humanities at the University of the Free State. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS?

If you would like to be informed of the final research findings, please contact me, Sharon Aitken, on 021 7621355 or sharonaitken@telkomsa.net. The findings will be accessible for 2 years after the research has been written up.

You are welcome to contact me with any questions you might have regarding the research. Furthermore, you are welcome to contact my supervisor (Dr P. Naidoo: 051 4012340; naidoop@ufs.ac.za), or the secretary of the Research Ethics Committee in the Faculty of the Humanities at the University of the Free State (Mrs C. Vercueil: 051 401 7083; vercueilcc@ufs.ac.za) should you have concerns or complaints regarding any aspect of this research.

Thank you for taking time to read this information sheet and for your interest in this study.

Sincerely,

SAitken

Sharon Aitken
Tel: 021 7621355
E-mail: sharonaitken@telkomsa.net.

University of the Freestate
205 Nelson Mandela Drive/Rylaan,
Park West/Parkweg, Bloemfontein 9301, South Africa/Suid Afrika
P.O. Box/Posbus 339, Bloemfontein 9300, South Africa/Suid Afrika

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Please fill in and return this page. Keep the letter above for future reference

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Study: *THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS.* .

Researcher: *Sharon Aitken*

INFORMED CONSENT FORM

I, ____ (parent's name and surname), the legal guardian of ____ (child's name and surname), hereby grant permission for my child to be contacted regarding participation in the above-mentioned research project.

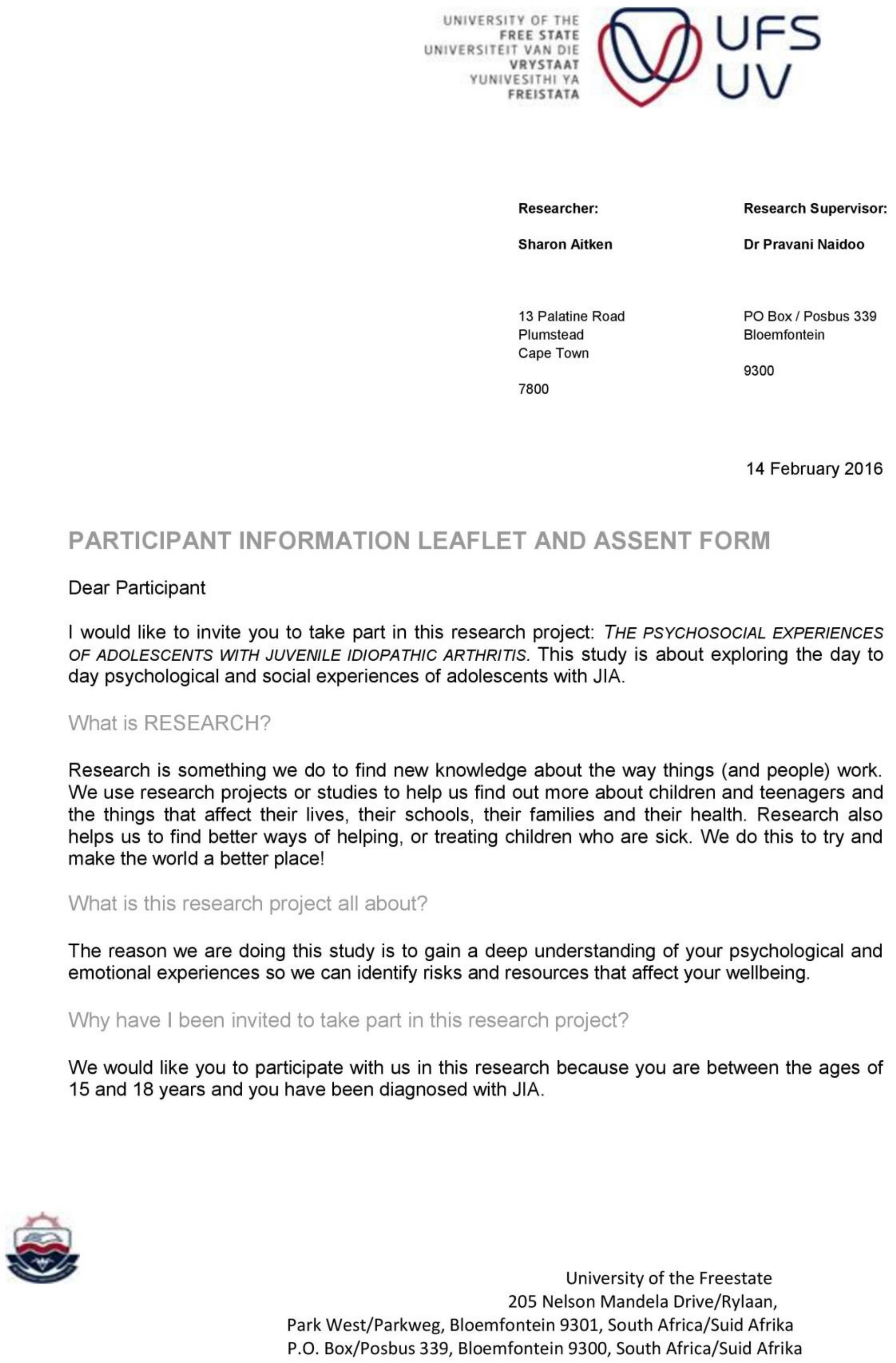
I further acknowledge that I have been fully informed as to what my child's participation in this project will entail, as well as with regard to her/his right to withdraw from the study at any time and to have her/his participation treated in the strictest confidence.

__________________________ ____________________

Signature of parent/guardian **Date**

University of the Freestate
205 Nelson Mandela Drive/Rylaan,
Park West/Parkweg, Bloemfontein 9301, South Africa/Suid Afrika
P.O. Box/Posbus 339, Bloemfontein 9300, South Africa/Suid Afrika

APPENDIX C: Research Information Letter and Adolescent Assent Form



UNIVERSITY OF THE
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Researcher:	**Research Supervisor:**
Sharon Aitken	**Dr Pravani Naidoo**
13 Palatine Road Plumstead Cape Town 7800	PO Box / Posbus 339 Bloemfontein 9300

14 February 2016

PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM

Dear Participant

I would like to invite you to take part in this research project: *THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS.* This study is about exploring the day to day psychological and social experiences of adolescents with JIA.

What is RESEARCH?

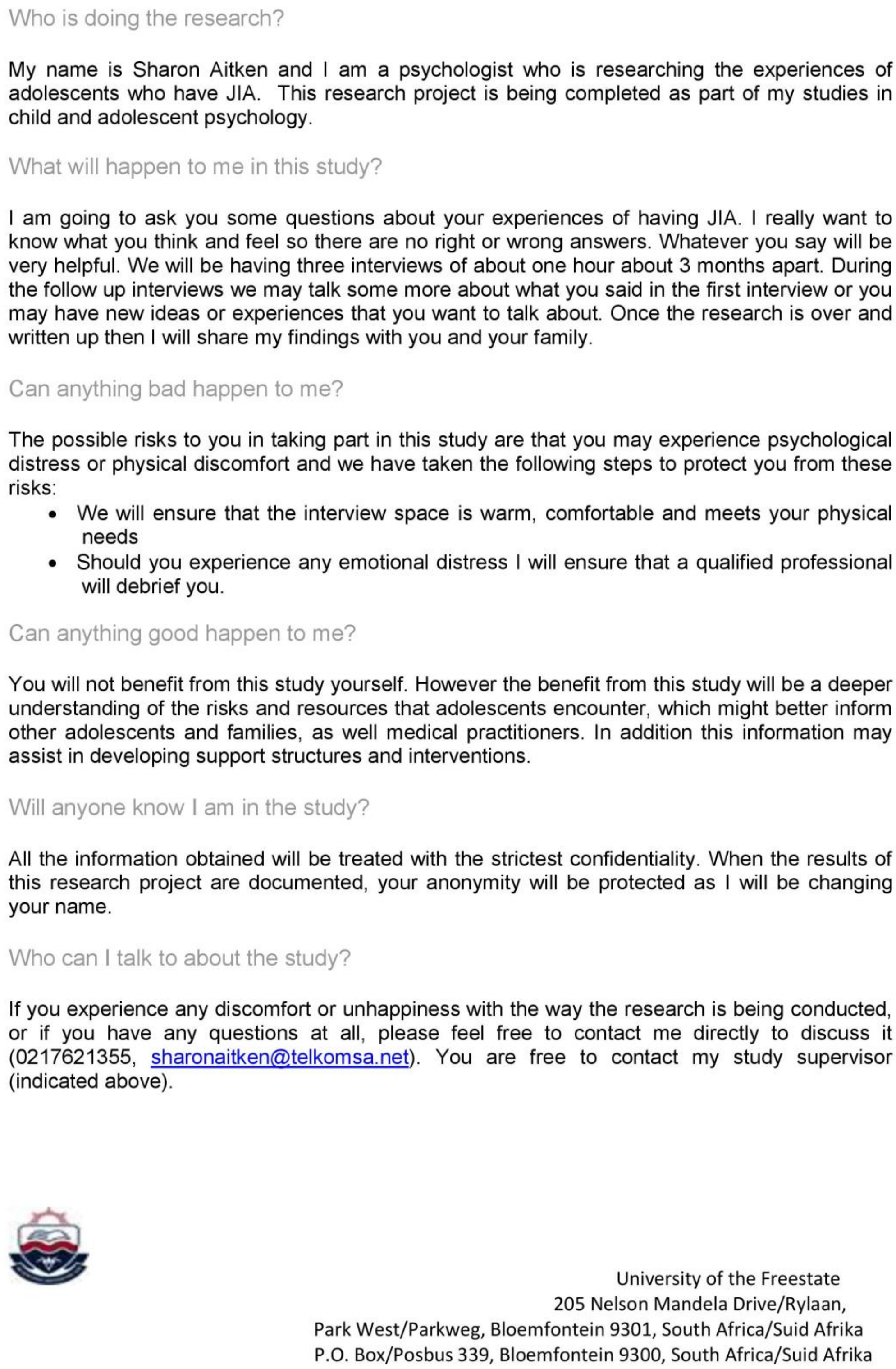
Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about children and teenagers and the things that affect their lives, their schools, their families and their health. Research also helps us to find better ways of helping, or treating children who are sick. We do this to try and make the world a better place!

What is this research project all about?

The reason we are doing this study is to gain a deep understanding of your psychological and emotional experiences so we can identify risks and resources that affect your wellbeing.

Why have I been invited to take part in this research project?

We would like you to participate with us in this research because you are between the ages of 15 and 18 years and you have been diagnosed with JIA.



Who is doing the research?

My name is Sharon Aitken and I am a psychologist who is researching the experiences of adolescents who have JIA. This research project is being completed as part of my studies in child and adolescent psychology.

What will happen to me in this study?

I am going to ask you some questions about your experiences of having JIA. I really want to know what you think and feel so there are no right or wrong answers. Whatever you say will be very helpful. We will be having three interviews of about one hour about 3 months apart. During the follow up interviews we may talk some more about what you said in the first interview or you may have new ideas or experiences that you want to talk about. Once the research is over and written up then I will share my findings with you and your family.

Can anything bad happen to me?

The possible risks to you in taking part in this study are that you may experience psychological distress or physical discomfort and we have taken the following steps to protect you from these risks:

- We will ensure that the interview space is warm, comfortable and meets your physical needs
- Should you experience any emotional distress I will ensure that a qualified professional will debrief you.

Can anything good happen to me?

You will not benefit from this study yourself. However the benefit from this study will be a deeper understanding of the risks and resources that adolescents encounter, which might better inform other adolescents and families, as well medical practitioners. In addition this information may assist in developing support structures and interventions.

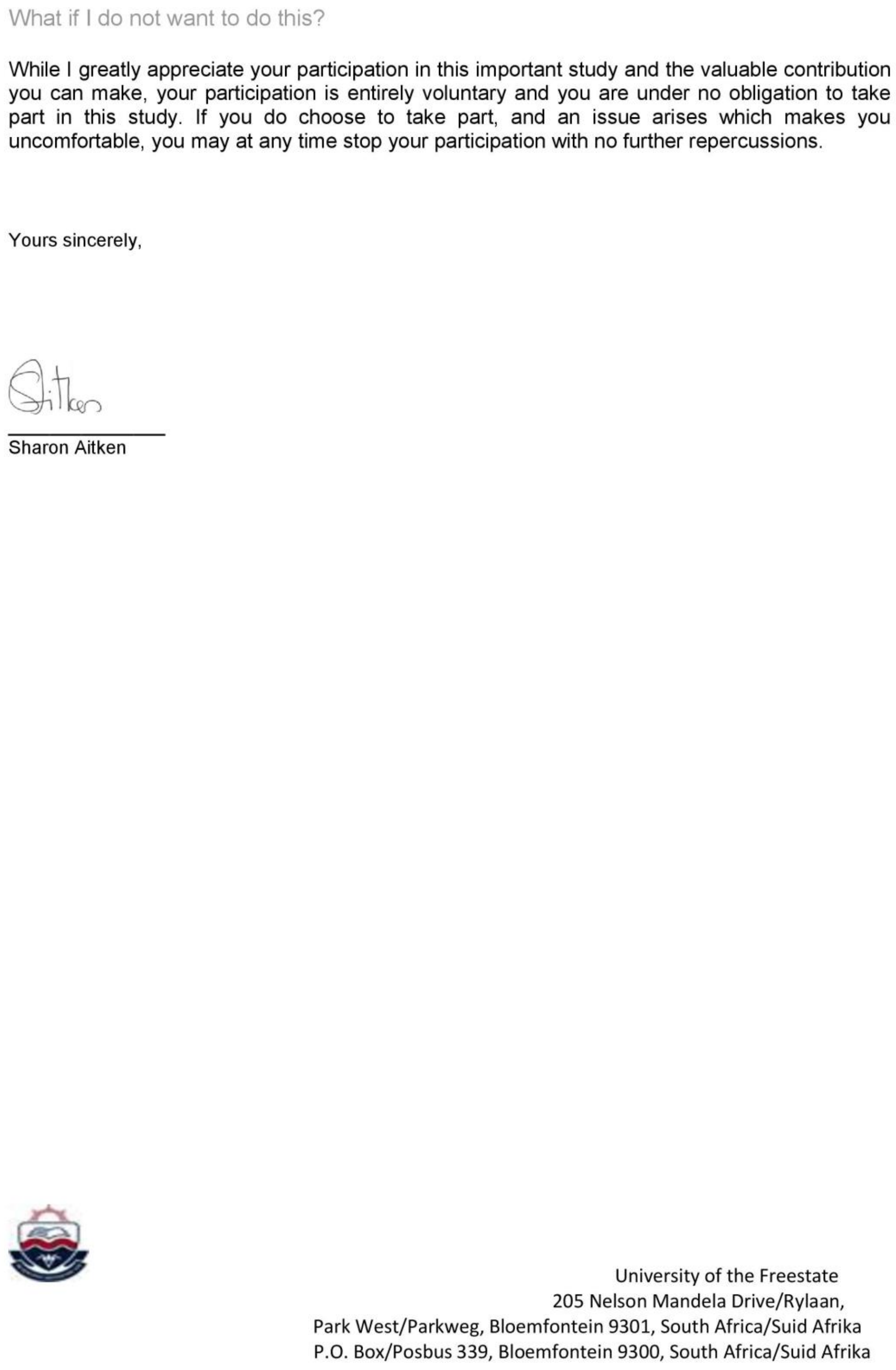
Will anyone know I am in the study?

All the information obtained will be treated with the strictest confidentiality. When the results of this research project are documented, your anonymity will be protected as I will be changing your name.

Who can I talk to about the study?

If you experience any discomfort or unhappiness with the way the research is being conducted, or if you have any questions at all, please feel free to contact me directly to discuss it (0217621355, sharonaitken@telkomsa.net). You are free to contact my study supervisor (indicated above).

University of the Freestate
205 Nelson Mandela Drive/Rylaan,
Park West/Parkweg, Bloemfontein 9301, South Africa/Suid Afrika
P.O. Box/Posbus 339, Bloemfontein 9300, South Africa/Suid Afrika



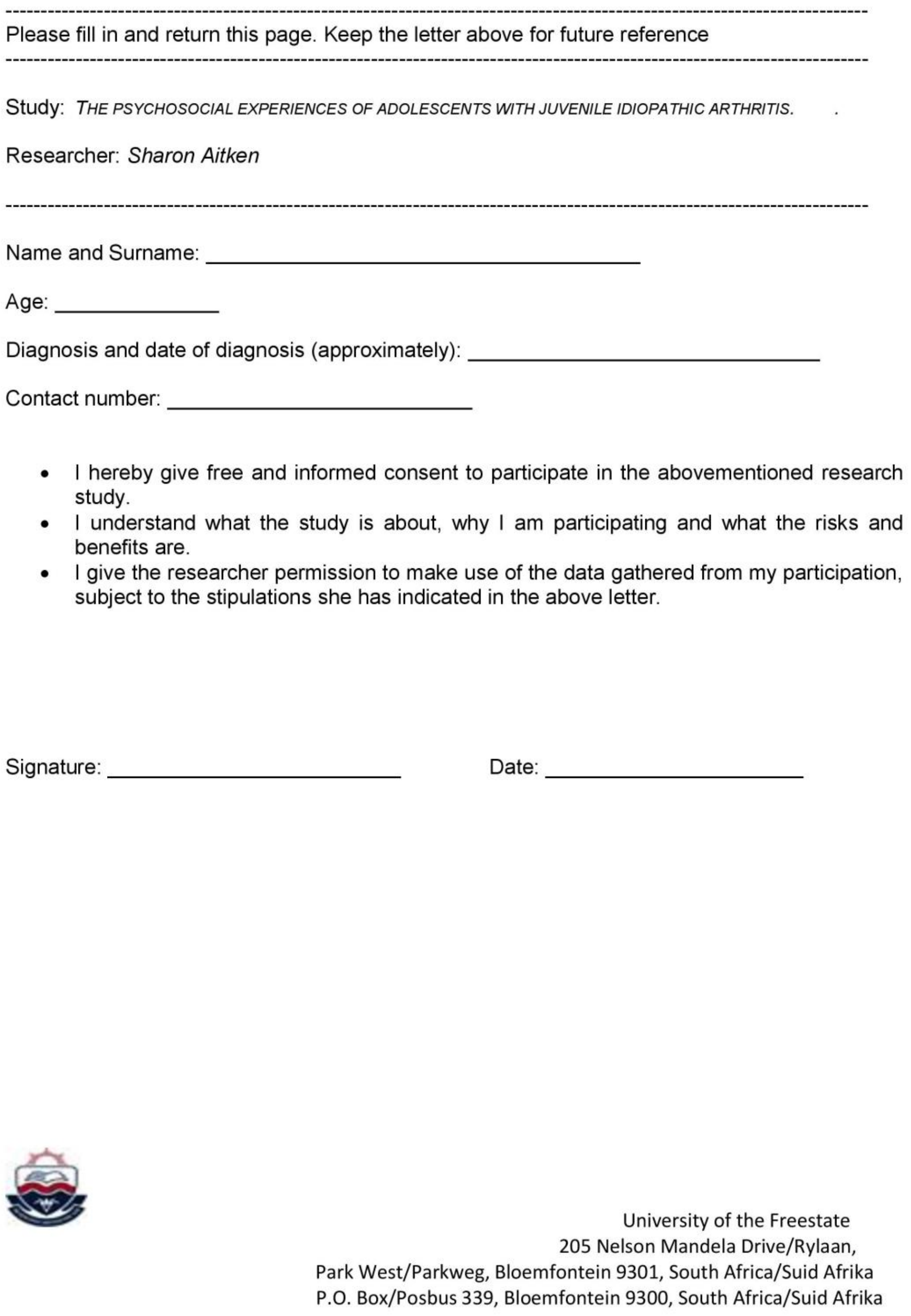
What if I do not want to do this?

While I greatly appreciate your participation in this important study and the valuable contribution you can make, your participation is entirely voluntary and you are under no obligation to take part in this study. If you do choose to take part, and an issue arises which makes you uncomfortable, you may at any time stop your participation with no further repercussions.

Yours sincerely,

Sharon Aitken

University of the Freestate
205 Nelson Mandela Drive/Rylaan,
Park West/Parkweg, Bloemfontein 9301, South Africa/Suid Afrika
P.O. Box/Posbus 339, Bloemfontein 9300, South Africa/Suid Afrika



Please fill in and return this page. Keep the letter above for future reference

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Study: *THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS.* .

Researcher: *Sharon Aitken*

Name and Surname: ______________________________________

Age: ______________

Diagnosis and date of diagnosis (approximately): ______________________________

Contact number: __________________________

- I hereby give free and informed consent to participate in the abovementioned research study.
- I understand what the study is about, why I am participating and what the risks and benefits are.
- I give the researcher permission to make use of the data gathered from my participation, subject to the stipulations she has indicated in the above letter.

Signature: _________________________ Date: ______________________

University of the Freestate
205 Nelson Mandela Drive/Rylaan,
Park West/Parkweg, Bloemfontein 9301, South Africa/Suid Afrika
P.O. Box/Posbus 339, Bloemfontein 9300, South Africa/Suid Afrika

APPENDIX D: Research Information Letter and Consent Form for Parent Participants

UNIVERSITY OF THE
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Researcher:	**Research Supervisor:**
Sharon Aitken	**Dr Pravani Naidoo**
13 Palatine Road Plumstead Cape Town 7800	PO Box / Posbus 339 Bloemfontein 9300

14 February 2016

INFORMED CONSENT:

Dear Parent of Participant

I would like to invite your child to take part in this research project:

THE PSYCHOSOCIAL EXPERIENCES OF ADOLESCENTS WITH JUVENILE IDIOPATHIC ARTHRITIS. .

This study is about exploring the day to day psychological and social experiences of adolescents with JIA. The reason we are doing this study is to gain a deep understanding of adolescent's psychological and emotional experiences so we can identify risks and resources that affect their wellbeing.

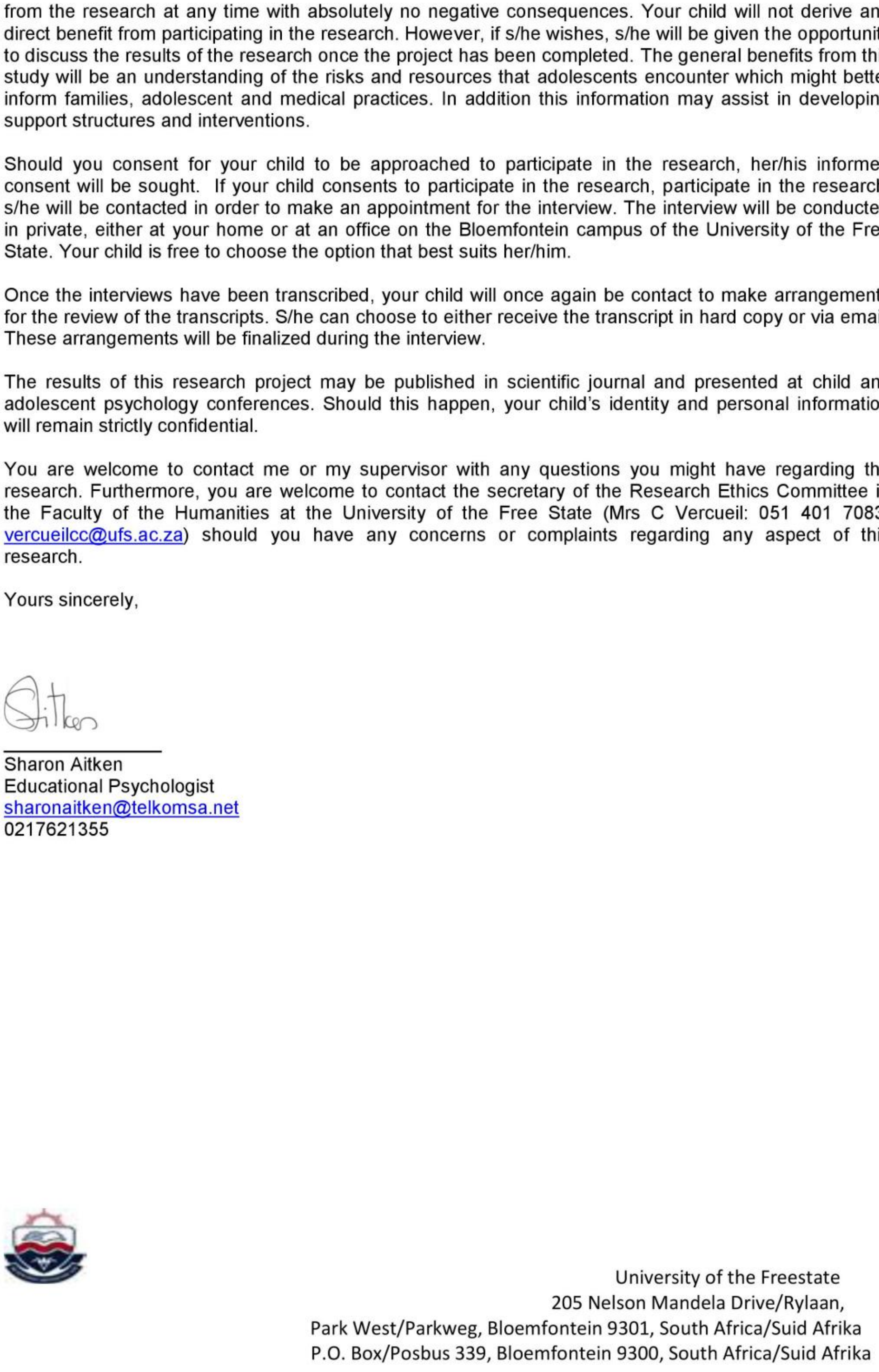
We would like your child to participate with us in this research because s/he is between the ages of 15 and 18 years and has been diagnosed with JIA. However, before your child can be approached to participate in the research it is necessary to obtain your consent as his/her legal guardian. This sheet will provide you with the necessary information to make an informed decision regarding your child's participation in this research project.

Participation in this research would require your child to participate in three interviews discussing some of the experiences s/he faces as an adolescent with JIA. This interview is expected to take between 60 and 90 minutes. The interview will be recorded on a digital voice recorder, after which the interview will be transcribed. I am the only person who will have access to the recording and transcript. Your child's identity will be protected by using a number or pseudonym in the transcript. Once the interview has been transcribed your child will be asked to read through it to make sure that it accurately reflects the contents of the interview. This should not take more than 30 to 40 minutes of your child's time.

Participating in this research project should not affect your child's physical or psychological wellbeing in any way. However possible risks to your child are that s/he may experience psychological distress or physical discomfort. We have taken the following steps to protect him/her from these risks:

- We will ensure that the interview space is warm, comfortable and meets his/her physical needs should it not take place at home.
- Should s/he experience any emotional distress we will ensure that a qualified professional will debrief him/her.

Her/his participation in this research project is totally voluntary and s/he will not be penalized in any way for choosing not to take part. Should s/he choose to participate, your child retains the right to withdraw



from the research at any time with absolutely no negative consequences. Your child will not derive any direct benefit from participating in the research. However, if s/he wishes, s/he will be given the opportunity to discuss the results of the research once the project has been completed. The general benefits from this study will be an understanding of the risks and resources that adolescents encounter which might better inform families, adolescent and medical practices. In addition this information may assist in developing support structures and interventions.

Should you consent for your child to be approached to participate in the research, her/his informed consent will be sought. If your child consents to participate in the research, participate in the research, s/he will be contacted in order to make an appointment for the interview. The interview will be conducted in private, either at your home or at an office on the Bloemfontein campus of the University of the Free State. Your child is free to choose the option that best suits her/him.

Once the interviews have been transcribed, your child will once again be contact to make arrangements for the review of the transcripts. S/he can choose to either receive the transcript in hard copy or via email. These arrangements will be finalized during the interview.

The results of this research project may be published in scientific journal and presented at child and adolescent psychology conferences. Should this happen, your child's identity and personal information will remain strictly confidential.

You are welcome to contact me or my supervisor with any questions you might have regarding the research. Furthermore, you are welcome to contact the secretary of the Research Ethics Committee in the Faculty of the Humanities at the University of the Free State (Mrs C Vercueil: 051 401 7083; vercueilcc@ufs.ac.za) should you have any concerns or complaints regarding any aspect of this research.

Yours sincerely,

Sharon Aitken
Educational Psychologist
sharonaitken@telkomsa.net
0217621355

University of the Freestate
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CONSENT TO PARTICIPATE IN THIS STUDY

I, ________________________________ (participant name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet. I have had sufficient opportunity to ask questions and am prepared to participate in the study. I understand that my participation is voluntary and that I am free to withdraw at any time without penalty (if applicable). I am aware that the findings of this study will be anonymously processed into a research report, journal publications and/or conference proceedings.

I agree to the recording of the semi-structured interviews.

I have received a signed copy of the informed consent agreement.

Full Name of Participant: ____

Signature of Participant: ____________________________ Date: _____________

Full Name of Researcher: ____

Signature of Researcher: ____________________________ Date: _____________

APPENDIX E: Semi-Structured Interview Schedule – Adolescents

Sharon Aitken: Sample of questions to be used in the first semi-structured interview

Aim: To gain initial rich descriptions of the adolescent's journey of having JIA as well as their everyday experiences of living with JIA.

Introduction to interview:

My name is Sharon Aitken and I researching the experiences of adolescents who have JIA. This research project is being completed as part of my studies in child and adolescent psychology. Before we begin I am going to go over things with you just to make sure that you understand. But please ask me as many questions as you would like to.

I am going to ask you some questions about your experiences of having JIA. I really want to know what you think and feel so there are no right or wrong answers. Whatever you say will be very helpful. We will be having two more interviews after this one about 3 months apart. During the next interviews we may talk some more about what you said in this interview or you may have new ideas or experiences that you want to talk about. Once the research is over and written up then I will share my findings with you and your family. Does this make sense? I will remind you of this when we next meet.

Ok then now I am going to check that you understand your rights and that you are feeling comfortable and then we can start talking about your experiences.

Domain Subject Area	**Questions and Possible Probes**
Setting the scene Objectives: To check that the participant still consents to be interviewed; Reconfirm ethical issues; Check for any other questions.	Are you still willing to be interviewed? Ethical issues: - Remind participant that she/he can withdraw at any time. - Inform her/him that the interview will be audio recorded. - Ensure that she/he is aware of confidentiality, that no identifying criteria will be used. - Ensure that she/he has the means to contact me or that procedures are in place should she/he feel emotional distress during or after the interview. - Ensure that she/he is physically comfortable. Do you have any concerns? Would you like me to tell you more about the research that I am doing? Do you have any other questions that you would like to ask me?

Exploration of the development of the illness Objectives: To gain rich descriptions of his/her journey with JIA (from initial illness, through diagnosis to present). To explore feelings and experiences around early illness, medical visits, 'unknowing', diagnosis, flare-ups/disease progression. To explore his/her current relationship with JIA.	**Can you tell me how you became ill and found out that you have JIA?** Possible questions to use if participant is reticent: - I was wondering what it was like for you when you first became ill? How did you experience it or feel about it? - Can you tell me the journey you went through until you were diagnosed? What were your thoughts or feelings during this time? - Do you remember when you were first diagnosed? Can you tell me some more about that? What was that like for you? - What has your life been like since the diagnosis? Do you remember having any flare-ups? How has your illness developed? - How do you experience living with JIA at the moment?
Exploration of day-to-day experiences Objectives: To gain a deeper understanding of their daily experiences of living with JIA.	**Can you tell me how having JIA has affected your life?** Possible exploratory questions - I was wondering: have you had to make changes to your life because of your illness? - Has having JIA affected your relationships? Can you tell me more about this? - Has there been anyone or anything that you have found to be helpful? - Has there been anyone or anything that has made life more difficult for you? - What advice would you give other children who have JIA - Is there anything else you would like to tell me about what it is like for you to live with your illness?
Ending Interview	Do you have anything else that you would like to share with me at this stage? Thank you very much for helping me with this and giving up your time. I will set up the next interview with you shortly during which we can explore some of these ideas in more detail.

APPENDIX F: Semi-Structured Interview Schedule – Parents

Sample of questions to be used in the semi-structured interview of parents of typical and atypical participants

Aim: To gain initial rich descriptions of the parent's experiences of the adolescent's journey of having JIA.

Introduction to interview:

My name is Sharon Aitken and I am researching the experiences of adolescents who have JIA. This research project is being completed as part of my studies in child and adolescent psychology. Before we begin I am going to go over things with you just to make sure that you understand the process. But please ask me as many questions as you would like to.

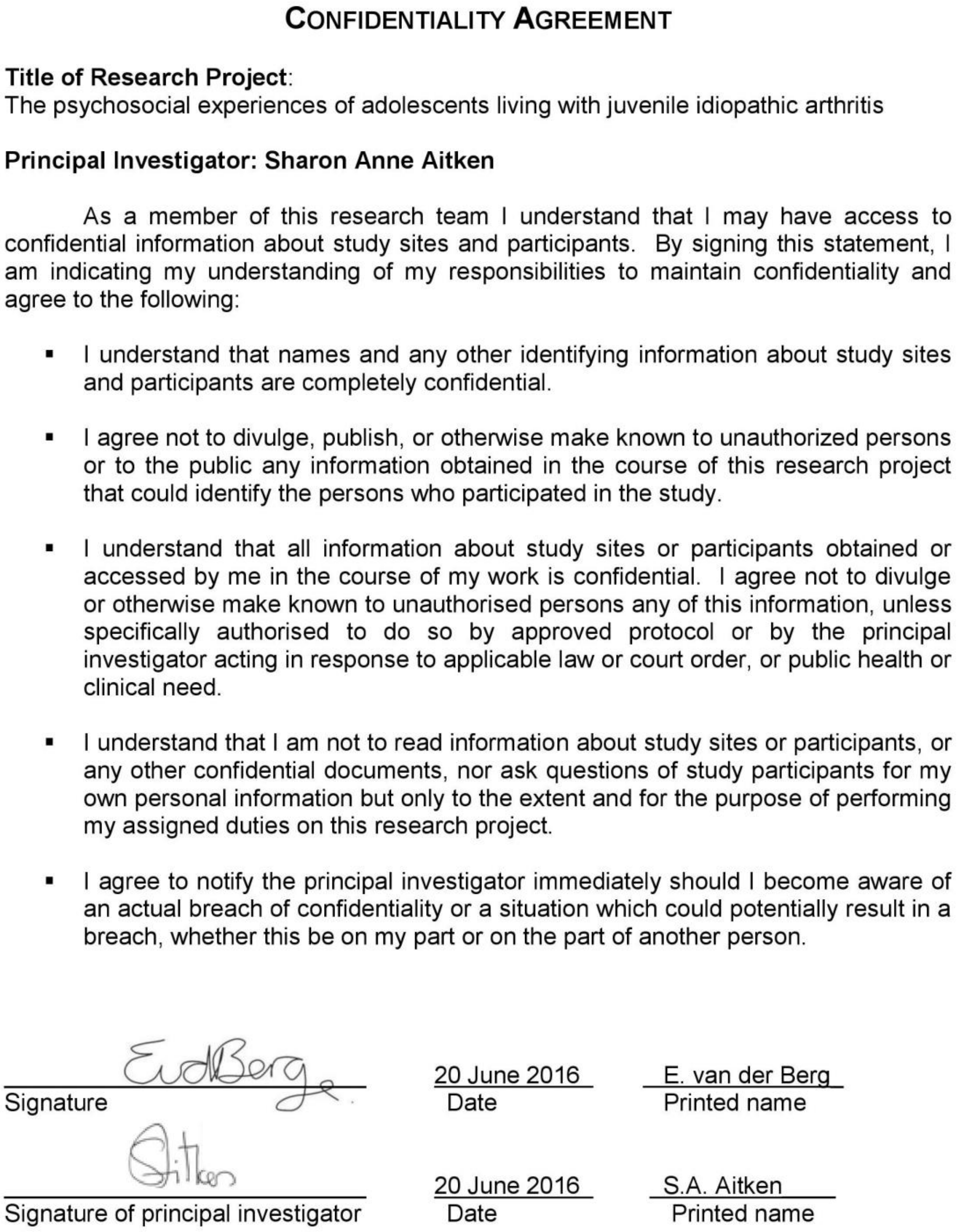
I am going to ask you some questions about your experiences of your child having JIA. I really want to know about your day-to-day experiences as well as what you think and feel. There are no right or wrong answers. Whatever you say will be very helpful. We will be having another interview after this one in about 3 months. During the next interview we may talk some more about what you said in this interview or you may have new ideas or experiences that you want to talk about. Once the research is over and written up then I will share my findings with you and your family. Does this make sense? I will remind you of this when we next meet.

Ok then now I am going to check that you understand your rights and that you are feeling comfortable and then we can start talking about your experiences.

Domain Subject Area	**Questions and Possible Probes**
Setting the scene Objectives: To check that the participant still consents to be interviewed; Reconfirm ethical issues; Check for any other questions.	**Are you still willing to be interviewed**? Ethical issues: - Remind participant that s/he can withdraw at any time. - Inform her/him that the interview will be audio recorded. - Ensure that s/he is aware of confidentiality, that no identifying criteria will be used. - Ensure that s/he has the means to contact me or that procedures are in place should she/he feel emotional distress during or after the interview. - Ensure that s/he is physically comfortable. Do you have any concerns? Would you like me to tell you more about the research that I am doing? Do you have any other questions that you would like to ask me?

Exploration of the development of the illness Objectives: To gain rich descriptions of the parent's journey with their child's JIA (from initial illness, through diagnosis to present). To explore feelings and experiences around early illness, medical visits, 'unknowing', diagnosis, flare-ups/disease progression. To explore his/her current experiences of their child's JIA.	**Can you tell me how you your child became ill and about the diagnosis of JIA?** Possible questions to use in an effort to build rapport. - I was wondering what it was like for you when your child first became ill? How did you experience it or feel about it? - Can you tell me the journey you went through until s/he was diagnosed? What were your thoughts or feelings during this time? - Do you remember when s/he was first diagnosed? Can you tell me some more about that? What was that like for you? - What was the emotional impact for you when your child was diagnosed? What was it like for your child?
Exploration of day-to-day experiences Objectives: To gain a deeper understanding of their daily experiences of living with a child who has JIA. parenting, discipline, family dynamics, the martial relationship, relationships with other children, sibling relationships	**Can you tell me how having JIA has affected your life and that of your child?** Possible exploratory questions - I was wondering: have you had to make changes to your life because of your child's illness? - How has your child having JIA affected your social relationships? Can you tell me more about this? - Can you tell me about your family relationships in light of your child's illness? In what ways has your child's illness impacted on your relationship with your spouse? How do you think your other children have experienced having a chronically ill sister/brother? - How has having a chronically ill child changed your parenting style? - In what ways has your child's illness impacted on you with regard to work and your financial situation? - Have there been experiences that have either challenged or helped you? OR are there any experiences that stand out for you? - What lessons have you learnt that you would want to share with other parents who have children with JIA? - Are there other issues that we have not covered that you would like to tell me about?
	Do you have anything else that you would like to share with me at this stage? Thank you very much for helping me with this and giving up your time. I will set up the next interview with you shortly during which we can explore some of these ideas in more detail.

APPENDIX G: Confidentiality Agreement for Transcription of Interviews



CONFIDENTIALITY AGREEMENT

Title of Research Project:
The psychosocial experiences of adolescents living with juvenile idiopathic arthritis

Principal Investigator: Sharon Anne Aitken

As a member of this research team I understand that I may have access to confidential information about study sites and participants. By signing this statement, I am indicating my understanding of my responsibilities to maintain confidentiality and agree to the following:

- I understand that names and any other identifying information about study sites and participants are completely confidential.
- I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research project that could identify the persons who participated in the study.
- I understand that all information about study sites or participants obtained or accessed by me in the course of my work is confidential. I agree not to divulge or otherwise make known to unauthorised persons any of this information, unless specifically authorised to do so by approved protocol or by the principal investigator acting in response to applicable law or court order, or public health or clinical need.
- I understand that I am not to read information about study sites or participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.
- I agree to notify the principal investigator immediately should I become aware of an actual breach of confidentiality or a situation which could potentially result in a breach, whether this be on my part or on the part of another person.

EvdBerg	20 June 2016	E. van der Berg
Signature	Date	Printed name
Aitken	20 June 2016	S.A. Aitken
Signature of principal investigator	Date	Printed name

APPENDIX H: Information Letter to Kids Arthritis South Africa and Web Advertisement

Dear Governing Body Member

Thank you for providing me with the opportunity to share my research project details with you.

I am a registered educational psychologist currently completing a doctoral programme specialising in the field of child and adolescent psychology. Relevant research with children and/or adolescents forms a significant part of this specialisation. As such, I will be conducting a research project in which I will be interviewing adolescents aged 15 to 18 years. The research project is focused on understanding the experiences of adolescents with juvenile idiopathic arthritis.

This research project involves an initial semi-structured interview with each participant in order to obtain a brief understanding of the adolescent's background and an initial exploration of his or her experiences of having JIA. A second interview will follow after 3 months, with a possible third interview 3 months after that. Selected parental interviews will also take place.

Participation in this research project is voluntary and any participant may withdraw from the project at any point. All the information obtained will be treated with the strictest confidentiality. When the results of this research project are documented, the anonymity of each participant will be protected by making use of pseudonyms. This research project is being supervised by Dr Pravani Naidoo from the Department of Psychology at the University of the Free State. The results of the research will be provided to you in order to share the understanding that is gained by completing this research project.

I would like to advertise my research on your website in order to find participants for my research.

I hope to meet with you in the near future in order to answer any questions you may have and move forward with this project. Please do not hesitate to contact me at any point should you wish to discuss things further.

Kind regards
Sharon Aitken
Educational Psychologist
021 7621355

______________________________	______________________________
Date	Date
______________________________	______________________________
Signature of researcher	Signature of research supervisor

Do you have juvenile idiopathic arthritis?
Are you between 15 and 18 years old?
What is living with JIA like?

Why do I need your help?
I am doing a research project on how JIA affects the lives and experiences of South African adolescents. I want to use this research to help parents, doctors and teachers understand your needs and improve their support systems.

What would you have to do?
Send me an SMS or e-mail if you are interested and I will set up a meeting with you. During this first meeting, I will explain all you need to know about participating in this study. This study will last for around six months.

If you are interested I'd love to hear from you:
SHARON AITKEN, 0834171271/0217621355'
sharonaitken@telkomsa.net

APPENDIX I: Information to Medical Specialist

Dear Dr

Thank you for providing me with the opportunity to share my research project details with you.

I am a registered educational psychologist currently completing a doctoral programme specialising in the field of child and adolescent psychology. Relevant research with children and/or adolescents forms a significant part of this specialisation. As such, I will be conducting a research project in which I will be interviewing adolescents aged 15 to 18 years. The research project is focused on understanding the experiences of adolescents with juvenile idiopathic arthritis.

This research project involves an initial semi-structured interview with each participant in order to obtain a brief understanding of the adolescent's background and an initial exploration of his or her experiences of having JIA. A second interview will follow after 3 months, with a possible third interview 3 months after that. Selected parental interviews will also take place.

Participation in this research project is voluntary and any participant may withdraw from the project at any point. All the information obtained will be treated with the strictest confidentiality. When the results of this research project are documented, the anonymity of each participant will be protected by making use of pseudonyms. This research project is being supervised by Dr Pravani Naidoo from the Department of Psychology at the University of the Free State. The results of the research will be provided to you in order to share the understanding that is gained by completing this research project.

I was wondering if you would be interested in helping me find participants by contacting patients that you deem suitable to ascertain if they might be interested.

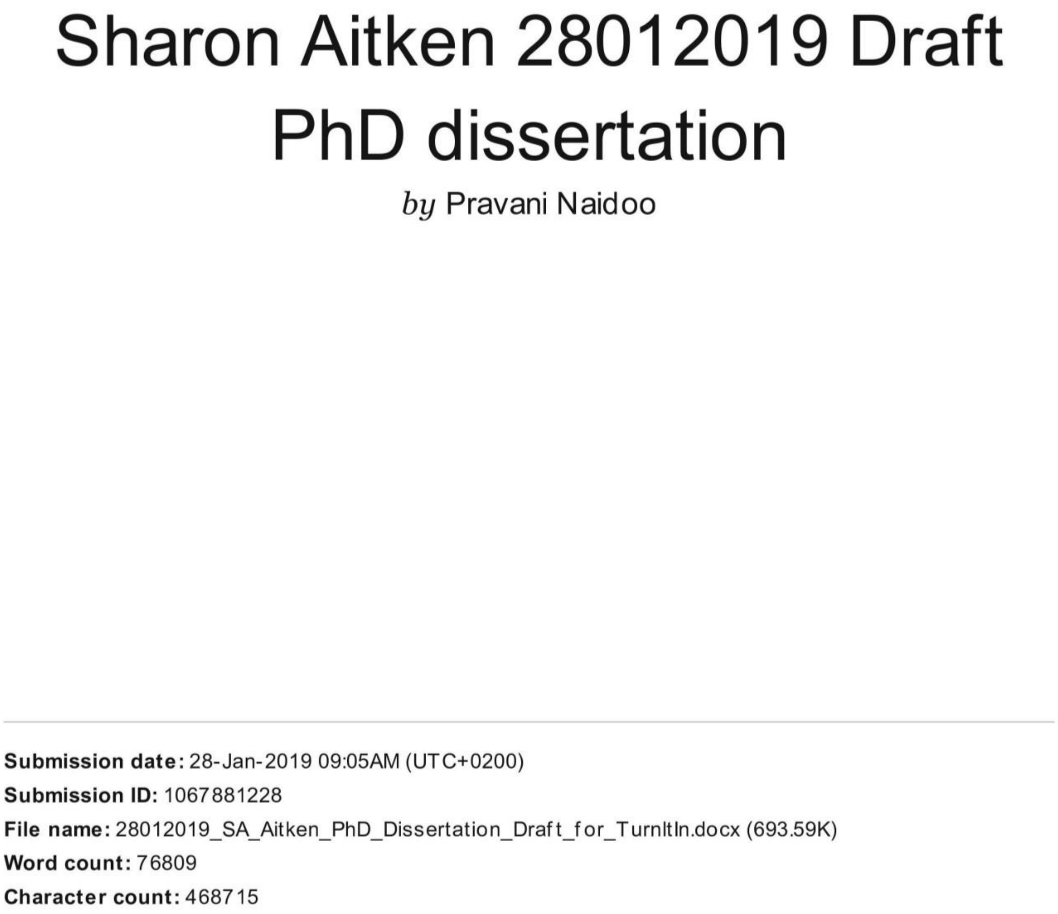
I hope to meet with you in the near future in order to answer any questions you may have and move forward with this project. Please do not hesitate to contact me at any point should you wish to discuss things further.

Kind regards
Sharon Aitken
Educational Psychologist
021 7621355

Date	Date
Signature of researcher	Signature of research supervisor

APPENDIX J: Turnitin Originality Report

Turnitin is an internet-based plagiarism detection service available at the library of the University of the Free State. Similarity index percentages of below 15% indicate that plagiarism has not occurred. A similarity index of **8%** was indicated in the feedback received after submitting this dissertation to Turnitin (see extracts provided on the following page).



Sharon Aitken 28012019 Draft PhD dissertation

by Pravani Naidoo

Submission date: 28-Jan-2019 09:05AM (UTC+0200)
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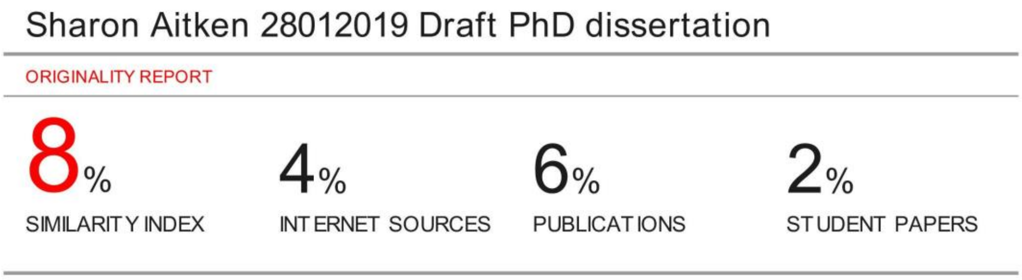

Sharon Aitken 28012019 Draft PhD dissertation

ORIGINALITY REPORT

8%	4%	6%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

APPENDIX K: Rayne Case Study

Transcript 1: Rayne Interview 1

1. **Interviewer (S)**: And now it's recording so we'll just put it here so that we can see that its recording and then what I'll do ill just every now and then I'm just going to just press it so that I can see that its actually still is working because it's the worst otherwise.
So why don't you tell me how did it all begin for you, I mean from the early?

2. **Interviewee (R)**: It's been for like a long long time, I think I first got it when I was, I think eight I got diagnosed.

3. **S:** Diagnosed at eight, so and then obviously sick before then?

4. **R:** Yes, ja, I had like, everything I was sick, I had like joint problems all the time and I got diagnosed at eight and I was, I don't know somewhere in primary school, Grade school, something ja, and then ja just like um it did take a long time to like get the proper diagnosis everything, lots of doctors' appointments and everything.

5. **S:** And what kind of illnesses, I mean you had the joint pain, were there other symptoms that you had because everybody's unique, everybody has different kind of….

6. **R:** I had stomach problems as well, and like throat problems, and I had um had a tumour when I was 12, ja

7. **S:** What kind of a tumour?

8. **R:** Um ag, I've forgotten it, it was in this cerebrum thingy here.

9. **S:** Was it benign?

10. **R:** It was benign ja. Um but it started growing when I was eight and they didn't see it, but only, ja got bigger and everything, they only removed it when I was 12 ja. And then ja, normal like. Obviously when I got flu its like um like more hectic and everything.

11. **S:** It exasperates all the systems

12. **R:** Ja, yes ja

13. **S:** Symptoms. And when you say you have stomach complaints, what is that?

14. **R:** It's just like, constipation, diarrhoea, all different things like um like there, if I eat certain things, like dairy then it gets worse and everything.

15. **S:** And wheat?

16. **R:** Yes, Ja basically so I just like cut down on those and then um I think it's visaligro, the dizziness thing, you get dizzy all the time, that as well, ja. And ja [inaudible, 02:18]

17. **S:** All sorts of different symptoms

18. **R:** Ja, ja

19. **S:** so how long did it take you to get a diagnosis?

20. **R:** Um…

21. **S:** When was the earliest you can remember being ill?

22. **R:** Ah its ja, Grade 3.

23. **S:** Grade 3?

24. **R:** That's when I had a problem with my hand, I had joint pains in my hand so I had to use a splint in my hand and I couldn't write so I had to use like a computer so I could write and do some work, ja that's what I remember.

25. **S:** And then you would've only been diagnosed then later, after that?

26. **R:** Ja probably, ja

27. **S:** Can you remember when you were diagnosed?

28. **R:** I can't, my mom probably knows, I honestly can't remember, I've just, I've had this for like my whole life so I can't remember exactly when I was diagnosed.

29. **S:** Hmm so you can't remember when you were told?

30. **R:** No, no can't remember when I was told

31. **S:** Hmm, mm and who's your doctor?

32. **R:** Dr X

33. **S:** Also Dr X also Dr X ja. So how does your illness impact on you at the moment?

34. **R:** Um well right now, um with high school and everything, sort of stress and everything, this, it has flare-ups and everything, right now it's not that bad, like I had a flare-up like I think last term, which is a few months ago and um it just meant I missed like a lot of school and everything and so I fell behind a lot in my school work, ja. Um, but right now it's not too bad, um.

35. **S:** Are your flare-ups stressed related, as well?

36. **R:** Yes, that's what they, that's what they think it is, ja it's all stress, like like your emotions trigger it and everything, that's what they think it is right now, ja.

37. **S:** Cause different people have different triggers. Definitely, a virus I know triggers mine, and mines definitely also triggered by stress.

38. **R:** Yes, ja that's always ja

39. **S:** And so at the moment how are you, where is the pain and?

40. **R:** It's not that bad, honestly right now. It's my stomach that's the main problem and but it's not too bad, ja I think I'm keeping it under control right now which is good, ja.

41. **S:** And what strategies are you using to keep it under control?

42. **R:** Um just take my medicine all the time, like not like um stressing out too much, like exams are finished so it's good it's like a relief and everything and then try not to like go out that much like long nights and everything. I just like try and take it easy and everything so it doesn't get like, unbearable.

43. **S:** Mmm, so there was something that you just said um trying to control your stress ….

44. **R:** Ja.

45. **S:** How do you do that?

46. **R:** Um, okay so I think it was the beginning of this year I was very very sick and I missed a lot of school and I was just like home bound for so long and then um I just like we needed to fix this. I started going to see a physio for the pain, then I started to go see a psychologist as well, and she like kind of like basically said we have to, it's all the emotional pain and I have to like just, um, control my emotions which will help with the pain, ja, I think that's worked.

47. **S:** Did it work?

48. **R:** Yes. Ja, I'm still seeing her, but it has worked a lot.

49. **S:** So were you bed ridden or house ridden?

50. **R:** House ridden basically, ja, I was just, ja, I was very sick, I missed so much school.

51. **S:** Sure and when you say very sick, what is very sick?

52. **R:** Um it was um, it was basically, I have head pains, headaches a lot and they get very bad and I can't like, um, [dog barks] ooh Pinkie, I can't see anything too bright or anything. I can't, like, if I stand up and walk it even makes it worse. So that's the main thing is my headaches, ja.

53. **S:** Is there inflammation in your brain that causes …

54. **R:** That's what they think it is, ja, and it's just like the dizziness and the nauseous all the time as well. It just like very hard to like go through the day-to-day activities and everything, ja

55. **S:** Mmm, and how is your school around that, I mean so how many days did you miss, you say you missed a lot of school…

56. **R:** Um, like, I went like once a week or something – but I still missed a lot. I probably missed a lot, like a month probably. I missed a lot, ja, but then my primary school was very helpful when I was sick but my high school isn't like that, helpful, ja. Like the teachers they, some of my teachers do help me catch up with school work and everything, others don't, ja.

57. **S:** Do you find that um they don't understand?

58. **R:** Ja, I don't think they understand, ja, but then I have um close friends who help me catch up a lot ja.

59. **S:** And are they accommodating with like allowing you to bring you something to keep you warm?

60. **R:** Ja, ja they are.

61. **S:** and let you move around a bit?

62. **R:** Yes, yes they do, they are very helpful with that, but I don't normally do that ja.

63. **S:** why, why don't you do that, just out of interest?

64. **R:** um I just ah, I don't, I mean it doesn't really get that bad that I need to like stand up and walk around in class or anything, during exams, like it doesn't get that bad, I can sit still for like a few hours.

65. **S:** Mm, mm so you not needing those kinds of allowances?

66. **R:** Unless it gets like really really bad ja.

67. **S:** And then you were saying the other way you cope is to make sure you take your medication…

68. **R:** Yes

69. **S:** So what are you taking?

70. **R:** Oh so many things

71. **S:** Really, tell, tell me what you taking?

72. **R:** Oh my mom knows everything but I just, I'm on Trepiline, and then Ebutech

73. **S:** Is the Trepiline for the chronic pain or for the sleep?

74. **R:** Ah the chronic pain

75. **S:** For chronic pain

76. **R:** Also for the sleep, that's very nice

77. **S:** Also

78. **R:** What else, um Syngen

79. **S:** Syngen? That's not one of the biologics?

80. **R:** I think it is, ja. I was on it before, but then when they gave it to me as an antidepressant, even though I didn't really need it, but ja. Ja um and then other stuff as well, my mom knows everything, ag I can't think, ah Vasinal, yes that's the other one.

81. **S:** Okay

82. **R:** Ja, I can't think of everyone, ja.

83. **S:** So it's like a handful of pills?

84. **R:** Yes, it's a lot.

85. **S:** Do you spread it out through the day or…

86. **R:** Morning and night

87. **S:** Morning and night, ah. Shoo and that can't help with your stomach?

88. **R:** No it doesn't, um, like my stomach I don't even know what happens, just like one day its fine the next day it's like terrible, so I don't know. It just like kinda comes and goes, so ja …

89. **S:** Mmm, mmm, I think that's what a lot of the participants have been saying is that the unpredictability

90. **R:** Yes, definitely.

91. **S:** You just can't plan.

92. **R:** Ja exactly, like if you plan, like if I make plans with friends and the next day I'm sick and I can't go then I have to cancel. So I miss out on a lot of my social life as well when I'm sick, ja.

93. **S:** And how do your friends deal with that?

94. **R:** Um, I have a very close friend whose known me, my whole life, and she knows my sickness and everything so she understands but she um, she is helpful and everything. They all understand what I go through, but I don't think they really like know, like, or when I miss school they think that I just got a cough or something but its just not that simple you know.

95. **S:** Do you think they think you bunk?

96. **R:** Ja

97. **S:** Okay

98. **R:** I'm sure they do.

99. **S:** Do you find that sort of negative vibe, I'm not saying that they mean or anything but do you get any of that kind of like, undercurrent of like …

100. **R:** Ja.

101. **S:** Really?

102. **R:** I do sometimes, when I… because I don't expect it to come, like you said like, I can be really happy the one day at school and the next day I'm sick, they think that I'm bunking, ja so that's the thing ja.

103. **S:** and i think it's very difficult to if you don't have the arthritis where things swell up ….

[10 minutes]

104. **R:** Yes. Ja, you don't have any proof that you sick, it's just ja…

105. **S:** It's like invisible sort of.

106. **R:** Ja.

107. **S:** Ja, ja so you are having that and then how do you manage yourself mentally, I mean I know you now have a psychologist so that's …

108. **R:** Ja, she does help a lot, ja she's mainly the one that I talk to about everything that I really, like I'm not really open with my friends about my emotions, mainly just to her.

109. **S:** How come not to your friends?

110. **R:** Um, I don't know, never really been like the person who's like really open to everyone and everything like that, I just don't want to feel, like I'm being a burden to my friends, and telling them all my problems and everything so I don't usually tell anyone anything, ja.

111. **S:** Just keep it to yourself

112. **R:** Yes

113. **S:** Do you also protect your parents?

114. **R:** Um, what like I don't tell them anything, what?

115. **S:** Do you sometimes not share with them?

116. **R:** Usually not, usually it's my sister, older sister, but never, not normally my parents.

117. **S:** And why do you not want to share it with your parents?

118. **R:** ah I don't know, I just I don't feel open enough, comfortable enough to tell them everything because there's like a lot of things we would have to get into, ja….

119. **S:** Okay, okay. Is that because it's just too much of a mission and it's too exhausting to tell them everything or you want to, not, you don't want them to know how bad it gets or?

120. **R:** Ah, I think they know how bad it gets, but it's also like I don't think they understand as well.

121. **S:** But your sister does?

122. **R:** She does ja, I tell her everything as well but she knows like when I'm sick and she like helps me through it and everything.

123. **S:** So do you feel, I mean how does that make you feel, not being able to talk to anybody or?

124. **R:** It is a like sad and depressing sometimes, that I can't like go to someone when I'm really down like go and talk to them so ja so I just like, I journal and talk to my counsellor as well.

125. **S:** Well at least, I'm glad you have a counsellor because that's a big help.

126. **R:** Ja, it is ja.

127. **S:** So your coping strategies then is, is making sure you taking your meds, um got your counsellor, got some people that you can chat to, are there ever other ways that you help yourself?

128. **R:** Um, I guess one of the things like, um, like if I miss school and I fall behind, I get more stressed so I like try to like catch up, like if I miss school I try to catch up the work and everything at home and help myself at home and everything which makes me like, um, more comfortable and less stressed and everything, and I don't get that sick, ja.

129. **S:** And if you compare yourself to typical teenagers, how do you see yourself?

130. **R:** Um, probably like I do go out a lot and I have friends and we do, do see each other a lot and I go to parties and everything and have fun, but like there's only a certain amount of things that I can do, like other people can like stay at a friend's house and like for like two nights in a row and not go to sleep for like two days and everything and I can't do that. I can't like manage through that, but I do um like I do appreciate my friends and everything a lot and I do have fun with them so I don't think I'm that different, it's just like the pain and everything obviously.

131. **S:** And I think form what you saying, um its learning how to manage what you can do?

132. **R:** Yes, basically, ja

133. **S:** … and then not overdo it when you are feeling good…

134. **R:** Yes, ja, that's the problem you see when I am feeling good I wanna overdo it and then ja,

135. **S:** and then you suffer the consequences of that?

136. **R:** Yes.

137. **S:** Um if you were to give advice to somebody whose just been diagnosed with JIA, what, what advice would you give them?

138. **R:** Um, I would um, I would just you know, I mean it's hard to get through, but you just have to get through it, like you think you're going to struggle getting through it and everything but it does get better and everything. Medication does help, when the swelling does go down like the joints do get better. But it just it's a tough road, but you can get through it, there is an end, ja.

139. **R:** Mm and how would you tell them to get through it?

140. **R:** Um with you know trying to be as normal as you can, like seeing your friends and everything and coping, trying to cope with school and everything, doing, just like trying to ignore basically your problem but still like have it, and take care of it and everything, I know that's really bad advice, but ja.

141. **S:** No, no, no there's no such thing as bad advice, I was just trying to understand what you were saying, so have I got it right that um the way in which you cope, what you would suggest to them is ja you've got the disease, manage the disease but don't make it your life.

142. R: Yes, ja basically don't.

143. S: If you can forget about having it then go …

144. R: Yes

145. S: Go live?

146. R: Yes, cause that's what I would do, rather go and if you a teenager with this, you have to enjoy teenage years, ja because I mean you're only in high school for a few years and you only have these certain friends 'til you're out of school and everything, so you just have to you know enjoy your time.

147. S: And do you have dispensations and things for your exams, somebody to write for you or?

148. R: Um no, no, no, I write them all myself and everything.

149. S: That's not a problem for you?

150. R: That's all fine

151. S: And you don't need extra time, that kind of, I know sometimes, one of the reasons I got into doing the research is cause I had to help a kid with getting extra time for her exams because it had affected her fingers …

152. R: Oh did you. Yes, ja, in Grade 8 um for our end of year exams I was very sick, and I had to be, I couldn't do any of them so ja I missed, I almost repeated the grade.

153. S: That's what I was going to ask you

154. R: Ja, I was so close…

155. S: So were they going to repeat you because you didn't know the work or were they going to repeat you because you hadn't been to school enough?

156. R: Ah because I hadn't been to school enough, ja they were going to make me repeat the grade but then ja I just …

157. S: Hmm I had that happen to a girl who had fibromyalgia, I was, I was, ah it's one of the things I'm hoping to do with the research is, is make the schools more aware of the fact that actually you don't need to be, you can still pass without having to go to school ….

158. R: Ja, that would be, that would be really helpful, ja.

159. S: What other things do you think I should be sharing with professionals and teachers and things?

160. R: Um

161. S: What would help?

162. R: Ah, maybe just like um, making them more aware of the problem because people see, they don't like see arthritis as a big thing, it's just like they think it's just a joint pain and it's much more than that. So making them like more aware and more like um knowledgeable about the, the disease and everything and that its um, it, like it, ja, like you said it looks invisible but it's there, ja.

163. S: And that it's so often systemic.

164. R: Yes.

165. S: and it's not just oh my little pinkies sore.

166. R: Yes, exactly, ja

167. S: Mmm, another thing that has come out of the interviews and I don't know if you've experienced it, is relationship with doctors

168. R: Oh yes

169. S: How's your relationship been, and how have you found, and not just Dr X um but the doctors and the professionals that you've worked with in general?

170. R: Um, it has, I do have a close relationship with them like um I think it's quite good. Dr X especially I have a close relationship with her, my mom, they like work together or something like that ja. Then I have my neurologist as well, he's very nice to me and everything, but ja, I mean they all very nice and very helpful ja.

171. S: So you have a good relationship, what would you say to somebody who didn't have a good relationship with their doctor?

172. R: Well I mean it depends on if the doctor actually helps or not, usually they are very helpful but they can be really rude, like I had a neurologist before, he was very very rude, but he was brilliant.

173. S: How was he rude?

174. R: He was just like, he wouldn't take an interest, he would just like….

175. S: I'm just checking

176. R: He would just um like send me on 50 million tests and everything and do this, he wouldn't like take an interest in my life or anything he would just like, like he was very professional that's the thing ja but he was too professional.

177. S: You mean like …

178. R: No

179. S: ….conquer on the term professional. Okay so he did his job but didn't create much of a relationship with you. I had something else that somebody mentioned which was that um she found that the doctors talked to her mom or her parents and not to her

180. **R:** Yes, yes

181. **S:** Even while she was in the room

182. **R:** Ja, it's always a problem, especially with my mom

183. **S:** Really?

184. **R:** Ja always ja, specially with Dr X its usually with my mom talking, ja

185. **S:** And how does that make you feel?

186. **R:** Um it, I mean I guess my mom knows more about medication and everything so she does talk more but I mean I still don't get like, like she doesn't know what I'm going through, she can't really describe it for herself so like I do want to talk but I'm not very good at describing, I don't know if you can tell.

187. **S:** You doing just fine, you doing just fine. So please tell me when I'm getting it wrong cause I'm just trying to reflect back to you what I'm hearing, so do I, am I hearing correctly that your mom does a lot of, most of the talking and that sometimes you might disagree with what she's saying?

188. **R:** Yes, I do disagree sometimes

189. **S:** And then you…

190. **R:** I input, and say whatever is wrong

191. **S:** You do input?

192. **R:** Yes, ja

193. **S:** Okay, okay that's what I wanted to check, cause I wasn't too sure if you were then not saying

[20 minutes]

194. **R:** No I do, if something is wrong I do say it ja.

195. **S:** Do you think that's something that needs to be fed back to the doctors?

196. **R:** What like?

197. **S:** That they need to actually speak to the teenagers

198. **R:** Ja definitely cause it does, um, um ja definitely to speak to us alone ja, cause sometimes I mean….

199. **S:** To speak to you alone without your folks there?

200. **R:** cause I mean. I mean my parents, our parents should be there, obviously, but I mean it would be nice if they focused more attention on speaking to us instead of speaking to our parents.

201. **S:** So a maybe have a session with you and your folks and then see you on your own for 10 minutes or something

202. **R:** Ja, maybe ja

203. **S:** Do you think there are things that you would share with your doctor if your mom wasn't there?

204. **R:** I would like, you know like embarrassing things like that, I would say ja if my mom wasn't there ja…

205. **S:** What, what would be embarrassing things, would you be able to tell me an embarrassing thing or?

206. **R:** um just, ah

207. **S:** What would be embarrassing?

208. **R:** Um well I mean like different pains in like the weird places and everything, you're not sure of and everything and all those things ja.

209. **S:** Okay, okay

210. **R:** You not sure if it's like relevant to what you going through but you want to tell someone but you can't like, like it might not be relevant, ja.

211. **S:** Can you bounce those off, past your psychologist?

212. **R:** Um I have some, ja, ja.

213. **S:** Ja, I'm just going to pause on those, ja, yes I can understand, yes it would be much easier to ask particularly around female issues if your parents were not in the room.

214. **R:** Ja definitely ja

215. **S:** Um so one of the things I'm hearing with Dr X is that she's very good at keeping you guys in a paediatric environment whereas a lot of the rheumatologists actually when you 13 you move into adult.

216. **R:** Yes

217. **S:** How would you envisage that process going for you? She keeps you until you what, 16 or 18.

218. **R:** Ja, I think its 16, I think it's 18 cause I am 16 now but I still see her so, I think its

219. **S:** So you still see her?

220. **R:** Ja, I don't see her that often ja but I think um like the environment, like her office and everything is very child friendly and everything is very like um comfortable and everything and when you go to like, if you go to like more, the older rheumatologists people um it would be more professional and everything and I don't know I think I'd probably prefer staying with Dr X in her um more comfortable environment ja, but I mean I know sometime I'm going to have to….

221. **S:** Do you think there’s something that can be done that helps you through that transition phase?

222. **R:** Um

223. **S:** What would you want to happen?

224. **R:** Maybe like not going straight into the different phase, you can like um maybe see her in the same office that you would see the other, the older rheumatologist doctor and then you know if that makes sense.

225. **S:** So you would want to see her in the new environment for a couple of sessions.

226. **R:** Maybe. Ja and then, new doctor comes in like ….

227. **S:** And then bridge over to the new person?

228. **R:** Ja

229. **S:** Is it something that worries you at this stage, or you not thinking about it much?

230. **R:** No I don’t really think about it, like I’ve gone into so many doctor’s rooms that I really don’t mind, I really don’t think about it much.

231. **S:** …and of course, they wouldn’t all have been paediatricians, paediatric …

232. **R:** Ja but I don’t think I really worry about it that much, like I know it’s going to happen nothing you can do to stop someone aging ja.

233. **S:** Mmm, what is it I need to ask you? Is there anything at this stage that you can think of that I haven’t asked you that would have been important, I mean we can literally take a while to think if there’s something

234. **R:** Ah I can’t think of anything right now, I really can’t think of anything now

235. **S:** Mm so often I turn off the phone, the recording device and then all of a sudden we can come up with 101 things that we want to talk about

236. **R:** Oh, oh I can’t think of anything right now, I’m not too sure, ja.

237. **S:** Have you found it helpful um being in touch with other people who have JIA?

238. **R:** Oh yes we did, when I first got diagnosed, no, no a few years after I got diagnosed, we had like, I remember we had like a get together type group thing we all, couple of teenagers and I we got together and we spoke about everything, and it was parents in one room and children in another room, it was very nice and then we um started like a group, WhatsApp group, Facebook group and everything and then. But there was an older girl Nicole, but now she’s like in her 20s something she’s doing great and everything, she left the group and she’s like fine, and then Micaela, I think you saw her but ja I’m still in contact with her sometimes. But it was nice like we would give each other advice and everything and it was very helpful. It was nice you know to see other people and what they going through, like the same as me and everything, so it was very nice.

239. **S:** So are you keeping that going, so you still see Micaela, are there others?

240. **R:** Ja, I still see her, ja she's a family friend, I still see her but um but not so much anyone else, we just kind of, we kinda grew up and like everyone's getting better and everything, so we don't really talk that much anymore ja.

241. **S:** And possibly want to be with people who don't have that….

242. **R:** Yes, no exactly …

243. **S:** Get some normality in your life ja. Um have there been any specific highs or lows in this journey of yours, anything that's been like a particular challenge or a particular help or specifically traumatic or joyous?

244. **R:** Um well the operations are obviously a low for me, ja …

245. **S:** The operations again was the brain tumour.

246. **R:** The brain tumour ja and then just like the normal like colonoscopy's and everything

247. **S:** You see now that's not, we don't know about all these things so ja that's, that's, I didn't realise you've had those …

248. **R:** Yes, no, I've had them, ja and …

249. **S:** So colonoscopy's, how many of those have you had?

250. **R:** Um probably like three, ja, it's the whole stomach thing and everything, ja um

251. **S:** And what does the colonoscopy, has it shown anything?

252. **R:** No, never shows anything, ja

253. **S:** That's good

254. **R:** Ja

[Laughing]

255. **S:** That's a good sign

256. **R:** Ja it is. Ja and then um, also lows like when I um get really sick and like I'm on crutches or something at school and I can't be involved in normal activities, so I feel left out a lot ja

257. **S:** So, ah, I'm trying not to put words in your mouth, um but the feeling of isolation has been a theme that's come up in others interviews

258. **R:** It has

259. **S:** Did, when you're feel sick, you feel that same way?

260. **R:** Yes I do ja. Cause it's just like um when I was in primary school, go on like, I had problems with my ankles and I would go on like crutches like every year, so I felt, I was like left out a lot in school ja, I couldn't do like PE and everything, it was just like ja…

261. **S:** Sitting on the side lines watching

262. **R:** Ja, I couldn't even go up the stairs without someone helping me, you know, so with like my school bag and everything so it was ….

263. **S:** So isolation and then dependent on people?

264. **R:** Yes, you do get, ja that's what I try to avoid being dependent on other people and everything cause I want to like be my own person and everything but then I have to rely on other people to help me, through this and everything ja.

265. **S:** Do you find that affects at times how you see yourself or your identity?

266. **R:** I think it does sometimes ja, like I was talking about it with my counsellor, about how I want to like be independent and everything but it's hard for me cause I wanna, have to rely on other people and everything to help me.

267. **S:** Mm, um and I think, I mean in adolescence that is the time period where you are really experimenting with your new identity and everything

268. **R:** Yes, yes, ja exactly, ja, ja

269. **S:** And so if you were to describe yourself now, identity wise, how would you describe yourself?

270. **R:** Um I think I definitely got more independence in my life and everything and I've become more like um you know I've learnt a lot through this, like how to handle myself and everything and I've got like, like I wouldn't, I know it's terrible to have this disease but it does like teach you how to handle situations and everything so I'm grateful for that. Um like I've grown a lot and everything, ja and I think I have changed, ja quite a lot ja

271. **S:** Do you think your peer group is on a path with you with that or do you, do you feel that perhaps you have learnt things that they have yet to learn?

272. **R:** Oh they probably still got to learn more things about it, but like I don't think anyone can know exactly what someone's going through unless you going through it yourself, ja so I don't think anyone's going to really understand it.

273. **S:** Ja I was thinking more in line of when you were saying that you have learnt how to cope with things at a much younger age?

274. **R:** Oh yes, ja

275. **S:** Do you think maybe that you have a level of maturity or insight into issues that they don't have?

276. **R:** I think I do ja, I think I have um I mean I have a higher tolerance of things, to pain especially ja and then um I think I have matured a lot ja I'm sure I have more matured than them, with them.

277. **S:** Why do you think that?

278. **R:** Just because um um, like I've just kind of been through things and like I know um I don't really know how to describe it um …

279. **S:** Its fine, take your time

280. **R:** Um, um, aaa, just I don't know, it's just I really become more mature and everything um ja

281. **S:** Are there things that they do that makes you know, okay I'm definitely more mature than them?

282. **R:** Well I mean ja, about like the way they see people and everything but that's ja, that's different ja. Um I think I have more sympathy for people who are sick and they don't really, ja so I feel I'm more mature in that sense ja.

283. **S:** And I have an interesting comment which was that they tend, somebody's friendship group tends to overreact to really what she thought was really pathetic thing.

284. **R:** It does happen, ja.

285. **S:** So that happens with you as well?

286. **R:** Yes, ja like if um like, especially this year, like last term there's was just a flu going around like the whole group, if one person got sick everyone got sick, it was just like they were all like dying and everything, so sick and everything, and I was just like you know, it's not that bad, like it is the flu but it's not that bad but ja they do overreact and everything and ja.

287. **S:** And how does that make you feel when they overreacting like that, I mean when they were like now being dramatic about having the flu, how did you feel?

288. **R:** I honestly think they just need to like, um I mean I do feel like it's really stupid what they doing, like but I understand why they do it because they haven't really like gone through this and everything …

289. **S:** And do you ever feel very angry?

290. **R:** I do sometimes especially when my friends don't, like they, they make plans without me and everything.

291. **S:** ooh ja…

292. **R:** Like if I'm sick and they make plans without me, I know I can't go but it still makes me very upset and then um ja when they don't like um, like if I'm sick for like a long time they don't send me a message saying oh how are you and where you been and everything, also makes me angry, ja.

293. **S:** So it's almost like you disappear when you not there?

294. **R:** Ja.

295. **S:** And have you talked to them about it?

296. **R:** No. I don’t talk to my friends about those things, ja no.

297. **S:** What prevents you from doing that?

298. **R:** I also don’t want them to feel like, I don’t want to feel like to them that I can be like a burden, jeez like the girl is always sick and everything.

299. **S:** Ja, she’s always sick and then now she’s making it out problem…

300. **R:** Ja that’s what I always worry about.

301. **S:** That’s what you worry about, being a burden. So anything else?

302. **R:** um I don’t think so, I don’t, can’t think of anything right now.

303. **S:** So we will probably have a second interview somewhere along the line, when I go through the data analysis, I may as well switch this off now.

[Recording ends]

Transcript 2: Rayne Interview 2

1. **Interviewer (S):** Well thank you very much for agreeing to see me again.

2. **Interviewee (R):** No problem. No problem.

3. **S:** And so this is our follow-up interview, but I just wanted to first check with the original transcript that I sent you for the interviews. Are you happy with everything?

4. **R:** Yes. Ja.

5. **S:** And I can go ahead and use those?

6. **R:** Yes sure, no problem.

7. **S:** Okay, super. And I will do the same process with this again.

8. **R:** Ok.

9. **S:** But -- So, I've come up with some areas that I'd just like to explore further, but I was wondering, since you had the transcript and since we were last together, if there was anything that you would like to say? Anything that came to you afterwards that you suddenly...

10. **R:** I don't think so. I don't think so. If I like, if I haven't figured it out in the other -- Sorry... . other interview, I'll just like ...

11. **S:** No, no, that's fine. Totally fine. Ja. No, it was just that sometimes people think some things, but to be honest nobody did. So.

[both laughing]

Nobody ever thought of something afterwards. So, perhaps before I go through sort of the areas that I have. From that initial interview, was there something important that we discussed that stood out for you, that you would like to tell me a little bit more about?

12. **R:** Maybe the part where we discussed about like the impact on school and everything, with the school and everything. Because ... Thank you mom.
[voice in the background: Ok, now here's your tea.]

13. **S:** Thank you very much for the delicious tea. So -- So you want -- You would like to just discuss the impact of it on your school and your school work?

14. **R:** Yes. Ja.

15. **S:** Do you want to just start there and tell me.

16. **R:** Sure. Not a problem. Because I think, having a . . . early in my age I think I ... The joints and everything. So when I was around eight, so that's Grade 5 I think, or something around there, and I did miss a lot of school. And I had trouble like, because I would have nerves in my hands and I couldn't write. So they had to ...

17. **S:** I remember you had splints?

18. **R:** Yes, I had splints and then I had crutches and just like, I missed quite a lot of school in primary school. Because, because obviously the workload wasn't so much in primary school, like I was able to catch up and pass and everything. But, ja, I just -- It was -- It did interrupt a lot of things. Like I was on crutches half the time. I had like electroids, those --

19. **S:** Electrodes.

20. **R:** Ja those electrodes on my knees, like on my feet and everything. And ja. And I couldn't really participate in many school activities and everything. But I did try, ja.

21. **S:** And tell me, what were the feelings that you had while that was all happening?

22. **R:** Well, I mean, besides the pain, like it was just like, felt kind of left out from everything. Ja, because I couldn't really participate in many things and I would miss a lot of school and just like events and gossip and everything. All of that stuff. Ja.

23. **S:** And -- And what kind of thoughts would go through your head when you were unable to participate, or ... Can you give me some examples?

24. **R:** Well like, for example like I would think that I was too different and everything and people would like be so sympathetic for me. I didn't always want that.

25. **S:** Why did you not want them to be sympathetic?

26. **R:** I don't know. I've always -- I don't think I've ever wanted people to feel that sympathetic for me, because it just makes me feel like people have pity on me and everything. Ja, and I don't really want that. I just want to be normal, and ...

27. **S:** Ah.

28. **R:** [laughing] Ja, I just want to be just a normal teenage girl. Ja.

29. **S:** Ok, so are you saying when they express pity that means you're not normal?

30. **R:** Ja, it does. Because I mean since -- I mean, since I've been eight I've been having a lot of that, sympathy, sympathetic and pity things and everything. Which I don't like. Like I obviously didn't mind in the beginning, but as like I got older and it still continued and I just didn't ... Ja. I just wanted to be back to a normal girl and everything. Ja. And I always had those kind of feelings. Ja.

31. **S:** And in, in that time when you were maybe sitting... Because I remember from the last interview you often had to sit out of PE?

32. **R:** Yes.

33. **S:** And you would be sitting on the bench, and at swimming. How was that for you? I mean ...

34. **R:** I didn't -- I wanted to be involved in school, like I wanted to get involved in it, but I knew that if I ... Because it primary school it was mainly my joints, like my hands and my knees and everything. Because I knew I couldn't, I wasn't able to do it, so I mean ... But I just felt very left out. Ja. So it was quite sad but I knew it was for the best.

35. **S:** So when you say, "left out", what, what were the emotions behind that?

36. **R:** Mainly like depressed and everything. I don't want to say that I was really depressed in primary school, but like, just like sad feelings. Like, and -- Ja. I'm trying to think of other emotions. Ja, it was mainly just sad and angry and everything. Ja.

37. **S:** Sad and angry?

38. **R:** Ja.

39. **S:** What was the anger about?

40. **R:** It was just like, why. Like of all times, like it has to happen to me now? And why the hand pain and everything had to happen to me now, when I could be in the pool swimming and like doing PE and everything. Just, ja.

41. **S:** And, and what -- What were you angry at?

42. **R:** At my arthritis. Having the flare-ups and everything and the joints and everything. Ja.

43. **S:** And the sadness?

44. **R:** Because I couldn't be hanging out with all my friends. Ja. ... for me. Ja.

45. **S:** So that was kind of how it affected you when you were younger and even then you said it was a struggle to keep up with your work.

46. **R:** Yes, it was definitely.

47. **S:** So, so how -- How did you manage that? How did you cope with that?

48. **R:** Well, my teachers, because it was a small primary school, like my teachers were very helpful and everything. I had my friend who was in my class would take all my work for me and everything. She was very helpful. Ja, but I did -- Like I missed a lot, but I did catch up everything. I think -- They just introduced exams when I was in Grade 6 or Grade 7. Ja. Which I had never done exams before and it just like hit me. And then I was just like -- I remember I was better, but I wasn't too well during exams. I used to come home after exams and just like sleep. And then like I was stressed for the next thing the next day, and I just didn't have the time to study. But I did cope through it and everything. Ja.

49. **S:** What enabled you to cope?

50. **R:** What, like what I did to help me cope and everything?

51. **S:** Ja, I mean it's, it's quite a daunting thing you went through.

52. **R:** It was, ja.

53. **S:** And you say you coped, so how did you cope. What happened that enabled you to cope? What did you do?

54. **R:** I just think the -- Well obviously the support really helped me, that I used to get.

55. **S:** The support?

56. **R:** From my friends and my teachers and everything. And then like, just like ...

57. **S:** So what kind of support did your friends give you?

58. **R:** They were very, well I mean I had one main friend in primary school. But ja, she was very very helpful. She always used to come and visit me and everything. And she was -- Like after my brain, when I had my brain tumour, they all like ... Like I got a huge note from my class. Like . . . get well.

59. **S:** That was when you were 12.

60. **R:** Grade 7.

61. **S:** Grade 7, ja.

62. **R:** Yes. Ja. That was -- That was very nice and everything. And then I just like, just like persevered to get through, because I didn't want to miss exams. Because then I would be like, you know like a normal person.

63. **S:** Where did you get the energy for that perseverance?

64. **R:** [laughing] I don't know. Honestly I don't. Probably all the times I slept after the exams. Ja. Ja.

65. **S:** Because I mean, perseverance doesn't really come out of nowhere.

66. **R:** Ja, I don't know. I can't really pinpoint exactly what went where, it just like happened. I just like, I think when it first started and I used to miss a lot of school and like I just got tired of missing school and falling behind and everything. I just wanted to like go back to being normal and everything.

67. **S:** So, so what did -- Everybody talks to themselves in their heads. Would you mind sharing with me maybe you can remember the thoughts, the way you enabled yourself to persevere? Was it through self-talk? Or, did you say things to yourself?

68. **R:** I'm trying to think. It was -- Oh, sorry.

69. **S:** No, it's fine.

70. **R:** It was probably just like, like, you can get through this, and if you get through this exam, then it's one day closer to finishing the school year. And then you can be like, go have fun and be normal with your friends and everything. Just, ja. After this, high school, and then you're closer to getting out of school and everything. Ja.

71. **S:** So sort of mapping it out step by step.

72. **R:** Ja. Ja. That's what I, ja, do a lot.

73. **S:** Just get through this bit, and then ...

74. **R:** Ja, that's what I used to do. Because I read -- I don't know where I read it but I saw a quote somewhere saying that if you get through, you just have to get through the next 10 minutes, and then another 10 minutes, and then another 10 minutes, until the day is over. And just repeat that. Like if I ever had a bad day, I would do that, ja. Just get through these 10 minutes, then the next 10 minutes, and then the next, ja. Just repeat it the whole day.

75. **S:** That's quite ...

[voice in the background]

76. **R:** Oh sorry ...

77. **S:** No, no, no that's fine. I was just wondering if I have to turn the recording off, but I think it will be fine. *Sjo.* So, so there was your sort of internal perseverance and resilience, determination, and the help of particularly the one friend.

78. **R:** Yes. Ja.

79. **S:** And then when you had your brain tumour, then the whole grade.

80. **R:** Yes. It was very nice.

81. **S:** And, I was about to say, how did that feel?

82. **R:** It was very nice. I felt very special. Like I felt -- It felt really good to have people who like cared and everything. And, ja.

83. **S:** And did your friends play any other role in, in sort of helping you cope?

84. **R:** I mean they did. They would motivate me all the time because my friends, especially now in high school, I have a larger friend group**.** And they all like exceed in everything, so they kind of like motivate me to like work hard and everything and ja. Because they, like, everyone has academic colours or ... and everything and they kind of make me push, you know, and do better and everything. Ja.

[10 minutes]

85. **S:** Are they making you do it or are you seeing their results and therefore...

86. **R:** I'm seeing their results, ja.

87. **S:** So when you see your, their results, what is it you are saying to yourself?

88. **R:** That I can do it, and if I just push I can be like them. I can get academic colours, which I'm not. But, I can try. Ja. Just to improve my marks and everything too. Ja,

89. **S:** So, so you're sort of using other people as, as a form of motivation as well.

90. **R: Yes.** I think I've done that for quite a while. I always used to like see other people and like use them as motivation and everything. Ja.

91. **S:** And is there anything that they particularly do for you then that is, that helps cope?

92. **R:** I think, so, my friend in primary school, her name was Sandra, she would like when it was ... When I was -- When I first started, she would obviously always come and see me. She would always like take home my work and everything, and do a lot of stuff. But now that I have been getting better, I mean it's been going on for a long time, she is still helps me get through things and everything, but it just like isn't as prominent as it was in primary school. But ja. I mean, they always help me and they always like take home work and help me catch up exams and study sessions and that stuff.

93. **S:** At high school as well?

94. **R:** Yes.

95. **S:** Ok, and then like group study sessions with you?

96. **R:** Yes, well once. We tried it once but it didn't work. So I mainly study by myself. But, ja.

97. **S:** And that one special friend. Can you describe the importance of her in your life at that stage?

98. **R:** She was like the reason that I tried to push. That I -- She was the reason that I persevered and everything, because she would excel. And the she would, she just like came to school and she was just like smiling and she was happy and she was so kind and everything. And like, ja, she just really motivated me and pushed me and like. Ja.

99. **S:** So it sounds to me like with her, she was -- It wasn't that -- She helped you with schoolwork, but she also helped you in other ways?

100. **R:** Ja. Like her, just like. She was just like -- Her soul was just like so pure and she would come to school and she would just like ... Like her -- She would smile all the time and . . . happy. She just made me think like that what I was going through could be like fixed and I would get through it quicker. And it wasn't that bad. Like I could be happy with her. Ja.

101. **S:** So she, she sort of improved your well-being?

102. **R:** Ja, like my attitudes basically.

103. **S:** Your attitude.

104. **N:** Ja, ... my attitude. Because I used to be like -- I do go through stages where it's like, you know, I'm just so sick of this. I just want to like give up and I just feel ... I'm like totally unmotivated. And then my friends always just get me back up into it and everything.

105. **S:** How do they do that?

106. **R:** I have no idea. But they just like -- When I'm going through like those periods of time when I'm just so unmotivated, I would just like stay at home and then I'd see my friends. Like I would hear about them at school and everything, and I would think, you know, I could be there at school. And I could be talking to them and everything. And I could have, be having fun with them and everything. I don't -- I don't think that they know they're doing this, but it does impact me. Ja.

107. **S:** Yes. So you hear about what's going on and then you want to be there with them?

108. **R:** Yes.

109. **S:** Ok. Ja. And how has high school then been different now?

110. **R:** High school ... Sorry, do you want me to stop the dog?

111. **S:** No, it will be fine. So you're Grade 9?

112. **R:** Eleven.

113. **S:** Eleven? Oh my word.

114. **R:** [laughing] It's ok, don't worry.

115. **S:** Yes of course, Grade 11. Wow, so it's quite a hectic year.

116. **R:** Ja. So Grade 8 wasn't the best year for me, because obviously it was the transition into high school. And ja, it was just like from my small primary school into Northcliff High, which is just huge. And just filled with people and everything. And I think high school -- Like the teachers weren't as helpful as they were in primary school. Like there were some of them, like the special ones would help me with work and everything, but most of them don't really like care, because I mean this was so big and everything. And I did -- I think it was in Grade 8 when I missed like a whole term.

117. **S:** That was the grade you nearly failed?

118. **R:** Yes, yes, Grade 8.

119. **S:** Because you missed so much. Ja, I remember. Ja.

120. **R:** So ja, I think that's because of the fact that they they didn't really help me; I had to do it myself. I had to do it with my friends' support and with my parents' support and everything. And I had to just get through it myself. I had to. Because I had to be at that school to do work. I had to like study and like ...

121. **S:** How did you get through it? You, you say, I just had to get through it, but how, how did that happen?

122. **R:** I just -- I just didn't want to miss anything else. And I just didn't -- Ja, I know it sounds like really weird, but I just didn't want to miss out on everything. And I wanted to just be involved and I wanted to be like a happy teenager and not missing school and everything. And be, just normal.

123. **S:** I hear you with this, I really hear you. But I'm wondering like how did you get out of bed? And how did you manage to make it ...

124. R: It was a struggle.

125. S: So how did you do that? Was it just the fear of missing out or did you have other strategies?

126. R: No, I mean I still have the, like, that every morning when I go to school, like if I just, I can't get out of bed my mom like pushes me out. And then if I'm in lots of pain, I just need like tons and tons of painkillers. It's like, no, you have to go to school. So it's mainly my mom that gets me out of bed in the morning.

127. S: So you have the motivation to get to school, but when you're in pain and you're tired in the morning, your mom gets you out of bed.

128. R: Yes. Yes.

129. S: So in some ways there you're still quite dependent on your mom in some ways to get you, get you going.

130. R: Ja. Ja. I just didn't want to be like lazy you know, and just want to lay in bed. Even though I mean it doesn't make -- Like pain ... lazy, it isn't really the same thing. But people think it is sometimes. Ja.

131. S: So, so, go through that again with me.

132. R: Like, if -- If you're in pain and you spend the whole day in bed, like it doesn't mean you're lazy. But that's what I felt like. Ja. I would feel like I'm being lazy in bed. I could be doing work and everything. Ja.

133. S: So you equated -- Because the pains gives fatigue.

134. R: Yes, exactly.

135. S: Which, which makes you want to stay in bed.

136. R: Ja. Ja.

137. S: So are saying you equated that in your head as being lazy?

138. R: Yes**.**

139. S: So you -- Ok.

140. R: Ja.

141. S: And do you think that's a, a fair thing? An accurate description of what's happening?

142. R: Probably not, but that I just, that's the way of motivating myself. Like saying I'm being lazy when I'm in pain, just kind of like ... I don't know, makes the pain, makes the pain diminish a bit.

143. S: Ok. Ok.

144. R: Ja, it just kind of motivates me. It's like, no you can't be lazy and you have to go out and do this... . And then I have to do it, so.

145. S: Ok. So you're not really calling yourself lazy, you're saying, I can't be lazy?

146. R: Ja.

147. S: Ok, I see what you're saying. That is slightly different.

148. R: Yes.

149. S: Yes. Ok. And anything else to do with the school work? Because if remember rightly, your, your flares are stress related?

150. R: Yes, definitely, Ja my -- Ja.

151. S: And have you just written exams?

152. R: No, exams are coming up next term. [laughing] So I go on holiday on Friday, then three weeks back at school, then exam starts. Exams are my worst, because I just ... Especially final exams. Because everything -- And ja, I've been go -- This is why I have I have a therapist mainly. So she helps me deal with the pain.

153. S: How does she help you handle the pain?

154. R: So she -- Basically we talk about like stress-related things and emotion-related things and we try to like, like control them. So that I know like if a flare-up is going to start, like I can just ... Because there are things that trigger a flare-up. In my case it's definitely stress and emotional pain and everything. Ja, so we, we just work on like how to control it and how to make sure I don't trigger a flare-up or anything. Ja, like that.

155. S: You said that the last time and I was wondering when I re-read the transcript, how do you do that?

156. R: What? The ways that I handle ...

157. S: Ja. What ways -- What strategies are you using?

158. R: well I think, the biggest strategy is talking to someone about it.

159. S: Ok.

160. R: Ja, that's probably the biggest thing. And then just like finding ...

161. S: So talking about how you are going , how you are becoming stressed?

162. R: Yes. That's probably the biggest.

163. S: So sharing.

164. R: Ja. Talking about it. And then -- Because it, it is really hard for me to talk about things, especially to my friends. Because I don't really open up to them.

165. S: You said so.

166. R: Ja. So I mean, I think that's the biggest thing, is just talking to her. And then she helps me like ... Like she helped me -- She helps me like identify my emotions and then like how to stop them from controlling me and everything.

167. **S:** Can you give me an example?

168. **R:** So we would talk about like needing ... Like at times I can be really shy and introverted. Like, she compared it once to like being a thorn underground and then like a rose, like a rose bush on top. I think that's what she said. Ja, like a big rose bush but there's thorns everywhere. So I won't let anyone like come near or talk about me. But I was like trying to like -- I was really fragile and everything, I can . . . it and stuff like that. And then -- Then we like -- What we do is like take my emotions and make them into a person. So like I would have like anger and I would describe it as like a girl in a red dress, and like Angelina Jolie and everything. And it just helps to like, you know, put a face on it. So that I know like -- It just -- I don't know why it helps me. It just does. And then I can just like say no, and just stop... . Well, I obviously haven't done that yet, but I'm trying to work on doing that.

169. **S:** So you visualise the different emotions you need to control, so that when you feel the emotion coming you can visualise and then ...

170. **R:** Kind of like confronting them. Ja.

171. **S:** And then come up with a way of ...

172. **R:** Ja, like confronting them. Ja.

173. **S:** Confronting them.

174. **R:** Ja.

175. **S:** Ok. And what would you -- If -- What are you trying to do when you confront them? So let's use your Angelina Jolie. Ja.

[20 minutes]

176. **R:** I would just try, like if she shows up, like just try to push her down. And I would say something to like contradict her. Like if she says something like you know, you can't do this, then I would be like ... I mean I haven't worked out -- I haven't been going to her for a long time, with her for a long time. So I'm still working on it. But I want to be like ... Like she would say something like no you can't do this, and I could be, ja I can. And just be like, bugger off.

177. **S:** So confronting your, your sort of negative self-talk by identifying it. Wow, that sounds very interesting.

178. **R:** Ja, it is. I think it really works.

179. **S:** And it's working well for you.

180. **R:** Yes. Yes.

181. **S:** Ok. And any other strategies and things that you use at high school? I'm just thinking now, so with the exams coming. You know they're coming. You've got a little bit of a break and then you've got three weeks. How, how do you go about preparing for ...

182. **R:** Well ...

183. **S:** Not the exam itself, but preparing yourself for this period that's coming?

184. **R:** Oh, breathing exercises mainly.

185. **S:** Breathing exercises.

186. **R:** Ja, breathing exercises. They're like exercises where you just like -- She tells me just like relax my whole body and I would like imagine myself on a beach, on a relaxing beach. And just relaxing every muscle in my body. So then I can just like be calm and I can start working.

187. **S:** So she's doing relaxation techniques with you?

188. **R:** Yes. Yes.

189. **S:** Wow. Ja.

190. **R:** So I think that helps as well. But exams, they always just hit me no matter what I do. And they always -- Just the stress, just hits me. Ja.

191. **S:** It's -- Ja -- It is difficult, especially if you, if you get -- If you are an anxious person. Exams are always stressful.

192. **R:** Ja.

193. **S:** And anything else at high school? Was it just all mainly work-related or were there any other difficulties at high school?

194. **R:** It was probably mainly work-related. Ja. That's mainly been the whole thing.

195. **S:** Or being fine socially?

196. **R:** Ja. And -- Ja, I think that's -- Ja. I mean, obviously I have ... with my friends and everything, that would just like increase the emotional ...

197. **S:** You have what with your friends?

198. **R:** Drama, always. But I mean, ja.

199. **S:** Oh drama. Not the subject.

200. **R:** No, no. Not drama. Just like fights and everything. But you know, us being teenage girls. Ja, so we always have fights. Ja. But I think that's, ja, probably ... It's mainly work-related, ja.

201. **S:** Ok. Anything else you wanted to talk about?

202. **R:** Not that I can think of right now.

203. **S:** Ok. So I think one of the things we seriously glossed over when we were just going through the history of your journey and that was the brain tumour and colonoscopies and how that might have impacted on you.

204. **R:** Ja.

205. **S:** And so I was wondering if you could tell me? We're looking more from an emotional perspective, and coping and thought and things. So how -- How did it happen with the, the tumour?

206. **R:** I actually, I honestly can't remember the exact time because I was just so young and I didn't process it as being such a big thing. I can't remember the exact time when I, when my mom told me it was a brain thing or something. I don't even remember what I was feeling because it was just so long ago and I felt so young. And like I was like, I mean everyone has this; I didn't think it was a big thing.

207. **S:** You didn't think it was a big thing. Ja.

208. **R:** Ja. So I didn't really process it that much. I mean, when I saw my parents were really upset about it, then I knew that something was wrong. And then ...

209. **S:** How did that make you feel when you saw something was ... Or when you saw them?

210. **R:** I just get very upset with myself; it makes me feel very guilty if I see them upset.

211. **S:** Oh, ok.

212. **R:** Ja.

213. **S:** So you saw them upset and then you felt guilty?

214. **R:** Ja. Ja.

215. **S:** And did you feel scared as well, or not?

216. **R:** I did. Ja, I must have. Ja. I felt scared, ja. I just can't really like -- I didn't really process it very well when I, when I found ... Like the one thing that I remember from when I knew that it was ... But it was an obvious sign, was that I used to have like really really good balance. Like walk along -- I had such good balance. And you have to do like this activity in PE and walk along a beam. And I took one step and I fell off. Took one step and I fell. And I could not walk along it at all and that's when my mom ... And we went to the doctor and ja. MRI scan and everything. Ja.

217. **S:** Ja. And how was it to go for an MRI scan at that age?

218. **R:** Ja, it wasn't -- I didn't enjoy it. Ja. It just was like -- Ja, sitting still for nine hours or whatever. Not hours, sorry, one hour or something. Not nine hours, sorry. But I hated it so much. Ja.

219. **S:** And how was the -- Because that's usually done in a hospital?

220. **R:** Yes.

221. **S:** And how was that environment for you as a twelve-year-old?

222. **R:** I didn't -- I didn't like it. Just -- It just felt so sad being in there. Ja. And just like ...

223. **S:** What made it feel sad?

224. **R:** Just like people in pain and people going through like, all these like ... I mean not death. People like on the edge of death and everything. And everyone is just upset. But then like on the other side you have people giving birth and everything. Of course that would be a joyous moment, but I was normally obviously not in the maternity ward. But like ...

225. **S:** So you were sitting with the adults or children who were very sick?

226. **R:** The children-- Well, I was very lucky, I sometimes had a private room. But it was mainly when I was, when I was in Grade 7 it was with children. Ja.

227. **S:** And you were seeing very sick children.

228. **R:** Yes. Ja.

229. **S:** And how did that impact on you seeing those children?

230. **R:** It just made me feel very upset. I was thinking like they have to go through like this, because it's normally very sick children, I was like they have to go through this like every day and everything. That must be terrible for them. And ja. Ja.

231. **S:** And did that make you have any concerns about yourself?

232. **R:** It did make me feel lucky, honestly, to not be in that much pain, but ja, not really. Because the children I would sit with had like diseases and stuff. And like the one time I had a lady with cancer opposite me.

233. **S:** A lady?

234. **R:** Ja.

235. **S:** An adult?

236. **R:** Yes, that was -- It was a few years ago though, it wasn't when I was a child. Ja. Ja. So it just made me feel lucky to not go through that, but also very depressed for them. Ja.

237. **S:** So it -- It's quite an emotional burden to sit there and see all those ill people?

238. **R:** Ja. Ja. And especially in the ICU ward after surgery. It was the worst. I hated it.

239. **S:** How did, how did you feel as they prepped you for surgery? Because don't they shave your head and everything?

240. **R:** Oh no, I luckily didn't. I was actually very scary thinking about it now. Like, I was very scared. Because I was just like, I was scared they were just going to shave off all my hair. Because it was only at back here, but I was scared they were going to shave it all off. I was like, no, you're going to have to just ... You can clip the rest of the hair up and just like shave underneath that. And it was just -- It was very scary. Because the, I think it's the anaesthesiologist, ja the person was like trying to talk to me and calm me down and everything. And I was just freaking out inside. And ja, it was just very scary.

241. **S:** What were you -- What were you thinking when you were freaking out inside?

242. **R:** I was just thinking -- Because I hadn't really -- I didn't really -- I hadn't really heard about like a brain tumour being done or like what happens when you remove it and what happens afterwards. I was thinking like what's going to happen to me. Like how am I going to feel after this and like, I don't know what I'm about to go through. Ja. Ja.

243. **S:** And did anybody take time to explain things to you?

244. **R:** I don't think so, no. I mean, I just know that -- Like I don't even know -- I don't know where it was. I don't even know how it looked or anything. I just know it was a brain tumour. I don't like know anything about it. I just know I had a brain tumour removed. Ja. Ja.

245. **S:** And -- And -- How -- How did they react when you said you didn't want them to shave your hair, all you hair off?

246. **R:** Oh, well. I mean, my mom actually told them that. Because I made sure I told my mom. I was like, I'm clinging to her the whole time, I don't want to shave all my hair off and everything.

247. **S:** What, what was so scary about them shaving all your hair off? I'm not saying that it was scary. What was the issue for you?

248. **R:** I just didn't want to feel -- I didn't want to go to school and like everyone make fun of me. And then also this pity and sympathy and everything. Ja, I didn't want that. Ja. It was -- I think it was a very scary part of my life during then. Because in the ICU ward I would sit in myself, by myself, sorry, in like this small room. And then I didn't want to eat. Because I didn't -- I didn't have the appetite for anything, so I didn't want to eat, didn't eat for a few days. Like I just, then my parents -- I had like a bandage on my head obviously and my parents wouldn't let me see how it looked. So I just sat there like feeling around and everything, and there were ... bandages and everything. And there was like a metal bar at the end of my bed that was reflective, so I would try like, try look, and see how I looked and everything and just see like pimples and like hair growing and everything. And just like this whole thing on my head. And I would just get so upset.

249. **S:** Do you think it would have been better or worse if they had let you see what was going on?

250. **R:** Probably worse.

251. **S:** Ok.

252. **R:** Ja. I mean it was a good thing, but I did want to see how I looked then.

253. **S:** What -- What -- What was it that made you want to see?

254. R: Well, I mean I really care about my appearance most of the time, ja. So I really just wanted to see how people would see me. Like how people saw me in bed and everything. Ja.

255. S: And so you were in ICU; were you by yourself or ...

256. R: I was by myself in a separate ward, ja.

257. S: And how was then, was the interaction between you and the nurses and the doctors?

258. R: Well the nurses were -- The doctors were pretty helpful and everything. I remember the one day when I was like, was very like depressed about being there and I like started crying. And like the nurses just happened to be walking past and that time they came in and I had a sore throat. And they had to give me stuff and everything, because I felt so depressed. And they were very helpful and very kind and everything. But I was just very upset about being in there. Ja.

259. S: And -- And -- And did you have any thoughts about the consequences of having the brain tumour and having it removed?

260. R: No, I didn't really think about it. I really think about that much at the time.

261. S: Ja, it's probably because you were so young.

262. R: Ja. That's the thing. I didn't really -- I didn't really know anything about surgery like that and everything.

[30 minutes]

263. S: And if you reflect back on that now?

264. R: I think I definitely would have ... I definitely would have been more scared than I was back then. Because I would know like everything about it. I would research it and know everything about it. Like I didn't even know, what's it called, catheter or whatever?

265. S: A catheter yes.

266. R: Ja, I didn't even know that was in me like half the time. I just came -- I was just like. I don't know what I was thinking. I mean, obviously I didn't go to the toilet; I don't know why I didn't just put two and two together like that. I didn't even know. I just saw this tube one day and I was like, what? What even -- What is this? I didn't even know.

267. S: So nobody had told you were, had had a catheter inserted?

268. R: Ja, no-one told me that. No. So it was very shocking, honestly. And ...

269. S: So it was shocking to find out that you were, that you had a catheter?

270. R: Ja, because I didn't know about it. I just saw it the one day and I didn't want to ask and didn't know what they were. So, ja.

271. S: So there wasn't lot of -- You weren't given a lot of information about what was happening.

272. R: Not really, because I think I was just so out of it as well from the medication and everything. Ja.

273. S: And on reflection now, what would you have wanted? What would you want -- Would you have wanted things to be different? Or have -- Or have them approach it differently?

274. R: I feel like -- I think -- I think it was the best that I didn't know that much about it. The doctors didn't tell me much about it. Because like -- Because of that I didn't like freak out as much as I would. And ja, I think-- I mean, I obviously want to -- I do want to know about things and what's going on with me and everything. So I did want to know, but I'm grateful that they didn't tell me, because, ja.

275. S: So you think it was sort of age-appropriate that they didn't?

276. R: Yes.

277. S: And maybe explaining to you beforehand that you were going to have a catheter inserted? Do you think ...

278. R: That would have been -- Ja, that would have been nice. But I mean the doctors, the nurses were very nice. When I went through a, for a colonoscopy, like the doctor or nurse was talking to me, she was like, do you know whether you're going to be getting a tube through here and there, and everything is going to be okay. And all that stuff.

279. S: Was that your first colonoscopy?

280. R: I think so, ja.

281. S: And so in that situation -- So tell me, was it -- The nurse was more informative?

282. R: Yes, she was very nice. Ja, she was, ja, talking to me about it and like I think this was just before I was going into theatre. So there was like a whole bunch of people sitting outside and everything, and like I just ... They just all looked fine and happy and healthy and everything, and then the nurses were like, you're going to be ok, we're just going to put you under anaesthetic and then they're going to put a tube with a camera through here and everything. And then I said, I'm happy that you told me that and helped me. Like calmed me down and everything.

283. S: And how was the doctor through that procedure? Because you would have gone for a pre-interview ... Not an interview.

284. R: Ja, like a ...

285. S: Pre-session. Ja. Consult.

286. R: Ja, no, he was very nice and he was very sweet and everything. Ja. So ja.

287. S: But how did that impact on you emotionally? So you'd had the brain tumour operation and now you had to go back into the hospital for a colonoscopy.

288. **R:** Oh, I hate hospitals so much right now. Ja, I just -- It just makes me very depressed, ja, to just go back there and think of the times like that when I was in there the whole time. And I sometimes -- I do feel like sometimes it makes me more emotionally, what's the world, word? Like it helped me get --

289. **S:** That's ok.

290. **R:** Not stable. But it helped me -- Oh ja, I just got, my emotions got stronger, like I could handle more things. If that makes sense.

291. **S:** Ok, became emotionally stronger.

292. **R:** Yes. Ja. Because I mean I didn't -- Like I would think about times when at least I wasn't like in hospital or anything and going through the brain tumour surgery and everything. So I think it did make my stronger emotionally. Ja.

293. **S:** How did you get your -- I mean, that did make you emotionally stronger. How did you deal with... You hate hospitals; how did you deal with having to go back?

294. **R:** I just use to go in there and think I will come out and I'll be feeling better. Ja. But I just ... I don't know, obviously my mom also made me go because she knows what's the best for me.

295. **S:** Are there any other ways in which you make yourself feel better? Not necessarily just with the colonoscopy, but when you've had a flare-up?

296. **R:** Ja. Well at home and everything, just making myself more comfortable. And like, just, just relaxing, using the relaxing techniques. Just like making myself comfortable on my bed or wherever I'm sitting, or ... Ja. Just doing what I can. Ja.

297. **S:** Is there anything that brings more quality to your life?

298. **R:** Well, I don't want to say TV shows, but like watching that when I'm tired and like exhausted or just doing some activity. Like I used to knit, and then ... Or crafting or something to keep me busy. And ja, I just like ... Because when I had the splints ... No, sorry, this was, this was nothing to do with it, but I had like plantar warts on my feet so I had them removed and I was in so much pain. Like I didn't walk. I was like -- But I was like putting up posters in my room and I was like just trying to walk when I was in such pain and everything else. Like I could just stick some poster up to keep me busy, to distract me and everything.

299. **S:** You can stick?

300. **R:** Posters. I don't know what they were.

301. **S:** Ok.

302. **R:** I was re-doing my room or something. So I just remember that.

303. **S:** And then that brought -- How did that -- That made you feel better?

304. **R:** It just distracted me, the main thing was it distracted me. Ja.

305. **S:** And if you get distracted, the consequence is?

306. **R:** The pain it's, goes away. Ja. Well it diminishes. It doesn't go away completely.

307. **S:** Doesn't go away. And then does that put you in a better space?

308. **R:** Yes, it's distracting. I think that's also the main thing that I do when I'm in pain. That's probably why I always want to go to school, because I want to distract myself. Like, if I'm just lying in bed then I know that I'm going to feel sick and get worse. But if I go to school I know that I'll be distracted from the pain. Like just, you know, have a better day. Ja.

309. **S:** So you've had the two colonoscopies. Was the second one easier or was it ...

310. **R:** I, I honestly don't remember, to be honest. But it probably was easier, because I just ... Ja, the thing is like I didn't know why I was going into hospital so many of times, because no-one really told me. So I -- I didn't really process it as being a big thing. Ja.

311. **S:** You were older with the colonoscopies. Do you -- How do you feel about them not telling you why you were going in?

312. **R:** I didn't -- Well, just the thought of people, ... people like putting tubes up me, just ... I really don't like that, ja, because I feel like... I didn't, like I didn't research it, like the same thing. People would tell me what's going on, but I didn't like go and research it. So I didn't read much about it. Ja.

313. **S:** And why did you choose not to research it?

314. **R:** I just didn't think it was a big deal, that's the thing.. I didn't really think it was a huge thing. Ja. I thought it was like getting your tonsils out. Ja.

315. **S:** I had mine out, it's a big thing [laughing]. Ok. Then, actually you answered some of my questions. One of them was about that you're developing maturity and being able to handle situations.

316. **R:** Ja. Ja, it's definitely developed. Definitely. Ja. It's just like going through those things definitely made me stronger. Definitely ja.

317. **S:** And, and can you give me some examples of, of situations that you've handled that have been as result maybe of your, your illness?

318. **R:** Well, I mean, definitely I'm not going to say I handle situations well, because I don't. But I mean, when my best friend moved away to Durban, then I just, I was very upset. But I like tried to keep calm and everything. Then just in high school with all like the exams and everything, like I was also under a lot of stress, but I can control that more. And it's easier to get through sometimes. And ja. Just -- And all the drama with my friends and my group, the fights and everything.

319. S: How do you handle that?

320. R: I'm very bad at handling that, terrible. I usually just ignore people.

321. S: You mean you ignore the drama that's happening?

322. R: Well I'm usually the one that starts the drama. I don't know why, but it usually is.

323. S: And how-- Well that's interesting. Why is it that you think you start the drama?

324. R: Because 90 per cent of it is because of boys. And I'm the only one in my group that really like talks to the boys, so it's always like me who starts the drama.

325. S: What do you mean drama? What do you ...

326. R: Just like-- Like for instance, my friend ... Like I had a guy that I would kind of, ja, I don't know, it's not a boyfriend or something. Then he would also have feelings for my best friend Susan. So, that like, ja. It was -- So it was mainly my fault. I felt like it was my fault.

327. S: You felt it was your fault?

328. R: Ja, I always feel like it's my fault. That's why -- I used to tell my friends everything that went on and I used to tell them like all the drama and everything. But now I don't tell them anything anymore. Because I don't want to ... Because I know they have very strong opinions and they always disagree with me, which always causes a fight. So I don't.

329. S: So, so you just learnt to keep it to yourself?

330. R: Ja. Which is very hard to do, because I want to tell them these things, but I just don't want them to like judge me and disagree with me. Ja.

331. S: And do you find they are very judgemental?

332. R: Yes.

333. S: Are they judgemental about what you go through with your illness as well?

334. R: I feel like they are. Like, they've never said it, but I feel like they are definitely.

335. S: What, what gives you that impression?

336. R: Like I think like they feel like I miss school purposely, to like get out ... Like it just happens that I miss ... I can't control when I'm sick and I think they think that I can. And they think I know when I am going to be sick and I'm going to miss a test, because I'm just, you know, faking it.

[40 minutes]

Ja. I haven't really -- They haven't really said anything, but I think that's the way they feel.

337. S: So, so what, what gives it away to you?

338. R: Just well because whenever I'm sick and I miss school, which is often, they never like send me a message and they're like, hey are you okay and everything. They just like, ja. They don't even say anything to me.

339. S: So they're not being very supportive anymore?

340. R: I think like they are just used to me missing school and everything.

341. S: Ok.

342. R: So they just, ja. I just would like a text saying, where are you, are you feeling ok, and everything. Ja.

343. S: So how does it feel when you're sitting at home ... I mean obviously that's why you want to go back to school. So you're sitting at home and nobody is texting you?

344. R: It feels very lonely. And isolated and everything. Ja. And it's very sad. Ja.

345. S: Ok. I think -- I mean that was one of the other things that, that, that we were exploring the last time, is that whole, people don't understand the ...

346. R: Ja, they don't. They don't.

347. S: Especially in your case where it can change from day to day and it's unpredictable.

348. R: Ja.

349. S: And -- And you also mentioned about being, feeling like you're a burden and I was wondering if you could tell me more about that?

350. R: Ja, that -- I think I've always -- It's hard -- It's kind of hard to put into words now. But I mean, it makes me feel like I am just ... Like I'm making people feel sorry for me and I'm just making people like ... Like make my friends think that they are having to be responsible for caring about me and everything. And ja. I'm trying to think of what else I can explain other than ...

351. S: So are these things that people have actually said to you? Or are these things that you think they might be thinking?

352. R: That I think that they're thinking. Ja. They never said that to me. Ja.

353. S: Ok. Do you think that's related to the fact that you when you go into the hospital and you see the sick people, you, you take on board ...

354. R: Ja. Like their feelings and everything. Ja. And like when I go into hospital, I feel like ... Ja, I do feel like a burden because like the medical bills are expensive and all that stuff. And then just like, that's the worst thing that I hate. Because I know everything is so expensive, and I can feel the pressure on my parents and everything. I hate it so much.

355. S: And kind of what do you say to yourself in your head when you're feeling that burden?

356. R: Like just thinking, you know, if I didn't have to be this sick ... Like I shouldn't -- Like if I didn't have to be this sick then they wouldn't have to pay all this money. And they must be so angry at me for being like this and making them pay for me to go to hospital, or like to a therapist, to a physio and everything. Ja. I just feel very guilty.

357. S: And do you -- Do you discuss that with them?

358. R: No. [laughing] No, no.

359. S: What do you think they would say if you did?

360. R: I think they probably would obviously disagree with me and be like, no it's for the best and we're trying to get you better and everything. But I think they do worry. They do worry about the medical bills and everything. Ja.

361. S: How do you know that they worry?

362. R: Well I mean we do -- I mean, money is an issue in every household and ja. With me we probably have a lot of expense, like with me and my medication and everything. My brother goes to Saints and he does row and everything, so they have him as well. And then just everything is just so expensive and I just feel like so bad for making them pay and everything. Ja. Ja.

363. S: *Sjo.* That is just -- I'm just -- Ja. That's such a big burden for you to carry.

364. R: It is, ja.

365. S: And, and I'm wondering how do you cope with that burden, when, when ...

366. R: I did -- I got a job, so I get my own income but it's barely anything. So.

367. S: You got a job? And the reason for, for getting a job?

368. R: Well not only the independence and that like feeling of like getting my own money, so I can pay for my own things. But I just, ja. I wanted to get a job also as a distraction, ja, from everything. So, it just, ja. It works out well. Except for the long hours and the minimum wage and everything. Ja.

369. S: So what do you do? What job do you do?

370. R: I work at Wakaberry in Cresta. Ja, with my sister. So I mean it' very -- It's R16.50 an hour that I get. So it's very low.

371. S: What do you do?

372. R: I just -- I only work Sundays because I have school obviously. But I just like help with the customers and I just like think doing that really helps with like my confidence sometimes. Like talking to customers and everything. Because if you can tell, I speak very fast. And then it's like, I also gain confidence just talking to them and helping them out and everything. And I just feel like very independent when I work there. Ja.

373. **S:** So, so you started -- You, you chose to get a job partly to relieve the burden of the guilt ...

374. **R:** Ja.

375. **S:** Because of finances. And it's also had -- It's also improved your feelings of independence and, and quality of life? Has it improved your quality of life getting a job?

376. **R:** What like?

377. **S:** Emotionally or, or just how you feel about yourself in general.

378. **R:** Ja. It makes me feel better about myself. Because I feel like, you know, I've got a job and you guys still get pocket money every month and I get some tips and everything and all that stuff. Ja.

379. **S:** In comparison to your peers?

380. **R:** Ja. Only one of them has a job and it's so much better than mine. But it does feel -- It makes me feel very happy to have job. Not when I have to go to work, but just like. Ja.

381. **S:** And is there any -- Are there any other things that actually enhance that feeling of happiness and well-being?

382. **R:** When I go out. When I go to parties. I just feel very-- Ja, especially going out to house parties. Don't tell my mom. [laughing]. When I go out to parties and everything, then I can just like you know, be with my friends and have fun and let loose. It makes me feel very like, you know, normal. And like fun, and, ja. Like I'm not one of those girls that just like lays at home in bed when all my friends are having fun outside and everything. Ja. I love going out. Ja. It is obviously quite hard for me to go out sometimes. Ja.

383. **S:** Then it's the balancing act?

384. **R:** Ja.

385. **S:** But so, ok. So going out and socialising is obviously quite important to you.

386. **R:** Yes.

387. **S:** And other things that help you be happy, for want of a better word?

388. **R:** Let's think. Oh well, I have set a goal. For, that I want to do. I want to go into journalism after school.

389. **S:** Ok.

390. **R:** So, I want to work towards that goal and then just like, that makes me feel happy when like, when I like go and research it. And like research Rhodes and everything. Go to all those like ...

391. **S:** Are you going to go to Rhodes?

392. R: Well, hoping. You know, it just makes me feel happy. Like I want -- Like I feel motivated to go to work and everything.

393. S: And when you're in a happy space, how does that impact on ... Do you think it impacts on the disease?

394. R: Yes, it probably -- Ja, it does. Because, I mean, ja, it's like I said, a distraction. And it just like -- Ja, it makes me just feel happy and independent and free. And just like ...

395. S: I was wondering, are you more well when you're happy?

396. R: Yes. Yes, I am. I'm definitely more -- Definitely feel better. Ja.

397. S: So it is kind of intertwined.

398. R: Yes. That's the thing. Ja.

399. S: So, if you're in a good space and you're getting lots of happy activities, then you do better.

400. R: Yes. Yes. I mean it's still -- I'm not going to say the pain is totally gone, because it's still there, but ja. But I mean it's better than I, it would be if I was depressed and at home and sad and angry and everything. It's much better when I'm in a happy place and smiling and laughing and everything. Ja.

401. S: And anything else? I'm just trying to get as much down as possible.

402. R: I understand.

403. S: Are there other things that, that add to your quality of life?

404. R: Ok, let's think. Well that helped me improve: I've started like going to the gym and improving fitness and everything.

405. S: Ok. Ja.

406. R: So that's -- That has really helped me, yes.

407. S: What, what kind of a routine do you have with gym? Or how does it work?

408. R: I do -- I started -- Well I've been going to the gym -- Well I went when I was much younger before I got the arthritis and everything. And then I started -- When it got worse I started seeing a physio and everything. But now I go to a biokineticist at the gym. And I see her weekly and I just, you know, it's just like, sometimes when I'm feeling ... Like if have the headaches and the sore neck and like spasms everywhere, then we just do like small exercises. And she like helps to massage those spasms and everything. Otherwise, I do like the bike, the treadmill, like lifts and squats, and run up the stairs and everything. Ja. It makes me feel very like healthy and fit and everything, even though I'm not. But, ja.

409. S: So how often do you go to the gym?

410. R: I try to go as often as possible. Well, I usually go with my brother because he's very fit and everything and loves going to the gym. So usually with him.

411. S: So often as possible.

412. R: Ja. As often as possible. But like three times a week. And then I do -- I go to see my biokineticist once a week. So ja.

413. S: So that's almost four times a week then.

414. R: Ja. When I, when I try, ja.

415. S: It's interesting now that that also adds to your quality of life.

[50 minutes]

What exactly is it about it?

416. R: It makes me feel more active and I think the active feeling, like ... You know when you have like a splint and you have to get your hand moving otherwise it won't get better. Ja. So I think you know, just feeling like ... Just working out just makes me feel more active and I like ... It just makes me feel young. I'm on a good road now, like I'm going to get better and everything. Ja. It makes me -- It actually makes me -- Contributes to the motivation and everything.

417. S: Ok. So it's like all of these factors just almost feed off each other.

418. R: Yes, it just like -- It's kind of like a cycle. You know, like if I -- Like if I miss some day when I'm sick and I don't go to the gym and I'm like ... I feel so like unmotivated and like so sick. I'm not going to be able to go to school tomorrow. Then I can't and then I get stressed and I like can't study because I'm sick and everything. It just like all follows each other.

419. S: So then you get a downward spiral.

420. R: Ja. Ja. Yes.

421. S: And so, so a lot of your coping strategies with your psychologist are ways of stopping that downward spiral ...

422. R: Ja**.** Just ...

423. S: And then coming back up again.

424. R: Ja. I try to get on top again, ja.

425. S: That -- That must be quite empowering I would think?

426. R: Ja, it is. Since I've been seeing her, I think it was since April or something, I mean I've gotten much much better with handling things and everything. I still have like, you know, downward spirals and everything, but I have ... I'm like -- I'm more motivated to get out of them. Like I know how to control them and everything. So I get out of them easier. Ja.

427. S: *Sjo.* I won't forget your comment that you said. I know this is ...

428. **R:** It probably was bad. [laughing]

429. **S:** No, no. Sorry, it's just such a quick change of subject. I'm actually feeling a bit tired myself. You said something that has always stuck with me about people's lack of awareness.

430. **R:** Oh yes, that. Yes.

431. **S:** And you said, you said, you know it's not just like it's my pinkie that's sore.

432. **R:** Yes. I know. Exactly, it's not. Ja.

433. **S:** And it always has stuck with me. I was just wanting to explore that lack of awareness a little bit more with you, because it was something that seemed to come through quite strongly in the first interview.

434. **R:** Ja. So, about that. So like I do really think that people don't have enough ... Is it -- Ok. Mic going closer.

435. **S:** No, no, no. You carry on.

436. **R:** Ok. I don't think that people have more, enough awareness or research on it. But I know that every year in biology we do a section on diseases. And like osteoporosis and arthritis is always mentioned. I think -- I feel like when people think of arthritis they think of like some old granny like walking around with a wooden stick and having like arthritis in her knees and everything. And I just don't want people to ... I want people to like realise it happens to people my age and people younger. And it's like a thing that really impacts your life. Ja. Because I don't think they really understand.

437. **S:** And, and how does that lack of ... We know the disease impacts on you. How does the lack of awareness and understanding impact on you?

438. **R:** I just like -- It makes me feel quite angry because I want people to understand that it's like a bigger thing and I want people to like become aware of it. Because I mean, like this -- It didn't run in my family, arthritis. My parents are fine, my sister's fine, everyone else is fine. It just happened to me. So I just want people to know, you know, that it can just, it can happen to you. And you know, it's a, it's like a lifetime thing. You're always going to have flare-ups in your joints and everything. But -- And I just want people to become, become more aware of it in all honesty. Ja.

439. **S:** What would it mean to you for them to become more aware? Why is it so important?

440. **R:** It would just-- I just want people to have more knowledge about it, because I feel like ... Oh sorry. I just want them be -- Ja, have more knowledge about it and everything, because I want people to know and understand that's the reason why I'm sick and the reason why I miss school. And I don't want them to like, ja, like I said, picture some arthritis in some way where it only happens like down to the generations. Like your old great great granny or something. Like it, it really impacts people. And I just want them to realise that. And the effect of it. Like I don't want to compare it to like a deadly disease or like cancer or something. But like, I know it's not the same, but I just want them to be like as aware. Not as aware as like cancer, because like you know that's got like the most awareness. It seems small, like arthritis seems quite small and like it doesn't really ... Ja, it's like a really small thing in like the huge medical industry of like leukaemia all that stuff. And mainly cancer, I don't know. Like Alzheimer's and everything and the ASL. But like it -- I know it seems small but I feel like it is ... It impacts people's lives a lot. Ja.

441. **S:** So it's sounding to me like your passion about the lack of awareness is based on your own experiences. Can you share some of those experiences with, with us? Because you say, I think you said it makes you angry.

442. **R:** It does, ja. Like when I used to go to school and I used to be in crutches or like had a splint and everything, people would go like, oh did you break your hand? Did you like twist an ankle or something? And I was like, no, it's arthritis. And they would just like, like go, ok. Like I don't think they realised that it was kind of like ... Like it was important. Like I don't want to say it was that important, but it was like ... It was painful. I think people think of arthritis as not being in that much pain, when it is very painful. Ja.

443. **S:** And, and did anybody verbalise anything to you?

444. **R:** What about? Awareness?

445. **S:** No, no, about-- So, so you were in pain and you were in splints ...

446. **R:** Ja. No, they didn't really. They didn't say anything. That was the thing. Like I think they just brushed it off as being a small thing.

447. **S:** Ah. A small thing.

448. **R:** Ja. And they didn't... I just want them to be like, you know, more conscious about it and everything. Ja.

449. **S:** Why do you think they brushed it off?

450. **R:** Because they don't -- Because I think people -- Ja, like I said, people don't think arthritis is like a very like painful and lifetime thing. And that's -- Ja, like I say, they probably just think you have a bent pinkie, and so. I mean, they probably think this is the reason. Like it feels like this, this is the only pain. This is like nothing at all to me. I feel like they think it's this and not like a flare-up in your knee. Ja.

451. **S:** So when you say this -- Because we're going to transcribe this, so you are showing me your pinkie.

452. **R:** Yes. My pinkie. My bent pinkie.

453. **S:** Your bent pinkie. So are you saying that you think your friends think you're missing school just because of your pinkie.

454. **R:** Ja, I feel like that's what they compare it to. Like you know like, if you have like a joint like this where it's not painful. It's just kind of there. I think they think that that's like arthritis. So like if I had like a sprain in my knee, they would just think, you know, well she has arthritis. So you know, it's ... It's not a big deal and everything. It's like it won't be painful and everything. Ja.

455. **S:** So you -- People aren't aware of the level of pain you have to deal with.

456. **R:** Yes. Ja.

457. **S:** That children have to deal with because you've got arthritis.

458. **R:** Ja. And I think -- Sometimes I think people think I'm using it as an excuse for something. Like if, if I'm in PE for example. And I just like -- You know, do you ever like just suddenly get a flare-up? In your knee?

459. **S:** Knee? Ja.

460. **R:** Ja. Literally like all the time.

461. **S:** Just at random. Like one day it won't be there, and then suddenly there'll be a flare-up somewhere else.

462. **R:** Ja, exactly.

463. **S:** My knees are usually pretty bad.

464. **R:** Like at school, like if I just get a flare-up in something, I go to PE and I'm like no, I can't manage it. And they're like, but you seemed fine today? And then I just feel like think I'm just like, you know, using that as an excuse for something. Ja. So that's what I want people to become more knowledgeable about. Ja.

465. **S:** Why do you think they think you're using it as an excuse? Because you said -- You kind of alluded to something. You said: so you seemed fine.

466. **R:** Ja. That's the thing. Ja. People think I'm fine, but like unless I'm like limping or like I can't write, or something like that, they think I'm fine... .

467. **S:** But, how would they know you were in pain?

468. **R:** Probably by the look of sadness and depression, ja. Because when I am sad I do show it.

469. **S:** What do you think they are looking for to know that you're in pain?

470. **R:** Like -- Like something -- Like indicator. Like -- Like a bruised knee or like something, something like a, like a -- What are those things called. A sling.

471. S: Sling.

472. R: Ja. Like one of those. To show that I'm in pain. But they, they don't see it because, I mean, I can't control like ... I mean, you obviously can't see when you're in pain in your knees or something like that. But they don't -- They don't see it, so they don't believe it.

473. S: And your knees don't swell up?

474. R: Ja, exactly. Well they do sometimes, but my friends don't really notice it.

475. S: So it's a small swelling.

476. R: Ja.

477. S: So because there's no obvious sign ...

478. R: Ja, they don't believe it. Ja.

479. S: Ja. Have you had any of that kind of feedback from teachers as well, or adults?

480. R: I haven't. I do sometimes -- I think my teachers have been quite supportive, but I feel like they do sometimes think that it's not a big thing as well. I mean, my -- They pretty much are quite aware of arthritis, my teachers. Especially the biology teachers. Ja. And my grade tutors who I talk to every time I'm sick or I need to go home, and I miss school or something, like I don't think they realise as well that it's a big deal and everything. I also think they just like brush it off.

[60 minutes]

Because there are people in my school, in my grade, that are having, that are going through a lot more trauma than I do. There was just actually a girl, . . ., who just got diagnosed with leukaemia. So I mean, if like me being compared to ... Me having arthritis and a sore knee, compared to her, is just like ... The teachers would obviously brush mine off and then like do a fundraiser and everything. Ja.

481. S: And, and in your head, how do you compare yourself to the girl with leukaemia?

482. R: I always do compare myself to them. Ja. Because I always think, ja, like I would say you know what, then I'm not really going through that much. Can you imagine what she's going through? And I would be like, you know, you can ... If she can get through that, then you can get through this. Ja. Ja.

483. S: So -- And -- And this lack of awareness, do you encounter it ... How -- I mean, is -- Is --

484. R: I don't think anyone's like actually like really asked me about arthritis or anything. I did have someone, I don't know who it was, someone told me ... Oh ja, my friend told me that she was diagnosed with a form of arthritis, but she didn't know which one it was. And I feel like she's the only one who actually knows some information about it, because she has the same as me. Like, flare-ups in her hands and everything. But I've never seen people like you know, be like, ja she had arthritis so it means this and she can't do this and she gets this, and everything. And ja.

485. **S:** You're very passionate about their lack of awareness.

486. **R:** Ja.

487. **S:** Would you -- And this is just an interest for me. I'm just wondering, would you ever consider then doing a presentation to the school?

488. **R:** I, I wouldn't. I wouldn't do it just for the, only for the fact that I just feel like the school wouldn't be interested. Also for the fact that I can't speak in front of schools. Ja. And I feel like the school would be like, why is she having this whole presentation on something like, like that, you know. So small. Ja.

489. **S:** If you could create awareness, what would you do?

490. **R:** I mean I am -- I think I am creating awareness right now. My mom -- I don't know if you know about her Arthritis Kids NGO. Has she told you?

491. **S:** No, no.

492. **R:** Well she has -- She's -- It's very small. Like it's just her and her friend, her, her family friend, and they basically like collect ... They get sponsored and then they buy clothing and items and everything and they take it to children with arthritis in Baragwanath.

493. **S:** Ok.

494. **R:** So -- And then I'm part of an Interact Club at my school. I'm like one of the presidents or whatever. So I suggested that we do something in partnership with my mom's NGO and we can like, you know, collect clothes and then donate it to the school. So I want to make people aware like that, like fundraise and stuff. Ja.

495. **S:** And how does it make you feel to ...

496. **R:** It makes me feel happy to make people more aware, and like, especially to ... I mean, I always feel happy when I'm helping out other people. And ja, just, it makes me feel happy that people are becoming more aware of this and especially people ... If you go to Baragwanath, like the children there who have arthritis, like ja. I want people to see that it's not like, you know, it's not a sore pinkie, children with arthritis in Baragwanath and everything.

497. **S:** Especially because those kids can't get the meds.

498. **R:** Ja, exactly.

499. **S:** And I'm wondering about your self-concept, because ... How has being involved in the NGO and Interact, how has that affected your self-concept, or how you view yourself?

500. **R:** Well I mean, it does make me ... If we like -- Ok, well let me try and word this. If we like go to like an orphanage for Interact, it makes me feel like, like I am, like what I have is very small and it makes me obviously feel lucky for myself that I'm not those people. But it makes me feel happy about helping them. Ja. So I mean it does change ... It does have a -- Does make me change my view on things, because I see how other people experience troubles in their life and everything and then I compare it to mine, ja.

501. **S:** So I'm just interested, because when you were talking about yourself when you were younger, it sounded like maybe ... Well let me ask you, what was your concept of yourself? How did you view yourself when you were younger and ill?

502. **R:** Ja, ok. When I was in primary school I did view it as a big thing, like I did think that it was something very serious. Well, I mean it is, but like, I thought it was like something, you know ... It's like, you know, people must know about this, because like I have it so maybe many people must have it. So they must have awareness on it. So I thought it was like this huge thing and everything. And I got to high school and I started doing Interact and everything, and I was getting like a wider view on everything. And ja I just would think that, that it isn't that, that big of a thing. But I mean, I don't want to contradict myself. Because I mean it is. It depends on what ... Ja, no, now I feel like I'm contradicting myself. Because it depends on what you ... Because I just said it was a big thing. It is, but like depends how you view it. Like if you're comparing it to something like I was.

503. **S:** So you're talking like almost like it's on a continuum.

504. **R:** Ja, kind of, ja.

505. **S:** So it is a serious things, but maybe not as serious as some other things, but definitely more serious than the like flu.

506. **R:** Ja. I know that it sounds -- Ja. It sounds really stupid to what I'm saying, but ja.

507. **S:** And, and -- I'm -- But how did you used to think about yourself, rather than the illness? When you were little. Or primary school. When you had the brain tumour and the ... All of that. What was -- I'm just interested to know if your self-concept, how you thought about yourself then, has changed since you've become involved in the NGO and Interact.

508. **R:** So I do -- How I feel about myself ... I used to look at myself and think I was the same, in primary school. Because I, ja, like ... Sorry. Ok. Sorry. I used to -- I used to think I was ... I used to view myself as ... Or how I would feel, I would feel very like isolated. And I would feel like you know, I'm just, I'm just so different and everything. And I mean it was sometimes a good thing and other times it wasn't. To feel like that. And then when I got to ... I started getting involved when I got to high school and everything. I just like ... I started seeing myself as being pretty normal. Because I obviously started getting better and everything, and I started to view myself as, you know, I mean, I can be normal. And then ja, just like, I think helping out people and joining Interact just makes me feel like, like I'm doing something good. Because when I was like in primary school for instance, the Inter people used to help me out with like school work, and they used to come visit me and send me good wishes and everything. I feel like I would want people to feel like that, like how I was in primary school. Ja. Does that answer your question?

509. S: No, no, it does. I mean, you're giving me wonderful information. Everything you're giving me is information.

510. R: Ok good.

511. S: It really is. No, it really is. It is. So, so, so would you say then that it's sort of improved your concept of yourself?

512. R: Yes.

513. S: And in what ways has it done that?

514. R: What, the like helping out and everything? It just -- Ok. Let me think. It just made me feel like I'm doing good and like ... Because I just really want other people to like feel happy and to ... I want them to like go through something, like if they're going through a hard time, I just want them to get through it, and just like ... Wow, my language is terrible right now.

515. S: It's fine.

516. R: I'm sorry.

517. S: ... brain's not always working so well. And by doing those actions, does it give ... Does -- How do you think about yourself? Is it mainly for you, or it's, it's just giving back?

518. R: It's not mainly for me it's mainly for the other people. Like I do -- I'm not answering your question properly. I do, when I look at myself and like compare myself to how I am now and how I was then, then I would say that I have definitely come a long way. Like -- Like self-confident wise and self-conscious wise and everything about ... I've become more aware about the issue. I've become of other issues and everything, and how I can help out and ja. It ...

519. S: It sounds to me like you've become a lot more independent.

520. R: That's what I'm trying to aim for. That's really what I'm trying to aim for. Like, especially like, I mean next year when I turn 18. I want to become more ... I want to like have a job, I want to have a car, I want to just like become ... Because you know just ... People -- I just don't want to have like people think that I'm different because I have arthritis. And that I can't like, you know, get a car and I can't do this and everything, and I can't be independent.

It’s like, I want to have a job, but I want people to know that ... I mean you can, you can go through daily life when you have arthritis. Because with like perseverance and motivation and all that stuff, you can. But I mean, I think ... I also just want people to know that it is hard sometimes too. Ja. I want them to like understand that.

521. **S:** What is -- What is hard about it?

522. **R:** Just, like for me it’s definitely the feeling of getting unmotivated. Because I have like this cycle when, when I’m in a very dark place.

[70 minutes]

I have like a cycle like I get sick, and then I feel unmotivated, then I don’t go to school, and then I just get stressed and sick and the whole thing repeats itself. Ja. And I just -- Ja, I want them to understand that it’s not like, some easy quick thing and it doesn’t like really impact me. Because it’s very hard for me to get out of the cycle once I’m in it. Ja. Ja.

523. **S:** Let me have a look. The other thing you told me about, and I think it feeds right into this spiralling down, spiralling up, and your coping strategies that you’ve been learning. That mind shift you made, do you remember discussing that? That something -- You were lying in bed the one day and you were feeling really ill and you just said: this has got to stop.

524. **R:** Ja. Yes.

525. **S:** Can you remember it or not?

526. **R:** I can’t remember -- I can’t remember the exact moment, but I can remember just feeling like just so, like I said, lazy and just like lying in bed and feeling sick. And I’m like you know, I, I could be working hard, and I could be, be like my friends, and like having a goal set and like working towards my goal. But like you know, this, this illness has just made me miss out so much on everything. I just want to like, you know, make it stop. Ja.

527. **S:** And do you think that’s where now all of these skills you’ve been learning, would that have been this sort of pivotal moment?

528. **R:** Yes. Yes.

529. **S:** I wonder if -- So, so -- I’m just so interested about the timing of it. If, if there was anything that you could link it to?

530. **R:** Timing-wise I think that I just like got so sick of ja, being sick. Like I would just, I would just feel so exhausted by like missing school and then catching up and having people be like, ja are you ok, and everything. My friends just like kind of losing contact with me. And I didn’t really like -- Like, I wanted to be involved in everything. I just got so like tired of like the medication and the infusions and doctor visits, physio visits, and all those things. And I just, ja, I just wanted, needed it to stop. I needed to go back to how I was. ja. Or how I want to be.

531. **S:** So it sounds like at one stage then the illness took over you.

532. **R:** Ja. It really did. Ja.

533. **S:** And, and then you got tired of the illness being predominant and sort of said, I need me, me back.

534. **R:** Yes, definitely. I would definitely say that. Ja.

535. **S:** Ok. Ok. Let me just have a look at what else have I got here. It's just that you've share so much ... I wanted you to, and I've just got to double check if there's anything that I missed. I think the only thing that I wanted to explore a little bit more with you that's left is ... You, I think you've said it a few times today already, that I -- Is that you've just got to get through it.

536. **R:** Ja.

537. **S:** You've got to ignore your problem.

538. **R:** Yes.

539. **S:** And I -- I was just wondering how do you do that?

540. **R:** Like I said, motivation and distraction. Ja. Ja. I think that's ... I mean I think distractions are just my main thing. Like just when I'm, I can't get out of bed, I'm just thinking if I can go to school, if I can work, then I can be distracted from like what I'm, what pain I'm in now. And then I can just get through it. Ja. And like I still have the technique of saying, you know, just like 10 more minutes ...

541. **S:** Ten more minutes.

542. **R:** Then get through the next 10 minutes. Ja. Ja.

543. **S:** Because you actually did bring that up earlier. Ja. It's just, it's actually all been quite intertwined.

544. **R:** Yes. Ja. [laughing]

545. **S:** So, and -- And as it is. And then what I'm thinking is, is ... From what we've discussed today and what you've been so kind to share with me, is there anything you feel you still haven't ... You still need me to hear or something I should hear?

546. **R:** I don't think that there is. I think I've pretty much said everything I can think of right now. Ja, I don't think there's anything else. Ja. I can't really think of anything. [laughing]

547. **S:** I always just ... I've learnt to give you a little bit more time, because as soon as I press that button ... [laughing]

548. **R:** Ja, then it's -- Ja. But I think that's pretty much everything I wanted to say. Ja.

549. S: Ok. Well thank you so much for sharing with me.

550. R: Ok, no problem. No problem.

551. S: Ok, let me just stop that.

[recording ends]

Transcript 3 A: Ann Interview 1A

1. **Interviewee (A):** She said to me, you know, do you trust me? And I knew it was going to be something awful. Because and then she said to me has a chronic pain syndrome and basically can't be treated by medication. It's got to be treated by behavioural therapy and, you know, psychiatrist, psychologists, this that, this that and she's got to be forced to go to school and she's got to actually learn to accept it herself. And I find it so upsetting to hear that, I really do.
2. **Interviewer (S):** Ah, as a mom. It must be, I mean what about it is so upsetting?
3. **A:** Because I still can't understand, I mean pain to me, there's got to be a scientific reason for it. It's it's there, it's what's going on in her nerves and her whatever that's causing such, I mean [Inaudible 00:41] has got neuro information,
4. **S:** Yes, she was telling me, yeah.
5. **A:** Which is, yeah which is. You know she's been much better. In fact, I was absolutely furious with Dr X when she told me all this and I promised that I'd never go back and I was I was livid. But in fact, ok so it has also coincided with different medication she's on, but she's so much better. She could never have sat here before talking to you like this. She is so much better.
6. **S:** What would have happened before?
7. **A:** She'd be lying in bed. She couldn't get I mean she could barely lift her head off the pillow. You know she, she would have the most terrible nausea and pain and she, dizziness so she could hardly walk and. Yeah.
8. **S:** Yeah. You know there there, I I I think the problem is that medicine does not know enough, so yes there is a reason but they can't fix it.
9. **A:** But I want to know what's going on physically in the head with, with, the nerve nerves receptors or whatever they're called. What is going on that they can't fix that with medication that she has to learn to accept it? You know. Why can't they fix it? I just, that's the basic thing.
10. **S:** I think that that, and I think that is the, it it's hugely difficult, and you can spend a lot of your energy um fighting that… and one of these days they will make the medical breakthrough, but they haven't yet. So.
11. **A:** Yeah. You know my mother is a retired nurse, she's in England actually, and um you know I remember speaking to her about, a few months ago on the phone, about just this and she just said to me, "You know, you know the doctors maybe they can't fix her." God

did I find that upsetting [laughs]. She said to me, “You have to understand, maybe they just can’t fix her”.

12. **S:** So it’s that sitting with the unknowing that is so difficult.

13. **A:** Yes, Yes.

14. **S:** And the wanting to fix it and then

15. **A:** But I still, even now we sit here and talk about it and you say this to me, I still can’t understand why they can’t fix it. I mean why can’t you fix pain? … How do you control your pain?

16. **S:** I live with it.

17. **A:** You just live with it? Well that’s basically what my mother said as well. And Dr X. So she has to learn to live with it.

18. **S:** So you learn to manage your lifestyle so that you don’t trigger. I haven’t done very well this week. Um and you learn to live with the pain and you try not to take too many pain meds because they’re not good for you.

19. **A:** Yes, that’s exactly what, all these things that Dr X has said. Yes.

20. **S:** No I hear you. I hear you because I had to walk that path myself which is why I am so passionate about these teenagers. Um and trying to find ways of putting support systems in place. The parents are the primary caregivers um, there needs to be systems in place for the parents. There needs to be systems in place for the children for psychological support. Um most of the psychologists are not experienced in chronic pain themselves, they have never lived whit it. So it’s it’s now, this research is hopefully going to enable us to start putting things in place for the South African situation that helps parents and teenagers and other professionals.

21. **A:** Yeah. Absolutely, sounds fantastic it’s definitely what we need. Sorry I’m just gonna get some tissues ‘cause I know I have to get some tissues. Wait [laughs].

22. **S:** Ok that’s fine.

23. **A:** Started in her foot and her, but it was absolutely incredibly painful and I could never understand it and I took her from orthopaedic surgeon to orthopaedic surgeon and they would just say, “Oh she’s got Sever’s” or all sorts of stuff. And I said, “But how is it that she’s in such enormous, enormous pain?” and they would say, “Well, it’s just pain”. And then one day she was doing, she actually did dancing at that time, and um I said to the dance teacher, Rayne was with me looking absolutely awful - white as a sheet and everything, I said to the dance teacher, “You know Rayne can’t dance now because she’s got Sever’s.” And she said, “Oh no that’s awful, my daughter has too.” And I see this daughter doing pliés across the room and I just knew then that this pain wasn't the same pain that, you know, it's not the same pain. I mean sometimes I feel like going back to these orthopaedic surgeons and saying to them: How could they have not noticed at the time that, you know, seeing the degrees of pain and the degrees of sickness, how could they not differentiate? I mean

24. **S:** They don't seem to be able to.

25. **A:** No it's incredible. And also they expected her to just live with it. You know, "It's just pain". I mean that was just the start of it, you know, that was just the foot.

26. **S:** So that was the beginning of your journey.

27. **A:** That was the beginning of the whole thing, it started with her foot.

28. **S:** And then the medical, medical profession not being terribly helpful.

29. **A:** Totally unhelpful. Well at least the orthopaedic surgeons. And then eventually one of them did one of those big scans that, what are they, nuclear scans that look at the way the flow goes

30. **S:** The MRI or

31. **A:** No it was one of those nuclear scans that looks at the way the flow goes down the leg in the veins or something. And, what's it called? I don't know. [Dog barking] No stop it, Pinkie. And then

32. I'll never forget it actually because um the the uh the radiographer said to me, "mm" and the next minute there was a doctor on the phone from Fourways, miles away, saying to me, "What's going", because he was looking over there at the scan 'cause, "What's going on with this child?". And I just knew then, and this was after she had Sever's for about 2 months that they finally did this scan, that there was something terribly wrong. He said, "I want to know exactly what's going on and I want you to get this orthopaedic surgeon to phone me straight away, there's something terribly wrong here".

33. **S:** Ooh, lovely.

34. **A:** You know so I was absolutely horrified. And then I went down and I took her to the orthopaedic surgeon and I said, "This is what he said" and this and that. And he said, "Well I don't know what's going on". [laughs] And that was it. And it just went on and on to various other orthopaedic surgeons and neurologists until I finally got as far as Dr X.

35. **S:** And how did you get to Dr X?

36. **A:** Through my GP.

37. **S:** Ok. So somebody, the penny dropped for somebody, they put the pattern together.

38. **A:** You know, it was, then it all went into her hand. And when it finally went into her hand the neurologist just sort of looked at me and said, "Actually I think thin this is um you know arthritis". And he said to me, "You must got down straight away downstairs to this um rheumatologist. He's downstairs, go straight away." I went down there and um the receptionist was so rude to me and she said to me, "Fill in this form." And the whole form was about, she was 8 years old, "Can she catch a bus? Can she make tea?" and I said, "But you know this isn't applicable to Rayne, she's only 8". There were a whole lot of things like that. I was so upset. And she said, "Just fill the form in" and I said, "I'm not coming here, I'm going". And I remember at that stage there weren't even cell phones, were there cell phones? I phoned from a call box I think, I phoned my GP and I said to her, "I just can't do this any longer" I said, "There's something terribly wrong". She said, "Come in to see me" I mean she's so wonderful, she said, "Come straight away." I went in and I sat there with her and she got on the phone and she found Dr X. And she said the only thing with Dr X is that she's at Hospital Y and I said, "No, that's fine".

39. **S:** She's a what?

40. **A:** Hospital Y.

41. **S:** Oh at Hospital Y

42. **A:** And I said, "No that's absolutely fine, I'll go to Hospital Y". You know as soon as I met her I knew that this this was a totally different form of medicine. I mean none of these doctors had ever actually examined Rayne totally, as a whole. I mean Dr X just sat there and I mean from the top of the head all of the way down, she went through everything and examined her totally.

43. **S:** Was that then a sense of relief? To finally be with somebody who could help.

44. **A:** It was a real eye-opener to see the medicine practiced on a totally different level, I must say. It was a, was it a relief? Well, I don't know. It was incredibly frightening because there were a whole lot of other aspects to it – they thought she had leukaemia and all sorts of other things, yeah. But yes I suppose it was a relief that I was on the right, it was a relief that I had found the right doctor, yes. It wasn't a relief that that it was something so serious.

45. **S:** Yes, no, no.

46. **A:** Because I never thought it was, you know [laughs]

47. **S:** I think it's very important to have the right doctor because they're very containing.

48. **A:** Yes

49. **S:** Even though you're going through a very scary process. If you've got the wrong doctor it's just awful.

50. **A:** I mean she just, to give you one example: When I was at Hospital Y with her, and Dr X was actually there as well, and she was talking to us in her little office and she said, "Of course the one thing you must think of is the possibility that she has leukaemia" and then I just sort of got up and said, "Excuse me" and I went outside and went "[sharp intake of breath]" and I could see Dr X inside just carrying on talking and didn't blink an eyelid. And I just came back in and sat down more composed and she said, "Now we're going to do further tests and everything" and I just, you know the way she handles things, she was she was excellent. I I I felt, I felt I was certainly on the right track there, yeah.

51. **S:** So it's been a very long road for you, still is a long road for you

52. **A:** Yes

53. **S:** Are the medications finally working? Have you

54. **A:** Well did Rayne tell you about her whole um history?

55. **S:** She has gone through the whole history, she had trouble at times [10:00] finding certain words. But I will, I'll e-mail you for clarification about some of those things. I think she said now at the moment, she's in a good space?

56. **A:** She is in a good space it's amazing. But you know since Rayne was born she had, she was always sick. You know, constantly sick, all sorts of weird things going on all the time. And one of the things she had all the time was headaches. So when she was 5 years old I finally took her to, my GP organised an MRI scan, which everyone said was clear - including the GP, including the radiologist, including the paediatrician. So then I took it, then, she was still having terrible headaches, then I took her to a paediatric neu uh neurologist yeah. Who treated me like and absolute, she obviously thought I was some [Inaudible 10:46] housewife, treated me like an absolute idiot, said, "No, she's just got headaches". And then for all the years that we were with Dr , Dr X kept saying to me, "You know these headaches, they probably are part of her arthritis and everything". And I said, "Yes, 'cause I had that scan when she was five and it was clear". But then I could never find it after that you see. And then eventually, uhh it was, eventually the defining moment came when A – Rayne came home from school one day and said that she was, she had, it was primary school, and she was doing gym and she was walking thingy you know the bar whatever it is, and she said, "Mommy I couldn't walk more than two steps and I kept falling off" You know I just knew then. I just knew then. And then 2 days later she came and I picked her up from the office and she said to me, "This is the worst headache I've ever had in my whole life" and the receptionist kept saying to me, "What's wrong with her?" and I thought, "You know I'm not doing this child any favours. There's got to be something terribly wrong in her head." And then they did the scan and they found a huge big tumour in her head. Huge. And eventually when I found the old scan it had been there. It had grown from a tiny size in those 5/6 years, because she has auto inflammation, to this huge thing which had pushed part of her brain forward on the side here.

57. **S:** I think she said in eth cerebellum

58. **A:** Yeah, cerebellum yeah… So. But anyway I mean it's just been over the past 3 months, 2 months since Dr X called me in and said, "We have to accept this is a psychological thing now as well and treat it in a psychological way."

59. **S:** In the form of getting acceptance -

60. **A:** Getting acceptance and everything, yeah.

61. **S:** - around the fact, it's not going to go away.

62. **A:** Which I thought would never work. But at the same time, I took her back to the neurologist it was a routine appointment, and I mean Rayne was in a helluva state, she was absolutely, she could hardly walk she had so much pain. He put her in hospital straight away, which Dr X had said to me, "Don't take her to any more doctors, she's not allowed to go into hospital anymore." She actually said to me she thinks Rayne likes being in hospital. I was so upset. That Rayne would say anything like that. Anyway that's what she said. I was so upset. So he…

63. **S:** [Inaudible 13:02] yeah

64. **A:** Yeah I know. So he took her into hospital and um tried a whole lot of various things with her. Did an EEG with was totally abnormal and all sorts of things. But they've always been abnormal, I think it's because of whatever she's got in her brain. And then um he's put her onto, I don't know if I remember that darn thing, she's on Epitec now.

65. **S:** Ok, what does that do?

66. **A:** Epitec settles the brain.

67. **S:** Ok brain, yeah yeah

68. **A:** [laughs] and I can't tell you what a difference that it has made. It's absolutely incredible…You know she was on similar things like, well since the operation she was on a whole lot of similar things, they were all epilepsy type things to settle the brain. But nothing has ever worked like this. Yeah. So suddenly her pain is, I mean hugely better. I mean she still has days obviously. But now hugely better, I mean she's been to school for about the past 2 months everyday which is amazing.

69. **S:** Which is, again, going to improve the mood and everything.

70. **A:** Yes exactly. Yeah exactly.

71. **S:** And how have you seen her social experiences? I mean being a child with chronic illness

72. **A:** Well, you know, she's had these friends, she's been in the same school basically from primary school to high school, and she's had these friends. Sometimes I think they're really fantastic good friends and sometimes I think they're not. But this is an example of their understanding: the one friend who is a sort of very close to her for the past 8 years, we were in the car the other day and Rayne was saying something and talking about going to the doctor and then Brenda suddenly said, "Rayne, you know Rayne what is wrong with you anyway?" [laughs] I mean she didn't even know, no clue, they have absolutely no clue.

73. **S:** Yes.

74. **A:** And I'm quite sure that they think that half the time she's putting it on. I'm quite sure they do.

75. **S:** Do you see any sort of getting, of her being isolated at times? Or excluded?

76. **A:** Yes, definitely. Definitely, I mean I did use to wonder whether that was, I don't know maybe it was a personality thing you know children they don't, they fall out, they don't like this or that. I tried to put that down to that rather than the disease. But, but clearly if you're not at school for a lot of the time, your friends move on, you know, that's what the problem is.

77. **S:** They do.

78. **A:** I remember once she'd been off school, in fact it was after having her her brain operation, she'd been off school for ages, and she came back and saw her best friend, I mean I still get upset, she saw her best friend and she went running up to her and said, "Stephanie, Stephanie" and this child basically ignored her. She said, "Yes" because she was playing with somebody else and she said, "Yes". I mean I still feel heartbroken about that now.

79. **S:** They do move on very quickly.

80. **A:** I'll never forget that either.

81. **S:** They move on very quickly at that age, they're very young. You forget, we like to think children are little adults but they're not. They really are not developed so. How has it impacted on you and your husband's lives, having a child chronically ill?

82. **A:** Well I think he tends to, always trying to jolly her along, you know, and not see the worse side of it. Constantly feel that there's a positive side, that in the end that it'll come out and she'll get better.

83. Whereas I, you know, I tend to… I don't know, I tend to, I don't know if I tend towards the more negative side because it is negative. But, you know, when I see her lying in bed day after day after day crying in pain. Some sometimes I actually think in in in a family like this, I mean there's 3 children and Dr X and I, sometimes she'll just lie in bed with the door closed and nobody even says, nobody even notices. You know they just walk past the door because they so used to it. I mean how do you get to that stage in a family, really? You know, they know that she's not going to come to a family function, they know that she's not going to be able do this or that. But they don't think about it anymore, they just accept it as normal.

84. **S:** Are they there for her at times or?

85. **A:** Well her older brother seems to be more like Greg, tries to jolly her along and he

86. **S:** Which is not always helpful

87. **A:** And he's certainly very much involved in his own life. And not particularly interested. And her older sister has all her millions of issues as well, so [laughs] no. No so she's actually quite on her own really, yeah.

88. **S:** And the financial implications

89. **A:** Well no, there were huge financial implications. For one thing we weren't even on medical aid when it started. Yeah. Huge financial implications. I mean the medication she has, huge amounts of money spent on that and tests and…

90. **S:** And biologics are -

91. **A:** She hasn't been on biologics

92. **S:** Oh she hasn't been on biologics

93. **A:** No. They've talked about it often but, she was on, I don't know, what she was on was uh

94. **S:** Methotrexate?

95. **A:** Oh no she'd been on all those. Polygam.

96. **S:** Polygam. Oh that's to boost the immune system.

97. **A:** Yeah, she's got primary immune deficiency by the way. That's one of the…

98. **S:** You did write that in

99. **A:** I can't remember. She's got primary immune deficiency.

100. **S:** That seems to come up with some of them. Oh I've got it on the audio so I don't need to write that down.

101. **A:** So that was one of the first things that Dr X found. That she had these, this primary, well she had immune deficiency. So I don't know anything about immune deficiency all I could think of that it was AIDS. I was absolutely devastated, I didn't say anything to her. And she said, "Look at her um C4 cells and her CD8 cells". And then I drove home from Bara one day and I pulled over on the side of the road and I phoned her and I said to her, "Dr X please, if you are you trying to tell me she's got AIDS?" [laughs]. Because I couldn't tell her to her face. I couldn't answer, it was just such a terrible thing. And she said, "Look, I have thought about it but she just doesn't fit the profile" which I thought was a bit, anyway, I thought that's fine, she said, "But I need your permission to test her if you want me to, we can talk about it". I said, "You know you can test her whenever you want to, just don't tell me you doing it. I'm giving you permission. Don't tell me you're doing it." You know. And then it came back negative, thank God.

102. **S:** Sorry I'm just keeping an eye on this because it does switch itself off. So yeah the financial implications are huge.

103. **A:** Yeah, no the financial implications are absolutely huge. I know.

104. **S:** Which puts another whole stress, another dynamic on…

105. **A:** I mean, yes, all all these things like psychologists and things aren't paid for. I mean we're on hospital plan, you know, so they're not paid for. And then the other thing is she's, Dr X suggested she sees, well she has to up her exercise plans, you know for a more healthy lifestyle. So she sees a biokineticist who's been absolutely fantastic actually, I wish I'd started with that before.

106. **S:** Have you thought of yoga?

107. **A:** Well Dr X always says to me, "Why don't you send her to yoga?" [laughs]. She actually has, from from a very young age, look she doesn't do ballet anymore, [20:00] she was never, that had to stop. But she carried on doing like sort of tap dancing and everything. All the way through everything because she had a fantastic teacher who who saw her through the whole thing and always used to say, "Rayne even if you come and talk to your friends, just come and sit on the sideline" I mean, isn't that great?

108. **S:** Mm, wonderful.

109. **A:** You know she was absolutely fantastic. And you know what, she also has chronic pain because she had she had cancer. She actually died a couple of years ago, she was young. So she could relate to to all this as well. Yeah.

110. **S:** Are there other ways that it impacted on your family? Or the siblings?

111. **A:** Um, I don't know. I've often wondered whether, I mean stupid things come out like, "Ann, you pay all the attention to Rayne" I'm sure they must think that's stupid [laughs] because it's absolutely ridiculously stupid for them to say really.

112. **S:** But that might be how they feel

113. **A:** Well, I mean certainly my older daughter has many psychological issues and it annoys me to think….

114. **S:** Is it around Rayne?

115. **A:** Oh no, she has an eating disorder. Which actually started at the same time as Rayne, when she was about eight. It started exactly the same time. Which always annoys me. Anyway.

116. **S:** What annoys you about it?

117. **A:** Because, you know, I felt like she was, you know, trying to get attention. You know. I'm sorry this eating disorder stuff I'm …

118. **S:** Struggle with it.

119. **A:** I really do struggle with it. And I mean she was bad hey, she's a bit better now.

120. **S:** Anorexic or bulimic?

121. **A:** Anorexic, bulimic, what was it over-exercising…

122. **S:** Oh yes, yeah.

123. **A:** I mean she was hospitalised and everything. She was, she was awful. And totally nutty. But anyway. Anyway. But I'm, I, I know that she thought so but to me that was an excuse, you know. It was an excuse. So yes there was her and her problems. [laughs]. No, I can't really

124. **S:** And have you had to change your parenting styles at all?

125. **A:** Um, I don't, in what way?

126. **S:** So some, from what sometimes when I work with parents who've had children with other illnesses or disabilities of some kind, there can be a tendency to overcompensate and not necessarily discipline when discipline is needed…that's just an example of

127. **A:** Well, funny you say that, funny you should say that actually because I, maybe I have been too soft on Rayne maybe I have. But the other day she did something which was totally, you know, beyond the call and extremely rude, and I really had a fit with her. And it's the first time that's ever happened. And and you know I don't maybe think I would have done it if she hadn't been feeling well. You know, I don't know.

128. **S:** That is interesting.

129. **A:** Yeah, I really [laughs] really had a fit.

130. **S:** So that's interesting so it's possible that

131. **A:** It's it's possible, yeah.

132. **S:** Yeah. And um if if you were to give other parents advice, now, if you suspect [laughs], or somebody has just had their child diagnosed, what what do you tell, what would you tell them? What advice would you give them?

133. **A:** Yeah, what advice, I would say, "There's a long road ahead boy, there really is." Because for me, I mean, for us we always thought there was going to be an end somewhere, you know, she's going to go on this and it would end or that and it would end. I mean it's a whole change of your whole lifestyle, your whole plans for your future. Everything changes totally. You know one of the, one of the good things to do is to become get some sort of um help group together with other parents so you can talk to them.

134. **S:** Support systems

135. **A:** Support system in that way, yeah…I mean what I've always tried to do with Rayne is try get her involved in other things and, you know, other activities constantly. Even, even if it's making jigsaw puzzle, you know things like that… Then, I don't know, it's all very depressing, I can tell you [laughs]. I mean when when did you start um with your with your …

136. **S:** I can trace mine back to 20, when I was 23, but I only got diagnosed about 6 years ago. And a history of constantly being ill. And then pains in different places and then this is not about me.

137. **A:** Yes Yes.

138. **S:** Um so one of the things I was just wondering about is have there been any specific, it's all been a long road there's lots of challenges, any particularly low or particularly high moments that stand out for you that maybe you haven't mentioned today yet?

139. **A:** Well I do remember one time when she was at primary school as well when they hadn't diagnosed her and I couldn't understand why she was always sick. They had a dress up day and, it was something to do with Dickens novels or something, and she was wearing a she was wearing you know sort of a brown outfit and um, she was on crutches at the time because she had Sever's (so they said), and they phoned me to ask me to pick her up because she was so sick and she was standing on the side of the road and I drove and I saw this child there on crutches with this Dickensonian thing, absolutely white as a sheet. She looked like something like out of a little [inaudible 25:33] or something. I thought, "There has got to be some", this was also a defining moment, I said, "This can't be possible, that this child can look like this." It can't. And you know she would get bruises and things as well. She would have, her eyes were totally black. It was, she was so white she was like transparent. And yet nobody seemed to think anything about it, it was the weirdest thing. You know, honestly. So that was one particularly low point. Actually I think even Dr X telling me the other day that this was all a psychological thing and we have to work on that was a very low point. Ah I was terribly upset. I still get upset about it.

140. **S:** It's not all, it's not all psychological, it can't be because she's got chronic pain. Um

141. **A:** But she thinks that the chronic pain is, is exacerbated by low mood and things like that. That's what she thinks as far as I can work out. You know, problems at school …

142. **S:** Stress. Stress definitely.

143. **A:** Stress about, stress about missing so much school also, so she's always behind in her work

144. **S:** Yes, I see what she's saying.

145. **A:** Yeah. But to me there's always got to be some sort of scientific answer to what's happening in her head and all her nerves and there must be an answer. I mean she's been on opioids and all sorts of things actually. When I took her to this final neurologist she's with now he he got her off everything, he was very good, and he said she must never be on anything like that. She's only on low dose pain killers now. But um

146. **S:** So for you really, the greatest frustration is the fact that the doctors can't fix it and they don't know

147. **A:** [laughs] Yes!

148. **S:** And there is no answer

149. **A:** I actually, I actually dislike them for it, I really do. I really do. All these years they've been, you know, training and all these things they've been doing and that's all they can say to me. You know.

150. **S:** It's a false belief we have in society, isn't it, that the doctors can fix everything, and they can't.

151. **A:** Exactly, see that's what my mother said. She said, "You have to learn to understand that they just can't fix it." No it really, it really really really upsets me. It makes me feel huge hatred actually [laughs]. Oh dear.

152. **S:** And anything else that you can think of that maybe we haven't covered today?

153. **A:** You know, no, I'm just trying to think. I'm very interested to see what the psychologist is going to say to me on Monday. I'm already getting all uptight about it [laughs]

154. **S:** Have you, has, so Rayne's been to see her?

155. **A:** No, Rayne's been to see her.

156. **S:** And you're having a feedback session?

157. **A:** And we're having a feedback session. Which I feel very stressed about.

158. **S:** What is stressing you about it?

159. **A:** I don't know what she's going to say

160. **S:** Ok.

161. **A:** She's going to say something that's going to annoy me, is she? I don't know [laughs]

162. **S:** The not knowing, the not knowing is not a good space to be in, is it?

163. **A:** I know, terrible. But I do feel, no look, I mean when I see Rayne now over these past couple of months, I feel extremely hopeful. But then on the other hand, she's been on medication before to settle her brain and control all the pain etcetera, and it seems to work for a while and then you know it all comes back again. So, but anyway at the moment this has, this has been extremely good.

164. **S:** Yeah. Well

165. **A:** I mean one of the things she takes vast quantities of is Trepiline [Trepilone?], I don't know if you know Trepiline [Trepilone?]?

166. **S:** Yes

167. **A:** I mean she takes 4, see it's also to do with fatigue, she takes four Trepiline

168. **S:** So what's that 40mg? She, is she taking the white ones or the blue ones?

169. **A:** The white ones.

170. **S:** Yeah I think that's 40mg

171. **A:** No it's 100, 25 each.

172. **S:** Oh she's taking, oh yes that's right it's the blue ones that are the 10.

173. **A:** Yeah. Yeah. So she takes 25 each now. Because I took a Trepiline I think it was a couple months ago, I just took a Trepiline because I woke up and I just couldn't sleep and I, I mean I slept the entire next day. How can they actually, you realise that she's on all this medication, I don't know how she does it. I really don't.

174. **S:** It is, it is one of the big themes that have come through is the amount of medication these children need to be on.

175. **A:** Yeah.

176. **S:** But I'm gonna stop the interview now then um.

[recording ends]

Transcript 3 B: Ann interview 1B[6]

1. **Interviewer (S):** So thank you very much for allowing me to come back and re-interview you.
2. **Interviewee (A):** Pleasure.
3. **S:** So, basically I just wanted to ask you initially -- I think we went through the whole story before of how Rayne became ill.
4. **A:** Right.

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[6] Interview repeated to improve quality of data.

5. **S:** And a lot of our interview sort of revolved around the anger that you had towards the doctors because they actually ...

6. **A:** It's funny how you say that, because I was just thinking how, and I was just thinking immediately what comes out of my mind is anger.

7. **S:** Anger, anger.

8. **A:** Yes. Anger about why it was happening, anger about why they didn't do anything about it, anger about that everything progressed so quickly and not enough was done. Isn't it awful that it was just anger? You know. The compassion wasn't there so much, it was the -- I was just furious that this could be happening.

9. **S:** And I was wondering -- Because I don't think we even got to talk about -- I mean there was the JIA, the arthritis itself, but then there was also she got diagnosed with a brain tumour.

10. **A:** Yes.

11. **S:** And how that was -- How did you experience that as?

12. **A:** Ok. Well I mean, Rayne you know, since birth had not been a well child and she'd had headaches all through her, you know, toddler years etcetera. And you know the teachers used to just say to me, her nursery school teachers, she must drink more fluids and all sorts of things like that. And, and -- I knew there was something wrong, you know. I always suspected that there was something. And even before she was diagnosed with arthritis, I actually knew. I actually remember going to my friend and saying: you know, I'm absolutely 100 per cent certain she's got juvenile arthritis. Even when they were telling me she had mus -- She had a reflex dystrophy. Is it reflex? Sympathetic ...

13. **S:** Muscular dystrophy?

14. **A:** No, no, it's not muscular. It's reflex dystrophy.

15. **S:** I don't know that one.

16. **A:** Yes, yes. It's some whole thing. Ja. There's -- That's what the orthopaedic people had said. Ja. I just knew. But anyways, as goes her, her headaches, it just became part of her life, you know. She would come home from school, the nursery school, and she would just sleep all afternoon. And I just thought, well that's her. She's a quiet child. She's a tired child all the time. And so it went on all through her, into her primary school years. And the headaches just started getting worse and worse. And then eventually my GP said to me, this is ridiculous, we're going to do a scan. We did the scan and he, they just said to me, no this is clear. I can't remember, she must have been about six or five or something. And to see this little thing in that big machine. It was absolutely awful.

17. **S:** With the MRI?

18. **A:** Yeah, the MRI machine. Her little feet sticking out, you know. I remember taking it, the radiologist said no, this is fine. I took it back to her GP, she was in the same building, and she said oh, this is fine. A few weeks later, I took it to her paediatrician, and he spent ages looking at it. And he said no, this is, this is all ok.

19. **S:** That was the one she had when she was six?

20. **A:** It was the paediatrician who had been with her at birth, actually. And then as it continued throughout the year through into the next year, I eventually took her to a specialist neurologist, paediatric neurologist. A very well-known one, very well-known children's neurologist, who just treated me as though I ... She actually treated me as though I was a mad, you know, Northern suburbs housewife type thing. She barely even looked at Rayne. She barely looked at her. I mean that's when I talk about anger. When I think about it now I still feel angry about that. And then she said ...

21. **S:** I can imagine.

22. **A:** She just said to me, no everything's fine, she's got paediatric, paediatric migraines. And just, you know, increase her fluids and give her Panado. All sorts of rubbish.

23. **S:** So she basically only spoke to you and didn't really examine Rayne?

24. **A:** No, no she barely looked at her.

25. **S:** Ok.

26. **A:** No. I can't remember her doing ...

27. **S:** So she took a history or something?

28. **A:** Yes, she took a history, but she barely examined her in any way. So because of that I never took it any further. Because I thought, this is this fantastic woman who knows her stuff, and if she says everything is fine, then it's fine. She's got paediatric migraines and that's it. And then, you know, I think it was that same year Rayne started getting all these problems with her joints and her knee and her legs and her arms and all the rest of it. Even though actually since -- I realised afterwards since she was a toddler she had been complaining about pains in her legs.

29. **S:** Wasn't she the one who had the ankles from on the bicycle or was that not her?

30. **A:** No. No.

31. **S:** Ok.

32. **A:** But she had -- She would never walk, you know. We used to, we always used to have to put her in a pram. We thought she was just lazy, you know. And then she'd say her legs are sore.

33. **S:** Oh, that's what I'm remembering.

34. **A:** Ja. No, no the time when it became most obvious was when she was actually doing ballet and her, and her ankle was absolutely appallingly hot and swollen and, and sore. And when I took her to the paediatrics, to the orthopaedic surgeons, and they said it was Sever's. Yes, and I kept saying but how can it actually be so sore? And I kept saying to them, you know, not only is it sore, but just look at her. Oh she looked terrible. She was as thin, and she was white as a sheet, she had sores in her mouth. I mean, surely that's a tell-tale sign of something. I didn't realise that it was, but they should have known, you know. She had sores in her mouth and he just said, no no, she's just in pain.

35. **S:** How did that feel?

36. **A:** Well I, I thought that ok, well then she's just in pain, it will go away. You know. Because these people tell you, these specialists, these fantastic doctors who've been doing it for 12, you know, learning about medicine for 12 years. I thought that they must know. It's pain, it's going to go away. So it actually made me feel better.

37. **S:** So they didn't properly explain things.

38. **A:** Well he said it was -- He said it was what it was. It was Sever's and it would go away.

39. **S:** Ah.

40. **A:** Yeah. He kept, they kept repeatedly telling me it would go away. Even though I kept saying to them, you know, she's just so sick in herself. But no, they didn't, they didn't examine her as a, as a sick child.

41. **S:** So they didn't hear you?

42. **A:** No, they didn't hear me.

43. **S:** They didn't listen to you.

44. **A:** No, they don't listen to me. But these were men as well. They definitely didn't listen to me. [laughing]

45. **S:** . . . that's an interesting comment that you've made. Can you elaborate on that for me a little bit more?

46. **A:** I don't know why I actually said that, actually. But I mean I've found throughout my life that women doctors are much more approachable and much more compassionate and ... Apart from Rayne's brain surgeon, who was a male doctor actually. He was wonderful. I don't know what it is. These men that I saw -- Maybe it was because they were orthopaedic surgeons. Maybe that's a different thing. But they were very dismissive. And they were very confident that they knew that they were right. Because after I took her to the one at the small hospital, he then referred me to the one at the greater hospital, who was the great man.

And my goodness did he have a fancy suite with everybody waiting, and oh. I can't imagine how much money he must have spent on all these things he had. And he was absolutely adamant as well that this was some sort of Sever's, and it would go away. [laughing]

47. **S:** But they, they didn't listen to the other symptoms that you shared with them.

48. **A:** No, they never listened to the other symptoms. And it always amazed me that they could never see that she was a sick child. Because she looked absolutely awful.

49. **S:** How did she look?

50. **A:** You know, she had -- Her skin -- She was almost -- She's actually looking very well at the moment. She's doing very well. She was absolutely like translucent, she was so pale. It looked like she didn't have any blood in her. And she had these dark dark eyes, you know, dark rings around her eyes all the time. And sort of, you know, chapped lips and just the look of a child who was ill. And like sort of furrowed brow because she was in such pain all the time. It was -- It was bizarre that they never saw anything above her ankle. Because at that time it was mainly her ankle that was, that was sore.

51. **S:** They were almost separating that bit from the rest of her.

52. **A:** Yeah, they only saw they ankle. And I, I know I mentioned this before, but the reason when I realised that there was a real big problem was when I took her to her ballet class and her ballet teacher said, oh my daughter's also got Sever's and I'm telling you, she was pirouetting around the room.

53. **S:** Yeah, you said. Doing pliés and ...

54. **A:** Ja, no. And I thought, man, I'm sorry, this is really weird. How can it possibly be?

55. **S:** So you were really caught in a situation of knowing there was something wrong ...

56. **A:** I knew there was something wrong.

57. **S:** There was something wrong that nobody could ...

58. **A:** You know, you know how I knew as well, because I went to university with a girl who had juvenile arthritis.

59. **S:** Oh, ok.

60. **A:** And I, I -- And she had the same. She was pale and thin and she was actually ... It was many years ago, so I mean, she was in splints often. But there was something about her that I could see in Rayne. And there was, there was just something there.

61. **S:** And I'd just like to ask you. So there you were with this, sort of caught in this dichotomy or whatever you want to call it, of knowing there was something wrong.

62. **A:** Yes.

63. **S:** Visiting the doctors and being given a diagnosis that you knew wasn't the correct one.

64. **A:** Yeah.

65. **S:** How did -- Well, I know it made you feel like ...

66. **A:** Well I knew in my heart it wasn't the correct one. But as I said, I mean, you actually have to trust people who are such specialists. And you know they were so adamant that they were right.

[10 minutes]

That's the thing. I don't mind if people say -- You know when I met Dr X eventually, she always if she didn't know something, she would say ... She would say, look I'm not sure, I don't know. She would even get out text books and say, let's have a look her, you know. And she would be quite open about it, you know. She would say, I don't know. But also, you know, what I didn't realise at the time was that dealing with children is quite a different thing. None of these people were paediatricians, apart from the neurologist – she was – none of these orthopaedic surgeons dealt with children and joints and bones and things. I mean, do we actually have anyone like that here, in this country? I don't think so. No.

67. **S:** There -- The -- I think the paediatric side of things is very small in this country.

68. **A:** Ja.

69. **S:** Apart from your normal paediatricians.

70. **A:** Ja.

71. **S:** There are only three paediatric rheumatologists.

72. **A:** Yes, that's right. But as goes -- I mean, in all the times I was sitting in all their waiting rooms, I don't remember seeing children there. How do you think that impacted on Rayne? Being placed in an adult environment as a child?

73. **A:** Yes. No I think that it was -- It was -- It was very intimidating actually. It was nothing -- It was nothing warm or about -- There was nothing to make her feel at ease in any way. And there was always these very overbearing, very miserable, in inverted commas, men she was dealing with.

74. **S:** And she's a little girl.

75. **A:** She's a little girl, ja.

76. **S:** Do you think she was able to -- I mean, how were her interactions with them?

77. **A:** Gosh, I can't remember. I don't even remember her even speaking very much. But she's like that even now. I don't know, I hope she was better with you. But she's like that now. She, she doesn't speak very easily to people in the medical profession. Maybe it started there. I don't know. She's better with her GP, who's a woman and very motherly and very loving and very caring.

78. **S:** And she has a relationship with her.

79. **A:** She has a relationship with her, ja. She's, she's wonderful, her GP. But these, these guys she didn't have any relationship with. And certainly -- And even the neurologist, that was female, she was totally dismissive of Rayne too.

80. **S:** As in -- As in that she didn't hear Rayne?

81. **A:** She didn't -- I don't seem to remember her even speaking to her actually. Funny isn't it? Yeah.

82. **S:** And then we got to, was it 12 years? When they finally realised she was falling off the balance beam.

83. **A:** Yes, when was that. It was when she was 11 years old.

84. **S:** Or 11.

85. **A:** Ja. When she was in Grade -- When she was 11, ja.

86. **S:** Grade 6.

87. **A:** Yes, she was in Grade 6 actually. Yes, she was in Grade 6. And there were signs before that, actually, all building up. There was a time when I picked her up from school and she said to me: my head is bad, but this is the worst it's been ever ever. And I just knew then. And when she fell off the balancing beams and I knew then. And I told you, once I picked her up from school and she was dressed in fancy dress, all on crutches and splints and everything.

88. **S:** Oh yes, you said.

89. **A:** And looking absolutely absolutely awful. And I just knew then as well. And I thought, I mean, you know all these times they were so obviously there all these signs. Oh, they were so obviously there.

90. **S:** But no-one put them together.

91. **A:** No-one put them together. Well I mean, Dr X, Dr X did keep saying to me, she kept saying to me where's the original scan? Because I didn't want to do another scan. I mean, she'd had all these things. And I kept saying, no, but they -- She went to four different doctors and they all said it was clear, so I couldn't find it. I said, it's got to be clear. So eventually, I think it was that time when I picked her up from school, and she said it was the worst headache ever, that I actually phoned Dr X and I said no, now we must do a scan. And I mean, I'll give it to private health care in this country, I mean I did it the next day. And it worked.

92. **S:** Wow, that's incredible.

93. **A:** Just moved so quickly. Because I also didn't know a single thing about ... I mean, I didn't know anything about the brain or what was going on. I remember after she did the scan the radiologist came to me and said, now when are you seeing your doctor? Even then I didn't get the hint. I said no, I don't know, I think I'm just going to put it under her door. She said, ok, I want you to go put this under her door today then. So I just took it around the corner and I opened it and had a look. [laughing] But even then, I mean -- I haven't shown you these pictures, have I?

94. **S:** No, no.

95. **A:** Oh, I must show it to you. Even then -- Even then, I mean I didn't -- In fact it's just here, I'll just get it for you.

96. **S:** Ja, sure. I'll just stop this in the meantime.

97. **A:** Because I just, I ...

[Recording stops and restarts again]

98. **A:** And I see this.

99. **S:** Let me just put my glasses on. Is it the white?

100. **A:** Yes. That's the -- That's the tumour.

101. **S:** Jeez, that's big.

102. **A:** I know. So I see that. And even then I don't even think -- I think, oh look. And it says it's got, she's got this massive thing in her head. And I think, oh well, maybe they can just put a needle in it and ...

103. **S:** So, so, I mean, your emotional reaction at that stage was ...

104. **A:** What are you doing? [another voice in the background] Oh, ok, ja ... No I didn't think anything, because I just thought ...

105. **S:** Do you think you were in shock, or ...

106. **A:** No, I wasn't in shock. I just thought , oh look, look at this thing, and it's got this big white thing here. Well, I mean, maybe they can just put a needle in it and it will go away or whatever.

107. **S:** And then you found out.

108. **A:** No, and then I went back to my friend, who's a nurse, and I said I -- You know, they've done the scan now and it says she's got this big, they didn't know what it was, mass in her brain. And I said oh, but they'll just be able to take it out. They'll just be able to put a needle in and suction it all out, won't they? And she said yes, I'm sure they will. [laughing]

109. **S:** So, she didn't tell you?

110. **A:** No. I don't know if she even knew what I was talking about actually.

111. S: And then you had the, obviously the conversation with the doctor, and the doctor told you the procedure.

112. A: No, well, Dr X was dealing with it actually.

113. S: Oh, alright.

114. A: And then Dr X I mean, she called us in and went -- I mean, she always examines Rayne. I've told you before, from the top of the head all the way down. She went through everything. She actually phoned the neurologist while she was doing it and said ok, what else do you want me to do? She had to do all sorts of things, I don't know what. And then she -- And then -- That's another thing about her. I mean, they couldn't find the right surgeon for her and oh. I mean she, she ...

115. S: In the sense, in the sense of being able to do the procedure?

116. A: Yes, in the sense of finding a paediatric neurosurgeon. There was one in Cape Town, can't remember his name, and I think that was it actually. There was one in Cape Town. And they said to me, will you take her to Cape Town? And I said no, I don't want to take her to Cape Town, because I thought this was a thing you could just put a needle in and suction it out, you know. [laughing] So --

117. S: So what I'm hearing is there really, there really wasn't -- People didn't really explain clearly to you what ...

118. A: They didn't explain. In fact, I do remember at one stage when I was there sort of also being dismissed, that Dr X actually said to me, I want you to understand that, that this is actually a very serious thing. And only then did I actually think, oh, really? You know.

119. S: So they just kind of ...

120. A: I didn't know that they were going to have to, you know, cut open her skull and do major brain surgery or anything like that.

121. S: And when you found out about that, how was that?

122. A: Oh, it was absolutely awful. Even now when I think about it. So firstly we couldn't find a surgeon for her and then eventually they, they found this Dr O who was at Hospital Z. And I went to see him at the ... here. And he was absolutely fantastic. But I mean, even then he just looked and he just said very gently, he said look, we're going to have to take this out. And then I said, can Rayne just go out the room please? And then she went out the room and I just burst into tears and said, what's going on here, what is this? But I never wanted her to see me breaking down in any way. It was just so awful. And he just -- But even, even, even him, he was the most wonderful surgeon and the most compassionate man, he never really explained that afterwards there could still be problems. And that afterwards she could still have pain and after ... I thought that it was going to all, you know, this operation would happen and then everything, everything would go away, everything. Including arthritis, everything. I thought it was all --

123. **S:** Oh.

124. **A:** I thought everything would go away.

125. **S:** Ok.

126. **A:** And actually what happened was, after this operation it did go away for about a couple of months, and then actually everything came back worse. And Dr X once said to me that, you know, children who have had brain surgery get these terrible headaches and that's all it is, and there's nothing more you can do about it.

127. **S:** And that's one of the things that made you so angry. That you can't do anything about it.

128. **A:** That you can't do anything about it. I know.

129. **S:** So, the impact of the brain surgery on Rayne. What do you think?

130. **A:** No, I don't -- I don't think that she ever realised that it was such a big thing. No, she never. Because I never really said anything.

131. **S:** So she was quite protected from that perspective.

132. **A:** She was totally protected. I mean, when I drove her to have that operation, I kept stopping on the way because I, I think I was having panic attacks or something. So every 10 minutes I would like stop the car, I would pull in somewhere, and I would say, ok Rayne I just want to have a look, I think there's something wrong with my tyre, hang on. And I would go [loud inhaling sound]. It was absolutely, it was just awful.

133. **S:** And ...

134. **A:** I never thought I would get there actually. I never thought I'd get there.

135. **S:** And what support systems were in place for you?

136. **A:** No, well, no Gus was here. But I told him not to come because -- Not straight away, not straight away.

[20 minutes]

I didn't think that the drive was going to be so awful there. I think it's when you're driving that you start thinking of things.

137. **S:** Were you protecting him, or you just didn't think you needed ...

138. **A:** Protecting him. And I don't know if I mentioned this before, but the day before a woman had phoned me. She heard about this. She had phoned me – her son also had a surgery to remove a mass in his brain. And she said to me, I just want to say to you that I took my son to America; I would never trust any South African surgeons with him.

139. **S:** Oh, wonderful.

140. **A:** I know.

141. **S:** That must have been incredibly hard to hear.

142. **A:** I was absolutely in such a state. I was in such a state. Because I mean, I didn't, I mean, although my gut feeling was that Dr O was very nice and that, I didn't know anything about him. Nothing at all.

143. **S:** And it wasn't like you had a choice.

144. **A:** No, I didn't have any choice.

145. **S:** Because there was no-one ...

146. **A:** There was no choice. There was absolutely no choice whatsoever. Other than ...

147. **S:** . . . an incredibly difficult situation to deal with.

148. **A:** Other than to stop the operation. Ja. But you -- I mean that's why I was in such a state the next day when I was driving through. I kept thinking, am I doing the right thing? It was just awful.

149. **S:** And then -- So she went through the procedure and ...

150. **A:** Well then Gus actually came later in the day. The procedure was supposed to be in the morning and then of course ... delayed and then finally we got to the, and Gus came with through to the post-theatre room, before the theatre room. And then I just remember I just said to him no, you can go now, you can go now to him. Because I didn't -- Because I could just see he was getting so upset. Although I was so upset. I said you can go, I'll, I'll talk to you later. And then I had to go and take Rayne actually into the theatre. Oh God, it was awful. See I don't, I don't think she realised actually what was going on really. I really don't. To this day I don't think she even realised what a big thing it was.

151. **S:** Ja, ja.

152. **A:** Or what exactly happened.

153. **S:** Ja.

154. **A:** And then, then they had to -- She actually lay down and they had to ask me if I could put the anaesthetic on her face, you know.

155. **S:** On her, ja.

156. **A:** Put the mask on. Which I did. And then afterwards I just collapsed. I just -- And she went under and I just said, please please make this alright. Please sort her out. Please. Shame and they were very sweet. They actually walked me back to -- I was staying on the ward. Walked me back to the wards.

157. **S:** And that's quite intense.

158. **A:** Oh, it was awful. And then I had to sit and wait. I mean it was about six, seven hours or something. Well, a couple of my friends came over and waited. And then ja, I'm telling you, the relief when I walked down and I saw the doctor walking in his ... He was walking in his like a . . . and he was in black tie actually, because I think he was going out to a function afterwards. And there was this very handsome black dude in his black tie, Rayne's neurosurgeon, and the anaesthetist was also a black guy actually. All looking very smart and very confident. And I said, how did it go? And they said, oh, it was absolutely fine. And then they both gave me a big hug and I mean, they were, they were just wonderful.

159. **S:** So, very containing for you.

160. **A:** Oh, it was -- I just felt so much better.

161. **S:** Ja.

162. **A:** Until of course I saw her in ICU.

163. **S:** I was about to say, and then she was in ICU.

164. **A:** I mean when I saw her with the, with all the tubes and the paraphernalia, and I saw the extent of what had happened, it was just absolutely awful. And the pain that she went through afterwards, gee whiz. I mean they did keep it under control, but they couldn't keep it under control every minute of the day, kind of thing. And to see her in pain was, it was just agony for me. It really was.

165. **S:** What was agony about it?

166. **A:** Well, the fact that I'm her mother and I couldn't ... And I couldn't help.

167. **S:** You couldn't help.

168. **A:** I do remember once shouting at the ward there at the sister in ICU. And I was saying to her, she shouldn't be in this pain, she shouldn't be this, she shouldn't be that. And then I went through the whole list of things and then they sorted them all out and ... And then I said, and why is she wearing this? She was wearing one of those theatre things. They keep them in there.

169. **S:** Theatre gowns.

170. **A:** They keep them in there. I didn't even realise then. But it looked so awful. It was all grumpy and awful. And I said, surely you can put her in something better than this theatre gown. And then that's when they actually put their foot down. They said no [laughing]. This is what we put them in. It's easier to ... like this. But I had gone through a whole load of things, this and that and this and that.

171. **S:** But they actually did do some of the things ...

172. **A:** No, they did yes.

173. **S:** So what was your experience then of the aftercare?

174. **A:** Well I had been so worried that -- Because I had obviously been taking Rayne to this hospital quite often before for her arthritis and all sorts of things. And I had -- I mean the nursing staff, I mean, there was nothing wrong with them, they were fine. But I didn’t think, didn’t know -- When I saw Rayne in the ICU, I thought well, all these nurses on the ward know how to do all this stuff. You know, it was all so highly technical, and so many machines and all the rest of it.

175. **S:** Yes. Ja.

176. **A:** So I actually had a bit -- I knew the matron in charge. Although I think she thought I was a real pain though. I said, is it going to be alright, my daughter coming back to the wards? Is it going to be alright? She said, are you trying to tell me that my nurses can’t look after your daughter? I said, no no no. Well that was exactly what I was trying to tell her, actually. I mean, once she came off the ward where she was. Because Dr O kept saying to me, I don’t want to keep her in ICU, it’s not a place for a child. It was absolutely awful. And she, she came off ICU in about three days actually. And they were, they were fantastic, the nurses on the ward. I mean, she had her one dedicated nurse who did everything for her. It was actually a nurse who had been, who had just come back from England. She’d been nursing there for many years. ... lovely. No, they were fine.

177. **S:** So, she’s had quite a rough ride. Because then she’s also had the two colonoscopies, which are JIA-related.

178. **A:** Oh no, she has had, yeah. Her stomach has been terrible. Ja, no, she’s always had problems with her stomach. They said she had eosinophilic, eosinophilic sheets of eosinophils on her colon.

179. **S:** They have what?

180. **A:** Sheets of eosinophils ...

181. **S:** Do you know how to spell that?

182. **A:** Eosinophilic. O - E - S. I mean, that’s just inflamed cells.

183. **S:** Ah, ah. What do you think the impact of all, all the visits, for want of a better word, all the consultations to the hospitals, had on her identity and her self-concept as she was growing up?

184. **A:** I do remember once that she came back, and she was in primary school, and she came back after being in hospital after being sick for so long, and her best friend was standing there and ran to her and said, Stephanie, Stephanie, I’m back! And Stephanie turned her back on her and walked off with another friend. And you know what, I will never forgive this child for that. Never. I will never ever forgive her. I mean, now it's eight years down the line and I still think of it. And I know that girls are horrible, they are. But I mean she'd never actually settled down in a, in a real friendship. Because this little girl was her big friend since Grade 1. And then she was off school so much that she found other people.

185. S: Is this the little one that used to come and bring her the work from school and all that kind of thing?

186. A: Yeah, some, some of the kids would do that, ja.

187. S: Rayne seems to think there was one special girl who used to keep bringing her work and sitting with her when she wasn't at school.

188. A: No, I think that was her friend across the road, Holly.

189. S: Oh, ok.

190. A: Ja.

191. S: Ok. So you're saying it had quite a, it had social implications?

192. A: It had terrible social implications for her.

193. S: Could you give me some more examples of what you saw?

194. A: Well I don't -- Ok, there was that.

195. S: So the little girl who turned her back?

196. A: Ja. And -- Let me just think. You know she -- Even now, I mean ...
[whispering - unclear who is speaking]
She's gone now actually. Even now, I mean she's been with these same friends since they were in primary school, but there's like five of them, and she's the odd one out. And she's always been the odd one out. You know, it's always been two-two and Rayne. Because you know, because a lot of the time she's not there and so the two and two are always together. And then there's Rayne. And I know she's had terrible problems with friends at school. I mean, I don't know whether I can always blame it on her, her health problems though. I don't know. Can you? Can you blame it on their health problems, the fact that they're not there? I don't know.

197. S: Well ...

198. A: I do know this one little girl, the same girl who turned her back on her, once said to everyone: no Rayne didn't have a ... Rayne, Rayne didn't really have a major problem with her head, the operation wasn't so terrible.

199. S: So there was a sort of denial that there was actually anything wrong.

200. A: Yeah, they actually -- Especially her, I don't think she, she liked the attention that Rayne was getting. Maybe, I don't know.

201. **S:** How do you think those kinds of comments affected Rayne?

202. **A:** I think it must have been absolutely devastating. Absolutely devastating. I mean for other people maybe it wouldn't have been such a problem, but from her best friends, that they thought that. Because the teachers were always very caring to her, especially in her primary school. Because they, they knew what was going on there and they were very caring. No, I think it must have been absolutely awful.

203. **S:** Do you think perhaps that because of -- Do you think that the experiences that she has been through put her in a different space to her peer group?

204. **A:** Well I don't think it put her in a better space, that's for sure.

[30 minutes]

205. **S:** I'm thinking maturity, or developmentally.

206. **A:** I think that -- I think that she is far less mature than them.

207. **S:** Really?

208. **A:** Far less mature than them.

209. **S:** In what ways?

210. **A:** Well maybe it's because we've always sort of a bit maybe ... I don't know if this is a healthy thing either. Because she's the youngest in the family we've tended to baby her. Because she's been sick so often, we tend to try and jolly her on all the time and, you know, make light of everything.

211. **S:** So has it changed your parenting style in some ways?

212. **A:** no, it is a different parenting style that we have with her, definitely. Definitely.

213. **S:** So from that -- So ...

214. **A:** And certainly she, she's one of these children who doesn't easily catch on to things, whereas her friends immediately will, you know, get things. Like a joke, or whatever.

215. **S:** Sexual innuendos?

216. **A:** Yes, and things like that. She doesn't get it at all. She doesn't get it at all. I mean, just to give you an example, the other day Max, my son who's here, he brought a thing home – he's in matric – from school saying, can everyone give money for a matric leaving present, which will be a tree. And then we'll plant a tree. And Rayne said, oh that's nice mommy, but there's no room in our garden for any trees. [laughing] She sort of like doesn't get it. Oh God, I laughed. [laughing] I mean, it's very dear, it's very, it's very endearing that, that she sort of like doesn't, doesn't sort of catch on to a lot of things. She doesn't catch on to like sexual inn ... You know, she doesn't.

217. **S:** So in that sense, I don't know if I'd like to call that immaturity, more of an innocence?

218. A: Yes. I've always thought -- Although I must say, over the past year or so she's sort of coming out of it a bit.

219. S: Are you seeing a change?

220. A: You know, I think she's seeing boys and ... But before that there was nothing like that at all.

221. S: So you are seeing the developmental changes a bit more now?

222. A: I am seeing it now, I am ja. But I think part of it is that she's always considered herself to be very sort of not cool. Very uncool. Because she is like this, she sort of doesn't get things half the time. And she's not clever like her friends. Her friends are very clever. She's going around with a group of girls who are very high-achieving and very clever.

223. S: And then of course she is at a deficit with not being at school.

224. A: And she's not at school a lot.

225. S: So it's hard to keep up with the academics.

226. A: No, no it's incredibly difficult for her to keep up with the academics. I mean, she's just had to drop now from her ... Did she tell you? From maths to maths Literacy.

227. S: Ah.

228. A: Which is actually devastating. Al these years she's, you know, persevered. But because -- And I know what it is, she's missed so much along the line. You can't just miss maths. And I, and I, and I kept trying to go back and having tutors and trying to catch up with all the things. But it was just never there.

229. S: But there's only so much you can do though with the level of fatigue she experiences.

230. A: Terrible level of fatigue. Ja. For instance, on Sunday when she came home from work – and this is typical – she came home at five o'clock. Normally she comes home at three o'clock. She came home at five. She just went to bed and went to sleep. Her fatigue is terrible. I mean, you must know, the fatigue is a real problem.

231. S: And I ...

232. A: And she falls asleep in class. You know.

233. S: And yet she pushes herself to go.

234. A: Yes, but the -- Her doctor, X,at the beginning of the year said that she didn't push herself enough to go.

235. S: Ok.

236. A: And she must push herself more.

237. S: Is that to build up stamina?

238. **A:** No, that was because she felt she was getting into a psychological position that missing school was becoming too easy, sort of thing.

239. **S:** Ok.

240. **A:** And too comfortable. And she has to be stronger and push through it.

241. **S:** And what is your take on that?

242. **A:** Oh God, I was so upset. I was absolutely furious.

243. **S:** Do you, do you agree with her?

244. **A:** Funny enough, seven months down the line, I do think that maybe she had a point, yes. But Rayne is a lot better now at the moment, actually. But at the beginning of the year she was absolutely terrible. She was in constant pain all the time. I mean she couldn't even get out of bed. But Dr X was absolutely adamant that she had to push through. That this was a psychological thing.

245. **S:** How did it feel for you as a mom to hear that? Her physical pain, it was being described as a psychological issue?

246. **A:** Unforgivable. I still haven't forgiven Dr X.

247. **S:** Did she ...

248. **A:** I don't think I'll ever forgive her, actually.

249. **S:** Did she say it in front of Rayne or just to you?

250. **A:** She didn't say it in those words in front of Rayne. She said, Rayne you've, you've got to go to school. Got to go to school. And I don't think she mentioned -- She didn't put it to her that it could be anything to do with, you know, in the head or anything. She didn't, no. And she always tells me that she didn't say that to me, but the, you know, the implication was there. The implication was there very strongly, I'm not stupid, I know what she was saying.

251. **S:** And Dr X can be very direct. [laughing]

252. **A:** Yeah. Yes. Have you met her?

253. **S:** We've just chatted via e-mail. And even via e-mail she's ...

254. **A:** Yes, I know.

255. **S:** She says what she says.

256. **A:** Yes, she does. [laughing]

257. **S:** She does. So what I'm hearing ...

258. **A:** No, it was unforgivable, really. And then she sent us to a psychiatrist. She was actually in hospital at the time, Rayne. She asked the psychiatrist to come around.

259. **S:** So she -- What was she in hospital for?

260. **A:** For pain management.

261. **S:** Ok.

262. **A:** Ja. And also she, she has immune deficiency, so she gets lots of infections and things. Ja, so I think she had an infection and she was in for pain management.

263. **S:** And pain management being testing different kinds of meds to see what works?

264. **A:** Yeah. They tried to stop the cycle of pain.

265. **S:** Ok.

266. **A:** Which never really works, by the way.

267. **S:** Ja, ja.

268. **A:** I don't know. Have they ever managed to stop the cycle of pain with you? Never.

269. **S:** No.

270. **A:** No. And I kept saying to Dr X, why can't there be a scientific way of fixing this? There must be -- I mean it's something that is physically happening. Why can't it be fixed in a, you know, scientific way with medication of some sort?

271. **S:** Ja.

272. **A:** But no, apparently it can't. I don't know. I still don't understand why not.

273. **S:** So with Rayne being in and out of hospital, off school, very tired, sick child, in what ways does your parenting differ with her to that of your son?

274. **A:** And I've got an older daughter too.

275. **S:** Oh, and an elder daughter.

276. **A:** Yes, I've got an older daughter too. [laughing]

277. **S:** Oh, I'm sure that's in my biographical details, but I forgot about that. What's different?

278. **A:** I expect my son to be far more independent.

279. **S:** Ok.

280. **A:** But I often wonder, maybe that's because I think of him as a boy, and ...

281. **S:** Did you expect your eldest daughter to be more independent?

282. **A:** Well, my eldest daughter was a problem because she had an eating disorder. At the same time as Rayne got all this, she got her eating disorder. Which was very bloody annoying, I can tell you. [laughing]

283. **S:** Ja.

284. **A:** Because with that, as psychologists, can you see the link?

285. **S:** You know, with these things -- You see now this is where we derailed with the last interview.
[both laughing]

I'm not even going to comment on that. Perhaps we can discuss that afterwards. The important -- The point for -- Important thing for me is, your seeing the ...

286. **A:** No, so I, I probably treated my older daughter -- Ja, maybe slightly differently. But Max, I expected him to be independent and get on with his life, and to be strong.

287. **S:** And he's now in matric?

288. **A:** And now he's in matric. And he has been -- He's a South African rower, and he's been around the world, and he's been on his own, and he's always with his friends, and he just gets on with his life. And I still fight with him as well. But -- But, with Rayne, I was always much more gentle I think. Ja. But less so over the past year since she's been discovering boys, I think.

289. **S:** So, so did you change your expectations of what she should be able to do?

290. **A:** Well that's what Dr X always said to me. And in fact, even when she was in nursery school ...

291. **S:** I didn't say you did. [laughing]

292. **A:** Even when she was in nursery school, my teachers, the teachers said you treat Rayne... And she hadn't been diagnosed with anything, even though she was very sickly all the time, the teachers ... One teacher came to me, she said, you know you treat Rayne differently from the other two and you must stop it. She said, you expect too little of her and you expect too much of your son.

293. **S:** So then, definitely different parenting with the children.

294. **A:** I didn't noticeably -- I didn't notice it to that extent I suppose, but ...

295. **S:** Why do you think you parented differently?

296. **A:** Well because she was ill and in pain and, you know, you tend to approach them in a different, in a more gentler manner. In a more sensitive manner. I definitely did. But I mean, basically what Dr X said to me in the beginning of the year is that I must also stop doing that. And she once heard Rayne -- And I can't even remember, it was least year I think, Rayne being abrupt with me. Not even particularly rude, but just abrupt, just saying sort of [makes an unclear sound to illustrate]. And she took Rayne aside and said to her, do not speak to your mother like that. I thought. [laughing]

297. **S:** ...

298. **A:** Ok, sorry.

299. **S:** No, it's fine. So she actually reprimanded her ...

300. **A:** Yes, and she said to me afterwards, she said you mustn't let them ... This is, this is the children with chronic illnesses, is that you mustn't give way. You mustn't let them treat you like that, you mustn't let them speak to you like that. Mustn't be rude. So, ja, I must say I didn't really notice it until she said so.

[40 minutes]

301. **S:** What, what would you have done had one of your other children spoken to you like that?

302. **A:** Yes, I probably would have been very annoyed and told them to shut up. Yeah. But the thing is, I didn't do that to Rayne then because also it was in front of other people. I would never do that in front of other people.

303. **S:** Not even with the other kids?

304. **A:** Yeah, I might do it with the other kids. [laughing] I would with Max, yes. Ja.

305. **S:** Interesting.

306. **A:** Ja.

307. **S:** And, so -- So the parenting styles have been different.

308. **A:** Ja, they have been different.

309. **S:** And you've raised the issue that your eldest daughter developed an eating disorder at the same time that Rayne was diagnosed, or when she was sick?

310. **A:** No, the same time that Rayne had this big operation.

311. **S:** Oh, so she had the eating disorder at the same time that Rayne had the ...

312. **A:** Exactly the same time.

313. **S:** The brain tumour.

314. **A:** It must have been within a couple of months.

315. **S:** Before, or just afterwards?

316. **A:** Just after.

317. **S:** So one ...

318. **A:** Although clearly it was coming before. So, ja.

319. **S:** So one of the questions I neglected to ask you last time was how has Rayne's illness impacted on the family relationships and dynamics?

320. **A:** She certainly has a better relationship with her brother than she does with her older sister. Maybe because, throughout the time that Sarah-Jane had her eating disorder, and I was coping with all this with Rayne, I mean we never really knew with Rayne whether she had ... I mean, she sort of had overlapping auto-immune disorders and they could never put their finger on what it was.

321. **S:** Syndromes.

322. **A:** Yes, syndromes. I hate the word. Well, you know, whatever. Illnesses. And so I never knew whether it was something that could be more serious, or whether it was going to evolve into some, you know, absolutely appalling terrible thing. I didn't know. So. I've lost my train of thought now.

323. S: So no, we're just talking about the family relationships.

324. A: So I think I probably did concentrate on Sarah-, on Rayne more than on Sarah-Jane at the time. I'm sure that impacted on her eating disorder. And I'm sure that Rayne...

325. S: Are you carrying -- How are you feeling about that?

326. A: Well, I'm sure that Rayne saw me -- Look, I wasn't, I probably wasn't a very good mother to have a daughter with an eating disorder, because I found her very annoying. It was very annoying. Especially to come at that time. And extremely noticeable. She was ...

327. S: What were your thoughts around that? Did Sarah-Jane have an eating disorder ...

328. A: No, I thought she'd done it deliberately. And I still do.

329. S: And you still feel that way?

330. A: Even after all these years of therapy and all sorts of, you know ...

331. S: Therapy with yourself, or therapy for Sarah-Jane?

332. A: Oh, no, she had therapy and you know, all that sort of thing. And then the therapist used to call me. She had a fantastic therapist, she did. And would try to explain to me that I have to see the illness and not the fact ... The child and not the illness, or something. I don't know. Whatever. Don't tell her . . . that, by the way. I don't think it works. [laughing]

333. S: And did it impact on Max at all?

334. A: You know, Max was, went to a boys sort of boarding school and he was very much away from it.

335. S: Oh, so he wasn't home.

336. A: He wasn't boarding, but he was very much away from it all.

337. S: Lots of sport.

338. A: Lots of sport, lots of being away from home, lots of ... He was never here on holidays and all the rest of it.

339. S: So it didn't really impact on him.

340. A: So it didn't really impact on him. I do remember once we were talking about another friend of his who's also got juvenile arthritis, this, this young girl, and is constantly moaning and groaning and all the rest of it. And he once said to me, I don't care what she says, I know that Rayne,you know, has had an absolutely terrible time and I know what she went through. And what this kid was going through, he was saying, was nothing. Because she was very over dramatic this child.

341. S: Ok.

342. A: Yeah, and very 50,000 things wrong with her all the time. Ja.

343. S: And as a parent system – you and Gus?

344. A: Yes.

345. S: How's it impacted on your relationship?

346. A: Well I think that's he's left a lot, a lot of it to me. And in a way, I wanted him to because I didn't like to see him upset. And I constantly, you know, tried to protect him from it. Suppose I shouldn't have done that, should I? But anyway, I did. Because then I'd have to deal with him being upset and Rayne. I think that was the reason why. But as -- And actually, when I look back on it now, I should have, you know, expected more support and allowed it to happen. But I didn't. I pushed him away and said no, you, you're so busy and he's got his work to do and, you know.

347. S: And where are you with that now that Rayne's older?

348. A: What, where am I with my relationship with Gus?

349. S: Ja, do you still push him away, or ...

350. A: Well I still think that he doesn't really -- He doesn't really sort of like verbalise and talk about it. He, he, he's got a totally different way of dealing with her.

351. S: What, what is his way?

352. A: His way is sort of to allow her to get away with a lot and to jolly her along, you know. And to act stupid and silly, you know, and ...

353. S: To sort of lift her spirits?

354. A: Yeah, to lift her spirits, yeah. And to -- And also not to expect that much, you know. Whereas I seem to be, you know, the person who has to sort of put, put a bit of discipline into, into, into it in some way.

355. S: And manage all of the appointments and things.

356. A: Yes, and manage all the -- Oh no, he has absolutely nothing to do with that. Absolutely nothing. He doesn't know a single thing. Nothing. In fact, sometimes I think he doesn't even know what she's got. [laughing]

357. S: And how does that impact on you then?

358. A: You know I do find it a bit annoying, but on the other hand I have sort of like pushed him away from it. But when I look back on it now, I do find it a bit annoying. But he was never particularly interested, you know. Whereas I, you know, only after she was diagnosed did I suddenly discover that, that you can actually research all these things and then ... Before that I'd never done anything. I didn't think anything of anything. I just thought, oh well, I see she's got a sore ankle. But afterwards when she was diagnosed with juvenile arthritis, for instance, I mean I used to research all the time. I used to read about it and, you know, Google it and all sorts of things. And try and find, you know, new reports and new this and that. And he'd never do anything like that, ever. Ever.

359. S: Why were you doing all of those things? What, what was behind it?

360. A: Because I still in my heart felt that there was something else. And there was at the time.

361. S: Yes.

362. A: It was her head and her stomach. And I still think that there's something going on with her stomach.

363. S: You think that the stomach is separate to the JIA.

364. A: No I don't, I think it's all inflammatory. Ja. No it's all inflammatory. But I'm worried about what the level of inflammation is doing to her colon. I mean, she's had a couple of colonoscopies.

365. S: And ...

366. A: And actually the last one they said it was actually better. But still, you know. She's not on anti-, she's not on any ...

367. S: Does she have ulcerative colitis or not?

368. A: No.

369. S: No.

370. A: No. Inflammatory bowel. But it wasn't ulcerative. So it wasn't Crohn's.

371. S: Was she tested for Crohn's?

372. A: Well they didn't see any sign of ...

373. S: And Celiac's?

374. A: Yeah, she was tested for Celiac, she didn't have that. But apparently these, these stomach problems are typical of children and people with auto-immune diseases, ja. And it's terrible, hey. That impacts on your life totally. I mean, for instance, she'll go out and, and I'm worried about this. She, she goes out with friends for a meal and straight afterwards I know that she's in agony. I know. I mean, how do you deal with that? And then I feel like saying to her, you know, eat a bit less, or something. I mean, I know that's not the answer, but I don't know what the answer is.

375. S: Is it the type of food that triggers her, or is it the amount that she eats?

376. A: No, it's food that triggers the inflammation in her bowel.

377. S: Ah. Ah, I see. So it doesn't matter what she eats, she's in pain.

378. A: No, it doesn't matter. She's in pain.

379. S: And, all ...

380. A: I always think then maybe she's going to have a hot date some time or something. You're getting to that age now. Maybe she's on a hot date and he'll say, come for a hamburger, and then I think oh, what's she going to eat then? Because she can't have that, because it's going to upset her stomach and oh.

381. S: So it real ...

382. A: I wonder if she thinks of that? I don't know.

383. S: So it really -- I mean, when you're talking socially, it's really much more than the pain and even the fatigue in her case. Because now you have the stomach issue as well, which is rather compromising if you eat something that suddenly upsets your stomach.

384. A: She has a terrible stomach issue and she has terrible nausea all the time. The nausea is absolutely terrible. And why they can't find something for some people with nausea, I don't know. I don't know why it's so ...

385. S: And as to why it is happening, you don't really ...

386. A: Well they say it's all to do with her head, you know.

387. S: Her head?

388. A: Yeah, all to do with the migraines and the inflammation and ...

389. S: Oh, sort of like a vertigo?

390. A: Like a vertigo type thing. And all to do with, ja, the inflammation in the rest of her body.

[50 minutes]

But I just don't understand, I mean, can you imagine having nausea all the time? It's totally debilitating.

391. S: Totally debilitating.

392. A: I mean, she's had to run out of class before. Just get up and run out. And she said -- And she was absolutely -- She was devastated about that. She's, you know -- And she said that the teacher at the time when she came back, she said, Rayne you never have to ask me, you know, to go. You must just do what you do. But you see now that, you know, puts her in a position where everyone must have looked at her. And she hates that.

393. S: And ...

394. A: And treated her differently, the teachers. Not all of them do, by the way. I mean she has these -- She clearly has a file there and she has reports from doctors saying this that and whatever. But I'm sure that the majority of teachers don't even look at it.

395. S: And socially, what do you think the impact is of the teachers treating her differently?

396. A: I sometimes think that maybe people think that she puts it on so that the teachers will treat, you know, treat her differently. I don't know.

397. **S:** As in get away with things?

398. **A:** Get away with things, ja. Ja.

399. **S:** Do you think that might be linked to her not fitting in? Because you mentioned earlier she's -- She doesn't always -- She never seems to have fitted in.

400. **A:** No, no. I think that's possibly one of the issues, yes it could be. Ja. Could be. I mean clearly -- I mean, it's clearly, it's not only her. I'm sure a lot of people with chronic illnesses, people can't actually see what the problem is, so they think they're putting it on. And I mean, even ...

401. **S:** Could you tell me more, a little bit more about that?

402. **A:** I mean, even her good friends think, I think, that she puts it on half the time.

403. **S:** What makes you think that?

404. **A:** Well, I just -- There just -- I don't know, I just think that ...

405. **S:** Have you had any experiences that suggest that?

406. **A:** Well, probably because, for instance, and I've noticed this as well actually. She always seems to be absolutely terrible on a Monday. [laughing] Why is that? She's absolutely terrible after the weekend. I don't know, she's got terrible fatigue and she's absolutely terrible.

407. **S:** So what's she up to on the weekend?

408. **A:** No, nothing in particular. No seriously, she doesn't sort of socialise and go out drinking or anything, I can assure you. She doesn't. But Monday mornings are very difficult for her, you know. She -- And I -- She misses -- It often starts at the beginning of the week, her missing school. And then she seems to be able to recover a bit and go. And I mean, I know that she, she's, for instance, assignments, she's occasionally been able to give them in later. And I've just put through a whole thing with the neurologist. No Dr X actually put it through. Asking for extra time in exams and things, because her hands get sore, and then her back is sore, and then her neck is sore. And I just thought this is ridiculous. Surely she's entitled to extra time?

409. **S:** Definitely. She's definitely entitled to extra time. But how do you think that all then impacts ...

410. **A:** I don't know. Well I'm sure, I'm sure that people think that she's getting, you know, preferential treatment. What can I say?

411. **S:** But you haven't ...

412. **A:** No I haven't, I haven't.

413. **S:** You haven't actually heard, or nobody's actually said ...

414. **A:** No I haven’t.

415. **S:** It’s just ...

416. **A:** Oh the other day, I don’t know whether this is the, this is the, this is sort of going off on a slight tangent. She has sort of been friends with this boy for a long time, not, not a boyfriend.

417. **S:** No, a friend who’s a boy.

418. **A:** Well, sort of a boyfriend. Sort of a boyfriend. And then I was with the mother the other night, we had a movie club. And I said, what is going on with Rayne and Jude? And she said, oh no, they’re always on and off, but you know I just think that Jude, you know, he said to me that he just can’t handle all her complex health issues. Well I’m telling you, I wanted to slap her and him. I mean really. I’m sure she knows that too.

419. **S:** Do you -- So ...

420. **A:** So it’s very on and off, and mostly off.

421. **S:** So, so, so is it possible that although you’ve had, nothing has been directly said, you’re possibly picking up on body language or something along those lines that makes you think that people think ...

422. **A:** That she’s getting preferential treatment? [laughing]

423. **S:** Yes, and possibly milking it, for want of a better word.

424. **A:** No, I, I -- You mean, you mean that you, that people think that Rayne is milking it? You think that?

425. **S:** No, no, no.

426. **A:** No, not you, I mean, that’s what I’m saying ...

427. **S:** Are you, do you think that.

428. **A:** Well nobody’s actually ever said that to me directly, no. But I don’t know why I get that feeling, but yes I do.

429. **S:** Ok.

430. **A:** I do.

431. **S:** Ok, so ...

432. **A:** I don’t know why. I mean clearly no-one is going to say ...

433. **S:** The feeling is there.

434. **A:** The feeling is there. I don’t know why. Maybe because sometimes I feel that about other people. [laughing] Maybe it is. Maybe it’s a normal thing to feel? Like I thought that this child that ...

435. **S:** Because you can’t see something, then ...

436. **A:** Like this child who also has arthritis, that, Max's friend also, you know. I mean, her arthritis is very mild, I know, but she's full of dramas. But you know, I don't know the level of her pain. And I shouldn't think, I shouldn't judge her anyway.

437. **S:** Because you can't see some of the arthritises.

438. **A:** No, of course you can't, I know. You'd think I'd be more understanding. Don't know. [laughing] It's just easy to do, I suppose. Ja, I don't know why. I don't know.

439. **S:** So sort of an unconscious sense of judgement? Of judging people.

440. **A:** It is. Isn't that awful? Yes. Isn't it awful that even I as a mother of a child with a chronic illness will also judge other people like that? Like this child. I do. And in fact, even a few of the children in the group, you know, we have a help, a support group. You know, and then somebody will say so and so is whatever. And I'll think, oh God. [laughing] How can I be like that? Isn't that awful?

441. **S:** Is that, is that -- Where do you think that comes from?

442. **A:** It's a sort of like hardness actually. I don't know. I think it's because over the years I've, I've become more hardened to it. And because I know that you know, you've just got to fight through it all. There's no other way actually, you just have to push through it all. There's no other way. But there are some kids in this group, this support group we've got, who have absolutely everything. They've got huge amounts of concessions and all sorts of things. And this and that and oh, I don't know. Therapies and special beds and all sorts of things. It's just very irritating.

443. **S:** And why, why does Rayne not have all of those?

444. **A:** You know I actually tried to get her concessions years ago at the school. Now, she doesn't go to a private school. Now the private school, which is much bigger, she goes to government school which is much bigger and much less open to any accommodations. I, when Rayne was at her very worst, I had to go in and talk to them. And I was in tears; I could hardly speak to them. And I had a letter from the GDE that said she must have all these concessions, and they just said to me, no.

445. **S:** We can talk about that later.

446. **A:** Yes, that was just awful. So now I'm putting it all through again.

447. **S:** So, so the school basically, although in some ways they're supportive ...

448. **A:** They were much more supportive in primary school.

449. **S:** So in the high school they're not.

450. **A:** In the high school it's a much bigger school and ...

451. **S:** And they're not prepared to put dispensations in place?

452. **A:** Well they weren't then.

453. **S:** . . . and now?

454. **A:** And now I've put another huge thing through and her grade tutor, who's a different person now and has been very nice, she said to me, no she's going to send it up to the headmaster and it will go through to all the channels and we'll just see.

455. **S:** She ...

456. **A:** I mean she's not asking for anything that's -- I mean, all those kids there with, you know, a little bit of whatever they have, ADHD or whatever they have, nonsense. I mean, they have all these fantastic concessions. I mean, for me, you know -- Ok, now with her matric coming up it is important for, for her to be able to have extra time at exams, it is. But in the past, what was more important was for her to have extra time to give an assignment in. Assignments in. And I mean she never got that.

457. **S:** From the fatigue ...

458. **A:** Yes. Yeah. Because she's be off school and then she'd be behind and then this. And she never got that. Although individually some teachers were more accommodating than others, they were. But it was never a proper thing that came through from the school saying , you know, she can have extra time in any way. Never.

459. **S:** Well that's something we can follow up.

460. **A:** Ja.

461. **S:** I was just interested just now, because it's, it's part of the ... One of the things that's come up. You were mentioning the special beds and the physios. The financial implications.

462. **A:** No it is financial implications. We weren't even on a medical aid when Rayne was first diagnosed. And we got onto medical aid which was loaded, of course. You know. And it was ...

463. **S:** Loaded in what sense?

464. **A:** Loaded because we hadn't been on before. So they made it more expensive.

465. **S:** Oh, I see, I see. Ja.

466. **A:** I mean, there's five of us. So it's a hospital plan. Look, I have to say, they have been extremely ... I actually printed this out for you. They've been -- She's got her own case manager. They've been extremely accommodating.

467. **S:** Who are you with?

468. **A:** Momentum. They have been accommodating. They have. But now she's got this chronic health plan or something, which gives her, whatever, two specialist things a year and whatever. And I wrote to them the other day and I said, you know, what she actually needs is a biokineticist, biokineticist appointments.

469. S: I can't say that one either.

470. A: Because she goes to this biokineticist who's absolutely lovely.

[60 minutes]

And she needs more psychology, psychology appointments. Thinking that she would say, you're only on a hospital plan. No. But she's just -- Ok, she said, please ask them to send reports through, assessments. Ok here's the report, I'm going to give this to you.

471. S: Oh, thank you. Thank you.

472. A: Because it's come through from her biokineticist. And the psychologist of course hasn't sent one through, because she's always telling me she's so busy. Which is really annoying. But anyway, ... So she sent this through, this biokineticist. It is so good. It talks about all Rayne's pain and how she deals with it. And it came through this morning and said they're going to give her one appointment a week. Which is actually more than ...

473. S: With the psychologist?

474. A: No, for the biokineticist.

475. S: Oh, with the -- Oh wonderful.

476. A: Ja. Which is -- She only has one every three weeks, because you know it's expensive.

477. S: That's been so interesting, because some of the medical aids have been very accommodating and some of them have been incredibly difficult.

478. A: Well, I'm -- Well, my medical aid, it's been sort of like halfway. You know. But the thing is, I mean, we're not on a top medical aid; we're on a hospital plan.

479. S: So the financial implications ...

480. A: So the financial implications are huge, actually.

481. S: And do you think that impacts on Rayne in any way?

482. A: Ja, I think it does.

483. S: Do you think she's aware of it?

484. A: I know, I try to stop myself from saying these things, but you know. When she goes to see the psychologist, the psychologist is quite expensive. Look, I know, I don't hold it against them when she's a professional person, that's fine. But I'm always saying, ah Rayne can't you do without the psychologist? [laughing] Can't you see her once?

485. S: They do add up. It does add up.

486. A: It does add up to huge. It does.

487. S: Huge. And then ...

488. A: I mean, she charges, this woman, R330 for half an hour.

489. S: The biokineticist?

490. A: Yes. Which is actually, come to think of it, the same as a psychologist for an hour. Because she charges R650 or something, the psychologist. Yeah. So I mean, it's damn expensive for all these things adding up all the time. It really is.

491. S: In all the -- With all these difficulties that you've been experiencing, I think we've dealt with the challenges. Has there been anything that's specifically helped you?

492. A: Look, having this one particular friend of mine who I know you've spoken to her and her daughter. Well, I mean it's Di, you know Di. Having Di along the way all these years has really made a big difference. Because she actually seems to be -- She was the one who said to me, no they must pay for all these things. She was the one who said that. And I thought -- And I said, we're on a hospital ... And she said no, no, you phone them up and you tell them they must pay. Well I would never do that. That's what she would do, but I mean I sort of put it all gently and everything and it has worked out for all that anyway. But having somebody who I can talk to about it, you know, as I do with her.

493. S: And somebody who understands.

494. A: And somebody who understands. She's very understanding. That's made a huge difference. I mean I actually don't think I could have gone through it without her actually. She's incredibly understanding and she's incredibly strong. And she knows -- She knows a hell of a lot. She does.

495. S: So that's been -- And I think that's ...

496. A: And also because we're -- Sorry. But we're at -- Being in Arthritis Kids, look, Di doesn't have much to do with it, but I do it with another friend of mine. I don't know if you spoke to her, Sheryl?

497. S: Pienaar?

498. A: Yes. Oh, she's lovely, Sheryl. So Sheryl and I do the basic things with Arthritis Kids, but it mainly is going to the clinics and handing things out to the kids who are in need or whatever. And when I see the level of pain that the children are in there, and you know, how incredibly ill they are, I actually think that we're incredibly lucky. We really are. I mean, you should see some of these kids who go, who get into that clinic. I mean, they are, they are -- I don't know how -- I -- It's absolutely awful, some of them are being carried in on their parents' backs, they're in such a state. So --

499. S: And of course they can't afford all the fancy medications and things.

500. **A:** No, they can't afford anything like that. So, you know, it sort of puts everything into context really. You know. I ...

501. **S:** So, so what do you get from that, that is a support for you? Or a ...

502. **A:** Well, I suppose it's just, I feel like I'm making a difference. I mean, we don't, you know, we don't provide enormous amounts of medication or anything like that. We provide very small things. But I know it makes a difference, you know. And I know when we're there and doing sort of silly things like handing out hot chocolate or things, you know, silly things like that, I know, I can see on their faces. Oh thank you, thank you. They're incredibly grateful. I remember once Dr X saying to me that she just brought, she once brought a box of naartjies in for the children. She said every single child was so excited. It was such a small thing. I mean, when you see, you know, the level of poverty that some of these kids live in, you know, that a small thing like that will make such a difference. No, no I'm, I'm always pleased that we, we started this. I mean it was Di's idea that we, that we started this and it's made a difference. I know it's made a difference.

503. **S:** Hopefully it's going to catch on elsewhere as well.

504. **A:** Well now we're talking about sort of expanding it and making this big thing. Di must deal with all the legalities of it. I don't know. It's a huge big thing. Ja.

505. **S:** And if you were ...

506. **A:** But you spoke to Sheryl, did you? She didn't say anything to me. I'm seeing her next week. Have you spoken to Sheryl and Ashley? Ja, ok.

507. **S:** And if you had to share the lessons that you've learnt, or provide advice to parents whose kid has just been diagnosed with JIA, or whose child, rather. What, what would you tell them?

508. **A:** Well, you said to me earlier on, what did it do for you, you know, finding, you know, studying the disease in more detail. Well I think that's what people should do. You must read, you must learn, you must find out what people are saying in other countries and other treatments. Because, you know, you actually have to push everything through here actually.

509. **S:** Push everything through, meaning?

510. **A:** You have to, you actually have to take initiative. There are times when I, when you know, you have to say, look this is, could it be this, or this is sore or ...

511. **S:** To the doctors?

512. **A:** Yeah.

513. **S:** You have to case manage it for the doctors?

514. **A:** No I, I wouldn't say you have to case manage it. There's ways of doing it. But you have to actually -- You have to actually know what you're talking about, because in the beginning I didn't know anything and that's why I think I was pushed aside all the time. And now I feel much stronger about it. I mean, I've been with doctors and things who have absolutely no idea what's going on with Rayne. They don't have a clue. Even Rayne's GP, who is absolutely lovely, I mean she's fantastic. She's my family doctor and she's the one who saw us all through this. She still doesn't know really what goes on.

515. **S:** So quite a significant lack of an awareness.

516. **A:** Ja, there is.

517. **S:** So that would be something you would suggest they read up.

518. **A:** Yes. They need to know about ...

519. **S:** So they can combat the lack of awareness.

520. **A:** Absolutely.

521. **S:** And negotiate your way through ...

522. **A:** You need to study all the time. You need to read and study and know what's going on, to help your child.

523. **S:** And anything else that you would tell them?

524. **A:** Oh definitely to get some sort of support group going. That does make a difference. Well I don't really have a, a group. I mostly speak to Di and Sheryl actually.

525. **S:** But that's -- A group doesn't have to be big.

526. **A:** Ja. I don't want a big group.

527. **S:** Ja.

528. **A:** Sometimes I go and I look at these big groups and I think, oh God. I mean, I could not have that constant bombarding of, you know, of all these issues and things. No.

529. **S:** I think some things works for some people.

530. **A:** Yes. Ja, exactly.

531. **S:** So it would be a case of finding what works for you with regards to a support system.

532. **A:** Yes, yes. Ja.

533. **S:** And anything else?

534. **A:** What would I say to other parents? Well I must say, when, when you first get the diagnosis it's quite a shock. It's quite a ... You see, I think that I knew, I knew a bit more about it because I knew somebody that had it. Ja. I think, I think -- Look, little silly things like, never ever go to the doctor without a list of questions. You know. But people don't -- You know, people don't know that. A list of questions and a list of medications. I always actually take all the medications in a little box. [laughing] And I put them all on her desk. Because even writing medications down isn't enough. You should know how many, and whether this is generic, and everything.

535. **S:** Yes. Yes. And that's when you're visiting the different, all the different sort of doctors, to keep them on board with ...

536. **A:** Yes. Ja.

537. **S:** Where she is.

538. **A:** Ja, absolutely. Ja. No well there's no -- That's the trouble with, with disorders or diseases or whatever it is, like juvenile arthritis, is that you know, there's a lot of different doctors involved and there's not enough, you know, knowledge being shared between all of them. At all.

539. **S:** Not enough case managing.

540. **A:** There's nothing like that. Well, I always say that Dr X is Rayne's primary caregiver. But I mean, you know, most of them don't even know what she is or whatever.

541. **S:** And anything else that you would give as advice?

542. **A:** Well I think one of the most important things to do for your child, by the way, is to ... The child just has to keep moving all the time. It's very important in the beginning when, especially in the beginning when you see kids and you think, oh no, they've got a sore foot and sore this or a sore that. And please have a rest and don't do this, don't do that, they actually have to push through all the time. I mean, Rayne's physiotherapist in the beginning, when Rayne was on crutches and everything, she would never let her into, into her rooms on crutches. She would say, Rayne, you put the out here, I'm not having you have any crutches. Now you get off them and you walk.

[70 minutes]

543. **S:** Because otherwise they stiffen up so much.

544. **A:** Otherwise they stiffen up. I mean, this is very important, but you don't realise that.

545. **S:** Because normally, with a twisted ankle, you rest it.

546. **A:** Yeah, you rest it. Yeah, I know.

547. **S:** Ja. So out of -- Is there anything left from today that we haven't covered that you think would be important to share with me.

548. **A:** My mind is going totally blank.

549. **S:** That's ok, we've had a long session.

550. **A:** Yeah. Yes. I can't really think. I'm trying to think of areas that we haven't talked about.

551. **S:** We can always do a second interview if you want.

552. **A:** No no. I mean, it's alright, I don't mind. But no, I wouldn't want you to, you know ... When, when do you have to -- When do you have to do this all by, by the way?

553. **S:** It's got to be -- Look -- Thank you very much. I'll switch this off now, and then you can ask me all the other questions.

[Recording ends]

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APPENDIX L: Ursula Case Study

Transcript 1: Ursula Interview 1

1. **Interviewer (S):** Ok that's working. I think I position it that way. So it should be both of us. Um, yup it's going. All righty so I'm not going to really take notes because we're doing the audio record. But yeah so would you just like to sort of start off by telling me how you became ill, what happened, all, you know, what. Yeah just go for it.
2. **Interviewee (U):** Well I used to be very very active so I was involved in every type of sport that was available at our school. And then in 2010, for 10 weeks, I just became completely drained. Just drained, I got pain in in my upper arms and my ribs. So we went to a rheumatologist um Dr X and she said she said, "No it's probably just a virus, give it 10 weeks and see if it's out of your system".
3. **S:** So by drained you, were you, had no energy.
4. **U:** I had no energy, absolutely nothing. So um, it was 10 weeks and I was fine again. I wasn't, I didn't have full energy, but I was a lot better than I had been in those 10 weeks. Then I carried on with school and everything. Then the following year in Feb, in Feb, I started to get this intensely awful pain at the back of my head here. It was like just like as strip over here.
5. **S:** Ok, on the spine area or?
6. **U:** Yeah, by my head up from my spine here and it was, I couldn't lie down, it was, I was in so much agony. And then um I was swimming one day and I said to the coach, "No no no I need to get out I'm not feeling well". And so I sat there, I was very dizzy and I passed out.
7. **S:** Oh wow
8. **U:** Then I had ballet and I passed out as well. And so I just kept passing out, I was dizzy, I was tired, I started to get pain here. So we went from doctor to doctor to doctor. We went to neur, neurologist to see well you know maybe it's from my head, no they couldn't find anything. We went to numerous doctors and then eventually ….
9. **S:** How long was this all taking?
10. **U:** This this was about 4 months into the…
11. **S:** Of seeing different specialists
12. **U:** Seeing different specialists. Well. Yeah and then um we went to Dr X again and she didn't know what it was. So -
13. **S:** Either

14. **U:** - Either so, tests, into hospital, you know you know the route, all the

15. **S:** All blood tests and then scans as well

16. **U:** Tests, scans and MRI scans, I had a CAT scan in my for my just to see what was going on here. Um and then 6 months down the line, now I couldn't breathe…

17. **S:** Oh my word

18. **U:** So I was, I couldn't breathe often and I would be kind of, what's, like zone out, so I would completely, I wouldn't be aware of what was going on from me. And sometimes it would last a couple of minutes and my breathing would go all shallow and so they took an x-ray and they found I had pneumonia. So I had um a walking pneumonia so then they put me into hospital.

19. **S:** A walk in pneumonia

20. **U:** A walking pneumonia so it's like a pneumonia that doesn't, you don't really pick up, so you can walk, you can have it for months, weeks.

21. **S:** So you don't get the coughs or anything it just, you've just got pneumonia

22. **U:** No, basically hiding, yes. So I was put into hospital but then things just went bad. I started getting pain in my joints, um in here, my joints everywhere. So that I couldn't start to walk. So my walking became much slower, I couldn't do stairs. They put me on antibiotics in the hospital, then I was out because the pneumonia was fine.

Had to go back to school but that was just a nightmare, I couldn't um, I wasn't doing stairs then, I wasn't being able to walk around like I was. And so we told Dr X this and then um she said, "Ok well let's test for the HLAB27 gene".

23. **S:** Yes. Yeah.

24. **U:** And then um it came back positive and she said, "No, this is juvenile arthritis." But that process took 6 to 7 months.

25. **S:** Yoh, that was a long time of being in pain and being ill.

26. **U:** Mm, very long. Of going to doctor after doctor, of being in hospital, of blood tests, of scans, of tests. So yeah that's

27. **S:** How did it feel when she finally said "this is what it is"?

28. **U:** To be honest, I think as well because this disease is not known about it's uh the first question I asked my mom was, "Am I going to die?"

29. **S:** Oh, of course

30. **U:** I didn't know, I don't know what to expect, I didn't know yeah. So that was quite harsh. And to be honest I didn't really understand the journey that was ahead. So you know in my mind I expected, "Ok no, medicine"

31. **S:** Fixed

32. **U:** Fixed, that’s done.

33. **S:** And did Dr X not explain to you with the diagnosis what it was

34. **U:** She told us over the phone, because she found out about the HLAB27, then she said, “This is, I think this is it”. Then we had to make an appointment and then she explained everything.

35. **S:** Ok, so in that between part

36. **U:** The in between it’s difficult. And then if you look on the internet, there’s that’s not a great thing to do at all. So eventually my mom and I just stopped and this is not gonna happen. And now by this stage I was in a wheelchair.

37. **S:** Oh

38. **U:** So I had um stopped walking completely. Um so and school was just a no-no then, I was

39. **S:** So you were off school totally

40. **U:** I was off school. For my Grade 5 year I was not at school at all. Um

41. **S:** Then so did you get home tutored or how did it work?

42. **U:** Uh they brought the schooling at home, to my home so um then I basically did it myself. I went through which was difficult

43. **S:** Very difficult, I’m an ex-teacher, I know that is incredibly difficult.

44. **U:** it’s very difficult but um. And I, at the end I wasn’t managing to get through the stuff because I would sit up for an hour and I would fall asleep. I just, the fatigue was so awful.

45. **S:** And you would have been on meds by then.

46. **U:** I was on meds by then. I was on a lot of anti-inflammatories, um yeah. And then at the end of that year, towards September, she decided to put me on a biologic because I was in a wheelchair. So she wasn’t happy with the way that things were going. So she started me on Revelex which I had every 2 months. I went into the Donald Gordon Hospital for a drip, an infusion. And that was awful. I did not like that. That was

47. **S:** what, how did, was it because it made you feel so sick or [Inaudible 06:38] or?

48. **U:** Yes, well what would happen is I’d would arrive at the hospital at7 o’ clock in the morning and I would leave at eight at night. So there was, it was an entire day infusion. Um and then afterwards, for about a week afterwards, I was completely out of it, I was nauseas, I was even more tired. It was just harsh, horrible. Yeah.

49. **S:** I mean your state of mind during all of that, what was that like?

50. **U:** No do you know what and as well now being away from school, from my friends, and I had really good friends, I had a lot of friends, and all of my friends just um

51. **S:** Disappeared

52. **U:** Yes, disappeared basically. They didn't know, understand what was going on so I think as well they felt awkward about the situation. So that was incredibly hard and for that year I was very depressed. Very. I didn't want to get up out of bed, I didn't want to do anything, I just -

53. **S:** So you lost your whole friendship group

54. **U:** Yes. I lost everything and I was at a stage where I wasn't even speaking to my family. I I was, I was just, you know, in a couple of months I had lost my independence, my mobility, I couldn't go to the toilet by myself, I couldn't bath myself…

55. **S:** How old were you?

56. **U:** I was 11.

57. **S:** So just at that stage where you starting to become independent and separating.

58. **U:** Yeah, so it was

59. **S:** You couldn't even go to the toilet by yourself

60. **U:** I couldn't go to the toilet by myself, I couldn't bath myself. At night I would lie down um then I'd have to call my parents to come and turn me over, so two to three times a night. So I was doing, I couldn't do, I couldn't chew because of my jaw, it was very sore. Um. Sorry [starts crying a bit]

61. **S:** And then you sitting with that, so it's not just the side effects from the medication but you've also still got that pain -

62. **U:** Yes

63. **S:** - and although you on steroids and possibly um pain killers, it still doesn't take away that pain.

64. **U:** No no, nothing really took away that pain, nothing. It was bad.

65. **S:** If you had to rate that pain on a scale of like 1 to 10, where would it have been? With 10 being like excruciating

66. **U:** It would be a 10

67. **S:** Was it 10. Wow

68. **U:** Yeah it was, and it was draining that pain as well, so you've got the fatigue from the disease and that pain all the time. It was. And then I had nausea, constant nausea.

69. **S:** And so which which um diagnosis did, 'cause there's different forms of JIA?

70. **U:** Juvenile Idiopathic Arthritis.

71. **S:** So was yours the systemic one?

72. **U:** Yes.

73. **S:** Ok. Yes, ooh that's a tough one.

74. **U:** Yes, so yeah and I had it in multiple joints that's why we went onto the biologic.

75. **S:** And then how did it, so did you start to get better after? How long did it take to start getting better?

76. **U:** No

77. **S:** No you didn't

78. **U:** No, so then the following year I was still in the wheelchair, but we decided to go to school

79. **S:** That would have been Grade 6

80. **U:** Grade 6, yes. And I was going to school twice a week.

81. **S:** Ok

82. **U:** And that was as much as I could manage but I still got through and I did ok but um and I'd often say to Mom I said, "Mom, I would take the pain any day but I don't do the emotional pain." I said, "The emotional pain, for me, is much worse." And then going to school and not, people don't, my friends they didn't even say hello. So that was very hard on me.

[10 minutes]

In my Grade 7 year, still in the wheelchair um.

83. **S:** Wow

84. **U:** Um I was at school now but now I was at school for about 4 days a week. So the energy was starting to get better but as well through then my state of mind did get better.

85. **S:** 'Cause you could see the progress or?

86. **U:** No I think I just just you know realised that this is how life is and you know what I can either make it awful or I can live it actually. And so I decided that but that's not saying that things were rosy.

87. **S:** No, no. No, no.

88. **U:** I mean every, I was still struggling, I still had you know, basically every day I would cry a little bit or be down because

89. **S:** And what happened, do you think, that helped you sort of change your mind on how to deal with it?

90. **U:** I I honestly don't know. It was a process. It took about 7 months for me and I think I saw the effect it was having on my family. Not only them losing a child um mobility, but also now losing a child emotionally – they didn't have that same child. And so I think I saw that effect and I was like, "No. No. You know I have control over this." And so I -

91. **S:** Very brave of you

92. **U:** - tried. Yeah it was hard. Very hard. Very very hard. So that was my Grade 7 year, still in the wheelchair. And now starting high school which is a huge adjustment because now I needed someone, because in my primary school all the classes happen in the same class,

93. **S:** Oh you were lucky with that primary school, yes yeah.

94. **U:** So I was very, very lucky, very lucky, everything happened there so I could stay there the whole time. But now it was changing classes and going about, so they got a lady from the school to help me.

But you know fortunately I'm very, I've been so blessed with the school that I'm at because they have wheelchair lifts, they have wheelchair facilities, it was honestly phenomenal. If I had not been in this school I do not believe that I would be where I am today. I don't. They were very supporting, even when I started um to become sick they gave my mom a month off full pay to try and get me sorted. So they were very supportive, very behind me all the way so that helped tremendously.

95. **S:** That is incredible because not many not many of the schools do that.

96. **U:** But you know what, fortunately I'm at a very small school um so I think that that's helps. Yeah, small school.

97. **S:** Yeah. And then so so Grade 8 you were in a wheelchair?

98. **U:** Grade 8 I was in a wheelchair and towards…June

99. **S:** And still on the biologicals at this stage

100. **U:** Still on the Revelex. Still on that. So it was, that's now 3 years of hectic medication and then June came around and I just started getting worse and worse and worse it just

101. **S:** That must have been devastating

102. **U:** That was awful. I got where I was sleeping 18 hours a day. So I wasn't getting to school, I was losing weight, um in a period of a couple of weeks I'd lost 10 kilos I was weighing 38kg. Um I'd I was sweating all the time, I was dizzy when I stood up, and so my mom said, "I can't". It was whole of my August holiday, I slept 18 hours a day I was up for food and that was it. And um my mom phoned Dr X and said, "I can't do this, I don't know what's wrong with my child anymore". And so she sent through a blood form to do tests and it came back I had TB…So um and they hadn't picked it up because the year before, every year because I'm on the biologic I'm supposed to go for a TB test.

103. **S:** Because, does this suppress the immune system?

104. **U:** Yes because of the, and then, the year before my doctor had forgotten to put it on the blood test form. So it wasn't picked up then and she thinks I had it for about a year. So I just, it was it was awful and um that just made everything worse.

105. S: Something that could have been

106. U: Yeah. Prevented

107. S: Prevented. I’m just gonna check this is still working, oh it is yes

108. U: So that um that was a huge setback, I mean it was it was awful. So they put me on TB meds which are horrible.

109. S: Oh really

110. U: Yeah really horrible.

111. S: So you were um all, you still had to remain on all your other meds and take TB meds.

112. U: TB meds. Yes.

113. S: You must have just had handfuls of pills

114. U: It was, at one stage when um, one stage in Grade 6 in Grade 7, I was on 36 pills a day.

115. S: 36 pills.

116. U: 36 pills a day.

117. S: And then did you then have a special regime where you had to, you take this at this time and then

118. U: Yes, yes. So it was, yeah many pills and then I got TB and they put me pills on that but that, that makes you feel horrible. So that was also dreadful. And then um, I was still not well but then I was in so much pain but I was trying I was really trying. So I was standing up a bit more by myself

119. S: Did you go to physio as well or?

120. U: I had been to so many physios and the physio was horrible ah it, I think that was also part of the reason for my depression, it was it was **so** hard and the lady that was my physio was not a very nice woman.

121. S: What about it was so hard?

122. U: They, the woman that I was with did not understand chronic pain so um she was treating me as if it was an injury. And it really and it really wasn’t. So um my doctor was like, “No, no, this is not working”. So she sent me to a lady, a physiotherapist who deals with chronic pain and she was I really liked her. I mean it was, a lot of, it was painful and eventually what she said she said, “I don’t feel like I’m getting anywhere with you but I know of a hydrotherapist.” So went to hydrotherapy and that to me was really good. I could move a lot better in the water, my pain was less, so that definitely helped.

123. S: ‘Cause you were still wheelchair bound at this stage?

124. U: I was still wheelchair bound. So I wasn’t able to walk outside but I could walk a little bit in the water so but that that gave me hope I think as well. And um

125. S: So that would have been a shifting moment for you

126. U: Yes, that was, that was good

127. S: And…this is a very sensitive question, you don’t have to answer it. So in all of that depression, did you ever get suicide ideas and just think, “This is”?

128. U: Do you know what I don’t think I ever thought that I would do something. But often I'd just pray that I would die. So I [sighs] I didn’t think you know what “I want to take my own life” I didn’t, no. Because we’ve had a suicide in the family, my uncle committed suicide, and you know I saw the, what happened and I was like, “No, you know what” um but I just I just wanted to be out of it. So yeah.

129. S: Mm. So it, more of a “It would be just nice if I didn’t wake up in the morning” kind of thing.

130. U: Yes. Yes.

131. S: You’ve been through a long journey, haven’t you? Wow.

132. U: That was. So then um after I got TB, um my doctor thought now she’s going to send me to this um psychiatrist, Dr A. Um but he works at a mental institution and that’s the only hospital that he specialises in. So I had to go there for 3 weeks and that was -

133. S: For for observation?

134. U: For, he was dealing with my medication so he wanted to see and see what they could do

135. S: So you had to stay there?

136. U: For 3 weeks, it was the worst time of my life. Um well firstly what he did was, I was put onto this medicine called OxyContin by a pain specialist and I was on that for 2 years, and um he looked at it and said, “No, this is a highly addictive um medication” and “I was addicted to it”. And it’s a medicine that you’re only supposed to be on for a maximum of 5 days. ‘Cause they treat it for acute pain and that was it. And I was on it for 2 years. So that that was causing huge complications, I was having awful stomach pains and that was caused from this. Um it was causing major issues so I was in there, he needed to get me off of that as well um. Yes um but it was awful I mean

137. S: What was so awful about it?

138. U: It was, you know I was in this place for 3 weeks. Firstly I’d had TB so I was feeling the worst I’d ever felt before, um I wasn’t in a familiar space, my family could only come between 4 and 8 in the afternoon, um and you know, and it’s a mental institution so you’re surrounded by people that have very different issues. And I was

139. S: And was it an adult facility or a child facility?

140. **U:** Well, there were mainly adults there. There was a girl that, two girls that were my age and they shared a ward with me but um I was there in the ward and they were, all they were discussing is how they tried to commit suicide and how they'd um cut themselves and stuff.

So it was not a good environment, nice environment and the nurses then said to the doctors um, "She's not like the other people here so I think we must get her a ward by herself". So we, they got me a ward but then another girl came to stay with me um and she at night at 12 o' clock um there would be about six nurses in my room because she'd locked herself in the bedroom and she, ag in the bathroom, she was harming herself. So then they said um then they'd say to me, "Ursula just see if you cannot get her to come outside" and so now I'm -

141. **S:** Even more pressure for you

142. **U:** - 14. I need sleep, I, 'cause you know this disease is, I need sleep and now

[20 minutes]

I have to try get this kid to come out because they don't know what she's gonna do. So she came out and then they had to sedate her because she was hysterical.

143. **S:** So you manged to get her out.

144. **U:** Yes and um. But it was just things like that all the time. Its. It was horrible being surrounded by these people all the time and um as well they put me through very hectic um physio sessions. Because now they were hoping to break through my pain.

145. **S:** Oh, ok.

146. **U:** So then they put me through that.

147. **S:** And then in the meantime you going through a withdrawal off the the pain medication.

148. **U:** Yes. Yes which was hectic. And then they put me on, 'cause I had been on antidepressants before but now he put me on another antidepressant um to see if that wouldn't help as well. Obviously it takes a couple of weeks so uh you know the effects then. But um. So that was very hard I had a psychologist.

149. **S:** I was about to ask, did nobody do therapy with you?

150. **U:** Yes, I had a psychologist every day and I did like her.

151. **S:** At at the clinic?

152. **U:** At the clinic. I did like her but um it was still very hard. And then I had to go to group therapy because I was there. And that's not really a thing for me because as well they would discuss drug abuse or um lots of them were not issues I was dealing with.

153. **S:** No it's a totally different thing.

154. **U:** It's a totally different thing. It was um like the one session was about divorce. And um you see you see things like that

155. **S:** Yeah, it was not tailored to you, what you needed

156. **U:** No. and you see I wasn't there because of depression so they just took me to things so that I had something to do in the day. But um yeah it was the darkest time of my life. I was at an absolute low. Um it was it was awful. Yeah and it was 3 weeks. Then and um my doctor then said she has a patient that's like just been in a wheelchair and she asked do we think she should be sent to this clinic, she was 11, and I said, "No, I don't think so". I was 14, especially if you're that young and you just starting. I said, "No". And you know what I think it…it's just very different, so if you dealing with an illness and you're not a psychological or drug abuse or bipolar or schizophrenia then it's not really suited

157. **S:** It's not the correct environment for you

158. **U:** It's not correct, no.

159. **S:** And and since then have you do you have a psychologist that you see?

160. **U:** I did see a psychologist for a while after that and then um well because after that I started to walk.

161. **S:** Oh so you made, the treatment, there was a breakthrough

162. **U:** Yes, there was a breakthrough so I was taking three steps then the then um like the next week I would take 10 steps and then I'd walk a bit further and then I'd walk from down the passage. And so it was slow but then I was with a psychologist because now my life is changing again. I'd been a wheelchair for 4 years and now I'm getting out of one. So um it was very exciting and then that was the end of my Grade 8 year so it was 2 weeks before November exams, I hadn't been to school at all for the whole of that term

163. **S:** That's such a big adjustment for you as it is

164. **U:** Yes. So I had to come home, deal with all of this that's going on. It was 3 weeks of… hell, it was not nice I had to deal with that, deal with you know now starting to move again, I had to catch up and teach myself all the work from that and then do the exams, as well. So that was hectic that I don't know how I did that but it was hectic

165. **S:** I don't know how you went through that either

166. **U:** And so then I was with the psychologist um now because now I was wheelchair-free basically. I was still hobbling but I wasn't using the wheelchair into my Grade 9 year. But it was a huge adjustment now because you know I was, before I was sick I was the girl who was involved everywhere, then I was sick and I became the girl in the wheelchair, and now I was not sick and now

167. **S:** So you lost your identity

168. **U:** Now who am I? So that was difficult because I didn't know, you know, when, now, what do I do, what's, who am I? What what do, what can I do? What do I enjoy to do? And that was difficult because um I felt like I was now thrown into a deep sea of and I didn't know where to go what to do. So I decided um no that I'll just try different activities, try find who I am and involve myself in a friend group, um see how that pans out. And um and it did. It did work but it's very hard um

169. **S:** So what kind of activities did you try?

170. **U:** I then, because of still just walking, I couldn't do the physical, so I just did um the cultural. So I involved myself in the house plays and the um public speaking and things like that that I could do. Wasn't really my passion but I just needed to be involved, I, you know what.

And um so I did that for a couple [laughs at something] and so I did that um. And then I got a really good group of friends. Well, throughout my sickness, there was this one girl who was so good to me. She wasn't um my, who I would choose if I wanted to be a friend, but um she was so good to me she came to visit me basically every day that I was in the mental institution. [dogs playing] [Inaudible 25:43] Sorry, they he

171. **S:** Wow so she came to visit you every day

172. **U:** Basically, she was really really good to me. So I was very blessed with her. And then when I starting to walk again and then I started to involve myself in a friend group and they really really such nice people. Two of them are the people that used to be my really close friends before I got sick.

173. **S:** Ok so you actually managed to link up with them again.

174. **U:** Yes, it was actually quite interesting because um ah sorry

175. **S:** No I'm fine, I I love dogs

176. **U:** Ok, come. So um when when I got well again, they actually they came to me and they said, "You know um I'm really sorry, um we just didn't know, and I'm really sorry." So it, they could say that to me then but not while I was in a wheelchair, I think they could just, yeah, no. But that was very hard that was probably the hardest thing, being so isolated.

177. **S:** Because, I would assume, they didn't know how to deal with you

178. **U:** Yes

179. **S:** And then how did it feel when they said sorry?

180. **U:** It was really, it felt, I felt such relief. I mean I'd gotten over it but still it wasn't you know

181. **S:** I mean when they didn't come round, did you feel it was more the, sort of a rejection of yourself or I mean did you take

182. **U:** Yes, I did. I took it personally and um it was very hard to come to terms with. Um because I'd lost so much, I mean I'd lost all my physical thing, everything and now I'd also lost my friends and that. It was very difficult.
183. **S:** So you almost lost your life, as you say, the you that was you was no longer you
184. **U:** Basically. Basically. Yes.
185. **S:** So where are you now? I mean how is it now because you're in Grade 10?
186. **U:** 10, in Grade 10 now. Um you know I think I'm in a really good place. Now. But um it took a while. It took very
187. **S:** It's taken a very long time, that's 5 years
188. **U:** 5 years. 5 years. I mean um, you know I'm still not what I want to be. I mean I can't take part in everything, physical activity I can't it's just
189. **S:** So you can do no sports
190. **U:** Um I can swim. So I've been swimming so I've been attending the swimming trainings that there were. So that's nice. And then I try, I try and get involved but it is very painful. So um I'm not able to do that yet but I'm um you know I've really tried to involve myself in other activities. But the one thing that was difficult, I forgot to mention, when I was in a wheelchair was that you know it's so isolating as well. You can't go out to many many places because they don't have wheelchair facilities or that. And so, for example if you want to go to certain movies you have to go to a specific cinema because they not all cinemas have um wheelchair facilities. So and, you know it's not only the fact that you're in a wheelchair but so many places don't cater for a wheelchair. And so that's so difficult and um you know it's also embarrassing [laughs] um going places and now you're the person in a wheelchair. Firstly that's different to everyone else, then now people have to carry you up and down and that's embarrassing, that's not
191. **S:** What was what was embarrassing about it?
192. **U:** You know it's just uhh you know I'm, that's not who I am and that's how people are perceiving me to be and I and that was
193. **S:** So perceiving you to be
194. **U:** Just the kid in the wheelchair [laughs]
195. **S:** The kid in the wheelchair. Disabled person
196. **U:** The disabled person, yeah. That, they don't put me and the wheelchair person together because I was that person but they only saw the wheelchair.
197. **S:** The wheelchair and the wheelchair person
198. **U:** Yeah.

199. S: And then they have, are you, are you sort of saying that they have then an idea of what you must be because you're in the wheelchair and they don't see you.

200. U: Yes. Yes. So in that way I think as well I lost my identity because people, most people only saw me as as that [laughs]

201. S: That was you they saw the chronic illness or the illness but they didn't see you behind it.

[30 minutes]

202. U: The saw the chronic, yeah, but not who I was, no. And I think that was really hard because you know I'm sick, I don't have my legs anymore that work as well as they should, but you know what I'm still a person, I still have a personality, I still have everything and you. Yeah.

203. S: So this year for you, you are regaining who you were to a certain extent?

204. U: Yes. I do think so. Um but it's difficult.

205. S: Because you still can't be the person you were

206. U: I I'm yeah. And I'm not going to be that person again. And um you know as much as I want that to be, I'm not going to be that. And you know at times I think, "Ok, no, I've gotten over the wheelchair, I've gotten over" and then other times I'll just be like, "Damn that wasn't cool". No you know and life still isn't exactly how I want tit to be. After the TB she changed my biologics so I'm on a new one which I have every week so inject it. So you know it's still that

207. S: So you inject yourself.

208. U: Yes. There's still those things, that it just, I just want to get over it. I just want to be better. There's no quick fix and I think that's one of the major things is there's no quick fix for it.

209. S: And there's no guarantee of a fix.

210. U: Exactly. There's nothing like that. So and you know what I think I think I am coming to terms with it. I really do I I believe I'm in a good place. Um. But you know there's still those dips

211. S: The dips and the flare and you get flare-ups

212. U: Flare-ups yes and my knees uhh just a couple of weeks ago I had horrendous back pain such bad back pain and um we saw the specialist, Dr X, and she said, "Ok, let's take an MRI of it because we haven't done one in a long time". So we did an MRI and then um they found I have a slipped disc in my back. And um I had a cyst in my ovary. So it's just you know and then it just was annoying because it's like "Can things not just start to get better now?" So then they um took me to hospital again and they put an injection, they injected my spine to get it um to see if that would not help and so yeah.

213. **S:** And did it?

214. **U:** The pain is definitely better, they not, they not sure if the disc is back yet but. As well um I was still walking and stuff with the slipped disc. I'd had it for a long time but they think now I'm just so used to living with pain that that I don't really notice it so I'll just go around so um

215. **S:** And then of course I think the other difficulty with it being an arthritis is you just assume it's an arthritis flare-up and that it's just moved

216. **U:** Exactly. Exactly. Exactly.

217. **S:** and in actual fact it was something else.

218. **U:** So there's still flare-ups. I still get swollen, I just, so it's something I have to live with every day now

219. **S:** And then how do you manage school with that? Do you take days off or?

220. **U:** I you know what I'm trying to take as little days off as I can but I have to I have to try pace myself because otherwise things just start to going downwards and I become emotional because I'm tired and in pain and so I do take days off.

221. **S:** That's good, yeah.

222. **U:** Every now and then but it's not in excess.

223. **S:** And then how do our friends handle that you're not, that you're not there then you're there?

224. **U:** Do you know what I think now they, it's different now that I'm walking because now, I mean if I I'm not there then they all message me and then they, they really are good that way.

225. **S:** So WhatsApp or social media is very helpful to you to stay in touch

226. **S:** Yes, very. Very, yeah. So I don't take many days off but I when I do then they are there for me.

227. **S:** And how's the rest of the grade with you? I mean you've got your special friends but I mean part of the problem with adolescence is do you fit in don't you fit in, you wanna be the same as everybody else and how does that go?

228. **U:** Yeah. Do you know what, it was quite strange because the people that weren't my friends actually became my friends because um -

229. **S:** That's interesting

230. **U:** - they were the ones that actually helped me through it where my friends didn't. So that was very hard because I wanted to be friends with my friends but these people were the ones. So that was difficult. It was difficult. But they treated me nicely and you know there's only 50 of us in a grade, so it’s a small school but um they really were very good to me, very good to me.

231. **S:** So you’re not feeling um alienated by the grade as such?

232. **U:** No. No, not now um.

233. **S:** Not now. Before you were

234. **U:** A little bit, yes ‘cause I wasn’t involved. But now I’m, I’m ok and um

235. **S:** Of course at your age then you wouldn’t have had the social media to stay in touch with people either, ‘cause you were too young.

236. **U:** No, so that was hard, I was young, I was very young. Um, what was I going to say? Um

237. **S:** Sorry [whispers]

238. **U:** No, no, no, no, no worries. Um yes so I think because I just threw myself into everything, that was ok. But for example, if I think about my sister, um I mean she’s struggling a lot now. Um a lot more than when I was sick, now that I’m better but I’m pretty sure she’ll tell you about that. And um yeah I think those are those are her issues now

239. **S:** So you say she’s struggling, are you talking about with friendship issues or?

240. **U:** Yes, with a lot of things. Um with with a lot of things because I think as well when I was sick she was the kid in the wheelchair’s sister.

241. **S:** Of course. So it also changed her identity.

242. **U:** Changed her identity completely. And so people would come up to her and say, “How’s Ursula, how’s Ursula, tell me about Ursula?” Nothing about her. So that was hard and um watching my family suffer, that was that was incredibly hard for me. I mean my dad was stressed, completely stressed. My mom was a mess.

243. **S:** What was your dad stressed about?

244. **U:** I think if, you know he’s trying to keep a job for us and now my dad doesn’t know how to show his emotions. Ok so it’s hard for him so he the way he show deals with it is he becomes very stressed or he becomes irritated. So he ‘cause he you know

245. **S:** Bottles it up

246. **U:** Yes, bottles it up. My mom was a mess I mean she was my hero through everything. She really, I I would not have been where I am today if I did not have such a strong mom. And my sister was phenomenal. I mean she’s 2 years younger she was 9 years old and now she’s having to take her big sister to the bathroom. Yeah it was hectic. She’s taking, she’s bathing her big sister, she’s doing everything, changing and you know what she’s 9 years old and that’s not. That was so hard for me to watch that I couldn’t fix that for her. And that was 4 years of their lives. So as much as it affected me, it equally affected the family. And um

247. S: And your extended family as well?

248. U: Yeah, no I have um 2 cousins, 2 boy cousins who are like my brothers and they were just phenomenal. Really, they really helped me through everything yeah.

249. S: So family network was so, for you a huge support

250. U: Yeah. Yes, it really was.

251. S: Although also, at the same time, a serious concern.

252. U: Yeah. Yeah, sometimes and that you know when you asked me just now if I'd ever thought about you know, sometimes I'd think you know if I died it would be easier for them.

253. S: Easier for everybody else.

254. U: Then my mom doesn't have to deal with this and my sister can have a normal life. And [sighs] things like that so.

255. S: Yeah, seriously intense. And, yeah shew, to deal with all of that at your age is quite incredible…How do you feel about it now looking at the journey you've been through?

256. U: Do you know what, sometimes I feel like it never happened. Sometimes I feel like , "Oh my gosh, I can't believe that actually that was 4 years of my life" and but you know… you know there are things I could have handled better but I think I did the very best that I could in the situation that I was in um I think I did try the best that I could to get through it and [sighs] yeah no

257. S: So you look back on that and say

258. U: Yeah, I think so [laughs]. I do think so. And um

259. S: [laughs] Yeah, you did well

260. U: But you know another thing is that, you know this disease isn't known about and people often just think of it as a physical disease and it it comes with so many complications, it comes

261. S: What are your complications?

262. U: Well definitely the emotional things, it comes with that. It comes with the social being isolated from that. And you know ok doctors can treat the physical but there's they you know people don't really take that seriously - the other part of it.

263. S: The emotional side and the isolation

264. U: The emotional side and the isolation. Um

265. S: And are there no psychologists that specialise in that in your area?

266. U: They they do and so that helps but you know there's so many people that, you know, and I was, for 8 months I did not have that. Because they were trying to diagnose me and stuff. So I did not have that because they didn't know what was wrong.

And you what, as well, going to the right psychologist is very difficult because there's so many psychologists, I've been to so many psychologists and lots of them didn't understand or they weren't great. So that's hard

267. S: [Inaudible 39:38] they don't understand chronic illness.

268. U: It's very difficult, very very difficult. So I only found a really good psychologist two and a half years into my sickness. Which is difficult because um

269. S: 2 and half years without emotional support

270. U: Yeah and when your life has changed suddenly like that that's the time when you really need it.

[40:00]

Um yeah.

271. S: And you didn't have it. Shew so from your journey, if you…what advice would you give somebody who's starting that whole journey?

272. U: …It's gonna sound clichéd but, not to give up. You know honestly because um, and do you know, to live your life now and not wait um for things to get better because they're probably not going to get better that's just how things are. And I think that's my one regret is that I spent so long being, "ok I'll do this when I'm better, I'll do this when I'm better" that I actually wasn't living. So I that's what I would say is that "you know what, live life now". Live life now and just

273. S: As much as you can

274. U: As much as you can you know you not gonna be able to life live the way you want to but you can live to a certain degree and um yeah.

275. S: And how do you see your future panning out? You got plans and dreams?

276. U: I do, I do have, I want to study medicine I

277. S: Ok, yeah

278. U: Yeah I want to. I think this as well has made me want to do it especially um because I want to be able to help people in this situation. But as well I think, you know many doctors don't understand the full thing, they understand the sickness, they don't understand the, what comes with it – the emotions that come with it. So I think I would really like to be a doctor like that, to be able to say, "You know what, this is it's gonna be hard" and then get them you know to psychologists or to people. Not just [Inaudible 41:41]

279. **S:** So holistic intervention rather than just the medicine. Yeah.

280. **U:** Yes.

281. **S:** And are you still under paediatric care or have you transitioned to?

282. **U:** Yes I am, I'm still under Dr X but I'm now 16 so I'll probably have to go to um a adult

283. **S:** How are you feeling that?

284. **U:** You know, ok, you know Dr X will send me to the right person, I really trust her. So um yeah no, it's okay.

285. **S:** 'Cause I know

286. **U:** I don't like, I don't like it, Dr X I, she's my doctor, I'd prefer it she would take me but you know.

287. **S:** But she's, she's pushed it quite far I think

288. **U:** She really has, yes.

289. **S:** Yeah she's supposed to stop with you I think round about 13

290. **U:** 16

291. **S:** 16 ok

292. **U:** So she goes from 0 to 16, age yeah

293. **S:** She goes to 16, oh that's wonderful

294. **U:** but 16, I think by the age of 16 you start going to

295. **S:** And has she talked to you about how she's going to bridge it or is it going to be?

296. **U:** No I think we're gonna go through this year with her and then she will talk to us probably at the end of this year. She yeah

297. **S:** About how you're going to move across

298. **U:** Yes

299. **S:** And I mean you've been through quite a hectic situation, what, what kind of things kept you going? I mean I know you had you downs but you picked yourself back up again

300. **U:** I think you know my sister, a lot um. Yeah. But as well I think my guilt as well [laughs]

301. **S:** Your guilt

302. **U:** Yes, yeah. Um I think that was one of the hardest emotions to deal with, I just felt so guilty. I felt like this was my fault, my fault [sighs] that my family has to pay so much money that they have to go through this and so um … yeah and as well

303. **S:** Was is just the money or?

304. **U:** The emotions that they had to feel, the suffering they had to go through as well. So that was hectic and um I think you know I just watched other people's lives and I saw how they their lives were progressing and mine wasn't. And so I was just like, "You know I actually, I want my life to look like that. Well, it's not going to look like that but I can make it at least what it can be."… but that

305. S: Mm. Mm. So what was originally at one stage demotivating became

306. U: Yes.

307. S: a motivator to just

308. U: Yes.

309. S: I'm not going to keep my life on pause anymore, we're going ahead.

310. U: Yes.

311. S: Ok, wow. Is there anything from today so far that that you think is important that I haven't asked you or you haven't shared or something else you still feel the need?

312. U: I don't think so, I think I've been completely honest about

313. S: Oh I wasn't questioning your honesty, no no I just [laughs]

314. U: Oh no no no no no. I mean I think I've completely shared what was.

315. S: Ok I'm gonna have a look at my list just just quickly and um. Oh shame you haven't had your water. Um. I think we've covered everything… The coping strategies, what kind of coping strategies, I know we've we've kind of discussed it. Were there ways in which you um … you coped? I mean the things that made you feel better or

316. U: You know um my one psychologist suggested I keep a journal and that helped a lot. Because I mean a lot of the time I kept all my emotions inside, I didn't want to burden my family and that was difficult. And I was only seeing a psychologist once every now and then like a couple of, every couple of weeks. So keeping that journal really helped um. You know where I could just be completely honest you know and just say, "You know this is, life is not great" [laughs] and

317. S: Yeah, it went into the journal

318. U: Yes and um so if I read back at it now it's quite interesting to see how far I've come.

319. S: Oh that is interesting. So you can see how well you've actually progressed. And any other coping strategies?

320. U: Um, in terms of

321. S: So I mean you've pulled yourself back up by the bootstraps, you've made mental decisions, that, that was also coping strategy. But just if you were down, any other things that worked? For me sometimes just getting lost in a fantasy book for example [laughs]. That would be a great way to cope if I could just pretend the world didn't exist.

322. U: Yes, reading was one of my greatest friends while I was sick. It really was. I mean I was reading so much it was it really was an escape um to get away from this to just. And sometimes I would so look forward to just going to sleep so that I could forget about it and everything and um. Yeah but reading was really a good way, I mean I also took up knitting.

323. **S:** Ok

324. **U:** Yes [laughs] I made these scarves and that was that was nice to keep my time because there's not much else I could do

325. **S:** Productive

326. **U:** It was productive so that that's important

327. **S:** Finding a productive thing is important, ok.

328. **U:** That was important. Even when I'm at home to actually have an aim, to not just you know what, to be productive to at least do one task. If it's just one task in that day then that's good because the less I did the more depressed I became.

329. **S:** Ah

330. **U:** So um that was

331. **S:** So keeping busy

332. **U:** Keeping busy, and you know what, ok I couldn't be fully busy all the time I mean I was tired, I was in pain but I had just a goal – do one thing today and then that's it.

333. **S:** Baby steps

334. **U:** Baby steps, baby steps.

335. **S:** Shew, but that's yeah that's that's a great strategy to have…I think you've shared with me most of the lessons that you've learnt and you did you did give me the advice. Um so that to me I think it's everything unless there's something else that you can think of? ... And I'm always , I am coming back so um what's gonna happen, which I I I actually forgot to tell you in the beginning, is um I'm gonna take away all the data from the interviews and we gonna analyse it um. And then, if there's something I want to explore with you more, then I'll get hold of you.

336. **U:** Ok

337. **U:** Is that all right?

338. **U:** No that's absolutely perfect, yeah.

339. **S:** Ok, cool. Well then let me switch this off now. Um.

[recording ends]

Transcript 2: Ursula Interview 2

1. **Interviewer (S):** [laughing] So I was like so confused. It looks like it's working.
2. **Interviewee (U):** I don't know how you work that thing.
3. **S:** Ja, me neither. So how are you?
4. **U:** Sorry?
5. **S:** How are you?
6. **U:** No, I'm ok. I'm a lot better than I was a couple of weeks ago.
7. **S:** Ja.
8. **U:** Because I had awful awful back pain and so they sent me in for a spinal cordial block.
9. **S:** O.
10. **U:** And that seems ... [recording cuts out]
11. **S:** Ok. Wow. *Sjo*, you've been through so much, hey? Because I know when I was up there, you were, you were having a serious flare-up.
12. **U:** Yes. No it, it just keeps happening. Up and down up and down.
13. **S:** Ja.
14. **U:** So it's just frustrating.
15. **S:** So what is a cord, a spinal cord block?
16. **U:** Cordial block, yes.
17. **S:** Cordial block. And what did that involve?
18. **U:** So that, basically a radiologist ... So they sit you down on a table and you, you lie on your stomach. And then they inject your spine. So, so it's not a ... It's a horrendous procedure; it's not a very nice thing to go through at all.
19. **S:** It, it sounds awful. And what do they inject into your spine?
20. **U:** Well they first put an anaesthetic in and then they do cortisone, put cortisone in the spine.
21. **S:** Ok. And it has helped?
22. **U:** It has helped, yes. For like 10 days afterwards though it's a nightmare; it's so sore. Very very very sore and then it gets better. So definitely it does help, yes.
23. **S:** It's interesting that it works that way. I know because I had it in my ... I had a cortisone injection in my shoulder the other day and, but as you say, it took at least seven days before it worked. It was actually more sore.
24. **U:** Yes.
25. **S:** Was yours more sore?
26. **U:** Yes, it was a lot sore, sorer. It was more sore, ja definitely.

27. **S:** Ja. Ok, ok, so shall I tell you what I'd like to talk about today and see if that's what you want to talk about?

28. **U:** Perfect.

29. **S:** Ok, so I went through the previous interview and everything, which was, there was just so much information. Thank you so much it was so helpful.

30. **U:** No, it's a pleasure.

31. **S:** And so, so today was ... What I was wanting to look at is how you managed to get through that. The -- I -- And to talk about the down parts and what you did to get yourself through that. So I, I did make some notes and I've got them with me. In fact, let me put them in front of me so I can see them. But ja, so, so maybe if we could just start with how have ... How did you cope with this flare-up?

32. **U:** To be honest, this one was very hard. Like I was so sore. But as well I think with the more and more flare-ups that I'm having, the more frustrated I'm getting. Because I just, I'm just like well isn't it enough now? Can't it just stop? But I have a really amazing friend who helped me so much. So we were chatting every day and basically I think now I've just realised that I know it is going to get better. So I just need to get through those couple of days so that it does get better. And yes, well obviously I had some lows because I mean, I wish it would just finish now.

33. **S:** Yes.

34. **U:** I think it's more just about trying to manage it now, trying to still have a normal life. But -- And I know, I know it's just going to end, so I just have to try get through those couple of days.

35. **S:** And, and, and I'm going to be horrible to you this time and because I'm going to ask you specifics, so ... Because in future you know we might able, we might be able to share your experiences with other people and assist them much sooner, because you had that whole five-year period where you had to learn how to cope. So, so when you're going through this recent flare-up, and you, you know it's going to be over, so what kind of things do you say to yourself, or is that what you do? How do you get through it? Like, like, moment by moment, what happens?

36. **U:** Well, for the first couple of days I just, I basically I just sit and I, I'm just so, so frustrated and annoyed. So I don't really do anything, I'm just like: oh my gosh, can they not just help me? And then when I realise that it's not going to be a quick fix, then I start like: so ok, no, Katie, you need to get up now. You need to, you need to walk, you need to just push past the pain. You just need to do it, because that's just the way life is. And I try and not focus on the pain. So I rather focus ... So for example, I'll not just sit and do nothing. So I'll say: ok, no, I'm going to read now. Or I'm just going to do some work. Or I'm going to do, talk to someone.

37. **S:** Ja.

38. **U:** So that I try and get my mind off of the pain to try and deal with it. Which can be hard, because sometimes it's extreme pain. And then I've learnt different breathing techniques. Which ...

39. **S:** Ok.

40. **U:** Yes. Which have, which do help me. So especially if it gets really sore, and then I get in a bit of a tizz, you know, just feeling ...

41. **S:** A tizz being crying? When you say you ...

42. **U:** Yes.

43. **S:** Ok. Ja, what ... Can you put in your own words what is a tizz?

44. **U:** So if I'm crying or if it's just too much, I feel like I can't breathe anymore.

45. **S:** Ok.

46. **U:** Just like the pain overwhelms me.

47. **S:** Ah, ah.

48. **U:** Yes. And then I have to breathe, get myself back to a normal state. Just try and calm down and then do something to get my mind off the pain. And that especially helps especially when I'm trying to go to sleep, because that's one of the worst times. Because I've had a whole day and then I go to sleep and the pain's really bad, and then all there is, is the pain. And so that's when I've found the breathing techniques really helpful.

49. **S:** Because going to ... Pain at night is more difficult because there's nothing to distract you and that's your coping mechanism, is to keep busy.

50. **U:** Definitely, definitely.

51. **S:** Can, can you talk me through the breathing strategy that you use?

52. **U:** Ok so basically it, it's actually quite simple. So what I do is I just breathe in for four, hold for four, and breathe out for four. And so then I'm focused on the counts, I'm focused on that, and so that's what I do. It does, for me it does work. I do manage to actually calm down and, and things like that. And I used to also when I was going to sleep, just listen to music. Just -- Or like music with, with lyrics, lyrics that I knew, so that I could go through, you know, sing with it.

53. **S:** With it.

54. **U:** So that I wouldn't be focused on the pain.

55. **S:** And, and what kind of songs would you choose or do you choose?

56. **U:** I actually, I've got these really nice Christian CDs that I, I really love. So I've been, ja, I used to ... [recording cuts out]

57. **S:** And, and what are your favourites? Are there specific songs that you ...

58. **U:** I've got one favourite song and it's called "Forever". Ja ... [recording cuts out]

59. **S:** Can you remember any of the lyrics for me, just out of ... I'm not going to ask you to sing. [both laughing]

60. **U:** I'll just ... The chorus, well it starts by saying: "The moon and stars they wept / The morning sun was dead / The Son of God was crucified" and then, it's just, it's a beautiful song.

61. **S:** So that sounds ... That's, that's such an interesting way of coping. And going to school must be very painful then during your flare-up?

62. **U:** Yes. So I ... If it's really bad, like the first couple of days was so bad I couldn't move very easily. So I just stayed at home and rested. But when I did go, it's, it's very hard. I mean, carrying a bag and walking. Fortunately my friends were there to help, but it's just everything is so much slower.

63. **S:** Ja.

64. **U:** And , and it's, it's hard, you know, just getting up every 40 minutes, going to a new place, and, and it's just you're in so much pain that it's, that it's really hard. And as well the other thing that I found would be quite difficult for me ... [recording cuts out]. Can I carry on?

65. **S:** Yes, yes, yes. Sorry, my ... phone's doing something strange?

66. **U:** Yes.

67. **S:** I'm just going to move it.
[both laughing]

68. **U:** Ok, no problem.

69. **S:** There we go.

70. **U:** No it's fine, don't stress.

71. **S:** No it's fine, you carry on, it's fine.

72. **U:** Ok, so what I found quite hard though as well is because my friends are quite used to me being most of the time well and fine, and then when I come and I'm in pain, they don't seem to understand really.

[10 minutes]

It's that they think, they seem to think: oh well yesterday you were fine, and now you must just get on and deal with it. They don't understand and then they're like: oh, why, why are you complaining you're in pain? Why do you look so tired? Why why why why why. And I think that frustrates me as well. Because I just want to be like: you know, I, I'm in pain so I'm just trying to get through the day. And that, that's hard.

73. **S:** And, and you're using the word "frustrated" quite a lot and I was wondering, are there other words you could use to describe how you feel when your friends really don't understand you and you're in a lot of pain?

74. **U:** I do, I get annoyed or angry. I don't really get sad anymore like I used to, but I, I just, I guess I get annoyed that I just wish they would understand. And that, realise that, you know, just because I'm not in a wheelchair anymore doesn't mean that the disease is gone. And that if I come to school one day and I'm fine, the next day doesn't mean I'm going to be fine either. So this disease is just a journey, and so you just, there's ups and down. I some -- I sometimes get very annoyed; I don't really show it, I'll just explain it. Because I understand, I understand where they're coming from.

75. **S:** Ja.

76. **U:** I mean, it must be difficult to see, you know to understand, one day you're fine, the next day you're really battling.

77. **S:** And is there a feeling behind the annoyance?

78. **U:** I think as well it's from all the years that I was sick, well, in a wheelchair, and I think I'm also annoyed that I can't do things. That, that I'm going through a dip. And so I'm just trying to cope, I'm just trying to get through it, and then when there are so many added things to deal with ... [recording cuts out] pain enough. I just can't do it.

79. **S:** Sorry, say that again.

80. **U:** So when there's so many other things to deal with, so like to explain to your friends over and over and over again, it's just, isn't the pain enough? Can I just deal with the pain and then ja, everything else just carry on.

81. **S:** And then you just don't need the social lack of understanding at the same time, is that what you're saying? Or, ja. *Sjo*. And, and what kind of thoughts go through your head in those moments of frustration?

82. **U:** Sorry, just give me a couple of seconds.

83. **S:** That's fine, we have plenty of time. At least, I hope you have.

84. **U:** Yes, no, all day. When -- I guess because these are my friends that I've had for five years.

85. **S:** Yes.

86. **U:** While I was sick. And I guess it just brings back all of those, those thoughts of: even though it's happened for so long, can you just try and be a part of my journey? Oh sorry, I just need to charge my iPad quickly.

87. **S:** Ok, cool. I forgot to check with you that you're sitting somewhere comfortable.

88. **U:** Yes, no I am. Don't stress. Ok. So I guess ... [recording distorted / unclear] thought. I guess as well, I just ... In those moments I also just get frustrated with my disease. Or my situation in general. Because I just feel like I've had enough. You know, just enough of these ups and downs. Just, just can it not just all end and so we can get back to normal.

89. **S:** Is it just frustration, Ursula? Or is it more than frustration?

90. **U:** I, I think -- I mean because about a week ago, last week Saturday, I had a bit of a breakdown. And I haven't had one in a while, and so I just had a complete breakdown and the main thing: I was really angry. And I was frustrated, but I was really really angry.

91. **S:** And your anger ... I'm just interrupting, my apologies. The last time we chatted you rated, you rated, I think it was your level of unhappiness out of 10. What, what would your rate of ... If we lab -- With 10 being the most angry and one obviously not so angry, where would your anger have been? Where was it?

92. **U:** I think it must have been like an eight.

93. **S:** An eight. And, and can you describe to me that level of anxiety, ah, anger, sorry, in your own words? If you had to put some adjectives with it, I mean how would you describe that anger?

94. **U:** It was -- It was actually -- It was so overwhelming. So -- And I just, I felt like a bubble that just burst inside of me. It was just ... Adjectives, I'm trying to think.

95. **S:** Any -- What -- Maybe, what -- What, what did you say to yourself in a secret place in your head that you wouldn't say to anybody else, possibly?

96. **U:** I was -- I think I was very angry, if I'm very honest, I was getting very angry with the fact that I got this gene from like my parents and from ... And I was quite ashamed of that, but in that moment that, that's how I felt. I was just ...

97. **S:** Angry with them?

98. **U:** Well not exactly with, with them. Like I wouldn't say I was angry with my mom, but I was angry with the fact of that's how it happened. I just, I was just like: that's not fair.

99. **S:** Not fair, ja. And any other kind of ... Look, I don't know what you're like. When I'm angry, you really don't want to hear what's going on inside my head, because ... I don't know if you do the same thing in your head. Is there a lot of things that would not be shared actually with other people, because you, you put up a face or something?

100. **U:** Well I think some ... Well, I think obviously some, yes. I mean, I shared a lot of it with my mom, because I was really really really upset. And -- But I guess I'm just ...

101. **S:** What, what did you say to your mom? I mean, you say you had a breakdown, did you actually shout or ...

102. **U:** No, I just, I was hysterically crying. I was just in a ... And I got ... I was just so angry. I think it was tears of anger more than tears of sadness. I mean, I just think it's ... I mean I was sick for four years in a wheelchair, and now I just want my life to get back on a normal ... I can't think of a follow-up word for that, but just to normal life. It's just that this stuff keeps happening. Like I try and I try and be active, and I try, and there's just pain. And I can't get past that and I'm just so frustrated. But I think the other thing that ... Actually but I didn't share this; I've actually thought of something, was for example my sister has the same disease as me and I just, I guess ... But, you know, she can still take part in sports and stuff like that, and I can't.

103. **S:** Ja.

104. **U:** And, and that's one of the things that really bugs me.

105. **S:** Ja, understandably.

106. **U:** It's just not cool.

107. **S:** Ja.

108. **U:** That she can still take part in things. And, and don't get me wrong, I would never never never ... I would rather me not be able to ... But I just look at that and I'm like oh my, why, why can't I . . .? And it's not for lack of trying; I try and the pain is just too much. So that was one thing I think I kept ... Ja.

109. **S:** You kept it to yourself? Ja. And, and the feelings around that, because it must be ... I must be difficult to both have the same disease and you have it so badly. There must be times when you have thoughts maybe that go through your head that you're maybe not so proud of? Do you ever get that?

110. **U:** Yes, yes definitely. But I think when I ... I'm never angry with Rochelle herself or ... And like I say, I would never, I would take it any day; she could carry on doing that. But I guess sometimes I just think: oh my gosh, it's not fair. Like how -- Like yes, obviously I have thoughts that I'm not very proud of that go through my head.

[20 minutes]

111. **S:** Would you be willing to share any of those? I know that's a big ask.

112. **U:** Ja, no sure, no. So, for example, like before I got sick I was very active, very. I was very good at what I did and my sister's also active, but she didn't partake as much as I did or ...

And I, I was really good at what I did. And now if I just, if I think now you know, with what she's doing and stuff, I thinU: you know what, if I'd been walking and stuff I would have done it better. That's a horrible thought to have, but it's still ...

113. **S:** It's there.

114. **U:** Ja.

115. **S:** And how do those thoughts make you feel afterwards?

116. **U:** I feel very ashamed, because I would never never want to think that because ... But I think that also stems from the part of longing. That feeling f, of frustration that I can't be there.

117. **S:** Ja.

118. **U:** So I don't think it's like actually aimed at her.

119. **S:** No, yes.

120. **U:** It's just inside.

121. **S:** Ja. But I mean this is what happens, isn't it? When you're very ill and you're in pain, you're going to have thoughts.

122. **U:** Of course.

123. **S:** And then they're not "real" as such but they just, they happen. Ja, ja. *Sjo*, so you've been through a tough period recently again, but thankfully not back into the wheelchair.

124. **U:** Never, never, that will never happen.

125. **S:** Yes! [laughing] I, I've -- When I was going through the interview I had, you showed so much resilience, and, and I know at one stage you were saying it, it was a very bad time, particularly when you were in the wheelchair. And your pain was a 10 out of 10, and you were nauseous all the time. And at one stage, ja you, right at the beginning you thought: am I going to die? Can you, can you rem ... Go back to that time period. At one stage I don't think you had any coping strategies.

126. **U:** Definitely not.

127. **S:** Ja. How was it from ... How did you negotiate your way from moment to moment then – can you remember?

128. **U:** To be honest with you I, I don't think I actually did. I think I was just existing. I was just like, ok, well, I must ... I'm here, I'm just going to sit here and that, that's what's going to happen. But I think in the back of my mind all the time was I thought: oh my gosh, it's just going to be like two weeks and then I'll be able to get up and run and ... It will just be like a two-week thing, finished, done.

129. **S:** Yes.

130. **U:** And I think the more I realised that it wasn't going to be that, I kind of figured that then I had to come up with coping strategies. But before that I was just saying: ok, it's fine, it's fine, it's going to get better. But I didn't have any coping strategies. I mean, I don't know if I told you, but during that time especially I, I was just shutting people out.

131. **S:** Ah.

132. **U:** Just, just, I was just just -- Everyone. I was just shutting them out and just like: well this is horrible. And full of self-pity and stuff. And ...

133. **S:** Do you think, do you think it helped you in some way? Because I mean, that was right at the start, you had that intense pain, so you shut people out. Did it help, or do you think that made things worse?

134. **U:** I think in a way ... I think that you can say that it was both. But I think in a sense that it helped. I think I got to deal with a lot of my stuff, try and ... Because I've always been very independent.

135. **S:** Yes.

136. **U:** So try and work it out myself. But as I ... Then, as time progressed, I would thinU: oh my gosh, everyone's against me. And meanwhile I'd shut everyone out.

137. **S:** Ok.

138. **U:** And so, ja, it's difficult. I don't really know ... Because I wasn't in a space exactly to want to be around people.

139. **S:** Ja.

140. **U:** Ja.

141. **S:** Because you were sleeping so much as well. I mean you had no energy at that stage.

142. **U:** ... because I was sleeping all the time. And I think if you exclude my family, I think the reason why I shut people out so much as well was because I was ashamed. I was embarrassed I guess you could say.

143. **S:** Ashamed and embarrassed of what?

144. **U:** Because of who I was, and now I'm in a wheelchair. And like I had to cut my hair, I had to do a lot of stuff that ...: no, I'd rather just see people when I'm the old me and then they don't have to see me like this. So that was I think another reason why I shut people out.

145. **S:** Why did you have to cut your hair?

146. **U:** I had this horrific pain here, at the back of my head, and so the hair, actually the weight of the hair actually hurt it.

147. **S:** Oh.

148. **U:** So we just had to like cut it short so that it was more manageable.

149. **S:** So it wasn't ... It -- It wasn't even just being in a wheelchair, you had to change your physical ...

150. **U:** Yes.

151. **S:** The way you wanted your hair to be was no longer even under your control.

152. **U:** Ja.

153. **S:** Ok. *Sjo*. *Sjo*. Ja. And you said you, at one stage you thought that other people were against you, even though you had shut that out. How was that? I mean how did that, that feel, or your thoughts around that? Why did you think they were against you?

154. **U:** Well, I guess ... That was like a really bad period in my life and I was just very angry with everyone. Everyone except my sister, which was a strange thing. For example, like I used to go to physio, but the, the lady was really horrible.

155. **S:** I remember.

156. **A:** She didn't understand pain. And so my mom always used to take me and from there I was just, I was so angry. You know, this woman doesn't understand and I had to go back every week. And so that ... I think my anger with her built up to be anger with my mom or with my dad.

157. **S:** Ah. Why was, why did your anger transfer to them?

158. **U:** I guess because it's a safe place to be angry. Because they love you and so they are there with you. And so it's ok to be angry with them.

159. **S:** Ok.

160. **U:** And ...

161. **S:** Ja. Because that was a long time that you went through all that. I think it was, I think if I'm right it was five years in total that you were in a very dark space.

162. **U:** Yes. I think the worst was for a couple of months in 2011 and then it got better. So then I wasn't that angry with my family anymore, because I decided that I didn't want this life anymore.

163. **S:** Yes. So you went from, from being overwhelmed ... Ok, tell me if this is correct. You went from being overwhelmed by the pain and the situation, and then you had a mind shift.

164. **U:** Yes.

165. **S:** Ok, can you remember how that mind shift occurred – was there a trigger or was it accumulative?

166. **U:** I think it was accumulative, because I can't say that I can pinpoint a time where I was like: oh my gosh, I don't want this ... [recording cuts out] But I think it got to a stage where I realised that it wasn't just going to be a short thing; that it wasn't just going to be two weeks and then I'd be up and, up and about again. That it would all just disappear. And I think I realised that ... [recording cuts out] I need, I need to actually start living. I need to ... I can't just sit here anymore without having a life. And I think I looked around me and I saw all my friends and all my people like achieving things and they're doing well academically and doing well in sports. And I thought well, I want that. And I knew I wasn't going to be able to have it like they did, but I wanted at least a part of it. I think as well what motivated me is that, for example, say I was better in four, in a couple of months' time, I wanted to be ready. I wanted to be able to just go back to how things were. So like not just sit at home, not have friends and stuff like that.

167. **S:** So do I understand you rightly Ursula, you, you set yourself a goal of four months or a few months?

[30 minutes]

168. **U:** I think each time it was a couple of months. So like three or four months, I'd say: oh no, it will be better, it will be fine.

169. **S:** So in three months' time, it will be better?

170. **U:** And then eventually like at the end of ... [recording cuts out] that I realised: ok, doing that every couple of months is not going to work, because it doesn't get better.

171. **S:** Oh, I see, I see.

172. **U:** And so then I ...

173. **S:** When you say "getting better", that the illness would have gone. Or ...

174. **U:** Yes.

175. **S:** Ah, ok. Alrighty. So, so you were setting up a future hope: in three months' time it will be gone, so I just need to do what I need to do until then. Is that correct? Ok. And what kind of things did you do during those few months waiting for it to get better?

176. **U:** Well I started to talk to my friends again, like and try and interact with them again. And then ... so obviously go to school again.

177. **S:** In Grade 6?

178. **U:** But ... Ja?

179. **S:** In Grade 6 you went back to school, did you say?

180. **U:** Yes.

181. **S:** Ja, that was twice a week?

182. **U:** Yes, twice a week.

183. **S:** Twice a week.

184. U: Yes. And I started to throw myself back into my academics again. I mean I always had, but now, you know, that's basically what I had left.

185. S: And, and ... Because I mean, for you that was quite a big thing, because you said that the last time, that your friends disappeared. I think it was just the one friend who stuck with you.

186. U: Yes.

187. S: Who, who hadn't originally been a friend. Am I remembering correctly? Ja, so then you had to go back to school, or you chose to go back to school and recreate friendships.

188. U: yes.

189. S: How did you manage to do that? What strategies did you use?

190. U: ... if I look back on those years and think of all these things like, I don't know how I did that, what I did. But I think I just went back and I was, I was obviously friendly and nice to people. But I hid everything I felt.

191. S: You hid it?

192. U: Yes. I hid everything I felt, so that they wouldn't see that side of me I guess.

193. S: And what things were you hiding?

194. U: I guess I was hiding my, my sadness, my disappointment, my anger that they didn't stick by me. But they like they like realised that I was actually ok with it and that, that I was fine with just having friends like that. Because for me it was easier to deal with it like that.

195. S: *Sjo*. And, and how did they respond when you went back.

196. U: They pretty much like ignored me, you know. So I think they found it very difficult to be around me.

197. S: Because you were in a wheelchair?

198. U: Yes. So they would, they were friendly, but nothing more than that. I could sense that they were really awkward, so ja. So I guess I tried to make peace with that and not actually try and talk to them about it.

199. S: Did you want ... How did you want to talk about them? What would you have wanted to say?

200. U: Well I guess that I wanted to say in that moment that, you know what, I thought we were really good friends, can we talk about it? How do you feel about me being in a wheelchair, and this is how I feel. So we can try and deal with this together.

201. S: Ja. But that wasn't an option.

202. U: Well, no ... I didn't ... I guess I didn't want to do that. I didn't want to ... I just wanted them to be ok. So if they were ok with their lives then, then that was fine. I was just ... Ja.

203. **S**: Ja. So, so you had ... Would that have been more of a superficial relationship; you were getting your peer interaction. Was there anybody at that time who was a closer friend?

204. **U:** Yes, I did have one closer friend. She was really, she was really kind to me, really good to me.

205. **S**: And did that make ... I mean, how much of a difference did that make in your life, having her?

206. **U:** I guess I'll say again, it was, there was good and bad in a way. Bad in the sense that you know, I didn't exactly want her as a friend, I wanted my other friends. But ... And it really did, it made me feel, well in a good sense, it made me really feel like I had a purpose again and people that were there that actually cared for me. And so it made, you know, going to school easier because there was someone that didn't feel that they had to spend time with me.

207. **S**: Ah. Ja, ja. And, and did you say there was a negative side to that?

208. **U:** Well, not negative side. In me, I guess, I felt, I'm going to say like annoyed, because I wanted to be friends with these people but they didn't want to, and now I have this friend. And so, ja.

209. **S**: And what was it about her that made you not want to be friends with her?

210. **U:** I wanted to, but I guess I just wanted my old friends back.

211. **S**: You wanted them back. Ja. *Sjo*. And so, so, so the friendship, making a link with your friends again was, enabled you to cope better? And were -- And your academics.

212. **U:** Yes.

213. **S**: Ok. and was -- What other strategies did you use once you'd decided now, this was your life and this is how you were going forward?

214. **U:** I guess me and my sister that as well tried to do things together again. Obviously we couldn't do what we used to do, but ... ways [recording cuts out]. So that was also really, that was also really helpful. To try and like recapture something from when I was better. Just to, to look forward to things, to grow our relationship, to do things again together. Then, I don't think I exactly like had a coping strategy that I was like: ok, this is how I'm going to do that. I basically worked from morning to evening. So I wouldn't think about tomorrow and all that, just to try and thinU: ok, I need to get to there and to there. And set myself little goals through the day like: ok, so once I get there, then it's fine. Then I just need to get from there to there again, from there to there, and then I can go to sleep. So just working day by day like that was, it was very difficult.

215. **S**: Can, can you take us, take me through what, "I just have to get from there to there" – what were the "theres", what kind of things did you use as your little goals?

216. **U:** well, to be honest, they were really small and probably stupid, but ...

217. **S**: No, no, but it's important to know. For me to know. Ja.

218. **U:** It was, ok, so first getting up. And then I always ...

219. **S**: So the first goal would be: get out of bed. Ok.

220. **U:** It was, I was always anxious in the morning to see my friends, in the morning. It was always for me ... I was always anxious about that. So then it was, seeing my friends. Ok, and then that was fine. And then it was getting to first break, where I had to go to the loo. And then getting to second break, go to the loo. And then after school. And then you can go home. And then ja, then it's until tea.

221. **S**: Ursula can we unpack some of that, because I think it's very easy to, to forget that those were actually big goals for you, because you were in a wheelchair. So getting out of bed was not that easy. Because I mean, if I remember correctly at one stage your parents were having to help you go, even go to the toilet. That was when you were off school. So how did you get out of bed? How was that like?

222. **U:** Well, in the mornings my parents had to help me sit up and then they would actually help me to stand. I, I would actually do it, but they would, they would help me to stand. So it just feels like, felt like: you know what, you wake up, you can't even get out of bed. So it just feels like your whole day is just this big cloud. Because I mean, if you think of standing up and getting up, that should be easy, but to me each time I had to stand up was like a huge mountain.

[40 minutes]

So that was difficult.

223. **S**: And pain as well.

224. **U:** Sorry?

225. **S**: The pain.

226. **U:** Yes.

227. **S**: First thing in the morning.

228. **U:** That was, it was very hard for me sometimes to actually like want to get up in the mornings then, because I was like: I actually can't do this today. I actually can't do this whole thing of getting up and standing and being in pain and it being difficult. Sometimes I would feel like: no, I don't want this for today. But then you just have to get up and do it.

229. **S**: And how did you get up and do it? What did you say to yourself?

230. U: I guess as well at that time I was going to school two days a week, so on those two days I definitely knew, no I need to get up and I need to do it. And then I had those other days to rest.

231. S: Ah.

232. U: So, so I think that, that helped. And then the following year when I was going like four days a week, I was thinking: ok no, I just need to get to Wednesday so that I can rest. So it's fine, ... today, tomorrow, then I get a rest. And I'm thinking Grade 8, that was, that was a bit difficult for me then as well, because I was in a wheelchair but I was trying to go every day to school. And I think that's when I had like quite a few meltdowns, because I actually needed a break, my body actually needed a break, because I was really exhausted dealing with the pain. And so trying to manage that, trying to find a balance, to say: ok , I will go then, and then I'll have a break, and then I'll go then, and then I can have a break. Just to put those little breaks in front of me as carrots made me, made it easier for me to get up and say: I'll do it today.

233. S: And a break would then have been a day off going to school?

234. U: Ja.

235. S: So, so then if we go back then to that daily schedule of goals. Your mom and dad had to help you get out of bed and into the wheelchair, but then there was still bathing, brushing teeth.

236. U: Yes.

237. S: Take me through the day.

238. U: Ja, not a problem. So basically I would sit up in bed, they'd bring me breakfast. Then my mom would help me get over, get, well help me get over like get, put my, would help me get my feet right and I was sitting on the bed with my feet down. And then I would change my top and then she would help me with the bottom. And then get into the wheelchair, go to the bathroom, stand up again, get onto the toilet, stand up, get back into the wheelchair.

239. S: Did you still need your mom's help for that?

240. U: Yes.

241. S: Ok. Ja, you did. Ok.

242. U: And then brushing my teeth, I could do that. And then basic ... And then it was getting down the stairs, so then my mom or my dad had to help me to get down the stairs with the wheelchair. And then get into the car, go all the way to school – which was a nightmare because of all the bumps; the pain was really bad. And then getting to school, getting out again.

243. **S:** So all of these things were your goals: get to school, get out of the car.

244. **U:** Yes. Just little things. Be like: ok yes, you've got to stand, then I don't have to stand for ..., or I don't have to do that. So that makes it more bearable. Ja.

245. **S:** And then so you got to school and I'm assuming ... Ja -- What kind of a wheelchair ... I've never even asked you what kind of wheelchair – was it motorised or ...

246. **U:** It wasn't a motorised wheelchair, so it was just one of those normal wheelchairs, if you can say.

247. **S:** Yes. So push-wheelchair. So how -- Who pushed you at school?

248. **U:** Well, fortunately when I was in primary school, we have a very small school so you just have one classroom.

249. **S:** Ok.

250. **U:** So you have all your subjects in that classroom. So, so that was quite easy actually, because you stay in the same place the whole day. And then in Grade 8 there was a lady who does the photocopying at our school, so for each period she would just come and push me to the next period and then that's how it would work.

251. **S:** Ok, ok. But then you said one of your goals was going to the toilet. How did that happen?

252. **U:** Well fortunately because my mom works at the same school ...

253. **S:** Ok.

254. **U:** At the breaks she would come to take me to the loo, we'd go to the loo and then I would go back.

255. **S:** Ok. From a peer perspective, how was it that your mom had to come and fetch you, take you to the toilet, help you get into the toilet.

256. **U:** For me actually, surprisingly, it didn't really bother me that much. I actually liked seeing my mom then, because I guess, and especially in those times I felt like really vulnerable, really ... During those years, very ... I, I don't know how to put it. Like, I don't know how to say it, but just seeing her then was a comfort. Or to be able to express to her that I was in pain and she would actually understand.

257. **S:** And so, so setting yourself very very small goals but were, which were actually very big goals for you, small for everybody else, it just helped you keep that momentum through the day. And, and then when you were at home and not on a school day, what, what kind of goals would you set yourself?

258. **U:** Well, I think the major thing that was ... was actually bath time.

259. **S:** Ok.

260. **U:** So it was basically from when I got home to go to the bath, and then from the bath to bed. Those were the two goals then.

261. **S:** Ja. And then, and then, but you were only at school twice a week. How did the other days go? Well the other days, because I was still at that stage still battling with severe exhaustion, so: get up in the morning, eat, go to the toilet, and then I'd basically sleep until two, half past two.

262. **S:** Ja, you said you were sleeping 18 hours a day at one stage.

263. **U:** One stage ... That stage, when I had TB ...

264. **S:** Oh that's right.

265. **U:** I was sleeping like 18 hours a day. But then I was sleeping until two o'clock and then getting up and then I'll try and do some work. Ja, so those days were easier to get through.

266. **S:** Ok. So it was, it was the school days when you really had to use your strategies.

267. **U:** Yes. At home it ... [recording cuts out] because, I mean, I would sleep and then I'd wake up and feel a bit better. Ja.

268. **S:** And then you could do your school. Because you were doing your school work on your own at that stage.

269. **U:** Yes, so I was basically teaching myself.

270. **S:** Ja. And, and can you think of any other sort of strategies or perhaps anything in the environment – people, whatever – that, that enabled you to just continue the way you were continuing? I mean ...

271. **U:** Well I guess my sister was a major role player in that. I guess at that stage at well I was also looking forward to seeing my friends, so that was another thing. My cousins – that was also a really, also kept me going.

272. **S:** Your cousins? How, how did they help?

273. **U:** Well we've always been really close, and so they were I'd say one, two of my biggest friends when I was in a wheelchair. They were always ... I mean, we see each other basically twice a week and they'd always try and make ... My cousin ... I used to go to the bathroom and I used to be in so much pain and he would literally just stand and sing for me. So they were really supportive and they were really protective over me. Which they still are. And that really helped, to have people that are not inside my immediate family that also really cared for me, motivated me, really helped me.

274. **S:** And I'm just wondering because you said your favourite music is the Christian album, or the Christian songs.

275. **U:** Yes.

276. **S:** I was wondering if Christianity helped in any way for you?

277. **U:** Definitely, definitely. Ja, no. I'm actually glad you brought that up. My faith really developed while I got sick, and so it was really ... I think, I guess that was also a coping mechanism, because I would talk to God if I was in pain or I wasn't coping. So and I found myself talking to God basically all the time. So it was also like something to do to distract myself. Ja, so it, that helped a lot. To actually develop a relationship with God. Ja.

278. **S:** And now this is a very personal question again and you don't have to answer it.

[50 minutes]

Could you give me an example of a conversation that you might have had with God?

279. **U:** Well, I guess they varied a lot depending on how I felt.

280. **S:** Yes, they would.

281. **U:** So like, for example, sometimes if I'd be really angry, like sometimes I'd be really angry with God. And then I would just like ask Him why He would allow this. I don't know how to say, but like have a rant. Yes, just rant. Or, or I would just literally talk about anything that was going on. Because it was lonely at times, so it was just an easy way to talk about things. Talk about anything really; how I was feeling. And it also became like actually a diary that wasn't kept here. So I'd express how I was feeling, emotions ... [recording cuts out] like that. To actually deal with things through that, because I've never been one that could like write a diary. Like I more think about things. Ja.

282. **S:** Ok, that's ... So that, that actually we ... That's actually played a very significant role in your management and how you've coped.

283. **U:** ... [recording cuts out]

284. **S:** And is it still playing a, a role, or ...

285. **U:** Yes, it is. Yes. So if I'm having bad days, if I'm having flare-ups and stuff, sometimes I'll feel like ... Sometimes then I'll just talk to God. Sometimes I feel like that's the only safe place I can go where I can express my deepest thoughts and my deepest, how I'm actually feeling.

286. **S:** The, the, the -- Are you saying that the stuff, the thoughts that you have that you know you, you actually can't share with other people ...

287. **U:** Yes.

288. **S:** Those you can share with God.

289. **U:** Yes.

290. **S:** Ok. So that, that's quite an incredible outlet for you. As you say, an incredibly safe space to let those emotions out.

291. U: Definitely.

292. S: Ja, ja. Ursula are you able to chat again about what happened in that mental ... You called it a mental institution, which is why I'm using those. And you, you also called it your darkest time. You had ... They were taking you through the withdrawal from the painkillers; you were in the incorrect place – you shouldn't have been there because they were all, all had other things wrong with them. And I'm trying to remember how long you were there. It was a couple of weeks?

293. U: I was there for three weeks, yes.

294. S: Three weeks. Was there anything there that particularly helped you cope? I mean, was there anything different, because it was quite an intense time period for you.

295. U: To be honest, I actually don't think that I really coped.

296. S: You didn't cope.

297. U: So I think if I had to say the one thing that did make me semi cope, was the fact that I just wanted to get out of there. So just, I was like: ok, you just need to get through this, you need to get through these couple of days, so that you can actually get out. That was the only thing, but I didn't really cope. Ja.

298. S: Ok. And, and when you say you didn't cope, how do you know you weren't coping? What, what ...

299. U: Well, I was at a complete emotional low. So I was like crying all the time; I was like angry all the time; I was just ... I can't even express how I was feeling. It was just, just all too much. And I was taking it out on my family; I was taking it out ... So I knew I wasn't coping, because generally I can be composed if I'm ... Like a lot of the time if I'm emotional and going through hard times before I was in the clinic, the mental clinic, like I would hide a lot of that. And so If I, if I wanted to cry like I'd go to sleep and cry myself to sleep instead of letting my family see that. And at the clinic I didn't do that; I wasn't composed as I normally was. I wasn't -- I was just crying all the time and it didn't really matter. And I, and I didn't know how to control it. I just felt out of control with everything that was happening.

300. S: So looking back on that, that was, *jo*, an incredibly difficult time.

301. U: Yes, that was a horrible horrible time.

302. S: And, and yet it led to a breakthrough. Because if I'm remembering ...

303. U: Yes.

304. S: I can't remember why exactly you said it was a breakthrough. Oh you, you were starting to walk after that. It was a few steps at a time and that came after going to the clinic.

305. U: Yes. Ja.

306. **S:** Yes. Ja.

307. **U:** Ja, but I also think as well that the reason all of that came up then was, I'd been dealing with it like in a way silently, for ... [recording cuts out]. Not exactly expressing how I was feeling all the time. Not saying ... I was just trying to have a positive outlook all the time, and that's draining when you actually inside don't feel like that. And I think that it was all just accumulating to a point, and I just couldn't anymore. ... Ja.

308. **S:** So do you think that that then was a help in some way? To actually be able to let it out?

309. **U:** I, I guess so. I guess it was. I don't want to say that I'm thankful for it, because it wasn't a nice time; it wasn't pleasant. And it wasn't easy for anyone in the family. And so ... But I guess it did actually allow me just to deal with things from all those years.

310. **S:** What kind of things? Deal with?

311. **U:** I guess because I'd never really been angry properly. So people say I always dealt with my sickness so well, I always dealt with being in a wheelchair so well, and I was always happy and stuff like that. And inside I was like: no, I'm not dealing with it well. And so being able to then actually be angry with my circumstances; to actually be angry that I couldn't do what I wanted to do; be angry at my situation and be sad. Like actually in a way mourn the losses that I'd had. So I think that all came out then. All like at once. Ja. Which wasn't a very good . . . [recording cuts out]

312. **S:** So it was quite a cathartic experience – just, it just all came out. You keep saying it wasn't a pleasant experience. How would you ... How would you really describe it?

313. **U:** If I really describe: it was hell. It truly was. Ja. It was a nightmare.

314. **S:** Ja, ja. Did -- Was, was one of the ways in which you dealt with your illness ... You say you didn't let them know. Everybody was saying you were coping so well, but you didn't let them know what was going on inside your head and your feelings. What, What -- Which -- Why did you choose that way of doing it?

315. **U:** Well, I guess in front of my family, I didn't want to put, burden them with how I was feeling. I didn't want them to feel guilty or burden them. And in front of other people it was just easier, because if you ... I found that when I expressed how I was actually feeling in front of other people, they don't know how to react. It's just easier to say: no I'm fine, I'm fine. To actually express how you're feeling is, it just, is they feel awkward. And they don't know how to react. So I just eventually was like, I don't have the energy to deal with that. So it's just easier just to go along with it.

316. **S:** And just not, not open up that conversation. Ja. *Sjo* Ursula, are there any other things that you can think of that have enabled you to cope, or, or things that actually made it worse for you?

317. **U:** Well I think one of the things that did make it worse was the fact that people didn't understand. But I guess that was, I mean, you eventually learn to deal with it. So like when people are always saying: you must be positive, have faith.

[60 minutes]

And, and something like that, I just want to *klap* you. But ...

318. **S:** [laughing] Say that again; I want to hear that again. When they say, what? Just think positive, you want to do what?

319. **U:** Have faith. I just want to *klap* them. It's just ...

[both laughing]

It's just, ja, those things just are really annoying... . [recording cuts out] or like, God only ... What? God gives His strong ... *Ag*, God gives battles to His bravest soldiers or something. And I'm just like: no!

320. **S:** And God only gives you what you can deal with, those kinds of comments?

321. **U:** Exactly. Or, ja, just, just things like that, where people are not understanding. Or like for example, you want to just have a normal life or you want to just go to the movies, and places don't have wheelchair facilities. Or things like that. It's just ... Those things make it hard, extra hard. Harder than what it already is. But I guess ... Ja, you were saying?

322. **S:** No, I was just thinking then from, from a wider perspective, like a social perspective, it's actually quite incredibly difficult to deal with, because of the lack of wheelchair access and, and ... How do you ... I mean even something as simple as drawing money from the teller; I know they're often quite high. How, how did you get your head around all of that?

323. **U:** Well I guess that also caused me to withdraw a bit, especially in the beginning. And that also made me embarrassed, I guess. For example like sometimes we would have to go out and there was no wheelchair facilities, so we would have to ask strangers to carry me up the stairs. And in a way that's humiliating. I hated it, I hated that so much. And that would just ruin the whole day or outing or whatever we were doing. And so -- But I think eventually I just made peace with it. Like, you know what, who cares really. So you just, you're not going to see those people again, or you're just going to have to try to make the most of it. Of what ... [recording distorted / unclear] It's also hard, like wanting to go places but then realising, no, you actually can't go there because it's just not possible to, to go there in a wheelchair. And I think that was part of one of the things that really annoyed me, that so many things aren't cate ... They don't cater for wheelchairs or people with disabilities, and ja, it really, ja, just annoyed me.

324. S: And was there anything else in the sort of, the, the more social, the wider sphere sort of, of the country that either assisted or didn't assist you? So sort of beyond school and beyond your friends and family – was there anything else out there that impacted on you?

325. U: I don't really think so. I think it was just the fact that there weren't that many wheelchair facilities . . . but I think it was easier as well for me, as, as I was younger and not an adult yet. I think if I was an adult it would have been a lot different. Because at least here I was still in school, I was still at home, like I didn't have my independence like that. So my life basically was just centred here, around here, so it was ok. So it wasn't like ...

326. S: And so let's go back to where you are now. [laughing] So you're in Grade 10, almost Grade 11. How are you feeling, how are you feeling about next ... Well, how have the exams gone? Because that's sitting still for a very long time and you've flared.

327. U: Yeah, well actually we haven't started. Well ...

328. S: Ok.

329. U: ... [recording cuts out] exams, which I can't even know if they were this week or last week. So, I think they were this week. I guess it was just really frustrating because ... I had a flare-up or whatever, and now I have to deal with exams as well. That's quite difficult. For example like on this Thursday I'm going for injections into my knees and then have like an exam straight after. And so ... [recording cuts out] not cool.

330. S: No.

331. U: And it, it's too much to deal with all together. But you know, I manage and I think now I've really learnt that you just need to manage it. You need to manage your time, and you must just go with the illness. So like you prepare in advance, because you don't know what tomorrow's going to be like. So ja.

332. S: So how, how are you preparing for Thursday? Because you're going to have the injections ... It's cortisone injections into your knees?

333. U: Yes.

334. S: And so we both know, ok so initially you're going to have the anaesthetic, which is not too ... Do they do anaesthetic into yours first, or straight cortisone?

335. U: Straight cortisone.

336. S: Ooh, straight cortisone in there. So we both know that's going to be very sore, and for a couple of days afterwards, and you're still writing exams. How, how are you preparing for the exams knowing that you're going to have those knees?

337. **U:** Well, I've prepared ... I try to prepare for as many exams like now, that I can do, like now before I go in, so that when I, when I'm over that then I can like just revise and try and do that. But it's quite difficult, because we write every single day now.

338. **S:** Ja, ja.

339. **U:** So from that first day we're basically officially starting exams and we write every day then. SO that's quite difficult. But you know, I'll be fine. And then I just think of when I was in Grade 8, I wasn't there for that whole term because I was sick and I had TB. And I came back a week before exams started and I was ... fine, and I studied and I ... So it's ok; it will be ok, I know it will be.

340. **S:** So you use ... You're also using past experiences where you've successfully negotiated these things.

341. **U:** Yes.

342. **S:** Ja. I was wondering, more from a physical perspective, how are you preparing for those exams? Comfort-wise.

343. **U:** That was an issue as well, because I was studying on the . . . for like hours, so many hours straight, and I would get up and oh my gosh, my back would be sore and stuff like that.

344. **S:** And your neck?

345. **U:** Yes, so everything. And I would get up and oh my gosh, my hips, my knees, everything's just . . .

346. **S:** Exactly.

347. **U:** So I've now like, well, I cushion myself when I study. So I have to make sure I'm comfortable when I'm sitting or that I'm getting up at regular intervals, or that I'm ... Because I get really tired as well, so I'm actually incorporating rest into it, because I know that if I don't do that, my body just ..., I get tired. And I can't actually afford for that to happen, so just monitoring it, like: ok, my body needs a rest, let me have a rest. Or -- Yes. So that I don't actually waste the time that I do have and I don't land up not being able to study because of the pain's bad.

348. **S:** Because you, you've pushed too far. So, so you make sure you ... So that's another coping strategy then, that you're actually physically managing the fatigue side of things so that you don't spiral downwards. Ja.

349. **U:** So what I've become good at is listening to my body. Is realising that like, I can now feel when my body's starting to go downhill. I can now feel when it's, when it's a different kind of pain when my body's saying: no, I need rest. I'm starting to be hyper aware of those type of signs where I know: ok, whatever I had planned for this afternoon, I can’t actually do. I need to actually give my body a chance to recover and then go again. Because I know from past experience again that if you just keep going, it does start slipping.

350. **S:** And then you get a serious collapse.

351. **U:** Yes.

352. **S:** If you just keep going.

353. **U:** Yes.

354. **S:** Ja. What are the warning signs for you Ursula? How do you know?

355. **U:** I know for example like, well, my fatigue does get worse. Or my body just come, becomes achy. So it’s not a sharp pain, it’s just it starts to become achy, and then I can ... It’s just a specific type of pain that I know this is not just the normal pain I have. I know that this pain will go away once I’ve had a rest. And so I think ... And then I’ll have sometimes where I just take a day off school. To just to sleep, to just let my body rest, and not put so much pressure on the body. So like, or make sure that I’m not carrying my bag ... [recording distorted / unclear] someone is carrying it for me. To just ... Being aware of those signs. I also know because the ...

[70 minutes]

I get tired and my pain gets a bit worse and then I become a bit ratty, so I become a bit emotional. And I know that that’s, you know, that’s going ... A breakdown is going to happen. And I know it’s because of my body. And then I just, even if I come home and just have a rest and I don’t do my homework, but try and catch it up some other time. Because it ... Ja?

356. **S:** No, no, carry on.

357. **U:** Just because it’s just better not to have like a complete breakdown physically or something, than to just keep going.

358. **S:** When you say rest, I mean, we all use these terms, but I don’t think people quite get what rest is when you have, have JIA. When you say rest as a, as a way of making sure that you are coping, what do you mean by rest?

359. **U:** I actually have to lie down and sleep. Ja. But that’s ... I can’t just like sit down on the couch and, you know. I actually need to sleep and I, and I just need to lie down. That’s the best position for my body when it’s . . . like that. So like I’ll try and have undisturbed rest, because then my body can fully recover for the next day or whatever.

360. **S:** And, and how long is an undisturbed rest?

361. **U:** Well, it, it depends, but say for example I’ll come home in the afternoons and I just can’t anymore, I’ll have a sleep for about four hours.

362. **S:** *Jo*, that's a long rest that you need.

363. **U:** Yes.

364. **S:** Ja, ja.

365. **U:** My body gets really tired now as well, so and it's still that. So, but fortunately it doesn't happen very often. So like in the two months, two months, then I'll just be like: ok, now I need to go sleep for four hours.

366. **S:** Ja.

367. **U:** And then ... [recording cuts out] again and then I'm back on track again.

368. **S:** So would this be part of your preparation then for the coming exams?

369. **U:** Yes.

370. **S:** Is to build in those rest periods?

371. **U:** Yes, it would be.

372. **S:** Takes quite a lot of future planning.

373. **U:** It really is. It really is. Because -- And as well from past experience I know that today might be fine and then tomorrow I'll wake up and I'll have pain. And then it renders me, you know, I can't focus properly.

374. **S:** Ja, I was going to say, then you're going to get that cognitive fog as well.

375. **U:** Yes. So it just means I need to ... If I'm having a good day, it means I need to try and do what needs to be done, so that ... Because I know that my disease goes up and down. I know that. I know my body isn't, isn't fully on track yet. So it's just, I just need to use the time when I'm feeling good, I need to use the time then so that I can incorporate for example a day where, where I'm not going to be feeling great.

376. **S:** And, and Ursula I keep coming back to this, and it's just because I know, studying myself and having to write lots of reports from my work, I'm picturing you physically writing that exam with those knees. Do you put anything in place? Is there comfort? Are you allowed to put your knees up instead of having them bent? Is, is that part of ...

377. **U:** Yes. Fortunately my school is really amazing, so they really do cater for me. So if I need to put my legs up I can put my legs up... . [recording cuts out] I can bring a cushion if I need to. I can, I ... Ja, so I can bring a whole lot of things in if I need, which is really ... Really helps a lot a lot that they understand. Because I am thinking about the day after, and a two-and-a-half-hour exam after my injections. And so that definitely will help a lot, that there are thing that are, that can be put in place that I can actually use. Ja. So for example in the, in the winter exams, because the cold affects my joints, not ... And it's not really nice. I can wear whatever pants I want to wear, for example, just to keep my leg joints warm and ok.

And I can bring in hot water bottles and stuff like that, so that the pain doesn't disturb my exams.

378. **S:** *Jo*. Ja. And I'm, I'm just thinking with the future planning, is that extending also into your long-life future? What are, what are you seeing your future to be? Because you've got Grade 11 next year, which is really exciting, and then it'll be matric. Where are you going from there?

379. **U:** Well I guess I don't think I've planned that fully in advance. [laughing] Because you know I think these next two years will actually be telling of how I cope. And ... [recording cuts out] see. Because I want to study medicine, but that is a hectic course. But I, I really want to do that. And so I think Grade 11 and matric will really see how I cope, how I cope physically. And I'm really trying for these next two years to not fill my timetable up too much.

380. **S**: Ok.

381. **U:** So that I'm not too overly tired. I just focus on the things that I actually want to do, so I'm not just taking on all these extra things. So, so that I can just focus on my academics, focus on what I, what I need to do. And I think that's also something that I've learnt, is to prioritise. So you know, some things are just not important – I don't need to do them. Just to make sure that I'm coping. So I think I've only really like planned up until the end of matric, like this is how I'm going to get it. Ja.

382. **S**: Well that is, that is quite the norm. Most Grade 10s have not planned past matric. I was ... Ja. But it's interesting to me that you, you, you're interested in studying medicine. Is that because of your illness?

383. **U:** I think that it has played a part in it, that I want to study medicine. I think I've always been interested in it. I like always learning and in medicine you can't but keep learning. But it definitely has played a part. I also, because I mean I've met so many doctors that only care for your physical and don't really understand the other side. And I think I want to be ... My whole experience has inspired me to be, you know ... I want to be a doctor so I can also understand what they're going through. So not only seeing the patient with the symptoms but also understand exactly what they're going through, because so many doctors haven't understood that.

384. **S**: From the emotional side of things – is that what you're saying? Ja. And would you be looking at then going into working with people with arthritis?

385. **U:** I, you know what, I do want to. So do rheumatology, but paediatric rheumatology. I'm thinking of, ja, doing that. I guess ...

386. **S**: And there's a huge need, because I think there's only four of them.

387. **U:** There is, in South Africa, there really is. So I think I've just planned towards getting my normal doctor's thing first. [laughing]

388. **S**: Step by step.

389. **U:** Yes. And then look at what happens from there.

390. **S**: And is looking at your future something that also helps you cope? I think you've kind of answered that, because you, you do kind of put those small goals and then bigger goals in place. So, is that something for you that helps?

391. **U:** Yes, I think definitely it is. Because you know, you have to work really hard to get into med school, and that's one of the things that keeps me going even when I'm in pain and I don't really feel like studying. I'm like: no, you know what, you actually need to do this, because one day that's where I want to be.

392. **S**: So, so also from ... It sounds to me like you almost ... I don't know if this sounds right; you almost, you've trained yourself to cope with high levels of pain.

393. **U:** Yes, I think I can say that now, ja. Especially this year and like last year. I've, I've really ... Now it's just about managing pain, training myself to cope when the pain is bad, just getting through that. And I think I'm becoming much better at that now. So if I'm in pain, you what, I just carry on and I do it.

394. **S**: Ja.

395. **U:** I ... [recording cuts out[] because you know I like don't want to wait for you, so I go and do it. Ja. So that's basically what keeps me ... Ja, I just keep going.

396. **S**: That life doesn't wait for you. Ok. *Sjo.* Ursula sorry, I've just realised that we've been talking for an hour and 20 minutes. How are you feeling?

397. **U:** . . . I'm fine, I'm really fine.

398. **S**: You're fine?

399. **U:** Are you ok?

400. **S**: Yeah, no, I'm, I'm fine thank you. Ursula, do you, do you have anything else at this stage about coping and anything ...

[80 minutes]

I think there's only one thing I've forgotten to ask you about. Ja, is there anything from your side?

401. **U:** I don't think so; I think that's pretty much it. But I think what I must do, because I was thinking back to when I had that meltdown, and I was thinking you know what, when things like that happen, I must just write it down to see how I'm feeling and stuff, and then I can maybe send that through. Because that ...

402. **S:** That would be wonderful. Ja. And if you don't want to send it through, we could do another quick interview; it doesn't need to be an hour and 20 minutes. So I mean like for example through these exams, or as you say, if, if something starts to come to you, just send me an sms and we can set up a time. Even if, you know, whenever suits you, and we could just do a quick interview. Because I know you don't necessarily want to be writing again.

403. **U:** Ja, well, it, it doesn't matter. So that ... I think that could ... Because to think of things, I can't really pinpoint, but when things happen I must just make a note so that I can tell you. That would be easier for me.

404. **S:** Great. Because I'm going to be still collecting all the data and transcribing it and then I really want to start working through it in January already. So there's plenty of time to get in the extra information. What I've been wanting to ask you is, the term "wellness" – what would the term "wellness" mean to you? Or well-being?

405. **U:** Ok, well I think if you asked me that like a couple of years ago, my answer would be very different.

406. **S:** What would it have been then?

407. **U:** It probably would have been you know, being completely physically fine, running around, no pain and whatever. I think that's what it would be. But now to me it's, I want to say managing, but not really. But it's, it's dealing with your pain. So it doesn't matter ... It doesn't necessarily mean being a hundred per cent, because I think I'm well and I'm not a hundred per cent. And so just caring for your body, just, just ... I don't know how to put it in words. Just -- You know what, you have pain, you have fatigue, but it's just managing it. Not being a hundred per cent well, but just going on through it.

408. **S:** And how can you be well when you're not well?

409. **U:** Well I think even though sometimes, especially if I think of that flare-up that I had and you know, I wasn't well then, but I still ... You know what, I forced myself to get up and move and stuff like that. I still felt well even though the pain was extreme. But I think I just forced myself to get through it, to try and move it to one side and just deal with everything else.

410. **S:** What aspects of your life, despite the pain, make you feel well?

411. **U:** Make me feel well or unwell?

412. **S:** Well. Ja. So you've got that pain, you've got the flare-up, we know, I, you and I both know ... Well, I don't know to the extent that you experience it. How do you find wellness within that? What, what are your indicators of wellness?

413. **U:** Well I guess when I'm not nauseous. Ja, that helps. When I'm not as tired as I usually am and when I've just got more energy. Not as much pain. Just -- Ja.

414. **S:** And do you think wellness is more than just physical?

415. **U:** Yes, definitely.

416. **S:** What else do you think it is?

417. **U:** I think wellness is about not necessarily just about the pain level, but how you're doing emotionally, how you're actually dealing with what you're going through. So if your body is in pain and whatever, but you're ok physically, *ag*, emotionally. I think you can say that you are well. Because sometimes that'll happen to me. So if I'm having a flare-up and I'll be in a lot, like a lot of pain and ... But sometimes I'm feeling fine inside. I'm, I'm, I'm actually at peace and I'm like: ok, it's fine. ... is actually like ok well, you know what, I'm fine.

418. **S:** Is there anything that you think contributes to your wellness and well-being?

419. **U:** Well I think taking time out for yourself. Not people-pleasing all the time. Doing things that you, you actually want to do. Taking time to rest. Being around people that build you up and stuff like that.

420. **S:** You're tired, I can see.

[both laughing]

I'm going to ... I think we should call it quits now. I'm going to switch off the, the recorder.

[recording ends]

Transcript 3: Adele Interview 1

1. **Interviewer (S):** All right, so um, I will just keep checking that. Um. So what I was just wondering was how was the journey for you as a parent? I mean because you have two girls, both of them with JIA, and from what I understand um Rochelle's diagnosis was obviously much quicker, but with Ursula you walked a very long road.
2. **Interviewee (A):** In one word, it was hell [laughs]. It was hell. Um and I think, I think possibly um you feel like a bit of a chameleon, a bit of an octopus because you there is such grief that goes with the absolute loss. So the loss, I mean Ursula was a very um able bodied, she was sporty, she was a ballet dancer, she did, so there's grief all the time. Um, there's a high level of anxiety because you're kind of thinking, "What more could you be doing for these kids?" and you were, you know, night times I would lie in bed thinking, "Who else could we, could I possible see?" I mean we went the the ridiculous routes from, you know I mean I don't know if they told you about the therapies but from all the, anything, I would have I would have run around naked with biltong on my head if that was going to help, know what I'm saying, you were so desperate. And I think, constantly, um living in hope that this next this next treatment is is gonna bring some relief to the pain. Um and at the same time, Rochelle hadn't been diagnosed yet so you're trying to keep life as as normal as possible and yet we had we had a a very unique situation where Ursula wasn't able to do anything, um, at all. So, um, it was it was… painful. It was painful, as a mother when um you take a kid to the doctor and it's an antibiotic and 3 days later it's it's better, I've felt completely helpless. To watch this kid suffer physical pain as well as emotional pain um it was it was really really difficult.
3. **S:** And it seems to take an awful long time for her to get diagnosed.
4. **A:** Absolutely. Um, it was a very, I think it was a very, it was a very um, it was very hidden um and triggered by pneumonia as I'm sure she's she's already told you.
5. **S:** [laughs] um, yeah, so it was a very long and and that is, appears to be the more typical path… to -
6. **A:** Yes. I think it's very difficult -
7. **S:** Because so few people are aware of what… it is
8. **A:** I I don't… exactly and it didn't show up in her blood so she's not, it doesn't show up in her blood so she's got HLA B27 gene, both of them do, but in terms of her rheumatoid um factor, it didn't come up there. So um she we went from cardiologists to neurologists to, and I knew this kid was sick, in fact I actually thought we were going to lose her at one stage because she was, her breathing was, and she looked terrible, she looked absolutely terrible

um [sigh] rings under her eyes, she wasn't sleeping, she couldn't breathe um and she couldn't walk. She just collapsed, the one day she just collapsed and couldn't walk. You go, "What what what is this?" Um, so the diagnosis was a long process and I think that was terrifying. As parents, we were petrified because we didn't know what we were doing, it was the unknown because we, I think if you had a diagnosis and um a prognosis, you know even if -

9. **S:** And a plan of action

10. **A:** Exactly! But it was the not knowing what the heck were we dealing with and it was terrifying. I, I, yeah I, you just, you just don't know what you're dealing with.

11. **S:** So how was it when you did finally get the diagnosis?

12. **A:** I remember, it was very shocking I mean I'd never heard…

13. **S:** Because she told you on the phone didn't she initially?

14. **A:** Um, we were at the hospital and she said to me, "You are going to be dealing with um, this is going to be very complicated" she said um. So I can't, I can't remember now whether it was, I think it might have been over the phone…

15. **S:** Ursula thinks that it was the phone first then you went in to see the…

16. **A:** It could well have been, I can't remember [laughs] so much has happened but I remember thinking "What?" I did not know this occurred in children, I'd never ever heard of this. And again petrifying because "What was going to happen?" and when they gave us the prognosis she said, "I can't tell you, I can't tell you whether this is going to get better, I can't tell you if this is gonna be a lifelong sentence, I can't tell, I cannot" … and that for me was the hardest. I didn't know if my child was ever going to walk again um

17. **S:** Because it's been a long road, she was telling me…

18. **A:** 4 years… in a wheelchair

19. **S:** 4 years in a wheelchair?

20. **A:** Yeah so it's only ben a year and a half that she's been walking and she still can't do everything but but compared to, I mean she looks completely different, she's a different looking child to what she was in in the wheelchair. She could do nothing - we had to cut her food small, turn her at night time….Yeah, we had to turn her at night time, she couldn't ….

21. **S:** So it had a huge impact on family dynamics

22. **A:** Massive, massive

23. **S:** I mean your lack, loss of sleep, everything….

24. **A:** Yes. Yes.

25. **S:** And financial implications, it must have been horrendously expensive

26. **A:** It was huge, that was huge um we were very blessed in that um people gathered around us and um we had a trust fund set up and a couple of people did a couple of fundraising um because it was her, it was the biokineticist, it was the physio, it was the psychologist, it was all the specialists, it was the chemo, it was, whoo, it was just everything. Yeah. So and the meds, just the meds themselves we were out we were out of medical aid by end of Feb. Yeah

27. **S:** I would imagine so, yeah. And um, just out of interest, with medical aids does, does it, is it covered on the chronic illness eventually once you've got a diagnosis?

28. **A:** It is, yes, it is. Fortunately, so our Revelex is covered and that was, that's the biologic, and that was covered and that was hugely expensive, fortunately they covered all of that. But um all the other expenses, the chronic medication was covered, but all your things like her physio wasn't covered, all of the other we had to um once the medical aid was up we had to cover that.

29. **S:** And then then you walked the same road, but not as long with Rochelle?

30. **A:** Yes and when we, I mean we took her in and she was also starting to complain of pains and battling, she was battling with gradient slopes and stairs and that kind of thing so we then, I thought "hmm" we'll go have this um sorted and I was really hoping –

31. **S:** Just checking

32. **A:** No please keep checking, it's fine, checking, that um.

I was so hoping that she was going to say to me it was growing pains and when she told us and I think [sighs] I think uh Rochelle I think froze because I think she kinda thought "This , it's it's another wheel, this is what she's gonna, it's gonna be wheelchair bound". And I just, my heart I thought, "I can't do two kids in a wheel, I can't do this, I'm battling with 1 [laughs] kid in a wheelchair, I don't know if I". So it was shocking um that and the strange thing is I'm carrying the gene…

33. **S:** Yeah it is, because it is genetic

34. **A:** Yeah, I'm carrying the gene. my husband's the one with arthritis so his mom had horrendous rheumatoid arthritis …

35. **S:** So you've got the gene on both sides…

36. **A:** I've got the gene and he's got the arthritic gene so

37. **S:** Yes, He's got the auto-immune…the RF or whatever

38. **A:** Yes…correct, that's correct so I think we've got yeah just a real lovely combination between between the two. So it was it was very hard um…I think I think what is hard about the disease is it really is a waiting game so you, they put you on meds and then we'll just wait 6 weeks, and then you realise that doesn't work and then we'd try another one, and we've got to first wait, because you can't start the biologics until you've done a trial period on the methotrexate and, and understandably they don't want to put, so it's it's that waiting game. And every, and you kind of think, "Ok we'll give it 6 weeks" and then nothing's happened and and she was ill ill ill. Um

39. **S:** She sounded, from what she said to me she sounded like she was exceptionally ill

40. **A:** It was very bad. It, I mean her schooling just, it it was it was very bad

41. **S:** The school seems to have bent over backwards for both of them

42. **A:** We have an amazing school. Um and God alone knew that we needed a school with wheelchair facilities and came with a wheelchair lift and they, they were amazing. One of the teachers kitted out her backroom so when Ursula didn't cope she could go in and sleep and be put in a comfortable chair, Ipad. They really were amazing. And sadly so this doesn't happen in all schools

43. **S:** Oh no, we know, I know, it it's generally not the case.

44. **A:** I think that the school has learnt um with us um, but generally yeah, I I don't know, I mean I just, I feel for, we're fortunate that we've got a medical aid, we've got, I don't know what would happen if we didn't have the means to that. What would happen in a in a massive school where you're just a, I don't know I just? And I think I think the hard thing is I think, with Rochelle for example, I think largely it, I mean Ursula was so visibly um there was something wrong, but it's an invisible disease as I'm sure you well know. That you look absolutely fine, but gee whizz you know what, the pain and the fatigue that goes with it, and with Ursula the nausea was debilitating.

45. **S:** And um, how do you see that it's impacted on them with their peer relations and that kind of thing?

46. **A:** Um, during that time when Ursula was wheelchair bound, she certainly became completely isolated. Um and she understood here, in in her head, but she couldn't accept it here. And she understood that kids didn't want to hang around somebody in a wheelchair, she got it but it hurt like hell. So it would break my heart, I never knew what to do as a parent if she was invited for example to a party – do we rather just stay at home and she doesn't have to see it or do we take her and she experiences that that that pain? I never knew what to do.

47. **S:** How did you decide?

48. **A:** I let her decide.

[10 minutes]

So she would then decide [10.00] what she would want to do but every now and then you think, "What, do we just say – don't" and then she would go and come back in floods of tears, so it would be. Or we'd go to sports day then I'd think, "Do do we take her to the sports day so she can be part of it but but then she's missing out?" and she would come away, and she'd hold it together, and she'd come away and she'd be devastated afterwards because she can't do those things. So I never knew whether it was better to have her involved or not or I I never knew what the right thing was and I I actually realised that neither would be right. If she stayed at home she'd be miserable because she was missing out and if she was there she'd come home miserable and it was just, so it was miserable it was lonely, it was isolating. Um, she had one outstanding friend not, a little girl called Emily who constantly fed her um work every day and um would write little notes in every little class, lovely you know: "Mr. Stewardson lost his temper in class today, we've got this homework and' so it's, she would write her per period, that she would -"

49. **S:** She had a lifeline

50. **A:** - yes, great. So every day she would then bring that or her little chocolates home or whatever and that was fantastic, she was she was gold, she was gold. But a lot of her very good friends, and she had, she had a, she was quite a social butterfly, just dropped.

Rochelle, on on the other hand um, I think in a lot of ways, Rochelle had to grow up very quickly. It was very hard I think she was robbed of those of those 4 years. And then dealing with her own diagnosis, I think in a lot of ways felt "My diagnosis isn't as bad as K****'s" so um so that came with lots of other very complicated ramifications. Um and I think that she was frustrated because nobody really got her, so at school nobody understood.

51. **S:** Because hers was very invisible

52. **A:** Very, very invisible. And she was dealing with being the invisible sibling and it was just, "Hi Rochelle, how's your sister?" So you know she just became wheelchair kid's sister.

53. **S:** And yet their relationship seems to have been good?

54. **A:** They are, they have been heartmates since they came out of the womb. They are made for each other, those, they are really very, I'm very [laughs] glad, very blessed, felt very blessed, they are really bonded, they are best buddies. So they they're each other's antidepressants, they they really do, they just get each other. But I think at times Rochelle would love somebody outside of the situation just to get her. Just you know just because it is so hard inside here, and nobody, and she didn't have any peer, you know there were lots of Aunties and Grannies, people older, she wanted a peer just to get it -

55. **S:** To be able to relate to.

56. **A:** - Cause she'd say, "Oh my sister had a bad night" or "I'm really sore" and the response would be "Oh, my cat you know today" so there was nobody who who got it. So I think she felt very lonely and alone. Um in terms of her peers.

57. **S:** And with regards to independence, I mean it's a silly question to ask given the nature, but adolescence is about becoming independent and reaching, working through those milestones. How have you seen that work? I mean how's that been?

58. **A:** Well that, that, interesting you say that um, I mean Rochelle, Ursula let's start with Ursula didn't have that independence obviously. And I remember when she started walking, the very first time she went to movies um, still going, I walked her, dropped her off, walked her to the machine and I realised, "Oh my", I had to learn independence, I had to learn that this child needs, it's ok, she can actually get out the car, because that's what people do they drop their kids off and the kids walk in but I walked, so I had to learn -

59. **S:** When she was better

60. **A:** Exactly, we had to learn what was normal again. We didn't know what normal was so we had to learn "normal" all over again. So, certainly Ursula had no independence. Um, I mean I had to live her physical life I was her body for her.

61. **S:** You were turning her you were literally turning her at night and all that kind of stuff

62. **A:** Yes… yes. Whereas Rochelle hasn't lost that independence um as much as there are times when she's very sore or she um, she copes, she, she just, she works it through. And so in no way has she lost her independence. But Ursula very much so, didn't, and I think the, think that was very frustrating for her, I think that um, yeah it was very destructive for her and um.

63. **S:** And as a parent dealing with children who are undergoing so much pain, how did you change or did you even change your parenting styles? I mean disciplining and, how did how did that work?

64. **A:** Um… uh, you know what I don't…I'm trying to think now, we, I must say we've got 2 very easy girls. I've got very easy girls they're very compliant, I'm just trying to think of an example or um…

65. **S:** I was just wondering if when she, for example when Ursula got sick, did you change the way in which you parented… with regards to discipline? …Overcompensate or

66. **A:** I don't…I don't think so … you know what I think she was so, she was so lacking in energy that there was nothing, we were Grade 5, she basically slept through, there was no energy, the child was so fatigued that I think that my, our parenting became all-consuming in this child's illness. So that consumed all our time is thinking "What else could we possibly do?" I think perhaps what um um, because there was no schooling happening at that stage, perhaps it was a thing of just perhaps more motivating and trying to um be positive and funny and that kind of thing constantly. You know trying to pull them through the day and I think that that's possibly how the parenting role took, yeah

67. **S:** So it's developing coping strategies -

68. **A:** Yes. Yes.

69. **S:** -to help the family move forward. What were the best coping strategies, did you find?

70. **A:** We had to laugh. So uh we we laughed at the most ridiculous things. A sense of humour, definitely. Um surrounding ourselves with people. Um we had the most amazing support, um in fact for an entire year I had a woman cook for us from Monday to Thursday because it was impossible: we would go from, I was working full time, I would often, my afternoons were full with um bio or kineticists or physios or whatever it was. So we were only getting home 6/7 and I still had to bath her so she would still need to be bathed and everything took a million years to do. It was not, you know, just getting into the car was folding up the wheelchair and picking her up and getting her in and putting her, so it was just everything took so much physical energy. Um and that was exhausting so surrounding us with people. And I think that I had to learn to need people and that was hard. It was hard to learn to need people that if people offered help um, in the beginning um Ursula would have to be at home, we were staying in another place, and um I had no-one to look after her and I had to work it wasn't a, I had to work. So I was finding women that I had known, acquaintances, they were coming into my house so I would show them "Here's the coffee, here's the, and this, you're going to have to take her to the toilet", show them how to do everything and that was **hard.** With these women that were basically strangers to me, coming into my home, looking after my child um you know for all those hours and that was very stressful. I had to plan 2 weeks in advance seeing that there's finding women who were prepared to sit for the entire morning um yes looking after her so that was incredibly stressful and I had to learn to need people.

71. **S:** So were these friends that you knew or

72. **A:** Friends, um in the church, we well connected in the church so um women that were available, made themselves, availed themselves to help us there, um so whoever was on pension or [laughs] nothing to

73. **S:** So really important to have a good resource network

74. **A:** Wow, no you cannot do it on your own. Particularly when one is just not um well. And then I mean in her last year she got very ill, and one of the side effects, I mean she got, she then got TB, I'm sure Ursula told you, she was very ill, she was very ill, the sweating and that kind of thing and um there was a point where I was, what was I going to I'll tell you now… oh I can't remember

75. **S:** You coping strategies, yeah uh needing people um

76. **A:** And I think dealing with it as a family and and talking about it so the kids knew exactly what was going on, the therapy that she was going into, did she have questions that she could ask, that she could talk and

77. **S:** So involving her in the whole process.

78. **A:** Yeah, and involving all of them. So Rochelle was as Ursula would be with everything um. And I was concerned about Rochelle because her diagnosis, obviously I think she felt that hers wasn't as horrendous so she wasn't going to get the the attention that she needed all the care she needed um, which concerned me because I think she felt "Ooh mine's not so bad" um

79. **S:** So therefore couldn't ask.

80. **A:** Yes, and I think it, so that came with with a lot of, she became, you know that was hard because I, you were living in two different, on two different planets all the time. With this normal child, I mean Rochelle was was fine and coping, and this child who just could do nothing and it was it was getting that balance was ridiculous.

81. **S:** And then Rochelle also got sick on top of that although she was… better, much better, she was still also ill.

82. **A:** And we were then had to start the whole process again of testing out meds, what worked, what doesn't work,

83. **S:** You must have been gutted.

[20 minutes]

84. **A:** No it was terrible, it was, that's it I was gutted

85. **S:** And then how did it impact between you and your husband? I mean with all this work you've been putting in I mean it must have impacted on your…relationship.

86. **A:** Yeah, look the um what was amazing is um we pulled together and he was very hands-on. So he was the practical, he would often help with the, all the practical things because she was, she was heavy, so going up, and ok we had ramps we had ramps in the house but, um but there were certain times where he had to, and she would only trust Dad to do the stairs and things like that or carry her. So he was very hands-on that way and for that I was grateful. Um there was, it was survival mode, the water level was just below the eyes and so we would be exhausted. So there was very little time and when we were together it was um "I contacted so and so the doctor", "I think we should look at this therapy" whatever, and we were so exhausted that that's exactly what it became. There wasn't any other time than disease time, illness time, therapy time. And what was amazing was Trev then um became, he became far more involved in Rochelle's life um so, because I was very consumed with Ursula, so he would he would make sure that he was getting to her sports matches and her extra-curricular. So he was there all the time so he undertook there which was fantastic and um that was that was great. But in terms of our communication, was literally about "Ok this is what" and then fall asleep because there was just there was just nothing more so if anything he would get the left overs of me because I had nothing more to give um

87. **S:** Shew. And um… what advice would you give other parents who find themselves in a similar situation with the diagnosis of JIA and I mean

88. **A:** I think, I think one of the best best things we did was we do it one day at a time. I think when I, when we think of the bigger picture, I would I would go into panic paralysis that I think, "I actually can't do this, I can't I can't bear to think of what this might be". So we, I just knew that we, "Ok today's Thursday, I just gotta get through to tonight, that's all. What do we have on, that's all. And then tomorrow is Friday, I'll deal with Friday tomorrow" so it was just a day. Because if I looked at the mountain, I couldn't do it. So it was just one foot in front of the other. Um, surrounding us with people, I think that's the other thing. You've got to need people and it's hard it's hard to ask for help, it's much easier to give.

89. **S:** So you also lost your independence, it wasn't just the girls

90. **A:** No, no, we lost a lot, there was mourning, there was grief. You know, grief of their dreams, grief, there were lots of things as a family we couldn't do anymore you know if we went camping, we couldn't camp or hike or anything of those things and there was loss. There was, absolutely there were lots of things we couldn't do as a family or, I remember the one night, Ursula being in hospital and I was with her and she was in tears she was miserable it was awful. Rochelle had been selected as the mini mayor of Jo'burg and she'd just given a speech. Now my husband was with her, my daughter was in tears, my other daughter had just been given a standing ovation for a speech, and I thought, "What do I do? I've got one part of me who's in in mourning here and who just can't pick herself up and the other one who's elated and I didn't know how to." It was such a dichotomous living and it was so ambivalent and it was so hard celebrating and mourning at the same time. And not feeling that I'm I'm not, you know I felt that I was robbed of Rochelle's opportunity of those, you know I didn't, there were lots of things we couldn't do as a family and um. And I think it frustrated my husband more. I think there were times when he was really frustrated and really angry that things weren't um, weren't, you know those previous dreams or whatever that you had for your family were not there. Um, so yeah, I would say that. Need people, you gotta need people and that's hard um. I'd also say don't read too much. You know you read, you start reading, you actually, you can read yourself into oblivion that you start panicking. You know you land up burying your kids because of all the stuff you're reading. And I think that there's so much out there that you you're not sure of. Stick to 1 or 2 sources that you know, "this is a reliable source or somebody that knows", that you, that you're, the info you're getting about the disease is reliable and you're not just reading wherever. Because that that is petrifying for me when I thought "Oh my gosh, this could happen or that could happen, and the side effects of this medication". It it was, it was horrendous.

91. **S:** And did you, was it helpful getting, finding other parents whose kids had also had JIA or was that not helpful? Was it possible, even to find a support network?

92. **A:** You know, there, I, we went to a, we had a support [sigh], in the beginning there was a support group put together and I thought this was fantastic. And Rochelle, Ursula at that stage was very angry um but I thought this would be great if she could network with others, I could network with parents. And we arrived and Ursula was the only one in a wheelchair. So it was really, I thought "Oh, we're gonna be", like even if somebody's limping or whatever but everybody was completely mobile and my daughter was the only one there –

93. **S:** So they were more like Rochelle

94. **A:** And the OT's took them off and they got their activities and I went to go fetch her, and I'll never forget this, I arrived there and my daughter was sitting by herself because everybody had disappeared from this room and I thought, [near whisper] "I can't do this." So we didn't do support groups after that. I just, I couldn't do it and I just realised, even there I was the only parent, when I shared I just I just blubbered I just cried and cried and cried you know. And as as kind and everything was well I, I think oftentimes my story would scare scare parents that um, they didn't you know they didn't know, they were awkward, they didn't, they were scared that this might be. I remember on the face, there's a Facebook support group um and um people would ask and I'd say you know, "I'm quite happy, my daughter's in a wheelchair, we could" I can't remember but the conversation was cut off. So so that was, I didn't I couldn't find somebody else that, except for D* C*******, I think you're probably going to see M*******.

95. **S:** I am seeing her, yeah

96. **A:** She was wonderful and um and that was great that we could we could really draw on each other and every now and then we would just phone each other and have a good yak about where we were at and how to help each other at school and that kind of thing.

97. **S:** Because I mean you need a lot of emotional support too.

98. **A:** Yeah, yeah, you realise that it's that it's a family thing and people often say to me you need to be seeing somebody and I say, "When? Between 2 and 4 in the morning?" because you're so spent and so, I had good friends and you know they would, we would sometimes just go out for half an hour and they would just support and love and you know. Or they'd come here in fact, on Friday night they would come here, bring supper and they'd come here and just say, "How can we help you? What can we, where?" And fortunately our GP is a very good friend of ours so she she was, and I think that that's what you've got to do - my other piece of advice is you your GP is your key to all your specialists.

99. **S:** They they they're the case manager

100. **A:** Absolutely and if you've got a good GP you are just made. Because she was amazing how she was the stopgap to all the specialists. If we didn't understand, uh uh, she'd phone so she was amazing, she was vital um to dealing with with our case.

101. **S:** Yeah, shew. Yeah it seems so, when you're reading it in the textbooks, it seems so straightforward -

102. **A:** Absolutely

103. **S:** -and yet when you get to the nitty gritties of the practicalities and the hours of exhaustion and the the ramifications in all areas of your life is…

104. **A:** And I think each child, each story is so different. So every child has got a different joint or a different need or a different um, and it was our new normal and we had to embrace "This is our new normal" and that's what we've got to, we've got to deal with the new normal. And so try and and have fun things we would do and still try and go to theatre. As hard as it was to go to theatre because it's, at times we couldn't get her to sit in the chair because it was too uncomfortable, and she was told she was a fire hazard or a this, or we couldn't get her there or we'd have to carry her down the stairs in front of the whole movie. And you know she was a teenager and that was. You know it's all those issues of, you know what, you'd have to be carried in front of everybody and it was so so self-aware and. So I think that was that was hard and I think for Rochelle I think she was robbed of those 4 years. And she had to grow up and suddenly she became this caregiver. And she was amazing, but I now realise the ramifications. And we're dealing with the ramifications now for her of dealing more with where is she…

105. **S:** Who is she and those kinds of things

106. **A:** Absolutely, yeah

107. **S:** Um, let me just have a look and see if there's anything else that I particularly wanted to ask you. Um…We've gone through all the…you've talked to me about your coping strategies, yeah the humour, the support networks and um…

108. **A:** And your GP, yeah your GP is important… your key

109. **S:** Your GP is you're your fundamental

110. **A:** And I think just trying to find out as much as you can about it but from a reliable source too. And that's that's the scary thing about it is you just, and what works for this kid isn't gonna work for this kid you know, that's just

111. **S:** And that unknowing, you're going to have to end up becoming comfortable with the the not knowing

112. **A:** Yes

113. **S:** Which must have been incredibly difficult.

114. **A:** And even now we don't know I mean it might well be that this turns into something that they've gonna have to manage for the rest of their lives.

[30 minutes]

And certainly their eyes, they see life very differently, you know, their spectacles have changed a lot

115. **S:** Oh yeah, yeah, that's where you get the disjunct between them and their peers

116. **A:** Correct

117. **S:** Because once you've been through something like this… yeah, you

118. **A:** Absolutely, in fact K****'s got a kid who's got leukaemia and she's the one that's connected with her because she knows, as much as they don't – it's not like mine - but she just knows this kid needs this kid needs somebody to get her through this illness because

119. **S:** I I I must say just just from talking, the two of them, a thread that did seem to come through was the need for peer support with other kids who have the same difficulties or similar difficulties. Um not necessarily where you have to go, but just social media where they can check in with each other and…

120. **A:** And we've tried, we've tried that but it just didn't work. And you know sometimes the, you've gotta you've gotta just have the right connection, you know what I'm saying? So sometimes maturity levels aren't there or the different stories or. It would have been wonderful had they… been able to connect with somebody who had the similar story.

121. **S:** But of course it's just a unique disease per child -

122. **A:** Correct

123. **S:** - that you can both have it and yet be different.

124. **A:** Completely different, yeah

125. **S:** One can be having fevers all the time and

126. **A:** Yes

127. **S:** Um. Anything else that you can think of that's important that you can think of that we haven't covered?

128. **A:** Um [sighs]

129. **S:** And you've given me the advice for parents

130. **A:** …Yeah if I think of anything else, Sharon, I'll let you know and um.

131. **S:** What was your personal coping strategy when you got down? What did you do?

132. **A:** There wasn't time to do anything, that's that was the thing, it was I was finished I I really was, you know I um… people said, "Oh you should give up work" and I think that, you know what, work became like a natural antidepressant it, you know it kept me going. It did, because you, otherwise you… you become so consumed by by all of this because. My work was wonderful they, when she was first diagnosed and she collapsed and couldn't move, they said "Take a month off, we'll pay, take a month off and get her sorted". Well it didn't take a month, but it was wonderful just that they, it was great that I could just be, you know, go off to a million appointments um … I think that, I think, I've got 2 or 3 very good friends who who would check in with me regularly um… [sigh] I think my faith, as much as I struggled with that, it was it was it was what got me through. And I think that when Ursula was in the clinic 2 years ago I really, I came home, and I just "This is ridiculous, I can't believe this", and I just, I really, every now and then the wheels would just come off and the wheels did come off with. And the I think that that was hard because um as much as you mourning and you're mourning it so deep inside, I didn't want my kids to see that. So you would try and show the hope and keep them going and keep positive and we're looking for answers and we keep laughing and we do fun things and we and you know keep motivating because you, it was like sometimes dragging and trying to find the energy to say, "Come on, we're gonna keep going, keep going" and yet inside I was crumbling and there were times I was "I can't actually". And there were times when I would cry with them and I would we would cry together and we'd mourn together and weep together um. But I don't think there was time, there what, I don't know

133. **S:** But those are coping strategies

134. **A:** Yeah I think those were, yeah

135. **S:** Those were those were, yeah. I mean to mourn together must be a very powerful experience to acknowledge "This is really happening".

136. **A:** "This is frustrating and it sucks and it's ok, it's ok" And it was good and I think that that's what I think, if anything, the kids have learnt that it's ok not to be ok. You know, I think the world is full of it's, it's always gotta be joyous and positive and I said to them, "You know what I think what we've learnt from this is to be real, you know rather, if we are real with one another, we can deal with this and it's ok it's ok to crash" Rochelle's wheels would come off and then she'd go off on her own and I said, "It's ok, let the wheels come off and let's cry together, let's get it out um and then we can we can face another day" So I think that was

137. **S:** I think that's, Wow, that's quite an incredible… not a not a strategy, a way of being to just acknowledge we are where we are.

138. **A:** Yeah, and this is the new normal

139. **S:** This is, yes

140. **A:** And it sucks and it's gross but this is it and this is what we've got to cope with, it's what we have

141. **S:** Instead of trying to hide it and cover up… Ok

142. **A:** If I think of anything else, Sharon, I mean yeah the

143. **S:** Send me a note, um you're welcome to e-mail me um but I I think that's enough for today. I'll I'll go through and I'll process it and then you'll probably hear from me.

[recording ends]

APPENDIX M: Rochelle Case Study

Transcript 1B[7]: Rochelle Interview 1B

1. **Interviewee (R):** Ok.

2. **S:** Just get that pointed the right way around. So Rochelle, so nice to chat to you again

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[7] (The recording device did not record the whole of interview 1A. The interview was reconducted and labelled Transcript 1B)

3. **R:** Oh no, it's also nice.

4. **S:** That's fine.

5. **R:** Ja, ja. There we go.

6. **S:** Ok. Super. So thank you again for re-doing this interview for me. So basically today, I don't know how much you can remember, but we're basically going to go through the story of your illness. And ja, I think a lot of it, not a lot of it, some of it was your experience with Ursula being ill first. So ja, why don't you just start taking me again through, right from the beginning, and I'm watching this like a hawk today. I'm going to make sure it does not stop recording. [laughing]

7. **R:** Ok, perfect. I'll try and remember most of what I said.

8. **S:** [laughing]

9. **R:** So, when I was nine it all started when my sister obviously started getting sick. No-one really knew what was happening. And I was about the beginning, no sorry, the end of my Grade 3 year. So I was still very young, didn't know much anyway. So I'm sure you know the whole story of Ursula's illness and everything.

10. **S:** Yes.

11. **R:** And so it all progressed until eventually about a year later we found out it was arthritis. And I think for those first two years I, I didn't understand fully what was going on; I was too young. And I mean, I still remember asking my mom if Ursula's going to die, you know. But ja, so I think it was just a lack of understanding then. But just, I think that almost made our relationship more real, you know. It wasn't, I wasn't, there wasn't any . . ., any sympathy, like you know. A hard kind of sympathy.

12. **S:** Yes.

13. **R:** It was just a real relationship that we're going through to get that, that, you know, ja.

14. **S:** It must have been --. When you say you asked your mom if Ursula was going to die, what, what were your feelings at that stage?

15. **R:** I remember having thought about it a lot as a nine-year-old. Just kept thinking about what it would be like to not have my sister there. And obviously at that stage, not having her there would mean, you know, not having a play buddy or something like that, you know. I think at that stage also I remember not feeling too overly worried about it, but I was scared, you know. Like I wasn't completely worried that I wasn't ever going to see her again, I was just: is this going to happen or not?

16. **S:** Yes.

17. **R:** It was more like yes or no. There were not a lot of emotions because I was just confused. But I remember when I did ask her, I was quite scared of her answer. And, and the answer that she gave me obviously I mean you know, was a massive massive relief. But I think for me it was just more at that stage just happiness, like: ah, I still have a play buddy. Which in some ways I didn't, you know --.

18. **S:** Of course.

19. **R:** ... So, but ja, ja. It's just -- And then -- So I think that was one of the scariest parts for me, is that never knowing what was really going on. Was she terminally ill? Was it a, was she going to be paralysed from the neck down? You know, all that kind of stuff.

20. **S:** Yes.

21. **R:** Things you see on TV and what people were saying. Obviously as a young, young girl I didn't have much discernment. But ja, eventually I got into the swing of things and I saw how everything went and what to do and went into a routine. And about two years in I then started feeling pain in especially my legs. So, for example, walking in a shopping centre, they would get really sore after a while. And I would tell my mom and I think I personally knew that I had it as well. But I don't think my mom thought so.

22. **S:** Ja.

23. **R:** Ja, I remember her just leaving it for a while, just not thinking that it would be that relevant to follow it up.

24. **S:** Do you th --.

25. **R:** But eventually --.

26. **S:** Do you think she left it because she really didn't, just didn't want to go there, or she really didn't think you had it?

27. **R:** I think -- I think it was more she didn't want to go there. I think in a way because I remember a while before we actually went, she was speaking about how I could have the gene. And so I was like ok, cool, that's ok. And I remember her saying she didn't actually want to have me tested. She didn't -- She wasn't going to get me tested because there's no point. So it was like, I think it was more a matter, if you look at that now, a matter of no, she just didn't want to. But I think after a while, I just said: well Mom, if this is what it's looking like and my joints sometimes swell up a bit, so it was quite clear that we should probably go and have it checked out.

28. **S:** Which joints were swelling up, Rochelle?

29. **R:** Pardon, sorry?

30. **S:** Which, sorry, which joints were swelling up?

31. **R:** My knees. It was mostly my knees, ja. They've always been my biggest problem.

32. **S:** Ok.

33. **R:** So, ja. So I remember when we did go it was my mom, my dad --. My mom, my dad and myself obviously, and, and I think they reacted faster than I did to it. I was completely fine with it for quite a while.

34. **S:** How did, how do you mean they reacted fast to it?

35. **R:** Oh, ja, sorry. I think my mom, for example, she got out and she burst into tears.

36. **S:** Ok.

37. **R:** And the realisation hit them faster than it did me. I was completely calm about it. I was like so not perturbed, I was like: ok, whatever.

38. **S:** And was this in the doctor's rooms, or --.

39. **R:** Ja, just as we left actually, so.

40. **S:** Ok.

41. **R:** So it was literally at that time that I was, I was so not worried about it, you know. And I think it hit them more because of seeing how Ursula, Ursula suffered, I think they were more scared. And I think it took me about two months for me to finally be like: wow. What is going on? What is going to happen? And then I did get a bit scared and a bit down about it. I think watching Ursula suffer like she did, I think I was a bit scared of, you know, not being able to walk or being in that much pain. Like watching her scream and stuff like that. I think that was quite scary for me, you know. What if that happens to me? But I think it was harder at that time for my parents, for them to imagine that, than for me, because I think I was pretty fine with it. So --.

42. **S:** What do you think --. Sorry. What did you --. What do you think made you "fine" with it, having seen the extreme that Ursula went through?

43. **R:** Well, I think firstly they could diagnose me much faster than they diagnosed my sister.

44. **S:** Ja.

45. **R:** So in the time that it took Ursula to get diagnosed she was already not walking.

46. **S:** Yes.

47. **R:** But with me it was immediate. So I was put on medication immediately, which meant that it probably couldn't get worse.

48. **S:** Ok.

49. **R:** And, and mine was a lot less severe. And I think, I don't know. I, I just never was truly truly afraid of it. I, I just kind of guessed that if Ursula had gone through it, then I would be fine. And I have no idea why, but I just, I was so at peace with ...

50. **S:** Do you think part of it was because you had been suspecting?

51. **R:** I think so, because I think when my mom went it was quite a shock to her. Even though she probably knew, it was still that she has to face it now. But me, it was one of those things that I genuinely knew. I just knew. And so when they did tell me, I was, it was fine. I was, had made peace with it already I guess. Yes.

52. **S:** And then from there, how, how did it all progress?

53. **R:** So obviously mine didn't move as fast or nearly as badly as Ursula's did, so it would be aches and pains in different places occasionally. Also sometimes on the netball court or playing hockey, stuff like that, where I'd just have to say no, I can't. And it took a while I think for the people around me to understand what was going on. Because obviously seeing my sister she was, they were just like, if Rochelle's not in a wheelchair then she should be fine.

[10 minutes]

You know?

54. **S:** Ja. And when you say you were on the hockey field or doing netball and then you said to yourself: I can't. What does that mean? What, what, what, what happened?

55. **R:** So I think the problem with me a bit was that I kept pushing myself.

56. **S:** Ok.

57. **R:** So when I would think that the pain was too bad and I want to go off, sometimes I just keep myself going. So that by the end of the game it would be, the pain would be so bad that I could barely walk. You know, it would take a really long time for me just to get to the car because of how I pushed myself.

58. **S:** And then you'd stiffened up and had the pain and --.

59. **R:** Hmm.

60. **S:** Ok.

61. **R:** And then in the morning it would be really bad, and stuff like that.

62. **S:** Yes. Ja.

63. **R:** So I think a big part was for me learning where to know my body, where to stop and where not to stop. But for a really long time I just kept pushing myself. I was like, oh, it's nothing, I've got to keep going.

64. **S:** Was part of that because of Ursula?

65. **R:** I think so. I think I also, I didn't want to be one of --. I didn't want to be a burden. I didn't want to be a burden in any way. I didn't want to seek attention. So it was easier just to keep going, pretending that you're fine, get off and continue with life. And I also, you know, she was the one that needed the attention at that moment. I didn't want to be taking that away. And I think in a lot of ways I compared myself to her, saying that I'm not nearly as bad, so I should be fine to just go on. I must just get over it.

66. **S:** So, I'm not in a wheelchair and nobody needs to help me out of bed, so therefore I should just push through. That kind of mentality?

67. **R:** Completely. Or stuff like, you're not nearly as bad, you should --. You're fine to continue, you know. So I think the first time that I ever told myself to stop was when I literally collapsed on the hockey field, because I was --. I don't know if you've ever had it, but my legs just buckled in.

68. **S:** Ja. Ja.

69. **R:** And I just --. Ja, I was in so much pain and I was sitting on the side, and I remember just crying and crying and crying. Not all because of the pain; I think it was more just watching. Because it was the first time that I had actually stopped. And I think that was for the first time that I could actually feel the, what my sister went through sometimes to watch her friends do things that she couldn't. And, so that --.

70. **S:** Was --.

71. **R:** Yes, sorry?

72. **S:** I was just going to ask: so you cried then when you collapsed. Was that sort of when it really hit you what was wrong? Or --.

73. **R:** I think, ja. I think for, as I was saying, for a while I'd just been so fine with it, you know.

74. **S:** Yes.

75. **R:** And just ... But when something like that happens, as you say, it does hit you. I realised that wow, what I used to do every single day of my life, I now can't do. And what my friends are doing right in front of me, I can't do. And I think that was the first example of me not being able to do everything. And I think that was hard for me to see wow, this, this is real, you know.

76. **S:** Ah.

77. **R:** This is a thing. So, whereas in the first --. I wouldn't say I'd been in denial, I just don't think I'd experienced everything yet to be able to see that it was quite hard, until that moment. Ja.

78. **S:** Ja. And, and I mean, knowing what you were doing for Ursula, I mean unfortunately I keep remembering the previous interview. But I, I think you were sick and yet you were still having to help Ursula at that time, weren't you?

79. **R:** Ja, completely. So whether I was sick or not, obviously it wasn't as bad, my life had to go on. Ursula was the one in a wheelchair and she couldn't dress herself, couldn't take herself to the bathroom, stuff like that. So, no matter what amount of pain I was in, I would always have to help Ursula first. I think that was a, came a lot into losing a bit of my self-worth, because I think for a really long time what I wanted was attention from people that I was so lacking, you know. And although it was completely right and I wouldn't take it away in a minute, I still needed that attention from the people that gave it to her. Such as people from our family, close friends and stuff. And when -- I -- It's -- I was speaking to the psychologist the other day and she said it's almost a, it's, it's subconscious, I can't do anything about it. But what happens is when your, for example, you have a sister that's sick, and you see that you almost want an illness so that you can get similar attention. And it wasn't that I completely wanted it, but the fact is that when I did get an illness that was the same as hers, just not as bad, I didn't get the attention anyway.

80. **S:** Yes.

81. **R:** So I think I felt pretty --. I think after a while, now that I'm, I'm, when she got better, I almost lost a lot of self-worth because I felt that I wasn't worth attention then in any case.

82. **S:** So that's been quite a theme in your life, because you were in Grade 3 when Ursula got sick, so what, that, that's nine years old, and then you got sick at the age of?

83. **R:** Eleven.

84. **S:** Eleven. So that was two years of the focus being on Ursula already, when you needed attention, being nine, and then when you did get sick, the attention you're saying was still on Ursula.

85. **R:** Ja. So I didn't get what I --. What I wanted at that stage was just somebody to ask me how I was doing. For example like I think big things were, for me were when people would come up to me and say: how's Ursula? You know. And: you have to be strong for Ursula now and you've got to take care of her and stuff. And I would just be wanting to stand there and say: but I'm also sick. So I think eventually I had to kind of get over that and just see that, that was ok. And obviously, I mean, I would, I would do it all over again for my sister. I would honestly, I would do everything --.

86. **S:** Of course.

87. **R:** All over again. So ja, even though I was sick, I would try centre everything around Ursula because I knew that what she was going through was hell. So, ja.

88. **S:** But how, but how do you get over that, Rochelle I mean, you said to yourself you need to just get over it that people aren't asking about you, they're asking about Ursula.

89. **R:** I think for, for actually all the years that she was sick, I just suppressed it, you know. Doesn't matter, I'm not important in this situation, just, you know, let it go. So I didn't speak about it, I just put on a fake smile.

90. **S:** You --.

91. **R:** You know.

92. **S:** You didn't speak about your own pain and your own illness and your fatigue.

93. **R:** Ja, I didn't speak about that. I didn't speak about the fact that I felt neglected, you know. I just let it pass. So I --.

94. **S:** Not even to your parents?

95. **R:** Pardon?

96. **S:** Not even to your parents?

97. **R:** No. I think the person that I did once in a while speak to about it was my dad, every now and then. Because I think he also felt very, you know, neglected. I mean I think he could cope with it much better, but I think he also just, he could relate a bit you know. And no-one would really ask, so I just let it go. But unfortunately what happened when she got better, I had such a low self-worth, such a low self-esteem; I felt pretty much worthless. I'm still getting through that now, you know. It's not -- Sort of every day, struggle to say that I'm, that I am worth, worthy. So I think at, what my coping mechanisms, coping mechanisms then was just suppress it, don't talk about it, get through it. But eventually when ... it just got too much, it all built up. I was like, ja.

98. **S:** And from, from the last interview I can remember you telling me some painful incidents about your extended family.

99. **R:** Ja. For example, like I would remember watching, watching my aunt coming and completely walk past me, usually not talking to me sometimes. And just focusing on my sister. Or when my aunt from New Zealand came down, you know, there was a massive incident with her, between her and Ursula, that completely destroyed pretty much our relationship with her, our family's relationship with her. But you know, I never ever got to be a part of that kind of relationship in the first place, because it was all about Ursula. So in terms of having somebody that I respect so much just walk past you and not say hi or not ask me how I am, was quite hard.

[20 minutes]

100. **S:** And she knew you were ill at that stage? Or --.

101. **R:** Yes, yes. So she knew. She very rarely asked me how I was and if so she'd just give me a pat on the back and say: keep going. Whereas my sister, she'd be there hours and hours you know, and taking her to the bathroom or sitting with her and talking to her. So --.

102. **S:** And how did that feel? Oh, sorry! [laughing]

103. **R:** [laughing] No, I felt incredibly alone and incredibly neglected. Very hurt, you know. Very insignificant to her. And I, I was and I think every now and then I still am quite angry. I don't think her necessarily, just at her ignorance, if I can say that ... Just the way that she can brush past it. That I was that unimportant. And although she doesn't mean it, and I know she doesn't, and I know she didn't mean to push me aside, unfortunately it still happened. So I think where I can understand why it happened, I can't yet fully be at peace with it, because I'm still very very hurt I guess.

104. **S:** Ja, ja. And it wasn't just her though, was it?

105. **R:** No, my cousins as well. I remember the first time my sister went into hospital, there was a big thing and they were there and I remember my one cousin cried. Always, you know, stuff like that, they were so caring about her. And the friendship between us started to diminish, you know. I was seen by my cousins even as "just the sister", you know. Even in my family I was seen as "just the sister". So that was hard because I used, I was very close to them. Fortunately our relationship is growing again.

106. **S:** Yay! Ja.

107. **R:** But also people like teachers at school. I remember there was a teacher that, well with Ursula basically all the teachers loved my sister. And it was that whole thing of, they would do anything for her, you know. [hammering sound in the background] ... helping her. Noise, sorry. . . . things and helping her. And I would just --. So I was, I wouldn't be noticed. For example the principal would give her, gave her a very expensive book voucher. And I got a small, a Chomp. [laughing] I remember. And I just remember thinking, you know, is this all I'm worth? Well not, not a Chomp. [laughing] That's not what I'm saying.

108. **S:** Yes.

109. **R:** But just like in their eyes. I remember, you know, they would be so caring about her and some of them just asked me how she was doing. So in terms of having school teachers where I would just crave attention from one of these teachers. There was this one that I just wanted to be recognised by.

110. **S:** For yourself. Just to --.

111. **R:** For myself. Just for her to notice me, or to compliment me, or to ask me how I was doing. I remember just wanting that attention from her and unfortunately, you know, it was always about Ursula with her. So I think that was, that was hard. Ja.

112. **S:** That, that must have been very hard. Very isolating.

113. **R:** I think so. And unfortunately none of my friends really understood.

114. **S:** Yes. Ja.

115. **R:** Or they didn't really care about my side of it as well. So they were always there when Ursula was well and then when she got sick they could see the transition, so immediately they were worried about her. So when I, when I could finally --. I met a friend during the middle of Ursula's illness, and she finally saw me for me, not for someone who was there and then Ursula got sick, you know. It was just me. She didn't have to be involved in trying, knowing what Ursula was like and then being there for her.

116. **S:** Yes.

117. **R:** It was just for me, so she's my best friend since then because it was so, it was for me, you know. So I think, I think that was hard in terms of friend-wise, family wise, teacher wise. I felt very alone. So I think also I just put up a bit of a, a wall, you know. I just didn't want to then tell people about what I was feeling, because they didn't understand.

118. **S:** Ja.

119. **R:** And, and I'm sure you know that . . . it's frustrating when people say ignorant things, kind of.

120. **S:** Ja. Can you give me an example of things people said to you?

121. **R:** No, in terms of stuff like: Ursula's your responsibility now, you know, you really have to take care of her. And that to be told to a ten-year-old girl is quite, quite hard, because then I felt like I should be doing everything. And then also a lot of times I was told: your pain isn't nearly as bad as Ursula's, suck it up. So I then, there again I would just prefer not to talk about my pain, because --.

122. **S:** How did that make you feel when they said things like that?

123. **R:** Very frustrated and very angry. But I think out of their ignorance they were just trying to help and be sympathetic towards Ursula, but empathy was lacking. But I felt invisible, you know. So ja, Ursula's pain was bad, but what about mine? Does that mean that because mine isn't as bad it doesn't exist? So, ja, I just started questioning whether what I, whether I could talk about it, whether it was right. Whether I was a bad person for feeling pain and then talking about it. So that, that would get really hard, you know. Or people coming to me and saying, I mean: it's so sweet that you're a helper; you're doing such a good job to be her little assistant. And I'm like: no! No, I'm not a helper! So I think they just saw me as being, as I say, her helper. Meanwhile I was just, I was her sister, you know. And . . . through it together and as hard as it was for her, it was hard enough for me, but together we're doing it. So I think I was also tired of being patronised, you know. Almost like looked down upon. Also being inferior because, I don't know, because I wasn't going through it I probably wouldn't understand much. So I would just . . . in the background.

124. **S:** In, in what way would you not understand things? Was it because of --.

125. **R:** Sorry.

126. **S:** Was it -- Ja. Why did, why did -- Why were they patronising you or --.

127. **R:** So I think they thought that I was too little to understand what my sister was going through.

128. **S:** Ok, ok.

129. **R:** I think they thought that I was too simple still, too little to completely get what was going on. I was just trying to be kind and help. But I think in terms, they didn't understand. I mean when I say "they" I mean teachers and friends and family. So, you know, like talk, talking to me in little sentences and that's it. There would be no real conversation because you know, they wouldn't ever engage with me in conversation about what was happening. So I think that was a bit hard.

130. **S:** And then of course nobody engaged with you when you were sick.

131. **R:** No.

132. **S:** Or when you became sick.

133. **R:** No, no. If they did, it was just about how, fortunately, I wasn't as bad as my sister. That -- Which, ja, I was grateful for, but I don't want to be reminded of, of it all the time, because it is still hard for me, you know, to be sick. So, so ja, I think in terms of them not understanding I can understand from their perspective, I really do, because I think there are many times where I've been like that to Ursula where I, I didn't understand and I probably also said some stupid things, you know. And I understand what it's like to just, to watch. But I think it taught me a lot of empathy, you know, trying to have empathy towards another person. Because it's so different from judging from the outside and having, you know, trying to pretend to know. Instead of just saying ja, that must be hard.

134. **S:** Ja. So people say the wrong things.

135. **R:** Completely. I think not out of malice or to be cruel, but I think more out of ignorance, you know. And trying too hard. You know I just wish they wouldn't. You know, just, just be and that's ok, you know.

136. **S:** And, and you, you , you're telling --. What I'm hearing is that because Ursula's illness was severe, people weren't acknowledging your illness.

[30 minutes]

Was this the case with the doctors as well? Because you have the same doctor.

137. **R:** Yeah, we have the same doctor, ja. I think -- Ja, well, I think Ursula has spent a whole, much more time with her obviously. But I think in terms of --. It's going to sound odd, but medication wise and stuff, like for my sister it would be like let's try this, let's try this. With me sometimes they would say: it didn't work on your sister, just let it go, see how it goes. Or I remember one doctor once saying: well you've seen how your sister copes, just try take some coping mechanisms from her and continue. So I think in terms of them not seeing that, us as different cases, you know, just treat me with ... like I was. And also, you know, doctors not talking to you, talking to parents. The -- Ja, that was a bit frustrating, I think. So they wouldn't quite talk to me about everything – what was going on with me – but they'd always talk to my parents or my sister about what was going on with me, you know.

138. **S:** Even to Ursula rather than you?

139. **R:** Pardon?

140. **S:** So you said they would even speak to Ursula rather than you?

141. **R:** Ja, ja completely. And then they would often compare it. They would say, so like how, what did you feel in terms of this? And they would be like, ah, if we look at hers compared to yours, yours is so much worse. And they would talk to her and say: see, now she's having the same thing that you're having, explaining it to her again. And I'll be sitting there like I, I, I don't know yet. [laughing]

142. **S:** So how did that feel to be in the room and nobody was talking to you? In fact, they were talking to your sister about you.

143. **R:** I felt less human than she did. I felt pretty much invisible. I think what they were trying to do is make my sister feel better, or try make me feel better in a sense. But I think, ja, I was, I felt pretty much invisible and inferior, like I was almost stupid, that they couldn't talk to me, you know.

144. **S:** Did you get that feeling that you were stupid?

145. **R:** I, I think I did now and then, because I think they would regard Ursula as the one who knew everything about the illness and they could talk to her, and me they were just like: ok, shame, keep going, you'll be fine, and then just let Mom explain to you or whatever. So I think in terms of just wanting them to know that I do have a brain, you know. [laughing] And that ja, I think I was as much affected by it as Ursula was, you know. So by talking to me about it as though it was new, as though it was a separate case to my sister's, would have been helpful, would have been kinder, in a sense.

146. S: Were all of your sessions with the doctors with Ursula as well?

147. R: My first one wasn't, it was fine. But the rest we pretty much would just schedule them together.

148. S: Yes.

149. R: So, if she goes, I go. So pretty much every six months that's what happened.

150. S: And then they didn't like see you and then see her, so you would both go in together?

151. R: Yes. So we'd be in the same room together, she goes on, they get it over and done with. I remember though, however, there must have been about two sessions where I was by myself. And it was a forty-five-minute session and she examined me for 15 minutes and for 30 minutes she spoke about my sister, or my sister's illness. And I think I was quite annoyed, because I was like, just focus on me for a bit, you know. This is what I'm feeling, you know. I don't expect her to examine me for the full 45 minutes, but you know --.

152. S: Why didn't you expect her to examine you for 45 minutes?

153. R: I don't know, she never has. She usually just takes a small time for me and then even if Ursula's not there she speaks a whole lot about Ursula So I think, even in that sense, that was quite tough. Because I would, I would sit there and be like: but I'm the patient now... .

154. S: And were you --. You were obviously not able to verbalise that to her?

155. R: No, no. And I wouldn't, because you know, sometimes my mom would bring up issues that she'd want to speak, issues about Ursula that she'd wan. to speak about, so obviously I wouldn't stop that. But I think it was just frustrating. And I would just sit there and listen; there's no point me, I didn't feel there was a point in me saying anything, you know. And I was so used to it by that stage – we just sit there, we talk about Ursula, we feel sorry for her, we go home. So ja, she just, I remember she examined me, she was like: just keep doing what you're doing. And then she immediately turned to speaking about changing Ursula's medications when Ursula wasn't even there, you know, that she could be examined and stuff like that. So --.

156. S: And how much dialogue did you have with the doctor – did she talk to you directly when Ursula wasn't there?

157. R: Ja, she spoke to me more, more so. Fortunately with this one she, she's quite nice, so, so with our main rheumatologist she's, she's, she's actually quite good about trying to talk to me. I think it's more the GPs and the other doctors that speak more to my parents and

Ursula. So I think she was quite fine, good with it. Every now and then obviously still speaking to my mom as though I wasn't there, which I just feel is super frustrating.

158. **S:** What kind of things did she talk to your mom about?

159. **R:** She'd speak to my mom about, for example, asking my mom what symptoms I was having, r asking my mom how my pain is. [laughing] I mean, I was right there, so silly stuff like that. And then, you know, talking to my mom about changing medication, if I would be fine with that. And stuff like that. So ... --.

160. **S:** And she never asked you if you would be fine with it?

161. **R:** Yes, asking if I myself would be fine with it ...

162. **S:** But she didn't --. But she didn't ask you directly, she only asked your mom?

163. **R:** Ja, ja.

164. **S:** Ok. And how old were you at that stage?

165. **R:** I was probably 12. , I'm not sure.

166. **S:** So more than capable to answer those questions.

167. **R:** Ja. [laughing] I think so. So ja, that would be frustrating. But it's just one of those things and you just have to expect it, and you go there and deal with it and go home. Ja.

168. **S:** And has your relationship with your doctors changed as you've grown older?

169. **R:** I think completely. I think as I've gotten to know them more, through Ursula's illness and mine, there's more of a relationship, if that makes sense? So now I can actually ask her to talk to me.

170. **S:** Oh, do you?

171. **R:** Ja, I, I, so I remember she was talking to my mom and I just nicely asked a question about it, you know. So like: if that would be the case with me, then what would happen? So just direct, just keep directing the . . . back to me.

172. **S:** So you still had to --. You --.

173. **R:** [loud noise in the background] Oh goodness, sorry!

174. **S:** What is that?

175. **R:** Ok, so I, I don't know if you could hear me over that?

176. **S:** I couldn't. No, no. But it sounds to me like you had to take the initiative to make the doctors talk to you?

177. **R:** Ja, completely. Just trying to direct the questions to me to be able to get the information coming to me. But eventually when I, now I'm starting to be fine with it. And she's a lovely doctor, so we can joke around a bit and have laughs and I can like sarcastically say: no it's fine, I, I'm going through it not my mom. So fortunately we are that, we are comfortable enough you know ... [loud noise in the background] Sorry.

178. **S:** [laughing] It's ok. It sounds like you have a Tyrannosaurus rex in the background.

179. **R:** [laughing] No, me too, I'm starting to wonder. So --.
[sound of door opening and voice in the background: "Sorry, can you hear anything?"]
No, not at all. Sorry.

180. **S:** I think our interviews are jinxed.
[both laughing]

181. **R:** There's something wrong! Ja, so I think eventually you do start developing a relationship with your doctor and you can laugh about some things. So ja, they --. It's much better now.

182. **S:** And tell me, what kind of medications have you been put on? And how did that all work?

183. **R:** So, I started off on methotrexate.

[40 minutes]

And I would take it with tablets. But I would get so sick on them with nausea, so we swopped to injections.

184. **S:** And --.

185. **R:** And then anti-inflammatories, like cortisone, Arcoxia, Arava, all, all the kinds. And Plasmoquine changed with them, just depending on how it's going. Eventually they took me off the methotrexate, but ja, still on just normal anti-inflammatories. Ja.

186. **S:** And the methotrexate injections – did you have to inject yourself?

187. **R:** Yes, I injected myself. I would, I prefer to inject myself.

188. **S:** Why was that?

189. **R:** I don't know. I guess I saw my sister doing it so I felt I should be brave as well and just show my parents that I was as brave. [laughing] But no, no, I think it was more just because I wanted to be in control of it and I think --. I don't know, I think it's easier to inflict pain upon yourself than have someone else do it. [laughing] If that makes sense? So I just ja, I, can do it faster in my own time, the way I want to do it.

190. **S:** Because this is supposed to be very sore, those injections.

191. **R:** I think for me they were fine, I honestly I didn't mind them. But the nausea was still very bad. And I think, I think more now, oddly enough, is the psychological effect, is whenever I smell anything like it, or Dettol, because we always used to use Dettol just before we use it, before we inject ourselves. Whenever I smell something like that I get this rush of nausea.

192. **S:** Oh ok.

193. **R:** It's a whole, ja, it's odd. But it's more psychologically. I don't think I enjoyed doing it.

194. **S:** No, no, no. It, it must have --. I mean, what were the kinds of thoughts that would go through your head before you injected yourself?

195. **R:** If I remember correctly --. Because I remember when I was on holiday once, having to take all these injections with us, and just sitting there thinking: I can't wait until it's over, you know. And I would, I would inject my stomach, so I can remember just clenching onto my stomach and just doing it quickly, or getting it over and done with. Although it wasn't that sore, I think I was, it was just the anticipation. I was, I was scared and I was always nervous before each one. Oddly enough, no matter how many times I did it. So ja, I think I'm still even to this day, I wouldn't ever want to go back to that.

196. **S:** So yours, your illness at this stage is stable at the moment, or have you had some flare-ups and --.

197. **R:** Ja, recently I've had a, a flare, but you know my flairs come every now and then as you know. But pretty much my illness has been stable throughout the time I've had it. But recently for example my ribs have been getting really really sore, this last year. And that makes it really sore to breathe. So ja, that's why I went in for a cortisone drip, actually on Wednesday. So ja, it just depends on how I'm doing.

198. **S:** So, and, and how long does the cortisone drip take to work?

199. **R:** They say roughly about a week.

200. **S:** Ok. So you won't be feeling the benefit of that yet.

201. **R:** No, no, not just yet.

202. **S:** And the fatigue, how --. Do you also experience the fatigue?

203. **R:** So the fatigue for me is probably the worst, for me. Only lately I've had a really low thyroid, so that could be contributing, but for the past, I think, four years, my fatigue has been incredibly incredibly bad. And I think just in terms of making myself get up, or study, or just make myself sit and do work when I'm so fatigued, is quite hard. For some reason the fatigue has hit me very very badly. Unfortunately it is part of the thing of having an HLA B27 gene.

204. **S:** Yes.

205. **R:** The fatigue, it was going to come. But it's a big struggle for me, you know. And whereas pain is hard, I think fatigue is also incredibly hard. Just bringing your focus properly, or having the energy just to get through the day and to keep going. And I've had a --. I burn myself out a, quite often. I had really bad burnout, stage two, two years ago, where I was completely burnt out, you know. I could barely get up in the morning to go to school.

206. **S:** *Sjo.*

207. **R:** There was just nothing in me. So fatigue for me is really bad. And it's not necessarily sometimes if I just go and have a good night's sleep then I get better, you know. It just, it's a constant fatigue, and pain is tiring as well.

208. **S:** Rochelle tell me, can you tell me more about how the, what the fatigue is actually like, because you, if you say "fatigue" to people, they kind of go: ja, oh ja, ja, no I also get tired. But it's not the same, is it?

209. **R:** No, no. It's like my entire body has, is tired. My -- It almost feels like my limbs are too heavy sometimes, you know. My body gets tired. And pain – I get tired from the pain. So it's not just where I had a late night, so when I go and I have an hour nap, I'll wake up and I'll feel better. It's a constant tiredness of I'm lacking energy. It's not I need sleep, it's not I'm lacking sleep, but it's I'm lacking energy. So I feel dead weight all the time. And I'm just dragging myself through the days, you know. It's not anymore loving what I'm doing, it's just getting through, if that makes sense.

210. **S:** Ja. Ja.

211. **R:** Trying to get through to make it to the end of the day. And for example, stuff like, it's not always physical exertion that makes me tired; it can just be a day at school and I come home and I just need time off. Because I -- It takes a lot then for me to bring my focus back and to, to get motivated to study again. So ja, I think fatigue is not only when somebody would maybe come, as you say, they would come and say: no, I've also had ... tired from studying. No, this is constant. And I think after four years of having fatigue like this, I'm tired of this fatigue.

212. **S:** [laughing] Tired of being tired.

213. **R:** Yes, I'm tired of it.

214. **S:** And I mean, that, that level of fatigue has to impact on the rest of your life, so where, how, how does it affect your sort of, your life in other areas?

215. **R:** Well, obviously I am just constantly tired, so as I was saying, I, I don't have the energy just to go out and have a blast and just enjoy. Like every now and then I will, you know, but I just at the moment, or when I am tired, I just survive. So it's a matter of surviving a night and not necessarily enjoying it. And then I think also in terms of not being able to do things, sometimes I just have to say: no, I'm not coming to this today because --. And I know it sounds petty, but it comes with the disease and you have to pace yourself, you know. And so in terms of school work sometimes it's just having to come home, rest for 30 minutes, do some school work, and then rest again, just to make sure I'm pacing myself. Otherwise I, I, I honestly can't, you know --.

216. S: Yes.

217. R: Continue.

218. S: Ja.

219. R: Ja, I just get ... So, it's just limiting sometimes what I'm doing.

220. S: And, and how does that impact on friendships?

221. R: Well, not great at the moment, because I battle, I have always battled to make friends. But in terms of this, I never actually want to go out with friends or want to do things, because I just need time, you know. Just need space. I, I can't have them over a lot.

222. S: Ja.

223. R: Because I don't think they understand all the time.

224. S: Yes.

225. R: For example, if they just want to go and have a *jol* and they just want to talk a lot and bug me and everything, and I'm just drained. And I'm sitting there and I'm quiet and they always think something's wrong. It's not that something's wrong, I just have limited energy. Ja.

226. S: And, and, and when you explain that to them?

227. R: Well I, as you say, they probably say: I know, I'm also tired ... So I think they won't understand. And I think as for example with me, I won't understand all the things that Ursula has been through. [noise in the background] Sorry.

228. S: No, that's fine.

229. R: I think, ja, just having to accept that they won't understand and doing what I have to do. Ja.

230. S: And do you think it impacts on the quality of friendship that you have with them?

[50 minutes]

231. R: Completely. I think every now and then they get frustrated because I'm just not there, you know. I'm just sometimes surviving with them and I'm just there, and I think they want to go do stuff and have fun, you know. And sometimes my fun will just be just sitting on a couch and just having to sit and chat or sit and watch a movie or something like that. Not going on too many hectic adventures. [laughing] So, ja. It's just, I think that they, they find it frustrating. I think I find it frustrating that they don't always understand, or that they try to understand but they just don't.

232. S: And, and what do you think prevents them from understanding?

233. R: I think a thing with this kind of disease is that we will never fully understand until we've been there. Sounds clichéd, but ja. I think also with me is that you can't physically see it.

You can't see that I'm in a wheelchair and you can't see that I'm in pain. You can't see that today was, today's pain is worse than the other day. So whereas with my sister it was easier to see, wow, she's in pain, she needs help. With me it's, it's not visible so then therefore I think sometimes they do think that it's not visible so it's not too bad. So -- And because I don't speak to them about it I think every now and then it's just, ok cool, and then move on with it. So ja.

234. **S:** Ja. Ja. And with your teachers?

235. **R:** My teachers have gotten a lot better. Thankfully they're very supporting and now in high school they, they do understand. Not all of them know about it, so when I do say that I'm, I'm just in a bit of pain and stuff, they're just like: from what? So I have to say I have the same thing as my sister and they seem quite surprised you know. I don't they're quite used to me being in pain or being tired. I remember on Thursday I'd just come back from the cortisone and I was in a lot of pain, and I actually had never cried at school, never. And I just burst into tears at school. And one of my teachers even said: wow, this is, I'm not used to this, you know. So I think they're just not used to seeing it from me, you know. They're very supportive when they do see it and they do . . . realise, but unless I show them or tell them, they won't know.

236. **S:** And do you, do you not want to tell them?

237. **R:** At the moment I don't think it's, it's necessary. I think it just depends. I don't, I won't go up and volunteer the information. I don't want to seem like I'm seeking attention or anything like that. But ja, I think it is a mixture. I'm not a big fan of talking, of telling people that I have it; I don't want to be seen with my disease. But it's such a mix because I don't want to be defined by my disease, but I also want them to know. So --.

238. **S:** So you don't want to be defined by it, but you do want it acknowledged.

239. **R:** Yes, exactly ja. Complex me, silly girl. But ja, I think the majority of them do know and they have been told. Obviously my mom has told them all, so sometimes every now and then they just need a little bit of a reminder. So they do know, I just, they, they don't remember I guess.

240. **S:** Ja. And when you say you don't want to be defined by your disease, could you let, tell me a little bit more about that?

241. **R:** So I think for four years, you know, when Ursula was in the wheelchair, we kind of became known as: so Ursula was, you know, the girl in the wheelchair, I was the sister of the girl in the wheelchair, my mom was Mom, and we all had our little roles in this little story. But people didn't necessarily see us sometimes for who we were, you know. It would be:

she is the girl in the wheelchair. If you want to introduce us, you know, it would be: this is Rochelle, she is the sister of the girl in the wheelchair and who helps her up, just like that. But was that really me, you know? Or is that really me? And I think a lot of the time now what I'm struggling with is my identity. You know, who am I? I was so used to being the sister of a girl in a wheelchair. You know that was what I would do: I would come home, I would get her dressed, I would help put her into bed, I would bath her, stuff like that. And that's what my routine was. And when I was, when she got better, that wasn't there anymore. So who am I, you know? What do I enjoy doing in my free time? I, I don't even know that anymore. I don't know what I enjoy doing anymore. What, what, what it's like for me to do something for me. So I'm still trying to find that part of me. And I think that all came from being defined by this illness, you know. This is what she has, so that's who she is. And having to say that no, no that's not. It's not just that.

242. **S:** Who are you?

243. **R:** I don't know yet. [laughing]

244. **S:** But what bits of you do you know?

245. **R:** I know that I love helping. Like I would, I would do that, I would love to do that. You know, I love drama, I love doing drama. I love doing netball. But I don't know what I want to do after school, where I want to go. I struggle now, even now, to make friends, because I don't know what I enjoy doing, you know. Who, who do I want to be acquainted with and stuff like that. So I think I'm still finding out.

246. **S:** Ja.

247. **R:** And it sounds a bit clichéd and everything, but I think I really am, because for a long time I was just there for my sister.

248. **S:** From nine.

249. **R:** And now that I'm here for me ...

250. **S:** Ja, for -- You were there for your sister from nine years.

251. **R:** Ja. And I'm four, I'm 15 now, so.

252. **S:** Ja, it's a long time of your life.

253. **R:** Ja, ja.

254. **S:** It really is. Ja, *sjo*. So you, you're still finding out which kinds of friends you like and who you want to be friends with. And at the same time the illness creates the fatigue, so you can't do things that they want to do.

255. **R:** I'm very limited, I'm limited in what I can do. So although I want, if I find what I want to do, I, I have to be careful as to what I can do, you know. Although I love my netball, I can't always play it, you know. Though I love my drama, rehearsals are like every day for five hours. Can, will my fatigue handle that? So it's, it's stuff like that that I, although I want to find who I am, I'm still limited. But as I say, I don't want my, my limitations to define me. So, so although I can't do it, I can be there and I can try and you know, I can try anything. So ja.

256. **S:** And you, you mentioned something earlier about managing your illness. So is -- How do you balance that with trying new things?

257. **R:** I think it comes a lot with knowing my own body, you know. I think a very important thing for all kids who have this illness is just knowing when to stop. What can you do. You know, I was a pleaser and as I said, I just wouldn't stop. But eventually if I wanted to try a new thing, I must go for it. Make sure that I'm with people that are aware of my circumstances and not be afraid to say: listen, I can't do this because it is too hard. And not being afraid or ashamed to say: I can't, you know. And not being --. Just, I have to firstly accept it; fully accept that there are some things that I can't do. And then make sure that I'm pacing myself because otherwise, as I'm sure you know, the next day can be hard, or that evening can be hard. So just making sure that you don't, you don't push yourself. It's good to push yourself, but not to where you can't cope. Knowing yourself, you know.

258. **S:** So I think you said earlier that when you're ok, you go for it and try new things, but listening to your body and --.

259. **R:** So, I don't want to stop my life for this illness or for my sister having an illness, you know. I want to be able to do things and need to do things. It's ok to want to do it. So I think that was really important for me, to just keep, keep trying, keep doing things. Also physical activity keeps my body going, keeps my joints working, so that's important. But in terms of, ja, in terms of just knowing when that it's ok to try, but it's ok to stop.

260. **S:** Ok, ja. And that's just something you learn as you go.

261. **R:** Ja, as I said with that first experience on the hockey field, sitting on the field, that was the first time that I was like: wow, I can't do everything. But eventually it gets easier.

[60 minutes]

And the people that are around you say no. Then, if they're supportive, they can tell you, you know: stop now, it's ok. You know, they will support you in it, you know. And they will, they will be gracious about it. So it's important to have that support system that understands, but it's also important to, to know for yourself and stand up for yourself.

262. **S:** And how do you think your illness has impacted on your parents? Or has it impacted on your parents?

263. **R:** No, no, no definitely, definitely. I think for them it's incredibly hard for them to watch us be in pain or suffer. But as much as it impacted, there's still so much, you know, that we could do together still. So many good times that we had and still have. And although it can be so hard, it can still --. It doesn't take away from the fact that life can still be good, you know. So I think of course it did impact them; it was hard for them to watch stuff like this. They had to give up a lot of their own stuff you know, just trying to --. Mom had to take a lot of time off work and Dad was often just driving me around because Ursula was in hospital. Stuff like that.

264. **S:** Ja.

265. **R:** Dad had to kind of take that role of just trying to be there for me, you know. While Mom was a lot of the time there for Katie, Dad had to be there a lot of time for me. And that was a vital part for me, you know – have someone come and watch my sports, or someone to come and drop me off here, or just to go for a drive for me, you know. So, of course it impacted them, but they've been amazing . . . They've been such a source of strength for all of us.

266. **S:** Yes.

267. **R:** Ja, honestly just amazing amazing people.

268. **S:** *Jo*, tough time for your family.

269. **R:** Completely, ja. It has been tough but it's, it's odd because I think while we're going through it, it doesn't . . . you know, it's just one of those things that you cope with, you know, you survive. And although it's tough, as I was saying you just, life goes on and I think you adapt and you learn to laugh. And that there's nothing wrong with laughing and having a good time and being us, and ja. So I think that was very important. And we were all so important for each other you know, keeping the balance with each other. Ja.

270. **S:** And I think, I think that's quite an important thing for me, is to --. That, that, that it becomes the new normal, doesn't it? So your -- The, the laughter must still be there and --.

271. **R:** Completely, completely. You know, we, we just have to adapt. I thought, because it was there for four years, it can't be something abnormal for four years, it became my normal. And . . . became my normal; we just have to go with the flow. We just go with it. And one step at a time, one day at a time. But it's important to, as I said, it doesn't define us. So this disease that my sister had doesn't define the relationship we had with each other. It didn't become sombre and depressing at home, it wasn't all . . . and respectful. You know, it was, I mean, our relationships grew phenomenally. And I mean, making jokes that other people wouldn't think of us making about the disease or the wheelchair or having fun, you know, in a wheelchair. [laughing] Or, you know, making sure that we still had that important part of our lives, you know, of just being us, you know. Still having, playing board games, or going out with each other shopping and stuff like that. Ja.

272. **S:** Do you think that having been through all of this, obviously it's changed you, but I'm wondering how you see yourself in comparison to your peers?

273. **R:** I think it's quite hard, because obviously firstly I, I don't have the greatest self-esteem, but I do see myself as having a different kind of relationship with people. Seeing how my sister suffered and knowing what it's like to be a bystander to somebody so close suffering, I think I can empathise more with people. That's not saying I'm perfect at it, but it's just, I have more of an understanding. And I think that's important. And I think also just viewing the world differently, you know. Whereas one girl can come and complain about her iPhone, or her, the way that she didn't get this and this and this, and knowing that I'm just grateful that my sister can walk, and that today I can walk. I think a change of perspective like that is eye-opening, honestly, you know. Seeing that there's so much more to life than materialistic things. That relationship is important. And like going back to times when I thought my sister was dying, for example, there were a number of times when I didn't know what was going to happen to my sister. I didn't know whether I was going to be with her in the next year. And I think that was so important just to savour the time we had together and to cherish, to cherish every moment. So I think my, in terms of gratitude and what's important, has changed, you know, compared to what others think. And I think I've seen the world now through different eyes. I mean I remember sitting in hospital, being in the surgery room, the recovery room, and. And I think that, circumstances like that happened so many times that I have a different understanding of the world. I, I have seen things that many people haven't seen. And I know how to deal with things now differently to how other people would.

274. **S:** *Sjo*, so you were by yourself when the girl was wheeled through?

275. **R:** Yes I was. My sister and my mom, they were in the procedure room – my mom was just walking through her when she was being anaesthetised and everything, and obviously I couldn't go through, so I was alone, there was no-one else in the room. And it was only this little girl. And so ja, that was . . . hard. Stuff like that always sticks in your memory. Or another one was for example my sister, she had to go into ICU, and it was all rushed and the entire family, ja Mom and Dad were with her and everyone was with her, and I got into the ICU and they pulled me back, the, the doctors, and I had to stand by the door and watch. And my mom and my dad and my sister went off, and I had no idea where they were, I had no idea what was going on, but I just had to stand by the door and watch. And I remember a woman being wheeled past me and ja, she had just been in a horrible car accident I think. And just, I just remember seeing these things and being alone. And I think ja, that was quite hard, you know.

276. **S:** So it sounds like you were exposed to things that people of your age normally wouldn't be exposed to, and on your own.

277. **R:** Ja, I think so. I think although it was hard, it was good to have my eyes opened now. That I, I obviously haven't experienced everything, but as I said, empathy, it allows me to see what other people are going through. But moments like those are scarring ones, you know. People -- I remember also in the ICU, a person had just died and their body was wheeled past and I was alone, but I didn't know what was going on. So it's that thing of being alone, not knowing what was going on, just seeing things that ja, are just hard to do by yourself I guess.

278. **S:** *Jo*. And that made --. I'm going to say this anyway: that must make you different to your peer group?

279. **R:** Completely. I am very different. I stick out like a sore thumb actually. And as I said, I don't make friends easily. It's hard for me to relate to them sometimes because of the issues they're going through, or what is important to them, you know.

280. **S**: Can you give me some examples of things that is important to them and you have a different perspective?

281. **R:** For example --.

282. **S**: I mean, you gave me the iPhone. Ja?

283. **R:** There was a massive breakdown that a girl had because on Instagram a boy hadn't tagged her in a photo. [laughing] And this was like a big issue for her, you know, and she was really hurt. And I couldn't relate, I just could not relate that this was an issue, you know. And I'm just thinking that I, there are so many things that are going through, that they're going through their lives. It's like not having the latest phone or you know, not having the best of these, or having, or having to spend too much time with their family, you know.

[70 minutes]

Where I couldn't spend enough time with --. I wanted to spend more. I just wanted more of my sister, you know. I think, so, just different in terms of what is important. And I think --.

284. **S:** Do you find that isolating at all?

285. **R:** Yes, I, I'm very lonely. I'm incredibly lonely at school. And I, I'm not trying to boast or sound cool or anything, but I think in some ways our maturity differs. And I'm, and I'm seen as to be very serious and stuff like that. But I feel very alone. I have very limited group of friends, not many, you know. So it is lonely. And then things like this do happen where I am in a lot of pain and stuff; they won't understand and then I do feel alone, you know. Ja.

286. **S:** And Rochelle I was wondering, if somebody were to be diagnosed with JIA, what kind of advice would you give them?

287. **R:** My first advice would be: it's ok not to be ok. So, so what would happen is that obviously with me, I would feel like I have to be ok for my family and my sister, not be a burden. But also emotionally wise, you know. I had to, you know, it, it was seen I just have to be happy, you know. But what I realised is that it's ok to not be ok. It's ok to have bad days, it's ok to have bad pain days. It's ok to, to not be the happiest. It's ok to go through those patches, as long as you pick yourself up after a while. But for me that's the most important, is that to accept the fact that what you're going through is hard and that's ok. It's allowed to be hard. But just keep going. I think the next thing that I would give them is, I'm not going to say "remain positive". I hate it when someone tells me to remain positive!

[both laughing]

But just, just keep going, you know. Whether you're in a bad state, whether you're in a good state, it's one step at a time, one minute at a time, one day at a time. Sometimes all I'd have to do was isolate the day into bits of like, I'm just going to get through this morning and then we'll have this. And I'm going to get through this afternoon, and then we'll be fine. So just doing it step by step. Because it is scary, you know. And fatigue and pain, and that is scary. And then also very important I think is just knowing your body. As I was saying, knowing when to stop and when to keep going.

288. **S:** Ja.

289. **R:** Just to make sure that you're looking after yourself, you know. So that you can do what you love and you must do what you love, but don't push yourself, you know. Just know what you can take.

290. **S:** Ja, ja. That's very wise advice. *Sjo*. Is there anything else that we haven't covered today that you'd like to share with me?

291. **R:** Goodness. I don't remember. I'm trying to remember all the things from the first interview.

292. **S:** I don't think that's important. What's important is where we are now. I have the, some of the stuff from the other interview, so I think where you are now is just perfect. Ja.

293. **R:** Ok, good. No, I just, I just think, ja. It's just one of those things that it happens in life, but you've got to keep going. But go through the motions, I guess.

294. **S:** Ja. As you said, day by day, moment by moment. Ja. Because it is so unpredictable. Ja.

295. **R:** Completely. But that, that's the hard part about this disease. Ja.

296. **S:** Ok, then I'm going to stop there. Hold on one moment.

[recording ends]

Transcript 2: Rochelle Interview 2

1. **Interviewer (S):** And now it is --. Ooh, wait wait wait wait, stop stop stop stop. [recording stops and then restarts] And we are on. So, thank you very much again for helping me.
2. **Interviewee (R):** Absolutely no worries.
3. **S:** Ok, so we're going to focus on something slightly different this time; we're going to be having a look at a little bit deeper into your coping strategies and also how you've found perhaps more enjoyable or more upbeat moments whilst you've been ill. And, and, and how you actually manage that whole process. So one of the first things that I wanted to look at, having gone through the transcript from the last interview, is, wow, while you were ill a lot of the focus was on Ursula. Well, all of the focus was on Ursula. And I was just wondering, you --. If you could just tell me a little bit more about how you coped with that focus of being, of you being ill but the focus being on Ursula. How, how did you manage that?
4. **R:** So I think a very important thing for me was having someone that I could speak to, and somebody that knew my side. So one of those people was my dad and him and I grew really close during those four years because he just really got me, he got where I was coming from. There was no judgement, he just, he was just totally accepting and totally understanding. So it was really important for me to have that close relationship with him. I think one of my problems though was that I bottled a lot of things up. So some, every now and then, actually most of the time, I would just let it be. So if I felt neglected I would, I wouldn't say anything, which was a big problem because eventually it built up. What I learnt helped, and what I learnt helped and stuff, is finding things that help me and not being afraid to use them. For example, having friends and being loved by them. Allowing myself to have that friendship. And also just talking, talking about it. I think only in the last year did I start like saying to people, especially like my family you know, I need more attention, I need to, to feel more support from you guys. And I think that was important; it was very important for me to start talking to them about it.
5. **S:** What do you think enabled you to start talking? Because you, you did --. You were talking the last time about expressing your feelings, as you said now, bottling them up. And I think that was when you were what, about 11 years? Were you still --.
6. **R:** Ja, ja, ja.
7. **S:** And so what now in the last year has enabled you to start being more vocal?
8. **R:** I think it was finding a bit of self-worth and seeing what I am in worth. Having attention. I am worth having love and being supported. And I think that took a long time for me. It still, it wavers, but as I said: it's just, it's, it's so important to know that you are worth still having

that attention. I think also I was really hurt and I obviously I've bottled up a lot of things, but when I started talking about other things I realised just how good talking was.

9. **S:** Ok.

10. **R:** And I thought that if I could let this out, maybe it would be just as beneficial, and it was. It really, ja, it was one of the best things I've done. Ja.

11. **S:** So, so you started talking about other things first, sort of breaking the ice as it were. What were those things that you talked about?

12. **R:** So I think most of the things that I started talking about being, how, how hard it was to watch her, to watch Ursula like, like that. I wasn't used to talking about that obviously, because I didn't want to speak to people about my hardships. But ja, I think I started sharing a bit with my mom and my mom would share with me, and when she started opening up to me then I could start opening up to her.

13. **S:** Ok.

14. **R:** And so ja, about how I was struggling as well. And about how, when my down points were, where I was struggling in, such as being exhausted, being lonely without her, and stuff like that. And soon I could actually say: and I also, I feel lonely altogether because I ...

15. **S:** Sorry, that last bit: you feel lonely altogether because?

16. **R:** Because --. So I think it just led on to the fact that I could say I feel lonely altogether, and I need your guys' support as well.

17. **S:** Oh, you need your guys' support as well, so not just for Ursula. So, so it sounds like then what you did was you just started opening up about your feelings around Ursula first with your mom, and then she reciprocated.

18. **R:** Yes, ja. And that helped.

19. **S:** And, and then you were able to start to verbalise how you felt abut yourself?

20. **R:** Yes, ja. Just baby steps. [laughing]

21. **S:** Just baby steps, ja. And I went back also, you remember that first interview where we lost the recording, I was going through bits of that as well. And one of the things that came up was that during that time when you were suppressing your feelings, you, you got into a lot of negative self-talk. And somehow you came up with the strategy of every time you came with a negative thought --.

22. **R:** Ja, so I think that started off with I didn't feel worth having attention.

23. **S:** And how old were you then Rochlle, can you remember?

24. **R:** I think I must have been 12, 13.

25. **S:** Ok.

26. **R:** I think 13, ja. Or no probably 12 actually, sorry.

27. **S:** Probably 12.

28. **R:** But, but I think I felt so bad about myself that I couldn't get attention without being sick, without having something. And I felt pretty useless in that sense that I couldn't get that. And I went through a really really bad stage in which I just couldn't see self-worth, I couldn't love myself at all. And it's really hard, it was really hard for me to . . . through it but every time I felt something, I'd say something negative about myself, you just bring up back another positive. Which is incredibly hard at the beginning and it takes a while, but I made sure that I was doing it every single time. And of course it started with small things like: you are good at this, you're good at that, and eventually --.

29. **S:** Can you give me some specifics? Specific example, what would you have said?

30. **R:** So for example I remember once I just thought, I just kept saying to myself: you're not worth their love, you're not worth their love. And I just, and all I --. Like it wasn't even relative to that thought, but all I said was, you know: you actually are good at taking care of your sister. And another example was not even involved with my sister, it was talking about how I'm, I'm good at school or how I'm making my parents proud or how I, I --. Difficult things like this, say, you know you are beautiful, or you are loveable, or stuff like that, that took a while. But I just started with the small things: you are good at this, you are good at that, and ja.

31. **S:** And, and then you were able --. And are you now able to say things like: you are beautiful, or --.

32. **R:** I think so. It's much easier. Obviously not all days, like "wooh". [laughing] But no, I think it still, it's not perfect, my self-worth, but it's much better than it was, you know. I can value myself, I can give myself time, because --. Give myself allowance to do things because I feel more worthy of that.

33. **S:** And that's something that you've actually done really by yourself with the, the confronting your negative self-thoughts.

34. **R:** Completely. And I think no matter how much other people tell, or would tell me, you know: you are beautiful, you are this, I wouldn't believe it. And until --. I had to do it, you know. Just, it, it's hard at the beginning, but it's those first steps you know that --.

35. **S:** Can you remember what made you come up or how you came up with that idea? Because you were in a dark space.

36. **R:** Ja. Actually, I don't remember fully but I think it probably was just because I think I didn't want to be that burden to anyone else or to myself anymore and I think in terms of --. It's quite coincidence because I, I kept thinking I'm being such a burden to everybody else, and I thought that if I'm going to think I'm being a burden, I'm being a burden.

37. **S:** Ok.

38. **R:** So I decided that to help make everybody else's lives easier as well you know, let's, let's try, let's try. So I'm not pulling other people down as well . . . this negative self-talk.

39. **S:** Ok, so it sounds like the focus or the impetus for changing your thought structure was, was your initial feeling of being a burden and then thinking that if I think I'm a burden, then I will be one. But it was more driven by others than yourself – your thoughts of others, for others.

40. **R:** Ja. Which is quite odd.

[10 minutes]

But it actually landed up working completely, you know, in my favour; it really helped me. And I think that was a ... [recording distorted / unclear] and if I think about it now, I should have thought about myself before I did. You know, I should have said: because of yourself, let's try make you feel worthy. But I did it for other people – which I'm grateful I did, because it worked, and it's still working.

41. **S:** But it sounds like that's possibly a really positive personality trait that you have, is that you think of others. And then by using that strength of yours you were then able to find the momentum or the energy to change how you felt about yourself. It's quite incredible.

42. **R:** . . . the things --. [rustling noise /interference with microphone] Sorry, sorry.

43. **S:** No, it's fine.

44. **R:** What were you saying, sorry?

45. **S:** I said it's quite incredible that you were able to do, to harness one, a strength in one area and then bring it into another area.

46. **R:** I think at that stage, and still now, most of my life revolved around Ursula and wanting her to have an easier life than she was having. And as I say, I didn't want to be a burden, so I was so prepared to do anything just to make sure that I could help her. And I think, ja, eventually it just helped all of us, and I'm quite glad that I used that strategy and not another one, you know, that could have been harmful to myself or --.

47. **S:** Ja. And when all of the focus was on Ursula, I mean, I know we are talking about you and not Ursula. In that time when all the focus was on Ursula, even your focus was on Ursula. Were, were there moments when, despite that, despite the fact that you were feeling isolated, you were able to find more positive moments in your life?

48. **R:** Sorry, can you please repeat the question? Sorry.

49. **S:** No, I know that was a bit long, wasn't it. So, so you were --. Everybody's focus was on Ursula, including yourself; is that, that correct, yes? And so, and that caused you to become withdrawn, During that dark period, is there anything, were there moments of positivity in your life, or moments that lifted your spirits?

50. **R:** Of course, of course. I mean, just having such a good relationship with my sister was enough for me to say that this is ok, I can feel this and it's ok. I would far rather see Ursula happy, you know. I remember just some of the best moments I had was just sitting with her and laughing, sitting with my family and just laughing. So I think just being real, you know, and not putting on fake things. Eventually when I could be open about everything, it was far more, it was far easier to be real with each other, you know. And when that was . . . then I could actually talk to people. It's so much easier just to be real and being real would mean that we could laugh about things together and what I realised is that because she's in a wheelchair, not everything has to be bad, you know. There was still our relationship, we still had so much fun doing things that we could do.

51. **S:** What --.

52. **R:** So I tried to make --. Sorry?

53. **S:** Carry on.

54. **R:** Sorry?

55. **S:** Carry on. You tried to make?

56. **R:** I tried to make sure that our lives didn't revolve around the illness, or that the illness didn't define us, you know. That we, despite what we were going through, could still have a good time together. And I think that's what got me through, was mostly just the relationship and how much stronger our relationship got with each other, my sister and I. And just how much more we bonded and how much more we learnt about each other, and I think that's what also helped me to just keep going and to see it's worth this; it's worth not feeling great just if my sister can, can have an easier life. I know that she loved me so so much and she didn't want that. I think that's a way in which our relationship really helped, because she didn't want me to be hurt and I didn't want her to be hurt, so she was a big part in pushing me and helping me to feel worthy and helping me to feel good, because, ja. So I think such a good relationship with those people close to me, that was the best that I could have.

57. **S:** So Ursula was also helping you with your self-worth, feelings of self-worth? Or --.

58. **R:** Completely. You know, she, even though she was going through such a hard, hard space, she was so so caring about others around her, you know. I mean she'd be sitting in the hospital ... you know what, how are you doing. And I think in the whole illness she was the only one that really saw me sometimes, you know. Which is quit ironic because, you know, she was the one that needed it, but she really really saw me. And so ja, she was one of the driving forces that told me, you know, you've got to keep going and you've got to make sure that you do ok, so that we both ... [rustling noise /interference with microphone] And she also would make sure that I was getting time for myself ... take some time off and you know, go spend some time with myself. She was, she was amazing in that way, ja.

59. **S:** Ok. And you said --. So, so Ursula was also supporting you, and then you said when I interrupted you, you guys were sharing really good moments together. Can you give me some examples of those good moments?

60. **R:** Oh, there're so many. Just doing I think normal things, like, well one of my favourite things was sitting on my sister's bed and really just ... [rustling noise /interference with microphone] and laugh and laugh and laugh and laugh, you know.

61. **S:** And what kind of things would you laugh about?

62. **R:** Oh goodness, everything. [laughing] But just, you know, we'd sit together and watch a movie or --. We would even sometimes, you know – it sounds absolutely horrible and maybe not ... – but like not laughing at the disease, but making sure that it wasn't so serious. Like ... [recording cuts out] you know. Getting comfortable enough with the disease that we could joke around, around with it. You know, about how slowly I would push Ursula, or how frustrated ... [recording distorted / unclear] Yeah and just going shopping together, just, I think about it and those are some of my favourite memories, you know, pushing her in the shops. . . . so one of my, a very silly memory, but one of my favourites: we went to the theatre together and you know, trying to push her up a ramp, and I was laughing so hard that we both just sat at the bottom of the ramp in front of everyone just laughing and laughing. And I was sitting on the floor and crying from laughter. And I think just, you know, just being light-hearted about it; not everything had to be so serious about the disease. I think everyone else was like: oh no, we can't say anything. But you know, it was our reality and like every reality there are, there are good sides. So just accepting what we were in and seeing the good side. Also just, just spending time with her, just talking. Ja, just when you could --. Hospital times, those were horrible horrible times, but I remember going and sitting with her and bringing games to play with her. And those were one of our best bonding moments, because she was at her worst. But spending time, we were just so real with each other. And just sitting --. Sometimes she couldn't sleep, and just sitting, lying with her. Just good moments, good moments with her, ja.

63. **S:** So although you were doing that to help her, in actual fact you were receiving, you were also receiving support.

64. **R:** Completely. I think it was just, our relationship is so great that no matter what I do for her, it will always be reciprocal, reciprocated. I would always get it back, I would always feel loved, you know. And I think that's just how magical our relationship was and I think we pulled each other through.

65. **S:** And just tell me some more about how you laughed at the illness and what kind of things did you make jokes of?

66. **R:** So I remember, you know, people would pass by in the shops and for example they would nudge each other and you know all those times they would look at you and they would just stare or --.. I remember there was once a little kid and she came running up and she screamed at my sister: what is wrong with you? And I think she was about three and I think, I mean, ... would be pretty offended, but I mean ... could understand where they were coming from. So we could see the light-heartedness in that, you know, and me asking her: what is wrong with you?

[both laughing]

But also silly stuff that would happen. For example, she'd be sitting in an aisle and somebody would, there was a man that came up to her and told her that she was a fire hazard because she was sitting there in a wheelchair. [laughing] And it's just, like usually I would be very offended about that and I think for the first like while we were like a bit shocked, we were like: oh, ok. But soon we were laughing about it. I mean, she's a fire hazard. [laughing] So silly things like that and people's reactions. Or the way that, you know, making mistakes with trying to push the wheelchair and just having that strength to get up a, a hill or something. Silly things like that. Or ja, I can't even remember some of the stuff. But just knowing that it's ok to laugh and to have fun.

[20 minutes]

And ja, I guess it was good.

67. **S:** And I remember from the, one of the previous interviews, one of the lines that struck me was it wasn't just you and Ursula that took your attitude. I think you said as a family we didn't let it get sombre and depressing; we didn't let the disease define our family.

68. **R:** You see the problem is, I think, is when an illness or an issue is the core point of a relationship. So then everything you do and everything you say will revolve around it and it kind of warps the sense of what everything is, you know. I think this is the most basic, one of the most basic examples I can give is right, when people introduce us, it would be: she was a girl in a wheelchair, and she was the sister of a girl in a wheelchair. That's very simple, very basic, but it's a way of defining us by our illness and I think one of the things we had to see was that that illness is not what our family is about and is isn't what we want to surround ourselves with.

69. **S:** So --.

70. **R:** So we had --. Sorry?

71. **S:** No, I was just going to say, so how --. So you wouldn't let it define you; were you guys able to redefine yourselves? Consciously.

72. **R:** Completely. You know, we couldn't make sure that the wheelchair, the wheelchair . . . almost stopped us from being who we are. We couldn't make --. And such things as laughing – we were always making it fun and we would laugh at everything and we couldn't make this illness make everything depressing and we couldn't, you know, stop doing what we wanted to do because there as an illness. It was very serious but you know, we still, we still are us you know. We were just us in a different situation, but it wasn't a different us, if that makes sense.

73. **S:** Yes.

74. **R:** So --.

75. **S:** So the circumstances have changed but you haven't.

76. **R:** Completely, completely. And we had to not only adjust ourselves but just stay true to who we were in that situation. So obviously we had to adjust a few things, you know, but not just adjust who we are. So still have our humour, still have that good will, still have that family sense, you know. Just making sure that we didn't revolve around the illness, because then it would just get worse and worse and we would all be sombre and the situation would get worse. So just ja, making the relationships stay the same ... [recording distorted / unclear]

77. **S:** Ok. And so, so you, you, you told me a lot about Ursula being the girl in the wheelchair, but if I remember correctly you were defined as the sister of the girl in the wheelchair. How did you go about changing, or did you go about changing that, that definition for yourself?

78. **R:** You know, it still isn't always changed, like I still sometimes get known for the, I'm known as that, but I think also you know when, when it's important for it to matter to me and when it's not important. And with the people that are important to me, they know there's more to me than that; you know, they know that I have a personality, they know that I have a different side to me. And I think it's knowing when to be affected by things and when not; when to let things go and when to be like: this is an issue. And then at times when something is an issue, it has to be sorted out. So I remember sometimes you know, with my family, I would have to just make sure that sometimes I have a one-on-one talk with them and just speak about how --. And I'd be honest with them and say you know I'm tired of being the sister of the girl in a wheelchair. And I think then they were able to say: wow, you know, she's not only that, she's much more.

79. **S:** Are you talking about your extended family there or your parents?

80. **R:** No, not my extended family because ja, aunts and cousins, I think, ja. I remember having a specific talk with one of my cousins, and I wasn't intending on telling her that I feel silly about being known as the girl in the wheelchair, but I think from the conversation we had she said: wow, I've really seen a different side to you. And I think from then on it changed. So I also had to stop playing the role of just being the sister in the wheelchair and I also had to have my own identity, you know. So being around people I couldn't only be ..., I also had to have my own identity. I had to go have conversations on my own and sort out my life so that they could see: wow, she also had a life.

81. **S:** So you actively started talking to people about you and yourself and, and things other than your illness?

82. **R:** Yes, yes. And I think it took a while because I'm quite scared of confrontation, but I was pretty comfortable with them and I was pretty comfortable with the fact that I'm not only a sister of a girl in a wheelchair – I have an identity. And when they could start seeing that, it felt so much better because then they could treat me as a person on my own, you know. And I think that's important, is to know when to confront people about something and to know when to just leave it, you know. For example if my parents had to introduce me to one of our guests, a guest, like: she's the sister of a girl in a wheelchair, it didn't matter to me because they're not going to know me well and that's fine, you know. And if I can ... that's ok. But for the people that I'm closest to, I don't want to have to serve that role of, you know, only the sister of the girl in a wheelchair and doing this, but I want to be my own person. So I think, ja, just knowing when to force them to make a change and when it's ok to leave it.

83. **S:** Can you give me an example of a moment when you did make a change?

84. **R:** I remember having quite a long talk with my cousin about something and I pointed out to her that it hurt me a lot when people would push me aside and not notice me, and she was like: oh wow, ja sure, I'm sure that's hard, but I've never done that. And, that's what she said, and I had to be honest in that moment and I said very openly, you know, I said: sometimes I do feel quite neglected by you, and we were close once you know, but that kind of stopped. And I think she was quite shocked at my openness, but thankful, because then she would change . . ., and that was good. And then friend-wise, you know, I obviously had different conversations with my friends, and once I got really angry, but --. Because they just kept --. No-one asked about me ever, you know, it was all always about my sister and never about my illness or how I was doing. And one day I just said, you know, I'm important too. I'm also here and I'm your friend and I would appreciate that. And obviously for a while there was a bit of friction but I think just being truly open to them, they were at first shocked bit soon saw that I'm my own person and I need more attention . And they were very nice and very decent about it, so it soon changed, ja.

85. **S:** So, so even with your friends, the focus was on Ursula's illness and you had to address that with them.

86. **R:** Completely. I think the problem is, is that Ursula and myself went to the same school – we still go to the same school – but --. Well what happened is that obviously they, they've known her when she was better, then she got sick. So they've known the whole story, so I just became like a part of that story, you know. Whereas I met another girl, it was mid-way in the illness, so Ursula was already in the wheelchair and stuff, and she, this girl saw me for me. Not who I was, not who K**** was before the illness and how it all changed, but she just saw me for me in that moment. And that's one of my strongest relationships now, is because she was there for me fully, you know. She didn't have to be there for Ursula... she could just be there for me ... [recording distorted / unclear] So ja, my friends did notice obviously that Ursula had gotten sick so they turned their attention to her, and I think that was really hard, knowing that they were my support structure. So having to talk to them was very important, but sometimes I was quite harsh about it and I think they got quite annoyed. So eventually some friendships didn't work out fully because you know, we couldn't see eye to eye. And ... that that's also ok because then that friendship wasn't the greatest for me anyway, you know., if I wasn't getting what I needed from it and that ... was fine to not have that friendship. And just to value the friendships that are meaningful.

87. **S:** And what kinds of things did you say to your friends in those moments when you had to, you had to pursue what was happening or confront what was happening?

88. **R:** Obviously I couldn't speak too extensively about the illness because they obviously wouldn't understand fully, but it would just start very basically about what --. I would tell them more about what our home routine was like, you know and show them more what it was like for me, show them my side, such as you know, every morning I have to get up and I have to dress Ursula. And I come home, I make her lunch, and I undress her and put her to bed.

[30 minutes]

89. And then sometimes I do physio with her, and stuff like that. And I would share more about what it was like from my point of view, you know, so that they firstly could see ... And then I would try as much as possible to open up about my emotions and just say how, how it's quite lonely and how, and how --. What I really need from them at this moment is just for them to be there for me. And I'd try and do it as gently as possible. And honestly I didn't, I didn't --. I wasn't angry at them for it because I completely understood where they were coming from. It's not easy to, to constantly be the one seeing this transition happen and so, you know, I totally understood where they were coming from and how they didn't understand. So that's why, as gently as possible, I just tried to tell them that my side is also important and I'm struggling a bit. And when they saw that, they were very gracious about it and as I said, some weren't, and that's ok.

90. **S:** Ja. Ja. You were then able to sift out the people who could make a difference to your life from, from then and not have to --.

91. **R:** Completely. And I think one of the big things is making sure that you're not completely always surrounded by negative people – people who are going to bring you down and make it worse. Because sometimes I just needed fun – people to have fun with or stuff like that. So ja, ... some people I wasn't as close as we once were, but that was ok with me.

92. **S:** And, and the whole idea or topic of identity, particularly with you, has been quite a big theme because you, you almost had a double loss of identity. Your disease was invisible and yet you were also even more invisible because Ursula's disease was quite pronounced. That you almost got sucked into the orbit around Ursula. So when you were talking to your cousins and you were sharing more about yourself, what kind of things did you share with them about yourself in order to get them to see you as a person and not Ursula 's helper?

93. **R:** So, basic stuff like what I, you know, just anything. And tell them about stuff I liked doing, updating them about how school was doing. But then also you know as I said before, just talking to them about how, what my routine was like at home with K****, you know. And what my role was. And then also just talking to them about what I liked doing, or who my friends were, or what's new in my life. And just having, you know, a normal everyday conversation with them. Also just talking about things that I take interest in and things that you know, disappoint me, things that I'm struggling with with Ursula at the moment. Until they could see that she does battle with it now and then and that, ja, they could take it from there to see that I did also have a side, ja.

94. **S:** And the friend who arrived and hadn't known Ursula and saw you for yourself – can you tell me what do you think she saw? Who were you?

95. **R:** Oh God. [laughing] So we met on something we call the Mini Council. So it's a charity group and what we do is every year – and I was in Grade 7 at that point – and every year 80 students from across the country are selected to be on this group. And so there was only two per school, and I was managed to be selected and so was she. And at that point I made it as pretty much head of that council group, so I was head of those 80 people, and then of another 80 Grade 11s. So it was quite a different space we were in, you know, we were experiencing things together. We would go to squatter camps, we would go to orphanages, we would go to disabled homes, we would go to places like that. And it was quite a different environment that we were in together, so I think it was a different way of knowing each other. We experienced things that were the same, such as going to these places, so I think we had that in common, so we could see the world differently. I think she could also see that I had a different perspective on the world than many other people do. I think she could see that I was, I was a bit different from other people. Not necessarily good, I don't know, but she did see that I was different. I don't know, I'm not really good at talking about myself.

96. **S:** I know. You do have difficulty around that. Ja.

97. **R:** Pardon, sorry?

98. **S:** I said I think you, ja, you do have difficulty verbalising about yourself. Ja. Why is that do you think?

99. **R:** Pardon? Why? Ja. [laughing] I just don't --. I think sometimes it still has to do with self-worth, just not knowing really if I'm --. What, what is good about me, what is not good about me. Ja, I still don't really know why I would be appreciated or liked. I'm getting there, the way I keep telling myself, doing the whole positive-negative thing, but I think, ja. I just don't know, it's just uncomf --. I'm not used to talking about myself, ja.

100. **S:** Because when you said she saw you as being different, or you think she saw you --. You, you almost gave that a bit of a negative overtone. So I was just wondering, she stayed your friend, so she saw you positively different. What, what do you think she might have seen about you that was different?

101. **R:** Well obviously the way that, what my priorities are. Obviously having Ursula being ill, you know my priorities were completely different to like, you know. What was important to me was not what everyday teenagers had, you know, what was important to them. So for example, relationships were important to me, and I think she valued that more, is because I really wanted a good relationship above material things, you know. Wanting this or wanting that. It was just more about that we could be close. And I think I was also a bit more real, you know – it wasn't all about materialistic things – and I think she could see that I was just who I was and who I was is just how I'm going to stay, you know. Also, I wasn't afraid to have a good time with her, you know. Just to be open with her and to, to let go – which is not something I did with normal people. But ja, she was, she was just, I think, accepting of the fact that I'd been through a hard place, but I could still be me.

102. **S:** And how did this developing friendship with her impact on your own sense of identity?

103. **R:** Well, it was --. She's one of the closest friends I've ever had and I've actually never had such a good friend, and I think the reason that that was so was because we could both be so real with each other. And knowing that she, knowing that she could see this in me and knowing that she could have that respect for me, I think my self-worth obviously went up a lot. I think also she could show me the things that I enjoyed doing – she would make sure that we had a fun time together. And through that I could see what I enjoyed doing, what I liked doing, and who I liked to be around, you know, what kind of people I wanted to be associated with. What kind of people I didn't want to be associated with, and stuff like that. She just carried on pointing out to me just what I loved doing and what, what I loved about life, you know.

104. **S:** So, so although you lost your identity with the, with your own illness and also with, with Ursula being so sick, this friendship that you developed --. Because you -- I know last week you --. Two weeks ago we were speaking and you said you didn't really know who you were yet. But this friendship through reflect, through her reflecting back to you, you're starting to see who you are. Ja.

105. **R:** Ja, completely. I think that she was a vital part of me just seeing --. And obviously not, I still completely don't know who I am, you know, but she was just a vital part of me seeing --. Of -- She just reminded me again what I loved about life, what it is about life. She was such a happy, she still is such a happy person, you know. Unfortunately though she's, she immigrated to England about four months ago, so ja, that's quite hard. So I'm still battling to find somebody I can be very close with. And obviously with technology and stuff it's so like easy to contact each other. But I think just the fact that she was so happy and so, just loved life, I think that was such a good example for me.

106. **S:** You said you, you don't know who you are, and yet it sounds to me like there are a lot of things that do actually define you.

[40 minutes]

107. **R:** Ja, I, I guess so. I think when I say I don't really know who I am, it's, I think I see what I love about life, especially in terms of the smaller things, you know. In terms of where I like going or who I like to hang out with. But stuff like the bigger things of what I enjoy doing, I'm still sometimes uncertain of. Such as you know, what kind of a, a person I want to become and what kind of person I am. What I, what bigger things I enjoy doing, not just the small things like reading and stuff, but what, what, what, what makes me happy, you know. What is that first things that I could do that makes me happy.

108. **S:** And do you think what you're experiencing is similar to your peer group and what they're experiencing?

109. **R:** I think it could be. I think we all go through that stage of our lives, especially around this age, where we're all like: oh, I don't know who I am. And I think we're all finding ourselves. So I think it very much could be. I think, however, that I'm a bit different from that in terms of I'm still trying to find out fully what kind of a person I am, you know. I'm very serious compared to the other, the girls at school, so the minute I step onto the school grounds I become very serious for some reason, don't know why. And so I think they see a very different . . . to me, so I'm just trying to still figure out who I am around people. Like ja, ja.

110. **S:** I, I find it interesting now that you describe yourself as very serious because in our interviews, I mean, there's definitely a serious side to you, but there's also a very light-hearted Rochelle. So do you not share the light-hearted Rochelle at school?

111. **S:** Oddly enough I've been told by many many people, including my mom, because my mom teaches there, that I'm very very serious at school, you know. By many many people. And I think, I think it's also a bit of an understanding difference, the fact that they don't know my story and they wouldn't understand it. And even if they do, they don't fully understand it. So I think ja, it's more an understanding difference and sometimes I think I view people differently I think. I have sometimes a different discernment. I think also just a different sense of what I, of what I enjoy doing. For me just quality of life is ok. But for them I think sometimes, you know, who took the best selfie or who tagged them on Instagram is important to them. So I think in that respect I can look a bit serious because I'm not necessarily completely into that. And so I think that's what makes a difference between us. And I think, ja, I don't know why I get so serious at school, you know. Because I, at home I'm fine, I'm a very different person. Which is weird. Which I think is also why I don't know who I am, because in one place I'm serious, in another place I'm a bit of both. So, ja.

112. **S:** Ja. Are you comfortable with being called serious at school?

113. **R:** I'm trying hard to bring in some light-heartedness, I really am trying. [laughing] I think I'm, I'm really fine with it you know. I think it's just one of those things that I'm known as. Fortunately I have a good group of friends and ... [recording distorted / unclear] who know who I am . But also, this could also be their opinion of me and that's ok, I don't mind. But I think it is important though that I do have a, a light-hearted side to myself so I'm not seen as just this regimented serious person. I need to have some sense of laughter and fun that I can share throughout my . . . and in my life. So I think it's important that they point it out to me, so that I can try make a difference and try change in certain aspects. But, ja.

114. **S:** So it sounds like really what you're doing is integrating different parts of your personality, and that it is actually ok to be serious in some situations and light-hearted in other situations; it's still you.

115. **R:** Ja, ja. I think sometimes though I just need to like bring both in, because I don't --. I think --. I don't want to be seen as aloof and cold, and I think sometimes that's the way it can be taken. So I don't want to hurt people from how serious I can be. And I think although I can be seen as reliable, I think I also, I need people to trust me in the sense of that I don't , you know, . . . with them or if they need something you know, they --. Ja. So I think a bit of a both. And obviously I will, you know, be serious when I need to be and light-hearted when I need to be, but sometimes just both is, is fine. Ja.

116. **S:** And other than light-heartedness and seriousness, how else would you define yourself?

117. **R:** I, I remember my mom used to know me as her sunshine kid because, you know, I would just mess around, you know, and just love life. And I think that's faded away a bit during Ursula's illness. Actually quite a lot. ... But I think you know, just that sense of just loving life. I just, I, I pick up the mall things to just love about life, you know. It doesn't have to be a big thing – it can be while we're driving I see this like beautiful beautiful view and I just think wow, it's a good life you know. And I think just the small moments that I take that make me who I am, you know. I think also about me, I think --. What else about me. I just, I love learning. I love learning. I love learning new things, I love knowing things. And I love experience, wanting to know things from other people's perspectives, you know. I know what it's like to be shut out and not have my perspective known, and I think I want to be able to be able to let other people know that their perspective is important and try understand their perspective. Because I know what it's like to be misunderstood or not understood. So I think that's what I, what I try do, you know, is try see what it's like for people, show empathy. That's, that's one of my biggest goals in life is to have empathy. So that's what I, what my main goal is. And just I think with me it's just, it's pure relationship;

the simple things in life, you know. I don't want anything too big or too much, just simple things in life. Ja.

118. **S:** Achievable things.

119. **R:** Completely. I think I'm not going to say I want to own a Ferrari one day or stuff, because that's not important to me, you know. So just having achievable things like saying I want to laugh every day. Or I want to be able to pick out a good thing every day, you know, something that really was good. And whether it be the way that somebody opened up to me, or the way that I saw somebody helping another person. So I think just the simple things in life that are achievable, those are what my life must be centred around. You know, achieving what I can after school, you know, getting degrees and stuff like that. I think that's important, ja.

120. **S:** And have you thought of a degree you want to possibly pursue?

121. **R:** I probably want to study medicine and at the moment I'm very interested in neuropsychiatry. So specialise into medicine, into psychiatry. But it's a big goal, but it's just for a simple reason of it's a mixture of science and ..., you know, seeing where issues come from, stuff like that.

122. **S:** So, so although you, you say on the one hand you don't really know who you are and in actual fact there's a lot about you you do know.

123. **R:** Ja, ja.

124. **S:** Including your future. Possible future.

125. **R:** Pardon, sorry?

126. **S:** Including what you possibly want to do in the future.

127. **R:** Ja, ja completely. I think, I think I know most of my, my goals. I think I know what I want in life and stuff like that. At the moment I think what I don't know in my identity is that I don't know what truly makes me tick, I that makes sense. So I think at the moment I, what I do is I take on as much as possible which can lead me to burning out, but I don't know which one truly makes me happy, you know.

128. **S:** Ok.

129. **R:** So I do too much just for wanting to please other people but I don't know what I would do for myself.

130. **S:** Well maybe we could think about that a little bit. At the moment, what --. Because you talk about finding small things every day that make you happy, and maybe you could just share with me, because those things add to your quality of life even though you're ill. So what are the kinds of things that you would look for in everyday life?

131. **R:** Small moments to --. For me laughing is important, so just to, to laugh a bit you know. To -- Small moments that we can have a real good laugh with each other. I think meaningful moments between me and my sister.

[50 minutes]

132. Those are very important to me. So a moment where we were with each other, which we often are, such as, I mean it sounds silly but I mean yesterday we just had a good cry with each other. You know, we just sat and we just cried with each other. We just watched something and we were just thinking about all that we've been through and just started crying. It was just holding on to each other and although it was a hard moment, it was a good moment, because we were so real with each other and we were so authentic, you know. And we don't cover up; we don't try to hide the fact that these things have happened. We were just being real with each other. And I think also, for example, what we do every morning when we're driving in the car, there's this . . . we like looking at and it's just full of flowers. [laughing] And it's silly but it's just a beautiful thing and we're like: ah, it's a good thing. And it's just small moments like that. Or seeing somebody help another person, or just giving something to a beggar on the side of the street and just having them look happy, you know. That's, oh, it's just, it's good for you hey.

133. **S:** And are there any bigger moments or activities and things that make you feel happy? Or, or that life is good.

134. **R:** Some of the things that I enjoy doing I find is for example drama; I love doing drama, you know. So I do a lot of productions and stuff like that and I think that's what I try to get involved in. Or being active, you know, trying to be as active as possible where possible. That, that's quite important to me, not always in terms of I love being active, but in the sense that I can be active. So my disease isn't that bad yet that I can be active. And I think it feels good and it's one of those things that just gives me a, a kick in life is that you know, you still have the ability and you're doing good. And so just the fact that I can do something is good, is good enough for me. Ja.

135. **S:** And anything else?

136. **R:** I think getting involved in projects such as when I sat on the Mini Council where I sat for about a year. That was intensive work of, you know, organising and meeting with people. I think I was busy every single weekend and some days in the week. And a lot of charity events; big charity events that we organised. And I think those kind of big projects are very important to me. Those are also great to be able to give back to people, or, and get stuff for myself. You know, I learnt so much. So doing stuff and just to be able to learn. Also just learning at school or in life or from other people. That's it, that's important to me, you know, just being able to make who I am from what I learn.

137. **S:** And is there anything else in your environment that adds quality to your life that's not self-driven?

138. **R:** I think being surrounded by a loving family, you know, like that, that gives you motivation any day to do something, you know. To do anything that I need, now that, that's enough motivation for me. So I think that's really important to me, having a really loving home and a strong family. I know we've had our ups and downs and then I would feel the blessing once we get past that, I would just realise how strong they are and what an important part they are ... just of me keeping going, you knowing. Having a person, people to do it for.

139. **S:** So your family's quite an important part of your quality of life.

140. **R:** Completely.

141. **S:** Ja.

142. **R:** They're one of my main reasons that I just keep going for.

143. **S:** And then, and then in the wider circle of the environment, of, of places – what, what else helps you and, and boosts your mood?

144. **R:** I think, well, obviously nature, as I said, just going past. But I think just generally being, it may sound odd, but being free, not confined to certain things. This is going to be a very odd one as well, but I know when Ursula was in the wheelchair and then there were ramps everywhere and everything had to be accessible and everything was changed so that it could be accessible. And not having that stuff anymore is, oddly enough, is, is freeing, you know. It's quite nice. So just to, to be free in what we can do or being free to have options. Not having to use this or park here, or, you know. But just being free in terms of, it's not defied, defined by limitations in which, everywhere where we are, you know ... But the major limitations of you know ramps and lifts and you know, that kind of stuff. Ja, which is, which is great.

145. **S:** So it's more of the freedom now to be able to go places and see things and do things has added quality back.

146. **R:** And when we are there, it's just you know, to enjoy it fully. You know, not being held back because of what we can do. And obviously there are some examples of stuff that we can't do still, you know, obviously. Like going away and hiking for a very long time. That, that's quite hard, you know... . [recording cuts out] But in, in a bigger scheme, you know, we have more freedom. Ja.

147. **S:** And friendship-wise, does that impact on your quality of life?

148. **R:** Completely. Obviously I do battle to make friends, so that is quite a big difference, but as I was saying with that, that friend that's in England. So just having a good talk with them, having someone to laugh with. And also someone who is not your family but still loves you that much, is quite special. So ja, I think of course, of course they do. They make up a big part of what I enjoy about life and what I have fun, when I have fun, ja.

149. **S:** And anything else you can think of that brings moments of happiness or well-being to your life?

150. **R:** Well sometimes well-being for me is if I'm in a really bad space, is just to make sure I keep going. Although it's not happy, it's, it's just a thing that just will get me out the bad space to help me, is just to keep going, you know. And sometimes that's hard you know, to just be positive. And I'm not saying you have to be positive all the time, but when you're in that bad space, is to just accept that you're in the bad space and that it's ok to not be ok, but then to move on from it when you can, when you're ready. And although obviously this never makes me happy, but it's in the process of making me happy; it's in the process of just accepting where I am. And knowing that I'm, no matter what I am experiencing, that it's ok, you know, that I have the right to experience that. And I think, I'm not happy in that moment, but working towards happiness at the end of that bad space, is important to me, in terms of well-being. Because that's going, it's going to get me there, whether slowly or . . . [recording distorted / unclear] it's going to get me there.

151. **S:** So that even in the moments of illness when you're not actually happy at that stage, just knowing that you're putting steps in place for future moments is, is what gets you through.

152. **R:** ... [recording cuts out] me ja, that, that I just, I can keep going, you know. I think, I think just accepting that it's ok to be happy and it's ok to not be happy, you know, for that moment. And then you have to move on. So just allowing myself that space. And then as you say, implementing steps ...

153. **S:** So, it always sounds strange to me to discuss well-being and illness. How, how do you see well-being and, with a chronic illness?

154. **R:** For me, well-being is just having a good day, ja. Unfortunately with a chronic illness we know that it might never fully go away, you know. I might never lose this disease; maybe it will burn out – who knows. But for me well-being is being comfortable day by day. So in terms of comfort levels in my physical life, so not being in that much pain, you know. Because unfortunately one of the things that you have to accept about the chronic illness is that, as I was saying, it might not go away, and we don't know how long it's going to be therefore. So for me well-being is still being able to walk, still being able to do something that's active, you know. And for now, that's enough for me, you know. Being able to have comfort times when I'm not in pain – those are the moments that I value and those are the moments that I feel that it's ok, that I'll be fine. And also well-being and health in terms of mentally, is just knowing that not every day is going to be ok, but when the day is ok, is to value it, you know, and to take what I can from it.

[60 minutes]

And I think that's what well-being for me is, is just knowing that it's not always going to be ok, but when it is, it's good you know. So being able to walk, being able to still move around with even just a little bit of pain is ok for me, you know, because I still have that, that freedom, as I was talking about. Because obviously we're going to --. Every day has its ups and downs, but there's times when the pain isn't that bad or when the fatigue isn't that bad. That's ok for me. Ja.

155. **S:** So it is possible to find wellness in illness.

156. **R:** Completely.

[both laughing]

I know it sounds --. And although I'm not saying ... [recording distorted / unclear] and life is great, you know, I'm just on a journey that keeps getting better, it's all great. Because no, it's not all great. It's not always easy. Sometimes it's horrible, as I'm sure you know, but sometimes it's just, I just see wellness in my illness. It's just having those good days when you can say: wow, today's a good day. And to appreciate that. Ja.

157. **S:** And, *sjo,* ja, you shared so much with me again. Thank you so much. I was just wondering if you had any final thoughts, anything that we haven't really covered, from your perspective? Anything about coping or things that help you or even anything totally different, that you think is important to share.

158. **R:** I think the most important thing is to allow yourself to feel whatever you're feeling, you know. Is, is to allow yourself ... to be down or to be happy, and that neither of them is wrong. Neither of them should give you less credibility or less support. And so allowing yourself to be where you are, but to make sure that you're going to keep moving forward from what you are. But just give yourself the space to feel what you're feeling. And then, then try something that will further you in, in your journey, in where you are. And if ... [recording distorted / unclear] and then that's ok, you know. Just to know that where you are and where, what you're doing, is fine. You know, just trusting your journey. So, ja. I think that's important.

159. S: Cool. And I was just wondering if religion or spirituality has been of any --. If, if that's impacted on you in any way?

160. R: Oh of course, of course. My Christianity is such an important part of my life. You know, just valuing the way that for me, what I believe is that there, there is a, a God you know, and He has a purpose for my life. So just trusting in Him and having that hope. And I think, having hope and having that somebody that I know has a plan for me, that, that just provides me hope every day, as much as possible. And of course not every day – my faith does falter, my faith of course does falter. And of course ... that is ok. But just to keep working on it and to know that it is, it is ok. My God is there for me. And even though my faith can falter and be rocky, you know, I still know deep inside that there is a plan for me; He is in control. And I think that's important for me; it's a big part of my hope and what, how I continue.

161. S: And if I remember rightly, you also have pets. Do you not have --.

162. R: Yes, yes.

163. S: And I was wondering, does that add, or do they add to your quality of life in any way?

164. R: Ja, so, I mean every day they bring in little cute moments and joy, joy moments. I mean I remember when Ursula was sick, we had a little, a dog who would when she was doing physio, you know, go jump on the bed and bark at the physio and make her ... So cute moments like that, that keep us going. Just gentle reminders that there is still joy, and there are still good things, you know. And ja, I think small things like that, they're, they're such big parts of who we are now, you know, but it's, they're fun. It's good to have that, ja.

165. S: And, and is it mainly just that they're fun and they're cute, or do they also respond to your illness and emotional well-being?

166. R: As I was saying with Ursula, you know, he would go and he would lick her, her better. When she was, you know, he would sit outside her door, he would sit outside the bathroom. He would not leave her side. And when you're crying, you know, it, it's weird but it's almost like they know, you know. And they just can respond to that, which is --. It's, it's a comfort level that, it's a different comfort level, if that makes sense, you know.

167. S: So you've actually experienced that, not just Ursula?

168. R: Yes. I think obviously more with Ursula because it's more obvious, you know. But I remember ... [recording distorted / unclear] when I was crying, was they just came and they, they just came and sat with me, you know. And just sat and sat and sat and then they'd lick me and play around a bit around me, but just sit with me. And I think it's a different level of comfort; it's a different joy that that kind of --. That's just, it's just a gentle reminder that, you know, you are loved.

169. **S:** Ok. And if we think then --. So we've looked at family, friends, spirituality, something as simple as love from pets. If we look at all that wider sphere of life, is there anything else there you think that adds quality or well-being?

170. **R:** This is going to sound absolutely absurd, but I'll just go with it. I think it's just knowing, which is silly, but how big this world is and how small I am in comparison to it. It may sound silly, but I mean if you look at just how great this universe is, you know, how massive it is, how incomprehensible it is, and how I'm such a small speck in it. It just shows that I'm part of such an amazing, wonderful thing. And, and being such a small speck I almost feel insignificant but so significant. You know, insignificant in the terms that I'm, I'm nothing compared to the greatness of what everything is and how big the galaxy, you know, is. But I'm still important, I still, I have the ability to be loved and to love. I think it just shows that no matter how small I am, that, that I still am important. So, it's an odd concept, I know, but ja, it just --.

171. **S:** It's an interesting concept.

172. **R:** Different. But just, ja, just knowing that I'm just a tiny tiny part of such a big thing, is, ja. It puts things into perspective.

173. **S:** Ok, thank you. And are there any last thoughts or shall we finish here?

174. **R:** I don't think so. I don't think so. Not that I can think of at the moment. But thank you so much for doing this.

175. **S:** Ok, great. Then I'm going --. And thank you very much. I'm just going to switch off this recorder.

[recording ends]

APPENDIX N: Jessica Case Study

Transcript 1: Jessica Interview 1

1. **Interviewer (S):** Okay so thank you very much for wanting to help me with this research, basically what I'd like to sort of find out from you is initially how was the journey to being diagnosed for you, how did that all go, when did it start, anything along those lines.
2. **Interviewee (J)**: I'm not sure when it actually started but it was a long time and a lot of not being diagnosed and a very ankle surgery. Ya, and I think it took like four, four years, yeah I'm pretty sure it took that long to find diagnosis, yes.
3. **S:** When do you, what is your earliest memory of not being, or being ill, or having, how did it start?
4. **J:** My mom says it started possibly when I was small because I always had that [inaudible, 01:06] pain in the arch of my foot but that was from when I was like six.
5. **S:** Possibly from six years already
6. **J:** Probably, and then I just got worse and went to my ankles and then, the arthritis or whatever went to my ankles and when I got to high school it just went everywhere.
7. **S:** Oh my word, everywhere you mean like?
8. **J:** Knees, hips, wrists, elbows but that's not the enthesitis, the arthritis is mainly in my feet and my wrist.
9. **S:** So the arthritis is like inflamed joint that you've got and the enthesitis is the inflamed tendons and ligaments and um so how were you finally diagnosed, but first maybe, you had an ankle operation?
10. **J:** Yeah they removed an extra tendon and then it didn't do anything at all so ya then we carried on looking.
11. **S:** okay, ya that must have been very frustrating?
12. **J:** That was quite.
13. **S:** How did it feel?
14. **J:** Ag it's just, although I thought yay it's going to get better but it didn't, so it was a bit annoying.
15. **S:** Who were you seeing then, were you seeing like an orthopaedic surgeon?
16. **J:** Ja. Orthopaedic surgeon, had two of those.
17. **S:** Two of them?
18. **J:** Yeah, and a rheumatologist, she didn't pick up on it as well.

19. **S:** So you went to a rheumatologist?

20. **J:** Yes

21. **S:** Okay, but they didn't pick up on it until you were older?

22. **J:** Um no then we went to a paediatric rheumatologist, yeah.

23. **Interviewee 2 -Mother (M)**: No, she referred you to a that other women…

24. **J:** Biokineticists, but then we went to the…

25. **M:** and then I got desperate and through connections at the hospital and got hold of Dr Y cause we weren't getting anywhere.

26. **S:** Yes, ya it's a very frustrating path because

27. **M:** It's an extremely frustrating path because she doesn't swell up and get nice red joints that they can pinpoint.

28. **S:** Typical

29. **M:** ya, ya.

30. **S:** Not your typical presentation.

31. **M:** Biokineticists, worst idea ever.

32. **J:** Yeah it didn't help.

33. **S:** what, what, what went wrong with the biokineticists?

34. **J:** she doesn't, she told me to tell her when it hurt and she would stop and she didn't stop…. and I was in crutches

35. **M:** she was sobbing by the end of the appointment she was in so much pain.

36. **S:** so she just pushed you through all that um inflamed ligaments?

37. **J:** Ya, pretty much

38. **S:** So then you went, you eventually got to Dr Y can you remember how old you were?

39. **J:** Sixteen

40. **S:** 16 at that time, so and then how did that go down cause that was at the Red Cross children's hospital or…

41. **J:** It was at Groote Schuur

42. **S:** At Groote Schuur

43. **J:** Yeah, they were very nice, and they said, they picked up that I had bursitis in my…

44. **S:** Bursitis as well?

45. **J:** Yeah so and then they like, that was a flag for them so then they looked for them, the first time they diagnosed me.

46. **S:** and then how did it feel to get this diagnosis?

47. **J:** It was a good day, but then it didn't get better

48. **S:** It was a good day but it didn't get, what was good about the day?

49. **J:** You not going crazy because there's no markers or anything so that was nice, and the psychologist's I'd seen at the time also said it could be emotional pain so that made me think that it was still in my mind, so that was nice to know.

50. **S:** So it was almost like a confirmation that you, you, it wasn't emotional?

51. **J:** Yeah

52. **S:** you weren't making it up?

53. **J:** Yeah

54. **S:** and its wasn't in your head?

55. **J:** Yes

56. **S:** It was real?

57. **J:** Yes

58. **S:** and when you said there was no markers, what do you mean by that?

59. **J:** All my blood work came back normal and there was no swelling or anything so ya.

60. **S:** And did you have the genetic test?

61. **J:** Um

62. **S:** HL

63. **J:** I'm sure we did, probably um but we don't, we only have like one person in the family with an auto-immune so it wasn't even very obvious from that.

64. **S:** mm, mm yeah, so you said it was great, or no it was a good day to get the diagnosis.

65. **J:** Yes

66. **S:** So that was quite sort of confirming for you, or affirming for you, um what went wrong from there that you said it just didn't get better.

67. **J:** It seemed like, okay you finally know what's wrong, you can actually do something

68. **S:** So this was two years ago?

69. **J:** Ya, and then it didn't, it just seemed to get worse, suddenly its more tablets and more tablets and more injections.

70. **S:** ah and what did they start you off on? Can you remember?

71. **J:** um they started me off on Brufen, just that and then they did my blood work and then we got Sulfasalazine and then more blood work and then they did methotrexate and then they did steroids and then they did Enbrel and then they took me off methotrexate because it made me feel too sick and then they put me on leflunomide or Arava.

72. **S:** Is that one of the biologic…als?

73. **J:** No, its just a, like a substitute for methotrexate

74. **S:** Okay
75. **J:** Yeah
76. **S:** And so how are you at the moment, currently?
77. **J:** Um well it hasn't been good this holiday at all but it seems to be calming down a little bit
78. **S:** Do you think its weather related or?
79. **J:** No, well possibly but I had a horrible end of term and apparently my arthritis is…
80. **M:** Stress
81. **J:** Ya, very related to stress
82. **S:** So, and of course you are in matric and its June exams and June exams are hectic, so you feeling maybe a bit burnt out
83. **J:** aha
84. **S:** Okay, so it flared everything.
85. **J:** Yes
86. **S:** Ya, and do you get a lot of, what other symptoms do you get?
87. **J:** Tiredness, definitely tiredness, um ya that's pretty much
88. **S:** How bad does the tiredness get?
89. **J:** Very, um quite, quite bad but ya it's just, it makes you want to sleep but its, you can deal with it I guess.
90. **S:** Have there been days where you haven't been able to go to school?
91. **J:** Um no well maybe but I go anyway
92. **S:** So you just push through it?
93. **J:** I don't like missing school, so no
94. **S:** So you'd rather just go through and of course you at Westerford, so ja quite a lot of pressure
95. **J:** Definitely
96. **S:** And um tell me how has it impacted on the rest of your life?
97. **J:** Um, I'm not sure, I mean
98. **S:** Or has it impacted, maybe that was a bit presumptuous of me.
99. **J:** Yes, no it definitely has, um I get angry at people very easily when they like isn't it only for old people or something stupid like that, no, um it certainly affects all my university forms cause I can't put sport of anything and then you lose like a lot of points for that …
100. **S:** of course, wow I didn't think of it affecting your academic career
101. **J:** So that's annoying, um

102. **S:** Moving that a bit closer. So you were saying um also ja so it's affecting academics because you can't do sports, so were there sports that you particularly wanted to do?

103. **J:** I liked water polo a lot and I did do it up until Grade 10 but then not anymore.

104. **S:** Ah because that's a low impact sport except for I would imagine shoulders, wrists, elbows

105. **J:** When I went like that a lot, to try stay, when I move my foot up and down to try stay up and it hurt, and knees it also hurt so yes.

106. **S:** Um so, what was it like suddenly not being able to do the sport that you wanted to do?

107. **J:** Well it was a bit frustrating, but I think it made it easier than have to keep explaining why I can't do something

108. **S:** So having to explain to the coach, actually no I can't do anymore, and how were they with that?

109. **J:** um the one coach just dismissed it by telling me he also has problems. Then the other coach when I told her that I can't do it, she was like "oh ya, I know someone who has something similar to that" and then it wasn't similar at all, so she tries, but failed to understand I think.

[10 minutes]

110. **S:** So do you think that the teachers, there's just not enough awareness with the teachers about what it is that you are experiencing?

111. **J:** Yeah, some, it really depends, some of them are very nice, some of them don't care but *I* don't tend to tell a lot of them cause they don't really need to know sort of thing.

112. **S:** so do you have dispensations and things for exams, for handwriting?

113. **J:** Um I have extra time but I'm very um pedantic about how my handwriting is so it's still fine but I still get extra time for my exams.

114. **S:** I can imagine by the end of your exams your wrists and fingers might be, or shoulders even.

115. **J:** My shoulders, my shoulders are actually fine, they're the one thing that isn't affected, it's more like this spot in my elbow.

116. **S:** Yes, where it goes, ah ya, where the hand connects up to the elbow then you get that sore point. And how's it sitting, I mean matric, all those long exams?

117. **J:** Um the Enbrel has actually helped with my back pain and the hip pain so it's gotten better but I still squirm around a lot but it's gotten a lot better

118. **S:** And do they allow you to get up and walk around and stuff?

119. **J:** Um they do but you have to warn them before the exam, yeah so you cant…

120. **S:** The different invigilators?

121. **J:** Ya

122. **S:** Okay ya and you mentioned earlier, did I, am I remembering correctly, that you said you got angry with some of your friends?

123. **J:** yeah not just my friends, like a lot of people

124. **S:** Can you tell me more about that anger cause this is the kind of thing we sort of wanting to explore?

125. **J:** Okay um well it's just everyone has a different solution, like some of my family have said why don't you go be cryogenically frozen or something like that and they all come up with these different solutions which just, I don't, I'm on the right path so and I don't, they don't really understand very much, other people, which is just annoying. Other people are saying it's for old people or that's not possible or silly things like that or I understand, you know, no no they don't.

126. **S:** They don't understand

127. **J:** I mean it's nice that they care

128. **S:** It's that they care

129. **J:** But in the wrong way

130. **S:** But in the wrong way, okay

131. **J:** Um, sometimes I want to just be alone and that has ended a friendship because they said my reasons for wanting to be alone are irrational and tiring for them, so that made me angry too.

132. **S:** Okay, Oh, why did you want to be alone?

133. **J:** It just, sometimes I need to just deal with what's happening to me and, I don't feel like sharing that with other people, so, yeah

134. **S:** And any um, any ways in which your friends have supported you? That worked maybe.

135. **J:** They, I'm not sure, they're there if I want to talk and they're there, ah, they're just, I can't explain it, they just, they do it right and they very forgiving, I think that's the thing they very forgiving, so if I get very very angry at them for no reason just because some, what's going on, they still there, they just talk until I calm down.

136. **S:** Okay, so it sounds like you have got a good social network going, good strong group of friends. Okay that's helpful. And do you find you able to do everything that they do or I'm talking sort of socially obviously because you probably couldn't do sports?

137. **J:** No um, no sometimes it's too exhausting to even think about going out and if they sleep over at my house then I want them out in the morning, but they don't so there's still that communication lacking but ya

138. **S:** Aha, Okay, so from what you saying it sounds to me like part of the difficulty is that um people don’t understand the amount of fatigue that you experience and the amount of rest that you actually need to be able to manage your lifestyle as it currently is.

139. **J:** Aha

140. **S:** and you lost one friend about, over that, have there been any other incidents?

141. **J:** No, I mean I’ve grown more distant from people just because we weren’t that close to start with so, a very small group of friends who are always just there for me.

142. **S:** How small a group, how many in the group?

143. **J:** There’s probably about, there’s three that I’m very very close with, and then like another five or six that I um close to be not that I share everything with.

144. **S:** It must be difficult to share

145. **J:** Yeah

146. **S:** Because nobody understands really, unless they have it themselves

147. **J:** Ya

148. **S:** Hmm, so has it affected your independence at all in comparison to them do you think?

149. **J:** Um, I’m more dependent on my mom than most teenagers are.

150. **S:** In what ways?

151. **J:** Like, well okay ya I have to be home when we inject Enbrel because I can’t do that myself, it’s too painful.

152. **S:** Okay, when, how often do you have to inject that?

153. **J:** Just once a week, but the other injection I can do myself cause it didn’t hurt that much but this one I can’t bring myself to do it.

154. **S:** Ow

155. **J:** and then like um, I’ll, if my moms always, if I go out then she’s always sort of on standby because I want to come home after an hour and ya

156. **S:** So you can feel good, ready to go out and then

157. **J:** No

158. **S:** And then you get there and it’s too much?

159. **J:** Yeah, yeah pretty much and like next year, I can’t go to a university that’s not in Cape Town if I’m just not at that point where I can, so yeah.

160. **S:** Would you have wanted to?

161. **J:** Not particularly but like Wits for Medicine I could of applied there but I didn’t so

162. **S:** Okay, ah and um are there any other ways you think it’s affected you in comparison to your peers and how they developing?

163. **J:** I think they, I'm not sure, it's just there's a lot of, it's more the being angry that restricts me cause I don't, yeah

164. **S:** Yeah, can you tell me more about that?

165. **J:** I just am angry a lot, yeah, just a lot

166. **S:** just angry about?

167. **J:** Everything

168. **S:** Everything, disease and how it's affected you.

169. **J:** Yes

170. **S:** that must be exhausting as well.

171. **J:** Yes, angers not nice to feel but

172. **S:** Do you go to therapy for that or not?

173. **J:** Um, the school counsellor says I must but we still looking for a therapist, so yeah

174. **S:** That is tricky, cause you really want somebody, you don't want another therapist telling you it's in your mind

175. **J:** Aha, there is a clinic at the hospital, at Groote Schuur but um it's at a time where I have Afrikaans tutoring so yeah

176. **S:** And the trick is?

177. **J:** It's just I can't rearrange it because it's in a group, so then the whole group would have to, yeah

178. **S:** and perhaps you not ready to go?

179. **J:** Where to the?

180. **S:** I don't know, perhaps you not ready to go to counselling yet or are you?

181. **J:** No I'm fine with that it's just too, the schedules too busy

182. **S:** Ah, okay [Clears throat], um the main emotion that you have with regards to this being anger, um something that has sort of come through some of the interviews particularly with the arthritis that's on the inside and not noticeable on the outside is um

183. **J:** Is what, that I get, but you don't look sick, but ah yes

184. **S:** I did not actually want to put those words in your mouth, but have you experienced the same thing, you don't look sick so how can you be sick?

185. **J:** Yeah

186. **S:** What's wrong with you?

187. **J:** Exactly

188. **S:** That must make you quit?

189. **J:** Yeah I think, then I just move on because if that's their logic then fine, there's like HIV people don't look sick even if they dying but yeah

190. **S:** But that's something we all know about

191. **J:** Exactly

192. **S:** Um so you been, you find you very angry um how do you cope with that, what do you, do you have any strategies?

193. **J:** No, no, ah I took it out on myself but then my, the school counsellor told my mom

[20 minutes]

194. **S:** How did you take it out on yourself?

195. **J:** Lots of different ways

196. **S:** Could you give me some examples?

197. **J:** I just like, it seems so illogical because I'm in pain but I would just hit myself like repeatedly, repetitively so yeah but I don't do it anymore

198. **S:** You found other ways of coping?

199. **J:** No, not really

200. **S:** Strange because you say you wake up in the morning and you really tired and you don't want to go to school and yet you get up and go to school, so that sounds like you've found some way of coping, what makes you go to school?

201. **J:** Um I really want to do well, but yeah

202. **S:** So would be, can you please correct me if I'm wrong hey, I mean would that be then that future goals and your future life and what you want out of life is what really motivates you to get up on those days that you really feeling ill?

203. **J:** Perhaps but I just really don't like doing badly at school

204. **S:** It's just that you don't like doing badly, so there's no future life that you're

205. **J:** well I do want to do, I mean I do want to do something that requires me to do well but I mean, I don't think like Grade 3 me knew that yet so yeah

206. **S:** That you still wanted to do well and that's what made you get up to go to school?

207. **J:** Yes and I don't like staying absent

208. **S:** What is it about being absent that you don't like?

209. **J:** I'm not sure, it's like giving up

210. **S:** Giving up

211. **J:** Yeah

212. **S:** Ah, so is that one of your coping strategies you refuse to give up?

213. **J:** I'm not, maybe giving up was the wrong word, hmm, I'm not sure I just don't like it.

214. **S:** That's okay, that's cool, and are there any other things that have helped you through this?

215. **J:** Umm at home there's things that make me more comfortable like pillows and blankets and hot water bottles, yes

216. **S:** Are you allowed to take those to school?

217. **J:** No

218. **S:** Really

219. **J:** No

220. **S:** Wow, so you've got to sit in the middle of winter in a cold classroom without any hot water bottles or anything

221. **J:** Yeah we used to be allowed to but now Matrics aren't so I'm not sure why but

222. **S:** And if you were to get a doctor's certificate?

223. **J:** Perhaps but I mean I think, it's like 8 hours of school, if you can deal with it you know

224. **S:** Do you know if there's are any other kids at your school who have this arthritis?

225. **J:** Yeah, there's one in my grade but she's in remission now

226. **S:** Mmmm

227. **J:** Yeah

228. **S:** How long has she been in remission for?

229. **J:** Just like a week over a year

230. **S:** Wow, so how does that make you feel?

231. **J:** I can't really compare, it's very, it's very different, like the ways it went, hers was very sudden and very severe and then it got under control more quickly, yeah.

232. **S:** So I mean, technically if there's two of you in the grade your teachers should

233. **J:** She's says there've been, they have pretty much what I say some are understanding and some aren't, yeah

234. **S:** And have there been any particular low moments over the last few years that you can think of?

235. **J:** Every Friday on methotrexate

236. **S:** Okay

237. **J:** Yeah

238. **S:** The injection?

239. **J:** Yeah that's, it's horrible, it's like forcing yourself to be sick

240. **S:** What are the side effects for you?

241. **J:** Um, on methotrexate?

242. **S:** Mmm

243. **J:** Very nauseous for four days, and then you have to do it in another three days and very tired and um it made me hate certain foods and made me really only want to eat cheese, it was really odd

244. **S:** But that's what did it for you?

245. **J:** Yeah

246. **S:** And on the new one?

247. **J:** There's no side effects on the new one

248. **S:** Just a very painful injection?

249. **J:** No the Enbrel's the biologic, the leflunomide just one tablet that has no effect whatsoever.

250. **S:** And the Biologic's you on every week still

251. **J:** Yes

252. **S:** And there's no side effects to that one?

253. **J:** Apart from the pain and the bruising, yeah, that's all

254. **S:** Move it around your body the injections or?

255. **J:** Um it freaks me out too much to do it in my stomach so I just alternate legs each week

256. **S:** Must be really scary

257. **J:** Not really, just sore

258. **S:** So you got to psych yourself up for it?

259. **J:** Yeah

260. **S:** How do you manage to do that?

261. **J:** Well my mom does it for me and I am generally a complete and utter brat when it comes to it and yip, but I often bring a dog to sit on the counter next to me and that helps for some reason.

262. **S:** Okay, dogs are amazing creatures aren't they, especially when you sad or in pain

263. **J:** They very selfish, my dogs but they're good comfort

264. **S:** [Laughing] so um just, what else have I got here to ask you, I think we've covered a lot of it. Um [clears throat] so you've told me a little bit about the way you've had to adjust your life in response to stress and sport and that kind of thing, is there any other changes you've had to make, you gave up sport, you know with the stress what do you do?

265. **J:** Um I take, during exams I take a lot of rescue remedy and I prefer to study at night but I don't do that anymore so I try finish my studying by like latest 10 and then rather study, wake up earlier to study, yeah

266. **S:** Okay and um how would you describe yourself to another person now?

267. **J:** What do you mean?

268. **S:** With your illness, how would you describe yourself?

269. **J:** What like tell them, how I tell them I’m this

270. **S:** How do you see yourself?

271. **J:** I’m not sure

272. **S:** You not sure

273. **J:** Yeah I don’t, I’ve never had to do that, yeah, I don’t tend to, I’m very happy with my friends so I don’t tend to go out and make new friends

274. **S:** Mm mm, do you, do you, how, do you think you would be if you weren’t sick? What would be different?

275. **J:** Wouldn’t be so angry, um, I’m not certain

276. **S:** Sorry they are difficult questions

277. **J:** I would, these others, okay yes, my life wouldn’t be a toss-up between everything, that would be nice because everything I have to decide am I going to go with the pain and have fun or am I going to just not go with the pain, sort of like

278. **S:** Choices

279. **J:** Yeah, like, like um for example my friends want to go to rush this holiday at Trampoline Park and then

280. **S:** Oo Ya

281. **J:** and I went there for my birthday but it was like a decision am I going to, I really want to go but don’t I want the pain

282. **S:** Because the bouncing on the trampoline is going to flare everything

283. **J:** Yeah and last year for my Xhosa class we do this hike through Transkei and I was like in a 6 month debate of whether I was going to go or not

284. **S:** and how did it go out in the end, did you decide?

285. **J:** I did go and but we had to have someone to, cause we had to carry everything we needed for 10 days on our back so my teacher um organised someone to carry my bag for me to make it a little bit easier

286. **S:** Oh wonderful

287. **J:** So that was very nice

288. **S:** So you didn’t miss out on the experience

289. **J:** Nope

290. **S:** Hmm Sho, that was very nice of him or her

291. **J:** yeah it was really nice

292. S: And did you end up in a lot of pain?

293. J: Um Yes, yes I did and I took, even though I took all the preventative high-dose steroid pills on there, on the hike and I like strapped every joint up to stop it hurting, but I still, it was still sore even though

294. S: and how do you cope with that level of pain?

295. J: Um, I, I just relax a lot, I think school work does distract me but then it gets really sore after sitting for a while so only can distract me for a while and some subjects are just, if I can't do it the first time then I get overwhelmed on days like that, then I have to go do something else for a while.

296. S: Mm so you've come up with quite a few strategies

297. J: Yeah

298. S: So would that hike that you were talking about, would that be one of your highlights in the last few years?

299. J: Definitely

300. S: Any others?

301. J: Um I mean there are a few that um things I didn't think I would be able do, but I did

302. S: Mm like what?

303. S: simple things, like academic-related stuff I didn't think I would be able to do but did so [30 minutes]

304. S: In the sense of like not physically be able to do or wouldn't be able to cope with it from an academic perspective?

305. J: Like just its extra work and then its tiring so

306. S: are you taking eight subjects or something?

307. J: I am doing AP maths but if I don't do well in it then they don't really mind because it's so difficult

308. S: Okay so you took on an extra subject as well

309. J: Yeah, but yeah its maths and I like maths

310. S: you like maths

311. J: Yes

312. S: Um [Clears throat] if you had to give advice to somebody whose just been diagnosed, what would you say to them?

313. J: Um, I'm not sure, it's different for everyone, I think find the right friends and make them understand if that's possible, I don't know, just surround yourself with the right people and don't do anything you think you can't do so like if you really, like sometimes you have to be selfish, if someone really wants you to do something for them and you just think no I really can't, then don't do it so yeah, learn to say no

314. **S:** Learn to say no

315. **J:** Yes

316. **S:** To others?

317. **J:** and to yourself as well, so if it is just overwhelming then just say no

318. **S:** So it sounds like um learning what you can do and what you can't do it quite important

319. **J:** Definitely

320. **S:** And have you had relapses, not relapses, do you have lots of flare-ups?

321. **J:** Quite a few especially after doctors' appointments because then they push everything, I know they trying to see like what's going on but it still hurts a lot, yes

322. **S:** How have you found, because I mean in your case you were, you did see some, I mean you didn't actually get diagnosed till 16. But you were ill before that so you went to see paediatricians, or just or both adult and paediatric doctors?

323. **J:** Well I went to my general, um GP, General Practitioner, and I went to, and then he referred me to an orthopaedic surgeon

324. **S:** Also adult then, adult doctor

325. **J:** Yeah, and he was the one who said the ankle surgery, then yeah, and then I went to another orthopaedic surgeon, then I went to a rheumatologist, then I went to a biokineticists and had MRI's, and bone scans and x-rays and blood works for a lot of them and then I went to a paediatric rheumatologist

326. **S:** That's interesting because yours was almost in reverse then so you went to all the adult doctors and then only a paediatric

327. **J:** Yeah because, just want to, mom your phones ringing. Yeah because a lot of them don't count me as a paediatric so, like orthopaedic surgeons I had to go to an adult one because I wasn't classified as a paediatric

328. **S:** Because it's, sometimes they stop at 13 and on 16.

329. **J:** But Dr Y and Dr Z they, I think they have patients are 21 still

330. **S:** And how did you find your relationships with your doctors?

331. **J:** Um I did not, um hmm, I did not like the biokineticist at all and never went back to her

332. **S:** What didn't you like?

333. **J:** She doesn't understand no

334. **S:** Okay

335. **J:** Yeah, that's the biggest one, um and she wasn't listening to anything I was saying, but she had all these own theories of hers which is fine I mean that's what she's trained to do but sometimes you actually have to listen to the patient too.
336. **S:** Hmmm
337. **J:** I didn't like either of my surgeons, the orthopaedic surgeons, um yeah
338. **S:** Why?
339. **J:** They just very arrogant, and they were late, the one was late for a surgery
340. **S:** Late for surgery
341. **J:** Yeah by like 2 hours or something ridiculous like that, and um the rheumatologist was nice
342. **S:** Which rheumatologist did you go see?
343. **J:** Um I went to my dad's one, Dr Z, yeah
344. **S:** She was mine
345. **J:** Really, she's nice but I liked her but I mean, I only went to her twice I think, and then my doctors now are very nice and I like them.
346. **S:** do they, I don't want to put words in your mouth again, need to stop that, what is it about them that you do like, what's different?
347. **J:** They listen to you, and they want, they don't try stop you from doing anything, so like with the hike they like were saying no it sounds like a really good opportunity, if you feeling up to it you should go for it there was never any you shouldn't do it, you must do what you want to do.
348. **S:** So they empowered you
349. **J:** Yeah, they very, they just try make you as happy as possible so when methotrexate was so bad they kept trying to offer me to go onto the lower leflunomide but it's really expensive so and at that stage we didn't have a good medical aid or a good medical aid pharmacy but then they kept pushing for it, because they said it will make me feel better and yeah.
350. **S:** So did you change your medical aid policy to be able to go on it?
351. **J:** Well we changed it for Enbrel because that's also really expensive so and then we just switch, and then my mom was eventually the one that said she can't do matric on methotrexate.
352. **S:** So you have to do this, because it is quite expensive isn't it.
353. **J:** Yes
354. **S:** And how has it affected your relationship with your family or has it affected it in any way?

355. **J:** Um hmm I think it's made me closer to my mom, but more furtherer from my dad, but we didn't really have a good relationship to start with, and he's never home anyway so but like when he does come home, than he doesn't quite understand, he thinks I can do things that I can't but as he also has, he has gout I think so and he's also in pain I should expect him to understand but he doesn't so

356. **S:** mm, do you think that's because gout is obvious, with the swelling and the heat and stuff?

357. **J:** Um

358. **S:** Are you comfortable love?

359. **J:** Yeah, yeah, I just moved a lot, no I just, it's his way or the highway and because he's, he works out of the country so it's his way, but then it's me and my mom's way so when he comes home its sort of a clash

360. **S:** How long does he come home for?

361. **J:** Two months at a time

362. **S:** Oh so that is quite a big, long clash

363. **J:** Yeah and then but he's away more than he's home so

364. **S:** and do you have siblings?

365. **J:** No

366. **S:** No siblings, okay, so it wouldn't have affected any of, impacted on that one then, not unless you have any invisible friends or something. I just have to check on my questions, I think we've covered everything, um, yeah I think we've covered everything from my side, um is there anything that you think I haven't covered, or something that you'd like to share that you haven't been able to share yet or that you think might be useful for research.

367. **J:** No not really, maybe I think, just I think if people feel they need a psychologist go for it cause they probably do. That's the only thing

368. **S:** So maybe having a psychologist as well as a rheumatologist.

369. **J:** Yes

370. **S:** Alright, well thank you very much.

[recording ends]

Transcript 2: Jessica Interview 2

1. **Interviewer (S):** And it's working. So I'm going to pop that on the table between us so I can see what's going on there. Thank you very much again for agreeing to the second interview – the first interview was really helpful. So ja, maybe we could just start off with how you are at the moment, what kind of space you're in, how, how are you?

2. **Interviewee (J):** Better than previous times.

3. **S:** Better than when I saw you last time? Because last time you were a little bit ...

4. **J:** Ja, better than last time.

5. **S:** You were having a flare-up I think, last time.

6. **J:** Ja, I am now, but it's not nearly as bad, so.

7. **S:** Ok. So, so what's wrong at the moment? How's the flare-up affecting you?

8. **J:** It's just in my knees, in my ankles, in my chest, which is very annoying. Ja.

9. **S:** And what's annoying about it?

10. **J:** You wake up and you feel like you have a ton of bricks on your chest; that's not fun to wake up to.

11. **S:** No. No it's not. And you think, I mean, if I remember correctly yours is stress related, isn't it?

12. **J:** Ja. So it was fine during exams, but then after when I stopped studying so much the it was like: ok, hello.

13. **S:** Oh, so it was fine during exams and then when you finished ...

14. **J:** Ja, that's kind of what happens now. It doesn't ... It kind of waits a while and then it comes. Ja.

15. **S:** A bit sneaky.

16. **J:** Ja.

17. **S:** It comes and gets you. Ok. When, when we chatted the last time, and we went through how long it took you to get a diagnosis. And basically if I remember rightly your mom could remember you having problems from about six years.

18. **J:** Ja.

19. **S:** But you only formally got diagnosed at about 16 years.

20. **J:** Ja.

21. **S:** Ja, ja. So I was, I was just wanting just to explore a little bit more if you can remember the thoughts that you were having during that time period when ... I mean, you were getting sick or you were getting sore, but nobody seemed to know what was wrong.

22. **J:** It was quite frustrating, but also you got a new diagnosis like every week, so it was like: ok it's fine, now we know. But then, no. So I don't know; mixed feelings of frustration and happiness.

23. **S:** Intense periods of frustration and happiness?

24. **J:** Ja. Because it was like: no this is what's wrong with you, we're sure. Ok great. No.

25. **S:** And what is so great about getting that diagnosis?

26. **J:** You can finally tell people: actually, I'm not crazy, I do have something wrong. No I don't need cryogenic freezing or whatever you're suggesting. I have a diagnosis.

27. **S:** And then the diagnosis wasn't always right.

28. **J:** Ja.

29. **S:** And how did that feel?

30. **J:** Well, that was frustrating. But it was like quite far apart. Like you got a diagnosis and everything, like: no, you're fixed now.

31. **S:** Can you take me through that just a little bit? So the first diagnosis was, led to I think the ankle operation, hey?

32. **J:** No, the first one I could barely walk at school, primary school, so I went to the doctor and they're like: you have tendonitis; go on crutches for however long. Ok. Then that kind of worked I guess because I was not using that foot at all, so it was then being rested. So then that was fine for a while. And it got, slowly got sorer and sorer. Ok let's go, let's go see ... And they took me ...

33. **S:** So the same, the same area got more sore again?

34. **J:** Ja. So then they took ... We went to an orthopaedic surgeon. Like, then they gave me a steroid injection; that worked maybe for a little while but then it came back and we went in for surgery. Then they took out the 10, the extra tendon that probably wasn't doing much harm anyway, and all the built-up nonsense and that. Then that did nothing. It did absolutely ...

35. **S:** So what was going through your head while this was all happening, that they fixed it but then it wasn't fixed?

36. **J:** Well that was, there wasn't much going through, because I was quite a bit young still – like 12 or something, 13. So no, just ... I think it only really got frustrating in high school, when they really couldn't find anything wrong.

37. **S:** And can you take me through that a little bit, that frustration? Maybe any ... What kind of things did you think about, or say to yourself, or ...

38. **J:** I, I didn't -- I don't really remember, I was just angry because I knew there was something wrong and then no-one was finding anything wrong. I know there's something wrong. So there's that. And then the doubt ...

39. **S:** How, how did you know something was wrong?

40. **J:** I don't think you live your whole life in pain and no-one thinks there's something wrong.

41. **S:** And even when then psychologist said it was emotional pain?

42. **J:** Well, there wasn't anything like very bad that had happened. Not like, I don't know.

43. **S:** So there was nothing to have emotional pain about?

44. **J:** I mean, ja. There was nothing that was really happening that was very ... Nothing that happened that was very wrong. So, ja.

45. **S:** Because I think the last time you said to me, when you finally did get that diagnosis you were very relieved because you weren't going crazy.

46. **J:** Ja, I mean you get the doubts that, do you know there's something wrong, or do you just, ja, think.

47. **S:** Can you tell me more about the doubts?

48. **J:** Well, it doesn't help if you watch documentaries about Munchausen's and then you think: am I faking this for psychological attention? But, ja.

49. **S:** So, so you actually did question yourself at times as to whether you were ...

50. **J:** Ja.

51. **S:** Creating it.

52. **J:** Ja.

53. **S:** *Sjo*. And, and was that because everything kept coming back negative, or because nothing was working?

54. **J**: Yeah, it ... No, it was just because there was nothing physically wrong with me. Like there was no swelling; there was no blood work saying ja, you are positive for this. So, ja.

55. **S**: And then, how did you manage that? How did you cope with that feeling of ...

56. **J**: I didn't. I cut everyone out.

57. **S**: You cut everybody out?

58. **J**: Ja.

59. **S**: Ok.

60. **J**: There's like two people that were persistent enough. Ja.

61. **S**: A friend, or ...

62. **J**: Ja. And I ... And then you start to like make new friends again. Ja.

63. **S**: So, so, so how did cutting everybody out, help?

64. **J**: Then I didn't ... I don't know. Like, it didn't help but it was the way I did things. I was just like: you're never going to understand, just going to cut you out. You don't understand, don't want to talk to you.

65. **S**: Ok. And, and what brought about that feeling that nobody understood? What ...

66. **J**: You can't really understand things you've never experienced. And they were being annoying, like: I can totally relate – I sprained my ankle. No you can't; that's going to go away.

67. **S**: And you also know what's wrong. Or they knew what was wrong.

68. **J**: Ja.

69. **S**: So you basically shut everybody out?

70. **J**: Ja.

71. **S**: And that was a way in ... How, how ... So it must have helped you in some way?

72. **J**: No, not really, because then you're alone.

73. **S**: Then you're alone, ok. So it wasn't a good coping strategy.

74. **J**: No, I wouldn't give people advice to do that.

75. **S**: Why, why did you cut them out? Was it just because they didn't understand, or was there more to it?

76. **J**: I don't know. I was just getting frustrated with everything they were saying.

77. **S**: Like the cryogenic freezing and the ...

78. **J**: That, ja, I can't really cut those out, because I live with my grandparent. No, I don't want to be cryogenically frozen. So, ja.

79. **S**: How did that comment make you feel, when some ... Was it your grandparents?

80. **J**: Ja.

81. **S**: I mean, were they serious, were they joking?

82. **J**: No, they were dead serious. It's like they heard about this great place where you can ... I think it's cryogenic, that sounds right. It was something with a "c" and freezing.

83. **S**: Ja, there is such a thing as cryogenic freezing.

84. **J**: Ja, no.

85. **S**: So what was the emotion that you felt when they suggested that?

86. **J**: At first I laughed because I thought it was funny, and then I got frustrated because, you're my family; I expect you to understand more than other people. But ja. My other grandparents are super cool; they don't try get me to do anything. They're just like: so how are you feeling and stuff? Ja.

87. **S**: So they're more in tune with what kind of things to actually say.

88. **J**: Ja. Or just not ... If they don't, then they just don't ask. Which is perfectly fine too.

89. **S**: So is, is that preferable for you?

90. **J**: I think, ja, I think if people don't know what they're talking about, then they should just leave it. But also I always say things I have no idea what I'm talking about, so maybe I should take my own advice.

91. **S**: So, so people weren't really getting you and that led to a lot of anger and frustration. And then you did get your diagnosis.

92. **J**: Ja.

[10 minutes]

93. **S**: And then you had ... And how was that, to finally get the real diagnosis? Because that was with Dr Y wasn't it?

94. **J**: Yes.

95. **S**: Yes.

96. **J**: ... yes. Well that was quite a relief, because it didn't seem like something you can misdiagnose. So that was kind of like a ... And they were reassuring: you've come to the right people; we're going to get you right. And then they said like the first ... They're like: it's going to be like a long process. Everyone else would be: no, it's easy to fix. Well, no it's not, but ja.

97. **S**: So they were ...

98. **J**: More realistic.

99. **S**: More realistic right from the start.

100. **J**: And then also they didn't have like a set thing. They're like: we don't know if it's more amplified pain or if it's more arthritis. We don't know. So they were like ... They knew but they didn't know, which was also more reassuring because they weren't telling you like straight up that they know exactly what's going on.

101. **S**: And what, what is so ... It sounds like for you that it's really problematic if somebody said they know exactly what's wrong and they're going to fix it.

102. **J**: Well, that's just because of all of them kept telling me, so I think I just have negative ideas towards that now.

103. **S**: That you don't believe them?

104. **J**: Ja.

105. **S**: Ah. So for you it was very, then ... How did it feel that they weren't saying to you: we can fix it; we know what it is?

106. **J**: They said that they can help and like we will get there eventually. So they didn't say straight up that they can't do anything about it. They just felt more honest than anyone else.

107. **S**: And how was that experience of adults being honest with you?

108. **J**: Well, I think it helped because they were so much nicer than any other person that ... Like I don't know, the surgeons, the orthopaedic surgeons, they weren't very nice. So ja, I think that also helped because they were more used to dealing with people younger than me and older, or my age, so.

109. **S**: What was wrong with the orthopaedic surgeon again that you didn't like?

110. **J**: . . . he was 45 minutes late for my surgery and like he had nothing on before ... , so that was a bit annoying. And he was just rude.

111. **S**: Rude in what way – brusque or ...

112. **J**: Ja and he spoke to me like a two-year-old, or he talked, spoke so he knew I wouldn't understand a word he was saying.

113. **S**: So he couldn't really relate to you.

114. **J**: No, not at all. I don't think he can relate to normal humans though, so.

115. **S**: Ah, so it wasn't just an adult-child thing; you just don't think he had very good people skills.

116. **J**: No, he didn't have good bedside manner.

117. **S**: And then of course you got to Dr Y and they were honest and said they weren't sure and that it would be a long journey ahead. And then if I ... When I went back to our original interview, then things actually got worse for you thereafter.

118. **J**: Ja. I think it was also like I can acknowledge that it's really sore now, because there really is something. So then it started hitting ... And I paid more attention, like, a bruise isn't just a bruise – it's like side effects from your medication, so you've got to be more careful about what you're doing.

119. **S**: So you don't think then that the disease actually got worse, it was just ...

120. **J**: I think it did, because it like didn't used to be in my back, then it went into my back. And it didn't used to be in my elbows but then it went to my elbows and stuff. But it was what, I think, the other doctors had gone through, they hadn't test, like hadn't tested any of those points, so then with, I was like: oh, actually that has been sore for a really long time.

121. **S**: And, and you just hadn't been aware of it.

122. **J**: Ja. I think the only new one was my back, because it suddenly got sore. But then that was also the first one to go, because it was the new ...

123. **S**: Why, why do you think you weren't so aware of it beforehand?

124. **J**: Well, my ankle was the sorest one, so I think I was just focusing. Like, if I take, like if ... Because I'm on Enbrel, Enbrel now, so that sorted out my back. And I was aware that everything else was sore, but now that my back's fine, I'm like: my ankle is really sore! But it was probably as sore as before.

125. **S**: So, so getting the diagnosis also then created more awareness about your, your body and what was, was actually happening.

126. **J**: Ja. So, I don't know. I'm just a lot more in tune of like if I suddenly lose weight, I'm like: what. Or if I suddenly put on weight then I'm like: ok, that's fine, that's good.

127. **S**: What's, what's the -- What -- You said -- You made a face when you said you lost weight, like it wasn't a good thing, and then when you picked up weight it was ...

128. **J**: And then ja, because I don't know, every time I went back my weight would be lower and lower. It's so frustrating. But ja, I think it's gone back to normal now.

129. **S**: And what's frustrating about the low weight – what does it indicate?

130. **J**: Well, I don't know, it's just it was like the thing that was causing my parents the most worry.

131. **S**: Ok.

132. **J**: It's like: are you eating? I am eating, I promise I'm eating. I don't know why.

133. **S**: Do you think they were concerned about the side effects of the meds or something?

134. **J**: No, I think they were more worried that I was being a teenager and not eating.

135. **S**: Ah.

136. **J**: And then I was like: I promise, I am eating. So ja. And then that kind of got like to me thinking, what can be causing this because I am eating a lot. So, ja.

137. **S**: And what was causing it?

138. **J**: I don't know, it still just sometimes goes and comes back.

139. **S**: So you just suddenly lose weight.

140. **J**: Ja. Or just suddenly don't get hungry at all. So it's very frustrating because all of my medication, all of the side effects are like increased hunger, loss of appetite, increased hunger, loss of appetite.

141. **S**: So it could be the meds, it could be ...

142. **J**: It could be anything.

143. **S**: It could be anything. How was it though ... I was just wanting to explore, and maybe it wasn't an issue at all with you: the relief of getting the diagnosis and then although they warned you it could, it would be a long road, you then did actually get worse. I mean, how, how was that for you?

144. **J**: Quite annoying. And I remember talking to my mom, going: Mommy, I'm meant to be getting better. And then she's like: no, you're just, you're just allowing yourself to feel pain now and we are getting there, and stuff. But that was, now, now you just kind of learn to deal with it.

145. **S**: You've got to learn to deal with it.

146. **J**: Ja. And you've got to find friends who let you complain as well.

147. **S**: You find friends who let you complain?

148. **J**: Let you complain.

149. **S**: And you learn to deal with it. How did you learn to deal with it?

150. **J**: I don't know. You get a lot of comfort.

151. **S**: Get a lot of comfort. Ja.

152. **J**: Ja, like, so I know a warm bath is a comfort and you can put something that smells nice in it. And you get a blanket and lots of socks. I have so many socks now.

153. **S**: And, and what are the socks for?

154. **J**: I don't know, you always feel good when you've put on a warm pair of socks.

155. **S**: Is it the warmth for the joints from the bath and the socks, or is it more comforting?

156. **J**: The socks are more comforting and then the bath obviously helps with the joints. Ja.

157. **S**: And emotionally, how do those help?

158. **J**: They make you feel calmer.

159. **S**: Make you feel calmer.

160. **J**: Ja. I don't have very good coping mechanisms, so I wouldn't give those to other people.

161. **S**: Ja, it's not about judging your coping mechanisms, it's just about finding out what strategies you've used.

162. **J**: Ja, not very good ones.

163. **S**: Ok, but that sounded like a good one, that you made yourself feel emotionally better by comforting, using comfort things.

164. **J**: Ja, that's possibly the only good one.

165. **S**: And you found friends to vent to.

166. **J**: Ja.

167. **S**: How did that help?

168. **J**: Well, certain people don't understand what's going on and what to say and what not. Some never ever understand.

169. **S**: How, how did the ones who knew what to say and when to say it, how, how did they learn that? Did ...

170. **J**: I'm not sure. Maybe you should ask Hannah ... Ja, I don't know.

171. **S**: Well, maybe we can ask Hannah just now if you want to. Is she one of the special friends?

172. **J**: Well she, she doesn't say anything that like has ever made me angry. There are other people who continually ask me like every single day: are you sure you can do that? I've been waking up those stairs for like five years and I think I can do it.

173. **S**: Can we unpack that a bit? What is it that' so ... Because you made a little bit of an annoyed sarcastic face kind of thing there. What is it about them asking you those questions that makes you feel that way?

174. **J**: I'm not sure. They need to understand that I can't do certain things, but most things that they can do I can also do.

[20 minutes]

I don't know. It's just annoying to be treated like you're going to break every five seconds.

175. **S:** It's annoying feeling you're being treated like you're going to break.

176. **J:** Ja.

177. **S:** Is it just annoying or is there something else behind the annoyance?

178. **J:** I don't know, I'm feeling like it's just annoyance.

179. **S:** Just annoyance.

180. **J:** Because it's repetitive, like, ja.

181. **S:** And does ... Is it just irritation from lack of understanding, or is there more behind that?

182. **J:** Well, if they don't understand it's very difficult to communicate, because it's like such a huge part of my life. It kind of dictates everything else. So, I don't know, that kind of puts a strain if they don't understand.

183. **S:** So how does Hannah deal differently with it? What is it that she does?

184. **J:** She's very calm.

185. **S:** She's calm?

186. **J:** Ja, like there's, there's possibly ... There's like four, probably four friends that I really really trust and talk to.

187. **S:** Four friends?

188. **J:** Ja. The rest of them they don't need to know.

189. **S:** Ok. So you there, are you saying that having a small group of friends that are really there for you or that, and that you really trust, is that a coping, a, a way of coping, or ...

190. **J:** Probably, ja. And there's like different people I go to for different things.

191. **S:** Ok. Can you tell me more about that?

192. J: Well, if it's ... If it's more like ... Ok, ok so if there's something like I can't . . . I can't do this, I don't want to do this, then I go to my one friend. If it's like I'm really sore today, I just don't, just can't get away from it, then I talk to another friend. If it's something more like another issue, if it's like something to do with someone else, then I'll be like: can you help me with that. Ja.

193. S: What -- So, so is it ... I'm just trying to understand what it is you go to them for. Is the one to complain about how you're feeling or to vent?

194. J: Ja.

195. S: Or, or is it to get, actively seek help from them.

196. J: If it's like school work, I'm just so so tired.

197. S: Oh.

198. J: And just can't, cannot have any idea of how I'm going to do that, then I'm going to go ask someone please can you just explain this to me.

199. S: Ok.

200. J: My mind is going crazy and another one would be like ... Another one would be for: I'm really really sore today. Then that would probably be more like encouragement.

201. S: Ah.

202. J: Ja.

203. S: To get encouragement from that person.

204. J: To be like just, ja.

205. S: So how does that person ... What do they say back to you?

206. J: Well usually they start by asking like can they do anything to help me, and it's always no, because what can you do to help? Ja. And just, encouragement.

207. S: So you've found having a small group of supportive friends helpful?

208. J: Ja.

209. S: One of the other things that you mentioned the last time that I also wanted to explore was, you use your dogs as a coping strategy.

210. J: Yes. My dogs are very, very good now. So they sit with me if I study. And my one dog, he sits on, he sits on the counter and eats biscuits with me when I have to inject myself.

211. S: So, so can you show ... So, do you do it in here or in the ...

212. J: I do it in the kitchen.

213. S: In the kitchen. And then you sit on the kitchen counter?

214. J: Well no, I stand and then my mom does it, because it's just so painful that I can't physically force myself.

215. **S:** Force yourself to inject yourself.

216. **J:** I could do methotrexate, but I'm not on that anymore. And then I hate it so much, so my dog, my mom brings my dog in to sit with me.

217. **S:** Ok.

218. **J:** Ja.

219. **S:** So you're standing in the kitchen and then where's your dog?

220. **J:** On the counter, ja.

221. **S:** On the counter eating biscuits.

222. **J:** Ja.

223. **S:** How does that help?

224. **J:** Well he's such a goofy dog that he ... And he's very, I don't know, he's so in tune with emotions. Like the other day I came home and I was really, I was crying and he like pounced on me and licked my face until ... And like wherever I went he would like nudge my face to make sure I'm ok. So, he's very ... Ja.

225. **S:** So he's really in tune with how you're feeling and then --

226. **J:** Ja. He kind of ignores me when he knows I'm ok, but if he picks up something's wrong, then he'll come and be all supportive.

227. **S:** Is it just the one dog that's supportive?

228. **J:** Yes. My other dog's too self-obsessed. Ja.

229. **S:** So do you think, do you think that would be a strategy that might work for other people? Would you ... Having animals for comfort.

230. **J:** I think so. I think ... dogs . . .

231. **S:** And I was wondering, so you've got quite a lot that you have to cope with, because there's the medication and the negative side effects, and there's things like the injection.

232. **J:** Ja.

233. **S:** And then there's also, the fatigue is quite bad for you.

234. **J:** Ja.

235. **S:** So pain and the fatigue.

236. **J:** Especially if you get sick on top of it – it just knocks you completely.

237. **S:** So, so how do you cope with the fatigue and, and getting sick?

238. **J:** I really don't, because I got sick like right now before my exams – I had sinus and ears and stuff. And just I couldn't ... And then they changed my pain medication to codeine and upped my steroid dose to like 40 milligrams.

239. **S:** While you were sick?

240. **J:** Ja. And then I was just knocked completely out; I lost so much study time because I would sit and stare at this page and not know what to do with this page.

241. **S:** Because the medication was so strong.

242. **J:** I was so like ... Ja. Because I think they told me to take like four Gen-Payne tablets a day, which is so much codeine and you just, ja, you can't function like a normal human.

243. **S:** So, so there is no way for you to cope with that.

244. **J:** You've just got to rest, like a lot. Because like normally I like get way more tired than other people, I think. Like they, if they have to stay up late before exams, fine, they can sort of function normally. If I have to do it I'm like a zombie the next day. I just can't.

245. **S:** So you just have, don't have the same energy levels or stamina.

246. **J:** No, no stamina. Zero.

247. **S:** Zero stamina.

248. **J:** Ja.

249. **S:** Ja, ja. You said something important just now, for me, and I've just gone blank on what you said. It was to do with the fatigue. Resting – is resting not a coping strategy?

250. **J:** I am so bad at forcing myself to rest. So I -- Ja. During -- Especially during exams, there's always something else I can do and something else I can do and something else. Ja.

251. **S:** So you just keep busy.

252. **J:** Ja.

253. **S:** And then you don't rest.

254. **J:** Not during exams, no.

255. **S:** Not during exams.

256. **J:** And then like on a Friday I just come home and like: I have to study, I have to study.

257. **S:** And then you just force yourself.

258. **J:** I kind of come home from school on a Friday and just like, I can't do anything. So then I lie down for probably a long time, like three hours.

259. **S:** Three hours rest.

260. **J:** And then I ... It's like nine o'clock then and then it's like: ok, let's study. But why? But I do anyway.

261. **S:** So do you think rest is something that needs to be incorporated into your life more regularly or ...

262. **J:** I think so, but also with being in matric, you don't get a lot of rest time. So, ja.

263. **S:** And then it sounds like keeping yourself busy is maybe another way in which you cope, or not?

264. J: I don't think so. I just, I, I know I force myself to do stuff, even though I know I'm going to be so dead from it. So I don't think it's a coping mechanism.

265. S: What do you think it is?

266. J: I'm not ... It feels more like an obligation. It'd like, ok, you like this and you have to do this to get into university, so go do it. So, ja. Ja.

267. S: Ja, I think we discussed that the last time, didn't we? About setting goals for yourself that you were sort of ... You didn't, you didn't want ... You wanted to succeed at something. But then you weren't too sure. Not giving up, I think it was, but then you weren't too sure if that was actually the right ...

268. J: I can't even remember that.

269. S: So do you think it's a sense of obligation to do things that makes you do it?

270. J: I think so. And also I feel guilt about everything.

[30 minutes]

So if I don't do it then I'll feel guilty.

271. S: Oh.

272. J: Like everything. Like about a snail I squashed when I was seven.

273. S: You feel guilty ...

274. J: I still feel guilty about that.

275. S: And what kind of things do you feel guilty about now, that make you push yourself hard?

276. J: Well it's just like, if they can do it so can I. Go and do it. If you ...

277. S: "They" being?

278. J: Anyone else.

279. S: Sort of like your peer group?

280. J: Ja. So, ja.

281. S: So if they can do it, then you must be able to do it.

282. J: Ja.

283. S: Or should be able to do it.

284. J: Yes.

285. S: And then you push yourself.

286. J: Ja. But that's just ... For me then there are like a million other things I feel guilty about.

287. S: What are the million other things you feel guilty about? Are they related to the illness?

288. J: No.

289. S: Ok. You just generally ...

290. J: Feel guilty about everything.

291. S: You take stuff on board yourself.

292. J: Ja. Like silly things, ja.

293. S: Like squishing the snail.

294. J: ... it's just annoying.

295. S: And the anger? Last time you were very angry that I saw you. No, you weren't angry that I saw you. You were angry. When I was seeing you, you were saying that you were very angry.

296. J: Ja.

297. S: Sorry, that came out all wrong. And I was, I was wondering how that is at the moment.

298. J: It's going better. Like, I was in a very bad space. I think it gets worse during exams, but ... Sorry, there's like dog fur or something.

299. S: Something in your eye.

300. J: Ja. So itchy. I think it's going better. I haven't done anything majorly bad to myself, so, that's getting better.

301. S: No more hitting.

302. J: Ja, that went sort of slowly away.

303. S: What do you think has helped the anger?

304. J: I'm not really even sure. There's nothing that I can like pinpoint. Ok, I think we did go on a very relaxing holiday that just was so great. I came back extremely extremely relaxed and it's just been much better since then. So, ja.

305. S: So a relaxing holiday. What did that involve?

306. J: Well we went to Mauritius, me and, just me and my mom. So it was like away from my dad's swearing, it was away from friends, it was just away from everything. And then it got better. And then it got worse when I came back because there's like a friend who was saying: I can't deal with your life anymore. Like, you told me you could. So that was a bit ... That was very difficult to deal with.

307. S: What -- And, and how was it difficult? Can you describe how you were feeling?

308. J: She was probably like the closest person to me at the time. But then it was like: I can't deal with this, it's too exhausting for me. I was like: it's exhausting for you? Ja. But ...

309. S: So, so being supportive of you was just too much for her?

310. J: I ja, I just found it frustrating, because the only time I really called on her was on a Friday when I had to do methotrexate and I was like: I can't do this. So ja, that was quite frustrating.

311. S: Frustrating, or is there another emotion attached to it?

312. **J:** Well, there was definitely anger and there's still, because it was like a very close group of three. And, and then she just was like not talking to me.

313. **S:** And wasn't talking to you.

314. **J:** And then when we asked her why, she said that it was stuff that the other girl had said to her, and why am I getting involved then. But then she said, sent a message: ja, I can't deal with your life, it's too exhausting. Whatever. But that's fine now.

315. **S:** And it was just frustrating? It wasn't ...

316. **J:** Ja, I got very very angry. Like every day I think was a nightmare to ... at that time.

317. **S:** How long was that for?

318. **J:** Probably like a solid month.

319. **S:** Oh, ok.

320. **J:** I think I was driving my friends insane.

321. **S:** Why? What did , what were you doing do you think that was driving them insane?

322. **J:** I would just be so grumpy with everyone, everything. And trying to get me ... I think the biggest problem for my mom was trying to get me to do Enbrel on Friday. And I'd just refuse and be super childish and like lying under tables. A complete brat. So I think that was exhausting for my mom.

323. **S:** And then does that also lead to feelings of guilty?

324. **J:** I think at the time, but it's not something I like hold onto a lot. Ja.

325. **S:** That's -- It's interesting that you don't hold onto that but you've held onto ...

326. **J:** The snail. [laughing]

327. **S:** About the snail, ja. What is the difference between them for you?

328. **J:** I don't know; I can't understand my mind. I have guilt I hold onto, like this girl died in America. I've never met her, I don't know her at all, and then she died and I was like: I'm so sorry. And I feel guilty. And I'm like: but you've never met her!

329. **S:** Which girl is this?

330. **J:** She, she died of cancer, so.

331. **S:** Oh, ok.

332. **J:** Ja. Dr Y. I don't ... Ja.

333. **S:** Do you think maybe you felt a link with her or something, through the fact that you both were ill?

334. **J:** No.

335. **S:** No.

336. **J:** It's too different.

337. **S:** Too different.

338. **J:** Ja. ...

339. **S:** I was just wondering, because one of the things I actually had here to ask you about, and it's interesting that you raise this friendship issue, because I was going to ask you how your illness impacts on your relationship with other people. Particularly when they don't understand.

340. **J:** I think it's quite difficult. Well that girl clearly couldn't handle. Then, but there's other people who always just are like, like they ... Ja. So in that group of three, one would never stop supporting me, but she's also very ... I don't think it's the healthiest friendship to be honest.

341. **S:** Ok.

342. **J:** Ja. So I think she's also there for my support for her.

343. **S:** Oh, so you were supporting ... It was a two-way thing.

344. **J:** I think so ja. So it's not the healthiest friendship, because she's quite a destructive person. But ja. And then I think it's also made me make new friends with more people who are like curious and ask me questions and like ja. I don't know. Then they just become ... And come and mainly talk about other stuff, and then become friends.

345. **S:** Ok. So they start ... They ask you about yourself first because they're curious, or because of your friend?

346. **J:** No, because they're curious. Well my English teacher last year announced it to everyone.

347. **S:** Oh.

348. **J:** Which is not what my intention was. And then ...

349. **S:** How did that come to pass?

350. **J:** How did that?

351. **S:** How, how, how come she announced it to everybody?

352. **J:** They're quite strict about what we write on our slips because the usual doctor's appointment will get you like detention, because why did you come late to school when you could have booked it after school? But because the clinic only runs on a Wednesday and Friday, then I write "rheumatology appointment" . . . Wednesday or Friday only. So then he read out my late slip to the whole class, and I was like: not what I wanted you to do.

353. **S:** Oh I see. Ja, School Y is seriously strict about that kind of stuff.

354. **J:** So, ja. Because if I'm late ... If I go to a doctor three times in a term, then I would get detention, but because they now know that that's only on a Wednesday and a Friday in the morning, then I'll be fine.

355. **S:** So they give you detention for going to see the doctor?

356. **J:** No, if you're late, if you could have arranged it at another time.

357. **S:** Oh.

358. **J:** But because I can't. If you like always book appointments and you come to school late all the time, then they get very edgy with you.

359. **S:** Oh, ok.

360. **J:** Ja.

361. **S:** Ok. And then ... So this teacher read it out, read your late slip out to the whole class?

362. **J:** Ja.

363. **S:** Wow. So what was going through your head?

364. **J:** It was like: are you serious? Because then you have to face the stupid questions like: isn't that something only old people get? I'm not 80, so what do you think? I think sarcasm is a coping mechanism.

365. **S:** Sarcasm is a coping mechanism.
[both laughing]
So, and the emotion behind it when he just announced it to everybody?

366. **J:** I just ... I don't know. I was just like: well, you've done it now, so.

367. **S:** You've done it.

368. **J:** I think he also realised because he stopped in the middle of it and then looked at me.

369. **S:** But it was too late.

370. **J:** Ja. Bu that's, that was fine. Ja.

371. **S:** So then people became curious?

372. **J:** Some people certainly became curious. And there were the stupid questions of like: isn't that something only old people get?

373. **S:** Say that again, I couldn't hear.

374. **J:** Isn't that something only old people get.

375. **S:** Oh, ok.

[40 minutes]

376. **J:** No.

377. **S:** No. But were you more comfortable talking about it now than you were when you cut yourself off from everybody?

378. **J:** Well, it depends to who. So there were certain people who like gave you a look, like what, that's weird. Then I will just stay away from them. But no-one's been like ... There's never been anyone who's been horrible about it. And ja.

379. **S:** So it sounds to me like you've choose ... You've moved from cutting everybody else off to choosing how far you will explain what's wrong with you with the different people.

380. **J:** Ja.

381. **S:** So you're judging from their faces and what they say, you decide ...

382. **J:** Ja, I think it's sort of the first thing I tell people because I want to let them know what they're getting themselves into. Ja.

383. **S:** And why, why would you want to let them know? What is it that they're getting themselves into?

384. **J:** There's going to be like certain times where I'm just calm, and certain times when I just don't want to talk to or be around people. Or I'm just in a bad mood from things that they can't understand.

385. **S:** So you're warning them up ahead.

386. **J:** Ja.

387. **S:** If you can't deal with this ...

388. **J:** Then go away, I don't want you here.

389. **S:** Ja, ja. So you're making more friends now.

390. **J:** Ja.

391. **S:** and does that help?

392. **J:** I think so. Ja, you do still have to deal with the ... And then they tell their mothers. That's annoying., because some mothers would come up to me and be like ... This one mother came up to me and was like: you know, when I had cancer I spoke to my cells and it just, it went away. I was like: are you sure it's not the chemo that you were on? But -- And then she was like: you should talk to your cells, communicate with them; it will get better. I'm not going to, no thank you.

393. **S:** what, what did you think about what she had to say?

394. **J:** I thought she was crazy to be honest. Which isn't nice, because I was judging, but I was just like, ok.

395. **S:** So just another example of people saying the wrong things. Ja.

396. **J:** It's sometimes quite humorous though.

397. **S:** Like that event.

398. **J:** Ja.

399. **S:** Do you find that humour helps you? Because you mentioned sarcasm earlier.

400. J: I think so. Like, all my hair fell out here, so it's like growing back crazy and you can't do anything but laugh at that. I think that helps. It was like bad when it was falling out and you felt so bad, because every time you would brush your hair it would just fall out.
401. S: What was it, why was it falling out?
402. J: Well the methotrexate ...
403. S: Oh, the methotrexate.
404. J: Ja, is chemo... . But now that it's growing back you have to laugh, because it's just so ridiculous.
405. S: So humour's a definite coping strategy for you then.
406. J: Ja.
407. S: So sometimes it's not about necessarily coping strategies; sometimes it's people seem to find quality of life even though they're ill. I don't know, do you find things that bring quality to your life? Because I mean, when you think you're injecting yourself and you've got the negative side effects, is there positive aspects within that?
408. J: Of the injections? Well ja, because it's making me get better, but I think, ja.
409. S: And are there any positive things in your life?
410. J: Of course. Like ...
411. S: Of course.
412. J: Like dogs. Like they're a positive ...
413. S: Like dogs.
414. J: Ja. I think that's also ... I have this one friend who's like also, he says: I wouldn't be able to deal with this. It's like, well, you don't really have a choice. It's like, you're not ... You didn't say, here ... get sick. You're not given that. So, and then he's like: when I'm old and in pain, I would just want to end my life. I'm like: stop being so negative. So I think there's that aspect as well.
415. S: To not be negative?
416. J: No, I'm negative a lot. I just think you can't be like: I want to kill myself.
417. S: Oh.
418. J: Ja.
419. S: Why, why would that not be an option for you?
420. J: What? To commit suicide? Well, I mean there's like a million people you leave behind. It would only just pass on the pain to someone else.
421. S: Ah, ah.

422. **J:** And like I'm not depressed. And ja, there's like lots of exciting stuff. It's not like I never ... Ja. It's not a good option.

423. **S:** So despite being ill and in a lot of pain and having the side effects, there's still a lot of exciting things in your life.

424. **J:** Ja.

425. **S:** So what, what kind of things add value to your life?

426. **J:** It's very simple stuff. I don't know.

427. **S:** Tell me.

428. **J:** I don't know. There's not like ... I don't know.

429. **S:** It doesn't have to be deep and meaningful. Sometimes -- Often it's simple things.

430. **J:** I'm all for like, I don't know, my family, my friends, my dogs ... water.

431. **S:** Plants, water.

432. **J:** Beaches. The sky. I don't know. I don't care about, ja, other stuff. Like material stuff isn't that important to me. Ja.

433. **S:** So are you saying it's the experiences of being with other people or being on the beach.

434. **J:** Ja, just, ja. I don't know. It's not ... Ja. Exciting things. Things to look forward to.

435. **S:** Things to look forward to. What are the kinds of things you look forward to the most?

436. **J:** My cousin coming in December.

437. **S:** Your cousins are coming.

438. **J:** That I'm really excited for.

439. **S:** Oh, ja, where are they coming from?

440. **J:** Australia.

441. **S:** Is it one or two, more cousins?

442. **J:** It -- I'm not sure because I don't think ... She's my cousin and my, her mom's my mom's sister, but my mom's sister died. So it's her dad and his new wife, and I don't know if she's bringing any of her children.

443. **S:** Oh.

444. **J:** I don't know what you would classify them – step-cousins?

445. **S:** Ja, I suppose. But you're looking forward to meeting the cousin you already know.

446. **J:** Ja. So things like that.

447. **S:** It sounds like relationships with other people are important to you. Meaningful relationships.

448. **J:** Ja. But I don't want to be around people all the time. I need to have space too.

449. **S:** You need space too?

450. **J:** Ja.

451. **S:** Why is that?

452. **J:** I don’t know. I’m very socially awkward, so I don’t really like being around people.

453. **S:** Oh, so maybe you just prefer your own space at times. So it’s not a fatigue thing, or is it a bit?

454. **J:** Ja, like I can be fatigued around people and then they must just know that I want to sit down and just talk and not do anything major.

455. **S:** And just sit with them.

456. **J:** Ja.

457. **S:** Are you very uncomfortable today?

458. **J:** No.

459. **S:** You’re moving a lot.

460. **J:** I’m just ... Sometimes -- Hannah! I think your dad’s here.[shouting]

461. **S:** Do you want to say ... Shall I just pause this?

462. **J:** Ok.

463. **S:** Let me just pause this.

[recording a ends]

[recording b starts]

464. **S:** New one, new recording. Alrighty. There we go, it’s starting again.

465. **J:** Ok.

466. **S:** Alrighty, super. So I was just wondering if you’ve thought of, if there’s been anything positive for you that’s come out of being ill for so long?

467. **J:** I discovered that my dog actually likes me – that’s good. And that who my real friends are. And I think it will help me later on in life, because when I’m ... You always know that, no, look at what happened when you were 15 or 16. You’ve gone through that, you can get through this too. Ja.

468. **S:** So, so, so what is it that you have learnt that will help you get through things later?

469. **J:** Well, it doesn’t help crying about it, as much as that feels good. Ja.

470. **S:** Can you think of anything that you could use later on in life that you’ve learnt from this hardship?

471. **J:** Well, I don’t know, maybe if someone else is going through it you could help them. Or ...

472. **S:** How, how would you help them? What could you share with them?

473. J: I think you'll just know, you'll have a better understanding for what not to say, and that helps. Ja. Like this one girl who helped Naomi – Sarah – when she came up to me like a few weeks back she was like: you know, if you ever need someone to talk to, I've been through this with Naomi before, I know what ... Ok. Ja.

474. S: How did that feel?

475. J: Well that felt good. I didn't, I didn't like take her up on her offer to talk, because like I had found a great group of friends. But I mean it felt good to just know that some others cared who didn't have to care, sort of thing. Ja.

476. S: *Sjo*. So any other positive things that have come out of it?

477. J: I'm sure there is some, but I can't really think of it. You find really good ways to get up off the floor.

478. S: You find good ways to get up off the floor?

479. J: Ja, ja. I think ... Ja.

480. S: So it was just maybe those things.

481. J: I can't really think of too much more because there are just so many things that cause frustration.

482. S: If you think back to how you were in the early days of your illness and how you are now, have you seen any changes in yourself?

483. J: I am a lot more socially awkward. So much more socially awkward, it's bad.

484. S: Ok. Can you tell me more about that?

485. J: I think it -- I just didn't -- I just stopped really going out. I didn't go out much before but then I stopped completely. And when my mom and dad would go to friends, I would be like: no, I don't want to go. And then like even with cousins I haven't seen for a while, the ones that ... Ja. Like we don't ... I find quite difficult to talk to. But then there's, then there's some that I haven't seen for ages but I still get on really really well, but the ones I used to be able to talk to ... Ja.

486. S: What do you think has caused you to become more socially awkward?

487. J: I'm not ... I don't know. I think I just went more and more into myself; didn't feel the need to talk to people that much.

488. S: So are you, are you saying that because you haven't been talking to people, you've maybe got less experience?

489. J: Ja.

490. S: Or is it ...

491. **J**: ... But also I think that, but then I think: you've made good friends in the past few years, so how can you say that? But then I realise ... Like at the matric dance I went to, it was like, I didn't talk to anyone apart from the people I was friends with. And when they all went to dance, I refused to dance. And then at the other, when I went to my friend's one, and I didn't know anyone there except the Bio teacher from my school, so I spent the whole time talking to him. Or hiding in the bathroom because I just couldn't bring myself to talk to anyone.

492. **S**: Is that because you were feeling shy? What, what does socially awkward mean?

493. **J**: Ja, like you're shy and you just sit there and go like ... You don't know how to talk to people. You just play with your hands and ja.

494. **S**: And then hide in the toilet.

495. **J**: Ja.

496. **S**: And you didn't ... Why did you not want to dance?

497. **J**: I feel too awkward dancing. I have never danced. ...

498. **S**: It's not something you enjoy?

499. **J**: No, not at all.

500. **S**: And ja. How -- Well the last time we were chatting, you were talking about your future, med school.

501. **J**: Oh ja.

502. **S**: You were going to, you know, you were going to have to stay in Cape Town and everything. And I was just wondering, since then, have you thought more about your future and ...

503. **J**: Ja. Well, right now I'm forcing myself not to think about it because I think and then I go like: oh my word, I've messed up my language. That's it, that's my chance taken away. And then it's like: I really want to go to Stellenbosch, but they haven't accepted me, but UCT have, but then I don't want to go to UCT because it's so like messed up at the moment. So I don't think about it much. I only applied to two universities because I can't leave Cape Town.

504. **S**: Cape Town. Ja, you said. It kind of cut out Wits and all of those other universities.

505. **J**: But looking at what happened at all of them – fine, I don't want to go there.

506. **S**: Ok, so you're trying not to think about your future at the moment. That's a, that's a combination of having ... Not feeling so confident about your exams but also what's going on generally on the campuses and the wider social ...

507. **J:** Ja.

508. **S:** So what might you do if you don't go to university next year?

509. **J:** Well -- No, I will go to university because I've been accepted for B.Sc.'s at both.

510. **S:** Ok.

511. **J:** It's more a choice of, if I go to UCT then I can never go to Stellenbosch, because that's their policy. But if I go to Stellenbosch, I can still go to UCT. But it's really difficult to be like: I'm not taking this medical like position you've offered me and, because I want to go to Stellenbosch. So I want to go do a B.Sc. and there's no guarantee that I'll ever be accepted again. So ... It would just be really nice if Stellenbosch would just be like: you did well, here you go, come study medicine. But that won't happen, so ja. Ja.

512. **S:** Ok. And there's a, there's a ... I'm just going to put it out there; there's this sort of theory that you can find wellness even though you're ill. That you can find quality of life and well-being even when you're quite ill. What do you think about a theory like that?

513. **J:** Wait, let me just make sure I'm understanding. So if there's like dying from cancer and they're like so sick and they ...

514. **S:** Well even ill like you and I.

515. **J:** Ok, but like you said they have no quality of life – is that what you're talking about?

516. **S:** I, I'm saying that you could have quality of life even though you're very sick.

517. **J:** Ja, I think so. I think it's more mental-based. Ja.

518. **S:** Can you tell me more about that?

519. **J:** You've got to get . . . you know ... If you always focus on like: I'm so sick; I can't do that because I'm sick, I can't ... Then you're not going to have quality because you're making yourself miserable. Ja.

520. **S:** So what kind of things do you think would add quality of life in illness? If it's mental?

521. **J:** Ja.

522. **S:** What, what kind of mental things?

523. **J:** I don't know. You must just try and be happy. That sounds like so superficial.

524. **S:** How would you try be happy? What kind of things could you do, could a ...

525. **J:** I don't know. I think for me I find things I like and go do it. So I really like dogs and it's a toss-up, always a toss-up of: is this going to affect me more than the happiness. That's probably really, that's the most annoying part, because you always have to debate. So I like dogs and I like helping out, so then you go walk dogs.

526. **S:** Then you walk dogs for TEARS.

527. **J:** Ja, well today was my first time. It was something I decided to do and try and then that makes me happy, and then you stick with it. And then you come home and realised: oh, I'm really achy. And you go do something that makes you happy and then ...

528. S: So what would you do if you were achy, to make you happy?

529. J: Watch probably a happy movie or Harry Potter. Ja. Ja.

[10 minutes]

530. S: So rest and watch a movie.

531. J: Ja. Or ...

532. S: So am I right in saying that you find things that make you happy and then you have to make a decision: can I do this or not, is it, is it worth the consequences of getting tired and sore?

533. J: Every, everything you have to make a decision about.

534. S: You've got to make a decision.

535. J: Every single ...

536. S: And then if there are consequences then you try and find something happy that you can do when you're not that well?

537. J: Yeah. Or you just, or you just like know that this, this made me happy, so just deal with it; it won't last forever.

538. S: The, the tiredness or the pain afterwards.

539. J: Ja.

540. S: Ok. So for you it really is a lot about finding good moments.

541. J: Yeah.

542. S: And not focusing on being sick so much.

543. J: Ja.

544. S: And do you think there's anything else that you want to share with me today that you can, that you haven't maybe, or that I haven't asked?

545. J: I think if you're putting together advice for young people then they need to sort their families out too, because your ... Ja. You need your family.

546. S: Ok. Do you want to tell me some more about that?

547. J: My dad's the worst at understanding and he's so impatient about everything, which is so ridiculous considering he has gout and is in pain and all the time. He should understand. Ja. Very frustrating.

548. S: So you're saying that in order to help other adolescents with this illness you need to actually work with the family as well?

549. J: Ja. Get their family on board with.

550. S: And how does a family need to be on board? What would they need to be?

551. J: Like my mom, because she lives with me all the time, she's more like, she knows more. She'll be like ... I don't know, she just makes sure always that I'm not overdoing myself. Like you get so energetic sometimes because you can't, like you can't do anything and then you just want to bounce off the walls. And then if I do that, she'll be like: you must stop that, you're going to hurt yourself. Why don't you do this instead? And then, and then if we're out then she'll be like: ok let's take a rest. Or: do you want to turn back, if we're walking the dogs. My dad will be like miles and miles ahead, and then he'll come with all his swearing and we're just like: calm down. Ja.

552. S: So, so really making sure that families understand.

553. J: I think -- Ja. And I think they should all just be present at, like both parents should be present at the doctors. My dad's never been to an appointment before.

554. S: What does that mean for you that he never came?

555. J: I don't ... That's just how our relationship works; there's not much there, so. That's -- I kind of didn't really expect him to come. But it is annoying when there's, when some of my friends were like: can we come just to see like what's going on and then he has no interest. I'm like: but they don't even have to come, you should ... Then that's a bit of a contrast. Yeah.

556. S: That he hasn't shown an interest.

557. J: Ja, not an ... His friend came down once, and his friend is super cool and we get on well because he's also, he's really really sick at the moment. So then we were comparing medication and stuff, but my dad found it like a joke that methotrexate . . . And I was like: it's not a joke at all. So ja.

558. S: So it's about getting family members to understand experiences.

559. J: And not offer cryogenic freezing.

560. S: And not offer cryogenic freezing.

561. J: Ja.

562. S: Ja. Anything else you think I should include?

563. J: Not that I can think of right now. I don't know, find ... If you're going to go to a psychologist, find one that's not going to tell you it's emotional.

564. S: Ok. So don't go to a psychologist that's going to tell you ...

565. J: It's emotional pain.

566. S: It's emotional pain.

567. **J:** Ja. It’s very frustrating. And like going back and saying: your cousin going to Australia was probably the event that triggered it all. No, this happened way before my cousin came to Australia, went to Australia.

568. **S:** That kind of fits in with something I think you raised earlier today and the last time, was that, people not listening to you.

569. **J:** Ja. It’s quite frustrating.

570. **S:** Not hearing your experience.

571. **J:** Ja. That is quite frustrating. And just trying to make it work. Like, it doesn’t have to make sense. Like it doesn’t have to.

572. **S:** What doesn’t have to make sense?

573. **J:** Well like, sometimes things just happen; you don’t need a reason.

574. **S:** Oh, for, for, to, to have the illness.

575. **J:** Ja. Like it doesn’t happen ... It doesn’t have to be a single trigger event. Like we think, we don’t know, it might have been when I had glandular fever I think, when I was younger. But we don’t know and that’s fine, because it just happened. But it bothers me when people try and find something to blame it on. It doesn’t have to have ...

576. **S:** It’s not going to change things.

577. **J:** Ja, and prob ... And I feel like probably right now ... Oh yeah, the one, the first psychologist I went to said it’s because I’m always stressed about exams. And I was like: I’m pretty sure when I was six I wasn’t stressed about exams. I was not stressed. And then the second psychologist I went to tried to say it was because I’m like dealing with the loss of my cousin. But I don’t know, I think that I really feel like I got over that long ago. It’s not like I never see her and I still talk to her a lot, so.

578. **S:** And when somebody tells you, or told you, these psychologists told you that your, your illness was the result of emotional pain, how did you experience those comments? I mean, how did you make sense of them? What did it mean to you?

579. **J:** Well, I don’t know, I got frustrated because I mean it’s going back to that: you’re crazy, you’re not sick. And then it was like back to the mental illness. No, just no.

580. **S:** Tell me more about the “no” there.

581. **J:** Like, you just ... I don’t know. It’s made worse by my mental feelings but it, I don’t think it was ever the result of it. But ja. I’m very ...

582. **S:** It sounds like you have very definite ideas about your own illness, health, well-being.

583. **J:** Ja, ja.

584. **S:** And how is your independence now? You’ve got ... Matric is over actually.

585. **J:** Ja, it is. I think it's more difficult to be independent because I'm dependent on someone to stab me every week. But ja, it's not ... It's more, I'm more independent because now I can drive, so then I can be more independent than having to wait for my mom to come home and be like: can you take me please? But ja, there'll still be ... I think I'll be more dependent on my mom that other people my age. Ja.

586. **S:** Because you still have to have those injections and things.

587. **J:** Ja. And it's like you need a place to go to when you're feeling very bad, and that's going to be home.

588. **S:** And when you look at your long-term future with this illness, how do you foresee that going? What are your thoughts?

589. **J:** I think it's just something you have to deal with. I think it is getting better, so that's more hopeful, but I thinks it more, it will be more way long term because it's genetic and there'll be a chance of passing it on. So that will be like way future.

590. **S:** You mean to your own children?

591. **J:** Yeah.

592. **S:** So do you think that's something you're going to have to deal with later?

593. **J:** Ja, I think you've just got to see I guess. Do more research into it and stuff. Espec -- Because like my dad has all those problems and my granny has auto-immune, so it's clearly genetic. Ja.

594. **S:** So one of the impacts for you in the future may be will you have children or will you pass it on to your children or ...

595. **J:** Ja. But that would be ... I think that's something that I'll probably deal with in the future.

596. **S:** Ja, you don't need to deal with it now.

597. **J:** No.

598. **S:** No.

599. **J:** ... and I guess I have thought like maybe if I do, if I keep my place at UCT or get a place at Stellenbosch for medicine, then I'm going to have to go through the training, and being on my feet all the time would have an impact. But I'm sure there's ways around that. Ja.

600. **S:** So any, any final thoughts?

601. **J:** No, not really.

602. **S:** Ok. Well, thank you very much. So we'll stop that there.

603. **J:** Ok.

[recording b ends]

Transcript 3: Judith Interview 1

1. **Interviewer (S):** And it's recording, so I'm just going to put it on the table here.
2. **Interviewee (J):** Ok, that's fine.
3. **S:** And that is working. So thank you very much for agreeing to the interview.
4. **J:** Oh, it's a pleasure.
5. **S:** And I was ... Ja, so basically all I want to just ask you about is the journey and the process that you've been through with Jessica and how it's impacted on you. So I don't know if you want to start with from when you first started noticing maybe there was something wrong with her. Just take me through the journey.
6. **J:** *Jo*. She had symptoms which were vague from ... Ok, looking back I think it probably started when she was six-ish. Before that even – I don't know. She spent so much of her junior school years on crutches and everything came out as orthopaedic type problems. And I never suspected an arthritis problem. She just -- Although she injured easily and didn't heal. And would be in pain for much longer than anybody else. And only after, I mean, what did we see? An ankle specialist, a knee specialist, a somebody else, I can't even remember. But we saw lots of specialists, because they only work with ... So she would hurt her knee and then she would hurt ... Or it started I think in her ankle, and then she hurt her knee, and then it would be ...
7. **S**: A knee guy or a ...
8. **J:** A, a knee guy and then it would be an ankle guy, and then it would be ... And so the ankle guy actually operated when she was in Grade 8 and it had no ... Because, you know, the lovey MRI showed fluid in her anthrolateral gutter or something stupid, which we could do something about because there's fluid. So let's go and drain it. Ja. No, no, no relief. And then it was her knee and she hurt it and then ... Everything, she would do small things and it would just and she'd be in pain and she would start limping on the other side because she'd be walking funny and ... So eventually after ... In Grade 8, after Grade 8, now I was starting to get beside myself because I was so sick of the sound of crutches.
9. **S**: This, this is, this happened since she was six?
10. **J:** Six. I mean she hurt herself when she was six at a Grade 1 picnic and it took forever. I mean she took her to the doctor because, you know, all she'd done is like twisted her, rolled her foot.
11. **S**: Oh, rolled her ...
12. **J:** And then it was sore and he said no, she has probably bruised her bone. And then, and then it was just everything. She was constantly in braces and bandages and crutches and

whatever. And I got so sick of the sound of crutches – those crutches drive me insane! The noise of crutches. [laughing] So and then I eventually thought, no, she just ... All the ... And it was getting worse and worse, every joint and every injury would just take so long. And she would never really get ... You know, it would never really be pain-free. And then I just asked that the head guy at the hospital, you know, is a friend of mine, and I said: just ... Oh no, then I took her to a rheumatologist who didn't diagnose her.

13. **S**: Ok.

14. **J:** That bone scanned her. Which showed nothing except – whatever these things are. TJ ...

15. **S**: TJ, ja. Temporomandibular whatever.

16. **J:** Well, ja. Just sort of overgrowth. Almost just like more defined than ... But that was, that was all. And then she said: ok, well send her to a biokineticist. Worst decision of my life. Took her to a biokineticist and halfway through the appointment she was just crying from pain. Sobbing. And the biokineticist: are you sure this is not emotional pain? Well I nearly killed her. And then the biokineticist really hurt her and then she was sore for weeks after the biokineticist. And the only thing that the rheumatologist said was she's got bursitis in both hips. So I picked up on that and I was, said to Mike Burger: what do I do? I'm now ... Something, something's not right. What, what -- So he said: e-mail me. So I emailed him all the information. He said: look, I don't know, I'm just going to pass it straight on to Dr Y

17. **S:** Dr Y?

18. **J:** Ja, Dr Y. He said: I'm just going to send it. And they picked up the bursitis in both hips – major . . . something.

19. **S:** Ja...

20. **J:** Ja. What also irritated ... Ja. So what drove me mad is that when I saw the knee guy I said to him: for me it's where all the joints, where all her tendons join her bones, that's where I feel her issues are.

21. **S:** Issues.

22. **J:** And that's exactly what enthesitis arthritis is. I was so cross when I got the diagnosis, that three years before I had said to him this is what, where I think the problem is and he dissed me you know.

23. **S:** Did he just not even acknowledge ...

24. **J:** He just didn't even acknowledge the fact that I had said anything.

25. **S:** Oh.

26. **J:** And I’m a bit irritated that the rheumatologist didn’t pick up anything as well. And then ja, Dr Y got the diagnosis... .
[speaking simultaneously]

27. **S:** . . . Ja, so that was almost 10 years.

28. **J:** It was like 10 years before we got a diagnosis, ja. Because it was so iffy. And also she was negative for everything. So we’d done the tests; she was negative for everything. You know, she’s one of those ...

29. **S:** All the bloods.

30. **J:** All the bloods is negative; she’s always negative of everything, ja.

31. **S:** Even with the genetic – the HLA-B ...

32. **J:** We’re doing that now. No, no, no, HLA-B ... She’s negative.

33. **S:** Is she negative?

34. **J:** She’s negative. She’s, she’s that 30 per cent, she’s negative, and apparently it’s more in girls than in boys that they come out negative. No, she’s negative for everything. No we’re just doing the double-stranded DNA now because she lost her hair. So they need to do tests for it.

35. **S:** Oh ok.

36. **J:** Ja.

37. **S:** Ja.

38. **J:** They’re just worried that she kicked into lupus.

39. **S:** Oh, ok.

40. **J:** Which it isn’t, it is, was just methotrexate-induced, but they just needed ... The hair loss, they were just a bit concerned. Just want, just wanted to double check that she hasn’t got lupus. But she’s negative for everything. Everything. CRF, the lot. CRP protein, sorry.

41. **S:** That journey for you – can you explain the emotions that you went through with ... And feelings or ...

42. **J:** Frustration.

43. **S:** Ja.

44. **J:** And just ... Because I am her backup.

45. **S:** Ja.

46. **J:** So it irritated me having to defend her, because I knew there was something wrong. And although ... So it was difficult to have to defend the fact that she was sore and I knew she was sore and I knew she wasn’t making it up. And there was very much a feeling that it was made up. And I knew it wasn't, and I knew it wasn't normal. So it was, that was difficult.

47. **S:** How did that impact on you, that people thought she was making it up? That is was emotional pain or ...

48. **J:** No, the one ... The emotional pain just irritated me; that just freaked me out because I knew that it wasn't as well and it was very easy to just ... Because I was told that by two people. So that, that, that irritated me. So I got it from her one psychologist, just ... She was actually diagnosed while she was with him. And then the, the biokineticist who I thought was ridiculous. If you've got a child sobbing because you're hurting her you cannot continue treating her, telling me that she's got emotional pain. That was, ja. I mean my child was sore and she was crying. So that, that's ... And the rest I actually didn't care. I'm very much ... but I don't care. You can think what you like about me and my child – I know there's something wrong and I know she's not making it up, and I actually don't care.

49. **S:** So you were just able to push through that.

50. **J:** I really don't care.

51. **S:** You would just move on.

52. **J:** Think what you like, it doesn't worry me. I know it's not true, so. I very much, I actually don't care what people think, so. [laughing] I really don't.

53. **S:** And then when you got to Dr Y, what was that like?

54. **J:** Awesome, because he diagnosed her instantly. Nina and him both saw her and from the minute we walked in she said, there is this type of arthritis and all blood tests can be negative and all of that. And they did the test and she clinically was a textbook case.

55. **S:** Ok. Finally.

56. **J:** And so literally the diagnosis was instantaneous. Which was awesome and I was so happy for. Because I mean, people freak out like what, so what did you feel when you got to the doctor? I say I was really happy. But after years and years and years of having to defend yourself against things, it's actually nice to know that it wasn't ... Because she was starting to believe that it was made. You know, I didn't, but she was. So for her it was a, a happy moment.

57. **S:** And you say the diagnosis came through while she was with the psychologist ...

58. **J:** Yes.

59. **S:** Who said it was emotional, hey?

60. **J:** Yes.

61. **S:** And how did that go down with him?

62. **J:** I don't think, I don't think he believed it. We didn't stay there. She actually ... No he taught her a lot of self-soothing techniques and stress, how to de-stress yourself, because she was ex ... I took her more because she was so stressed. You know, she didn't handle exam stress very well, so I took her more for that and I, I just thought she needed another outlet just apart from me. So from that side of things I was quite happy. He creeped me out – I didn't like him – but she was happy with him, so that was fine. And so that just ... Because I mean that ... The first day when we saw him, I just like, you know. Because, "you do know emotional pain comes through the joints? " I was just like, I'm not even going to go there. You're not going to go there. So we didn't go there. [laughing] So from that point, ja, he did, he irritated ... But he did teach her a lot of, of ... Which she still uses. So that was, that was ... Ja, so, but the diagnosis for him was also pretty irrelevant, so ja. Ja. And then, so I took her back to the school and she was very happy with the diagnosis and it was all great. Took her back to school, she was quite happy that she had the diagnosis. I went back to work and burst into tears. And sobbed my heart out in front of everybody, because I knew the path from there because I've had the clinic for ... I see the patients on the other of it.

63. **S:** Ja.
64. **J:** So I knew. And I knew the drugs and I knew, and I just thought: oh crap! Not going there.
65. **S:** So, so on the one hand it was a huge relief to get a diagnosis and know now what was wrong.
66. **J:** Yes.
67. **S:** But with your clinical background, medical background ...
68. **J:** Ja, I didn't ... I didn't give her any of that, I just sent her off with a great big smile and said how nice. Drove back to work and promptly just, ja, had a meltdown.
69. **S:** Ja.
70. **J:** But ja.
71. **S:** And I think there is there also with the, with the diagnosis, is there is the relief, you were right, there was something wrong, but at the same time ...
72. **J:** Yes, there was something wrong and I was justified in ...
73. **S:** It's not great to get a diagnosis either.

[10 minutes]

74. **J:** Well that's thing, you ... It was pretty much fifty-fifty I guess. You know. Because you were justified in your, your thinking; you weren't wasting everybody's time like they all implied all the time, and ja.
75. **S:** Ja.
76. **J:** But on the other hand I think when I got back to work afterwards that the overwhelm ... That the negativity overwhelmed everybody else.

77. **S:** And the negativity – was that mainly the, the, the drugs that she would have to take?

78. **J:** It was, it was purely the drugs. Purely the drugs. Because they'd said start on Sulfasalazine, we might have to go onto methotrexate, and I thought: oh no. Please no. But so from that side ja, I just knew.

79. **S:** And what is she on now? Because she, she's been through the methotrexate.

80. **J:** She's finished with the methotrexate; she couldn't tolerate it. So we went onto, she's on Arava instead of ...

81. **S:** That's right.

82. **J:** She's on leflunomide instead of methotrexate.

83. **S:** Ja.

84. **J:** She couldn't. She was genetically predisposed to the nausea so badly.

85. **S:** Ok.

86. **J:** I mean she just, just was. Just could not tolerate it – injections, tablets, whatever it was, she couldn't tolerate it. That was probably the worst year of my life, well obviously for her.

87. **S:** The year on methotrexate?

88. **J:** Ja.

89. **S:** And do you want to, can you tell me what you saw with her on the, on the methotrexate?

90. **J:** Well, she was just so ... Four days out of seven she was nauseous. I mean, she shows me her work, her English poetry from when she was on methotrexate where there's nothing written, to when she was off the methotrexate, there's notes written all over. Her English was, was in her worst nausea phase at school. Total zone-out. Couldn't ... Hates English anyway; I mean, poetry's just not her thing, and then basically she would just ... And even now, I mean there's so many things we can't eat and so on, because it will ... She's got, she's got literally PTSD from, from methotrexate.

91. **S:** Ok.

92. **J:** She literally has. She has flashbacks.

93. **S:** Really?

94. **J:** She wakes up in the middle of the night freaking out that she has to have her methotrexate. Freaking out from nausea because she was dreaming about methotrexate. It's quite, quite severe.

95. **S:** That's very interesting.

96. **J:** Quite, quite severe.

97. **S:** I've never heard of that before.

98. **J:** Quite severe.

99. **S:** That, that's something I need to go and explore ...

100. **J:** I looked it up once and there was a woman who had methotrexate like 20 years ago and still to this day has that ... Cannot forget that nausea induced from the methotrexate.

101. **S:** And then that, obviously certain foods you just can't ...

102. **J:** Peanut butter. She had a peanut butter flavoured brownie. Cannot even smell the stuff. She lived on cheese – that was the one thing she could tolerate – and there's so many ... Like she was also ... at that stage, so I made like lentil patties. Can't tolerate those because unfortunately I gave them on a day that she was ... So all of those are out. So there's a lot of stuff that she ... But she still has these nightmares that she's still on methotrexate.

103. **S:** *Sjo.*

104. **J:** That's how severe it was.

105. **S:** I mean that's ...

106. **J:** Four days out of seven she was ...

107. **S:** *Sjo*.

108. **J:** So ja.

109. **S**: And how did you cope with that as a mom?

110. **J:** Oh and the, the nausea tablets, the thought of the nausea tablets makes her nauseous because she had to take them so . . . So ja.

111. **S**: It becomes quite intricate.

112. **J:** So the Zofran, when she had a tummy bug long after methotrexate, I couldn't give her Zofran because ...

113. **S**: She linked that.

114. **J:** She linked it to methotrexate.

115. **S**: So you have to give her something else.

116. **J:** So I had to give her Valoid, ja. [laughing] Because she couldn't ... Ja. Ja.

117. **S**: It's actually quite a, quite a deep emotional scarring.

118. **J:** Very.

119. **S**: Form the medication.

120. **J:** It's probably worse than anything, was the methotrexate. Ja.

121. **S**: Ok.

122. **J:** So, January I just walked in, I said: there is no ways she can do matric on methotrexate. There is absolutely ... And she had no side effects from Arava, nothing. Nothing, nothing, nothing.

123. **S**: And was there a reason you didn't try it earlier? I think it's because it's very expensive, isn't it?

124. **J:** It is very expensive and you know you're trying to get into remission as well, so you're trying to sort of like stick to the plan. And you know, you hope that the nausea's going to go away, but it didn't; it just got worse and worse for her. It never, it never ever ever went away. It just got worse.

125. **S**: And I think that's the difficulty with the drugs, because you have to be on them three months or so ...

126. **J:** Before -- To see any ... And then basically starting Arava you then almost go back a step because now you've got a high dose. Because I think you're on, I think a hundred milligrams. You're on a high dose for three days anyway with Arava, like 10 tablets a day and then six and then you start on just your one table a day. So you go onto a high dose anyway. And then it takes three months to, you know to see any effect from Arava, so it is difficult because you do almost stop the process and re-start it.

127. **S**: Ja.

128. **J:** But, but ja. There's no way she could do methotrexate anymore.

129. **S**: Ja. Ja.

130. **J:** No ways at all.

131. **S**: And from your side watching her go through all of that with the methotrexate?

132. **J:** Hell. Hell. Absolute hell. Hated it. Hated injecting her. Felt like the ... Just hated making her ... Oh, in fact the methotrexate she could do herself, it was the ...

133. **S**: This one.

134. **J:** The Enbrel that she can't. Just the thought ... And the way she had to negotiate her life. Oh. You know, if there was something she really wanted to do on a Saturday, then we would have to negotiate: ok, well you can inject ... Instead of the Friday we'll inject on ... And we would have to see what did she have on the Monday. Always a toss-up.

135. **S**: Because of the side effects of the methotrexate?

136. **J:** If there was something she really ... Because Saturday was so bad.

137. **S**: Ja.

138. **J:** So, you know, because there's always Friday to give the hangover, the methotrexate hangover, over the weekend. But for a teenager ... So she always had to ... Everything was always a toss-up as to what to do. Whether it would be ... So if it was something she really wanted to do on a Saturday, then we would delay it until you know, until later on Saturday night or something. But then it would impact if she had a test on the Tuesday, you know, she couldn't. For everything was a negotiation; it was terrible.

139. **S**: Choices all over.

140. **J:** Choices. Everything had to ... She couldn't ever do anything without weighing up what was the ... And I mean even now,, ok so she wants to go to Rush, you know, the trampoline place,

141. **S**: Yes.

142. **J:** So she has to think: does she want to be sore for a week? You know, how ... It's awful.

143. **S**: So does the enjoyment of going, going to ...

144. **J:** Outweigh the ja, the risks of, of flaring. The enjoyment's always won so far with Rush.

145. **S**: Sorry?

146. **J:** The enjoyment has always out won so far when it's, when it's Rush. Because that's her favourite.

147. **S**: She likes that?

148. **J:** Ja, she likes that.

149. **S**: I, I know there's a lot of jolting with the trampoline, but maybe it's not so bad, I don't know.

150. **J:** Ja, she is, she always flares afterwards, but it's not ... It hasn't actually been as bad as I thought. Ja. But everything ... So on methotrexate, the parties I knew, I knew. I would drop her off and I knew I would be on standby to pick her up. And I would drop her off in town, I would just get home, and she would phone me and say: I can't do this. And then I'd go back into town to go fetch her and bring her home again. Everything was a toss-up and it has ... I, I mean I'm an introvert as it is. I think it's become worse; I've become, I've become very ... I have to be on standby for her twenty-four/seven. I can't think, ok we're going to go somewhere for the whole day or whatever, because I always worry that I'm going to have to bring her home beforehand.

151. **S**: So it's actually impacted quite a lot on your social life as well.

152. **J:** Ja, I'm an introvert so it's fine with me, but my husband isn't and you know, ja. And he was a big one of not believing she was sore as well.

153. **S**: Ok, so ...

154. **J:** Is she just, is she, is she really sore, or does she just not want to do this? Is she really sorry, or does she ... Ja. A problem.

155. **S**: And so her illness impacted on the relationship between you and your husband?

156. **J:** He's away at sea so much so it's always difficult anyway when he gets home, but she also felt, you know. I mean, she doesn't get along that ... I think it's just, ja. I think she got her teenager and he didn't quite know how to handle her when he was away for so long. So I mean, their relationship isn't great anyway. But she picked up that he didn't ... You know, he would never say to her: are you just ... But he would always say ... She picked it up.

157. **S**: Yes.

158. **J:** She knew he was ... You know, he really didn't understand, he really was ...

159. **S**: Ok, but he also has ...

160. **J:** He's got gout-type arthritis thing. Ja, ja, ja. So you would think he'd be more sympathetic but he's not. Anyway. So ja, but I mean, it's certainly a lot easier without methotrexate, I must say. Because we only have to deal with the pain, not the nausea as well. But we're certainly nowhere near remission yet.

161. **S**: But that's a very painful injection, isn't it. I mean she, you have to ...

162. **J:** I have to do it and I feel also like the biggest horriblest baddest wolf on earth giving it to her, because it really hurts. And she's also nauseous from the alcohol swabs – it also is a trigger from the methotrexate.

163. **S**: The?

164. **J:** The alcohol swabs is also ...

165. **S**: Oh, the alcohol swabs, yes, ok.

166. **J:** Yes the alcohol swabs are also a trigger for her.

167. **S**: Ja, ja, ok. I understand that ja.

168. **J:** But she better get over it quite quickly if she's going to do medicine next year; she better get over that one. [laughing] She's got to use them. So ja, that's a ... She had to walk out ... Oh when my dad was here with us and we had to, when we were sorting out my gran's estate and we had to go get death certificates and whatever from the doctor's, she walked into the doctor's and he had a big pile of alcohol swabs – she walked out. [laughing] Instant nausea, out. Ja.

169. **S**: It's incredible the impact that had.

170. **J:** So the triggers are, are severe. Ja that's, that's ...

171. **S**: And how is it giving that injection? I mean obviously you feel terrible, that's what you said ...

172. **J:** We've got an emotional support dog on the counter eating biscuits and I just, I just ...

173. **S**: Just ...

174. **J:** That's it.

175. **S**: Got to be done.

176. **J:** Quick as possible, get it over and done with and there it is. Ja, I'm finished. I mean apart from the pain she doesn't have any side effects.

177. **S**: Is it a quick injection or is it a long ...

178. **J:** Well it's a mill, so it takes a while subcut. It does, you, you know, it's not long but it's not point two mills which you really can just zoot, so it does take a little bit of time to ... Ja, ja.

179. **S**: And, and how effective is the dog?

180. **J:** The dog's cool; the dog thinks it's too wonderful – you get stuck on the kitchen counter and get biscuits. He thinks this is awesome.

181. **S**: An do you think, do you think that's ... It comes through quite a lot with, with the different kids about animals start to play quite an important role with them.

182. **J:** He's quite sensitive to ... He doesn't ... He's not like with her all the time. He's not ... She's not like his, you know, person number one sort of thing, but if she is emotional he picks it up. Because when she had hysterics after she failed her driver's test the first time – it was one of those stupid situations, I just couldn't go with her, so she had to Uber herself there.

183. **S**: Oh, already out of her comfort zone.

184. **J:** She had to Uber herself there and then the guy, I mean her instructor, he, he brought her back, but she was just ... And I couldn't get home because it was . . . and I had to work late as it was and I could not get ...

[20 minutes]

And she was hysterical. She phoned me and I didn't know what was wrong. I mean, for all I know she'd crashed the car. She was hysterical. But the dog then ... And he was very good with her.

185. **S:** He calmed her down, ja.

186. **J:** So, so ja, from that. So he certainly picks up when she's very emotional, so I think he's very good. He just, I don't think he cares as long as he's getting his biscuits, but he gives her something to like . . . when I inject her.

187. **S:** To, to hold onto. Comfort herself with. Ja, ja.

188. **J:** As long as he gets his biscuits he really isn't, he doesn't really care. Ja.

189. **S:** Ja. So it's been quite a lot of ups and downs with the meds and ...

190. **J:** Ja.

191. **S:** Ja.

192. **J:** All the others are fine; it was just, ja. She's never had any side effects from the Sulfasalazine like some do and, and the prednisone, you know, when she's on high dose ... But I knew that from when she was little. Because she had, you know, a couple of respiratory incidents where she had to have high doses and she was revolting; she was a demon on it. And high-dose steroids do make her grumpy.

193. S: Oh ok, so, so her ... [speaking simultaneously]

194. J: But only if she’s on like 40 milligrams, then she, she is, she is a bit more irritable. So she wasn’t on that for ... Every now and then we’d sort of give her the, the dose. If she flares, ja.

195. S: And does, did it change your parenting style at all with her?

196. J: I don’t know, because she always had it although she didn’t have ... So ...

197. S: So from six at least you knew something was wrong.

198. J: I didn’t know something was wrong it’s just, I have to admit, there was just these stupid things. So she was, I was, ja, she was always kind of, kind of sore in something or the other, so. And it was always very much like: oh well, you know, if somebody’s going to hurt herself it’s going to be Jessica, you know. It was always that sort of thing more than anything else. Yes my baby. So, ja. But I don’t know if it changed, because it sort of went progressive-wise I guess, so ...

199. S: It’s been a long time.

200. J: Ja, ja.

201. S: Slow progression.

202. J: Ja, slow progression. So I think it’s ... I’m not sure if it did or didn’t. But ...

203. S: And with your husband, because he’s away and then he comes back, did it change his parenting style at all?

204. J: No.

205. S: No.

206. J: Not at all. No, definitely not. He, ja, he always works through me.

207. S: Ok.

208. J: So, ja. I know it didn’t.

209. S: Ok.

210. J: He ja, eventually kind of learnt just to ... What I said went, and ja. But so I think it’s more that I don’t ... I need to make sure that I can have access to coming home and being on call and on standby and all of that, so.

211. S: That you can drop everything and get here.

212. J: I can drop everything and leave, ja.

213. S: Ja, get to her.

214. **J:** Ja. So I think I ... It's probably more that, that I've been well, not a helicopter parent, but I've always known that I'm pretty much on standby for ... Ja. If she phones and says ...

215. **S:** It must have been quite devastating for you after the driver's test, not being able to leave work.

216. **J:** Not being able to ... Oh, it was awful because I couldn't get out of her what was wrong, you know. Ok you've just failed, that's fine, but you know. [laughing] I didn't know what's ... She was like: I'm Ubering myself to your work. I said that's fine, you can come. I mean I obviously, I expected her, she was going to just, she, she needed me and she was going to come to work and sit in my tea room.

217. **S:** Ja.

218. **J:** So I said: that's fine, if you need to do that, come. But then the dog calmed her down, so.

219. **S:** Ok. Ja, ja.

220. **J:** So she recouped.

221. **S:** And how have you seen her development in comparison to her peer group?

222. **J:** Again, not as spontaneous, and everything's a toss-up, and she can't just do whatever she wants to do. And, and is, you know, they can just go. You know the Transkei trip in Grade 11 – it's awesome, you can just go. Whereas with her it was a huge thing as to whether they, I would let her go, the doctors would let her go, whether the ... In fact, when it was coming up she was pre-diagnosis, so it was very difficult. I mean I've never had one academic-related conversation with the Xhosa teacher; we only ever had: do you think she'll be able to go to Transkei conversations with the Xhosa teacher. I never ever had an academic one with him.

223. **S:** She really enjoyed that trip didn't she?

224. **J:** Loved it. And I'm so glad she went and, but again, I said to her we'll, I will make a plan and get you out. If you need to get out I will get you out. So again we went with that proviso that ...

225. **S:** So you've had to have back-up plans ...

226. **J:** If it falls through, I will hire a helicopter if necessary to come and get you out, but I will get you out. So, but it was him as well – he wanted her to go. He was very worried I wasn't going to let her go. And then it's like, you know, this injection, she's got to have all her tablets, she's got to be ... You know, just be aware that, you know, something might happen.

227. **S:** Ja.

228. **J:** But she was fine, ja. She flared quite badly afterwards but she was fine. It did her ... The, the benefits definitely outweighed the risks. Definitely.

229. S: What do you see the benefits of that Xhosa trip being? Transkei trip, rather.

230. J: She just came back more, I suppose confident that she could actually do it and just more little like group thing. She was just, ja. It was just a confidence thing.

231. S: Did you see any growth?

232. J: Not -- I don't -- Ja, I suppose so. Just in her, her outlook I suppose. Just her ... Ja. I think it just gave her more positivity and ja. But she definitely came back with more self-confidence.

233. S: And where do you think the self-confidence impacted her? Where did you see it most?

234. J: She was just more ... I suppose ... Although it kind of faded after a while, but, but, but a little bit more dependent, independent, sorry.

235. S: Little bit more independent.

236. J: Ja. Although the licence has done that more than anything. Definitely. Now she can make her own plans. Like I mean before she'd never never phone TEARS and ask herself if she could go. I mean, I didn't even know it was happening and she's organised it all.

237. S: Oh wow.

238. J: And she's booked an appointment with the woman and, you know. She phoned and said no, what dates can I come and ... Because you know she can get there; she doesn't have to rely on Uber or me or me paying for Uber or anything like that. So that, that's ...

239. S: Oh, so she can just ...

240. J: Ja, so she's definitely ... Ja.

241. S: So she sort of, that, just getting that driver's licence has really ...

242. J: Just made her, you know, she's more ... Ja.

243. S: Independent.

244. J: Ja.

245. S: Ja. More in line ...

246. J: Although she, this is literally the third trip that she's done by herself. You know, because that K53 is revolting. I mean, you get a licence but you cannot drive. Well, you can drive but it's, it's stupid. Like we were waiting for the ... His -- Rudy had gone, her instructor, and there was another instructor with a young guy there. And he said: you know what you do now – you go home, you scrap everything you know about K53, and you start to drive like a human. And that's exactly what you have to do. It's the most stupid thing – the robot's gone red before you can even go through it because you've done so many flippen checks.

247. S: Checks.

248. J: That you can't get through the robot before it's turned orange. So ...

249. **S:** Ja, so then you have to learn how to really drive.

250. **J:** So then I actually had to do drive ... Ja, ja. Also I wanted her ... The car's indicators and things were on different sides so I didn't want to ... So she drove completely with the instructor, got her licence, and then from then on she did every trip to school and whatever until ... And then this week while he's been, my husband's been away, so she's had access to the car, his car. His bakkie thing she's drove to her extra Afrikaans, drove to her exam, and now drove to TEARS. Ja. And back from physio, so.

251. **S:** Ah, that's ...

252. **J:** So it's nice.

253. **S:** A nice growth period for her. It's really ...

254. **J:** Yes, it is. It's just given her that ...

255. **S:** And of course I'm wondering how the ... Knowing that school is now over.

256. **J:** Well that's just it, ja. And also with now the bulk of her exams are done, it's also different. She's like relieved, because she had a horrible timetable, so it's been nice that she ...

257. **S:** Oh did she?

258. **J:** Terrible. Ja. I mean, she got eight days before creative writing. Seriously?

259. **S:** Ja.

260. **J:** She had Friday, Monday, biology. Then her languages and her other papers and then Friday Monday. So Physics then biology Friday Monday. Everything else stuffed inbetween, and now she's got eight days off before English creative writing. So really, it was just craze.

261. **S:** And that's not easy with JIA either, because I mean the fatigue ... She would need a more balanced ...

262. **J:** Ja, ja, ja. So if your wrists are sore now ... She said even her left, so I said: but it's not just writing. So your right's going to be sore from writing, but your left's going to be sore just from flipping pages and turning books and things. Just from, it's just more use. You've been ...

263. **S:** And even just from the position she's having to sit in.

264. **J:** And just from the positioning, ja. And, ja, she had extra time for exams. She just needs it because she just gets too, too tired. But then the, the one invigilator gets a bit stressed with how she sits, because she sits funny to get comfortable. You know, she's got to move all the time. So she would wear skorts under her dress to not offend the invigilator. [laughing]

265. **S:** Ja, because she would have had to have done a lot of shifting around.

266. **J:** Yes.

267. **S:** Ja.

268. **J:** I didn't apply for being able to get up and walk around – she didn't want, she just wanted the extra time. And she just, she sits in funny positions. Knees up, knees down, turns here, turns there.

269. **S:** Ja, ja.

270. **J:** So they always look at her quite suspiciously because she moves quite a lot. She des ja, she battles to ... Some of these cushions are . . . [laughing]

271. **S:** Yes, I know, I know. Ja. And how do you think her illness impacted on her, on her friendships? What have you seen?

272. **J:** She had a close small, small close group who accept it and doesn't ... But even within that ... Her one very good friend who ..., they sat next to each other in maths on the first day in Grade 8, and she came back and said: this is such an irritating boy. And they've been best friends since then. And he's never, he's been a huge emotional support to her.

273. **S:** Ok.

274. **J:** Huge. I don't know, he has just been phenomenal, he really has. She can go to him for anything. I can, I can message him and say: what the hell's going on? Because he knows. So he's been great. He doesn't ... But you know, he, I think it's a boy thing. And then, and then the girls, it's been ... Most of them are absolutely fine, but then she lost a very good friendship because one girl couldn't cope with her illness. She couldn't cope with ... You know. It was a bit of an excuse because I think that she was just ... Ja. But it was just, ja, so some of them couldn't cope with, with it.

275. **S:** With what she's going through and ...

276. **J:** With what she's going through and ja, ja. For some bizarre reason. So she's got a small close group who, who's fine with it. But she got lots of comments about, no I've got arthritis I can't ... "Oh but that's an old person's disease."

[30 minutes]

So she, she did have to put up with a lot of that and, and you know, if she'd be on crutches because ... "Why are you on crutches? There's nothing wrong with you. " You know, things like that. You know she just couldn't ... You can't be bothered to explain anymore. She used to try and she's like: *ag* whatever. You don't care anymore.

277. **S:** And what was it do you think about the explaining that she eventually gave up on?

278. **J:** Because I think she just realised that they actually don't care and they're not going to, they're not going to, they're just never going to understand. As soon as she brings up the word "arthritis", they're just: oh, it's an old person's disease and you're wrong, kind of thing.

So she doesn't really ... bit like me, she just doesn't care anymore what people think. [laughing] So you want to think that – whatever.

279. **S:** Ja. And then from there she just chose her friends carefully.

280. **J:** Well I mean she was friends with them and the group sort of just evolved into a group that ja, ja, have just, is, is fine with it.

281. **S:** Do you think she experienced any negative labelling because of the disease?

282. **J:** I don't think so. I mean I must say, the advantage of Westerford is that they are so inclusive, you know, and probably the best school for her to have been at because they, they've got lots of stuff going on. And everybody manages to find their niche somehow in Westerford, because it's not just sporting or just academic or just whatever. So I think first-aiding helped her a lot, because it was a perfect niche for her.

283. **S:** What did?

284. **J:** First-aiding.

285. **S:** Oh first-aiding, yes.

286. **J:** Ja, ja. So she, ja, so she, it was her perfect niche, first-aiding. So she fitted in well there and managed to ... That, that sorted her.

287. **S:** Yes.

288. **J:** You know she didn't feel out of everything because she could still do that lot and it's very good for her. It's her ... She's very calm in the situation; she's very ... It's definitely her thing. So I think that was good. If she didn't have that I think maybe we would have had issues. But the problem was that ... Well not ... Westerford they're very much, you have to do a winter sport and a summer sport up until ... Grade 12 you can do winter or summer.

289. **S:** Ok.

290. **W;** But up to Grade 11 you have to do a sport in winter and you have to do a sport in summer. So she spent a lot of time not doing sport, although she was doing a sport, but because she was flaring or whatever. So she spent ... So I think two of the terms we got a whatever, a sports thing that she didn't have to do it.

291. **S:** Like a dispensation, ja.

292. **J:** Ja, you couldn't , you needed to apply for that, so I think one or two terms we definitely got that. But she didn't like getting them, so eventually she just went for Walking for Life, which was fine. So she could just do that and it was just basically around the school.

293. **S:** What was, what was it about getting the dispensation that she didn't like?

294. **J:** I don't know. She just ... I think it made her feel ... She didn't think she needed it, sort of thing, so ja, ja, you know, she ... I suppose the, the stigma of why don't, why, physically if we look at you there's nothing wrong with you, so why do you get a thing for sport?

295. **S:** Ja, ja.

296. **J:** So I think that's ...

297. **S:** And that, that idea of physically it doesn't look like there's anything wrong with you, has that been a theme through her illness?

298. **J:** That and the fact that when you mention the word arthritis everybody says it's an old person's disease. I think that's more than the physically there's nothing.

299. **S:** Ok.

300. **J:** I think it was more that, that people stop listening when they hear arthritis because not many people know that children get arthritis. It's just, it's quite a limited experience. You know you don't really experience it. So, I mean, I remember being shocked when I got my first folders when I worked, when I started working for . . . But they're children, they've got arthritis, you know.

301. **S:** Ja.

302. **J:** I mean you got used to it, but it's ... Ja. Ja. And also because she doesn't flare dramatically. She doesn't have big swollen, big knees, and she doesn't have that side of it, so you've got nothing to show.

303. **S:** There's nothing to show.

304. **J:** Ja. [laughing] So, ja.

305. **S:** And how, how have you found that the school has dealt with it?

306. **J:** We didn't go to the school at all, except to the sports thing for a sports dispensation every now and then, I, I wasn't ... Naomi's mom was, very much got the whole school involved with everything. Not me. Not interested. She comes and sorts out ... This school didn't need to know, really didn't need to know. It wasn't ... I raised it on her form, you know, you have to put what medication they're on.

307. **S:** Yes.

308. **J:** It went on that form. But I never, I never made it a big deal, you know. The sports people needed to know but apart from that there was really nothing that they needed to know.

309. **S:** And when they did know, they were all on board or did you have any problems?

310. **J:** She included ... No, I had no problems because I never ... I don't think the top people ever even knew about it, because I never, I never went --, You know, there was no reason for the headmaster to know about it. You know, it wasn't that I didn't want him to know, I just didn't see the ... I didn't see the need of going to him to tell him that ... So the psychologist knew about it because they had to do the, what's it called, the extra time form.

311. S: Extra time forms.

312. J: Yes. And, and she knew about it because she had a couple of issues that she had to go and see her for and she had to do the extra time form, so she knew. The Xhosa teacher obviously knew from a long time ago, because he needed to know.

313. S: Who knew? Who knew?

314. J: The Xhosa teacher.

315. S: Oh, because of the Transkei thing.

316. J: Because of the whole ... So he, he knew.

317. S: Ja.

318. J: And then her maths teacher; I don't even know how that came up, but her maths teacher knew about it. So she told the people directly involved with her who needed to know. And then they were the ones who needed to know.

319. S: So then ...

320. J: I never really went to the school and said: oh, my daughter's got arthritis, what are we going to do about it? She didn't -- Nobody -- You know, I couldn't, I just didn't go because it never even ... To be honest, it never even occurred to me to go until Kay was talking about, you know, "and this one she" ... I didn't even think about going to them. It just never occurred to me. She told the people who needed to know and, and, ja. And then ... The sports teacher knew because she had to sign the forms and the psychologist. Because she had to sign the forms.

321. S: Ja, ja.

322. J: So I, and I mean it filtered around I think too. I mean it certainly, you know, teachers talk, so I think it did filter through. So anybody who took the individual sports and that sort of thing. And the other day she had no shoes on after one of the exams and the one teacher was like: you know, you really still need to ... I know you're writing matric exams, but you need to ... And the other teacher walked up to her and said: oh just leave her man, she's got arthritis! [laughing] So ja.

323. S: So ok, so there was, it wasn't that the school was hugely supportive, because you didn't involve them ...

[speaking simultaneously]

324. J: ... And the people who did know were very supportive.

325. S: Ok.

326. **J:** But I didn't ... They were not supportive, just because purely I didn't tell them and I didn't ... You know, so I sent in the forms with her medication, but apart from that it didn't ...

327. **S:** So essentially a positive thing.

328. **J:** Ja, it was just ... The people who needed to know they knew and they were very supportive. The psychologist was, the, the staff, I mean the ja, the student counsellor type person was wonderful. She would phone me ... She phoned me a couple of times just if there was major issues.

329. **S:** Ok.

330. **J:** More from, you know, friend-type things, but she always phoned me if there was a problem. She was very sweet. And ja, she needed to, they, they signed the forms. That's the only reason why they knew. But no, it was really my choice, because I'm just that type of person; it didn't actually occur to me that the school needed to know. It wasn't like it was a diabetic who, where she may go into ... Or an epileptic who may have a seizure and are there people who know how to deal with it. There wasn't anything that anybody needed to deal with.

331. **S:** Ja, there's no emergency kind of situation.

332. **J:** No. She never missed school for pain or anything like that. She never ever ever missed school because she was sore.

333. **S:** How, how did she cope with, or how did she push through that?

334. **J:** Her -- She won't miss school for anything. She will not. She's got to be dying before she'll miss school.

335. **S:** And why is that do you think?

336. **J:** It's her personality. It's just her. It's just, it's just, she's very self-driven. It's just, she hates always missing ... She hated catching up, she hated missing, just you know, ja. And then she would catch up everything the next day. She would ... She absolutely hated it. She would get so cross with me if I made her to stay home for ... I mean, she, she got kidney stones the once I think, we suspect. Didn't actually have it investigated, but just I think it passed and just, when I picked her up she was so sick. And it eventually passed in a couple of hours, but she ... And I said the next day, because she just felt terrible and I said: you can't.

337. **S:** Ja.

338. **J:** And she was very cross with me for making her, for not letting her go to school.

339. **S:** So, so in some ways she was dependent, but you're describing a very independent, motivated, goal-driven girl.

340. J: Self-motivated, goal-driven, in that. But extremely dependent on ... Not dependent, maybe that's the wrong word. She just needs to know I'm there.

341. S: Ok.

342. J: More -- She knows she can depend on me and she knows she's, ja.

343. S: There's a support system in place.

344. J: If there's a problem, I'm the person she wants. And I suppose because she doesn't have anybody else, so I am ... My dad is good, but he's in Zim, so that doesn't help. But he is probably the only person who was completely ... Didn't question what we did, didn't question ... Just took her for what it was and was very sad when we got the diagnosis, and just supported her. And was there for her and ... I mean they've been very close since she was little anyway. But he's the only one who never questioned my medication choices, never questioned ... You know, none of that. He just, he was just there. If she needed him, she, he was there, and that's it.

345. S: He was there for both of you.

346. J: He was just ... No, for her, for her.

347. S: For her.

348. J: He was just there for her. That was her alternative support, ja, ja. So -- Because my parents-in-law, my mother-in-law ... Well, my father-in-law kind of lost it a bit so he didn't know what was going on, but my mother-in-law just ... If I have to hear about one more alternative therapy that we should try, I was going to cry. I really, I just, I would just learn to say: yes, that sounds interesting. Ok, and I'll send you the book. You do that. I'll send you the article. You do that. I'm not interested, not going to read it.

349. S: Ja.

350. J: We're on a path and we're going to stick to the path and that's it.

351. S: Was it that she wasn't hearing you, or was ...

352. J: I don't know. I honestly don't know. She's just one of those people who, ja, felt she had to offer alternative therapies. [laughing]

353. S: Had to give alternative therapies.

[40 minutes]

354. J: Just had to. It's just ...

355. S: Have there been any alternative therapies that have helped or not?

356. J: No, because I was so ... Because -- Ok, so she's thought this cryotherapy was a jolly fine idea. She flares in the cold, she hates the cold, so she decided that ... You know, seriously. Seriously. And also I didn't ... I mean she goes for physio now, but it's for the top of her back and it's purely exam-related. And before she went I said to her: you do that part of her, you do not touch anything else. That's it, that's where you work and you don't offer her anything else. Because anything else is going to hurt her. If she says she's sore, she means she's sore. Do not ... She's got knots in her back, her spine is out. I think possibly because of the scoliosis, you know whatever percentage of scoliosis she's got, and then she gets muscle spasms badly. Her top of her back. The lower back you can't do anything about with the physio – it's all enthesitis-related, nothing you can do. The top of her back, you work on that, you don't touch her anywhere else. So a lot of the therapies ... "Oh, take her for a massage. " No, she will kill the massage therapist. "Take her for" ... She'll kill them. No. You cannot touch my child. You can't press on points because you will flare the points that you press on, so no. So alternative therapies we didn't really try because you know what, I don't want you to touch her.

357. **S:** It wouldn't have worked with her ...

358. **J:** Because you ... I mean, she flares after her appointments, because they have to see which points are flaring at the time.

359. **S:** Yes.

360. **J:** And then they all flare afterwards. Every appointment we have a flare for two or three weeks. So no, you're not going to touch her. [laughing]

361. **S:** Ja, ja. So you straight ... I mean you were definitely sticking there with what worked.

362. **J:** Yes.

363. **S:** You knew what worked and that was it. And what didn't.

364. **J:** And I knew what hurts her. I know what ... If you're going to manipulate her joints, and manipulate her points and press her points, she's going to be in agony. And I know she's going to flare, I know. Go away, I don't like you.

365. **S:** So, so, were you ... It sounds like you were quite comfortable with voicing what you knew would work.

366. **J:** Yes, yes, I, I ...

367. **S:** Champion, championing.

368. **J:** And, and it was very much: if you want to do this, you can. These are the options. I always gave her the option of it, but I'm not going to force you to do anything. And I'm not going to drag you off to see anybody if you don't want to. If you want to try, that's fine. You need a psychologist, that's fine. Those sort of things. So the psychologist side of things, if she needed that, we did that.

369. **S:** Yes, ja.

370. J: But other than that ...

371. S: So she had a voice in the ...
[speaking simultaneously]

372. J: ... Oh absolutely. I never forced her to. And, and even the Enbrel, she knows she has to take it, we just ... It's just her meltdown point, you know.

373. S: Ja, ja.

374. J: You know it's just ... And some days when, some weeks when she's really sore and the thought of having a sore injection is just too much. But she knows she has to have it and she gets really grumpy and she takes it out on me, and I know I just have to take it because, whatever, that's just what it is.

375. S: So, so in some ways it does affect your parenting style.

376. J: Yes, I suppose so. [laughing]

377. S: But I don't think one would normally ... Well, I don't know, maybe you are, maybe you would have normally taken that kind of behaviour, but ...

378. J: Ja, especially if you understand where it's coming from. Because if it was a tantrum for no reason then ... I mean I still, I still get irritated, because you know I'll say: we have to do Enbrel tonight, and then immediately. Because I have to get her to the kitchen because there's only one room we're allowed to do it in because it's the same as methotrexate; she didn't want to taint any of the other rooms. Only one room was allowed to be tainted by methotrexate. [laughing] We had a vial lying around after we stopped and she found it and she was mortified. [laughing]

379. S: A vial of methotrexate?

380. J: We really must throw it out, it's still sitting in the cupboard. Oh goodness, so we ...
[speaking simultaneously]

381. S: . . . actually an interesting coping strategy, to compartmentalise the room in which she receives the medication.

382. J: Ja, ja, no we weren't allowed to.

383. S: And so it wasn't a ...

384. J: Weren't allowed to, never allowed to taint her bedroom, never. And nowhere else, so it was just always there. She had such bad things, so, so then we just with the Enbrel, so we just continued the injections in the kitchen.

385. S: So from -- So what you're saying is it's affected your relationships with some people, so for example your mother-in-law.

386. **J:** Ja, well, ja I suppose. I don't know if it affected my relationship with her, I just learnt to just ... I actually, I didn't actually listen to most of it. When she finished talking I said: hmm, ja. [laughing]

387. **S:** And I was wondering about with your friends – how, how did ... What was their understanding and how did you experience them?

388. **J:** [beeping sound in the background, then W shouting] . . . your pizza! [voice in the background: "ok"] Most of them are medical-related so it' not, not a, not a big thing. And again I'm not a big socialite, so ja. I've kind of had work friends and ja, so that was it.

389. **S:** But then because of the medical aspect they understood.

390. **J:** Ja, ja. They were probably the ... My good friend . . . she was probably the most supportive because she just, you know, she never gave me alternative options and whatever, she just, you know, just asked: how's it going? What's the story? You know. Are you getting anywhere? And that sort of thing. That's, they were fine, ja. So it does help having medical-related people.

391. **S:** Ah, as your support network.

392. **J:** As, as, ja, ja. But I mean, as an actual support system, very limited. Go into the gym toilets and have a breakdown. That was my breakdown point.

393. **S:** There still isn't really anybody who would ...

394. **J:** It was my ... It was sort of like the only time ... I would go to gym, go into the bathrooms, have a meltdown, go to gym, and feel much better for some reason. Go into the toilet – that was my breakdown point. But I mean, only when things were really bad, you know. Only when things were really bad.

395. **S:** So who was your support system then? You didn't have one. You're Jessica's support system and ...

396. **J:** Ja, so I just took on all the negativity and all the ...

397. **S:** And of course your husband, because he travels, works ...

398. **J:** Away.

399. **S:** Away.

400. **J:** And he's just, he's very dependent when he's home as well, so it just adds more ... Ja. Never can find his wallet, never can find his keys, never can find ... Where's this, where's that, who do I phone for this, how must I do this. So ja, very, very dependent, so.

401. **S:** So everything has to be driven by yourself.

402. **J:** I just ... Ja, ja. And it's just easier to do it and just get on with it. I think that's why I would have the breakdowns and the, the meltdowns in the bathrooms. Because it would get too much, I have my release and go.

403. **S:** So you had at least a space in which you could get it out.

404. **J:** Just -- Actually surprisingly one of the, one of his very good friends from Jo'burg who he's been friends with since junior school, he's a very ... Just, you can say what you want and he also just like: do you need me? Yes, no? And I would actually ... His neck's . . . as well, and when was the worst thing? When she went to, as first-aiding they went to their sister school in Khayelitsha.

405. **S:** Ok.

406. **J:** And they went and they, and she did first-aiding and they took the sports teams and whatever, and she was threatened at knifepoint twice in that afternoon. That, that blew my mind. And I really just, ja, that I couldn't cope with. So I phoned, I, I messaged him. I was walking, walking around the forest.

407. **S:** So that was done by the school.

408. **J:** Ja.

409. **S:** And ...

410. **J:** All of them. Groups and groups of them were threatened at knifepoint. She was threatened twice. The once with people, so she was ... And then the second time she was first-aiding, watching a match, you know, watching on the side lines, and the guy tried to take her away at knifepoint.

411. **S:** Oh.

412. **J:** So she ran onto the field. He said: come with me. So she said: I have to put my first aid bag down. You have to let me go so I can put my first aid stuff down before I can do anything, so he let her go. She just ran straight into the middle of the, the ... And they've never, they've broken ties with the school now. They used to go to Westerford to play, so they went and they normally used to go at the school, and they didn't. They had to go to a general sports ground where there was other people around – anybody could come in – and probably six groups of them were threatened at knifepoint. One of their friends had their cell phone taken away at knifepoint. It was unreal. So that, that was, I mean, it was in a bad time as it was.

413. **S:** Yes.

414. **J:** And then that happened as well.

415. **S:** And then ...

416. **J:** And I just, ja. So that was ...

417. S: And then you needed ...

418. J: So Gary was my, he was my backup.

419. S: And how did he back you up on that? What did he do?

420. J: No, just because he doesn't ... He's calm.

421. S: Yes.

422. J: He doesn't -- He doesn't yell at you for letting her go, or ... He's just, he's just a calm person and if you need him he's there, and if you don't need him it's fine, you know. And he just, he'll then message you later on in the day just to make sure everything's ok. He's just, you can just talk to him, you know. So he'll, you know, or he'll phone or whatever. So he's just, ja.

423. S: An easy relationship.

424. J: Ja.

425. S: And so how did Jessica cope with that?

426. J: We went to a psychologist.

427. S: Debriefing.

428. J: Debriefing, ja. Because the, that was when the school counsellor phoned me and said ... Because they all had school counselling; all the, everybody who was affected had school counselling. And the she just phoned me and said: look, I think she just needs something more because she's just not ... So then that was when we went to ... That was when she went to the guy, to Jonathon. And he was, ja. So that was fine. He did, he did help her with, with that.

429. S: So, so for you being an introvert you didn't really feel that you were being isolated as such, or your social life ...

430. J: No. I isolate myself.

431. S: Hey?

432. J: I isolate myself. [laughing]

433. S: You isolate yourself anyway.

434. J: But I do think I became more introverted, because I just ... I just needed my time. You know, I just, I actually couldn't cope with anything else. I didn't, ja. And it required too much planning sometimes. The exhaustion would just, you know, because I need to, the explaining I need to do and whatever. So I probably did isolate myself.

435. S: The explaining? Can I ask you more about that?

[50 minutes]

436. **J:** No, no, just like if, if you know, you needed to go and then I can't go with you; I need my own car in case I need to ... You know, that sort of thing. No I can't go for the whole day because I need to be ... You know, so ...

437. **S:** And was there a problem at times that people wanted ... You had to keep explaining those kinds of things?

438. **J:** I didn't, I didn't to be honest, let myself get into those situations.

439. **S:** Ok.

440. **J:** I don't ... Just like: I can't do whatever. Just, ja, ja, ja.

441. **S:** So in a way it has impacted in the sense that you haven't been able to do things that you might have chosen ...

442. **J:** Might have done, ja.

443. **S:** Might have, but not...
[speaking simultaneously]

444. **J:** But, but pretty much I do things, ja, with her or alone or whatever. But I, *jus* it's quite difficult because it's been going on for so long now that it's ... You know, I'm not actually sure if it has ... Ja.

445. **S:** Because it's been your life for such ... With her. Ja.

446. **J:** So it's probably seen as overprotective, but I knew what was going on and I knew I had to, you know.

447. **S:** And, and did people understand?

448. **J:** Ja, I think so. I think, ja. It wasn't like there were major amounts of people who I was turning down all the time, so it really didn't ... Ja, ja.

449. **S:** And of course you did say most of your friends are medically ...

450. **J:** Medical, ja, ja. So you know. And it wasn't really ... And I had to be the backup because there wasn't anybody else.

451. **S:** Ja, ja. It's, it's, it's tough because essentially you're a single mom.

452. **J:** Ja, and you know, no family ...

453. **S:** When he's away.

454. **J:** No family who's not going to judge you, you know, you just ... So ja. There's nobody here, so you cope and get on with it.

455. **S:** And the financial implications – how's that been?

456. **J:** You know we had a few months when we had to pay for Enbrel ourselves but ja. So she started on a lower dose than probably she should have because we, just, until the medical aid. And we've had to up medical aid and things, but I mean, you see my husband earns well so it hasn't been, really been a, you know. Hasn't really been a thing for us.

457. **S:** Ja.
[phone ringing and dogs barking in the background]
And we're back on.

458. **J:** And we're back on. [laughing]

459. **S:** Ok, so you don't think that it really impacted your socialisation, socialising at all?

460. **J:** No.

461. **S:** And the financial we talked about, that was fine. So have there been any experiences in this journey you've had that have either really challenged you or really helped you?

462. **J:** Helped, no.

463. **S:** Nothing helped.

464. **J:** [laughing] No. ... ja, all of it's been a challenge. But it's just, ja. I think any, I think any extra stress in her life was difficult to, you know. [sound of dog growling in the background] [whispering] She's gone man. So that's what ... The knife incident and that sort of thing, those were the times that I battled because you know she was sort of at a high level of ... I think she had to cope with it anyway, so any extra things. So exams I did, did, were stressful.

465. **S:** Yes, ja. Ja.

466. **J:** But . . . always been a challenge. [laughing] It really has. But it's ... Ja. It's getting better.

467. **S:** Do you think she's developed differently to her peer group?

468. **J:** She must have. I, I think so. I just think ... She's probably more mature in a lot of ways because she's had to weigh up everything; nothing's been ... So I think she's definitely, she's more self-reliant. She, ja, she ... And, and, but I do think she's not cut off from her friends but cut off from the, the general things that go on.

469. **S:** Yes.

470. **J:** So she would not cope with this cabaret that they have in Grade 11 where everybody has to do something and then there's a party afterward. It's long rehearsals and it's very noisy, and she battled with that. So she, and you know, the after-party just wasn't even a thing for her because she just had had enough.

471. **S:** Ja.

472. **J:** She couldn't cope with more noise more people more, ja. She, she, the tiredness of JIA is severe. Is severe.

473. **S:** The impact of the fatigue, ja.

474. **J:** The fatigue is huge. And it does impact on them dramatically.

475. **S:** And which then limits their socialising.

476. **J:** Yes. Ja, ja.

477. **S:** Because you’ve got to do enough just to get through the school day.

478. **J:** Yes.

479. **S:** Or whatever needs to be done, and then you have nothing left over.

480. **J:** And you actually don’t ... So it probably makes you less social because you just, you actually just want to be by yourself and recover and rest and sleep and that. Ja.

481. **S:** And she seems to be quite hard on herself about resting.

482. **J:** Oh God, she’s hard on herself about everything. Everything. Ja no, she pushes herself far too hard; to the point where I have to step in and just say: that's it.

483. **S:** Ja.

484. **J:** I have to drag her to the forest to have a walk, otherwise she just gets into a frenzy. Go out, get her some fresh air.

485. **S:** So it’s quite a big role that you play also in helping her balance her things.

486. **J:** Ja, she does need help with her balance. Not all the time; sometimes she’s fine. And she’s a night-time studier and it freaks me out, but that’s what she is, you know. And that’s, that's just who she is.

487. **S:** Ja.

488. **J:** So, ja. But it’s a sort of like a six o’clock type time where you would need to just get her out.

489. **S:** Ja.

490. **J:** And especially if she hadn’t had an exam and she’s been at home the whole day, you just need to take her. And then she’ll be much happier. And also the forest is when she talks, so when we’re walking around.

491. **S:** Oh ok, so then you can ...

492. **J:** It’s when she actually talks. Eventually it comes out, whatever’s ... If she’s in a very bad mood I know I have to drag her kicking and screaming, and then it’ll come out. Then it’s fine.

493. **S:** So you’ve got your strategies ... hey?

494. **J:** I’ve got strategies. The forest is my strategy, yes. Yes.

495. **S:** [laughing] And I was going to, I was going to ask: if you were to give advice to parents whose child had just been diagnosed with JIA, what would your advice be? What would you tell them?

496. **J:** Ignore everybody. Do what's best for you and do what works for you, and ignore the world. Seriously, ignore the world. Just ignore everybody. Don't listen to them. Stop listening.

497. **S:** What, what kind of things did you ...

498. **J:** All this stupid advice that people give you. If you know it's not going to work for you, you don't have to do it. But I'd say the same to maternity people as well. Stop listening! Just, you know, people feel obliged to give you their words of wisdom that are not words of wisdom. Be prepared for a long journey, but you'll get there. And just, ja. Ja. Honestly, just ignore people. That's really what I would tell them.

499. **S:** So to do what you need to do.

500. **J:** Do what you need to do and whatever you can cope with, do. Stop feeling guilty. Stop making people make you, you know, you mustn't be made to feel guilty for anything. Just ignore them; carry on. I always tell her: just, so what? You know.

501. **S:** Ja.

502. **J:** Stop listening to them. It doesn't matter. Just ignore them. So do what works for you and ja, ignore the crazies. [laughing]

503. **S:** And is there anything else you'd tell them?

504. **J:** Just be prepared for a long, you know, a long journey. It is what it is and that's it.

505. **S:** Ja.

506. **J:** You're stuck with it. You can, there's only one direction you can go, so just stick with it.

507. **S:** And it is so unpredictable.

508. **J:** It is so unpredictable.

509. **S:** You don't know how it's going to go.

510. **J:** Don't expect miracles, because they're not going to happen. And, and, ja. Just, just stick with your path.

511. **S:** Ok.

512. **J:** Because it's not going to . . . No matter what you do really, it's just, it's going to be what it is. So, ja.

513. **S:** So your current aim with Jessica is the remission. Get into ...

514. **J:** Hopefully get her into a medical remission at some stage.

515. **S:** Medical remission. And then hopefully full remission.

516. **J:** Ja.

517. **S:** If possible.

518. **J:** If possible, ja.

519. **S:** Ja, ja.

520. **J:** I think, ja, it's ... I mean they warned me right from the beginning that it's the most difficult and it's a slow path, so it's fine. We'll get there eventually I'm sure. We're just going to have to stick it out.

521. **S:** Ja.

522. **J:** And stress flares it, so, who knows. I mean matric year is a difficult one. You've got the varsity stress, you've got the matric stress, you've got, you've got a lot of stress.

523. **S:** There's a lot of stress in matric, ja.

524. **J:** You know, not knowing what's happening and all of that. I mean the varsity stress hasn't helped either with all the fees must fall stuff. That's also been a ...

525. **S:** Worrying about her future.

526. **J:** Ja, ja. You know, what you're going to do, what you ... And my husband's so: if the varsities don't open, what're you going to do next year? This is in the middle of matric. That's an "if" and we will cross that bridge when we come to it. You cannot ask her in the middle of matric to make some alternative plan. Just let her get through matric first. No, no but what if ... But she's off until ... Yes, but she can't actually deal with that now. Just leave her.

527. **S:** So you've had to really sort of...

[speaking simultaneously]

528. **J:** Be a buffer. I'm a big buffer. I'm a huge buffer. [laughing]

529. **S:** Buffer.

530. **J:** Yes, big one.

531. **S:** Ja, ja.

532. **J:** [speaking quietly] ... boy. And you have.

533. **S:** The therapy dog.

534. **J:** Yes. The therapy dog. Only because ... neurotic. [laughing]

535. **S:** Medicine dog. The medicine dog. And are there any issues today you think I haven't explored, or we haven't explored. Anything you think is important that we haven't looked at?

536. **J:** No, I don't think so. I think that's covered everything.

537. **S:** Ok.

538. **J:** Ja, I think so.

539. **S:** Is this a good place to stop?

540. **J:** Ja, I think we've covered everything that I can think of.
[both laughing]

541. **S:** Well thank you very much for your time. Let me turn this off. And I'm going to save it immediately because I am now so neurotic about this.

[recording ends]

APPENDIX O: Micaela Case Study

Transcript 1: Micaela Interview 1

1. **Interviewer (S)**: Okay so it's recording both of us now.

   I was just wondering what is the journey of the path that you've walked, could you just tell me right from the beginning from even before you got diagnosed, what was it like for you, how did you even know you were sick?

2. **Interviewee (M)**: So it when from when was a child, I had bad sinus problems, I've still got bad sinus problems and from that I got like a lot of infections and stuff.
3. **S**: and when you say child, how old were you?
4. **M:** From a baby, like …
5. **S**: A baby, oh my word.
6. **M:** Ja, I've always had like sinus problems and then um as I was growing up, like as a toddler I used to have like pains when I was like riding my bike or something and my mom just thought it was um growing pains, so she sort of left it.

Then I started just getting like repeatedly sick, in like just flues and colds like one after the other and so um my mom, I got um swine flu.

7. **S**: When?
8. **M:** In 2009 when the outbreak was, when the big outbreak was, um and with that I got Coxsackie B.
9. **S**: Ooo, okay
10. **M:** Ja, and so I was quite sick then and then um my mom just asked my paediatrician to do like a full work-up of my bloods and everything just to see like if everything it was okay.

Then it came back that I had um the HLA B27 positive gene and then so my paediatrician was actually quite good, she sent me straight off to Dr X at Hospital X and then from there she like assessed my joints and stuff and she found that I actually had like a lot of joints active.

So it was mainly my ankles, my wrists, my thumbs, my knees and my back, oh and my jaw and then from there, so I got diagnosed in 2009 at the end of the year.

11. **S**: How old were you at that stage?
12. **M:** Nine
13. **S**: Nine?
14. **M:** Yes. Um and then, so we started treatment and then ja, that didn't work well so we just switched.

15. **S**: What treatment were you on? Methotrexate or

16. **M:** I'm on, so I started like on the low grade stuff and then they, each time ….

17. **S**: Escalate?

18. **M:** Ja and then I went onto, ja, so um, I'm try to think, ja and then I'm not too sure when I went onto a biologic, it was about two, three years ago.

The first biologic if I can remember correctly was Enbrel that I went onto, um and it didn't work, and then we went onto Revelex which is a um 12 hour infusion.

19. **S**: Its recording isn't it?

20. **M:** Yes

21. **S**: Okay. Okay

22. **M:** Um and then um, so the Revelex was a 12-hour infusion, um so that was quite hectic like being in hospital um and it was once a month, once a month I think, if I can remember correctly, um but the, in between that um my jaw often gets so, round about twice a year, my jaw gets quite stuck and it gets quite sore, so and then …

23. **S**: One side?

24. **M:** Ja, its mainly the one side, um and so we went to a maxillofacial surgeon and he x-rayed my jaw and he found that there was some erosion, so now just twice a year we, I go to theatre and he injects it with cortisone just to keep it from eroding and it helps a lot with the pain

25. **S**: Okay

26. **M:** Um and then also during the time from when I started um the treatment, from when I was diagnosed until 2014, early 2014 um I was on high-dose oral cortisone, ja so that was quite hard because like I obviously got very puffy and I don't think because I was young I didn't realise it but only once I came off it and people were like wow you've lost a lot of weight did I actually realise and now like looking at pictures so that was quite hectic and then um, also with I'm not too sure um if its got to do with the whole JIA thing but I've also got um, I don't know something where your nerves are like hyperactive…

27. **S**: Okay, you can always text it to me later

28. **M:** Ja.

29. **S**: If you forget, if you can't remember now, no stress

30. **M:** Ja, um and so I'm often, I'm always very hot. My natural body temperature is like 37.5

31. **S**: So they like oversensitive, your nerves?

32. **M:** Ja, um

33. **S**: Your natural temperature is?

34. **M:** 37.5, around there

35. **S**: So almost like as if you running a fever?

36. **M:** Ja

37. **S**: Wow.

38. **M:** And then like I've got like a very sensitive bladder, like I call my bladder a teacup cause I always need to go to the bathroom [Laughing].

39. **S**: Aww.

40. **M:** Um, ja and then I went, in 2014 I went off the cortisone, um because I fractured my um tibia, um and then we did a um, it was just a hairline fracture, I hadn't fallen or anything, it was just from, it just fractured and so we did like a bone um density test and then we found that my bone density was quite low and they thought it was from, the cortisone was causing it um because I'd been on it for such a long time and for such a high dose so I came off that and that was quite,

Oh I went into remission at one stage in, I'm not too sure I think 2012. I was on Revelex, um and then…

41. **S**: That's a biological?

42. **M:** Yes, and then what happened was um…

43. **S**: Biologic.

44. **M:** Ja, and then what happened was I had my vaccinations um and I think it was the chickenpox vaccination and we thought I'd become allergic to Revelex um and so we took me off Revelex.

But then tryna get me back on, I had become resistant to it so um we couldn't go back cause I, they got me into remission on Revelex and it was cortisone. So then 2014 was quite hard because I was off cortisone I couldn't get, I couldn't go back onto cortisone, like they very sceptical about putting me back onto cortisone because of my bones.

45. **S**: Ja, bone density.

46. **M:** Ja, and the Revelex had become resistant to, and then um at a time, I think we did it in conjunction with Revelex, we used methotrexate, um and ja so that, I think that combination sort of worked quite well. Um and then ja so 2014 I went off the cortisone so that was quite tough cause I respond very well to cortisone.

47. **S**: So all the pain and the stiffness came back?

48. **M:** Ja and um so during like I'd say that time and now I've had multiple joints injected with cortisone, ja and it helps like quite a lot um…

49. **S**: How long did it last for, those injections?

50. **M:** It depends on my different joints like my thumb I've had injected I think twice, um the first time it was really sore but it helped, it helped for about I'd say eight to 10 months.

51. **S**: Wow

52. **M:** And the second time it didn't really help at all.

53. **S**: Okay

54. **M:** Um but then like my jaw I only do it like twice a year, um oh and I've had my toes injected because my toes get quite sore and then ja, so that was 2014, and then 2000.

I think late 2014 um I got staph in my nose like an overgrowth of staph and then I'm not too sure but I think it was late 2014 or early 2014, I can't remember.

55. **S**: Was that from the sinus problems?

56. **M:** Um, we don't really know what it was from, but um I kept getting recurring staph, like it, we couldn't get it away… antibiotics, like nose surgery washouts and stuff like that and it just wasn't going away.

I think I got it like at the end of um 2014 and it was a, um persistent staph and it had created like a barrier, so we had to go in surgically and like scrub it, um and then I went on antibiotics again and then I got it again.

57. **M:** Oh no

58. **S**: Last year in January, but then I also, so I'd gone to the ENT because my nose was just like playing up, and so I had staph and I had aspergillosis.

59. **S**: There's a new one for me, didn't know about that one.

60. **M:** Ja it's a fungus infection, but it had eaten through my septum, so I had a hole in my septum but he admitted me straight away and then also like last year um I was just getting sick and sick and sick. Like I had, I think last year I had pneumonia I think like twice to three times, I had flu so many times.

[10 minutes]

61. **S**: You were total immune compromised.

62. **M:** Ja, ja, um so last year after that um after the whole um staph and asthma attack thing, um, the, Dr X said that its very very rare that you get those two together, it's very rare that you even get aspergillosis.

So she wanted to um take me off all my medication and just start from scratch because she said, she thinks we've suppressed my immune system too much um and also then every time I get sick, like my joints flare up and then so, so last year was like really really tough, um because like I wasn't on any medications and then I…

63. **S**: So you were very sore last year?

64. **M:** Ja very much

65. **S**: because she took you off everything and then all the joints flared back up?

66. **M:** Ja, ja, everything

67. **S**: And fatigue and ….

68. **M:** Ja, I got like, I think one of my worst symptoms is fatigue, um ja and then so this year um we, oh and then also last year um we also tested because she wanted to see if I had umm…Immu, I don't know what it's called when you can't make white blood cells, I don't know what it's called.

69. **S**: That's okay. You know what between the two of us [Laughing] and research we will find out what it is.

70. **M:** Um its some immune deficiency disorder, um and so I had Polygam a few times which helped with like um getting sick umm.

Then late last year once my immune system had like recovered and stuff they tested again and they gave me vaccines and they tested for, if I had um created antibodies to it after the vaccine cause they thought I was losing all the antibodies, I wasn't building antibodies.

71. **S**: Okay got it.

72. **M:** Um and so, ah oh antibodies and then I wasn't so I didn't have the immune deficiency problem, um and then so this year, early this year um they started me back up on methotrexate and um Orencia

73. **S**: Oh that's one of the biologics

74. **M:** Yes, one of the biologics, um and so, so once a month infusion and it's just like two hours. Um and we haven't found that its helped, well I haven't, um helped that much yet and so we not quite sure if its working or not?

But then also like I think my fatigue is better because, but I've then got to take into consideration like I am in Grade 10 and like, at St Mary's which is a very, sort of prestigious school so they do push us, ja they do push us so I just gotta like look at my fatigue. It's quite hard to think am I tired because of arthritis or am I tired just because it's like hectic at school and stuff

75. **S**: And are the other girls tired I think, that's a question you've got to ask yourself?

76. **M:** Ja exactly, ja that's the thing, um in that perspective it has helped and then I think um I don't think it's made a huge difference but I think um … Oh um I think joint, my joints, I've got less active joints um but so oh and then I've also, they've sort of figured out like most of my arthritis is enthesitis, so like most, it's mostly not my joints, but my tendons that are um….

77. **S**: Which I think is almost a blessing even though it's very sore.

78. **M:** [Laughs] ja, um so that's ….

79. **S**: You don't get the deformity with the joints, with the Enthesitis

80. **M:** No. Um my joints are still active but it's mostly my tendons, um and so ja that's….

81. **S**: That was a long road hey?

82. **M:** Ja

83. **S**: starting from right from a toddler and then getting diagnosed at nine

84. **M:** Nine

85. **S**: Nine years, shoo, so basically it's been your whole life.

86. **M:** Ja, ja

87. **S**: And, ja so how, how do you experience that on an emotional level?

88. **M:** I think it is quite hard like I do have my mom and my sister um and they are very very like supportive and then I think the hardest I find is um at school because now like with exams and stuff I can't write, well I can write but I can't write fast and my hands get very sore and like sitting down for long hours like I get very stiff so I've had to have like special accommodations and…

89. **S**: Good

90. **M:** IEB has like approved it and everything and they've been quite good, it's just like the problem now with like I write in a separate venue, I've got extra time, um I'm allowed to like get up and like walk around…..

91. **S**: Good

92. **M:** and I then like type the exam and I don't know why but I almost, I don't know if it's just me but I do think like um when I've got extra time, cause I've got 10 minutes per hour so and some exams that are like 2 and a half hours I've got an extra 25 minutes and I'm like almost that's kind of unfair because there's so much you can do with an extra 25 minutes.

93. **S**: So you feeling a bit guilty about it?

94. **M:** Almost, ja um and then like last year, so this year we've chosen our subjects so we've cut down from like 14 subjects to seven subjects.

So um last year cause like I knew, I'm not a very creative sort of person, so I knew I wasn't going to take like music, drama, and art and the school said like um to take pressure off you we can um cancel out those subjects now you know you not going to take it and I tried it and it was just too much because it was like I felt very isolated.

They also said I didn't have to take a third language in Grade 8 and 9 so I had that period free to sort of catch up on work that I'd missed but I think that aspect has been probably the hardest.

95. **S**: Just feeling ….

96. **M:** Quite isolated

97. **S**: Isolated, different

98. **M:** Ja, Very much so, ja

99. **S**: And how do your peer group react, because I know, you tell me ….

100. **M:** No, no, no

101. **S**: No, you tell me I don't want to put words in your mouth

102. **M:** And so like being in high school my friend group has obviously changed quite a bit um and some people, like I've come across people in the years that have said ah I wish I had arthritis so I could get out of this and stuff. So that's like a bit harsh but then I do like, my friends now are very very amazing with it and very accommodating and very um understanding.

103. **S**: I think to explore that idea further about, I wish I had it, that's one of the difficulties with JIA isn't it

104. **M:** Ja

105. **S**: Is that you can be in a lot of pain but people don't see it or you can be exceptionally exhausted

106. **M:** That's very very much so

107. **S**: And then they look at you as if

108. **M:** Ja, no definitely like.

I think also, I don't know if it's just me but like my fatigue levels and my pain levels change on a day-to-day, like an hour-to-hour basis and so one hour I'll be fine, yes I can come to your party. The next hour I'll be like completely um bedridden with pain and exhaustion and like I'll have to cancel and some people don't understand that point of it

109. **S**: Because it's quite unpredictable

110. **M:** Ja very much and it's sort of like invisible almost, ja

111. **S**: And um when you were talking about um feeling, I think your words were isolated when you were given permission to withdraw from those subjects and I assume you chose not to, you carried on taking them except for the third language, has it been in any other way that you've been feeling isolated?

112. **M:** Ja. Well with the exam um things and then um the school, like St Mary's has been so so understanding. Like I've heard some other kids with arthritis and their schools have been completely like no get over it you know and St Mary's has been amazing um and so many of the teachers are like you know if you want I can come to your house and do this extra lesson with you and I think that even makes me feel like isolated almost because they giving me special treatment but I can't sort of be angry at it because it's so like generous.

113. **S**: Hmm so you can't be angry at them?

114. **M:** Ja, just at the situation

115. **S**: Just at the situation, but inside you not feeling great about it?

116. **M:** No, ja.

[20 minutes]

117. **S**: So okay, and um how has it affected sort of your family dynamic?

118. **M:** Um I think its affected it quite a lot because um my father is an alcoholic and so being like young, and when I was, my parents divorced when I was like a baby, so being young I didn't really know anything and then as I grew up like I started noticing things and stuff like that and then when I was nine I chose to stop seeing him….

119. **S**: Oh okay

120. **M:** ….and so in that way I think it's um changed quite a bit. Um I think it's affected my sister quite a lot because like my mom having now to look after me and stuff, um so there ja I think it's affected her quite a bit

121. **S**: In what way?

122. **M:** Um, I think mm I think she felt almost neglected, so from a young age she's always wanted the centre of….

123. **S**: Is she younger or older than you?

124. **M:** Older than me. Um and so with me now being sick and everything its sort of put her in the back seat and ja, ja

125. **S**: And how does that make you feel?

126. **M:** Bad, ja [crying]

127. **S**: Shame man, it's very tough because it does require a lot of attention. Okay and ja. Um So how often do you have to stay off school?

128. **M:** Um I used to stay off school quite a lot but now I sort of just deal with it because staying at home, knowing like how much work I can miss on a single day like stresses me out more than having to go to school.

129. **S**: And deal with the pain. So you just go and deal with it?

130. **M:** Ja

131. **S**: My hat off to you

132. **M:** [Laughing] ja

133. **S**: It's really hard. I think this is the problem with JIA is that it's not just about the arthritis, it's that it has such profound effects on your family, your peers and that's kind of what we, I'm hoping to bring to people's attention.

134. **M:** Ja, ja

135. **S**: I was wondering, so you've actually walked a very long path with this illness from young, how has it been dealing with the doctors?

136. **interviewee**: hmm um

137. **S**: How are they [laughing] or were they, are they, yes?

138. **M:** My Rheumatologist, I don't particularly like her

139. **S**: This is Gale?

140. **M:** Ja, my mom, I mean she really is amazing, like she's given my mom her phone number like and stuff like that, she really is a very like smart lady and she does um do like miracles but her bedside manner is not particularly great.

Um and I think, like I've said to my mom over and over again, if you're going to be a paediatrician and you're going to deal with this stuff like of course you're going to have to sort of shield yourself almost cause it isn't easy but having a bedside manner makes it a lot easier for the patient too, like communicate.

141. **S**: Hmm and how does she communicate with you?

142. **M:** She's very um short, like quite abrupt, very um opinionated so ja um

143. **S**: So does that make it difficult for you to voice your opinion and share what you feel?

144. **M:** Ja very much so

145. **S**: Does she listen?

146. **M:** I think she does but I think she feels quite superior almost; my mom will kill me if she hears me saying this, um

147. **S**: It's a reality

148. **M:** Um ja but then there's some doctors I've dealt with like um my, my maxillofacial surgeon, he's absolutely like, he's so amazing, he's so kind so like and he's made it so much easier to actually say what's on my mind than sort of just keeping it quiet.

149. **S**: So that's actually for me, um sad is not the right word but it's very disempowering for you, I'm putting words in your mouth so please say if ….

150. **M:** No, no, no, no

151. **S**: But it does sound very disempowering, you are there to have your needs seen to but people aren't hearing or listening.

152. **M:** Ja

153. **S**: I had somebody, one somebody else say to me that um the doctors tended to ask their mom how they were feeling without actually asking them, so they would be sitting right next to their mom in the room and the doctor would talk to the mom the whole way through, I mean have you had similar experiences or has it been different?

154. **M:** Not with Dr X, she asks me directly um I'm thinking that way it is quite good because but then it's so direct like that um, I'm quite a shy person so um if, and I'm like with adults like I respect them so if someone is like that I sort of shy away and like oh I'm fine.

155. **S**: So you don't feel able to tell her the real, the reality of what is happening.

156. **M:** Ja, almost ja

157. **S**: Okay, okay ja I think it's really important for doctors to hear this kind of information.

158. **M:** Ja

159. **S**: So are you staying, you stood with Gale but she'll stop seeing you when you 16?

160. **M:** Eighteen

161. **S**: Eighteen, okay so you not having to worry too much at this stage about transitioning from paediatric to adult

162. **M:** No

163. **S**: How do you think its going to be?

164. **M:** I'm not too sure because I mean Dr X is like very smart and she like really knows everything um and I'm not saying there's like no-one else like her but then, cause my mom's also got arthritis and I look at her doctor and she's very like laid back, like ah this treatment isn't working oh well, so that's sort of I don't know, it will be hard but ja

165. **S**: Do you think it would be helpful to have bridging strategies in place to take people, young I mean adolescents from paediatrics settings to adult settings?

166. **M:** Ja I think it would.

167. **S**: What kind of things do you think might work?

168. **M:** Maybe not particularly with the patients but maybe with the doctors because I think paediatricians are so used to working with babies to 18 year olds and then um doctors are so, actual other doctors are so used to just working from like 18, um with older people and so I think they forget like that okay you coming from a paediatrician like this is how it should like I should approach you and stuff like that, so this is what you used to.

169. **S**: So teach the doctors the skills?

170. **M:** Ja maybe have like a lot of communication like this is how I work, this is how, between um paediatricians and adult doctors, ja

171. **S**: So shoo you've been through a lot, how have you managed, how have you coped?

172. M: Um

173. S: Cause you obviously have, I mean you've had your hard times, what, do you have any specific strategies that you use?

174. M: I think I used to be a very sporty person, like I used to be in the A-team for swimming, hockey, netball, like I used to do every single sport and my academics like sort of took a back seat um and then when this came up I sort of had to stop sport um and so then my academics became quite a focus so I push myself very hard with academics and I come down on myself quite hard um.

Then also like going to gym, doing my own exercise, like just strength work um I think that's helped quite a bit personally.

175. S: So almost having a goal to work towards?

176. M: Ja definitely, ja

177. S: Even though you've changed your goals from the sport more towards the academics and then just personal fitness, but that's a way that helps you manage things.

178. M: Ja

179. S: And if you very down, what happens, what do you do?

180. M: Um I think like my dog, cause I'm very very animal-orientated person like I'm, we've, my sister and I been brought up with dogs so I'm quite a dog person and we've got five dogs um

181. S: Five?

182. M: Ja, three of them are rescues.

183. S: Oh my word, okay

184. M: um and so like my chocolate labby, and then this other rescue which is a weimaraner cross something we don't know, like great Dane, they've helped me a lot

[30 minutes]

185. S: So what, you cuddle?

186. M: Ja and play ja …

187. S: And just, you get that undivided devo, total devotion, unconditional love is what I was going to say ja

188. M: ja definitely

189. S: Ja so that also helps you. Okay well let me have a look at my questions and see if there's something here that we haven't covered, um okay, let's see, you told me all about that, hmmm ja, you've told me about that as well. Independence, as an adolescent you tend to become, the norm is to become increasingly independent and in your case of course that's not always happening, how is that for you?

190. **M:** Um I suppose it's hard, um but personally, my personality I'm quite a homey person and my mom allows me to have my independence like she allows me.

Like with going to school and stuff, we will have huge fights about how I must stay at home and the school will allow me to but I know the school will allow me to but I'm still going to school and um so she will allow me to like make my own decisions and stuff like that, um I think cause she knows it's important to me and like having my choice um but I think the normal independent stuff like I suppose it's just a different dynamic.

191. **S**: Are there things your peers are able to do, independence wise that you are not able to do, or is there a difference that you see or not really?

192. **M:** Not now, I'm not too sure as I get older possibly could be, but um no not now, ja.

193. **S**: Okay cool. And, okay that question not going to apply to you, I was going to say how would you describe yourself before your illness, although you were sporty.

194. **M:** Yeah I was very sporty

195. **S**: So how would you have described yourself before you got very ill?

196. **M:** Um very, very sporty, I was a, swimming was my main um sport um and I wasn't a bad academic like I was getting like low seventies um high sixties, um and then ja I was very sporty.

I was very outgoing I suppose ja, I think like a, also another big thing with this disease, I don't know if it's just me personally but I don't really like talking about it to other people

197. **S**: Thank you for seeing me…

198. **M:** No, no, no, no, no, like my friends and stuff they ask me stuff and I don't know …

199. **S**: What is it about it that you think that makes you, cause you not the only one, what is the reluctance there?

200. **M:** I think it's because it's such a very uncommon like, well it's not uncommon but it's not spoken about and its like, when the school heard that I had this they had never heard of it before because you don't really hear of children getting arthritis um and when you think of arthritis you only think of like the wear-and-tear that old people get and so I think that's part of the thing that with um people not knowing about it and not being educated about it, it's the whole thing that you've now got to explain what it is, like how you in pain, like how's the fatigue, like stuff like that so ja …

201. **S**: Does it reinforce a sense of difference or is it just more of a ….

202. **M:** Ja, Definitely

203. **S**: That and then also just I don't know do I have to go through this all again …..

204. **M:** Ja, ja, ja

205. **S**: Okay alrighty, okay. Um and so how would you describe yourself now?

206. **M:** Um I'm a very academic person, I'm very hardworking, I think

207. **S**: I can hear, yes

208. **M:** um and I think I sort of, I'm hard on myself in the sense that I sort of um tell myself to sort of get over it like get on with the day um ja I think I try like, sometimes I'm too hard on myself, because I'm trying like so hard to be like normal

209. **S**: mm mm, are you finding, do you find it difficult then to, to watch your boundaries?

210. **M:** Ja

211. **S**: so that you will push yourself over and then create a flare

212. **M:** Ja

213. **S**: so you still learning to manage that whole process …

214. **M:** Mmm, definitely

215. **S**: it's a difficult one that isn't it….

216. **M:** Jah

217. **S**: …cause I mean if you feeling good today you wanna just go for it and then …

218. **M:** Ja definitely and then you, definitely

219. **S**: tomorrow is like mm, ja okay. And um are there any specific experiences that you've had that really stand out for you that maybe you haven't shared yet?

220. **M:** good or bad?

221. **S**: either

222. **M:** Um well, there's another instance with my Rheumatologist and it was actually

223. **S**: Gale?

224. **M:** Ja, quite recent, it was last year, um and um I went in for Polygam and the immune like booster thing, um and it's a 24-hour infusion, well a 12-hour infusion, it's a 12-hours infusion, um so I hate sleeping in hospital, it's my worst I hate sleeping in hospital, um and so my mom thought okay we go in at six get you admitted and then if we've got it up by like seven, we get home, we can leave here at like half past 7, 8 and then we don't have to sleep here. Anyways and we got there at six um and my mom had told my doctor and everything and she pre-admitted me and she was like okay can we have the script ready and everything um and then, so we got there at six and it turned out that the script wasn't ready um so my infusion only went up at like half past 11, 12. So then we, well I was angry at that and then there were, she had also not booked a bed for me and we planned this like a week before.

225. **S**: Oh okay

226. **M:** um and so there were no beds except for one in the oncology ward so I went to um the oncology ward and I was in a room with another patient, um sort of an old middle-aged um woman and she was coughing quite badly um and then so I had to sleep there and we thought can I just go in the morning because um I just want to get home.

Then ja early that morning um this woman got up to go to the um the bathroom and she collapsed and so then like, it was quite a small room so I was about meter maybe half a meter away from her bed, where the two beds were and so they all, all the nurses rushed to put her on the bed and then they got the little….

227. **S**: defibrillator….

228. **M:** Ja those things, little paddle things and they were like doing CPR and everything and then she died and so that was quite traumatic for me like obviously I know people die, I've seen it on TV, but watching it happen like…

229. **S**: ….but still in real life …

230. **M:** Ja, so like its wasn't only overwhelming being um, having to sleep over at the hospital, being in the oncology ward, like seeing like a lot of cancer patients um and then having like a lady die next to me, so that was quite hectic.

231. **S**: Hectic ja that is seriously hectic. I think for me, I mean even with all the reading I did beforehand, it's these kinds of experiences that are just, un, incredible that is added to the whole burden of being ill, ja, shoo. Any good moments?

232. **M:** Um I think there have been, can't particularly think of one now, um ja.

233. **S**: That's okay. Um If you were to be introduced to somebody, a teenager say or a young kid who just been diagnosed with JIA, what would you tell them, what advice would you give them?

234. **M:** Um physically keep moving like, cause I remember I got stuck at one point and I had to be in a wheelchair cause I couldn't walk.

235. **S**: Oh you didn't tell me that, how long were you in a wheelchair for?

236. **M:** It was only about a week, oh I still remember that, it was actually, it was on holiday, um we went down to Cape Town and I was in the wheelchair um and my grandparents took me up onto Table Mountain.

237. **S**: In a wheelchair?

238. **M:** Ja and my grandpa, it was so embarrassing he was like beep beep watch out wheelchair lady coming through…

239. **S**: How old were you?

240. **M:** I was about I think 10, early 11

241. **S**: Pre-teen

242. **M:** Ja so that was a bit embarrassing, that was funny though. Um ja so keep moving physically. Mentally, I think like keep social and like keep your, like tell you friends about it but I think it's also hard then cause you don't know how they going to react.

I think ja, I think there needs to be more education out there for families about how to deal with being diagnosed and stuff because it was quite like, can't really remember but it was quite hectic.

243. **S**: hectic in what sense?

244. **M:** I think just being like, everything happened so fast, like I was diagnosed, I was put onto treatment, I don't think we quite knew how to just sort of, we knew to just take a step back and sort of be like okay what actually is this you know, how do we deal with, what are the tips and stuff like that ….

245. **S**: Okay so to actually have someone, what I'm asking you to do now for somebody else, to actually have somebody put together a book or at least something that enables people to know tips and. What do you think of a um, cause I know there's a Facebook page but it's mainly for the parents, has there been one for the teens?

246. **M:** We did try.

247. **S**: Yeah how did it go?

248. **M:** Um not very well, it was fine at first um and then it sort of just sizzled out, I think

249. **S**: Oh what about something like WhatsApp instead?

250. **M:** We did that also.

251. **S**: Also just sizzled out?

252. **M:** Ja

253. **S**: Why was that you think?

254. **M:** I think we were a bit uncomfortable

255. **S**: Sharing

256. **M:** Well for me personally I was like uncomfortable because I'd rather be with my friends at school, like they all going out, they fine, they in a sense normal, um I felt like I was sort of then being, sort of classified almost into a group.

257. **S**: Ah boxed

258. **M:** Ja so I think that …

259. **S**: … and was it then maybe, ah, I'm putting words in your mouth again…

260. **M:** No, no, no, no

261. **S**: ….but was it a case of then it became a negative space rather than a positive space

262. **M:** Ja, I think so

263. **S**: Rather than being able to boost each other a lot of other stuff happening?

264. **M:** Yeah

265. **S**: Okay. Um is there anything else that you can think of that you haven't shared today or I haven't even thought to ask a question about?

266. **M:** Um I think like I just know that, like I know Susan and I know Karen and like we sometimes speak over WhatsApp and we sometimes go out for lunch together and stuff like that and I've become quite close to them and I think it would be nice to sort of create sort of a support group but not a…

I don't know it's easy talking to them about it because they understand um and so I think like if there were people out there that were going through it and then um like I know one last year a girl got diagnosed and Dr X asked me if she could give her my number and so I said ja and so we've been talking and I think I've been able to help her a lot.

267. **S**: So what you talking about there is possibly more like a peer-mentor to talk

268. **M:** Ja

269. **S**: And possibly instead of something as intense as Facebook where you've got to chat all the time but a way of finding somebody that you can connect to and then do the occasional activity with, but not have to do with a whole group of people because you might not actually like them.

270. **M:** Yes exactly, exactly

271. **S**: [Laughing] I've got ja, alrighty and um the one thing that has come up before and I'm not too sure and I would like to check it with you, um some people have said that, obviously they love having their school friends but at times they find it rather difficult um because what stresses them is really ….

272. **M:** ja, not a huge stress for you. Me, I have felt that a little bit, ja

273. **S**: Do you get irritated with them when they stress about something that's really from your perspective not very important?

274. **M:** Sometimes I do, I think its more like some of them complain about small things and then I just get a little bit annoyed

275. **S**: They have no idea about the level of pain you're living through and it's like …

276. **M:** Ja definitely

277. **S**: So is there anything else or do you think we've covered everything?

278. **M:** I think we've covered everything

279. **S**: Thank you so so much

280. **M:** You’re welcome

281. **S**: You have no idea how helpful this has been. I’m just going to save this.

[Recording ends]

Transcript 2: Micaela interview 2

1. **Interviewer (S):** Ok Micaela, thank you very much again for coming ... Letting me come and visit you.
2. **Interviewee (M):** No, it's perfect.
3. **S:** So basically what we're going to do today is I'm just going to follow up with you on some of the things that we discussed.
4. **M:** Ok.
5. **S:** But first, I was just wondering from your side of things, after reading the transcript which you say was fine and I can go ahead with.
6. **M:** Yes, yes, yes. No, it's perfect.
7. **S:** So was there anything when you read the transcript ... Was there anything from there that you felt, I don't know, suddenly you thought, oh, it made you think of this or that or the other, or something you wanted to add.
8. **M:** No.
9. **S:** That you thought was important.
10. **M:** No, nothing I can think of.
11. **S:** Ok, cool. One of the things that I wanted to explore more if it's ok with you, is one of the things that came out was the whole unpredictability ...
12. **M:** Yes.
13. **S:** Of your illness from kind of a day-to-day perspective.
14. **M:** Yes, yes.
15. **S:** Hour to hour you even said. And I was wondering, with this unpredictability, what kind of thoughts go through your head, what kind of emotions do you feel when that happens? Like ...
16. **M:** Yes.
17. **S:** You're fine and then ...
18. **M:** Yes. I think as the years have gone on I've learnt to sort of almost predict it a little bit.
19. **S:** Ok.
20. **M:** I get to know my body.
21. **S:** So, so how do you know your body?
22. **M:** I know for instance, say if I'm starting to get a little bit more tired than usual, then I know I need to like slow down. Just stay away from doing like hectic stuff, like gym and stuff. . . . Examples like that. I think often it can be quite hard with it changing all the time, because

it's so up and down, you can't really structure. Like, if someone wanted to go rock-climbing, I can't really say a definite yes or a no.

23. **S:** And, and how do you feel about that?

24. **M:** I think it's hard emotionally because you know, you want to be able to do everything and ... That, and a lot of people don't understand the, the sort of, how fast it can just change on a day-to-day basis.

25. **S:** Ja, I can remember you were saying that in the last one. When you say "hard emotionally", can you describe those emotions for me? What -- I mean what is it that actually you're feeling and experiencing when that happens?

26. **M:** Sometimes anger at the situation, because stuff I wanted to do I can no longer.

27. **S:** How, how strong is that anger?

28. **M:** Sometimes strong. Depends on the mood I'm in actually that day. Ja, moderately strong in ...

29. **S:** Can you give me an example of what you do when you get angry about it?

30. **M:** What I do? I usually try and go to gym, which makes the situation worse. [laughing]

31. **S:** So you're too tired to go out and then you go to gym.

32. **M:** And then other than that I just make do with what I've got. If I have to -- If I'm -- Have to stay, just sit down and watch some TV or read. Mostly just to get my mind off it. Ja.

33. **S:** And, and how do you manage that with your thoughts? A lot of this is self-talk.

34. **M:** Ja.

35. **S:** So you've got the option of going to gym and, as you said, making it worse. Or taking alternative measures.

36. **M:** Ja.

37. **S:** How do you talk to yourself? What kind of thing goes through your head?

38. **M:** I think previously I've sort of said, no, I'm just going to push through it, you know, get it over. But ...

39. **S:** So, so -- What, what were you saying to yourself?

40. **M:** Like, just get over it, you know. Just ...

41. **S:** "Micaela just get over yourself."

42. **M:** Yes. Ja. Just, wake up if you're tired. Just move on. But now, I still want to do that, but I've learnt that if I go and do ... Instead of being off for one day, if I go and do this thing that I wanted to do, I might be off for a week. And so I think realising that in my mind I've just got to sort of weigh up the benefits.

43. **S:** The benefits. So when you're hard on yourself ...

44. **M:** Ja.

45. **S:** Ultimately you end up in a worse space.

46. **M:** Yes.

47. **S:** Is that a worse space physically and emotionally?

48. **M:** I think both physically, because I've gone and pushed myself when I shouldn't have, and then emotionally, because now I'm even more angry that I've sort of let it get to me, and I've tried to press through it. And it's just taken like five steps backwards.

49. **S:** And -- Ok. And how does that sort of day-to-day, hour-to-hour unpredictability sort of affect your overall well-being?

50. **M:** Such as?

51. **S:** Such as, sort of, how you feel about yourself, your sense of mood, all that kind of thing.

52. **M:** I don't think it's affected it too much. It is getting a lot better now because of medication and stuff. But before, I think my overall well-being, I was quite a mess. Like emotionally I was just having like mood outbursts because I was angry. And the well-being -- I was -- My body was very used to like being fine one moment and then not being able to move the next. So I think overall it did take its toll on me. But as it's sort of -- My medication is starting to work now. So ja. So I've gone from about 19 joints active, then to 11, and now to five.

53. **S:** Oh, that is wonderful news.

54. **M:** So ja. So I think that's getting better, but I've also sort of, because I've had it since I was nine, I've sort of learnt how to ... My way of going about, ja.

55. **S:** Ok. And one of the other things – I actually meant to start with it. We briefly touched on the sudden diagnosis.

56. **M:** Yes.

57. **S:** And how it was a bit of a shock. That's an understatement.

58. **M:** Yes. [laughing]

59. **S:** We never actually -- From there we just carried on discussing your journey, the journey.

60. **M:** Yes.

61. **S:** Can you tell me more about the impact of that diagnosis on you? Suddenly getting told.

62. **M:** Yes. On my whole family it was very hard, especially on my mom. Like she didn't know anything about it. And then my sister also, she went through -- Because I was nine, so she was like my age when I got diagnosed. And so she, because my mom ... Because my dad wasn't -- So my dad didn't believe the diagnosis. So my mom was having to do a lot of the stuff. So then also taking a lot of attention off my sister. And I think she had a hard time. I know she went through a hard time with that. And then for me I think it was also ... It was almost like I hit a brick wall. Because I went from being in the A-team for swimming, for hockey, for netball. My grades were average. You know, I was sort of, everything.

63. **S:** Yes. Everything being?

64. **M:** Like you've got it all. You're healthy, you're in the A-team for everything, you're doing well at school, you've got all your friends. and then all of a sudden, like I got ... I had to stop my sport.

65. **S:** Do you have to stop your sport because of the diagnosis itself or were you already stopping your sport before then?

66. **M:** I was already starting to sort of cut back on sport.

67. **S:** And then because of the diagnosis you were told you had to stop.

68. **M:** Ja. Ja.

69. **S:** Ok.

70. **M:** And then al -- I think also what had a big toll on me was when ... Because we had to tell the school obviously and then a lot of the teachers didn't know about it, and I had to tell all my friends about it. And so it was quite a big sort of change in dynamic about, sort of, my everyday life. So, ja.

71. **S:** When you say change in dynamic, can you explain that a little bit more?

72. **M:** I think like my ordinary day wasn't getting up, going to school, you know. I was almost looked as I was different. I'd sort of changed, because now the school sort of had to accommodate me in ways with like exams and tests and stuff. And my friends had to also sort of, what's the word. I don't want to say evolve. But get used to sort of the whole up and down and being, ja, being sore. Ja.

73. **S:** And, and -- So, so they had to get used to you being ill and the unpredictability.

74. **M:** Yes. Ja.

75. **S:** Can you remember back, I know it might be very hard. Can you remember back to the thoughts that you had when you got ... Who told you you've got, had JIA? Was it your mom or, or Dr X?

76. **M:** Can't exactly remember. Al I know is that when I got swine flu, my mom asked my paed to do a full work-up, because I was just getting sick. And then that came back with the HLA-B27 positive gene.

[10 minutes]

77. **S:** Yes.

78. **M:** And then she referred me to the rheumatologist, and I think ... I think we both found out together, but I was obviously ... I didn’t really know what was going on because I was so young.

79. **S:** But you got that diagnosis ... Because I can remember in our interview, first interview, you said it was very sudden, and you thought that there should have been more information provided about it.

80. **M:** Yes.

81. **S:** So I was just wondering, when you found that out.

82. **M:** Yes.

83. **S:** That diagnosis. What was going on in your head? How did you feel emotionally?

84. **M:** That -- That’s why I say, when we found out I think it’s like we hit a brick wall. Because it’s not like -- I don’t want to use cancer as an example, because that’s also awful.

85. **S:** No, you use, you please use your words.

86. **M:** But that’s -- It’s well known, you know. People know the treatment is chemo or radiation, and it’s sort of well known that there’s a lot of treatment out there and support and stuff. And all we’d, all my mom and I had heard, up to now.

[voice calling in the background]

Ma. Ok, she’ll open. All we’d heard about arthritis was wear-and-tear in old, older people. And so I think that was ... We didn’t know like where to start with medication, what to do with school, what to do, I don’t, just with everything. I think it was just the whole -- Ja.

87. **S:** So you really just, you didn’t even know where to start.

88. **M:** Yes, it was -- Ja.

89. **S:** And I’m sorry, these questions this time around are going to be difficult.

90. **M:** No, no, no, no.

91. **S:** So you don’t know where to start, so you hit that brick wall. What was the emotion attached to that brick wall?

92. **M:** I think it was almost scared, because it was very new and almost foreign. And also because it’s not known about and really very few people know, there was a lot less support. From -- For our whole family. And so I think that was quite hard emotionally. Like it was quite draining, because we always just sort of had each other to lean on. Like my mom, my sister, and I.

93. **S:** Can you name some of the emotions?

94. **M:** Well I was personally, I was scared and angry about having to, you know ... Because I no longer saw myself as what you call a normal kid. And I'd, I had to stop, so I was quite angry. And I was quite sad as well, because ... Oh. [laughing] I lost my thought now.

95. **S:** You were angry and you were quite sad as well.

96. **M:** Also because my life would sort of never be the same again. So I think -- And it was just, no-one knew anything about it. Like a lot of doc -- Like GPs don't know about it. And so they can't even help you. And people you're meant to sort of trust to treat you, can't really. So I think it was a lot of like uncertainty and ...

97. **S:** How did you feel about the fact that those people who were supposed to be able to treat you, you couldn't trust them? Is that what you said?

98. **M:** No, like GPs, like ...

99. **S:** Yes.

100. **M:** Because they didn't know about -- Because there're only, I don't know, is it three paediatric rheumatologists in South Africa, that actually studied the degree. For normal like colds and flu's, we almost felt like, do we go to a GP, because they don't really know my situation. How to -- A lot -- Even some specialists we go to, like, I can't think of one off the top of my head. But say, a dermatologist or something, you tell them and they're like, what's that? So you weren't quite sure where to sort of ...

101. **S:** You don't know who to go to, because you don't know ...

102. **M:** Ja. Yes.

103. **S:** Ok. So -- Is it possible for you to remember any specific thoughts that went through your head? Sort of after -- That period after being diagnosed.

104. **M:** I think a lot of confusion around the whole thing.

105. **S:** Can you verbalise those thoughts?

106. **M:** With the confusion I was very confused like why it had happened to me. And confused as to how to sort of move on, because I know at one ... When I got diagnosed, everything just sort of crashed, because the swine flu and the Coxsackie had all of a sudden ... I'd -- We -- My mom remembers, so she linked it now, that when I used to ride my – I don't know if I told you – ride my little pink bike, the little little one ...

107. **S:** With your ankles?

108. **M:** Yes.

109. **S:** Your ankles got sore?

110. **M:** Yes. Ja, I think it was my ankles that got sore, and she thought it was growing pains. And so we linked it to that. But we only think it was properly properly activated when I got the swine flu and Coxsackie. And so I think all the symptoms just sort of rushed together. And so, I think -- I think I got diagnosed in the beginning of Grade 4. In Grade 5, I was in a wheelchair for a couple of days.

111. S: We're going to explore that just now.

112. M: Ja. [laughing] So, so I think the whole emotions about just all of a sudden, I think I was ... I almost felt a little bit alone, because my friends, they didn't know about it. Like I was also quite young; I couldn't fully understand what was going on. And the -- I think having that, it -- And then also I felt, I felt a lot of guilt. Well not then, but now I almost feel a lot of guilt because my sister went through a hard time. I know like I can't really bear that on me, but I do. So, ja.

113. S: You, you've put that burden on yourself even though you know it's not really your burden.

114. M: Ja.

115. S: Ja. Can you remember any of the actual thoughts? So, for example -- I'm going to use myself as an example. I know how far I can exercise in a given moment.

116. M: Yes.

117. S: And then I push myself.

118. M: Yes. Ja.

119. S: Because I feel good. And then I come home and I feel bad; my body hurts. Then I self-talk and I say something along the lines: ok, that was a really stupid thing to do.

120. M: Ja.

121. S: You need to rethink about this and ... Ok, we'll stop there. That kind of a thought. Your self-talk to yourself after the diagnosis. Can you remember any of those thoughts? The way you spoke to yourself in your head? Or questions you had in your head, or fears that you had at the time.

122. M: I think in the beginning it was a lot of just questions about why. Why is it me? Like, how am I going to -- Sorry, let me just let that dog out. Ja, so in, in the beginning it was all a lot of questions. And again I felt quite alone and then I sort of ... Then I sort of -- I think I went into a stage of sort of criticising myself.

123. S: Can you give me an example?

124. M: So if I couldn't -- So, I'd want to run, but then I'd get sore. So I'd be like no, you need to get over it, it's in your head, just get on with it. And so I went through that stage.

125. S: So, in almost denial ...

126. M: Ja, so almost denial.

127. S: . . . . it was psychological, there wasn't actually anything wrong with you.

128. **M:** Yes, ja. So I -- And -- I think I sort of used to beat myself up a lot emotionally. Like I'm still now, academically I'm extremely hard on myself. And so, I think I went through that stage. And then ...

129. **S:** Did you have specific concerns about the implications of getting JIA?

130. **M:** Ja**.**

131. **S:** About the future?

132. **M:** Yes. That was one of my biggest sort of questions to myself. Like, how -- What is my life going to look like now? You know. I wanted to -- Because I was a huge swimmer, I wanted to go to do my CGA levels, which is like junior, I don't know, Gauteng sort of championships.

133. **S:** Provincials.

134. **M:** Ja. And I really wanted to go big with that, but ... I could still swim because swimming was low impact, but the amount of training I was able to do, it just wasn't possible. And so that was sort of out of the window for me, and I was just ... I'd sort of had my whole life planned, as a nine-year-old does. And I just, I was -- Kept asking questions, like what does the future hold now that I've got this? For a very long time it just got worse and worse and worse.

135. **S:** And what were your answers to yourself about what the future held?

136. **M:** I just -- I think I had to -- I found new things to focus on. So it used to be my swimming that I focused on thoroughly.

137. **S:** And then you said, I can't do that.

138. **M:** Ja. So I moved to my marks.

139. **S:** Ok. So you didn't have an in between stage. Sort of, you focused on your swimming you said, ok this can't happen anymore, what else can I focus on? There wasn't something that happened in between there?

140. **M:** So in between, I just sort of went into a complete slump. My marks dropped, I wasn't doing sport.

[20 minutes]

141. **S:** What were your thoughts?

142. **M:** I was also on cortisone at that time, so in about Grade 5, Grade 6 – I can show you a picture – I was very very puffy. And I think I'd put on about like 10, 15 kilograms from the cortisone, because I was on long-term high-dose cortisone. And so often I would look at myself and be like: I'm fat, and stuff like that. And then -- So that was sort of the in between stage.

143. **S:** And your thought about the future in that stage?

144. **M:** Yes.

145. **S:** What was it?

146. **M:** Yes. So it was -- I just didn’t know what was going to happen. Because my marks had dropped, I wasn’t doing sport anymore, and I didn’t like my appearance.

147. **S:** What -- Can you give a name to the emotion that you were feeling?

148. **M:** It was just very demotivated. I would have sort of passed through life. I wasn’t doing -- I wouldn’t -- I wouldn’t wake up with a purpose almost. It sort of felt like I lost my purpose.

149. **S:** Lost your purpose.

150. **M:** Ja. I was -- I wasn’t -- I wasn’t necessarily sad, I wasn’t necessarily angry either, I was just very much not motivated and I just ... I’d get up in the morning, go to school, get home, do my homework, do whatever, if it’s right or wrong, and go to sleep. And then do it again. It was no sort of -- I had no passion. And ja, so I went through that stage before.

151. **S:** Then what flipped you into the next stage?

152. **M:** It was actually -- I don’t -- I think -- So it was about Grade 6. So for about a year after my diagnosis I was just like kind of a mess. And in Grade 6, my term one ... So at this point I wasn't doing any sports, I couldn’t. If I did sport I would end up just bed-bound for a week.

153. **S:** Yes.

154. **M:** So my -- We have three terms, so my term one mark, my average, was about 55 per cent. So -- And I looked at it and I don’t know, I don’t know what ... I’ve never -- I -- Before that I’ve never really been fixated on my marks, but obviously they dropped. And I don’t know, something switched inside me. Term -- From Grade 6, term two onwards, I just pushed academically.

155. **S:** So it was almost like that report was it.

156. **M:** Ja. And, and I think I just said, I need to get out of this slump. Yes, I’ve gone through this, but it’s now ... You know. life throws you curve balls and stuff, and you’ve just got to roll with it. So, I think I just said: yes, it’s horrible what happened. I can’t do that anymore and I’m sad about that, but you know what, let’s find something else. So, ja.

157. **S:** Ok, so I think that leads very nicely into one of the other questions.

158. **M:** Yes.

159. **S:** And that was the debilitating symptoms and the special treatment.

160. **M:** Yes.

161. **S:** So you were saying, and I, I’ve just kind of got a quote here, that you had these terribly debilitating symptoms.

162. **M:** Yes.

163. **S:** And then the school was really great and they put support systems in place.

164. **M:** Ja.

165. **S:** And they were very generous. So you couldn't be angry with them.

166. **M:** Yes.

167. **S:** But you still felt very isolated by the special treatment.

168. **M:** Yes.

169. **S:** Is it possible for us to explore that one a little bit more?

170. **M:** Yes. No, no. Of course.

171. **S:** Could you say just a little bit more in depth on it?

172. **M:** So I think after being diagnosed, we had, used to have PE – physical education classes – two hours a week. And I obviously couldn't do those anymore, because they were usually land-based and like running or doing like high jump or long jump. A lot of, sort of, impact. So I couldn't do that anymore and the school was perfectly fine with it, which was fantastic. But then I'd sit on the side with like the people who had flu that week or something and they couldn't do sport, and they'd be like: oh, how come you're sitting here? And I didn't quite -- I also went through a stage of I didn't want to tell anyone what I had. Still today I've got some outside -- [long pause with noises in the background]. Sorry.

173. **S:** No, that's fine.

174. **M:** Still today I've got close sort of guy friends, but they won't, I don't tell them that I've got ... None of them know that I have arthritis. That's ...

175. **S:** Why is that?

176. **M:** I don't -- The -- For the truth for me is almost embarrassment.

177. **S:** Ok.

178. **M:** And I know with both this and the PE thing, it just leads to so many questions. And a lot of questions I almost don't want to answer because I'm afraid I'll get like pity.

179. **S:** Ok.

180. **M:** Sorry, sorry. [someone speaking in the background]. Sorry, sorry. Can we just pause?

181. **S:** No, it's fine.

182. **M:** And then -- A lot of the -- So with the PE -- So the first couple of times I didn't . . . . out of the PE classes. I would just sort of say, no I'm sick. I've got a cough, I've got flu. And then because it was week after week after week, I started having to tell people. And then it just came so many questions: what's that, what is it like, are you constantly in pain? And then came the pity.

183. **S:** Ok.

184. **M:** Like, I'm so sorry. I'm here for you. Like very nice condoling words, but stuff I didn't want.

185. **S:** And what was it about people showing empathy or pity that you didn't want? Why was that horrible?

186. **M:** I think it was both to do with -- It was almost again isolation. Like that's the girl who has juvenile arthritis, you know. We've got to be there for her and stuff. And then again the almost special treatment and ... There was something else I was going to say. No I can't remember. Ja, so it was like that. And then ...

187. **S:** What is it about this -- What is the -- What is the meaning of the special treatment for you? What is -- What is your interpretation of that?

188. **M:** Yes. Ja.

189. **S:** I, I know what special treatment is, but how is that, does that impact on you?

190. **M:** I think it's very -- It -- Emotionally it impacts me because during exams I can't meet on the tennis courts with my friends in the morning, where we line up and go into ... I have a special -- Another venue. And then -- So -- I think it's still hard for me emotionally, and I know I need it because otherwise without the extra time I wouldn't finish my exams. Without the laptop I wouldn't be able to write. Without rest breaks I'd, my back would get so sore. So I know I need it, but I don't want it, because I just want to be in a sense normal. And I just want to be able to, you know, have the time constraints that others have and, you know. So ...

191. **S:** So is it affecting your self-concept and your identity?

192. **M:** Identity, almost yes. I don't know -- I think for me it's a lot more sort of magnified than an outsider's perception. But for me, I, I think of myself I'm always going to be the girl who had, you know, a special venue for exams, and had extra time when writing a test, and stuff like that. And I'll often, you know, if we say come out of an exam and I've been able ... So, say it's an English exam and I've finished because I've had the extra time. Obviously it's still is 10 minutes an hour, but 20 minutes is quite a lot. And everyone else comes out: no I didn't have enough time to finish. And then, you know, it's sort of a like, well is this unfair? So it's often that type of thing. Ja.

193. **S:** So almost -- Ja.

194. **M:** It's very -- I don't -- I, I know I need it, but I don't know. It's, it's still very isolating.

195. **S:** Ok. And one of the other things that you, you, you did raise, which, which seems strange in comparison to what we've just said because everybody knows that, that you're sick, but the issue of invisibility was also raised.

196. **M:** Yes.

197. S: So people know that you're sick ...

198. M: Yes, I know. Ja.

[30 minutes]

199. S: But you -- Because they can't visibly see anything wrong with you, then ...

200. M: Ja. So I think also -- So when we were younger, when I got diagnosed, I think that was a huge thing, because often I would say, no I've got this thing, and they'd say, well you're not sick. Now I think as we're older we can understand like it's a little bit deeper than that. But like I said, often if people don't ... I haven't told them that this is what I've got, they're not going to know because I'll very rarely show it. And I'll very rarely voice it.

201. S: And that's because you don't want to be different?

202. M: Ja. I don't want to be different and I don't want to be pitied.

203. S: Ok.

204. M: Ja.

205. S: And how did it feel when somebody said to you, but you're not sick?

206. M: Ja.

207. S: How, how did that feel, and what were your thoughts around that?

208. M: I think -- What's the word. It was almost as if I didn't really know what to say, because I know I didn't look sick, but I knew what I was feeling. And I couldn't -- I felt like I couldn't sort of convince people that this was the truth and I wasn't just acting up. And so, ja, that was quite hard. Ja.

209. S: Do you think people did think you were acting up?

210. M: I think in the beginning -- Probably some people still today do think I'm acting up, but I think that's just one of the downfalls of having an invisible illness. But some people that -- Some of my friends have gone and read up on it and stuff, they're like, ok this is very rarely, sort of ... You can't really see it unless you know what a swollen joint looks like. Or -- So I think, ja, probably before a lot of people thought I was just acting up. Probably still some today. But I think that's just ...

211. S: And I'm going to say those horrible words again: how did you feel, standing there hurting ...

212. M: Ja.

213. S: And somebody denying that reality?

214. M: First Word is alone. Very very alone. And then I also sort of started to question myself, because once enough people tell you, no you're just acting up, you start to think well, am I actually feeling this or is it in my head? And so I think that was a very ... I was sort of just isolated to my own mind and then that would run wild with, you know, is this actually real, you know. Or are they just ...

215. **S:** And when you followed that line of thought, is this actually real, when ... How did that spiral? Where did it go to, those think, thoughts?

216. **M:** I was often left sort of unanswered in my own mind, because I knew what I was feeling, but I didn't ... Because people kept telling me no, you're just acting up, I didn't know if it was real. And so I think often, again, I just pushed through it.

217. **S:** I was going to ask if that was possibly why you were so hard on yourself?

218. **M:** Ja. And I think one of the reasons why I am hard on myself is because so that I don't get people saying no, you know – ok, pathetic is quite a hard, harsh word – you're being pathetic. Or ...

219. **S:** Have people actually said that?

220. **M:** Once or twice I think, when I was first diagnosed.

221. **S:** And was that children, or was that an adult?

222. **M:** I think one of them was an adult. So I think, ja. So ...

223. **S:** A teacher?

224. **M:** I can't exactly remember.

225. **S:** Can't remember. Ok.

226. **M:** I can't remember.

227. **S:** So the invisibility for you has played quite a big role ...

228. **M:** Ja, it has.

229. **S:** Also in the development of your self-concept.

230. **M:** Yes. No, for sure.

231. **S:** How -- I mean -- When you think of yourself during that time period, because obviously you've matured since then.

232. **M:** Yes.

233. **S:** When you think of yourself in that time period of having to deal with knowing on the one hand that you are ill.

234. **M:** Yes.

235. **S:** But then not knowing, because people have put doubts in your head.

236. **M:** Yes. Yes.

237. **S:** Where, where was your self-concept at that stage of your self-esteem or identity, whichever word you want to use.

238. M: Yes. Ja. I was very lost . . . . my identity, because I wasn't quite sure if it was just in my mind. And then I was also feeling very alone, sort of isolated. And then on top of that I was picking up weight due to the cortisone. And then on top of that I had concessions at school. You know it's just -- It's not like, I don't know, say bad acne, who, a lot of people had it. I think at my school there's two of us that have it. And the other one isn't in my grade. And we never see each other. So there's very few people that you can relate to, and so I think that's another aspect that's quite hard, is that you know my friends were great, they were reading up. But there's only so much you can read up and you, not experience. So I think when it come, when it came to my ... Especially my self-esteem lowered quite a bit because I think I was just very lost and demotivated. And I couldn't quite see where my life was going.

239. S: What words did you use to describe yourself at that time period? In your head.

240. M: I, I thought of myself as quite fat. I'm not quite sure. I think, just demotivated and just sort of, I almost thought of myself as just a little blob, just you know, floating by. So ja.

241. S: Thank you. I know these questions are ...

242. M: No, no, no.

243. S: They're difficult questions that I'm asking you. Then there was a whole also sort of a, a contradiction in being, as it were, where Dr X would talk to you directly, and yet at the same time you were intimidated by her bedside manner.

244. M: Yes.

245. S: I was wondering if you could explain more about how did it feel for you when Dr X spoke to you directly, and what was so intimidating about it?

246. M: I think it was very scary for me because she ... In her nature she's quite abrupt and strong and to the point.

247. S: Was it anything to do with her appearance?

248. M: No, no, nothing to do with her appearance. Just her mannerisms and the way spoke. And then being so young, not knowing what you've got, and then having someone talk directly to you and so abruptly, I think I got very scared. And to this day, I still sort of you know, I'm very polite, overly polite. And so I think that was also quite hard because I didn't like her as a person and I didn't like going to her.

249. S: But what was it about her that you didn't, don't like?

250. M: I personally don't think she should have been a paediatrician. I don't want to be rude or anything, but ...

251. S: Don't worry, this is about your experiences.

252. **M:** Because for me it was very very hard for me as a child hearing you've got this, this is how you're going to change, and all this.

253. **S:** So she was just ...

254. **M:** Straight to the point. And that was quite scary and that was quite hard. And I think in, with that came more the feeling of being alone again, because you didn't sort of have ... She was going to become, she is, my main doctor. Like if I go to another specialist that needs to put me on something, they need to consult with her first because of the medication I'm on. And so I started to feel very alone because I couldn't sort of be comfortable around Dr X.

255. **S:** Comfortable in what sense?

256. **M:** Just able to sort of relax and voice what I was feeling. I was often sort of, almost shy to say all, like, this and this and this is going on. Because I was scared of how she'd be, well your blood count's fine, and this is fine, and we can do no more. So that was also quite a ...

257. **S:** So, if you -- Did you try tell her something at a time and then she was rather brusque?

258. **M:** It wasn't one particular time. A couple of times it has happened where my CRP, which was the inflammation levels ...

259. **S:** The count.

260. **M:** In your blood I think. Often at times it's been very low, very normal, but my joints have been sore. And so then came again the thing of now do you go with the scientific information, or on the clinical sort of diagnosis. So I think that was also ...

[40 minutes]

261. **S:** So you would share what you were experiencing with her.

262. **M:** Yes.

263. **S:** And then how would she respond?

264. **M:** She would often say, well your CRP is fine and ... And then also often in those times where my CRP was fine, she ... I sometimes -- I don't think it would have happened, but I sometimes think that she, when she did her clinical exam of like touching my joints and stuff and my CRP was fine, I often thought she overlooked some of the inflamed joints and said they were fine. Almost -- Because she's told us that I've been one of her most complicated patients, and I think she wants to just get me into remission and just, you know, close the case. So, in that time -- But I have been sore, I've sort of been ... Because personally I'm a very scientific person, you know. I want the facts, I want studies proven, stuff like that. And so when my blood count was perfectly normal and say the MRI was normal, or whatever, but I was still sore, I was scared to voice it because I was scared that people wouldn't believe me. Or Dr X wouldn't believe me.

265. **S:** So, so you didn't possibly even then tell her that ... Did, did you stop telling her when you were sore?

266. **M:** I didn't. I sometimes just left out ...

267. **S:** You just didn't go there. You didn't go there because?

268. **M:** I was scared to not be believed. And I think that linked back to the, when I got diagnosed, people not believing me. Ja.

269. **S:** So you didn't think she would believe you. Ok. Ok. How did that, does that affect how you see yourself, that people didn't believe you?

270. **M:** At the time that people, a lot of people were not believing me, I was very self-conscious and I became very withdrawn. And I often wouldn't tell people if I was feeling sick that day or what. And I sort of almost began to just put on a mask and because I was afraid of just so many people just saying they don't believe me. And still to this day I won't -- If I'm in pain I won't voice it. If someone asks me directly, like are you sore, I'll tell them. But ja, I think it did ... I became very withdrawn.

271. **S:** Tell me, when people say they don't believe you, what is the emotion that then hits you? Or do you feel ...

272. **M:** Now it's more frustration. Because like with my dad, I don't even know if he believes it or not anymore. But it's frustration because it's almost like you can't get through to them. But back then it was just loneliness and sad. Because I felt if you're not going to believe me, and you're not going to believe me, then who's going to believe me? And who have, who have I got there to talk to? So that was, that was hard.

273. **S:** So in the one way Dr X for you was good in that she spoke to you directly and didn't speak to your mom. But the problem was that her bedside manner was so direct.

274. **M:** Yes. Ja.

275. **S:** And she contradicted perhaps what it was that you were feeling.

276. **M:** Yes, ja.

277. **S:** So you would say I'm in pain and she's say, well everything's normal.

278. **M:** Yes. Ja.

279. **S:** So there's nothing we can do.

280. **M:** Ja.

281. **S:** Or what did she say? Everything's normal, so?

282. **M:** She'd just say, well your CRP is normal. And leave it there. So we were sort of left to fill in the blank.

283. **S:** Ok, so, so if we tie that back into people not believing you, is that then where you would have also felt, well because that was normal, then does she believe me when I say I'm feeling sore?

284. **M:** Yes.

285. **S:** Which is why you stopped telling her.

286. **M:** Yes. I think yes.

287. **S:** Ok, ok. Wow, that's quite a, a tricky situation.

288. **M:** Yes, ja. No.

289. **S:** Because I mean she's your primary doctor.

290. **M:** Ja, it was. It was very.

291. **S:** And you need to be able to tell her everything.

292. **M:** Yes. Exactly.

293. **S:** So are there other things that you haven't told her, or is it just the pain? Because I mean, while your mom's not here, there's always female issues and things that are involved in arthritis.

294. **M:** Well, I know with like my period, when I started my joints just went ballistic. And so I don't think she -- So I'm on the pill now and we just skip the ...

295. **S:** Ja, so you just don't get one.

296. **M:** Ja. And every three months or so I'll have my period, but like every, without fail, every doctor's visit she's like, you have to face your period some time you know. So I don't think she believes me when I say it's making my joints sore. Like I can physically feel my joints being sore. So that's one instance. And then with more emotional things, like she would often ... When I had my Revelex infusion, which was a whole day, my mom and I would want to ...

297. **S:** That was the one where she was late? Is that you?

298. **M:** Yes. So my mom and I would want to ... Because I wanted to go to school the next day, you know, I didn't want to miss classes. And so my mom and I would get up at six that morning, be at the hospital by seven so we could get the medication up. And often she'd just sort of be late, and then I'd just have to go well on into the night, and then I'd get home at like 12. And so ...

299. **S:** If you had to label your perspective of that situation and her behaviour, what ... How would you label that?

300. **M:** I would almost -- With that particular situation, I felt it was quite disrespectful of my time and what I wanted. Because I think she thought -- Well, she -- Her perception on school is that you only need school so that you can have the social interaction. So I supposed that's true, but you know it's missing just days and days of school, because you simply only got the infusion up at 12. It was very, it was very much like, ok be there at seven o'clock, and then only get the infusion up at 12. I could have gone to school that day and come in the afternoon, and gone through the night.

301. **S:** So you felt she was disrespectful of your time and you as a person, and ja.

302. **M:** Ja. Ja. Very much so.

303. **S:** I -- There's some -- I've got to come back to come back to coping just now. But there was something that happened to you in hospital – you were placed in ...

304. **M:** Oh yes, I was placed in the ...

305. **S:** The adult ...

306. **M:** The cancer ward. The adult cancer ward.

307. **S:** The oncology ward.

308. **M:** Yes.

309. **S:** And ...

310. **M:** Someone died next to me.

311. **S:** The old lady died next to you.

312. **M:** Ja.

313. **S:** So what I was wondering was there you are with a very chronic illness, in hospital yourself.

314. **M:** Ja.

315. **S:** And this lady dies.

316. **M:** Ja.

317. **S:** So you came fact-to-face with death while you were ill.

318. **M:** Ja.

319. **S:** How was that?

320. **M:** That was ...

321. **S:** What were your thoughts?

322. **M:** Well first, firstly that day we only got the infusion up at 12 again, so that was again ... I was angry about that. And then I also got placed -- She hadn't booked me a bed, that's why I was placed in the oncology ward. Because there were no space, there was no space in the ward I was meant to be in. So that again was like, do you not care enough about me to make a phone call and say, can you book this bed. And then also having someone -- I felt -- When the person died, she acted almost as if it wasn't a big deal. She was quite dismissive of it.

323. **S:** The doctor.

324. **M:** Ja, Dr X. But for me, it like traumatised me completely.

325. **S:** In what way was she dismissive?

326. **M:** She was -- She was like, oh sorry. And then ok. And so at that point my mom was also sort of like angry, and we'd actually considered moving doctors. To an adult rheumatologist.

327. **S:** Ok. And that was hugely traumatic for you.

328. **M:** Ja.

329. **S:** You described it as being a hectic experience.

330. **M:** Ja, no, it really was.

331. **S:** Can you tell me, I mean that lady died in front of you, you've got a chronic illness. What kind of thoughts went through your head?

332. **M:** Yes.

333. **S:** Can you just be a bit more specific about your emotions, fears, concerns when that happened?

334. **M:** In the moment it was very like surreal, like I didn't sort of ...

[50 minutes]

I, I can watch TV like Grey's Anatomy and stuff and people die all the time, but when you're faced with it, it's very like surreal. And then having that on top of an illness. I know JIA isn't life-threatening, but it was still like I'm already going through a tough time and then to have that on top of it. I think it was very much an overload. And I can't remember exactly, but I ... That day I was just completely like, sort of switched off. Like I was very sort of unresponsive.

335. **S:** Disoriented? Or dazed?

336. **M:** Almost -- Just -- I, I was in shock. From the ...

337. **S:** You were in shock.

338. **M:** Ja. I was more in shock. And then after that I was quite angry.

339. **S:** Angry at?

340. **M:** At Dr X. And then I was very upset because I was just like, how can the lady die in front of me, and you know, I've got this illness and that can happen to anyone. And I started to get like very worked up.

341. **S:** And could this happen to you.

342. **M:** Yes, exactly. So it, it sort of made it real to me that it could happen to me, that I could all of a sudden just die one day. And so that was also quite hectic, so ...

343. **S:** At your age, to suddenly be face with the fact that you could die.

344. **M:** Yes, yes. Ja. That was very petrifying.

345. **S:** Petrifying.

346. **M:** Ja.

347. **S:** How long did that last?

348. **M:** My mom did send me to a psychologist and so she helped me quite a bit. And still today, like from that moment on I have sort of been like, you know, you can go to bed and think, ok someone could rob me, come in with a gun, and shoot me and I could be dead. You can wake up and be in the car and have an accident and you could die. So since that moment on I've sort of been like, you don't know what's going to happen.

349. **S:** You never know when you're going to die.

350. **M:** Exactly. And so realising that also at such a young age, I was ... I don't think it was fair. And it was a sort of, another sort of -- It just hit me in the face. And for I think about a month that was all I could think about. Like every, sort of, everything related back to that situation. Almost like, I'd see a flower and I'd be like there were flowers next to that lady's bed. Or I'd go for a shower – that lady went to the bathroom, that's where she collapsed, next to the shower. So it was very -- I was --

351. **S:** Traumatised.

352. **M:** Ja, very traumatised.

353. **S:** Ja, ja. So you were experiencing flashbacks.

354. **M:** Yes.

355. **S:** And then, and now you're still hyper aware of possibly dying.

356. **M:** Yes. Ja.

357. **S:** And the -- When you say you were petrified, how did that present itself?

358. **M:** I was more petrified, not personally of me dying, but more of like my family. And I, would you believe, I became very anxious that one of my dogs would die. Like someone would come and poison them or something.

359. **S:** Because your dogs are very important to you.

360. **M:** Ja, they are. And so I got very scared. Like every morning when my mom would drop me off at school, she was going to drive to work and she could be in an accident, or she could be in her work office and people could come in and raid the office. So it was ...

361. **S:** Profound impact on you.

362. **M:** It really did. I think it had a much bigger impact on me than we realised it would. Ja.

363. **S:** And then I can't remember if the wheelchair came before or after the lady died.

364. **M:** That was before.

365. **S:** That was before. Because that was another experience you described as hectic.

366. **M:** Ja, it was. It was also again, I think mainly it was just isolating, because ... I think because we're young, you don't really associate young people with a wheelchair almost. So, ja.

367. **S:** And did you have any thoughts about the implications of being in a wheelchair with regards to your disease?

368. **M:** Not at the time, I didn't.

[sound of door opening in the background and someone speaking: What time are you off?] For band practice?

[voice in background: Ja, just now]

I've only got it at six.

[voice: But I thought you were going to go to gym.]

No I'm not.

[voice: Are you not? Oh ok.]

369. **S:** Can we carry on? Is that ok?

[voice: Ja]

Ok, cool.

370. **M:** Where were we, the wheelchair?

371. **S:** Ja, ja.

372. **M:** Oh, yes. I don't think we realised how big an impact it would have on me. Because physically my joints got stuck. So we never ...

373. **S:** Because you were sitting in the wheelchair they got stuck?

374. **M:** Ja, and I wasn't moving. So after that, movement became like very important. Like going to gym and exercising and keeping my joints moving. Because getting them mobile again was such an experience. And ...

375. **S:** And your thoughts during that process?

376. **M:** I think with being in the wheelchair I just thought everyone was just looking at me. I just felt every -- I was just like on a showcase and everyone was just looking at me. And I felt very different again, because I was in a wheelchair, and there's a few number of people in a wheelchair. So I think I was very, I felt very isolated, and from that I got quite depressed because of feeling, like, alone.

377. **S:** Ok. So even though you were then out of the wheelchair, you still felt depressed.

378. **M:** I think getting back -- No, out of the wheelchair I was fine, but when I had to get back moving it was, psychologically it was, took a toll because it needed like a great amount of mind strength to move through like the pain. Ja.

379. **S:** The pain. The pain.

[voice in the background: Sorry, Sharon.]

Yes.

[voice: . . . . homework. . . . .Your homework. You said you can't -- What time do you have to start your homework?]

380. **M:** . . . .

[voice: Ok. So you're fine then? Ok.]

381. **S:** Ok, let's just start again. So you were saying the process of getting the limbs moving ... Were there any thoughts during that time period about your future because you were so immobile?

382. **M:** The only thing going through my mind at that stage was I'm never being put in a wheelchair again. That was all that was going -- I'm never going to stop. And I think that was actually quite a big almost breakthrough, because since then I've never stopped moving. And I think that's been a huge, almost type of medication for me, because my joints just kept mobile.

383. **S:** And that was one of the things that you came up with in the original, is that one of your coping strategies is gym. And I -- It's amusing that your mom just came in to chat to us about you going to gym.

384. **M:** Yes.

385. **S:** Can you give me more detail on what your routine is and how do you ensure your mobility by going to gym? What kind of things do you do?

386. **M:** So -- Was it last year? Last year I started going to a biokineticist – we found a really good one that created your own program, but didn't just send you away and see, and say, let's see you back in a month. We went there twice a week and they went through your program with you and made sure you did the exercises properly. And from that I got very strong and so that was able to sort of support my joints more. And then -- Ja, so usually I try and keep my strength, and then I sometimes ...

387. **S:** Strength being your muscle strength?

388. **M:** Yes. So I'll do like, I don't know, like leg day or core day. So like that. And then, I know my mom doesn't like it, but I enjoy running. So I won't run often, maybe like once . . . .

389. **S:** What is it about the running you enjoy?

390. M: I don't know. I'm -- It's just -- It's, it's almost an escape. You just put your music in and you just run.

391. S: And walking doesn't do the same?

392. M: No.

393. S: Got to be running.

394. M: Ja.

395. S: Obviously on a treadmill for you?

396. M: No, they've got a track at the gym, around.

397. S: Ok.

398. M: So I run on the track. So that's quite nice. Ja. And then ja. That's ...

399. S: And so with -- So, so as a coping strategy the gym plays two roles. On the one hand it keeps you mobile, keeps you strong, and all those other things. But you get a sense of ...

400. M: Sort of an escape almost.

401. S: An escape.

402. M: And then also because I think it releases endorphins. Afterwards I feel very good about myself and almost motivated. If I go, say in the holidays, if I go to gym in the morning, I'll get back and I'll be like ok, I'm not going to sit down and watch TV all day, I'm going to go do stuff today.

[60 minutes]

I'm going to go get this project done, I'm going to go do some community service, and ...

403. S: Wow, so it really perks you up.

404. M: Ja, so that -- I don't know if it's meant to perk you up so much, the normal average person. But gym really does -- I can get -- I'm in a very good mood if, after gym.

405. S: So, so part of it you think is because of the endorphins. Is there anything else about it?

406. M: I think it's just, you get away from everything else, and it's sort of, you've got to just zone, almost focus on what you're doing. And then you also just feel good about yourself. So, ja. I think, ja.

407. S: And then -- I'm just -- Sorry, have to put my glasses on. Ja, about the gym: is it also possible part of it being ... It's a social environment and ...

408. M: Yes. No, for sure. That's why I only -- I don't like to go to gym when it's empty.

409. S: Ok.

410. M: So I -- It's just something that I've sort of found out. I won't -- I don't -- I know the times when it's busy. So I'll go from either in the mornings, quite early.

411. S: Yes.

412. **M:** Or in the afternoons, from after like three thirty.

413. **S:** So that's another factor that makes it more enjoyable for you.

414. **M:** Ja. I think . . . .

415. **S:** Do you have friends there, or people that have become acquaintance friends, or ...

416. **M:** A couple, but -- Sometimes I go with my best friend to gym, but ...

417. **S:** But otherwise it's just being around people.

418. **M:** Ja, I think it's just being around. And I find the whole atmosphere also when it's busy, it's just. I don't know. Ja. It's just -- The vibe's very sort of uplifting and energetic.

419. **S:** Ok. Ok. Alrighty. And then I know how much your dogs mean to you.

420. **M:** Yes.

421. **S:** And you -- And they're part of your coping mechanism.

422. **M:** Yes, for sure.

423. **S:** Could you describe more to me about how that works?

424. **M:** So my Labrador is -- So we -- I'm quite angry with the breeders. We got her when she was five weeks, and you're only meant to take them away from their mothers when they're eight weeks. And they told us that their vet said no, it was perfectly fine, she'd had all her vaccinations. So she's got like an oral fixiation, thing.

425. **S:** Fixation? Ja.

426. **M:** Fixation. So she always has to have a teddy in her mouth; she loves teddies. She's almost three now and she likes teddies. But then also we've found, when she was younger, if you threw a biscuit up it would sort of knock her on the head. And we thought it was just something that would come with growing up and your, the mental ability. And she would just -- It would just plop on her head, she wouldn't see it. And so we thought nothing of it, until one day my sister was driving in and she went under the car. So she was -- Ten thousand rand later.

427. **S:** Ouch.

428. **M:** She broke her leg, and then we were like, ok no, something's wrong. So we took her to the vet and they said no, you need to go to the eye hospital in Fourways. So it turns out she has retinal -- Progressive retinal atrophy disorder, I don't know. Ok, so it -- I don't know, it's something to do with their blood vessels, but they go blind over time. And she is just -- She's almost, like -- I just look up to her so much, because she ... She'll often -- Like, especially at night she has quite bad night blindness. So, we've got stairs at our kitchen and I was bringing her in last night and she misjudged where the stair was, and so she tripped a little bit. But then she just bounced back up and just carried on walking. So I think in that way she, she's always happy. Like nothing can sort of detour her. So I think that, for me, almost is a role model almost.

429. **S:** A role model? Really?

430. **M:** Ja, I look up to her. And then my others, they're just there to like cuddle and you can play with them. And you know they're always there for you. So ja, the dogs have been a big coping method.

431. **S:** And, so when you say they're always there for you ...

432. **M:** Ja.

433. **S:** How does it help?

434. **M:** I think just knowing that someone is there that ... Who -- Because basically, for your dogs, like you're their whole world. And so also we've got our other big -- He's a cross. He's a rescue. And so he is best -- If you sit down on the floor, he'll come and sit on your lap; he thinks he's tiny. But I think for him he just loves, loves us. And I think he sort of thinks we've taken him in and rescued him. And it doesn't matter also if you just drive down the street, you've forgotten something at home, you come back and they act like they haven't seen you in months. So I think it's always knowing that there's someone that is there, if you call them, they're just going to give you lots of love and there's someone there to love. And ja, I think it's that ...

435. **S:** It's very, very emotionally uplifting for you.

436. **M:** Yes. Yes, very much so.

437. **S:** And sort of, do you get a sense of well-being from being with them.

438. **M:** Yes, for sure. Yes.

439. **S:** Ok, great. And we mentioned it early, being hard on yourself with academics. Your academics is a focus. Being hard on yourself with the academics has helped you achieve and in many ways improved your self-concept.

440. **M:** Yes.

441. **S:** From what I remember from our early conversation. I want to flip that and ask you, how does being so hard on yourself affect your well-being?

442. **M:** I have one of the smartest grades. The school has said we are probably going to be the smartest grade they've had in like a hundred-and-thirty years. And so I get an 85 percent average and I'm like top 20 maybe. And so I think in that -- I've told my mom, like you can get an 85 percent average, but in my grade it's still not the best. So being both hard on myself, I've come to, with maths, if I get below 90 I'm not satisfied. And so I think with that comes a lot of anxiety. Like I know I've got a maths test this Friday and I'm just a ball of nerves about it. So I think being hard on myself, it gives me something to focus towards, but it also takes its toll on me because I'm constantly coming down on myself, saying like no, that wasn't good enough, that wasn't good enough. So, you know.

443. **S:** So it affects your emotional well-being.

444. **M:** Yes.

445. **S:** It's created anxiety, the negative self-talk.

446. **M:** Ja. Ja.

447. **S:** Do you think there's a way you can keep academics as a focus and work, work obviously as hard as you can within your boundaries, without the negative self-talk?

448. **M:** I think as a person it's just who I am, to be hard on myself. But it has gotten better as I, I've started to sort of take notice of it and you know, try and be more aware of it. And go in more of, in a state of a mind of: just try your best and do as best you can and study to the best of your ability, and if you don't get a 90 then there's a next time. So that has ...

449. **S:** Ok, so you , so you're maintaining your goals.

450. **M:** Yes.

451. **S:** But you've changed your self-talk to a slightly more positive one.

452. **M:** Yes.

453. **S:** Does that -- Has that helped at all with the anxiety or not?

454. **M:** It has partly. Mom! [shouting]

455. **S:** I'm pretty sure that's my lift that's decided to wait until I'm finished.

456. **M:** Oh. [laughing]

457. **S:** And my lift is not going to think to move away.

458. **M:** Sorry, what was your question?

459. **S:** So has that changing your self-talk slightly, has that improved your anxiety and your sort of ...

460. **M:** Yes.

461. **S:** Ok.

462. **M:** It has. I've found that if I go into a test with, I'm just going to try my best, I've actually gotten better results. And I think that's because I don't have the anxiety of, you have to do well, you have to do well, you have to do well. And because I'm getting better results I'm a little bit more, less anxious. And more just wanting to do my best.

463. **S:** So, so it's almost like being hard on yourself spiralled you down a little bit.

464. **M:** Ja. Yes.

465. **S:** And now, now that you're being more positive, it's spiralling you back up.

466. **M:** Ja.

467. **S:** Ok, I'm pretty sure we only have about one or two more questions.

468. **M:** No it's perfect. Ja.

469. **S:** Let me see. Where did that one -- There was one issue that I had with regard ... Not issue, question, about independence. Because I found that the way you were talking, you actually stand up well for yourself.

470. **M:** Yes.

[70 minutes]

471. **S:** So, your mom may want you to stay at home.

472. **M:** [laughing] Yes.

473. **S:** And you even mentioned that sometimes you have some stand-up fights around that.

474. **M:** Yes.

475. **S:** And I was wondering, sort of, what does it mean to you to be able to make these choices?

476. **M:** It's very important to me to be able to make my own choices, because a lot of, sort of control has been taken away with regards to, I'm not able to do hectic sport and stuff like that. So being able to make my own choices, like this is what I'm going to do and ... It's become very important to me. It's become sort of almost one of the main features in my life that like choice is probably one of my main priorities. Ja.

477. **S:** So it's also a coping strategy.

478. **M:** Ja. No definitely.

479. **S:** As well as asserting your independence.

480. **M:** Ja.

481. **S:** What kind of choices are really important for you?

482. **M:** I think choices of what I'm going to do with my body.

483. **S:** From a medical perspective, or ...

484. **M:** Both that and out of medical.

485. **S:** Whether you're going to run or not.

486. **M:** Yes. With medical I've sort of -- Well I'm not really meant to go back on cortisone, but for that, when they were trying to wean me off, I said I'm not going back on cortisone. And that's my choice. And I also went through a stage where I just wanted to come off all medication. So my mom and I had a few fights about that as well. [laughing]

487. **S:** Who won?

488. **M:** I did. But I never came off the medication because I came to my senses and ...

489. S: So if I just explored that a bit, you and your mom had a big fight or argument about you coming off meds.

490. M: Ja.

491. S: And then your mom acquiesced and said ok, if that's what you really want to do. And then?

492. M: I think it was more the, her disagreeing with me that spurred me on to want to do it than ... And then once she'd said ok, then I was like well ...

493. S: But then the control was back in your court.

494. M: Yes. It was very much, I need control over certain aspects of my life. And it's -- I think one of the main things is what I'm going to do with my body. Whether I'm going to go to gym today or not. Whether I'm going to go to school or not. Whether I'm going to be put on this medication or not. And ja, that is one of the main things I ...

495. S: What, what happens when you're not allowed to make those choices?

496. M: I do get quite frustrated and angry, because I'll often tell my mom that if it comes to that situation it's my body, I can do with it what I want.

497. S: So you don't back down?

498. M: No.

499. S: Has there been a case recently where you've had to back down?

500. M: It wasn't recent, it was about end of last year maybe. I had to go for Polygam. Was it this year actually? I don't know. But -- And that is a twenty-four-hour infusion. And it's for white blood count, because my white blood count was very very low. And I hate with a passion staying over at hospital overnight. And so there were a couple of arguments with, I don't want this, I can do with my body what I like, I'm not having this. And it did take quite a while, and eventually I did have to sort of back down because I was getting very ... I was just getting flu after flu and stuff like that. So.

501. S: Ok, so it -- In the -- It sounds then that you chose to back down.

502. M: Ja. No, ja.

503. S: I remember you saying something about going into remission and then getting sick again.

504. M: Yes.

505. S: How did you deal with that? What was your emotion when you were ok now ...

506. M: Ja.

507. S: And how, how long were you in remission for?

508. M: Couple of months; maybe like three, four months.

509. S: And then you got sick again.

510. **M:** Ja. Ja. It was very frustrating. I was very very disappointed, and sort of like almost, I can't do this again. You know, sort of, I'd thought we'd reached the end but now we're back at the beginning.

511. **S:** So you'd been like ...

512. **M:** It was almost an anti-climax.

513. **S:** Ok. So the remission was there and your feelings were what?

514. **M:** Just, I was ecstatic. It was -- Ja. It, it felt like I'd just closed a chapter; I could move on now and then ...

515. **S:** The future was going to be yours again.

516. **M:** Yes. Ja. And then all of a sudden it was just back where I started. And it was just complete disappointment. So, ja.

517. **S:** Living with chronic pain myself, how does it affect you to be constantly in pain? Because I know the meds don't take away the pain. How do you manage that? What is it like and how do you manage it?

518. **M:** I hate to say it but if, if I'm not thinking about it, it sort of ... I think I've become accustomed to it. I've sort of ...

519. **S:** Do you think your tolerance has improved?

520. **M:** It, ja. Definitely. But ja, I think I've just almost become used to it. And, and ja. It's sort of, take pain meds, they'll take the edge off, and then just distract myself. Ja.

521. **S:** So you've basically learnt to live with it.

522. **M:** Ja.

523. **S:** So, so your strategies are: distract yourself, take painkillers and ...

524. **M:** Ja.

525. **S:** What happens if the painkillers don't work and the pain is very bad?

526. **M:** Then we try, I don't know, massage, ice, heat. Other than that I just try and sort of get on and just sort of push through it.

527. **S:** And from the, an emotional perspective of chronic pain?

528. **M:** I often try to just distract myself as much as I can with watching TV, playing with the dogs, doing work. So often if I've got nothing to do I'll sort of, sort of dip into a depressed state. So that's why I try and just keep myself busy.

529. **S:** So it's important to have things around to do.

530. **M:** Ja. Ja.

531. **S:** Do you get tired when the pain is high?

532. **M:** Yes. Very much so.

533. **S:** So you kind of need activities that don’t need much brain power. [laughing]

534. **M:** [laughing] Yes, very much so.

535. **S:** Ok. Alright. I mean I, I’ve got one or two questions, but I think that we’ve actually identified them. They were just things like -- And we did -- You kind of went through the fact that sometimes your friends stress about things that you don’t think are very important.

536. **M:** Yes. Ja.

537. **S:** But ja. I think we’ll leave that one, because it’s been long. It’s an hour and 20 minutes; I think we should stop, because you’re looking tired. Thank you so much.

538. **M:** Perfect. No, no.

539. **S:** Micaela, this has been so helpful.

540. **M:** No. Of course.

[recording ends]

Transcript 3: Ceri Interview 1

1. **Interviewer (S):** Um so I'm gonna just keep checking it…um
2. **Interviewee (C):** keep it … yeah. So when when I started the um the support group that um and we actually had a physical support group meeting, Ursula arrived in a wheelchair and people were so spooked by it because they might have medium kids, like not so severe and then they see this and they think, "Oh my God my kids going to land up in a wheelchair", and they never came back. They don't want to know about it, they don't want to talk, they don't want, they don't want to know about severe kids. They rather want to … kind of ignore it and make it go away.
3. **S:** And and just happens… what they think is going to happen and not have to face the possible…..yes
4. **C:** Deal with it…yeah…yeah…possible, possible realities. So that's why actually even I mean I'm a single mom and I work full time in a very demanding job so I, if I, if I, ifff I didn't work we could have really set this thing up very well. But I mean it's time.
5. **S:** Yeah no it does, it does
6. **C:** People… so its remained like a virtual thing and the few of us that know each other and become friends and we have the severe kids.
7. **S:** Well hopefully what's going to come out of the research is just even if we if I can create a booklet once the thesis and everything is done. Just some guidelines that are out there -
8. **C:** Tips…yeah
9. **S:** - maybe tips and and get everyone to collaborate who's interested you know. But so what I'm focusing my interview on today with you because the focus is actually on adolescents, um but it's very useful to get a parental perspective of the journey that Micaela has been through. So so I've got some questions here but I was just wondering if you could just start off by just sharing with me… how the journey went for you because it sounds like she's she was sick from virtually birth. And so what was that journey like?
10. **C:** Well in the early years she just got a lot of infections all the time. A huge amount of infections and she actually said to me, when she was about two when she was on that little black plastic motorbike, that her ankles were sore and I didn't I, I mean I have a nursing background and I didn't even realise. And then we just carried on and she just kept on getting many many infections like really all the time, and then when she was about nine it sort of escalated and she got pneumonia and very bad sinus problems and um repeatedly. I think that year that she turned 10, within the first 6 months, she was on about 10 antibiotics and eventually I actually said to the paed, "Isn't there something wrong with this child's

immune system?" And that was the first, the, you know, and I just said "I can't accept that this kids been so sick." So then she did an auto-immune profile and it came up that she's HLAB27 positive and she sent sent us off to Dr X and then [laughs] like you know I was completely ignorant and then Dr X says, "oh no your child got arthritis" and it's "Oh ok" you know? [laughs] take your pills and you kn

11. **S:** ah it'll all be fine yeah

12. **C:** yeah there you go. And and um without any actual … realisation of the severity of it all and the journey and whatever lay ahead and so that was what 6 years ago and it's been hectic, but I think because Micaela's got a very complicated type of arthritis she's got the enthesitis-related and then she's got polyarticular which is you know that joints

13. **S:** ok that many joints

14. **C:** yeah and she's also got an immune problem as well. She's got some kind of deficiency so…

15. **S:** Is that then part of JIA or is it something separate?

16. **C:** Yeah it can it can it's one of the weird… comorbidities

17. **S:** co comorbidities

18. **C:** So um her arthrit, Dr X always says her arthritis is infection-driven, so if she that's why we've struggled to get her into remission because she um she's never been in remission. Well she was in remission for maybe about 2 months – maybe, if that. And its, so, so repeated infection, she's had a lot of Polygam as well that's a immunoglobulin to try boost the immunity, and um she's failed on two biologics: um she's been on about 11 different treatments. She's had jaw erosions in her jaw, she's had a lot of intra-articular injections in her jaw, in her neck, in her feet, in her hands, I mean really sort of very severe. Um yeah and I mean… I've thinking about your visit I thought you know it's one thing the doctor um, if the parents wanted, but maybe they should tell the parents upfront what this could look like. Because if I'd known that maybe the first few years are going to be a more of an acute, very crazy, chaotic period, I think it helps you cope better because you're just on this constant rollercoaster. You know. But then maybe the doctors don't know what the child's going to turn out like because some could have you know have a much milder form of disease. Um yeah so I think I mean I mean it's it's been a very tough journey very very tough.

19. **S:** And as a single Mom

20. **C:** [whistles] Hectic can I tell you. Impacted my work, impacted I don't want to mention to you anything. Impacted our family I mean my my, I don't know if she told you, my my my older daughter really took strain as well, major strain.

21. **S:** That's… Yes… and what what form was the strain I mean?

22. **C:** She became um angry with me because I was spending all my time with Micaela and then she started acting out and she developed very bad depression and drinking, partying, acting out a lot. Um yeah.

23. **S:** I think for me that's one of the things that I'm realising is that there is the illness but because it is such a chronic of a chronic nature is that the the impact is very widespread…and it's not just related to the disease itself…I mean you you you must have times when you've been absolutely exhausted.

24. **C:** …broad… no not at all…No no for sure. I mean but, but ultimately I think that all the this is where the we I think this is where the moms who gain strength from each other because is that we realise you know it's up to us to get our kids through this. There is no-one, we can't just, it doesn't matter how desperate or awful this whole thing is, you have to get your kid through. You can't collapse in a heap, you know what I'm saying. So that's kinda kept me going.

25. **S:** So for you having a support network of just a small group of women?

26. **C:** Very very useful. I mean I knew that, because you know what, people don't get it. And I mean I'm sure, I don't know what Micaela shared with you…

27. **S:** It doesn't matter

28. **C:** I wanted I wanted to give her her personal space so that's why I didn't want to sit in, but the social impact I think for the child is enormous even if…maybe they don't even realise it but that becomes normality, but the social impact for them and for the family because [sighs]. Especially in those early years never know how your child's gonna be on that at that given moment. So…you know you'll be planning something and then you can't do it, and it's, so you can never actually plan, you can only plan down to the minute. And having those moms that actually, when you when you phone them and say, "You know what, yesterday was great but today is bad", they get it , people other people don't get it, we I'm sure you…

29. **S:** then just think you being difficult?

30. **C:** yeah and like, "what's going on?" you know. So I think the lack of understanding, I remember, that children actually get arthritis is a big thing, big thing, huge thing.

31. **S:** That that people just don't get it, you mean?

32. **C:** No

33. **S:** No yeah people just don't understand that children get arthritis um yeah

34. **C:** Yeah. So I mean I've found, I mean I know those moms still if I had to phone them and say,"Shit, I'm not just really not coping" each one of them would understand and listen.

35. **S:** So without wanting to put words in your mouth, in a sense it's very isolating?

36. **C:** Very. Very.

37. **S:** For both you and the child?

38. **C:** Yeah definitely.

39. **S:** And um

40. **C:** It's probably the biggest thing – that isolation. And misunderstanding.

41. **S:** and the misunderstanding that goes with it

42. **C:** Yeah

43. **S:** And then, I'm just projecting myself but, having to deal with the… tone of voice on the other end, "Oh you can't make it. Again", or something like that kind of thing.

44. **C:** Yeah, yeah. So that's actually one of the things that sort of spurred me on to do a lot of awareness. So I would I would sort of almost ruthlessly share on Facebook and you know I started a blog. And I mean I can actually share that blog with you that blog that I wrote. Um but I sort of stopped about a year ago, but it's it was almost like a outpouring of the journey, the daily journey. And I would do that just so people would, almost like bombastically push it in their faces that this is what it is. You know because people just do not get it.

45. **S:** And unfortunately then kids get diagnosed much later than they should be simply because they've got growing pains or whatever it is

46. **C:** Yeah yeah

47. **S:** I must say I'm neurotic in my practice now [laughs] the moment a child complains about growing pains…

48. **C:** Sore joints for more than 6 weeks.

49. **S:** …I'm like [clicks fingers] off you go [laughs]

50. **C:** Yeah yeah it's quite prevalent so yeah so so I mean you know

51. **S:** It is surprisingly prevalent considering how little people know about it

52. **C:** I know. I know. But something to capture the journey, I mean it's just, you know, I think you do get to, I mean it's you get to the stage of acceptance. I mean I spent a lot of time with a therapist that works on chronic pain, chronic diseases as well, especially because I had this support group going and everything and I just thought, "I gotta keep myself intact", and also for her. So I spent a lot of time, I mean, I think I am at a point now of acceptance, I still hate it, I hate it like the freakin… I don't know. We all hate it, I will always hate it for what it's done to my child. It's like robbed her of her childhood because as a result she's also a lot more mature and… you know and doesn't, silly things that girls her age get into she she didn't do and she won't do …

53. **S:** she's missed that phase

54. **C:** … so I try and push her a lot to try and do what, and she is very adventurous, actually, and she gets out and she, you know.

[10 minutes]

It's taught me that as well that "Live for today", so whatever today brings, you do it.

55. **S:** So if you're in a good space today off you go, and if you're not you do something else.

56. **C:** Yeah.

57. **S:** Day by day

58. **C:** Very much so.

59. **S:** Shew. Um**,** what was I going to ask you? Um…. Sorry my brain is not working well today… [pages through book]. Ok so you you've, you've had to make quite a lot of changes in your own lifestyle and mean being a full-time mom how's how how did you do that?

60. **C:** You know what, I actually… it was because I had to I wasn't in a situation where I had another choice so I kind of had to face it and say, "Go on". In the beginning my work were very understanding and they were giving me time off and flexibility and everything, but you know, because it's become so chronic, it's become more and more difficult, because people don't get it. You know, they don't realise that um… yeah so that's been a big thing for me and where, you know, whereas maybe I would have gone to different places in my career and things like that I realise that I just, this is now my new life and I've got, this is it um… I mean the support group helped a lot those friendships and relationships, realising that you actually, you may be isolated but you're not alone.

61. **S:** And it, the financial implications…

62. **C:** huge, huge, huge, huge, huge

63. **S:** …are huge. I mean I couldn't believe the amounts that I was hearing

64. **C:** Hundreds and thousands of rands

65. **S:** So if you don't have medical aid

66. **C:** No no, no no that's hectic. That's a whole other ball park. I mean that that is one thing that I feel, I mean, that's why I wish I could do this full time is that indigent children do not have access to biologics and that's just …evil. I mean methotrexate is a very good drug but it's like R150 a month but biologics are way better. And the state doesn't provide for those kids, and even the lower lower option medical aids you know it's a huge fright. Although we, you know we've been, I've always been very, I mean I've taken Discovery on a few times legally

67. **S:** Really? whoa

68. **C:** Yeah I I've paid for it. I got an advocate, Estelle she's big into patient advocacy and what, and when they wouldn't pay for some of Micaela's stuff, I challenged them and they paid for everything. I've done it about three times now and they know me so I mean I just write to Justin

69. **S:** ooh

70. **C:** … [laughs] and I just e-mail him and with a letter and he says, "ooh ok" and within 24 hours "boof" it's all approved you know.

71. **S:** That's good to know

72. **C:** Yeah. I always urge other parents to do it but you know they don't hey.

73. **S:** People are scared of lawyers

74. **C:** Yeah I know, I know, I know

75. **S:** But that's that's good for me to know because I didn't know that was possible

76. **C:** And then and then the other thing that needs to change big time in this country is the schooling systems because we've been so blessed to have, you know we've, I mean it's a huge chuck of my salary to go there but, Micaela would not have coped in a government school. Now Ronel still was at a government school but she hasn't really had so many joint problems, she's just been overall sick so she's missed a lot of school but in terms of writing exams and that she manages. Micaela can't write well, so. The government, I mean the government needs to change, change their way with these kids. A man, you'll hear, a man will tell you tomorrow that you know she's asked for help and they've said they don't have the resources. And they're at a good government school, can you imagine in the middle of a rural town? Shocking.

77. **S:** Yeah. Ok let me not get into my hobbyhorse around that being it's like um

78. **C:** Yeah it's terrible.

79. **S:** Yeah, um, I I agree, I know there's 1 or 2 that have been very good um government schools but a lot of them would just rather you …

80. **C:** sort it out, on your own…

81. **S:** …you sort it, you…you sort out your own stuff out.

82. **C:** I mean I don't know if Micaela told you she gets a scribe, she gets a laptop, separate venue. I mean, ok I had to push for all that because they've never done it before but we got it. You know, so I would say a mother's role in this whole thing is to be your child's advocate, whatever happens.

83. **S:** You've got to be there the one fighting

84. **C:** The voice

85. **S:** Yeah, the voice. And so, another interesting, now that you've mentioned the voice, something that's come up in some of the interviews is um…that the child adolescent in the doctors' rooms has not had a voice, that the doctor has worked mainly through the parent and the parents had to almost facilitate the child having…Did you experience the same thing?

86. **C:** Yeah. When Micaela was younger but I've urged her to, probably in the last 2 years, to, you know "You're your own person and your own body so you must tell Dr. X what". And now, I mean I just sit back in the interviews and they do everything.

87. **S:** So that would be another piece of advice that we could give parents

88. **C:** Hugely, hugely. And even even … you know in retrospect, little children, like when Micaela was um diagnosed, even younger, you know I think one should try and empower them as much as possible. That's, it's also my thing: be your child's advocate and empower them, empower them to make their own decisions to give their own injections, to choose you know. I always give Micaela a choice and it, you know so much is robbed, so much decision making is taken away from them, give them as much as you can.

89. **S:** as they can, yeah. That actually facilitates independence in a different way.

90. **C:** Yeah, because ultimately, you know, with my parents I truly believe that we are only here to equip our children for life, and this disease doesn't, shouldn't make them dependant on us, at all. I think Micaela is, I mean she's very dependent on me but she, it's not, she can also cope on her own.

91. **S:** It sounds from what you're saying that it's more the age-appropriate dependency, there is the illness but she's also, she's not…

92. **C:** yeah… fully… separate

93. **S:** …fully totally separate, yeah, yeah, yeah so.

94. **C:** So I think that and and the other thing I mean is a very practical thing I mean it's a stupid thing, but keep a record - keep a diary of everything for parents, make a list of questions, take your book. And even the child, you know, if something's wrong, especially at this stage, put it on your ipad, make a note for Dr. X. I mean Micaela was even emailing her, you know e-mail your doctor. Because they must start taking ownership as as early as possible.

95. **S:** Yes, because that is, it's their illness

96. **C:** It's been so hard I mean that's probably one of the hardest things to um to do in this psychological journey for a parent is to realise that it's their journey it's not your journey. You are part of their journey as an observer and support and everything but it's, I mean I felt for so many moms on that note, I mean it's a hard thing to do because you want to protect, you want to stop their pain and you want to take it away.

97. **S:** So you've almost got to change your parenting style

98. **C:** It's their journey, it's their journey. What can you do to make, to help them on their journey, and it's a different, it's a shift

99. **S:** Very different to wrapping them in cotton wool.

100. **C:** Yeah. And you know, you know, I mean, in the beginning I used to do this whole thing like "Where's your pain today on a scale of 1 to 10?" and I and I think it's a mistake because, we eventually came to an agreement Micaela and I at a very young age like 10, 10 or 11, that she'll tell me when she's sore. Otherwise it's a game of "focus on the disease".

101. **S:** And not her

102. **C:** Mmm, and then if she is sore then I say, "Oh I'm so sorry, can we do something to fix it, to help it". But but just that voicing I think is a, and I think it does make you closer to your child. Definitely. If your child is suffering.

103. **S:** Yes, yeah. It's it's it's interesting that you mentioned that as well, that the focus becomes on the illness instead of the child. Um and that has been a repeated theme of um the child becomes invisible and it's the disease that is seen.

104. **C:** Yes. Yeah. I think that I that maybe that's part of the natural healing process of a parent. When they, you know to get to acceptance they go through that. It's horrible, it's just horrible. I'd rather, I mean I do have ankylosing spondylitis, but I would rather have a 100 times more illness than her…

105. **S:** have to see her go through this

106. **C: …** for one day, yeah

107. **S: S**o in one, yeah, I mean it just occurred to me that for a parent it's actually really disempowering as well.

108. **C:** You feel so helpless.

109. **S:** Yeah

110. **C:** That that's another thing that recurred that's recurred with me with parents is this um this desperation because you cannot fix it. As parents, as adults, we want to, know we can fix everything. And especially until you get the right treatment, because I mean we spent like 3 years trying to get the right treatment - my child was in severe pain on Oxycodon for like 2 years, and you can't fix it. It won't go away. So you give them the most incredible pain killers and the pain doesn't go away. It's so frustrating. Very frustrating. So then then I mean what we've done and I mean it's, again, this needs to actually maybe go in your booklet, look for holistic treatment as quickly as possible, as early as possible

[20 minutes]

The hydrotherapy and the physio and the biokinetics. You know at one point we were so desperate I [Inaudible 20:10] we started biokinetics and exercise, exercise is very important. I don't know if that's come out in any of your interviews but exercise, strengthening, um holistic approach

111. **S:** keeping mobile

112. **C:** yeah. Because you're so focused on this disease and like the pills and injections, you forget about all these other things that go in actually very uplifting for the child

113. **S:** Yes and so you're moving, so you're incorporating the disease model but, at the same time, making sure you're looking more holistically, more

114. **C:** everything, and you know psychotherapy if they need it and mood uh look after their moods. You know I put Micaela on well, I didn't put, I took her to a psychiatrist actually early on because I thought, "I want", she became depressed at a very young age because of this and so I thought, "I'm gonna, we need some neuro protection." So I took her to Dr Z and put her on Zoloft and Limicton, actually eventually, and it's worked fantastically, she's doing very well. And she tried psychotherapy and it didn't work for her, she says, so whatever, but you know.

115. **S:** You know sometimes you have to, not everybody is good …

116. **C:** [Inaudible 21:16] mind…different things… yeah

117. **S:** … it doesn't work for everybody – psychotherapy. And I think also in a situation like this it needs to be the right therapy, somebody who works with chronic illness at least. Otherwise they don't get it… So a lot of holistic work, a broader approach. Um, if you look back on the journey, was there any particular challenge, anything that particularly challenged or anything that specifically helped? I mean you've spoken about your social network and the financial challenge, is there anything else that comes to mind?

118. **C:** That helped.

119. **S:** Or challenged.

120. **C:** Probably one of the biggest frustrations, even our lovely private school, to get the message, to get people to understand what is going on … for the child. So what I did, she – Dr X, she came and - have you met Dr X? Amazing woman - she came to our school and did talks. She's happy to do that for any patient, she won't charge you. She'll come on an afternoon and do a talk for all the teachers…

121. S: Wonderful

122. C: …so that is a huge challenge um, more in Junior school than in high school because in high school Micaela manages it herself with the teachers. But in junior school they have got no freakin clue, and I feel sorry for these Grade 1 and 2's, you know, what they hell are they? You know, how are they coping?

123. S: And they don't have the voice to remind the teacher actually

124. C: yeah so that's maybe the most, one of the most, biggest challenges. And also friends. To to understand. I don't think, you know Micaela never speaks to her friends about what's going on. I don't know if she's given up or if she actually, but she… maybe she doesn't want to focus on the disease, I'm not sure. Um but you know it worries me sometimes I'm her only, myself and her sister I think, are the only sort of places where she speaks about things, if she's not great. So that's also, I don't know, I don't know, because I know some of the other girls in the group have got 1 or 2 friends that maybe understand or whatever, but again it's isolation. It's isolating terribly…that…huge.

125. S: That theme has come up huge, huge

126. C: Did you realise it was such a big… thing – the isolation?

127. S: No, I did not realise until I started my very first interview.

128. C: And you know what it, for…

129. S: It's because it's so so different to cancer because with the cancer it doesn't seem to be so isolating because everybody understands cancer and they rally round but with the JIA I think because it's so invisible that "but what' wrong, you look fine, what's wrong with you?"

130. C: Kids withdraw and it's like a judgement. There's lots of judgement.

131. S: A lot of judgement

132. C: Huge amounts of judgement. So um, I was going to say something to you now, um…. Yeah. Oh yeah, there's comfort for Micaela to know that Ursula and Rochelle and Ronel and what have you and Sarah; but in your setting in your school there's no-one. And that's awful for a child… Are you hoping to get some tools out of this actually?

133. S: The idea is, the first thing is um obviously to get the the doctorate but from there is to start, I want to put a booklet together, I want to write a research article and send it out to the rheumatologists and the people who work with

134. C: Brilliant

135. C: I'm gonna switch this off now

136. C: You must actually get it published at, you must do it, you must get it presented at … [recording ends]

APPENDIX P: Leigh-Ann Case Study

Transcript 1: Leigh-Ann Interview 1

1. **Interviewer (S):** Let's just check that it can hear you, because your voice is more important than my voice. So, could you just tell me your name or something?
2. **Interviewee (L):** I'm Leigh-Ann.
3. **S:** Ok, that's wonderful Leigh-Ann, that looks like it's recording perfectly. So what I was wondering is if you could share with me your journey with your illness and sort of all the way though to diagnosis and treatment.
4. **L:** Ok.
5. **S:** Ok.
6. **L:** Well, in 2009 I first started getting back and neck pain. And at first we went to physio, I think. I went to chiropractors; nothing helped. We went to the GP; he had nothing to offer. It carried on like that for about three years, gradually getting worse.
7. **S:** So when did you first start ... How old were you in 2009?
8. **L:** I was nine.
9. **S:** You were nine.
10. **L:** Yes.
11. **S:** Ok, so it carried on for another three years, so at 12 you were still sick.
12. **L:** Ja, well, I mean it still carried on, but ja. I think in about 2010 we were referred to Dr F***** for the first time – rheumatologist. She initially said I had ... She initially said I had enthesitis.
13. **S:** Ok.
14. **L:** But nothing to do with arthritis. She said it was something I would grow out of; it was basically like intense growing pains. She said, ok. And then it just carried on getting worse. But she, well she suggested I go to yoga, which was carefully monitored. So I tried that. Then the one day after I had been to yoga, my back was just incredibly sore. It was like I got into the car and I was on the verge of tears. And so then we decided n, we had to go back to Dr F*****. So we went back to her and then she diagnosed me with JI, JIA. Enthesitis-related arthritis. And initially I think I went onto methotrexate and that didn't really help. Eventually I went, at the end of 2012, I went to have a nuclear scan and I had TB in that test to prepare me for going onto a biologic.
15. **S:** Oh, a TB test.
16. **L:** Yes.

17. **S:** You didn’t have TB.

18. **L:** Well, then the TB test showed that I did have TB.

19. **S:** Ok, ok.

20. **L:** And so I had to go onto medication for that for a little bit before I could go onto the biologic. And the nuclear bone scan did show that I had arthritis.

21. **S:** Ok.

22. **L:** So then we knew it was definitely that.

23. **S:** It was definitely juvenile arthritis.

24. **L:** Yes. So finally in January of 2013.

25. **S:** So that’s a four-year ... Four years to get your diagnosis.

26. **L:** Yes. Ja. The TB was gone; it turned out it was latent TB, so it wasn’t too serious.

27. **S:** Ok.

28. **L:** So then I, I started the biologic. The first one I went onto was Revelex.

29. **S:** Yes.

30. **L:** So that day I went in for the infusion in hospital. Everything was fine. By that afternoon everything was fine. That evening we were watching TV and suddenly I just sat up and my throat was swelling and I couldn’t breathe. And so we rushed to hospital. From the Revelex I had apparently gone into anaphylactic shock. So that delayed everything. I stayed in hospital for a week after that because I kept just going back to feeling like I couldn’t breathe.

31. **S:** Like you couldn’t breathe.

32. **L:** Ja.

33. **S:** So it just kept triggering the anaphylaxis all the time?

34. **L:** Ja.

35. **S:** So that whole week. Wow. Ja.

36. **L:** Jip. And then eventually, I’m not sure how far after that, I went onto Humira. Which is a different biologic. So I think I was on that for about two years, ja, before I seemed to go into remission. Every six months we took a bone scan and it gradually seemed to get better, but over those two years I started developing new symptoms. Headaches; I was exhausted all the time; dizzy; other pains that were different to the arthritis. So then Dr F***** diagnosed me with joint hypermobility syndrome, which is associated with dysautonomia.

37. **S:** Ok. Dysautonomia.

38. **L:** Yes.

39. **S:** That’s a new one for me.

40. **L:** It’s a dysregulation of the autonomic nervous system. So ...

41. **S:** Ok.

42. **L:** Ja. And that really brought on a whole load of other things along with it. Tachycardia. I couldn’t -- When I stood up I wanted to faint; I saw stars.

43. **S:** Hypermobility is part of that then?

44. **L:** Well yes, yes.

45. **S:** Ok. Alrighty. So, so now she’s diag you -- You, you’ve essentially got three diagnoses then?

46. **L:** Yes.

47. **S:** JIA, but you’ve also got enthesitis, because that didn’t disappear.

48. **L:** Well, well no. It was never enthesitis; it was enthesitis-related arthritis.

49. **S:** Ok. So ja, I know that’s one of the sub-categories under JIA.

50. **L:** Ja.

51. **S:** So you’ll get JIA, enthesitis-related. So you’ve got that plus ... So dysautonomia is then JIA plus a separate disorder, or is it something that often goes with JIA?

52. **L:** Well I think it is often associated with JIA.

53. **S:** It’s often associated.

54. **L:** But more with JHS, with the joint hypermobility syndrome.

55. **S:** Ah.

56. **L:** But it is associated with JIA as well.

57. **S:** Ok.

58. **L:** And then, going back to the JIA, the last bone scan I had was clear, so Dr F***** said that I was in remission. So I ...

59. **S:** Medical remission? That is, you’re still on meds?

60. **L:** No. Well yes, but then she said I should start coming off the meds. And things were good in terms of the JIA. I was still in a lot of pain from the JHS, but it was a lot better than it was. And then about a month ago I started getting really bad back pain again, and ja. So it looks, feels to me like the JIA is back.

61. **S:** Tell me, when you were in remission for the JIA, you continued taking meds for the other, the JH ... The dys, dysautonomia.

62. **L:** Well there aren’t any meds for that.

63. **S:** For that. So did you come ... You got weaned off the Humira for a while.

64. **L:** Yes.

65. **S:** How long were you off the Humira?

66. **L:** I think for most of this year.

67. **S:** Ok. And then now the symptoms are coming back again?

68. **L:** Yeah.

69. **S:** Ok. So how long were you in remission for?

70. **L:** I'd say about seven, eight months.

71. **S:** Ok.

72. **L:** Ja.

73. **S:** Ok. So is that sort of how far you could go for me with the treatment and diagnosis? Because if it is, I'd like to go back and just start asking you some more things in depth around that.

74. **L:** Ja. I think -- Well, no there was ... Last year I think at some point I started getting this funny rash, which wasn't too ... It wasn't too bad. But it was strange-looking. It had like a silvery outline, ja. And it turned out it was psoriasis, which changed the diagnosis from enthesitis-related arthritis to psoriatic arthritis.

75. **S:** Psoriatic -- psoriatic arthritis.

76. **L:** Yes. Which doesn't actually change anything in terms of treatment. But ja.

77. **S:** ... both, really. So I would like to go back, if you don't mind, right to that beginning stage with early doctors. So you mentioned that you'd been to paediatricians, and physios and things.

78. **L:** Yes.

79. **S:** Can you think back to that time period and just describe how was it for you going to see these doctors? And how emotion -- How did you feel emotionally? Any thoughts that were going through your head at that time period. I know it was a long time ago.

80. **L:** Well I was, I was very young.

[10 minutes]

I think I was quite confused. And it felt like ... I just wanted a diagnosis; even if was a bad diagnosis, I just wanted a reason for what I was feeling.

81. **S:** And what were you feeling?

82. **L:** Well, I was always in a lot of pain at that time. I struggled to do things that other children my age were doing.

83. **S:** Can you give some examples of that?

84. **L:** Like sports at school. It would -- Like I would struggle to run around; it would hurt my back. Even things like turning my neck.

85. **S:** So if you were sitting in a classroom and the chair, and you had to look at a teacher.

86. **L:** Ja.

87. **S:** Is that the kind of thing that would have impacted on you?

88. **L:** Yes.

89. **S:** So just now we're going to go back and ask you about how it, how it possibly impacted you on schooling. So, so you wanted a diagnosis?

90. **L:** Yes.

91. **S:** And can you explain to me more about that?

92. **L:** Well, it was difficult to not do those things without having a reason. It felt like I was just, you know, making excuses. Because no-one knew actually what was wrong.

93. **S:** So, so ...

94. **L:** So it felt like it was just in my head; that I was imagining the pain and ...

95. **S:** Ok. And did anybody else voice that, or was it just in your, your thoughts?

96. **L:** No doctor actually told me outright that it was in my head, but you know there were doctors that told me there was nothing wrong.

97. **S:** Did they say there was nothing wrong, or they couldn't find anything wrong? Just out of interest.

98. **L:** I'm not sure. That's a good question.

99. **S:** So that's something maybe I, I can follow that up with your mom.

100. **L:** Yes.

101. **S:** Ja, so, but your recollection of it was you were going to see multiple doctors and they kept saying ...

102. **L:** Yes.

103. **S:** There's nothing wrong. Ok. So I'm just interested, during that time period one of the reasons you wanted a diagnosis was because you were concerned that you were imagining it, because nobody could find anything wrong.

104. **L:** Yes.

105. **S:** Ok. And I'm just wondering, because you also said that at this stage you couldn't do sport, and betw ... Between say, the teachers and your friends and maybe the physios, or whatever, did anybody ever say anything that reinforced your, your mentalisation that it was possibly imaginary?

106. **L:** I remember once I overheard my parents talking and they were just ... I might be remembering slightly wrong, but they were talking about taking me to see a psychologist that my mom used to see, just to make sure it was a physical cause, had a physical cause and not a mental cause.

107. **S:** And how did that make you feel?

108. **L:** Well, it again made me wonder if maybe this was actually in my head and it was something that I just had to get over.

109. **S:** I'm, I'm always interested with, with the idea that people then ... There's the possibility that it might be psychological; that is what they're conceptualising. I'm trying to wonder, well I am wondering, how, how did that leave you feeling about yourself?

110. **L:** Well ...

111. **S:** Because I don't know if that makes any sense, that question?

112. **L:** Well, it made me question my ... It made me question how I saw things and how I felt emotionally as well. It made me wonder if there was, you know, something wrong with me.

113. **S:** Like what would ... What were you imagining was maybe wrong with you?

114. **L:** I don't know, I ... There was never a ... It was just a feeling.

115. **S:** Just a feeling ...

116. **L:** Yeah.

117. **S:** That maybe I've got all this because there's something wrong with me ...

118. **L:** Ja, maybe I'm -- Ja.

119. **S:** Put that into words. What were you going to say?
[both laughing]

120. **L:** I'm not sure.

121. **S:** Can't really find the words for that?

122. **L:** Ja.

123. **S:** That's ok. And you said, you said there were emotion ... It changed how you felt emotionally, the thought that it might be imaginary rather than physical. How, how did that change you emotionally?

124. **L:** Well, I suppose it made me feel like I can't ... I have to do -- I have to push through and do the things that other people are doing, even though I feel physically that way. Because it made me think that actually I don't feel physically that way, it's just in my head. So I need to push myself to do things that hurt and ...

125. **S:** Ok, ok. So what I'm hearing, and I want to check with you, is that when you kind of heard the conversation from your parents, that then maybe made you think then, ok, well maybe it is psychological. Although at your age you would have used the word imaginary. Therefore then, I must now ... It's therefore not really anything wrong with me as such, so therefore I must go do all of these painful things, because it's probably just psychological and then I'll push through the barrier and overcome it?

126. **L:** Ja. I think.

127. **S:** How did that work out for you?

128. **L:** Well obviously in the end I ended up in the car after yoga, with a very sore back.

129. **S:** So you were pushing through ... For how long did you try push through the so-called psychological barrier that you ...

130. **L:** Well I guess until I was about 12, which was when that happened.

131. **S:** So how many years are we talking, how many months?

132. **L:** Three.

133. **S:** You spent three years thinking it was psychological?

134. **L:** No, well I'm not sure when I heard that conversation. And I'm not sure when exactly I started thinking, this is not a physical, this might not be a physical thing.

135. **S:** Ok. Could you take a moment and give me an estimate? I'd really just be interested.

136. **L:** I really don't know.

137. **S:** Ok.

138. **L:** I have no idea.

139. **S:** It was sort of an insidious kind of thing ...

140. **L:** Yes.

141. **S:** That happened slowly but surely. Ok. Alright, that's quite interesting. And how was your relationship with those early doctors and physios and people that you saw? How did you find them to be?

142. **L:** Well, it made me very frustrated. Because a part of me was, was angry at the doctors rather than upset with myself, you know.

143. **S:** What was ...

144. **L:** A part of me still believed that it wasn't imagined.

145. **S:** And, and did they hear you when you said ... Did you say that? Did they hear?

146. **L:** I don't think I expressed that.

147. **S:** Because you were quite young.

148. **L:** Yeah.

149. **S:** How old again were you when it started – nine?

150. **L:** Ja.

151. **S:** So you were quite frustrated with the doctors. And when I'm asking about the relationship, I'm also asking, I'm sort of asking how did they treat you as a patient? How was that process?

152. **L:** I think a lot of them were quite patronising. You know, acting like I was a drama queen.

153. **S:** Can you tell me more about those experiences; maybe give me some examples?

[20 minutes]

154. L: I can't really think of a ...

155. S: So you maybe went in at a particular time with something that was sore. A particular doctor.

156. L: I know I felt that way after seeing Dr F***** the first time. When she said it was enthesitis and I would grow out of it. I didn't feel that way at first, when I saw her. But after I kept feeling ... The, the pain just kept getting worse and worse. And then I started feeling like, you know, she hadn't heard me and ja.

157. S: And was that a common feeling that you had after visiting? Because Dr F***** came quite long down, about three years later.

158. L: Ja.

159. S: And so -- And you had gone to people before then. Was that a common thread, your typical experience?

160. L: Yes. Well at first I think I kind of gave the doctors the benefit of the doubt. But then after a while I was very frustrated, not just in that they couldn't find a diagnosis or that they dismissed, they seemed like they were dismissing what I was feeling. But also ...

161. S: Feeling not emotionally, but feeling as in pain.

162. L: Physically.

163. S: Physically.

164. L: Yes. But also I -- I've -- I think a lot of doctors don't want to admit that they don't actually know what's going on. So instead of saying things like, I don't know what is wrong, they would say that there's nothing wrong.

165. S: Ok.

166. L: And they would ... And they wouldn't refer me to a specialist. It took me like three years to be referred to a rheumatologist.

167. S: So they couldn't -- They couldn't find anything wrong or said there was nothing wrong, and then didn't bother to send you to somebody else who might know.

168. L: Ja.

169. S: How -- I'm going to keep asking you this question. How did you feel about that? How do you feel about that now?

170. L: Well, I think it kind of ruined my belief in the medical system. Made me respect doctors a lot less. Ja, I think I was just quite angry with them.

171. S: How angry?

172. L: Very angry.

173. **S:** Very angry?

174. **L:** Ja.

175. **S:** If you could go back to those early doctors now, what would you say to them?

176. **L:** I'm not sure. I've never been a person who would express those feelings.

177. **S:** If you were to write a letter and you ... One wouldn't have to be aggressive. Because I can sense that's not your nature. If you had to do it in a nice way, say. Although it does look like you have a lot of strongly pent up anger there. If you could say it in a nice way, what kinds of things would you say to them? About how you felt or maybe advice for them.

178. **L:** Well, I think some of them I'd just like to show them that there was actually something wrong. Ja, I'm not ...

179. **S:** Why would you like to show them that?

180. **L:** I guess to prove that they were wrong and I was right. Not ...

181. **S:** And what would behind ... What would be behind showing them that they were wrong?

182. **L:** I think a lot of doctors are very arrogant. [laughing] So I don't know. I think some of them need to just acknowledge that, you know, that there are nine-year-olds that should be listened to.

183. **S:** Ok. So, ok. So from what you're saying there was quite a bit of anger towards those doctors. Ja, so, is there anything again, just to ask you again, is there anything that you would go ... Anything that you'd want to say them. Because you kind of said that you'd like to show them they were wrong.

184. **L:** Ja.

185. **S:** I was just wondering if there was anything else behind that or not. I mean, if you could totally be protected and say what you really felt, what would you say? Even if it was something you wrote and then threw away.

186. **L:** Well, I think they cost me quite a few years of my life in the end. So ja, I think I could punch them really hard.

187. **S:** That's how angry you're feeling; you would actually punch them?

188. **L:** Yes.

189. **S:** Ok. That's, ja. *Sjo*. That's quite a traumatic experience that you've gone through then for those few years. How else did it affect you? Thinking -- Being in pain, but being told there's nothing wrong with you.

190. **L:** I think it also made me feel quite alienated. Like I didn't fit in anywhere, especially at school.

191. **S:** What, what, what was it about school that made you feel alienated and didn't fit in?

192. **L:** Well, a lot of it was the fact that I couldn't join in with physical activities. I mean, I've never been a person who likes sports, but you know, to have that taken away from you entirely was hard.

193. **S:** Tell me what, what do you mean by hard?

194. **L:** Well, I mean now there are a lot of things that I'd like to do, but I can't. For instance, I'm very into photography, but I can't go out and take photos every weekend because my body will just be ruined. I won't be able to stand up after two weeks.

195. **S:** Is that from a fatigue or a pain perspective?

196. **L:** Both.

197. **S:** Both. So you're also experiencing a lot of fatigue?

198. **L:** Ja, that's -- It's huge. That's worst, my worst symptom.

199. **S:** Your worst symptom.

200. **L:** Yes.

201. **S:** Explain "huge" to me. What is huge?

202. **L:** Well, I can't -- In the afternoons, if I read for an hour say, and I maybe play a game of scrabble. I'm not a very physical person anyway. It's not like I ... Ja. Then afterwards I will be completely exhausted. I will -- I'll be able to watch TV and that's it. I won't be able to ... Sometimes I can't even like keep my eyes open, and I can't focus my vision, because I'm so exhausted.

203. **S:** Does this involve then possible having to miss school at times?

204. **L:** Yes. Well, I'm home-schooled, sort of.

205. **S:** Ok, I didn't know that.

206. **L:** Ja. Which has helped me a lot.

207. **S:** In what way?

208. **L:** In such that I don't have to wake up at half past five every morning to get to school at quarter to seven.

[30 minutes]

That I'm not constantly surrounded by noise and huge amounts of people. And I don't have to go up stairs if I don't need to, want to. I don't have to carry a heavy bag around all day to different classes. If I don't feel like working on a specific day, just because I'm so tired, I can stay at home and sleep or watch TV or read, if I'm up to it.

209. **S:** And how does the home schooling work?

210. **L:** Well, I do the Cambridge system, so I get all my text books and that ... I -- We -- Well I'm enrolled through the British International ...

211. **S:** School**?**

212. **L:** College. Yes.

213. **S:** Ok, ja.

214. **L:** It's a distance college.

215. **S:** Yes.

216. **L:** So I get all my text books and that from them. But then there are also work programs online and that. But -- And then I go to a woman who has a whole lot of other children and I see tutors there at her house. And I have my friends there, and ja. And then you just ... That's it really. Then I just enrol for exams once a year, or whenever.

217. **S:** So that's a very different form of schooling.

218. **L:** Yes.

219. **S:** It's obviously becoming more and more common in South Africa. How, how has that sort of impacted on your social relationships?

220. **L:** Well, I think at first it made me a lot more confident and it brought me out of my shell, because I wasn't constantly surrounded by very judgemental Saints people. Because I went to St Stithians originally.

221. **S:** Ok.

222. **L:** I felt like I could be myself a bit more.

223. **S:** So, so what kind of judgements were passed?

224. **L:** Well, I've always been a person who likes books and that kind of thing, which is not traditionally, you know, what teenagers enjoy doing.

225. **S:** Is St Stithians a big sports school?

226. **L:** Yes.

227. **S:** Ah.

228. **L:** Very. Yes. So ja, if you're not in A-team hockey or something like that.

229. **S:** Then ...

230. **L:** Ja.

[both laughing]

231. **S:** Ok. Then it's like that, ja. Ok, ja. And, and -- So then -- You couldn't be involved in sport.

232. **L:** Ja.

233. **S:** And you were at a sports school. And were there ways in which your peer group sort of expressed ... You felt -- Because you said once you were at the home school, you felt you could be more yourself, so what was happening at Saint Stithians, other than the culture, that made you feel you could ...

234. **L:** Well, even things like the music I like, and you know, I was never boy-crazy at the age of 10, you know. And I was always quite quiet there, so it was ... It's not like I was able to express myself much, because I was always surrounded by people who are louder and far ... They voiced their opinions far more easily than I did. So, ja.

235. **S:** Tell me, with it being a sporting school, what were your interactions with your peers like, given that you couldn't play sport?

236. **L:** Well, I think, because obviously no-one understood you know, what was wrong with me there.

237. **S:** Why, why was it that they didn't understand?

238. **L:** Well, I guess firstly no-one's ever heard of juvenile arthritis there. I think once someone asked me if I have old lady disease, something like that. Because obviously word had gotten out that I have arthritis, so. And I missed a lot of school as well, so that got rumours going.

239. **S:** Going. And was anything ever said? Directly towards, to you. Because I'm an ex-high school teacher, so I know what goes down. So I was just wondering if you had any direct comments or things?

240. **L:** Not necessarily. I know one, one time I was ... We were all walking to do PE, but now I always sat out during PE because I couldn't join in. Most of the time I did. And my friends were saying, *ag* they were so jealous of me because I got to miss out on PE, you know.

241. **S:** And how did you feel about that?

242. **L:** I was ...

243. **S:** What did you think? In your head?

244. **L:** *Ag*, I was so irritated with them, so angry with them. Because I just didn't get it, you know.

245. **S:** What was -- What made you so angry?

246. **L:** I think the ignorance. The fact that they thought I was lucky because I was in pain all the time, so I couldn't take part in sport.

247. **S:** Did you, did you explain to them?

248. **L:** No.

249. **S:** What it was all about?

250. **L:** No.

251. **S:** That wasn't a judgement on my part, it's just an enquiry. And, and just to make you feel better, a lot of people feel exactly the same and didn't explain. So -- But from your perspective, what was it that stopped you from explaining?

252. **L:** I think a lot of the time I was worried that ... Well, I think I was very worried about judgement at that stage, because well, Saints people are very judgemental.

253. **S:** And this was Grade what then? Grade ...

254. **L:** Grade 5, I think.

255. **S:** Ok.

256. **L:** I think I was about 11.

257. **S:** What did you think they would judge? Or what were you anticipating?

258. **L:** Well, people generally thought I was quite odd already.

259. **S:** Ok.

260. **L:** And so I think I just thought that they would think I was a complete weirdo.

261. **S:** Did you have a friend or somebody that you did try and explain it to?

262. **L:** No, not, not really.

263. **S:** So you were actually quite isolated at that ...

264. **L:** Yes.

265. **S:** Or, did you not really have a close friend at the school, or did ... Was it more that you just didn't want to even go there?

266. **L:** Well, I mean, I did have a group of friends. I had one friend in particular who I guess was my best friend. But I was never the kind of person who would just tell my feelings to someone. So ...

267. **S:** Or even about what you were experiencing with your illness.

268. **L:** Yes.

269. **S:** So very private.

270. **L:** Yes.

271. **S:** Ok. Alrighty. So you -- Ja. So it wasn't that you didn't have somebody to share with, it's just that you didn't want to.

272. **L:** Yes. And I think I didn't really know how to express it. In a way that it was understood.

273. **S:** So interestingly enough in your case, being home-schooled has actually allowed you to grow more as a person.

274. **L:** Yes.

275. **S:** That's -- And so, so what do you do now for social interaction?

276. **L:** Well, this year ...

277. **S:** Because home schools can be quite small.

278. **L:** Yes. This year I've struggled a bit socially, because I started AS level, which is like matric, and it was a lot of work. I was shocked at the beginning of the year. Especially seeing as I was so tired, so whereas my friends, or people that I'm doing it with, were able to, you know, study into the night and finish everything and have the weekend off, you know I would study every day from, until a certain time. Because I can't study in the afternoon. So ...

279. **S:** You have to rest.

280. **L:** Yes. And if I'm studying all morning, then it's not like I can hang out with friends. So I -- My best friend from last year and I kind of went separate ways, because she is a year below me, so ...

281. **S:** So she doesn't have the academic load.

282. **L:** Ja.

[40 minutes]

Well, and it was very difficult to socialise when I was so busy with school work and so tired from that.

283. **S:** And how does your illness impact on your life in general?

284. **L:** Well, a lot of the things that I would love to do, I can't. For instance, I've always wanted to be a vet, and lately I've realised that that's quite unlikely because of my physical limitations. Like I'm not going to be able to pick up a dog and put him on the table, you know. And things like the long hours and ... Ja. I mean I wanted to be a veterinary surgeon and I'm not going to be able to spend three hours at a surgery, next thing you know I'm like dizzy or my vision goes funny or ...

285. **S:** Do you also get the uveitis then?

286. **L:** I don't have uveitis.

287. **S:** Oh, it's just that the muscles get fatigued.

288. **L:** Yes.

289. **S:** Ok.

290. **L:** I think -- I think that's basically what it is.

291. **S:** So, so one of the impacts on your illness is that you see it as you're not going to be able to be, possibly not be able to be a vet. Because if you go into remission ...

292. **L:** Ja, but the dysautonomia is the real thing that ...

293. **S:** Is there no cure for that?

294. **L:** No, there's no ...

295. **S:** I know there's no cure for JIA either. Does the dysautonomia also go into remission though?

296. **L:** No.

297. **S:** Ok. So you know you've got a lifelong condition.

298. **L:** Yes.

299. **S:** And -- Wow. How do you feel about that?

300. **L:** Well, I think I kind of accept it and then something happens and I get really angry or sad about it. So for instance at the beginning of the year when I couldn't keep up with everyone else, I was very upset. Especially when I hear about ... Like my one friend, she'll stay up until like two o'clock in the morning studying, then the next day she'll go hang out with friends, and the next day she'll go to a party. And I'm not the kind of person who would want to go to a party every other day, but, you know, I'd like to do that occasionally. And it's not really ...

301. **S:** Do you -- You can't even go to one party and then it will make you feel really bad? Or ...

302. **L:** Well, I think it's more that I don't have the opportunity to because I miss out on the opportunity to socialise, because I'm so exhausted all the time.

303. **S:** So it is having quite an impact then on your social life?

304. **L:** Yes.

305. **S:** On your activities and things.

306. **L:** Yes.

307. **S:** Ok. And how has it impacted within the family? I don't even know if you've got brothers or sisters or ...

308. **L:** I have a half-brother and a half-sister. They're much older than me; they're from my dad's previous marriage. So my brother's living in Korea at the moment, teaching there.

309. **S:** So you're essentially an only child?

310. **L:** Yes, yes.

311. **S:** Ok.

312. **L:** It's had quite an impact on my relationship with my dad. He, he never understood what I was going through. And just comments he would make that would show that he clearly doesn't understand would get to me.

313. **S:** What kind of comments would he make?

314. **L:** Well, for instance, one time he was feeling sick. And so he couldn't go and play ball with the dogs. So he said, well why doesn't Leigh-Ann just go and do it? Because he was feeling too sick to play ball with the dogs.

315. **S:** What does that mean to you, that he would say that?

316. **L:** Well, I felt very, like I wasn't noticed. Misunderstood, I suppose.

317. **S:** Ok. So, so basically then your dad wasn't really understanding how ill you actually were, if he thought that you could throw the ball?

318. **L:** Ja.

319. **S:** And is there any other ways ... I mean, his lack of understanding, has he showed it in other ways?

320. **L:** Yes. I'm trying to think of an example. I can't think of another example.

321. **S:** That's ok, it's not a problem.

322. **L:** But it is just, you know, just things he would do or say. Ja.

323. **S:** That ...

324. **L:** Just showed that he didn't get it.

325. **S:** Just didn't get it. Ja. Do you think there was anything or is anything that could be done that would help him get it?

326. **L:** I don't know. I think in a way I was even more disappointed by that because he's got his own health issues. Not like mine, but I mean he gets shoulder and neck pain, which interestingly is, seems to run in that side of the family. Because my grandmother also has that.

327. **S:** So have they had themselves tested for arthritis?

328. **L:** Ja, no they don't ... I think it's just a genetic thing in terms of stress and posture and ...

329. **S:** Oh, ok.

330. **L:** Ja.

331. **S:** Ok.

332. **L:** But that made me think he would, you know, be a bit more understanding. So ...

333. **S:** And could empathise with what you were going through.

334. **L:** Ja, but ...

335. **S:** And any other ways it's impacted on your relationship with your dad?

336. **L:** Well, for instance for a long time we didn't talk or anything.

337. **S:** Ok. Why was that?

338. **L:** Well, it was a few things. He's very bad at showing his feelings and stuff like that. And he, he makes general other comments you know, not related to the illness, that just, you know.

339. **S:** No I don't.
[both laughing]

340. **L:** Make me feel -- You know, make me feel like I'm inferior, or ... Which is probably not what ... I know it's not what he means, but it still makes me feel that way, so.

341. **S:** What kind of comments does he make?

342. L: Well, things like about my photography. Like the other day I got this offer from someone wanting to buy a print of mine, and he rolled his eyes at the thought that someone was going to pay for art.

343. S: Ok. And just out of interest, how much were they willing to pay?

344. L: Turns out they weren't.

345. S: Oh. But you had an enquiry.

346. L: Yes.

347. S: How did that make you feel, getting an enquiry?

348. L: Very proud.

349. S: Oh.

350. L: Excited.

351. S: And then how did it make you feel when he rolled his eyes?

352. L: Quite hurt. Ja.

353. S: So, so there's parts of your relationship with your dad that aren't related to the JIA and then those ... That sort of relationship that you have with him also impacts negatively then on the JIA side of things with him. Are there any positive aspects? With your relationship with your dad?

354. L: Well, for a long time we didn't really have a relationship.

355. S: What was -- What caused that?

[50 minutes]

356. L: It was a, a number of factors. We had a dog that we rescued and he was ... He had some problems. He'd obviously had them before we got him. So he would snap at people, and he bit people a couple of times. And in the end we actually had him put down. Which was devastating for me and I blame my dad a lot for it, because it was his idea.

357. S: Ok. So there were a number of things that had ... And did the JIA and the other, the dysautonomia, has that sort of impacted more negatively on your dad's relationship in some way, or is it just pretty much that's how your relationship with him is?

358. L: Well, I don't know what it would have been like if it weren't for the JIA, but I think yes, it negatively impacted.

359. S: It did. Can you just give me some, just ... What, what -- How has it impacted negatively?

360. L: Well, it's not like we ever do things together. We never actually talk or have conversations or ...

361. S: And how's that related to the JIA?

362. L: Well, just the comments and that built up to ...

363. **S:** Ok. So, so he makes comments about JIA. And at the moment you can't think about any examples, which is fine. And then does that stop you wanting to share with him?
364. **L:** Yes.
365. **S:** Ok. Can you, can you put that in your own words for me so that I understand how his negative comments around the JIA is impacting on your relationship. How it makes you feel or whatever.
366. **L:** Well, because of those comments I don't tell him like about my day or ... Because ...
367. **S:** So like your fatigue levels or pain or ...
368. **L:** I guess I don't want to hear them being dismissed.
369. **S:** Ok.
370. **L:** Or risk them being dismissed. Because I'm sure he won't dismiss them, but I don't want, you know, I don't want to risk ...
371. **S:** You don't want to risk being hurt.
372. **L:** Ja. Or not being heard, but still putting myself out there.
373. **S:** Ok. Ok. And with your mom, how has it impacted on your relationship there?
374. **L:** Well, I'm quite close with my mom. So-- Ja, I mean she's very understanding and you know, she tries to understand and she reads up about it. And she -- You know, she's part of support groups on Facebook and, ja.
375. **S:** So are you -- Do you feel that -- So, so you can't share with your dad; is that different then with your mom?
376. **L:** Yes. Yes. I think most of the time I can share with my mom.
377. **S:** Is there stuff you can't share with her, or don't want to share with her?
378. **L:** Ja, sometimes. I mean there are some, some things that I struggle to vocalise anyway. And I don't know, I don't want to hurt her sometimes.
379. **S:** You don't want to hurt her?
380. **L:** Ja.
381. **S:** So, so some things ...
382. **L:** Telling her the full extent.
383. **S:** So, sorry. Say that again.
384. **L:** By telling her the full extent of some of the things.
385. **S:** Like? Tell me what you wouldn't tell her. Can you tell me what you wouldn't tell her?
386. **L:** Well, like at one stage I was really depressed. So I guess then I couldn't tell her the full extent of how I was feeling emotionally.
387. **S:** Because?

388. **L:** Well, I don't think I ... I think I -- I didn't want her to know. I didn't want her to realise how bad it was.

389. **S:** I'm just interested in, in ... I'm just wondering why it was you didn't want her to know.

390. **L:** I suppose I didn't want to hurt her feelings. I didn't ...

391. **S:** How would it have hurt her, her feelings?

392. **L:** Well, because I know it would have hurt her to know that I was feeling bad. It would have made her feel bad too.

393. **S:** I was just -- I'm just wondering what about it would hurt her, do you think? Or what did you think would, would hurt her about not, about telling her those things?

394. **L:** The knowledge that I was feeling so awful.

395. **S:** Ok. And -- Ok, that's cool. And then -- So, so generally you have a good relationship with her and you can share lots of things, but you prefer not to let her know when things are really bad, because you don't want her to feel hurt.

396. **L:** Yeah. I mean, most of the time I would tell her.

397. **S:** And are, are there any other changes in your relationship which you think are since you've had the JIA and being ill. I know, because for you it was quite young, but any other changes in your relationship?

398. **L:** I don't think so.

399. **S:** And it's -- What's interesting is that ... So changing to a totally different topic, is that adolescence is a time of becoming independent and pushing parents away, that kind of thing. And becoming closer to your peer group. But independence is quite a long, strong theme in adolescence. I was wondering with you, how has that move towards independence been? Say in comparison to your peers.

400. **L:** Well, a lot of the things that I would want to do independently I can't do, because well ... Like for instance, I can't go to the shops alone because what if I collapse in a shop and my mom's not there to help me, you know.

401. **S:** Does your arthritis get so bad that you can collapse in a shopping mall?

402. **L:** It's the dysautonomia.

403. **S:** Ok. And then it just ...

404. **L:** Ja.

405. **S:** So, so you're actually ... So the you're not very dependent, independent?

406. **L:** Ja.

407. **S:** So you -- Does your mom go with you most places?

408. **L:** Jip.

409. **S:** And with the -- Oh, you're not taking the Humira anymore.

410. **L:** No.

411. **S:** But when you were, was it the injection?

412. **L:** Yes.

413. **S:** Who gave you the injection, yourself or ...

414. **L:** Ja, I did.

415. **S:** Wow, you're brave.

[both laughing]

. . . I believe, it's so sore

416. **L:** I found it very sore, ja.

417. **S:** So, but you were able to give yourself that injection, so that's quite a level of independence.

418. **L:** Ja, I think in some ways I'm very independent.

419. **S:** Oh, in what ways are you independent?

420. **L:** Well, like I don't need anyone to tell me to do school work, or to ... Like, I'll do my own research into my photography and into things I want to do, and ... Well, ways that I'm not independent, that would be easier, is like I can't cook a meal because ... Not -- Mostly because I'm so tired all the time. So I can't always put my clothes away.

[60 minutes]

Or -- I mean, I can't always ... I can't feed the dogs a lot of the time, or, ja. I can't think of ...

421. **S:** So, so it sounds to me like the combined diseases that you have really really permeate your whole life.

422. **L:** Yeah.

423. **S:** And there's pretty much no escaping them day or night. How do you manage that? How do you cope?

424. **L:** I think I do a lot of escapist things like I read and I watch TV and ... Well, my photography is kind of an outlet in some ways.

425. **S:** Interesting, with your photography, just from what you've said, it's an outlet but it also brings something else to you. Well, that's what I was observing from your face. I was wondering if you could verbalise what else it brings to you?

426. **F:** I think it gives me a sort of power to express things and to create something. And to see, show how I see things in a different way.

427. **S:** And the emotion behind that, when you've done that?

428. **F:** Well, a lot of the time it helps me like relieve stress and makes me feel happy I suppose, sometimes. But it's more -- It's not -- It's not really happy, it's more of a deeper emotion.

429. **S:** Can you, can you access the words for that deeper emotion?

430. **F:** I'm not sure. It's something I'm very passionate about, so ...

431. **S:** So, as a coping strategy, the first thing you mentioned was escapism. It's sounding to me like the photography is, is obviously linked to the escapism. But it sounds like the photography is giving you something else. What is it giving you?

432. **F:** Gives something else to my life, apart from school work and the illness.

433. **S:** And, and as a coping strategy, the photography ... I'm, I'm just trying to help you find words without putting them in your mouth. So, so you know a coping strategy is something that enables you to deal with your illness. So it's, it's an escapism, it brings you feelings of happiness I think you said?

434. **F:** Ja.

435. **S:** And is there anything else that you find, like with the, with that lady, person who wanted to buy your print. How would -- Was there anything there that was maybe like, could be related to coping strategies?

436. **F:** I, I suppose it also gives you a bit of control. So, that's not ...

437. **S:** Ok, ja.

438. **F:** Ja.

439. **S:** Can you tell me more about that?

440. **F:** Well, because I can take a scene and change it the way I want it to be. So I can change the light and I can make something the way I want it to be.

441. **S:** So as a coping strategy, that's compensating for what in your life as it is?

442. **F:** Well, I've got -- I don't have a lot of control over ... I have no control over how I feel from day to day. Ja. I mean, even if I do something that one day helps me, doesn't mean it's going to help the next day. Sometimes it makes me worse the next day.

443. **S:** So you're having to change your coping strategies ...

444. **L:** Ja.

445. **S:** On a regular basis. What other coping strategies do you have? So we've got the escapism and the photography, which makes you happy and gives you a sense of control. Do you have any other coping strategies?

446. **L:** Well, I have got two guinea pigs.

447. **S:** Ok. Animal -- Ja, guinea pigs.

448. **L:** And my dogs, and they help me a lot when I'm feeling bad.

449. **S:** Can you, can you tell me how they make you feel better?

450. **L:** Well, just seeing them makes me feel better.

451. **S:** What, what about seeing them makes you feel better?

452. **L:** I just feel comforted and like I’ve got them, so I’ll be ok.

453. **S:** So with the guinea pigs, what happens that makes you feel better?

454. **L:** Well, like one of them is Charlie – he’s the younger one. And whenever I’m feeling upset he’ll, he’ll lick my nose and give me little nibbles.

455. **S:** So he knows when you’re upset? Can he sense it?

456. **L:** Yeah, sometimes I think.

457. **S:** Ok.

458. **L:** My dogs as well.

459. **S:** So they -- So Charlie gives you affection.

460. **L:** Yeah. The other one, Rusty, he also -- He has a different kind of affection; he talks a lot.

461. **S:** Really? A guinea pig that talks?

462. **L:** [laughing] Yes.

463. **S:** So what -- How does he talk?

464. **L:** They make little noises, like little bird noises kind of.

465. **S:** Give me an example. Or is that too embarrassing?

466. **L:** Ja.

467. **S:** Ok, sorry. [laughing]

468. **L:** But we know each other really well, so like I can sense when they’re trying to tell me something. Not in a weird way, but like if they need the toilet, then they’ll tell me by talking a specific way. So we have a connection.

469. **S:** So the connection with your guinea pigs, they under ... They know how you feel.

470. **L:** Ja. Well, obviously they don’t understand on a human level.

471. **S:** Of course, yes.

472. **L:** But ja, they ...

473. **S:** And caring for them? Is that part of the process that helps you feel better?

474. **L:** Well, I think ja, in some ways it shows me that I can actually do something. Because with my dogs I feel ... I mean, I can’t take them for walks, I can’t play ball with them, like I struggle to feed them because it involves bending over. So I suppose my guinea pigs give me something that I can do.

475. **S:** So that -- Would that fit in with a bit more control or independence or something like that?

476. **L:** Ja. Ja.

477. S: You don’t sound sure.

478. L: No. Yes it would.

479. S: It would. Ok. And what kind of dogs do you have?

480. L: We have three beagles.

481. S: Oh, those are cute. And quite energetic

482. L: Ja, well one of them’s about eight or nine, so she’s getting on a bit and she’s happy to sleep most of the day. In fact the others are, but they’re quite cuddly; they’re happy to sleep.

483. S: So how, how -- How are the dogs ... So now you’ve told me how the guinea pigs are, help you cope. How do the dogs help you cope?

484. L: Well, I think in the same, the same way. Like if I’m upset my one beagle, Romulus, will come and lick my face and nose me and wag his tail and, you know, climb on my lap.

485. S: And how, how does that help you cope?

486. L: I don’t know. I suppose it makes me feel loved and appreciated. Ja, I mean he’s always happy to see me. Ja.

487. S: And the other beagles?

488. L: Well, one of them is more my mom’s dog. So she and I don’t have such a close relationship. But the older one and I are close.

489. S: That’s the one who sleeps a lot?

490. L: Ja.

491. S: So, so how does she help you cope?

[70 minutes]

492. L: Well, she’s also always there if I need her, or ... Ja.

493. S: Ok. So your animals also help you cope. Are there any other ways that you cope? Any other mechanisms or ... Can I ask you, do you have a therapist?

494. L: No. I’ve ...

495. S: Would you consider going to see one?

496. L: I’ve seen a couple of people before and it’s never really worked out.

497. S: Ok. Maybe that’s something we can chat about just now.

498. L: Ok.

499. S: Ok, so you don’t have a therapist, so that wouldn’t help from that perspective. Any other coping strategies? Anything else that helps you just get through the day or get more motivated or something along those lines?

500. L: Not really. I mean, I really ... I’m like quite interested in new medical things that are going on; research in terms of that. Things like TED videos.

501. **S:** Yes.

502. **L:** Sometimes if I watch those and I do a bit of research, and I think about, I suppose what I want to do with my life, I guess that’s sometimes motivating.

503. **S:** Want to do, ok. So is that research around your own illness, or researching in general because you’re interested in becoming a vet, or ...

504. **L:** Well, at the moment I’m actually interested in going into medical research.

505. **S:** Ah.

506. **L:** And when I read about things about the body and stuff like that, then it makes me eager to learn more.

507. **S:** So would that be sort of planning and thinking about your future is also a coping strategy?

508. **L:** Yes. Although sometimes at the same time it makes me feel worse, because it makes me think about how difficult some things are going to be, and things I can’t do.

509. **S:** So it’s sort of a mixed one.

510. **L:** Yes.

511. **S:** Any other coping strategies?

512. **L:** I don’t think so.

513. **S:** Ok then. When you had that Revelex infusion and you went into anaphylactic shock, that was obviously a huge trauma for you. Have you had any other lows that have been bad? Obviously it’s bad because it was a low, but ... Not necessarily medical, but any other lows.

514. **L:** I supposed there was ... Before I left Saints, I was quite sick. I wasn’t going to school most of the time. So I guess that was a low as well. Not in such a quantifiable way. And there have been periods where I’ve been quite depressed for no apparent reason, not really a reason. Just where I’ve had, where I’ve been exhausted without a logical trigger.

515. **S:** Ok.

516. **L:** That I could point out.

517. **S:** So would that be ... You said it changes from day to day. So if you suddenly got a ... Your illness was exacerbated on a day, but without a trigger, then ...

518. **L:** Ja, well sometimes -- Sometimes, occasionally, it will be for like a few weeks where I just feel awful. For instance, whenever the seasons change, that’s a big one. Always when the seasons change I feel terrible. When it -- Last year, when summer started, I got ... I was exhausted – always happens when the seasons change. And I remember thinking it feels like my nerves are all on fire.

519. **S:** That could not have been pleasant.

520. **L:** Ja, it was -- It felt like I was burning. And I got strange tingles and very dizzy.

521. **S:** And, and, and so from a low point, I mean how'd that ... How, how was that emotionally?

522. **L:** Well ...

523. **S:** I mean, the physical thing is one thing, but what did that do inside your head?

524. **L:** Well, in a way sometimes I'm so exhausted that I can't fully think about the implications, but ja. Generally when I, when that happens I start thinking about how it's always going to be like this. Because it happens every season change for a couple of weeks.

525. **S:** And does the symptom ... does it sometimes change like that.

526. **L:** Yes.

527. **S:** You just get a new symptom.

528. **L:** Yes.

529. **S:** How do you handle that? I mean -- Or, or do you just take it in your stride, or, or does it cause thoughts in your head when you suddenly get a new symptom?

530. **L:** I think over the past couple of years I've learnt to, I wouldn't say laugh about it, because it's not ... I mean, obviously it's not funny. But I suppose I accept that sometimes my body just decides that today is not its day, and then something will go. And then the next day something else will go.

531. **S:** But I'm sensing a humorous undertone almost with you, or not?

532. **L:** Yeah.

533. **S:** Because you said, you, you don't laugh because it's not really funny, "but". Can you fill in what comes after the "but"?

534. **L:** I mean, some of my symptoms are sometimes so odd. Like we went to this one neurologist who turned out to be a bit of a fraud. Apparently he gives the same medication to all the patients he sees.

535. **S:** Ok.

536. **L:** But we were describing my symptoms, some of my symptoms to him, and he said something like it was cuckoo.

537. **S:** Oh. Ja. Ok.

538. **L:** So, ja. Which is ... It's just strange. Ja.

539. **S:** Ok. And just because you mentioned that guy saying ... Did he say you were cuckoo?

540. **L:** I think he was talking about the symptoms in general.

541. **S:** Oh, are the symptoms cuckoo?

542. **L:** Ja.

543. **S:** And when -- I mean now, you're much older now. How is your relationship with your doctors now?

544. **L:** Well this was -- I think it was actually earlier ... It was last year, at the end of last year. So he was one of the doctors that, you know, I was angry with.

545. **S:** He was one of the ones you were angry with?

546. **L:** Ja, because he put me on a lot of medication that I had no reason to go on. And it was serious medication; it was epilepsy medication.

547. **S:** Oh, ok. Like Lamictin or one of those?

548. **L:** Yes. And he wanted me to just come off some of the medication I was on. And I wanted to say to him, I mean, are you mad?

549. **S:** Did you, did you say that to him?

550. **L:** No.

551. **S:** That's interesting for me. This is not a criticism, it's just interesting. So, so why did you not say that to him?

[80 minutes]

552. **L:** I don't know. I'm not the kind of person who would say that, I guess.

553. **S:** Do you find then that because you're more reserved and shy, that you tend to listen to the doctor and you've got disagreements in your head as with this specific case, but then you don't verbalise or vocalise, as you say, that to them?

554. **L:** Most of the time I'll find that I'll listen to them and then later I'll think of things to say. In fact, pretty much all the time. And then ...

555. **S:** But in the spot you didn't.

556. **L:** Yes.

557. **S:** And does your mom go in with you to these meetings?

558. **L:** Yes.

559. **S:** And so when -- How does the conversation work with the three of you in the room?

560. **L:** Well, she often does a lot of the talking I think, when we see doctors. As I've gotten older I've, you know, done more of the talking because obviously I know more about what's going on.

561. **S:** Do the doctors talk to you?

562. **L:** A lot of the time they don't.

563. **S:** Who do they -- So they talk to your mom?

564. **L:** Ja. Find that quite a lot.

565. **S:** And, and how do you feel about that?

566. **L:** It's very frustrating. They don't do it as much now, but when I was younger, definitely.

567. **S:** But they're still doing it now?

568. **L:** Some, sometimes, ja.

569. **S:** So, so you're in that transition period from, moving from paediatric to adult, but you're with G***.

570. **L:** Yes.

571. **S:** So, G*** keeps you until what – 16, 18?

572. **L:** I'm not sure. I, I just turned 16 this year, so I'm still seeing her.

573. **S:** If I'm not mistaken, she's one of the few paediatric ones that will keep you until 18. How do you feel about moving eventually from G*** into a adult rheumatologist? Or rather, a rheumatologist who works with adults.

574. **L:** I haven't thought about it in depth. I think it will be ... We'd have to start from scratch basically with telling her everything that's happened. At least with G*** we go there and she knows us and we tell her what's happening now, and that's that. And she knows that ... Well, I guess she trusts what we say.

575. **S:** So it would be rebuilding that level of trust with a new person.

576. **L:** Ja.

577. **S:** Are you anxious, or ... About that, or ...

578. **L:** No.

579. **S:** You think it'll just come.

580. **L:** Ja. I've seen so many doctors, I don't really ...

581. **S:** So we were -- I've allowed us to become side-tracked. We were talking about the lows and the highs. That time when you went into anaphylactic shock, which was, sounds, appears from what you have said to have been like one of the biggest lows. Because the diagnosis was actually a bit of a relief from what you've said. That anaphylactic shock, how bad was that from a, from a low point of view?

582. **L:** Well, I don't think it was actually such a low point of view.

583. **S:** Ok. Ok.

584. **L:** Because it was something quantifiable that, I mean, I could put a name to and there's a reason that it happened, and I knew that it was going to go away.

585. **S:** Ok.

586. **L:** So ja, that wasn't such a low.

587. **S:** But it was a bit traumatic not to be able to breathe and everything.

588. **L:** Ja.

589. **S:** Was that scary?

590. **L:** Ja.

591. S: And tell me, when they put you in hospital – because they put you in hospital for a week – were you appropriately placed? Or ...

592. L: Yes, I think so.

593. S: Were you in a day ward or on your own or paediatric, adult ward.

594. L: I think I was in a paediatric ward at Donald, the Donald Gordon.

595. S: Ok.

596. L: I wasn't completely on my own, but it wasn't a bad ward. There was one other child there.

597. S: So there was no like strange things that happened?

598. L: No.

599. S: Ok, I was, was just wondering about that. I think I have covered everything on my list. But I was going to ask you how you would describe yourself before the illness and after the illness, but I don't know if you can do that with it being so long?

600. L: Ja, I wouldn't be able to do that with the arthritis. Ja.

601. S: And now, if you had to describe yourself now?

602. L: Well, I'm still I think fairly ambitious. Bit of a nerd maybe. [laughing] Quite reserved.

603. S: You don't see yourself differently to other people, you're not labelling yourself?

604. L: No I, I think I -- I mean I don't want to call myself a sick person.

605. S: You don't want to call yourself a?

606. L: A sick person.

607. S: So you don't, so you don't see yourself as a sick person?

608. L: Well I think, I mean I am, but that's not what defines me, even though it defines lot of my life.

609. S: Ok. You did also mention there that you're quite ambitious and I'm wondering, is that another of your coping strategies?

610. L: Maybe.

611. S: Ok. I am thinking this has been a very long interview and you are looking fatigued. So I'm going to stop this interview.

612. L: Ok.

613. S: I'm just going to ask you one more question and then we're going to stop, because we can always have a follow-up interview.

614. L: Ok.

615. S: And that is, is there anything today that you feel you need to tell me that I haven't asked you about?

616. L: Nothing that I can think of.

617. **S:** Nothing. Well, thank you very much for taking part. Let me just stop this and we can meet on another day.

[recording ends]

Transcript 2: Leigh-Ann Interview 2

1. **Interviewer (S):** And it's recording. Ok, super. So thank you very much for agreeing to have another interview. Today what we're basically doing is we're, we're really just going to have a look at coping strategies and quality of life and that kind of thing. But you sent me that wonderful e-mail, so, reflecting on our previous interview, so I was wondering can we just go over some of those ideas first?

2. **Interviewee (L):** Ja.

3. **S:** Do you, do you remember it, or shall I ...

4. **L:** I don't really; I'm going to get it up on my phone quickly.

5. **S:** Ok. Otherwise I can, I, I did make notes.

6. **L:** Ok, ja sure, you can use that then.

7. **S:** Ok so, so, the, the first thing that you sent to me was a little bit more information about your lack of social life, which was the way you phrased it. And you said that you felt your lack of social life was a combination of being an introvert and also your illness. And that when you do meet up with other people – which isn't very often – you feel, you can feel more isolated and angry. And you said that people don't know how good they have it and that causes you to withdraw more. I was wondering if you could just tell me more about that.

8. **L:** Well, it doesn't happen all the time. I mean, I do have a good friend, like that I'm meeting up with next weekend, so I'm looking forward to that. But I guess, ja, people at school especially ... I don't know what, what more I can say.

9. **S:** Ok, so maybe we could just look at the positive side of your social relationships as well. So, so you're meeting up with a friend next weekend.

10. **L:** Yes.

11. **S:** So, so what, what is working for you with regards to your social life?

12. **L:** Well I find that I just naturally I prefer small groups and you know, one close friend rather than being around a whole lot of people. I also find that less tiring. Yeah, so I mean, I've known her for about a year now and she kind of knows a some, some things about my illnesses. Like she doesn't know everything but she's quite understanding.

13. **S:** And you find the ... In what ways is she understanding that helps with your relationship?

14. **L:** Well, she seems fairly interested. I mean, I don't talk much about my illnesses. Ja. And I haven't talked to her about it for a while, but when I do I think she listens. She has said a couple of things in the past which I got a bit annoyed at. But like initially, before we were really friends, I was telling her ... We were having biology and I was just talking to my teacher because, my tutor, because we were doing stuff in class that was kind of similar to me, I think. And we just got talking about how tired I am. And of course everyone says: oh, you seem fine, you look healthy, you don’t seem that tired, you cope so well. [laughing]

15. **S:** Ja.

16. **L:** And you know, you still get all your work done. You’re actually lucky because it means you have to do everything, you have to get everything done, you know, a specific time. But it also means that I have less time to do everything, obviously. And I mean, they can work until like midnight and be fine the next day.

17. **S:** Ja.

18. **L:** Or they can work the whole day. Or if they want to go out in the morning, they can work in the afternoon. Which I can’t.

19. **S:** Ja. Ja. And, and so that comment made you feel how? I think you said angry just now.

20. **L:** Ja. I guess irritated. I don’t know if angry is ... Maybe angry is too strong a word.

21. **S:** And so this one friend that you have that you have a good relationship with, how is she different? I know you said that you were a little bit irritated with her at times, but, so she listens well.

22. **L:** I don’t know how she’s different. We just spent, we spent a lot of time together this year because we do, we’ve been doing the same work and ja. We’ve been working ... We’ve had a lot of work to do this year, we both have. So we’ve kind of got that in common. We want to do similar things later on in life, so there’s that as well.

23. **S:** Does she also want to be a vet?

24. **L:** She wants to be a doctor.

25. **S:** Ok. So you both want to go into medicine.

26. **L:** Ja.

27. **S:** And ... I’ve just gone blank on what I wanted to ask you. You said something. It’ll come back to me just now. Oh, I’ve forgotten, I’m sorry. Oh yes, yes, yes, that’s what it was. Sorry, I’m glad I took the time to think of it. You said you don’t talk about your illness much with her and I was just wondering why that was the case.

28. **L:** Well I don’t really talk about it much to anyone. I guess just in the past it’s led to misunderstanding. And people don’t really know what to do, what to say if I start talking about it. So they get quite uncomfortable.

29. **S:** Ok. Because they don’t know how to deal with it.

30. **L:** Ja.

31. **S:** Ok. And, and what are the positive aspects that you’re getting out of your relationships?

32. **L:** Just in general, or in terms of my illnesses?

33. **S:** Either, either.

34. **L:** I don't know. I mean it's nice to have someone to talk to just generally. I mean, it's nice to have friends. Ja. I don't really know.

35. **S:** I was just wondering maybe is it, is it also perhaps that it's nice to have a space in your life that isn't about the illness.

36. **L:** Ja. Ja.

37. **S:** So then you don't bring it up maybe.

38. **L:** Ja. Maybe also it's a break from school. Although sometimes we end up discussing school because we're both doing the same stuff.

39. **S:** Ja, you have it in common. So are you feeling less ... Because I know when you were at Saint Stithians you, you said you were feeling quite isolated, but you seem to have experienced more growth at the home school on a social level.

40. **L:** Yes.

41. **S:** Ok, cool. Because they're less judgemental? Is that ...

42. **L:** Ja. It's more, more of a close-knit group.

43. **S:** Ok.

44. **L:** Because we aren't that many of us. I mean obviously at Saints there're thousands of people, or well ... And at the study centre there are only like 30. Which makes a difference as well.

[10 minutes]

45. **S:** So you get to know each other a lot more.

46. **L:** Ja.

47. **S:** Ok. And then one of the other things – because you gave me three, three lovely things in the e-mail that you shared with me – you told me you wanted to talk a little bit more about doctors because you said: they don't tell me anything, they don't listen, they're arrogant, they make false promises. And then you gave me an example of the Raynaud's phenomenon and Dr X.

48. **L:** Ja.

49. **S:** And that she wasn't able to help you; the meds didn't work. And then there was a poster in her rooms that she was so proud of, showing how the medication could cure the most extreme cases. And I think in the e-mail you said you wanted to punch her when you saw that poster. So I don't know if you have more reflections on that?

50. **L:** Well, false promises are quite a big one for me.

51. **S:** Ja.

52. **L:** It, sometimes it seems to me that, that doctors either say: oh we can help you, try this, whatever. And then it doesn't work and then they lose interest. Well I don't know if they lose interest, but they're not willing to, I guess, explain or go further, look at more things.

53. **S:** So do you mean like do more tests and look at, look in a more broader ...

54. **L:** Ja.

55. **S:** And when you say you think they lose interest, how does that come across that makes you think they've lost interest?

56. **L:** I think just the way that they ... I mean, there's no point in going back to them really after that, seeing as there's nothing they can do. And I guess after you've tried like one or two medications, they kind of say: ok well, we've done all we can do, now go home and deal with it.

57. **S:** Ok. So they ... Ja, ok. So they, they're not continuing to try and help you.

58. **L:** Ja. Which I understand, because I don't think medicine is really there. I think a lot of my issues can't be helped and there is nothing that doctors can do.

59. **S:** Ok. Ok. And has anybody else offered you those false promises? Or is it most of them?

60. **L:** No, I mean, when I was first ... Before I was first diagnosed when I was much younger, maybe 10, we eventually ended up going to a couple of like natural remedies – homeopaths or ... And they always say: oh no, just ... They always think that they can cure everything, I found.

61. **S:** Ja.

62. **L:** But no-one outside of that, no.

63. **S:** Ok. And then the last thing that you mentioned was to do with your independence and, and, and your future. And you said one of the areas that you don't have independence at this stage is that your mom has to blow-dry your hair for you, and you expressed concern that your mom might still be doing your hair when you're 40. And I was just wondering if you could tell me more about that.

64. **L:** Well, my arms really struggle, my shoulders and that. I get pains in my arms like neuropathy, but I think it's not actually that. Because with the dysautonomia and the POTS, often you get these weird symptoms that don't actually show up on any tests.

65. **S:** What is the POTS again?

66. **L:** Postural orthostatic tachycardia syndrome.

67. **S:** Ok, that's right, that's right. Sorry, I'd forgotten about that. Ja, ja. So, so does it worry ... I mean, obviously it worries you about the future implications of being an adult with these difficulties.

68. **L:** Ja. Some -- Ja. Sometimes. It's not something I think about every day, but when I do think about it I do wonder.

69. **S:** What are the kinds of things that you wonder?

70. **L:** Well for instance, I've always wanted to study overseas, and at the moment that's looking very unlikely. Because of cost but also, you know, because I'll be in a strange country without any support system.

71. **S:** Ok.

72. **L:** And so if for instance I wasn't feeling well enough to go and buy groceries, or do the dishes, or make supper, or any little household task, I wouldn't have anyone to do it for me. So ja. And if for instance my blood sugar suddenly crashed, I wouldn't have anyone there to help me with that.

73. **S:** Ja. Ja.

74. **L:** Like, ja. It's not like in that state I can just go and get something to eat, so.

75. **S:** Ja. So, so -- It, it -- You're concerned about that it will actually restrict what you can do and where you can study.

76. **L:** And even things like ... Even if we went to ... Even if I went to a local university, things like getting around campus, I think I would struggle with. Not every day, but there would definitely be days where I would struggle.

77. **S:** Ja, ja. And would you ... Would it be a problem if your university that accepts you isn't locally based? Isn't in Johannesburg? Because -- Oh you, you want to be a vet, so that would be ...

78. **L:** Ja, well lately I've been thinking ... Lately I've been very interested in medical research, probably because of all my issues. I've been looking at neuroscience and the possibility of going into that kind of research.

79. **S:** Ok. Which would be a lot less physically challenging.

80. **L:** Yes. But you have to become a medical doctor first, which would be physically challenging.

81. **S:** Oh I see. Yes. And then you would go into research from there. So you've still got to do the seven years with the internship.

82. **L:** Ja.

83. **S:** Ok. Alright. So it really is the physical side that concern you with regards to do you have the stamina to pursue the course itself?

84. **L:** Yes. Ja.

85. **S:** And get around on campus and that kind of thing. Ok. Ja, I don't know. After what we've just discussed there and in our original interview, are there any other things that spring to mind for you, that you'd like to raise at this stage?

86. **L:** No. I've been thinking about it and I think I've mentioned everything.

87. **S:** Ok. So then what we've been looking at quite a bit is the sort of negative consequences of having your illnesses. What I want to explore with you if you can, if you're willing to do that, is to have a look at what has actually helped you in your environment. Whether it's yourself, or the extended family, or society I general. Is there, is there anything that's actually been helping you cope with your illnesses?

88. **L:** Well, as much as it annoys me when doctors say you have to learn to deal with it and pace yourself, I actually think that that is something that you need to learn to do. And I think I have learnt that to a certain degree. So I've learnt my limits and, you know, what I can do on certain days and what I can't do. And I think I've learnt to plan accordingly. So breaking things up into much smaller tasks.

89. **S:** Ok.

90. **L:** And a couple of rests inbetween.

[20 minutes]

Knowing when I need a rest.

91. **S:** Ja.

92. **L:** Knowing when I need to eat something. Knowing what I can and can't eat. And also in terms of my energy levels, knowing when I can have a cup of coffee and that'll lift me up, or when a cup of coffee will give me a migraine.

93. **S:** Ok.

94. **L:** Ja. Ja, not -- Maybe also not getting too angry when things don't work out. Learning -- You know, creating a plan B.

95. **S:** Can you give me an example of that?

96. **L:** Well, for instance last weekend I was going to go on that photo walk, but I had been so dizzy like the day before, that we decided it kind of wasn't a good idea. And I think in the past maybe I would have been a lot more upset about that, but now I know that, you know, this is just how it goes. So I'll try to do these things and I'll plan to do them, but I'll think to myself: ok, if I can't do that then I'll do something else.

97. **S:** Ok. And what ... So -- What did ...

98. **L:** Or at a later stage.

99. **S:** What did you do instead of going on the photo walk?

100. **L:** I think we just stayed at home. I did some work. I think we might have gone actually to a bookshop in Cresta to buy some textbooks. Ja.

101. **S:** So, so it's almost a case ... It's a case of having to know your body and listen to your body and then learn to accept that there's just some days where you plan things that you, you just can't do them, and then maybe just do something else, or rest.

102. **L:** Ja. I mean, it still makes me very irritated sometimes and I still get upset about it sometimes, but I think I'm starting to accept it.

103. **S:** And that has been a journey hasn't it?

104. **L:** Ja.

105. **S:** I mean, you didn't just start with acceptance.

106. **L:** Ja.

107. **S:** How -- What's, what's led to you being able to accept it and manage it so, how you do.

108. **L:** Honestly I think just time. I don't ... I mean I don't think there was any actual thing where I was like: ok, now I'm going to accept it, you know. It was gradual.

109. **S:** Just a gradual ...

110. **L:** Ja.

111. **S:** And last time we spoke, we, we spoke quite a lot about your animals and how your animals help you cope when you're feeling down. I, I was just wondering if there's anything else that helps you? Any other things that you can think of that have helped you cope – not necessarily even yourself, but if there is more that you do, that's also great. But I mean, if there's anything else in your environment that helps you cope?

112. **L:** No, well, maybe my animals; there's my photography. Maybe my mom as well. Sometimes if I watch TV and I get quite attached to characters in the TV series. So sometimes that makes me feel better as well.

113. **S:** Ok.

114. **L:** Ja, I can't really think of anything else. Maybe sometimes music.

115. **S:** And, and ...

116. **L:** Sometimes I just need quiet though, as well.

117. **S:** Sometimes?

118. **L:** Sometimes I just need quiet though as well.

119. **S:** Ok. Just, just time out.

120. **L:** Ja.

121. **S:** Just sitting in ... And so what does quiet mean for you? What happens, what do you do?

122. **L:** Well if I go and sit with one of my guinea pigs for a bit, or reading for a bit.

123. **S:** Ok, so, so mainly downtime.

124. **L:** Ja.

125. **S:** And do you have any religious or spiritual beliefs that help you cope?

126. **L:** No, not really.

127. **S:** Ok. I was just wondering. And ja, and your extended family and friends – anything there that helps you cope?

128. **L:** No, I don't think so.

129. **S:** Ok, and ... Ja. Quality of life – it's, it's an interesting theory that even though you are ill, you can still have quality of life and wellness, or a sense of well-being. And I wonder if you agree with that and if you experience that at all?

130. **L:** Well, I don't know. Some, some days -- Sometimes when I have good days I feel great and like everything's fine. You know, life's good. And then on other days I have bad days and just everything will feel awful and you know, I feel like my life's going nowhere... .

131. **S:** Ja. And, and, I mean, I know the coping strategies and the quality of life often overlap. Is there ways in which you, you bring, consciously maybe, bring into your life things that, that give you that quality of life.

132. **L:** No, I think it would just be the same as the coping strategies.

133. **S:** Slightly different though, because one of your coping strategies is actively managing, whereas some of your other coping strategies were the escapism with photography and being with the guinea pigs and your dogs.

134. **L:** Ja.

135. **S:** Is there, there any, I mean, other things that make you happy even though you're ill? Or give you a sense of satisfaction?

136. **L:** Well I also feel that from my school work.

137. **S:** Ok. Can you tell me more about that?

138. **L:** Well I enjoy setting myself a task and doing that task and like being able to cross it off the list. Whether it's like a maths exercise or some reading, some notes. And I quite enjoy that kind of thing. I mean I enjoy sitting down some mornings to do some notes for biology or, ja, doing some Physics, or something like that.

139. **S:** What is it about that that you enjoy? Or that makes you feel good?

140. **L:** I think partly the routine. And some of it I find quite interesting, which helps. Especially with biology. Ja. I'm not sure what more. I guess it gives me a sense that I can accomplish something.

141. **S:** Ok, so like a sense of achievement?

142. **L:** Ja.

143. **S:** And, this sounds like such a strange question, but have there been any positive outcomes from being ill?

144. **L:** Well, I think it's, it's gained me a lot of medical knowledge, which could definitely help me in the future.

[30 minutes]

And I mean it's gain, it's given me an insight into medicine and the body and I guess patient care as well. Ja, even just the research I've done because of all my symptoms ...

145. **S:** Yes.

146. **L:** Has taught me things.

147. **S:** I'm just making a note quickly so we can follow up on that just now. Ok, so, and any other positive outcomes for you?

148. **L:** Maybe in a way it's made me feel like I can handle things. I feel like, you know, if I can handle this, then I know if something bad happens I'll get through it.

149. **S:** And, and, and what is it do you think that will enable you to get through that possible bad thing in the future? What is it that ...

150. **L:** Well I guess the fact that I know that when I have bad days I also have good days. And my coping strategies. Ja.

151. **S:** Ok, cool. And any other positive outcomes?

152. **L:** Not that I can think of.

153. **S:** I was ... Let me give you more time to think.

154. **L:** No, I can't think of ...

155. **S:** Ok. So I was really interested that you said medical insight and that the research that you've done, patient care. Could you go into more detail about that for me? As a positive outcome.

156. **L:** Well, I know quite a ... Well, I know a fair amount I think about what the nervous system, and how the body works to control itself. And how, even though in textbooks they'll say, you know, when you take, when you eat food you know you release certain hormones which do certain things, that's not always the case. Sometimes the opposite happens. And, ja. And I guess things like learning the names of things and it's also made me more interested in things. So I'll go and watch TED videos about neuroscience and the brain, and I don't know if that would have happened if I didn't have all this to deal with.

157. **S:** Yes. And, and what prompted you to go and do all of the research that you've done?

158. **L:** I just really like answers. I just want to know why things are how they are. You can't always get answers, but you know, that's led me to go and find out about other things.

159. **S:** Ok, so it's sort of exploring why your illness is the ... Why you are the way you are and then that leads on to exploring different things.

160. **L:** Ja.

161. **S:** And, and what kind of a feeling do you get when you, you're researching?

162. **L:** Well, I can get quite absorbed. I get very interested and then one thing will lead to another. Ja, and sometimes I feel: oh that's why this happens. Ja.

163. **S:** So, so it's interesting, but at times it also helps you understand your own illnesses better.

164. **L:** Yes.

165. **S:** Makes, helps you make connections.

166. **L:** Ja. Ja, it kind of gives a reason for some things.

167. **S:** And, and I was just thinking about, because you did say quite distinctly that it's taught you a lot about doctor-patient relationships. And I was just wondering if you could elaborate on that?

168. **L:** Well, if I did go into medicine I don't think I would ever ... I wouldn't want to at this stage go into clinical medicine. But I think if I did, I would know more about how to give people information and you know, tell them what's happening, tell them, you know, that things don't always ... You can't always just cure something that's ... Ja.

169. **S:** And ...

170. **L:** I actually think I would know that. You know, I don't know if I would actually ... Maybe I would end up being the same. Don't know.

171. **S:** Do you, do you think that ... I mean we did discuss this a little bit last time and, and I'm just wondering with longer to reflect on it, if we look at from when you were young, when you started getting sick – which I think was about nine years – and now. Has all this research and having relationships with doctors, has it impacted on how you deal with your doctors?

172. **L:** Well ja, I think to a certain extent. I don't know. I've also gotten to know some of ... Well, I mean, at the moment the only doctor I really see is Dr X

173. **S:** Ja.

174. **L:** I've been to see other doctors like cardiologists and neurologists and endocrinologists and that. But now, it would generally be like one or two appointments and then that's that. So I guess because I've gotten to know Dr X maybe that also affected how I talk to her and how I tell her about what's happening.

175. S: And has there been a change in how you've ... Has there been a change in how much interaction you put into the relationship with Dr X? If I remember at the beginning it was mainly a one-way thing with Dr X telling you things, and you were saying you often had things in your head that you wanted to say but you wouldn't voice them. So I was just wondering if, if you've been able to get more of a voice?

176. L: Yes, I think I definitely have. And I think with other doctors as well.

177. S: Ok.

178. L: I've learnt to speak up a bit more.

179. S: And, and what kind of things do you say to them? How do you speak up?

180. L: I don't know. I guess I'll tell them if I don't want to try something new. I'll tell them like the consequences of certain drugs. And just more about how I've been feeling. And maybe also what I think is the problem.

181. S: Especially if you think you've, they've got it wrong.
[both laughing]
Or ...

182. L: Well, no. But I like to ... I find if I suggest something and then maybe they'll explain it more, instead of just thinking what they're thinking, not voicing themselves.

183. S: So, so it sounds like you have developed more of a voice with regards to your own illnesses.

184. L: Ja.

185. S: So would that be a positive outcome, do you think?

186. L: Yes. Ja.

187. S: So it sounds like you've developed a lot more independence around managing your illness, and even managing your doctors?

[40 minutes]

188. L: Ja, I think I have.

189. S: ... do you think. Ok, cool. And while we were having that discussion, did you think of any other positive outcomes? I don't know if anything else just popped into your mind?

190. L: No, not really.

191. S: When we were going through ... When I was going through the read, the, the interview again, I realised I, I never asked you what advice would you give to somebody who was diagnosed as JIA?

192. L: I'm not sure. Maybe that they should speak up for themselves and that they know their body better than anyone else does. And maybe to know your limits as well. Because I mean

I find that if I do push through, it always results in me getting much worse. And if I just carry on pushing through, it just results in a flare-up.

193. **S:** Ok.

194. **L:** So there's no point in trying to do that. If you need to rest, then you have to.

195. **S:** Ja.

196. **L:** Or be prepared to face the consequences, I guess.

197. **S:** So very much knowing your own body and pacing yourself.

198. **L:** Ja.

199. **S:** And what else would you advise them?

200. **L:** Maybe also knowing when something is not working for you. So if you know that you've been on a drug for six months and it's, you're still feeling no better, then say so.

201. **S:** Ok.

202. **L:** Ja.

203. **S:** Ok. Thank you. *Sjo,* ja, that was very helpful. I was ... Other thing that I was thinking of is that you said at times you, although you said you're managing everything very much better than you used to, sometimes you still get depressed when you can't, when there's no logical trigger for your flare-ups. So I was just thinking from what you've just said: managing yourself and everything and, and then all of a sudden there's a seasonal issue, and for no reason you just get a flare-up. Or no logical reason that you can see. So can you tell me more about that depression that you feel then?

204. **L:** Well I suppose it's a reminder of lack of control and that this is always going to be around. And at any moment it could hit you, whatever you're doing. But when that does happen, there's nothing you can do about it.

205. **S:** So for ex ... I mean, I think a very specific example for you would have been when you went into remission and then the illnesses came back.

206. **L:** Well, it's complicated, because when I went into remission the arthritis was fine, but I was still feeling pain from hypermobility. But ...

207. **S:** So you weren't ... I mean, you were in remission for JIA but not for the other ...

208. **L:** Yes. So I was still sick even though technically I was in remission. That's, it's just quite frustrating. Like lately my back's been sore and my, my hips have been worse, and my jaw's even been sore, which never happened before. And my shoulders have been terrible and my neck's been bad. And so for instance I had a, a cortisone infusion a few weeks ago and it made me feel terrible.

209. **S:** What, what is a cortisone infusion? Is it like a drip? Or ...

210. **L:** Ja, ja. It’s a, it’s a drip that goes in for a few hours; you can sit there in the hospital. Ja, and so that made me feel terrible. I don’t think it really helped much. But then the last few days I’ve been feeling more pain, so maybe it did help.

211. **S:** You’ve been feeling more pain, so it did help?

212. **L:** Ja, so maybe it did help and now it’s worn off.

213. **S:** Oh, I see. Now it’s worn off, ok. Gotcha, gotcha. Alrighty. And. and, so when you hit these depressed, these states of depression around the unpredictability of the illness, what kind of thoughts go through your head?

214. **L:** I think it’s mainly that it’s, it’s always going to be there, like hanging over me. Ja, and I’m just powerless, I guess, against it.

215. **S:** And, and are you able to get yourself out of that, or do you have to wait until you feel better?

216. **L:** I think I get myself out of it much quicker than I would have in the past, because I know that after a week weeks it’s going to go away.

217. **S:** Ok.

218. **L:** Ja.

219. **S:** And that you’re going to feel better again.

220. **L:** Yes.

221. **S:** So in the unpredictability there’s still some predictability.

222. **L:** Ja. I mean every time it takes a slightly different amount of time obviously to go away, but I do know that it will go away now.

223. **S:** Ok. And, and how does that knowing make you feel?

224. **L:** I don’t know. Maybe like there is some hope. Like I just have to wait it out. And maybe also like I’m entitled to rest when that happens, because after it’s happened I’ll be able to do the things that I can’t do now.

225. **S:** Could you tell me more about that thought?

226. **L:** Well I guess in the past I felt because no-one knew what was happening, or understood or anything, that people felt I was being lazy and that there was stuff I needed to do that I wasn’t doing. And I was just sitting around watching TV. So now I feel that if I need to rest, I should rest. And I deserve to have a chance to rest.

227. **S:** Ok. So that’s quite a shift in thinking.

228. **L:** Ja.

229. **S:** Ok. So, so it, it really does sound that as you go through with the illness you, you slowly but surely start to change the way you view it and develop strategies around it, and learn how to, to develop different expectations around yourself and what you're capable of.

230. **L:** Ja.

231. **S:** Ja. Ok. And if you think of yourself in comparison to your peers, what are the similarities and differences?

232. **L:** I don't know. I mean, I'm a lot more of a bookworm and I'm more studious and that kind of thing, but I think I would be anyway.

[50 minutes]

And I think maybe I have a better appreciation for good days when they happen. But at the same time I can't do what they do. I can't go out and see a movie at 10 o'clock at night or ... I certainly couldn't drink. Not that I'd want to, but I hear that they, they go to parties and drink. I could never do that, especially with all the medication I'm on.

233. **S:** Ja. Ja.

234. **L:** Ja, I mean, even if they ... [sound of dogs barking in the background] Sorry, that' my dogs.

235. **S:** It's ok, it's fine.

236. **L:** Ok. Even if they maybe go for a long walk or, I mean, go to like a colour fest kind of place, or anything like that. I would struggle with that, if I could do it at all.

237. **S:** Ja. And the similarities? How are you the same?

238. **L:** I'm not sure. I mean, I think maybe my family life in some ways. Ja, I mean apart from superficial things like fashion and TV and maybe the books, some of the books I read. I can't really think of anything else.

239. **S:** So, so are you saying that there's superficial similarities with your peer group, but other than that you really don't have much in common with them?

240. **L:** Well, I don't necessarily feel that; I'm just struggling to think of a deeper similarity to put into words.

241. **S:** Do you feel different to them?

242. **L:** Ja, in a lot of ways.

243. **S:** And is that ... I, I know we've discussed this before, but you did say that wasn't just illness-related, it was also personality.

244. **L:** Ja.

245. **S:** Do you think your illness has created a, a difference between you and them?

246. **L:** Yes, yes.

247. **S:** And that is around not being able to do things that they can do?

248. **L:** Yes. Ja, and maybe also because I can't do that stuff, I've focused on things I can do, like school work. Which has further made me different.

249. **S:** In what ways do you think that's made you different?

250. **L:** Maybe just that I certainly study more than most of them do. And, and I think in some ways that makes some of them intimidated.

251. **S:** Ok. Intimidated in what sense?

252. **L:** I don't know. In the sense that I know more than they do. [laughing]

253. **S:** Are you, are you getting better results than them?

254. **L:** Yes, definitely.

255. **S:** Ok. Ja. How does it feel to get better results?

256. **L:** Good. I mean, I think I would get better results anyway because of the kind of family I have and I would probably be studious anyway because of the kind of family I have.

257. **S:** How, how does your family impact on your studiousness?

258. **L:** Well, I don't know. A lot of it's self-driven, most of it's self-driven. But I mean, my dad got good grades, my brother got good grades, my sister got good grades. So I can't ... I don't know, I feel I now need to get good grades. But even though maybe that was at the beginning, now I feel like I want to get, get good grades for myself because of what I want to do in the future.

259. **S:** So it started off almost as a family expectation, but it's become something that you personally value yourself.

260. **L:** Yes. I think so.

261. **S:** And, and, and has that become a strategy for you to cope, do you think, or is it a way ... I sit something that adds quality to your life, doing well at school?

262. **L:** . . . in a way it is a coping strategy in that it is something that I can do really well. And it is affected by my illness because of the kind of hours that I can study.

263. **S:** Ja.

264. **L:** But I do well anyway.

265. **S:** And I was just wondering, on the idea of wellness ... Sorry, I'm jumping all over the place today. But on the idea of wellness, you said earlier the well days inbetween the ill days are ... What did you say? Not quite important, but are quite prominent in some way for you. Can, can you let me know more about those well days? And what they mean?

266. **L:** Well, I guess they make me feel a bit more normal. And maybe give me a sense of achievement or that I can achieve something. Ja. Ja, I can't think of ...

267. **S:** That's, that's mainly it. I've, I've kind of covered everything here that I needed to cover and I was just wondering if there's anything else from your side that you think we should still explore, or if something's occurred to you you haven't shared yet, you'd like to share?

268. **L:** There's nothing I can think of. The only thing that I can think of maybe is that, I suppose another one of my coping strategies, although it's more of a physical thing, is going to physio. Because I actually feel like that does more for my, for me, than the medication does.

269. **S:** Ok.

270. **L:** Like for instance, my arms have been really bad lately, so I've been struggling to do certain things. Well, I don't know if I'm struggling, but they've just been really sore if I stretch even a little bit or if I move them.

[60 minutes]

So last week my physio put a tape on my shoulder, which apparently is for stroke patients. But it ...

271. **S:** Stroke patients?

272. **L:** Ja.

273. **S:** Ok.

274. **L:** It keeps the, the joint in place and holds it up, you know so the, the weight isn't all on the muscles or the nerves in my chest. And that has helped my arm more than anything has in the past.

275. **S:** Ok.

276. **L:** It's still early days, but ja, I'm quite impressed by that. [laughing]

277. **S:** So that's giving you some quality of life, is the changes, some of the changes that are happening with the physio and the strategies. And so how often do you go to physio?

278. **L:** Once a week.

279. **S:** Once a week. And then does the physio give you things to do at home as well, or is it just treatment?

280. **L:** No, it's pretty much just treatment. I mean, we discuss things I guess, but just treatment really.

281. **S:** Ok, great. And is there anything else that we've forgotten or ...

282. **L:** I don't think so.

283. **S:** Ok. Then let's end that there. Thank you so much for, for taking the time out of your Saturday to help me again with the interview. I'm just going to stop recording.

[recording ends]

Transcript 3: Samantha Interview 1

1. **Interviewer (S):** Ok, so thank you very much for coming to the interview today. I am just testing that it's recording my voice which it's. So basically what I am going to be asking you about is from your perspective how the illness has affected Leigh-Ann and also how it has affected you and the family system. So I'm particularly interested in the first interview about the journey of diagnosis and if you can just tell me in your own words, how that has been for you as a mother and perhaps reflect on how you saw ...
2. **Interviewee (Sa):** It affect Leigh-Ann?
3. **S:** Affect Leigh-Ann, ja.
4. **Sa:** Well let me start right at the beginning. Leigh-Ann was a really difficult baby. She was born with dislocatable hips. She went into a harness the day after she was born and she stayed in that harness for three months. For the first six weeks she wasn't even allowed to take it off to be bathed. So she was in the harness all the time. She cried a lot. Constantly almost. The only time that she was pacified was being put to the breast. So we were reassured by the orthopod that Leigh-Ann was fine and I assumed that she was. And she went to nursery school from about, she was about four-and-a-half, I think. Because she, she didn't really want to go. Anyway, this is not really relevant.
5. **S:** Yes it is. Everything is relevant if you think is.
6. **Sa:** Ok [laughing]. So Leigh-Ann was always very reserved, self-contained, very able to focus and be by herself from quite a young age. When I say be by herself, I mean without other children. When she was about 10 years old she started complaining of pain in her neck and her shoulders. And we started going to physio, we went to a biokineticist, we went to obviously the GP. We went to a GP who had subsequently trained in Chinese medicine and she did acupressure, acupuncture. None of it helped. Eventually we went back to the GP and complained again. So when Leigh-Ann was young, she got a lot of sinus infections, so she was on a lot of antibiotics. Also relatively frequently on cortisone, oral cortisone. Any -- In any event. So she was about 10 and she started experiencing the pain and we started looking for an answer. Went back to the GP. The GP referred her ... The GP said he thought it might be fibromyalgia, so he referred Leigh-Ann to a rheumatologist. But the rheumatologist was an adult rheumatologist.
7. **S:** I was going to ask if it was an adult rheumatologist.
8. **Sa:** Strangely, because he works at the Donald Gordon across the road from Dr X. Anyway. So for some reason that didn't work out and I made a phone call to the Arthritis Foundation.
9. **S:** Didn't make -- Work out in that you didn't get a consult with him or ...

10. **Sa:** Yes, yes. For some -- I couldn't get hold of this person. So I contacted the Arthritis Foundation and they said, oh, well what about Dr X? So we went to Dr X. It was also at around that time that Leigh-Ann started menstruating. So she was just a little over 10, which I thought it was very young to start menstruating. We went to Dr X. We saw Dr X towards the end of that year, and she didn't then make a definite diagnosis of JIA. She -- I think it was at that point that Leigh-Ann got the cortisone infusion, the Solumedrol infusion, which did help. Because I think already then the pain was pretty much Leigh-Ann's back. It was really difficult because some children who present with JIA have huge swollen knees or swollen ankles. But there was nothing to see. You could see nothing. I think her range of motion was restricted in her neck. So that was reasonably tangible. So she had -- She -- So that was towards the end of the year. The next year, I think it was the next ... I think it was February the following year.

11. **S:** Of what year would this be?

12. **Sa:** That would be 2011.

13. **S:** Thanks.

14. **Sa:** We went back to Dr X. My -- I don't quite remember if we had the Solumedrol infusion the previous year or if we only then had the Solumedrol infusion. Anyway.

15. **S:** A lot happens; it gets really confusing.

16. **Sa:** Ja. So, it was in that ... Either in that year ... Ja, I think it was in that year that Dr X diagnosed Leigh-Ann with, with enthesitis-related JIA. And Leigh-Ann went onto -- I think it was then that Leigh-Ann went onto methotrexate. Oral methotrexate. Probably six tablets. She then went, tried various things. We tried Sulfasalazine. Some -- A few other things. Until Leigh-Ann went onto a biologic. Which she was on for two years. So that was probably ...

17. **S:** So that was Humira?

18. **Sa:** Yes, she was on Humira. Ja.

19. **S:** And the Revelex?

20. **Sa:** Oh yes, that was the first biologic we tried. Which obviously was an in-hospital infusion. It was just supposed to be as an outpatient and everything seemed to be going fine. We got home, Leigh-Ann was watching TV, and all of sudden she said she couldn't breathe. So I phoned Dr X. Because Leigh-Ann is not a drama queen at all, so when she tells me she's really sore or this is happening, I really believe what she's telling me. So we went to ... We -- We -- I phoned Dr X, she said, meet me at the hospital. We raced through and Leigh-Ann was having a, a mild anaphylactic reaction to the Revelex, which was really horrible. She spent a couple of nights in the hospital. Ja. And I think even at various points while we were still there, despite the fact that she was getting intravenous ... I think she was getting intravenous Phenergan. She still had periods where she struggled with breathing. And that's -- That -- Because of that reaction Dr X decided she wouldn't use Revelex again and we went onto Humira. Obviously feeling quite anxious about whether the reaction was going to be similar. But fortunately it wasn't. It was just horrible for Leigh-Ann to have to inject, because she found it really really painful.

21. **S:** Has she injected herself from the beginning?

22. **Sa:** Ja. Ja. She did.

23. **S:** Very independent.

24. **Sa:** Ja. She -- We tried EMLA**,** but it ... I don't think it reached deeply enough, so what we ended up doing was icing first. And towards the end she just eventually said she doesn't want to bother with that. So. And all this time Leigh-Ann was at school. She was at School X. But the, the thing that we were noticing was that one of our complaints to Dr X is Leigh-Ann was really struggling to fall asleep.

[10 minutes]

So she would take hours to fall asleep and she would be really exhausted. She also seemed to become very much more sensitive to touch, to sound, to any noise. And she'd have to climb the stairs at school, participate in phys-ed. Although event -- Towards the end of her time at School X we ... She didn't participate in phys-ed. And she -- She felt even more alienated from her peers. Because I think Leigh-Ann never really fitted in. Even before the diagnosis, she was different.

25. **S:** She wasn't a School X typical girl?

26. **Sa:** She wasn't -- She wasn't typical for her age for any school.

27. **S:** Ok. Ok.

28. **Sa:** She was just not. She was -- She's never been silly, she's never been exuberant, she's always been ... She's always been quiet. She's always taken a long time to warm to people. And even when she was in Grade 0 at School X, and I used to fetch her from school and she ... I used to say, what did you do at break? She would be the one sitting at the art table and all the other children would be playing.

29. **S:** I'm just going to interject just quickly. Because you said she was a very difficult ba ... No, that's the wrong word. But she has had difficulties since she was a baby.

30. **Sa:** Yes.

31. **S:** Is there any possibility that she might have been experiencing fatigue since then all the way through and ...

32. **Sa:** You know, I don't know. She -- I, I could never put her down to sleep when she was a baby. She would startle awake quite easily. So, it may be that her -- I mean, her sleeping difficulties just got worse, but they were always there. I mean ...

33. **S:** The physical fatigue and the insomnia obviously go together. But the arthritis fatigue is slightly different. But I, I'm just listening to you talking about often sitting at the table by herself and all those things. A possible sign of an underlying ...

34. **Sa:** Issue.

35. **S:** Arthritis fatigue without the pain yet. I don't know.

36. **Sa:** Ja. I've never ...

37. **S:** It would be interesting to ask Dr X what her, what she would think about that. Just for me in a long-term perspective of how it may have impacted on her social interactions.

38. **Sa:** Yes. You see, I've never viewed it -- I've never thought of it that way because I"ve always assumed that it was because Leigh-Ann was an introvert. That she preferred to -- Because she, she was always able to concentrate. She was able to concentrate from a young age and focus on a task from a young age. I was never very physical as a child and I guess I kind of just thought that that's the way she was.

39. **S:** So probably not, but ...

40. **Sa:** Ja. It's, it's an interesting perspective. Ja, so, I mean she had comments then as she got older and moved into Grade 5, Standard 3. You know, she'd have comments when she wasn't participating in phys-ed, oh I wish I had arthritis so that I didn't have to. Which was very hurtful. Because it showed such a lack of understanding for what she was going through, that I think it made her feel so isolated. And ja, you know, I -- I just think that she -- So from that point of view, apart from being from a purely physical point of view, school was very hard on her psychologically because I think it just ... Being surrounded by all those people who really were so clueless about what she was feeling and experiencing, I think just emphasised for her how alone she was.

41. **S:** Do you think it emphasised for about her illness as well, or did ... Did -- Or was it just more of an isolation thing?

42. **Sa:** No, I think also her, her illness. Yes. Ja, no, I do think it did, because she was in pain at the same time and, you know, there was just no comprehension. Even, I think a lot of the teachers just didn't get it either. You know.

43. **S:** I was going to ask about that.

44. **Sa:** And I think -- You know, it's so difficult when you're dealing with something that is essentially invisible. You know there's, there's a great deal of sympathy, and I'm not saying that there shouldn't be, for people ... For children who have cancer, for example. You know.

45. **S:** And we can see because their hair falls out.

46. **Sa:** Yes, you know.

47. **S:** Or the rheumatoid arthritis, where the joints swell up.

48. **Sa:** Really swell, ja. But with Leigh-Ann there was nothing to see. And so ja, that, that was really hard. I mean she tried to still ... She would go to birthday parties and I think she was doing that simply because she needed to have someone to sit with at break at school. So, that's what she's do. She would do what she needed to do in order to, I think, appear to fit in.

49. **S:** I was just wondering about that whole invisibility and I've now just lost my train of thought. You said something that was so important. It was about not seeing the, the disease itself. How do you -- Oh, you were explaining on how it was hard on her. Can, can you expand on that at all for me? In what ways did you see that her illness being invisible impacted on her. Sort of, examples or just flesh it out a bit more if you can.

50. **Sa:** Well firstly Leigh-Ann is not the kind of person who ... She's very private. So she's not going to arbitrarily share how she's feeling with people. She keeps a lot of stuff inside. She -- Ja. So in order for people to understand what she's going through, they either need to be able to see something, some outward sign, or she needs to be able to explain. And Leigh-Ann would not do that unless she was really close to someone. And I think that there have been very few people, in fact I don't think there've really been any peers that she has felt comfortable enough with to, to explain exactly what she's going through.

51. **S:** And do you think that is because she's an introvert, or is there another reason why she might not want to share?

52. **Sa:** I think it's because she's an introvert. I think it's because she's just, she's always just been very reserved and self-contained. I keep coming back to those two words. And I don't know if ... You know, I think it could be ... It's difficult even for me, who I like to think that I'm the one person who knows her the best, because I have spent so much time with her. And -- But -- You know even with -- She's not a complainer. I can look at Leigh-Ann and generally tell if she's having a bad or a good day.

[20 minutes]

She, sometimes when she's in pain, will be irritable. Not very often. And even when -- And when she's irritable, when she's in pain, I know it's hard for her to accept that. She -- She's hard on herself when she's less than perfect.

53. **S:** Is there anything that maybe happened? Is there anything else that might have happened do you think, other than her own personality, that makes her so hard on herself with pain, that she just will push through it?

54. **Sa:** It's not just with pain though. She's hard on herself, period.

55. **S:** Oh ok, with all sorts of different things.

56. **Sa:** Ja. She's very hard on herself academically. So, for most of us I think, to get 80 per cent we think we're brilliant. You know. For Leigh-Ann 80 per cent is pushing it, really. It really needs to be quite a lot closer to a hundred per cent. A part of that is because of the family dynamic, because my husband is renowned for his academic prowess [laughing]. Both his children from his first marriage ... Stephen didn't do that well academically. I mean, she didn't get ... Stephen got, I think, seven A's in matric, seven out of eight, or six out of seven, or something like that. Stephen didn't do that well at school, but I mean she always did really well at maths. She's now doing her Master's while teaching. You know there's all of this academic achievement and I honestly don't believe that my husband has ever put any pressure on Leigh-Ann to perform academically. But I think that she -- She's very aware and she can ... She knows what is important in this family and she desperately tries to live up to that. I forget now what we were talking about.

57. **S:** Oh my word, I've just gone blank as well. We were looking at the whole progression and then we were talking about school, and that's when I made a note here that I wanted to ask ... You were talking about how her peers were with her at school and how she was becoming more isolated and alienated, and they'd made some cruel comments; I wish I had arthritis. I was wondering, so did anything arise from the teachers? How did the teachers handle her illness?

58. **Sa:** You know I think -- I think that they ... I don't think they really -- I don't think they treated Leigh-Ann differently to the others. I, I don't think that they were necessarily aware of, of what was difficult for her. So for example, sitting on the floor cross-legged, you know, for, for periods.

59. **S:** Which would not have been a possibility for her.

60. **Sa:** It -- It -- She could have done it for a bit, but it would have cost her. And I don't know that -- I don't think that Leigh-Ann would have been able to say: look this is not working for me. Look, they did towards the end make some concessions, and right at the end before Leigh-Ann left School X, she ... That year she spent a lot of time at home.

61. **S:** So they allowed her to be off, have off days without pressure.

62. **Sa:** Ja. Yes. But we always felt pressure. I don't think it was just me. We always felt pressure. Always ...

63. **S:** That she should be at school.

64. **Sa:** Yes. That you have to explain, you know, I'm sorry but we're not coming in today because ... And I don't know if ...

65. **S:** Was this at the primary school as well?

66. **Sa:** Yes. Ja. Ja.

67. **S:** Because she, because she left, ja.

68. **Sa:** Ja, she left in Grade 6.

69. **S:** Grade 6.

70. **Sa:** Ja.

71. **S:** So even at the primary school they were pressurising -- Putting pressure that she should be at school, and you have to explain why she isn't at school

72. **Sa:** you know, I think the conclusion that I came to was that there was nothing ... That they weren't deliberately unkind. I just think that in a huge school setting like that, where you have close on 30 children in a class, there ... There is just so much going on, that to deal with somebody who doesn't conform to the mainstream, is, is just ... It just overwhelms people's resources. That -- That is the conclusion that I came to.

73. **S:** And like when the kids said things, were there any incidents where teachers ... They obviously wouldn't say, oh I'm glad ... I wish I had arthritis because. But were there any instances where they made possible negative comments that might have impacted on her? Being an ex-teacher I know the kinds of things that could quite easily have been said. I was just wondering if she ever reported anything like that.

74. **Sa:** I honestly don't remember anything, but that doesn't mean that it didn't happen. Ja, she was fortunate in Grade ... Because Leigh-Ann was an only child, essentially. And because I grew up as an only child. Even though I had older siblings, but they were so much older than me.

75. **S:** Older.

76. **Sa:** I was very -- I am very aware of the aloneness of the only child. And I think it's particularly when you, when you are an only child and you are an introvert, that it's difficult. Because if you're a gregarious only child, then it's probably actually great to be an only child. Because then you've got friends, but you've got your mom and your dad's sole attention as well. So you have the best of all worlds. Now why am I telling you this, I wonder?

77. **S:** Teachers? Possible negative interactions with teachers?

78. **Sa:** Oh yes! Thank you. So -- And because Leigh-Ann -- I really struggled getting Leigh-Ann to go to school. And before she had to start at School X, I think it was before School X. Ja. Because I knew how difficult it was for her, we actually got together some of the people who I knew would be going to School X and we had a big party. Where all the children were there. And I always tried to be involved. In retrospect I'm not entirely sure that that was the right thing to do, but I thought at the time that it was. And -- And I tried to be involved to try and ease the way for her. I have, have never been as social as I have been since having Leigh-Ann. I love my own company. I love to read and do my own things. And I have deliberately tried to expose Leigh-Ann to other children, because she doesn't, she doesn't have a sibling at home. So I was very involved at, at school. I was often the class mom. I was the class mom when Leigh-Ann went from the junior to the prep school and she, for that first year, she had a really, a really nice teacher. She was a bit wacky and not traditional and conservative, which was really great. And, what I'm trying to say is, I think that because I was involved, it might have altered some of the reactions from some of the teachers towards Leigh-Ann.

[30 minutes]

79. **S:** They might have been more careful?

80. **Sa:** Yes, they might have been. Yes. That -- That's what I think. Maybe I'm just giving my involvement way too much credit. But, but I think -- I think so. You know. Whether that was just because they appreciated what I did, or ... I don't know. I just think that -- I think maybe it helped.

81. **S:** Ja. But other -- So there may not have been any of the negative comments that, that could have occurred. But on general, although they tried to understand, they really didn't seem to get what she could and couldn't do?

82. **Sa:** I think so. I think so. I think the other thing that, that helped with, helped Leigh-Ann is herself. Because she was, she was never disruptive, you know. She was always going to be the kind of child who was a teacher's pet. She just was, you know. She was quiet, gentle, unassuming. She wasn't going to get a teacher's backup. And she was always -- She's always been very -- She's always wanted to please. Which in itself is probably a problem. But -- She's been struggling just lately with being hugely fatigued. So I've been looking at some samples on the Kindle of books that deal with chronic fatigue. And, you know, she does push herself. And so it's all part of the same kind of ... Seems to me, there's this personality type. And, ja.

83. **S:** So when you, you're talking about the chronic fatigue and the pushing yourself. And I'm checking with you, so tell me if I'm wrong. Are you saying that you think that maybe with regards to academics she pushes herself too hard, which then results in more fatigue?

84. **Sa:** I don't know that it's true, that she pushes herself too hard in terms of how many hours she spends working. But I think that she is preoccupied with what she should be doing, what she could be doing, what she's not doing. And I think that that whole mental anxiety-provoking thing is in itself fatiguing. And ...

85. **S:** Do you notice any mini flare-ups either with the arthritis or with fatigue when she gets into that headspace?

86. **Sa:** Well, you know, I don't know that it's coincidence that she writes her first exam next week, and that the last couple of weeks she's just exhausted. And, and I don't think that she has been putting in any more hours than usual.

87. **S:** So it's not physical fatigue.

88. **Sa:** You know fortunately -- Fortunately she is really bright, so she gets things really quickly. But there's also a lot of anxiety. And, you know, part of it I think, part of it's just her make-up. My husband's very anxious. I tend to be ... I'm prone to depression and just lately I've become quite anxious. So, you know, it's probably -- We probably also feed off each other and ... I don't know.

89. **S:** Well that speaks very nicely into my next question, which was going to be: how has her illness impacted on the family dynamic?

90. **Sa:** You know, it's difficult to know what the dynamic would have been had it not been for the illness. Because my stepson and stepdaughter are so much older, they're not really around much. Leigh-Ann gets on really well with Stephen

91. **S:** The stepson?

92. **Sa:** Yes. But he is -- He's very different to Leigh-Ann. He is -- He can't get enough of people. H's very gregarious, he's very loud, he ... Ja.

93. **S:** How old is he?

94. **Sa:** Stephen was born in '88. Where are we now? He is 28. Ja, turned 28 this year.

95. **S:** So he's almost like an uncle?

96. **Sa:** But not in terms of the way he relates. Stephen is kind of, I never want to grow up. I don't like this adulting thing. I don't really want to be responsible. He, he's, he's fought against it.

97. **S:** So he has a good relationship ... Or she has a good relationship with him?

98. **Sa:** Yes, yes she does. It, It's sometimes difficult for me to understand because he ... Maybe because I've never had siblings that I've had that kind of relationship with. He does -- He can rip her off, you know. And I think to myself, gee, that's unkind, but it, that's not how Leigh-Ann experiences it.

99. **S:** So he's teasing her and she's seeing it as camaraderie, rather than he's taking her down?

100. **Sa:** Yes. Ja.

101. **S:** And does she confide in him with regards to her illness?

102. **Sa:** I think that when he asks, she does. Again, not -- You know, it's difficult at the moment because Stephen is in South Korea busy teaching. So they, they speak only occasionally.

103. **S:** But before then?

104. **Sa:** I think that -- I think that they did, but Stephen wouldn't do it in front of me. Stephen would do it when they were alone and Leigh-Ann... I think Leigh-Ann does experience it as ... I think Leigh-Ann experiences Stephen as someone that she can talk to. Stephen who is 15 months, 18 months older than Sarah. Sarah tries. She tries harder than Stephen does, but Leigh-Ann doesn't have that kind of relationship with her. Sarah's -- Sarah also tries to adopt the kind of teasing that Stephen does, but it doesn't come off in the same way. So -- I mean, Sarah often, you know, she obviously wants to spend time with Sarah, but I don't think it's as easy for Leigh-Ann as it's with Stephen. With Stephen I think Leigh-Ann feels she can kind of just be herself, whereas I think Sarah's hard work. I hope that's not projection, but I think, I think that's how Leigh-Ann experiences her.

105. **S:** ... some personalities connect easily and some personalities ...

106. **Sa:** Ja.

107. **S:** You do work at harder, so.

108. **Sa:** Ja. I – Leigh-Ann doesn't have a great relationship with my husband, which is very sad for me. Because I grew up without a father; my parents were divorced when my mom was pregnant with me. So that ... I desperately want her to have a relationship with him. They -- In some ways they're quite similar. My husband doesn't ... I think -- I think I grew up as being ... I think I was quite an observer. I think I developed that as I was growing up and Leigh-Ann doesn't have that. Leigh-Ann is not aware ...

109. **S:** Not in tune with people?

110. **Sa:** Yes, he's not. He's not in tune with people. So whereas I, I will modify my behaviour based on what I see, what I think Leigh-Ann needs, my husband can't do that. It's much -- It's hard for him to first, to see what she needs.

[40 minutes]

And -- And -- And then it's difficult for him to, to adjust his response. The one thing that he has done is ... He -- He -- He's never sulky or upset with the amount of ... Amount of attention, time, emotional energy, that Leigh-Ann demands from me. But he doesn't know how to make his own relationship with Leigh-Ann

111. **S:** With her.

112. **Sa:** Ja.

113. **S:** Do you think he, he wants to be part of the process like you are, but is unable to do it? Is that what you're saying? Or is it just that he doesn't know how to make a relationship with her?

114. **Sa:** I'm not sure. I think -- I think that Brian-- I think Brian would score very low on EQ. So, I think for him it's kind of a case of, you know, this is how I am. And when how he is, is alienating ... Oh it's difficult. Because I mean, you want someone to be authentic.

115. **S:** Yes.

116. **Sa:** But ...

117. **S:** Is he aware that he is alienating?

118. **Sa:** I don't -- You know, when I try and talk to him about it, I don't think ... He doesn't think about things like that. When I ask him -- He, he just doesn't know what to do.

119. **S:** And is he the same with his own children?

120. **Sa:** He is ...

121. **S:** I mean ...

122. **Sa:** Yes, no, I know what you mean [laughing].

123. **S:** Sorry. I mean his other children.

124. **Sa:** I know. You know, he probably gets on most easy with Sarah. She's probably most like him. Stephen I think has gotten to the place where he just accepts that his father is like that. So for example -- Stephen -- I think Stephen really struggled with it. When Stephen was at school he went through a really really bad patch, where he was self-harming and I think suicidal. And Brian didn't know how to deal with that. Brian couldn't talk to Stephen about that.

125. **S:** I was just wanting to find out if it was the fact that she's ill and often dads can find it very difficult to cope with, because they want to fix it ...

126. **Sa:** There's nothing they can do ...

127. **S:** There is nothing that they can do. Or whether it is more to do with the fact that that is just who he is?

128. **Sa:** I think it's some of both of those. I think it's a bit of both. Ja. Ja, I think it's a bit of both. You know, he's been -- My husband went to School X, his brothers went to School X, Stephen went to School X. So when the subject of Leigh-Ann leaving School X was raised, I think that he actually handled it admirably. Because his father was horrified that Leigh-Ann would leave, not only that she would leave, but that she would leave to this weird system.

129. **S:** A lot of people have very strange ideas about the home schooling system.

130. **Sa:** Ja.

131. **S:** There's a very large knee jerk reaction to home schooling.

132. **Sa:** Yes. Ja.

133. **S:** So he was very supportive with this?

134. **Sa:** He was. Yes, he was. He didn't fight it at all, you know. It, it was really whatever is best for her. So, you know, whatever needs to be spent when, you know, medical aid is depleted or whatever, Brian doesn't bat an eyelid. You know. It's just on the personal side that he's unable to ... He just doesn't get it. So for example, if Leigh-Ann -- If we go -- We -- Leigh-Ann has stopped to a large extent going to movies. Because -- I'm guessing that she mentioned dysautonomia to you?

135. **S:** Yes.

136. **Sa:** So her body doesn't respond typically. So when she goes to movies, and she's never really liked going to movies, when she's in that ... Something happens when she goes from that dark environment, and the sound is way too loud, and then she has to go out into these bright lights and people milling about. That is very hard for her. She -- She -- It's not something that she can just relax and enjoy. And although she loves going to the theatre, she's also very picky about what she goes to see because she has some of that response there as well. So when we went to see *Joseph* at the theatre, for example. We get into the car and I can see that Leigh-Ann is really struggling and that everything seems to be amplified. All, all the sensory input is ... So I know that we need to keep quiet. We need to just ... So Brian talks. And I'll say, [whispering] Brain, Leigh-Ann just needs to be quiet. And he's quiet for a little bit and then he'll say something, or he'll hoot at someone. And it's very frustrating for me, because how hard is it to just be quiet? But you know, he's not -- He's just unconscious.

137. **S:** Unconscious, yes, not doing it deliberately.

138. **Sa:** No.

139. **S:** It's just unconscious.

140. **Sa:** But it's experienced -- I think Leigh-Ann, Leigh-Ann's experience is not that. Leigh-Ann's experience is that he doesn't maybe ... I think, that he doesn't care enough. I don't think she feels loved by him, and, and he I'm sure doesn't feel loved by her either.

141. **S:** Which is difficult for you then, because then it's all impacting on you. How is it impacting on you?

142. **Sa:** Ja, well, you know, it -- It is difficult for me. It's difficult for me because one of the things that attracted me to Brian is the fact that he wanted custody of his children and he got custody of his children. Which was so not like my father. Who never paid maintenance for any of us and totally ... We never had any contact with him. So, you know, that was a huge selling point. And now, I mean really they don't have a relationship.

143. **S:** Did they when she was little?

144. **Sa:** Yes. And I remember -- You must be careful what you wish for. I remember when she was little, I remember being on a game drive with the two of them and Leigh-Ann wanting to sit on Brian's lap and me wanting Leigh-Ann to sit on my lap, and feeling a little put out by the fact that she wanted her father. I mean, if only I could go back.

145. **S:** When did that all change?

146. **Sa:** You know, Leigh-Ann traces it back to a dog that we rescued.

147. **S:** She told me about that.

148. **Sa:** Snoofie.

149. **S:** And he was put down.

150. **Sa:** Now, Leigh-Ann -- Leigh-Ann -- Leigh-Ann puts everything on ... She -- For her, that is the pivotal event. But, I'm not convinced.

151. **S:** What is -- What was -- What does she see as being so pivotal about that event?

152. **Sa:** You know, before -- Before Snoofs was euthanised, we, we spoke about what we would do. You know, knowing what I know now, knowing what resources are available now, I would never have gone that route. But you know, you, you, you make your decision with what you know and are aware of at the time.

[50 minutes]

And, and the thing that I've always tried to, that I've always wondered about, is surely – Leigh-Ann won't verbalise this – but she must hold, feel some resentment towards me for not, for allowing that to have happened. I mean, we spoke about it. You know, we sat down the three of us ...

153. **S:** How old was she?

154. Sa: Gee, let's see. She is now -- She's 16. Romulus is going to be -- That's 12. She was probably about 11.

155. S: So, so, so you all talked about it and then he was euthanised, and yet the im ... That's a pivotal thing for her in her relationship with her f ... So, so why him?

156. Sa: Why, why did my husband bear the brunt of it?

157. S: Ja.

158. Sa: I think because he was the one who suggested it, was adamant. Ja. I, I think that you know, my husband think -- My husband feels that because it was discussed, that it was a mutual decision.

159. S: I see.

160. Sa: See. Whereas I feel that Leigh-Ann felt she had no choice.

161. S: She hadn't been heard. Leigh-Ann

162. Sa: Ja. She had to go along with it. I think.

163. S: I'm just trying to think, with time factor, where does this come in with her illness.

164. Sa: Ok, so it was probably -- So it was -- That's interesting, because if she was around 11, that was around the time she was being diagnosed, but it was after she first experienced symptoms. I, I still think that maybe it is ... I don't want to say convenient because that sounds very patronising. But it's -- That --That event gave Leigh-Ann something to hang her hat onto. I think that ... I think that there -- I don't think that that's it.

165. S: Ok. So it was more of an underlying deteriorating sort of relationship and that's a marker she could just say ...

166. Sa: Ja. Something that she could quantify. You know, she -- Ja.

167. S: So now where does that leave you and her with the relationship? And how has JIA and the other, which I find it difficult to remember ...

168. Sa: Dysautonomia?

169. S: Dysautonomia. How has that impacted on your relationship between the two of you and as, on yourself, as a mother?

170. Sa: Well I think it's fair to say that being a mother is way more difficult than I ever thought it would be. Way more difficult. I think for Leigh-Ann -- Leigh-Ann is much more dependent on me than she would be if she didn't, if she wasn't ... If she was well. And I think that that is very hard for her. I mean, there are times ...There have been time where she, she couldn't get off the couch to go to the bathroom by herself, you know. There are still times like that, where she's so dizzy or she's so exhausted, that she doesn't think she's going to make it if she walks unaided. For me it is hugely sad. I obviously want her to be able to, to live the life that she wants. And -- So, for example, I think for her, she's always wanted to be a vet. But then she thought maybe, maybe medicine. And I just think that -- I don't think that those are realistic for her, given the kind of hours.

171. **S:** Because the, the dysautonomia is ... That is now lifelong?

172. **Sa:** Well, I don't know. I don't know that it is.

173. **S:** Oh, that was the impression she gave me.

174. **Sa:** Ja. You see, I -- I -- Leigh-Ann doesn't seem to believe that she's going to get better.

175. **S:** Ja, I did pick that up. Ja.

176. **Sa:** Whereas I'm still hopeful.

177. **S:** That it can go ...

178. **Sa:** Maybe I'm deluding myself.

179. **S:** No, I -- I -- She -- Yes. That was -- I'll go and do some research on that for myself, because it's going to be interesting from a psychological perspective, is can you go into remission? Because so many of these immune disorders you can.

180. **Sa:** Ja. I, I believe that she can. I really do. And in fact, did she, did she mention that part of the dysautonomia is POTS?

181. **S:** No.

182. **Sa:** Postural Orthostatic Tachycardia Syndrome**.** So there's the dizziness, the feeling like you're going to faint.

183. **S:** The heart rate?

184. **Sa:** Yes. It's when you stand ...

185. **S:** Yes.

186. **Sa:** The heart rate shoots up. Ok. Because the blood is pooling ...

187. **S:** Ok.

188. **Sa:** And the heart rate increase is to try to get the blood to move up to the heart and the brain. So that is diagnosed via a tilt table test. During which Leigh-Ann did pass out. So she had a positive tilt table test. So now, now there have been studies that show that the younger you develop these things ... Because there are middle-aged people on these Facebook pages that I go onto, who have POTS and dysautonomia. But the younger you develop it, the more likely it is that you are going to recover. But obviously not everyone recovers, and maybe some people recover partially, you know. So, that's what I -- Why can't Leigh-Ann be one of the people?

189. **S:** So what I'm also hearing from you is a role in which ... The way in which maybe your role as a mom has changed, is a lot of research?

190. Sa: Ja, no. There has been. I've done a -- I have done a lot of reading. I don't know that it's been of any use to anyone, but I do see that as part of my role. Because no-one is going to have as vested an interest in Leigh-Ann as me. So I do need to be her champion.

191. S: May I ask a question? Do you feel that you need to be the champion because you're her mom, which is what you have just stated. Do you feel that perhaps the doctors do not have as much of a vested interest? Do you find you have to case manage for her, maybe because the doctors don't? Or ...

192. Sa: Yes, it's a bit of that. I think that the one doctor who ... I mean Dr X is the one who first raised the question of dysautonomia. She didn't call it dysautonomia. Through my reading I later found out that it's called dysautonomia. I said, but Dr X, isn't it? So she said, yes. So, you know, I, I know that she under -- That she -- That, that she believes it. That she knows about it. That she reads about it. I know that she does all those things. But there's also -- I think from her point of view, it's also frustrating as a, as a medical practitioner because this is where you realise that, that medicine is limited, you know. It is quite a disillusioning experience because you think science and medicine have the answers.

[60 minutes]

But what I was saying to Leigh-Ann just the other day, is you know, if something ... If there's a structural problem, a physical structural problem, medicine can probably help. But if there's problem in terms of the way something in the body is functioning or not functioning, medical ... Medicine does seem to be very limited. And so ...

193. S: How does that impact on you as a mom? Coming to that conclusion? Emotionally, what is the impact of that?

194. Sa: I think that -- Well, apart from the fact that it really makes me sad, it makes me feel helpless. I suppose it makes me feel anxious. You know, there's a very little predictability. I, I've always been quite an organised person who likes to know what's going to happen. You know. I like structure, and there's much less of that because you just don't know . If we go on holiday, for example, you don't know if Leigh-Ann is going to be able to ... How much she's going to be able to do. What she's going to be able to do. There's a, there's a lot of unpredictability, which, which makes me anxious.

195. S: So, so it's -- You bear the most of the burden in the parental system of looking Leigh-Ann, looking after Leigh-Ann.How's that impacted on the relationship between you and your husband?

196. Sa: I -- I -- Occasionally, like this weekend, I said to him -- On Saturday we went ... Leigh-Ann did the photography thing in the morning and then on the way home I phoned Brian and said, you know, why don't we meet at Ocean Basket for lunch? And he said ok, so we met there. And I said to Leigh-Ann would you mind going home with Dad afterwards so that I can quickly go to the shops. So she said ok. When I got home from the shops, I said to Brian, where's Leigh-Ann? "I don't know". So, when I'm -- Usually when I'm at home, I kind of know where she is, you know. And I said to him -- I said something to him about abdicating his responsibility [laughing]. But you know, largely I guess, I've just come to accept that's the way it is. You know. And, and I suppose where I'm at is that as long as he doesn't give me a hard time about the time and effort I invest in Leigh-Ann, I will accept ...

197. **S:** Ok, so you've kind of come to a, a working compromise around it.

198. **Sa:** Ja. Part of it is I know that -- He -- If I were to diagnose my husband, I would say he has generalised anxiety disorder. And he will be very focused for example on the alarm's got to be on, this has got to be locked. When we go out, the whole house is locked up. He locks every interleading door, hides the keys, puts the alarm on. And to me -- I just think that, again, he is controlling what he can control and, and trying to manage his anxiety that way. Because his anxiety about Leigh-Ann and her illness and what's going to happen to her, he can do nothing with that.

199. **S:** About that.

200. **Sa:** So he channels it into something that he can do stuff ... That he can do something about and I suppose that's how I've come to see it. He allows himself the luxury of withdrawing from ...

201. **S:** Day-to-day management?

202. **Sa:** Yes, because I'm there and I will do it. You know. So, ja.

203. **S:** Ok. And then socially. How has Leigh-Ann's illness impacted on your social lives?

204. **Sa:** Ok, I -- I -- Brian would like us to be more social, I'm quite sure. He would like us to have friends over. I know that it's very hard for Leigh-Ann, so I just pretend that he doesn't want to have people over [laughing]. You know, ja. I mean as far as the two of us are concerned, I'm always reluctant for the two of us to go out and leave Leigh-Ann alone at home. Even during the day. Like, so -- Going to the shops and maybe having coffee. He, he will do it at a push, but he doesn't really like to be gone long. Which is understandable, up to a point, I think. If we go out in the evening -- I mean, when Leigh-Ann was younger, we used to try and go out more often. And now as she's gotten older, we actually go out less frequently, the two of us alone. Leigh-Ann doesn't really want Agatha to come in and babysit her.

205. **S:** Her being the domestic?

206. **Sa:** Leigh-Ann doesn't what Agatha to come and ... But Brian doesn't want Leigh-Ann to be alone. So I mean, I really wanted to see this one thing that was on on, at Monte Casino, so this last weekend ... I think Leigh-Ann is also aware. You know. And I don't really want her -- I don't want her to feel ... This is, this is what I struggle with. I struggle with Leigh-Ann feeling that she is a burden. I don't want her to feel that. And I don't want her -- You know, so I think she will agree to allowing Agatha to come in and sit with her, because she knows that if Agatha doesn't, we won't go out. And I won't get to go and see this thing that I want to see.

207. **S:** I see.

208. **Sa:** Ja. So I think from her point of -- That -- That is -- I think that's how she experiences it and I so -- I don't want her to feel that she's a burden. So, ja, we do not have an active social life. I think it is also difficult, because I mean, we used to have far more contact with my husband's cousin, who has a daughter who is two years younger than Leigh-Ann. We used to have a lot contact with them. And I think as Leigh-Ann got sick ... Again, you know -- Well, first of all I think it started with Anna killing a butterfly actually. And her father saying, it's okay Anna, you do whatever you like. And I just don't think Leigh-Ann has ever forgiven her for that, even though she was like quite little at the time. And I think -- Ja. You know it's difficult, though. I mean she plays water polo for the province.

209. **S:** Difficult to relate?

210. **Sa:** Yes. You know.

211. **S:** So the social -- It actually has impacted quite significantly on your ability to socialise with friends and ...

212. **Sa:** Ja. Not that I have -- Not that I was ever very social.

213. **S:** Being an introvert.

214. **Sa:** My husband's also an introvert, but he does seem to like to socialise with, with few people, you know. And I'm quite happy for him to do that, as long as it doesn't affect us [laughing]. So I mean he has his outlets. He's a very avid birder. So, I mean, he -- He still goes birding. Leigh-Ann and I stay home. He goes -- He goes on trips for a weekend or 10 days or two weeks. And Leigh-Ann and I stay at home. He does that. He is involved in the church.

[70 minutes]

So, this Wednesday night I'll be cooking for 10 people who come to our house. Which Leigh-Ann also can't understand – why do they have to come to our house? Because then the dogs have to be kind of sectioned off in the house. You know, so he -- He does have that kind of social ... Ja.

215. S: And I think this is a non-question when it comes to Leigh-Ann, but I'm going to ask it anyway. Has the way in which you discipline her or manage her changed because she's become ill? Do you ...

216. Sa: Look, Leigh-Ann has never really needed a lot of discipline, but I think that if she was not in pain and if she was not exhausted, I would certainly want her to be more involved around the house, you know. On the weekend I make her bed because I know that it hurts her back. So I will make her bed. I very often put her stuff away, because I mean, she's exhausted. I don't expect her really ... I mean, sometimes she'll -- Very occasionally when I bake, she will get involved in baking. But she doesn't have oodles of energy to spare. So from that point of view, I parent quite differently from how I would have if she was well.

217. S: Very different expectations.

218. Sa: Yes. Ja.

219. S: And financially? The medication?

220. Sa: You know, fortunately, there's a word that I like to use, but it has such a religious connotations that I'm reluctant to use it. But it seems to be the most appropriate word. And that is we are really blessed. Because we're on the best plan that Discovery has to offer. They paid for two years of Humira, R8 000 a month. And if -- When we're in the, the self-payment gap, if Leigh-Ann needs anything we are able to afford that. I cannot imagine how devastating it must be to be a parent who has to ... You, you already feel so helpless, so powerless to help your child, and, and have to struggle with ... Some of the children that we see at, at the clinics, the arthritis clinics at Jo'burg-Gen and Bara, where they don't have money for proper shoes. They don't have money for proper schoolbags. They don't have money for food, you know. So financially, I mean it has ... It has been expensive, but you know what, we can afford it and I'm so grateful, you know.

221. S: Because the -- It is exorbitant, the ...

222. Sa: Ja.

223. S: So we are pretty much coming to the end of the interview. What lessons would you, have you learnt that you'd want to share with parents whose child has just been diagnosed?

224. Sa: That is something I really struggle with. You know there's the Facebook page, the closed Facebook page. And I don't really ever post on that Facebook page. I just don't actually think I have anything to offer those people. You know I, I really don't. I, I don't have the answers.

225. **S:** Why is it that you think that? Is it just because you don't have the answers? Or ...

226. **Sa:** Why -- Why would I know any better than them? And -- And maybe also because -- I don't know, people can be very judgey. Even with, when dealing with family, I give minimal information. I know they don't understand. My mother-in-law is a very nice lady, she's very sweet. She really really is a nice woman. And I, I often get the feeling she doesn't really want to know, you know? I just, I don't think they really want to know.

227. **S:** Why is that do you think?

228. **Sa:** I don't know. I think it's a bit of, they don't understand. I mean I, I've given -- You know, in the early days I ... Dr X's got some articles, you know, that she gives. And I've given those articles to family to read, and I don't think anyone has gone off and done any like googling. I just think they don't want to know. It's uncomfortable. Maybe they don't really believe. They don't understand. All they, all they know is that arthritis affects old people. Leigh-Ann's not old ... I don't -- I don't know.

229. **S:** If your family's not really supporting, where do you guys get your support systems from?

230. **Sa:** I don't think we really have one.

231. **S:** Ok. So it's very much the nuclear family.

232. **Sa:** It's very insular.

233. **S:** Very insular. Ok. That must be tricky?

234. **Sa:** Ja. It's -- It's not -- It's not normal. Ja.

235. **S:** And the -- The one thing I did forget to ask you is, have there been any experiences that have either challenged or helped you? Or Leigh-Ann? You've actually mentioned some of them, so I don't know if there's anything new that you would add to that.

236. **Sa:** Ja. Ja. I mean, nothing really stands out. School was very challenging. Ja. You know, just life is quite challenging. When we -- When we have gone on an overseas trip, my husband always pushes Leigh-Ann to go to, to accept a wheelchair at the airport, for example. And Leigh-Ann doesn't want that.

237. **S:** Especially not as a teenager.

238. **Sa:** Ja. I mean there've been times when she has had to. She's -- But ja, it's just -- Ja. It -- Things that are, that are everyday ordinary things, can be challenging. It takes a lot to get Leigh-Ann to go clothes shopping, you know. Which is, I think, very different from most teenage girls.

239. **S:** I can relate. I went clothes shopping with my sisters yesterday and when we got back – it was an hour and a half – I was exhausted. So I can understand why it would be difficult for her. Something straight forward as just clothes shopping.

240. **Sa:** Ja. Ja.

241. **S:** It’s exhausting.

242. **Sa:** And, and I don’t think that, that people can understand it. And I’m not sure that they can be expected to understand it if they haven’t lived with it. I don’t know that I would understand it if I had not lived with it.

243. **S:** And seen.

244. **Sa:** Ja. And I think that, that -- However -- Even, even with Dr X, however understanding she is, she has not lived with it. She sees children obviously all day, but she only gets snippets; it’s not a personal thing. So, ja.

245. **S:** Ok. Well, let’s end the interview here, because you’re also looking tired and I have to be honest that I’m feeling tired.

246. **Sa:** I’m sure you are.

247. **S:** So, so thank you so much for taking the ...

[Recording ends]

APPENDIX Q: Charlotte Case Study

Transcript 1: Charlotte Interview 1

1. **Interviewer (S):** Ok, that is recording now. Do you think we should come a little ... Ok, maybe we'll just speak louder. Ja, if we speak louder that's fine.

2. **Interviewee (C):** Yes.

3. **S:** That's perfect. You talk to me and let's see if it's registering.

4. **C:** Ok.

5. **S:** What is your name?

6. **C:** Charlotte

7. **S:** Thank you for doing this for me Charlotte. So I was wondering if you could tell me basically how did the journey start for you towards getting the diagnosis of JIA? Which one is your diagnosis?

8. **C:** I have JIA.

9. **S:** Ja.

10. **C:** But I recently went to the rheumatologist and she now thinks it's the psoriatic but, as you know.

11. **S:** Ok. That's the skin as well?

12. **C:** Ja. I haven't broken out in a rash, but I have like the pitting in my fingernails, and like my toes got a bit swollen, like, I don't know what it's called. It's ductitis or something. I'm not sure.

13. **S:** Ok.

14. **C:** You can ask my mom. So she thinks it might be that, but she's still leaving it as JIA. It started in 2014 – me and my mom went to Israel together and in like, in July, and I was having a lot of trouble with like my knees and my back. Like when I was walking up stairs I would ... Like my knees were really sore and I was really finding it very hard to like go up stairs and walk a lot. It was like quite painful for me. So in that August I think, or the September, my mom took me to the rheumatologist and she diagnosed me with juvenile arthritis.

15. **S:** Ok.

16. **C:** Yes.

17. **S:** Which rheumatologist did you go to see?

18. **C:** Dr X.

19. **S:** Ok. *Sjo*. So -- So that was quite a quick ...

20. **C:** Yes.

21. **S:** Because your mom also works with kids who have arthritis.

22. **C:** Yes.

23. **S:** Ja.

24. **C:** So she thought it was arthritis, but she wasn't sure.

25. **S:** Ok.

26. **C:** They seem to think it came in Grade 5, so 2012. I had a Coxsackie virus.

27. **S:** Ok.

28. **C:** And they seem to think it could have like come from that, but they're not sure.

29. **S:** So you basically -- You didn't really have any symptoms, you obviously got sick in 2012.

30. **C:** Yes.

31. **S:** And then did -- So -- So between 2012 and 2014, did you notice anything different with your health when you look back at it?

32. **C:** I've always had really bad allergies.

33. **S:** Ok.

34. **C:** Especially in September. In like the September time. Like in the change of season from winter to summer, like in spring, round about there. So, I don't know. I can't think.

35. **S:** Nothing that really stands ...

36. **C:** Can't really remember.

37. **S:** Ok. So then it was -- And then so you were -- You weren't ill just before going? You didn't notice any pains before going to Israel?

38. **C:** So, like, it was sore, but it was more like when I was mobile, I wasn't so much just like being, just like being, like sitting or whatever. It was more like when I was running, walking, being active.

39. **S:** And then what kind of -- What kind of did you notice? Was it pain or ...

40. **C:** It was pain and a lot of discomfort. Espe -- Also in my, like, sternum here.

41. **S:** Oh ok, yes.

42. **C:** It like got quite sore, especially with the Coxsackie virus. It was very sore. And then like after that like, when I was like lying in bed, like sometimes ... I think that was more in like last year, 2014, around there.

43. **S:** Was it before or after Israel?

44. **C:** It was be -- It was after. But like in Israel my, like, definitely my knees were very sore. They weren't very very swollen, like they were after I got diagnosed, which was really really funny. But like -- Or maybe I was just like noticing it more. But my mom like, because it's like, it was not so like, like a huge inflammation. It was like very like small and like not very noticeable. Like only like a ...

45. **S:** But there was some swelling.

46. **C:** There was some swelling. Yes.

47. **S:** Ok. Yes.

48. **C:** And all like my joints ... I think when I went the joints affected were my elbows, my hands. I don't think my back was that, at that time. My knees, my ankles, my wrists, and my, here, my sternum.

49. **S:** Your sternum.

50. **C:** Ja.

51. **S:** I know. Ja. Ok, so then ...

52. **C:** And my jaw. My jaw... .

53. **S:** Both sides or just the one side?

54. **C:** It's both sides, mainly this side. This side's definitely worse.

55. **S:** And it -- Does it affect -- It affects you up here by your eye, next to your eyes.

56. **C:** Yes. So I went to the, my, the EMT actually told me that it was coming from my jaw. Because I went -- I kept getting these horrific migraines and I thought they were coming from my sinuses. So it's like that kind of area, you know, over here.

57. **S:** Ja.

58. **C:** And he said, is it coming, like maybe it's coming from your jaw. So me and my mom were like, oh, I didn't think of that. Because I mean my jaw was always affected and I had braces, so when I had braces, oh my God, that was another story. [laughing] But ...

59. **S:** So, so it just got incredibly painful...

60. **C:** It was so painful. Especially like a few days after I like got them tightened or whatever. And like for the first like few weeks I had headgear. And I literally, I literally wore it twice because I could not bear the pain. It was horrible.

61. **S:** You had what?

62. **C:** Headgear.

63. **S:** Oh headgear. Oh yes.

64. **C:** To like move the jaw. Ja. So that was not fun.

65. **S:** So have you got degeneration in your jaw as well, or is it just the muscles and the tendons around the jaw that get inflamed?

66. **C:** I'm not sure.

67. **S:** Ok. So I, I'll check with your mom.

68. **C:** Ja, you can ask my mom.

69. **S:** Ja.

70. **C:** Sorry.

71. **S:** No, no, that's fine. And so, so you came back from Israel. So how was it to be experiencing the level of pain that you were telling me about? What was that like for you in Israel, because I mean ...

72. **C:** It was very tiring, because like in Israel you have to like walk a lot. Like use public transport and like us spoilt South Africans don't really know what it's like. So it was like very tiring and I, I definitely got tired, which is a side-effect of the arthritis, and I'm always tired. But it was definitely a lot worse without the like medication and that kind of thing.

73. **S:** Of course because you weren't taking any meds.

74. **C:** Yes.

75. **S:** But with your mom being a doctor, was she able to prescribe you something while you were over there?

76. **C:** I just took like Mypaid, Nurofen. I hate taking ... the worst thing ever. [laughing]

77. **S:** Ja. So it was very tiring for you.

78. **C:** Ja.

79. **S:** And did it limit your activity at all on that trip? Because I know from my nieces that to go to Israel, obviously Jerusalem, is like ...

80. **C:** Yes. So we actually couldn't go to Jerusalem. We went to Haifa, because that's where my grandparents live, and to Netanja, which is by the sea. We couldn't go to Jerusalem because of the war.

81. **S:** Oh yes.

82. **C:** We went in the war, the time of the war. So we were supposed to go to Jerusalem and Tel Aviv, but we couldn't. So we just stayed in Netanja. And Netanja, like, we stayed like in the centre of the city, but it definitely was a lot of walking. Because we didn't have like my grandparents with a car. So it was like walking. We didn't really like go very far, like we went to the beach, like walking around like the shops and that stuff. It wasn't like extreme, you know.

83. **S:** Yes. So did it impact on your holiday in any way, other than the pain and the fatigue?

84. **C:** I don't think so.

85. **S:** So there weren't -- You weren't feeling emotional in some way while you were there?

86. **C:** No.

87. **S:** Ok. And then -- So you came back to South Africa. And so when did your mom start suspecting?

88. **C:** I think if you ask her, she thought like, it started like a lot like, soon after like the coxsackievirus ...

89. **S:** So it was probably in the back of her mind already ...

90. **C:** Yes. Yes.

91. **S:** Because you were showing signs of being sore when exercising.

92. **C:** Yes. Just sometimes just I'd complain about like a sore joint, or like I couldn't breather because it was like very sore. And like, like my lungs expanded. So she like thought it was there and then like after that holiday she was like ja. Like I think in her mind she was like, ok, like it's this. Like it has to be.

93. **S:** We've got to get it tested.

94. **C:** Yes.

95. **S:** And then, how was ... So did your mom first tell you she thinks it's arthritis, that's why you're going to go to the rheumatologist.

96. **C:** Yes.

97. **S:** And how did that feel?

98. **C:** I was like, but arthritis happens when you're like a granny. Like, kids don't get arthritis, this is weird. But like since I've grown up with a mom who's a doctor, I've always been like quite interested in like that kind of thing. It didn't really like bother me so much. Like, I did Google it. [laughing] Doctors number one hate, but anyway. Like I did Google it, and I did like see like what are symptoms of it, and like what are treatments and that kind of thing. I didn't like think it was ... I didn't like think much of it.

99. **S:** When you were googling, just out of interest, how did that go for you?

100. **C:** I just wanted to Google like the disease, like juvenile arthritis. Like I was like googling and I like put into Google: do kids get arthritis?

101. **S:** Yes. Ja.

102. **C:** And juvenile idiopathic arthritis came up. I think it was the arthritis organisation, I think it was that page.

103. **S:** Yes.

104. **C:** Or WebMD, one of the two.

105. **S:** The South African one, or ...

106. **C:** I don't think it was the South ... I think it was the American one.

107. **S:** The American one.

[10 minutes]

108. **C:** So I went onto it and it like, I just read like a few things about it and that kind of thing. And ja. I, I like ...

109. **S:** There's a lot of interesting information on Google, and there's a reason ...

110. **C:** Oh no, I take it with a pinch of salt.

111. **S:** Ok, ok. So ...

112. **C:** Definitely. Definitely.

113. **S:** You didn't ...

114. **C:** Like, like if I Google -- Like you Google something like very ... Like jaundice and it comes up with like a minion, because they're like so yellow. Like obviously Google take the extreme extreme cases.

115. **S:** So you didn't get any negative experience from the ... So for you, googling on the internet and getting that information, how would you describe the feeling of getting it, that information? Or your state of mind after googling?

116. **C:** So like obviously it like -- It -- I never went onto images, because I did not want to see that. [laughing]

117. **S:** Ok, tell -- Can you tell me a little bit more about why you didn't want to go onto the images?

118. **C:** Because it was going to show me like a ... God knows even what. [laughing] Like a, like animated like almost.

119. **S:** So now you just showed me a knee that looked ...

120. **C:** Like I knew that was obviously going to be like ...

121. **S:** So swollen, double its size, is what you're indicating.

122. **C:** Ja, ja. My knee was a bit like that . . . size a few weeks ago. For me it was just like kind of a relief. Like almost like in my brain, am I just like making up this thing, like is this like a real like thing, this pain that I'm going through. Like is it real or is it like my brain like kind of like tricking me, like making it up. Like, does that make sense?

123. **S:** Ja. Ja. So almost like, am I imagining things, in a way.

124. **C:** Yes, am I imagining it, like is it ... Ja.

125. **S:** And, and did anybody ever suggest you were, along those kinds of lines? *Ag* no, there's nothing wrong with you, you're fine, just get on with it.

126. **C:** No. No-one ever did say that to me. Like I wouldn't always say how much pain I was in. I'd like -- Ja.

127. **S:** Not even your mom?

128. C: No, my mom I would. But ja. And also like when I was googling the symptoms of like juvenile arthritis, it literally just made so much sense to me. Like I was always tired. Like, you know, that kind of thing.

129. S: Ja. So -- So can you . . . tell me in your own words, once your mom had given you that temporary diagnosis, and then you googled it, what was the feeling behind it?

130. C: Like how did I feel?

131. S: Ja. You just -- So your words ...

132. C: I kind of felt a bit at ease.

133. S: Ok.

134. C: If that makes sense. To like know like that what I have is actually like a disease or a disorder, I don’t even know what it is. Like it’s an actual existing thing, you know.

135. S: So, it was, it was a, a, at ease being a more positive feeling then?

136. C: Yes. Like knowing that there are treatments and people can live with it, and there is a possibility of going into remission and ...

137. S: You’re not ...

138. C: What?

139. S: Going crazy. [laughing]

140. C: Yes.

141. S: Ok. And then so, so, the process was your mom thought you had it, you googled it on the internet, and then you went to see Dr X. And how -- So you went through the testing.

142. C: Yes.

143. S: Battery of tests and things.

144. C: Yes.

145. S: How did that go?

146. C: So like when they give you those forms, like on a scale of one to 10, how hard is it to do certain things. And mine were quite high; I was like an eight to 10 for most of them.

147. S: What kind of things did they ask you there?

148. C: Like, putting on stockings, putting on socks. Like, going to the bathroom. What else did they ask? Like just doing basic things that you do every day. That like most of the time you don’t actually think about. Scored quite high in those.

149. S: In the -- In that it was difficult for you to do it ...

150. C: Yes.

151. S: Or that it was painful when you did it?

152. C: Painful and difficult.

153. S: Ok.

154. C: It was difficult because it was painful.

155. S: Ok, fair enough.

156. C: And the bone scan ... I went for a bone ... I don't know even what it's called. Not a bone scan. Like when they inject you with dye, they see like where the activity is.

157. S: Oh, so they're looking up for where the inflammation is.

158. C: Yes.

159. S: Was that an MRI?

160. C: No it wasn't. It was ...

161. S: A nuclear ...

162. C: It was something to do with nuclear.

163. S: One of the nuclear scans.

164. C: Yes.

165. S: I'm -- I'm wondering -- How -- How do you experience having to go through – I've got to go through one, so I haven't been there yet. So could you tell me, how did you feel when they did the nuclear scan?

166. C: So, I have a fear of hospitals and I had to go to the hospital. [laughing] That was not fun. But I do have like anxiety, so. So it wasn't like so like scary like, I don't get frightened by those kinds of things. Like going for an x-ray, going for an ultrasound. Being in the hospital scares me more than the actual scan.

167. S: What is it about a hospital that scares you so much?

168. C: I -- I have a fear of vomit. I feel like that is, like, kind of scares me. And just like the like, like atmosphere of it. You know like, I just don't like being in it.

169. S: What is it about the atmosphere?

170. C: Like all the like sick people and like ... I don't like it when people are like unh -- I don't like it when people are unhappy, and I feel like hospitals like make people unhappy. Like you know like that kind of thing. And like I'm always scared I'm going to like contract some super bug, some type of virus, some super thing. Ja.

171. S: So for you ...

172. C: Germophobic a bit. [laughing]

173. S: Ja. So for you the whole hospital thing is emotionally uncomfortable.

174. C: Yes.

175. S: Because of the unhappiness of other people there.

176. C: Yes.

177. **S:** As well as the fact that it's – ok, this is so not a good word – an icky place to be.

178. **C:** Yes.

179. **S:** There's germs, all that kind of stuff.

180. **C:** Yes, definitely.

181. **S:** Ok. But you're not -- You weren't at all fazed about the procedure itself?

182. **C:** I mean like, I think I did have a ... I can't actually remember. This is terrible; I have such a bad memory. And you can ask my mom. But like I said, I think I was a bit nervous in the beginning, like the night before, a few weeks before. Because they had to like inject me with a dye and at that point I was scared of needles, but now I'm not anymore. So I think that was like, I was a bit ...

183. **S:** Ja. Being injected with dye is like, ooh.

184. **C:** Yes. But afterwards I was, I think I was fine. Like when they had to like scan over here, I was a bit claustrophobic and I was like: can this be finished already. But it was like ... come this close and I was like, ok.

185. **S:** What -- What got you through that without freaking out, or ...

186. **C:** I closed my eyes. [laughing] Ja.

187. **S:** So did you just pretend it wasn't happening?

188. **C:** Ja.

189. **S:** Ok.

190. **C:** But it took like two seconds.

191. **S:** Ok, so it was quite fast.

192. **C:** Ja.

193. **S:** So then you, you filled in all those forms, and then you had nuclear scan. What else did they do?

194. **C:** I had blood tests. I think that's it.

195. **S:** And the blood tests, how did they come back? What were your results?

196. **C:** I don't actually know what that was for, but I was negative for that gene, I don't know what it's called.

197. **S:** Oh, you're negative for gene HLA-B27?

198. **C:** I think it's that.

199. **S:** Or rheumatoid factor?

200. **C:** I have no idea, you can ask my mom. Sorry. [laughing]

201. **S:** I'll ask your mom.

202. **C:** I'm sorry. They tested for that and I was negative for that. I think it was the 27 one though.

203. **S:** Ja, that's a genetic marker. Ja.

204. **C:** I don't know what else they tested for. Also for like liver function, like the general one.

205. **S:** Did you come back positive on anything?

206. **C:** I don't think so.

207. **S:** How -- I know I keep asking you how did you feel. But what was it like to go through the testing, particularly with the blood tests, and have them come back negative?

208. **C:** I was relieved, because like from what I understood, what they were testing for was genetic things, organ function. So when they came back as normal, negative, it was good.

209. **S:** Ja. And how has -- Then what, what kind of treatments did they ... Well, did they start treatments straight away when they got all the blood results?

210. **C:** Yes. I started with six methotrexate, once a week. I think that was it in the beginning. And a folic acid every single day, besides when I took the methotrexate. And I did that for I think ... I think it was like three weeks, like a few weeks, and I had a really bad reaction to it.

211. **S:** Ok.

212. **C:** I got very very nauseous and I got really bad stomach cramps. So she said ok fine, drop it to, I think five. Four, drop it to four.

[20 minutes]

And take a pred -- No, I think she just said drop it to four. But then it wasn't doing anything. SO then I went onto Arava for a month or so, two months.

213. **S:** And is Arava a disease suppressant or a biological?

214. **C:** It's a disease suppressant.

215. **S:** Same as methotrexate.

216. **C:** It's the same as methotrexate, yeah. But that did nothing, like literally nothing. Like the four methotrexate was doing more than the Arava. So I went back onto four methotrexate with one prednisone every day. Five milligrams every day.

217. **S:** After food.

218. **C:** Yes, after food.

[both laughing]

And then recently, I think September, end of Oc ... End of August.

219. **S:** Yes.

220. **C:** I've been taking Humira.

221. **S:** And that's the biologic.

222. **C:** The biological, the injection, ja.

223. **S:** Do you inject yourself?

224. **C:** No, my mom does it. [laughing]

225. **S:** How has your reaction to that been?

226. **C:** It was just like -- What, in what sense?

227. **S:** Anything. Any sense whatsoever.

228. **C:** It burns. It feels like an anti-tet; it's so sore.

229. **S:** And you've got to do that every week?

230. **C:** No, once every two weeks.

231. **S:** Once every two weeks.

232. **C:** Yes. So twice a month.

233. **S:** But you told me earlier you have anxiety.

234. **C:** Yes.

235. **S:** So ...

236. **C:** I get very, very scared. Because like I know that it's coming. Like I tell my mom to just do it like whenever, I like don't tell her to count to three, I just say do it. Because it burns so much.

237. **S:** And, and if you put that on a scale of one to 10, with like 10 being extremely painful, how, how bad ...

238. **C:** Like eight-and-a-half.

239. **S:** Ow. That sounds so sore.

240. **C:** And I mean, like I do have quite a high like pain like threshold. It takes like a lot, so. It's sore. But like it goes away after a few minutes. But like it doesn't leave a bruise or anything, which is nice.

241. **S:** And the side effects for that one? It's Humira you said, ja.

242. **C:** Yes. I haven't experienced any side effects, so.

243. **S:** Ok. I mean obviously the side, one side-effect is it makes you better. [laughing]

244. **C:** Yes.

245. **S:** But no negative side effects for you?

246. **C:** No.

247. **S:** Ok, but the methotrexate was obviously pretty hectic?

248. **C:** Yes.

249. **S:** And can I ask you, so, so you got diagnosed and you started on the methotrexate and everything. How was your arthritis actually impacting on your life at that stage? Because you said you filled in all those forms and it actually came out quite a high level of difficulty, so where, how was it impacting on you?

250. **C:** Like, it wasn't like stopping me from doing anything at that point. It was just like harder to do things, but ...

251. **S:** In what way was it harder?

252. **C:** Like when I was climbing up the stairs, when I like had to bend over to tie my shoe, when I had to like bend, like bending. My back was extremely painful. Like when I would like lie down on my bed in the like night, I would, like it was literally like I wanted to cry it was so sore. But that was more last year. But in 2014 I don't really think it was -- It was -- It did -- Like wasn't as bad as like the like ... Like I don't -- My mom said that my doctors says that like this flare-up that I've had recently was one of the worst flare-ups that she's seen me have. But I definitely think that I've experienced more pain after I've been diagnosed than before I've been diagnosed.

253. **S:** Oh, that's interesting. That could be the ...

254. **C:** But, I don't know.

255. **S:** So, so when you say, I don't know, do you think ... Are you saying you don't know because maybe it's just psychological, now you're noticing it?

256. **C:** Yes.

257. **S:** Or is it maybe that the disease has progressed a little bit further?

258. **C:** I definitely think that it has progressed a little bit further. Like my back has become affected – before it wasn't so bad, and it's definitely become worse. And ...

259. **S:** So, so now in this recent ... So, it took a while then for the meds to actually kick in. So the methotrexate obviously didn't do very much to help.

260. **C:** So it did, but it wasn't doing enough.

261. **S:** It wasn't doing enough.

262. **C:** Because I couldn't handle the full dose of the six which I was supposed to be, so I could only take four. So it wasn't doing enough. So she said the biological just . . .

263. **S:** And is that making a difference?

264. **C:** It takes about like five months, or five doses.

265. **S:** And you've been on it for how long?

266. **C:** Two months. So she said like it takes five doses and I think I've taken like three or four. So I haven't noticed -- Like it's -- I don't know if it's helped or not. But like, it hasn't made such a huge difference. So ...

267. **S:** How -- How is it when you get told you’ve got to try this medication, you’ve got to be on it for five to six months to see if it works, and only then if it’s not working, you change it?

268. **C:** Yes.

269. **S:** So they’re kind of experimenting with, to find out what works. What is that like, psychologically, or any other way?

270. **C:** I just hate it, because I hate taking medication. Like I’m always like really worried, because like all of the medications I’m taking are like, what’s it called, processed in like the liver. So I have to go for blood tests like every three months to make sure the liver function and some other organs are fine. So I hate taking medication because I’m always like scared of like the “what if” factor. And it’s also like a bit annoying that I have to be on it for so long to even see a difference. Like I have to take something that’s going to like possibly harm my body, and I’m not even going to see a difference.

271. **S:** It might not work.

272. **C:** Yes.

273. **S:** And tell me, this recent flare-up that you’ve had. How -- Can you explain to me in detail how, what is a flare-up for you?

274. **C:** Like psychologically or just ...

275. **S:** Everything. Because we know, both of us know, it’s all intertwined.

276. **C:** Yes.

277. **S:** Ja. What would you say? When did the flare-up happen?

278. **C:** It happened begin -- Like mid- -- Like beginning of September, like ...

279. **S:** Oh, recently.

280. **C:** Very recently.

281. **S:** So you’re basically still in the flare-up?

282. **C:** So, it’s kind of like died down a bit, like a lot.

283. **S:** Was there a trigger?

284. **C:** Allergies.

285. **S:** Oh, you did mention allergies earlier.

286. **C:** Yes. Allergies.

287. **S:** Ja. And have you been writing exams at school?

288. **C:** No.

289. **S:** Because are you also at Yeshiva?

290. **C:** No, I’m at King David.

291. **S:** You're at King David. Ok, ja. Ok. So then it wasn't stress related, it was just allergy-related?

292. **C:** Yes.

293. **S:** Not "just" allergy, but you know what I mean, it was allergy-related.

294. **C:** Yes.

295. **S:** Ok, so the trigger was allergies. And then how -- What, did you just wake up one morning, or ...

296. **C:** So what actually happened was I developed a hematoma on my leg, just like here.

297. **S:** Ok, what's a hematoma again?

298. **C:** It's like a -- You can feel it if you want. It's like a bruise underneath the skin and it forms a bump.

299. **S:** Oh, it's like a big hard bump.

300. **C:** Yes. Yes. So this ...

301. **S:** And if you push that, obviously ...

302. **C:** So it was huge, like it was really really big. Now it's shrinking, it's self-absorbing.

303. **S:** As big as what?

304. **C:** It was like this big.

305. **S:** Ooh, like as big as an egg?

306. **C:** Yes.

307. **S:** Like half an egg.

308. **C:** Like it was really really big. It started off like this, so I was like ok, it'll go ... It started off small and it just like grew, and I'm like oh, I have an egg on my leg. [laughing] So I showed my mom and she says it's probably just a hematoma or whatever. So then it started shrinking, which is what's supposed to happen, then ok fine, it's a hematoma. And then it got big again. And then my ... In August -- So in Grade 6 -- It's a, it's a long story.

309. **S:** That's fine.

310. **C:** In Grade 6, in 2013, I injured myself at gym. I got my foot stuck I in a cross-trainer.

311. **S:** Ow.

312. **C:** Ja. [laughing] Really embarrassing, but anyway. So it injured ... I didn't like tear anything or like cause any hectic damage, but it did like pull and injure some of the tendons or ligaments, not sure the difference, in my ankle and in my foot over here. So in the beginning of August, that got like, over like my ankle and here, got really like, the tendon in my big toe got really sore. So I went to the physio, I was like, it's probably just that injury, it's fine, it'll go away. Because with like the change of like hot and cold it like sometimes it gets a bit sore.

313. S: So in cold weather your foot and ankle injury is exacerbated?

314. C: Yes, yes. So when it got, was quite cold, it got quite sore. So then I went to the physio and it was fine. And then this hematoma appeared and my ankle and my, these two toes, my big toe and my, that little toe. And the like, my ankle and the tendon here, as well as my knee, got really swollen. So I thought the like ...

[30 minutes]

Ok, so the knee was from the arthritis and the toe, like the toes we also thought were from arthritis, but then we also thought it was from the tendon as well. So, it was like, big.

315. S: Ja, ja.

316. C: So because of like all the swelling, I don't know the medical term, but the like lymph nodes like couldn't drain. So my whole leg, like my, from over here, like from about mid-thigh ...

317. S: Mid-thigh.

318. C: To like my ankle.

319. S: Yes.

320. C: My whole leg was swollen.

321. S: Oh my word.

322. C: Like, but like noticeably swollen. So it felt like I had a log.

323. S: Show me with your hands. How swollen was it?

324. C: My knee was literally ... So this knee was a bit swollen, and this knee was about double the size of my swollen knee. So it was like really big.

325. S: So it was more than double, swollen.

326. C: It was huge and it was very sore and uncomfortable. Like when I would move it, it always used to click. It still does click, but like it was very sore and very uncomfortable. And like my -- This was very sore and it was swollen, so every time like ... Like it was bigger than this.

327. S: The hematoma.

328. C: Yes, the hematoma. My leg was like that swollen.

329. S: Your -- So it's a couple of centimetres on either side ... All the way around.

330. C: Ja. Yes. and like it was like ...

331. S: Swollen up.

332. C: The whole leg.

333. S: The whole bottom leg.

334. C: Like I actually felt like I had like a log as a leg. [laughing]

335. S: O dear, ja.

336. C: And I couldn't walk up the stairs and at King David there are a lot, a lot of stairs. And you have to walk a lot, like around school and whatever. So I couldn't go to school. Like I left school the one day because I could not manage. And then -- On that Thursday. And then the Friday I missed school; I could not for the life of me, I just could not walk.

337. S: Ja, Ja. And so you -- Did you have crutches?

338. C: So it wouldn't have actually helped, because I couldn't bend my knee.

339. S: Ok.

340. C: So it was kind of like a, like a straight leg and like hobbling along situation.

341. S: That must have been so difficult.

342. C: Ja.

343. S: And then what other side effects ... I mean, not side effects, other symptoms were you experiencing in the flare-up?

344. C: It was mainly just my knee and like this leg, as well as my back.

345. S: What happened with your back?

346. C: The sac -- The sacriliac joint.

347. S: Sacroiliac.

348. S: That, yes. Joint, especially my left side. The right side's also quite bad, but the left side's definitely worse. So like when that like swells it pinches a nerve and like sends like that like tingling sensation down the leg.

349. S: Down the leg.

350. C: Which was great. [laughing]

351. S: And fatigue?

352. C: Yes.

353. S: When you flare up.

354. C: It was definitely a lot worse. It was definitely worse. But I'm always tired, so.

355. S: But now when you say, I'm always tired, I mean, there are different interpretations of I'm always in, always tired. Can, can you put that more into words for me? What does it mean to be always tired?

356. C: So when I wake up, it takes me like five hours to wake up. Not a morning person. But I just always feel like drained. Like no matter how many hours of sleep I get, I am like ... Literally I always feel like flat. [laughing] Like I -- Like -- Like my battery is always like on 20 per cent, or like 30 per cent. Like I always feel really really tired. I mean I do go to sleep like quite late, but that's like because of the anxiety, like it also comes into play. Like when -- Like at night, like it's when like the anxiety's the worst. Because you just think like about the whole day, like what happened. And then like it gives a lot of insomnia. So it does not make the situation better.

357. **S:** So by what time do you usually go to sleep?

358. **C:** 12. Like half past 11, 12. Sometimes half past 10. Ja.

359. **S:** So the fatigue for you is quite a big factor.

360. **C:** Yes.

361. **S:** How does this then impact ... Ok, so obviously when your leg was swollen you couldn't go to school.

362. **C:** Yes.

363. **S:** And how did you cope with your school work during that time period?

364. **C:** I just ask my friends to like send me, like as the day went on I just like caught it up as they sent it to me. It was fine.

365. **S:** And the school's reaction? How are your teachers?

366. **C:** So at -- Like how King David works is you've got like home room, which is like when you have like a tutor. The tutor gives you like the announcements and you go there for registration every morning. And they like, in primary school they're like your class teacher, if that makes sense. And then there's a one above that, which is the director. And the director has a tutor group from Grade 8 to 12 like from each grade.

367. **S:** Ok. So they're basically like kind of your mom at school, if that makes sense. And they -- If you have any problems with teachers or any problems with classes or anything like that, you go to them. So they know that – both of the director and the tutor – know that I have the arthritis and that I will have to miss school. And they -- They like -- She -- My director -- If you want to leave school you have to go ask your director. It's a bit of a situation. And she's always like very understanding and she will always let me go if I'm in pain. So ja. The ...

368. **S:** So ...

369. **C:** And the, the teachers don't actually like care if you miss school. They don't care for like what reason you miss school. They're like, as long as you catch up the work, whatever. Like ...

370. **S:** So although you're missing school, it's, it's not impacting on your relationship with the teachers there? So you haven't got people moaning at you: why weren't you at school?

371. **C:** Huh-uh.

372. **S:** So it's all actually well managed around that side of things.

373. **C:** Yes.

374. **S:** And when you had your flare-up, how does it ... How does it work with your friends and ...

375. **C:** So it's a bit difficult, because they don't really understand like what really, what the condition really is. Like what it like really means to experience that kind of pain and whatever. I mean like the do like, like try to sympathise and like always will help me try and catch up. And like ... ask me how I am and whatever, but they don't like really understand like what it's like. It's like a bit difficult.

376. **S:** How do you know they don't understand?

377. **C:** Because just like the way that they act and like the way like they say things and that kind of thing. Like the questions they ask.

378. **S:** Can you give me some examples?

379. **C:** They will like ask me like ... I can't think of a good one.

380. **S:** That's fine.

381. **C:** Like, will your knee be this swollen for like a long time? Or, how long do the flare-ups happen? And like, are you always in pain? Like it's like that kind of thing, you know. And they try understand, but they never like will completely understand, you know.

382. **S:** So it does sound like they, ja, they're trying to empathise and understand. But you feel that they can never completely understand. Why is that?

383. **C:** It's kind of like if you, if someone like breaks their hand, or a bone in their body. Unless you've broken a bone in your body, you're never going to understand like how annoying it is to have a cast, or how annoying it is ... Like, how much pain you're in. Or like, that kind of, like how much pain, like how sore it is. That kind of thing. You can like be in pain, but it's never going to be like the exact same kind of thing. Like even someone with arthritis, like juvenile arthritis, they could also be in pain, but it's never going to ... Like they could experience the way ... Like their idea of pain and my idea of pain could be completely different. So they'll like understand ... The friends and people will like understand that I have, am in pain, like I'm going through a flare-up or whatever. But like, they will never like really like "get" the like, like feeling. If that makes sense.

384. **S:** So, so what you're saying is they will not ever fully understand simply because they don't have it, so they can't understand. Really. Because they haven't felt it. Like, if I haven't broken my arm, I don't really know what it's like.

385. **C:** Like obviously like you know it's sore, but you don't really like know ...

386. **S:** Know.

387. C: Like the pain.

388. S: Yes.

389. C: Like, does that make sense?

390. S: Yes. No, I hear you. What you're -- So what you're saying -- I think I'm understanding you correctly, is that it sounds like you've got a really supportive network of friends ...

391. C: Yes.

392. S: Who are really trying to empathise and understand.

393. C: Yes.

[40 minutes]

394. S: Ask you questions so that they know what's going on with you. But even when you say, ja, it's really sore today, for them what is really sore in their experience ...

395. C: Exactly.

396. S: So if they haven't had something ever that's as sore as how you're feeling, as much as they try, they can't understand.

397. C: Yes.

398. S: Ok, cool. Ja, well that makes sense to me. Do you -- So in your case you get swollen joints, particularly your knee. Is there a difference with your friends when they can see something that indicates that you're in pain, and when the pain is there but there's no visible swelling?

399. C: Definitely.

400. S: Can you tell me more about what that is, how that works?

401. C: When I was having the flare-up it was very, like in, my knee was very noticeably swollen, and they kind of like really ... So it was sore, but sometimes like it ... This is a bit weird, but sometimes when like the joint is sore, it's not as, I mean swollen, it's not as sore as if was less like very swollen. It's a lot less sore than if it's a little less swollen, you know.

402. S: Yes.

403. C: Because there's like more cushioning.

404. S: Yes.

405. C: So like it was sore, and it was a bit sore, like it was quite sore, but it was not ... It was more, like, uncomfortable. And like when I would move it, it was very sore. And like, so when they saw how swollen it was, they were like, oh my God. Like, they like -- I think they like realised that it's like a thing, it's a condition, like, you know.

406. S: What do you mean by, they realised it was a condition?

407. **C:** They like realised that like when I say I'm in pain, I feel like it kind of like got illustrated, if that makes sense?

408. **S:** Ok, so you -- Yes. Tell me, just carry on telling me.

409. **C:** Like, they saw how swollen it is and then they like looked at their knee and like realised like, that is not normal. Like some like -- Like I'm dealing with something different. If that makes sense?

410. **S:** So are you saying the swollen knee made the pain visible?

411. **C:** Yes.

412. **S:** And before that?

413. **C:** They were like -- Like sometimes they could see like in my face I was in pain, but they didn't realise to like the extent. And like I feel like -- So I wasn't in as much pain as sometimes like I generally am, but because they saw it was so swollen, they were like, oh my God.

414. **S:** So the knee, although it was swollen, was actually you were in less pain than you often are when they can see nothing?

415. **C:** Sometimes, ja.

416. **S:** Sometimes.

417. **C:** Like it was very sore, but I've been in a lot more pain. Ja.

418. **S:** And you also mentioned something else. It was, I can't remember your words exactly, but: oh, this really is a condition. You said ...

419. **C:** Yes.

420. **S:** They saw your knee and then ... Do you suspect that before that ...

421. **C:** Ja, they did, like they do know that like, like it's a thing. Like a lot of -- There are people that suffer with it. But just like me -- Because people don't really talk about juvenile arthritis at all. Like they -- And even like in biology where we're learning about the skeletal system, and they only talked about rheumatoid arthritis. You get so many other kinds of arthritis, but they only talked about rheumatoid arthritis and they called it arthritis. So people like assume that the only kind of arthritis you get is rheumatoid arthritis, is the bone on bone.

422. **S:** Ja.

423. **C:** People don't realise that there're other kinds of arthritis, and they don't realised that like kids can get it too. And like they knew that I had arthritis, but they didn't like ... I don't know if they like ... I can't explain, like ... Like you could see it like kind of make sense in their brain, if that makes sense. Like you could see them completely realise that I have it.

424. **S:** Ok, so it was like ...

425. **C:** Because sometimes it's not as visible. Like they'll like -- Like it's a bit swollen and like it does, my knee does look different to their knee. But that was very noticeably different to their knee.

426. **S:** How do you think it would have been had there been no swelling of the knee? Because you know some kids have juvenile arthritis with no swelling at all.

427. **C:** Exactly. So for them I think -- And like for me, like on a general basis, my hands, like when I write for a long time, my hands get very very sore. And I'm currently, we're fighting with the IEB so I can get extra time, because they only gave me rest breaks. Which were the biggest mission ever.

428. **S:** I know. I do the IEB concessions, I totally understand. The testing is quite strenuous.

429. **C:** Ja, so I want to go for the test so I can get extra time, because the rest breaks are really not helpful for me. Because ...

430. **S:** You need a scribe. Or the use of a computer maybe?

431. **C:** I like writing for myself. Like I, like as I write, I like think of more things. I think I would struggle with a scribe and typing would take me way too long. [laughing] So I want to try get extra time so that I can take as many rest breaks as I need, and like I still have more time. Because I do write like slower because of like the pain.

432. **S:** Yes.

433. **C:** Because rest breaks are like dumb, because you have to put up your hand and you land up wasting so much time. So, ja.

434. **S:** So it actually, I mean from a school perspective, there's the flare-up that impacts on your school. But then there's also things like the exams. And then you say it's in your sacroiliac, so I would ... The sitting time.

435. **C:** It's not so bad. My back mainly gets sore at night when I like lie down. Or when I like bend and stand up. Like com -- Like very extreme movements of the back is what really is sore for me.

436. **S:** How -- I was just wondering, because you ... It sounds like your friends are very supportive and that's just wonderful to hear. How about your peer group? The people that you know but they're not necessarily like good friends. At school you've always got the ones that aren't your friends. How do they -- How does -- How do they see what's wrong with you, or how do they view you?

437. **C:** I like, I like try like not tell people, like if that makes sense. Like I just say, oh, like something happened. Because I don't want people to be like, oh shame. Like I don't want them to pity me or like think less of me and like my abilities and what I can do. Because like it's not stopping me from doing anything. So like if like people in my class ... Is that what you're like referring to?

438. **S:** Yes.

439. **C:** Like people in my class, like when I miss school, I was like, o ja my knee was swollen because I've got arthritis and whatever, and then like I'm like pretty like subtle about it. Like I don't like make such a big deal about it. And I do like with the -- Like I do like with my friends and like ... Not really with my mom, but like my friends, I do downplay the pain. And like that kind of thing. Like I don't make such a big deal about it.

440. **S:** Why do you handle it that way, out of interest?

441. **C:** I don't actually know. [laughing] It's just like, I feel, I think it's like my coping mechanism.

442. **S:** How, how would it help with you to cope? How does it help you cope?

443. **C:** I don't know. It's just also like my personality. Like I don't like being the centre of attention. I don't like having all eyes on me. I don't like it when, like that kind of thing. Just, I don't like being ... Like I just don't like it. Like I -- So like I don't want to be the centre of the discussion or like that kind of thing. I absolutely hate it.

444. **S:** So you just want to keep a low profile?

445. **C:** Yes.

446. **S:** And you were saying it is, when we were discussing your peer group, that it doesn't ... You can still do everything. It doesn't -- It's not impacting on your activities at school. So does -- You're not finding that there are certain things that your friends or your peers want to do that you can't get engaged in?

447. **C:** If they were, it would be more because of my anxiety than my arthritis.

448. **S:** Ok.

449. **C:** Definitely more than that.

450. **S:** So something like Rush? Have I got the right place – Rush is the one with all the trampolines?

451. **C:** Yes. [laughing] So like that would definitely ... I would not want to go because firstly it just doesn't like interest me. Like I don't get the point of it, because I'm not an acrobat so I can't do cool things on a trampoline. All I can do is jump up and down. So like that like, just like, I personally don't think I would have fun there.

452. **S:** Yes. Ja.

453. **C:** But ja.

[50 minutes]

454. S: So in general it's not really impacting on what you can do in rel ... So you, are you still doing all the activities you used to do before 2012? The coxsackievirus.

455. C: I stopped dancing. So I used to do ballet and modern. And ballet I stopped because I just didn't like my teacher and my teacher made me kind of lose the passion for ballet I used to have. And modern I just -- So I can do some of the things, but I just find it kind of hard because of my back especially and my knees. Because it's really hard for me to bend and that kind of thing. So ...

456. S: There has been some limitation there.

457. C: Yes.

458. S: But the ...

459. C: There has been some limitation but I will ... Like if -- I don't know. Like I'll go to a party and dance, like that kind of thing. Just not do it like every single week and that kind of thing.

460. S: And with your fatigue – how has that impacted on peer relations? Or has even impacted on peer and friendship relations?

461. C: I don't think so.

462. S: Ok. Do you possibly have to manage your fatigue?

463. C: What do you mean?

464. S: So I have to decide, can I do this, or can't I do this.

465. C: Yes definitely, I do have to do that, ja.

466. S: Is this going to leave me too tired now? Can I go out two nights in a row, or I can do the one night, but it's not a good idea for me to do the second night. I don't know.

467. C: Ja.

468. S: So how does that happen in your life?

469. C: I don't -- Like I don't know if it does so much actually.

470. S: Ok.

471. C: Like I kind of just like, like push through, if that makes sense.

472. S: So you just don't let it keep you back?

473. C: Ja. Because the truth is, like, I can't go ... Like I try. Like I could be in bed at nine, but I still only go to sleep at 12. Like it's like that kind of thing. I can't like ... Ja.

474. S: So would pushing through your fatigue be some, be a way in which you cope? Or ...

475. C: I don't know.

476. S: Ok. No that's fine, that's fine. Everybody -- As you said, it's a different illness for everybody.

477. C: Yes.

478. **S:** So everybody experiences it in a different way.

479. **C:** Experiences it in a different way.

480. **S:** And everybody lives in a different environment and has different social group, so everything is totally different. This sounds, is going to be sound maybe a strange question given that your mom is a doctor. How has the relationship with your doctor been?

481. **C:** It's been good. Like I can ask her any questions and she's been very nice. And ja.

482. **S:** And you feel quite confident in her . . . and things.

483. **C:** Definitely, yes.

484. **S:** So does she speak directly to you?

485. **C:** Yes.

486. **S:** Ok, so she's not going via your mom?

487. **C:** No.

488. **S:** Ok. I was just wondering about that, because in some other people they find their doctors talk to moms instead of them. So, so you haven't had that experience?

489. **C:** Like sometimes they go on a ramble about God knows even what, but it has nothing to do with the condition.

490. **S:** Oh really? Is that your parents, your mom and the doctor talking and they're talking about medical stuff?

491. **C:** Yes. And I'm just like, don't you have other patients to attend to?
[both laughing]

492. **S:** Do you ever feel like then they're just having a discussion and you're not part of it? r ...

493. **C:** No I don't actually.

494. **S:** You don't feel like that.

495. **C:** I don't mind actually.

496. **S:** You don't mind. Ok good, good. And have you had any involvement with any other doctors other than Dr X?

497. **C:** As what?

498. **S:** I don't know, some, some people have to go and see like physios and ...

499. **C:** I went to biokinetics for a bit.

500. **S:** How did that work out?

501. **C:** So, because it's like a chronic thing, she gave me exercises and like some, like I do them at home. Because there's no point like just going there to do it, like it's nothing, because there it's just the same exercises. And sometimes they help and sometimes they don't. Some work, help more than others.

502. **S:** And how was your relationship with the biokineticist?

503. **C:** It was good.

504. **S:** It was good.

505. **C:** Yeah. She was very nice and, ja.

506. **S:** Did you feel that she listened to you?

507. **C:** Yes, definitely.

508. **S:** Ok. And then, JIA, it's tricky. Because you're living with constant fatigue and pain.

509. **C:** Yes.

510. **S:** And what helps you get through those kinds of things on a daily basis?

511. **C:** I like watching TV. [laughing] Like when I get home from school. And just like not like, kind of just like getting, like taking my mind off it. So like getting -- Like just concentrating in class and talking to my friends and that kind of thing.

512. **S:** And just, ja. So just doing things.

513. **C:** Yes.

514. **S:** Ok, so that's a coping strategy for you?

515. **C:** Yes.

516. **S:** Ok. And are there any other factors that actually help you cope? Sort of broad -- Anything from like friends to whatever. Anything that helps you cope with your illness on a daily basis.

517. **C:** Thinking that people have like worse conditions that are life-threatening and that could affect them more than what I'm going through.

518. **S:** How does that help?

519. **C:** It just like makes me feel better, if that makes sense? And like thinking that like, God forbid, it could be something so much worse. And that like, thank God, it's just juvenile arthritis. Obviously sometimes it's bad, and sometimes you just like want it to go away, but it's definitely something that you can live with and that you can manage. And there are things that can help you, like physios and biokinetics and medication.

520. **S:** And, and obviously things that you do yourself that help you.

521. **C:** Exactly.

522. **S:** And within the family situation? How's it impacted on your family?

523. **C:** I don't think it has. I don't know. We've done nothing different, or ...

524. **S:** You've done nothing different, ja.

525. **C:** Well like obviously like it's been a bit of a situation because of the Humira. It's like a bit expensive, so there was a bit like ... And the medical aid wouldn't pay for it. So there was a bit of that like kind of thing.

526. S: Are they paying for it now by any chance?

527. C: No.

528. S: Ok. So there was a bit of a financial aspect to the medication.

529. C: Yes.

530. S: But your -- Is it just you in the family? Are you the only child?

531. C: No I've got an, two older sisters.

532. S: Two older sisters.

533. C: Ja.

534. S: And nobody else has it, only you?

535. C: Ja.

536. S: Ok. So -- So there's no impact on your family – your relationships are all going fine and everything.

537. C: Ja.

538. S: Ok. And what else do I need to ask you that we haven't covered. How -- What would you -- If somebody had been recently diagnosed, what advice would you give them?

539. C: Oy. [laughing] That's hard.

540. S: Do you want me to reframe the question? Would it be easier if I said, what lessons have you learnt from having this illness? Or would you prefer just to stick to what would, what advice would you give somebody?

541. C: If you're in pain, take painkillers, because it will get worse. Just, just take the painkillers. [laughing]

542. S: Ok. So always take your painkillers. Ja.

543. C: If it's sore.

544. S: If it's sore.

545. C: I'm very bad at doing that, because I hate taking medicine.

546. S: So when you say it gets worse if you don't take your painkillers, what do you mean?

547. C: Like the pain will get worse. So just like just stop it while, while, while you can.

[60 minutes]

And that there'll be up days and down days. And it's unpredictable. [laughing]

548. S: Can you ...

549. C: And that there are things you can do to make it better. There are people there to help you. And, ja.

550. **S:** So if you were to use yourself as an example, and you say there are things to make it better. And they, so they'd say, like what? What, what examples could you give them? About how people can help.

551. **C:** You can go for physio. There's this thing called hydrotherapy where you do like biokinetics in a warm pool. I haven't gone for that though, but apparently it does help. Biokinetics definitely does help if you like go to someone who can help you with like the affected areas. It definitely does help. If you just like stay active and always like stay fit and whatever, because otherwise it just gets worse.

552. **S:** Are there people other than the medical fraternity that help make it better? Or make you feel better?

553. **C:** You can like talk to someone who has the condition.

554. **S:** Do you?

555. **C:** That definitely does help sometimes.

556. **S:** Do you have someone you can talk to?

557. **C:** One of my friends from Yeshiva actually has it.

558. **S:** Ok.

559. **C:** So sometimes we, we complain to each other.

560. **S:** Ok. So it's, it's a -- You -- To have a venting space.

561. **C:** Yeah. Yes.

562. **S:** With someone who really understands.

563. **C:** Yeah.

564. **S:** Ok. So would you recommend then to a new person that they try and find somebody else who has it? If they like the person obviously.

565. **C:** Yes, yes. If they think it will help them. Because I know some people don't like talking about their feelings and what they're going through and that kind of thing. So.

566. **S:** And one of the interesting things that you raised was the unpredictable days, and that you said they need to just realise they're going to have up days and down days. Unpredictable days. What would you tell them about coping with those unpredictable days? Like you were fine, and the then your knee was swollen.

567. **C:** Yes. Make the best of it. [laughing] There's nothing you can do to change what, the condition that you have. If you're going to your doctor, they're obviously doing what they can, and there's a limitation to what people around you and the doctors and the medical field can do. So if you find things that make you comfortable, or that make the pain better, or that make like, like you feel better, or just like happy or whatever, then just do it. And just make the best of it.

568. **S:** So learn -- So are you saying learn active ways to manage the bad days?

569. **C:** Yes.

570. **S:** And thoughts, things in your ... Things in your head, thoughts. Sorry. How do your -- What would you recommend around head space on those unpredictable days?

571. **C:** Surround yourself with things that make you happy, the people that make you happy. Positive energies.

572. **S:** Positive energy being?

573. **C:** Things that make -- Like again, things that make you happy, people that make you happy. As opposed to like people that you hate and things that you hate; it's just going to make you feel worse when you're in pain and you're like uncomfortable. Like try make yourself happy and comfortable. Ja.

574. **S:** Ok, so that's interesting. So you think -- You were saying that, learn how to manage the unpredictable days, know that there are people who can help you make it better. Any other advice you can give them?

575. **C:** No. Not that I can think of. I can't think of any more.

576. **S:** No, that's fine. Because I mean we, we ... You know, I mean you've ... You are doing such an amazing job for ... I mean, this is such a great interview. And I mean, if there is something else, I'm flying up again, and if you're willing we can just explore some things. Often in the process inbetween, you might, you might have ...

577. **C:** Yes. Thought of something, yeah.

578. **S:** Mulled some things over. So are there any specific lessons that you think, like life lessons that you've gotten out of this process? Or ways in which you may have grown? Because that's usually what a life lesson is.

579. **C:** Yes. [laughing] I don't think so. I don't know. You see, like I don't know if it's because like I've been exposed to these kinds of things from like a very young age. These kind of like conditions and ...

580. **S:** Because of your mom's work?

581. **C:** Yes.

582. **S:** And that you may talk about it at home.

583. **C:** Yes. And like because my sister's a medical student, she's also always been intrigued by this kind of thing and she always used to ask my mom questions and that kind of thing. So I don't know like -- And like my grandmother has a heart condition and she like, ja, she survived the holocaust and she ... Like she's like an amazing person. So I don't know if it's just because I like, I've always had like this thing that other people have it worse. Like some people are like living on the street and some people are trying to, are fighting cancer. And like I've always had that philosophy like in my head, so ...

584. **S:** If you had to put that philosophy into words, maybe like a motto, but what would it be?

585. **C:** Be grateful for what you have, because other people have it worse, or because other people don't have it. And like especially like going to a Jewish day school, people are so like so materialistic, and so spoilt. And like, you just like think about it and you sometimes have to take like a reality check, because it's like the people you're around and like you just like kind of sometimes get consumed by all of it, and you also just want and want and want. And then like sometimes just like takes, take a step back and have to like realise that like some things you just can't ever have. And some things you will never have. And it's just like how life is and you have to learn to love what you have.

586. **S:** Do you think -- I'm trying to think how to phrase this question now. You were mentioning that your peers were rather materialistic.

587. **C:** Not all of them, but just like some people, you know.

588. **S:** Do you think -- Ok yours is a situation, different situation. Your grandma was in the holocaust and your mom and your sister talk about lots of medical things. Do you think possibly that with your illness, you may have learnt things that your peers haven't? That you may be in a different space to them, developmentally? Maturity.

589. **C:** I think because I've like grown up with two older sisters I am in some sense more mature. Like I've been like a bit more mature for my age than like some of my friends.

590. **S:** Do you notice any other differences between you and your friends? Or not possibly your friends, possibly your peers.

591. **C:** I mean like it's a difference between everyone. Like everyone wants different things in life and everyone has different priorities in life and that kind of thing. Like ...

592. **S:** Not really then.

593. **C:** Ja.

594. **S:** Other than normal unique, I mean differences between people. Do you view yourself differently since you got your diagnosis? If you had to describe yourself, would you describe yourself differently?

595. **C:** No.

596. **S:** So you don't have a way of saying I'm, this is who I am.

[70 minutes]

Who -- How would you describe yourself?

597. C: I hate doing these kinds of things.

598. S: I apologise.

599. C: [laughing] Caring. I hate doing this; it makes me sound so vain. I would say caring, kind-hearted. Kind of the same thing. Generous. Self-conscious, self-aware. [laughing] I don't know what else.

600. S: You said self-aware, which means conscious about who you are and how you behave? Is that your interpretation? And your, consequences of your actions on others, that kind of ... That self-awareness, has it shifted since you got ill?

601. C: I don't think so.

602. S: Ok. And have you ever felt now that you're different to your peer group?

603. C: Well, everyone's different.

604. S: Ja, everybody is different.

605. C: But -- I don't -- No.

606. S: You know -- You don't think so.

607. C: No, I don't think so.

608. S: It hasn't made a difference.

609. C: No. No.

610. S: You don't feel different to them. And adolescence as a period of increased independence, less relying on your parents. How's that whole adolescent process been for you from an independence perspective?

611. C: I've always been like quite, like quite an independent person. I don't need people to like come with me places and like ... Like I've always ... Like I never like need people to do things with me in that kind of independence way.

612. S: And at school, when you've got your leg and, do people help carry your bags and that kind of stuff? Does that ...

613. C: No.

614. S: You still carry your bag?

615. C: Ja.

616. S: You are independent aren't you?

617. C: [laughing]

618. S: So maybe the only area where you might not be so fully independent is just with that injection.

619. **C:** Ja... . So I probably could do it, but I'd flinch, and I'm just scared I'm going to flinch and then pull it away and then the liquid's going to just go everywhere.

620. **S:** Have you had any real highs or lows through this experience?

621. **C:** Not that I can think of. Not that I can think of. I don't know.

622. **S:** That's ok. It's totally fine. And one last questions. Is there anything that I should have asked you today that I haven't asked you and you think you should share?

[male voice in the background: Are you still here?]

I'm still here. She's amazing, what can I say? Ja. Anything that you, you think you could contribute that I have, have neglected to ask?

623. **C:** I don't think so.

624. **S:** Ok. Then I think that is it for me and it's for you. Thank you so much for participating.

625. **C:** Thank you very much. Of course. I'm so glad I could help.

626. **S:** Ja, you are a darling.

[recording ends]

Transcript 2 : Charlotte Interview 2

1. **Interviewer (S):** Ok, perfect. So thank you Charlotte ... Am I pronouncing your name correctly? Charlotte?
2. **Interviewee (C):** Yes.
3. **S:** Ok, cool. I was just worried that I didn't get it correctly, remember it correctly. So thank you very much for doing the second interview with me. And today what I want to explore is the ways in which you cope with your illness and ja. Let's, let's just start with that. I know the last time that I saw you, just for a brief summary, you, you got the coxsackievirus in 2012 ...
4. **C:** Yes.
5. **S:** But you were finally diagnosed after your trip to Israel in 2014.
6. **C:** Yes.
7. **S:** And that trip in Israel was where you got a lot of the pain in your knees from the walking. And then it was only after your diagnosis that you actually started to get the swelling.
8. **C:** I think the swelling just got like bigger or I just like noticed it more.
9. **S:** Ok. Ok. Ok that's great. So then can we just talk about the pain and ... Because I know that you said in the, the forms, that your level of pain was scored quite high at both the pain and difficulty in movement.
10. **C:** Yes.
11. **S:** Ja. So can you tell me: how do you manage that pain? How do you cope with that pain on a day-to-day basis?
12. **C:** If it's like very bad I will take like a Nurofen or a Mypaid or something. But if not, like, I don't really like taking medicine so I kind of just like do certain like exercises or stretches or something that can relieve it a bit.
13. **S:** Ok.
14. **C:** Or I'll do things that won't exacerbate it.
15. **S:** Ok, so, so what kind of ... So, so what kind of stretching exercises and things do you do?
16. **C:** It depends what's sore at the time.
17. **S:** Ok, so have you, have you been given specific exercises?
18. **C:** I did go to biokinetics for a little bit; I do like those exercises. But that was mainly for my back and knees.
19. **S:** Ok.
20. **C:** So like if something else is sore then I'll just kind of like find something that relieves the pain.

21. **S:** So you've developed strategies yourself? Or stretches yourself?

22. **C:** Sort of, ja.

23. **S:** Ok so I know, I know that you also get a sore jaw on both sides.

24. **C:** Yes.

25. **S:** So, so for example how would you cope with that? What do you do?

26. **C:** So like I would either like just like massage the temple area, like where I'm sore. Or I have a bite plate, so that actually really does help. So I put that in if I'm like clenching my jaw or doing something that's really sore. And I like try stay away from like very chewy foods.

27. **S:** Ok.

28. **C:** So like biltong or something like that which is like very chewy and like not so great for the jaw.

29. **S:** Ok. Alright. And then you were saying that you don't ... Medication is one of the things that you can take to help you, like Nurofen, but you don't really like taking Nurofen. Could you just tell me ... I mean, medication. Could you just tell me a little bit more about that?

30. **C:** I suppose it's a bit like a fear of mine because of all the other medications I have to take for the arthritis, like the methotrexate and the Humira. Even though that doesn't really ... Well, the methotrexate does. Like a fear of like going into liver failure or organ failure. Just to like not overload my organs. So I just try and limit the amount of like things I take. But obviously I know that if like I don't take them and I don't take the medication and whatever, the arthritis can really like damage my joints. So if like I really am not coping, like it's really really bad, I like take something. But if it's very mild and I feel like I can cope without taking it, then I will not take anything.

31. **S:** So, so it sounds like it's a bit of a balancing act for you, managing the pain.

32. **C:** Yes.

33. **S:** and whether or not to take the meds.

34. **C:** Yes.

35. **S:** And has your doctor told you that taking the pain meds is going to put extra strain on your body, or is that something that you feel sort of yourself?

36. **C:** It's something that I feel. I don't know. Ja.

37. **S:** Ok, so, so you're just very conscious about the effect that medicine has on your body and so therefore you'd rather limit it if, if you can.

38. **C:** Yes.

39. **S:** If you can, ja.

40. **C:** Yes.

41. **S:** Ok.

42. **C:** Like I'd rather take something more homeopathic.

43. **S:** Ok.

44. **C:** So like Traumeel or something.

45. **S:** Ah.

46. **C:** I don't take it very often either, but like I just, ja. Sometimes like I'll take like a Biral or something, because like sometimes stress could really aggravate the pain. So I'll take like Biral or something like that to like try like relax more, and maybe the pain will go away you know.

47. **S:** Yes. And so that's interesting that you use Traumeel and Biral, which are homeopathic. What were your thoughts around making that decision?

48. **C:** I don't know. [laughing] Because I don't know, I just like believe that stress, like my stress ... I personally think like stress has a lot to with like everything that goes on in my body, because I am like an easily stressed person. And I feel like if I'm stressed I just can't cope with things better or the pain is a lot worse or ... Ja.

49. **S:** And you -- So you describe yourself as an easily stressed person. What kind of things would stress you?

[recording a ends]

[recording b starts]

50. **S:** Ok, starting again. So, so you've, you've also had a look at the homeopathic medication as an alternative to typical medication, and I was wondering what, what made you think along those routes?

51. **C:** So my mom's also a . . . doctor. She also like if I have a cold or if any of us are sick, she'll get us to take homeopathic medicine first. So I find that has kind of rubbed off a bit on me. And I also feel like it's a bit more natural and a bit less harmful towards the body. And, but like a slightly more healthier option. . . . just taking like very hectic like other medication. So I don't think it's necessary to take, to overload the body with a whole bunch of chemicals. [laughing]

52. **S:** And I was just wondering: is, is it ... You seem to have taken quite a lot of control over your medication in the choices that you make. Does that assist you in any way with your illness?

53. **C:** I don't think so.

54. **S:** I was just wondering, how does it make you feel to make those choices?

55. **C:** I don't think it's, like makes me cope better, I just think like it's the healthier kind of option and like way to, I don't know, go around it.

56. **S:** Ok. Alright. So you, would you get any feelings of sort of empowerment or anything like that from ... Or independence or anything from making the decisions?

57. **C:** I think like ... I think it has to do with my personality a bit. I also have anxiety, so I think that, like I do have a bit of a fear of losing control and like control of situations. Like I have a fear of alcohol and like drugs and stuff for that reason, because like something that you consume completely changes the way you act and the way like your body functions and everything like that. So I do definitely have a fear of losing control. So I do think like that the way that I go around taking medication and that kind of stuff does like have something to do with that part but I don't think it has so much of an effect on my illness, like the arthritis illness.

58. **S:** Ok.

59. **C:** Ja.

60. **S:** And then I was ... So, so deciding to do meds and exercise – those are ways in which you help with your pain management. Are there other ways in which you could, in which you manage your pain?

61. **C:** Not really.

62. **S:** Ok. Because that last time that I chatted to you, you also mentioned things like ... Hold on one moment. Things to make yourself comfortable. You said you'd some ...

63. **C:** Yes.

64. **S:** And I was just wondering if you could tell me more about that?

65. **C:** So like if I'm sitting I'll put like a pillow behind my back or I like sit with my feet elevated for my knees to like make my legs straight. Ja.

66. **S:** And is there anything you do that makes you emotionally comfortable?

67. **C:** I don't think so; not that I can think of.

68. **S:** Oh, ok. Cool, cool. And you also mentioned something last time about surrounding yourself with positive energy.

69. **C:** Yes.

70. **S:** And could you tell me a little bit more about that and how it helps?

71. **C:** So like I won't be around like if someone's like in a bad mood or, and it has nothing to do with me, I'll try and like go away from it because it makes me fell stressed. Because I'm like, I take on other people's stress and other people's like that kind of thing.

72. **S:** Ja.

73. **C:** So it doesn't really help my whole well-being.

74. **S:** Yes.

75. **C:** So I'll try like move away from that, or I'll try like do things like that. Like try go away form other people who are, have a negative like mood or something going on like that. Ja.

76. **S:** Yes. Because you said that stress aggravates your arthritis quite a bit.

77. **C:** Yes.

78. **S:** So, so, so you move away from people that have got negative energy. What kind of positive energy attracts you, or what, what helps you?

79. **C:** If people are happy or excited or like even if people are sad like I'll try make them happy and that like try like, does make me feel a lot better. You know like put them in a positive mood.

80. **S:** Ok, ja. So you, so, so then surrounding yourself with the right people is quite an important coping strategy for you.

81. **C:** Yes.

82. **S:** Ok. And you also mentioned to me that your gran is quite a role model and I was wondering if you could tell me a little bit more about that.

83. **C:** What do you mean?

84. **S:** Because you said she went through the holocaust.

85. **C:** Oh.

86. **S:** And that ... Ja, sorry, it's a bit awkward in the waiting room here so I'm trying not to break any confidentiality. But ja. It's just the last time that you said you think about how life could be a lot worse with people having life-threatening illnesses or ... And you also then mentioned your gran, and I was wondering if how that affected your coping strategies or the way in which you deal with your illness.

87. **C:** It, it definitely makes me feel like a lot better and a lot like "thank God I just have arthritis", you know, I don't have something like that is really like terrible and like properly life-threatening. Like obviously arthritis is not great and I'd prefer not to have it, but I'd rather have arthritis than, you know, God forbid, cancer or something a lot more serious.

88. **S:** Ok. So, so essentially what you're saying is you, you, you're almost putting you're illness into perspective.

89. **C:** Yes.

90. **S:** So on a continuum from really bad to being healthy, you've kind of situated yourself in a way that enables you to, to see it more positively.

91. **C:** Yes.

92. **S:** Ok, ok, great. And then, ok, so I've got some questions about different ways of coping that sometimes people use, and so I'm just going to run through those, and then maybe you can just tell me which one of those maybe resonates for you. Would that be ok?

93. **C:** Perfect.

94. **S:** Ok, great. So then I was just wondering: other people have found that spirituality or religion enables them to cope better with their illness, and I was wondering how, how have you found that?

95. **C:** I don't, I don't really ... I haven't actually thought about it as like a coping strategy. Like I don't really use it.

96. **S:** Ok. If you think about that a little bit now, does anything spring to mind, or not at all?

97. **C:** Not really.

98. **S:** Ok, that's great. I mean that's fine. [laughing] We're just going to try all the different ones. And then, I don't know if you've got any pets?

99. **C:** Yes.

100. **S:** So I was just wondering do you find that pets impact on your coping strategies or anything like that?

101. **C:** No.

102. **S:** No. Ok.

103. **C:** No. [laughing]

104. **S:** [laughing] That's fine. And then support people like maybe family, friends, or teachers. Do any of those, can you think of ways in which you use them as coping strategies?

105. **C:** Yes.

[10 minutes]

106. **S:** Uh-huh. What, what, what do you do there?

107. **C:** I just think that like having someone like that's close to you or someone that you can talk to is like quite nice.

108. **S:** In what, in what way does it help?

109. **C:** It just like helps that they can be there for you like if you're not having a great day, like if you are in a lot of pain and they can like really like understand or just like try sympathise or empathise. And it does, it does help to an extent.

110. **S:** Is it ... Because I can remember last time you were saying that you're from, you've got a really good support network of friends and they really do empathise. Although I think you did say that they, they can't really understand.

111. **C:** Yes.

112. S: Ja. Ja. So can you think of any other coping strategies that you use? To help you manage the pain.

113. C: No.

114. S: Alrighty. Well, the other, the other one that I wanted to know how you cope with, because this is one I think everybody struggles with, and that is the fatigue. And I was just wondering how you manage that fatigue on a daily basis?

115. C: It's, it's really hard. If like it's a ... Like if I wake up and I'm like: oh my God, I, I don't think I can handle the day, I will take a vitamin like a Berocca Boost. There's a lot of coffee consumed in a day. And that is something that I really struggle with. And I don't really think that I do have a good coping strategy for it.

116. S: Ok. And, and yet you are coping with it. So, so what is it that you do? So you, you've, you drink coffee and Berocca. What, what kind of thoughts do you say to yourself around the fatigue when you're having a bad day?

117. C: Like: there's only five hours until you can go and lie on your bed or like that kind of thing, you know.

118. S: Ok, so maybe we could go right back to the beginning and let's imagine it's a bad day and you're in bed. Do you wake up knowing it's going to be a bad day?

119. C: No.

120. S: Oh, you're back. I can see your face now.
[both laughing]
So you, ok, so then how, when does the fatigue hit you?

121. C: So I do wake up a bit tired in the morning, but it takes me a while to wake up because I'm not a morning person. I think like middle of the day mainly and then like towards the late afternoon.

122. S: So it kind of creeps up on you during the day?

123. C: Ja.

124. S: And then, so, so how do you mentally ... What do you kind of say to yourself around the fatigue?

125. C: I'll be like: you're not tired, you can just like carry on, just push through. Like, there's only like three more hours left of school, or four hours left of school.

126. S: And then after school? What would happen?

127. C: Sometimes I like get home and like I have . . . . [recording cuts out]

128. S: And have a nap?

129. C: Ja. Not great, because then I can't sleep at night, but ...

130. **S:** Yes, yes. And is there any other way you manage your fatigue?

131. **C:** No.

132. **S:** Ok. So, so then maybe what we should do is move onto the whole idea of having quality of life whilst having a chronic pain illness. And I was wondering what kind of things bring quality to your life?

133. **C:** Definitely family and friends.

134. **S:** Could you explain more for me?

135. **C:** I feel like if I'm around the right people, that I kind of forget you know like how much pain I'm in or something like that. Like if I'm having fun. Or it just doesn't seem like such a big thing.

136. **S:** So that's almost kind of a distraction, would it be?

137. **C:** Yes.

138. **S:** Takes the mind off things.

139. **C:** Yes.

140. **S:** And, and, and what does it bring to you? How does it add quality?

141. **C:** It makes me feel like happy and like I have people that care about me and, ja. Definitely like my hobbies also.

142. **S:** Ok, ja. Can you tell me about your hobbies?

143. **C:** Like if I'm baking or singing or ... I know like doing my make-up or doing someone else's make-up, it like also acts as like a distraction and I can feel like I'm not defined by something that like I don't want to be defined by. I'm defined by something that I'm good at or something that I love doing.

144. **S:** So, so am I understanding you correctly that by engaging in baking and singing and doing make-up, it ... You're not defining yourself by the illness. Is that what you're saying?

145. **C:** yes.

146. **S:** You're, you're creating a bigger definition of yourself.

147. **C:** Yes.

148. **S:** Ok. And what -- How -- How -- So you've got a bigger definition of yourself. Are there any feelings or thoughts, other thoughts, that go with doing your hobbies?

149. **C:** No.

150. **S:** Ok, that's fine. And are there any other aspects in your life that brings and adds quality to you? Or to your life?

151. **C:** No.

152. **S:** Just mainly ...

153. **C:** Not that I can think of at the moment.

154. **S:** So mainly having people around you and being able to engage in hobbies that you enjoy.

155. **C:** Yes.

156. **S:** Great. Well then I think the only last thing that I have to ask you is: people talk about being well within an illness; so wellness within illness. And I was wondering ...

157. **C:** Yes.

158. **S:** If that means anything to you and if you experience that at all?

159. **C:** Definitely. Like if everything ... If I like have very few inflammations or if I'm not in a lot of pain or if I can do something that I normally struggle with doing, it definitely ... I'm like well, you know. Like obviously it's still there, like, like it's still there, but if like I can be doing better – I've improved or something like that.

160. **S:** So, so I know recently, before your exams, you went through a flare-up.

161. **C:** Yes.

162. **S:** And then, and think that when the last time that I saw you it was starting to get better. So could you use that as an example for me of how you find wellness in illness?

163. **C:** Yes. So like when I, when you ... That was like a particularly bad flare-up because my whole leg was swollen and it was very like hard for me to walk and to stand and to like walk up stairs and down stairs. And also like it made me feel a bit more self-conscious because like my whole leg was swollen and it was physically swollen. So like when it went down and I could finally like walk properly and not have to wear like a knee brace and an ankle guard and everything like that, it definitely made me feel a lot better and like I had gotten better. And I could like manage with life better.

164. **S:** And, and, and so ... *Sjo*, so essentially you, you're kind of on a continuum from when you've got very bad illness and then it's not so bad. And then when it's not so bad, that's when you int ... You interpret that as a moment of wellness.

165. **C:** Yes.

166. **S:** So then has, has your ... How has your definition of wellness changed since you were, since you became ill?

[20 minutes]

167. **C:** I suppose that when I wasn't ill, like not like after a cold or not having a like cold or flu or a stomach bug, and that was my definition of being well, whereas now it's I'm not in so much pain and nothing's very swollen and I can walk and I can run and I can do things.

168. **S:** So it is quite a big shift, isn't it?

169. **C:** Ja.

170. **S:** Ja, ja. I'm just going to just check my notes and see if there was anything else that I wanted to follow up with you. Oh yes, of course, because you've just written your matric exams. Grade 12 ...

171. **C:** Not matric.

172. **S:** Sorry?

173. **C:** I'm only in Grade 9.

174. **S:** Oh, you're only in Grade 9. Why did I think you were in Grade 12? Silly me, sorry. So you've just written your Grade 9 exams.

175. **C:** Yes.

176. **S:** And I can remember when we were talking last time, that exams were difficult for you. Of course you're not in Grade 12 because you were going for your IEB, your dispensations, your exam dispensations.

177. **C:** Yes.

178. **S:** How, how did you manage to cope through those exams? Because you told me putting your hand up to get a rest period was a bit of a waste of time.

179. **C:** Yes.

180. **S:** So, so how did these exams go for you?

181. **C:** So I got five minutes extra time. The IEB phoned my school like literally, I think it was like a few days before, like maybe two days before exams, to say that I get five minutes extra. So that really really did help. I don't use the rest breaks, because the invigilators are a bit dumb. [laughing] So that definitely did help a lot. And also, because it's summer it's not as ... Like, my hands don't get as sore as in winter. So that definitely did help. I mean there were some exams where I could not move my hand afterwards.

182. **S:** Ok.

183. **C:** But it was definitely a lot better than July.

184. **S:** So mentally ... I mean, how long are your exams? An hour and a half, two hours?

185. **C:** Ja, so some are an hour and a half, some are two hours.

186. **S:** So I mean even in winter when the pain was more difficult, how do you manage your pain and fatigue during the exam? What, what kind of things do you do?

187. **C:** I feel like just because like the adrenaline's going, like I don't really feel ... Like obviously like in some exams I did feel tired and like I was like: oh my God, my hand is so sore I can't keep writing. But because the adrenaline's there and the like thoughts of like: I need to finish this exam, or like it's the last exam I ever have to do in this subject, or I need to do well in this exam because I'm taking this subject next year. It definitely did help to like get through the exam and to keep pushing myself. Ja.

188. S: So a lot of mental self-talk does seem to help you cope in the different situations that you find yourself.

189. C: Yes.

190. S: Ok Charlotte. I don't know if after this discussion that we've had, if there's anything else that pops up for you? Any specific thing that we haven't covered that you need to, that you have to use coping strategies for, or anything you've thought of that brings quality of life now. If you want to take a moment to reflect; see if there's anything else that comes up for you.

191. C: I don't think so. I can't think of anything at the moment.

192. S: That's fine. I just noticed something out of the corner of my eye and that was insomnia. How do you cope with your insomnia?

193. C: Oh ja, insomnia.
[both laughing]
Lots of relaxants and anti-anxiety things – that does help.

194. S: Is that the like Biral or herbal tea or what do you take?

195. C: So I've been taking Zoloft.

196. S: Ah. Ja.

197. C: And in winter I drink herbal tea – it's too hot at the moment for some tea. Ja. It definitely has gotten better.

198. S: And when you wake up in the middle of the night and you can't go back to sleep, what do you do? Or how do you think; what are your thoughts?

199. C: I don't generally wake up in the middle of the night.

200. S: Ah. Is it ...

201. C: Ja.

202. S: Is it more of a problem falling asleep?

203. C: Yes.

204. S: Ok. So you've actually put little strategies into place. So, Zoloft, herbal tea.

205. C: Yeah.

206. S: And if those don't work then, then what?

207. C: I would like, maybe like meditate or ...

208. S: Ok.

209. C: Listen to music. Or you know like those ambient sounds, like the white noise sounds. Ja.

210. S: And when you meditate, what do you do?

211. C: It's like breathing exercises.

212. S: And who taught you those?

213. C: I have an app on my phone.

[both laughing]

214. S: Wow, that's very independent. So you downloaded an app to help with insomnia?

215. C: Ja.

216. S: Ok.

217. C: It's a meditating app.

218. S: Ok.

219. C: It's called "Calm".

220. S: Alright. And does it work?

221. C: It makes me feel more relaxed. So like it makes me a bit more like sleepy. I also have like a lavender-scented candle, which I light if I'm like, like before I go to sleep every night. Ja.

222. S: So you actually have quite a few coping strategies for the different ways in which your illness impacts on you.

223. C: Yes.

224. S: Ok. So I'm not going to ask you again if you've thought of anything else, because you probably haven't.

225. C: No, I haven't.

226. S: Alrighty, then we'll stop the interview now. Let me just stop it and thank you very very much for taking part again.

227. C: Of course.

228. S: Ok, let me stop this now.

[recording ends]

Transcript 3: Julia Interview 1

1. **Interviewer (S):** Yes, ok, so that's recording. So what I was wondering is, if you could just start off by telling me the journey of the diagnosis.
2. **Interviewee (J):** Ok.
3. **S:** From, from her becoming ill, from your perspective as a parent, how did that process unfold?
4. **J:** So she had a very very severe Coxsackie infection about five ... About four years ago I guess now. Five years perhaps, five years ago. Actually this time of year, more or less exactly this time of year. That involved the typical rash and the costochondritis, the inflammation of the joints in the chest. And lasted the usual, you know, time the viral illness lasts. But it totally left Charlotte with a sort of chronic fatigue for a while.
5. **S:** So that was 2012 wasn't it, when she got the Coxsackie.
6. **J:** I think it was, yes, I think it was. I'd have to check that with her because she'll know better the year. But if I work backwards that's about right. About -- So it was difficult to differentiate because it was more of a chronic fatigue than actually joint involvement for a long time, and then she got better. The paediatrician and I was certainly hoping it would run its course and you know, go away.
7. **S:** So more like a post-viral fatigue?
8. **J:** Yes. Then she started developing quite a lot of joint pains and I consulted the paediatrician, who also thought it was a post-viral syndrome and hopefully will burn out. Two years ago July we went on holiday to visit my family in Israel and it was boiling, boiling hot and she was complaining that her knees were sore and her ankles were sore and I thought that's really quite strange and not in keeping. So I was watching her quite carefully and then I noticed that there was some swelling of one of the knees and she actually was struggling to go up the stairs in the hotel where we were staying. And I pretty much realised that this reactive arthritis, as initially we thought it was, wasn't actually going away and we're going to have to actually treat it. So when we came back in August two years ago, made an appointment, took her to the paediatric rheumatologist. I told the paediatrician that I think it's now time and took her to the paediatric rheumatologist and we started on ... She made the diagnosis as juvenile idiopathic arthritis.
9. **S:** Which type did she ... Was it the poly or ...
10. **J:** So it was definitely a poly mul ... It's a multiple joint involvement.
11. **S:** Multiple joint involvement.

12. **J:** Yes. It's a polyarthritis, not a monoarthritis. And she started her treatment. By that stage it was really severe. It was really really severe. To the extent that ... Obviously when we came back it was still winter and she was actually struggling to even bend to put on her stockings for school. It was really bad. So subsequently ... The initial treatment worked fairly well, but not a hundred per cent.

13. **S:** That was the methotrexate?

14. **J:** That's the methotrexate**,** and the prednisone. She -- The -- The doctor looking after her, Dr X, then tried Arava for her in the January of the following year, without any response, no benefit at all. So that was stopped. Went back the methotrexate for, for a while. Do you want me to repeat?

15. **S:** No, no, no. I was just checking if it's working. Don't -- Just ignore me when I do that.

16. **J:** Ok. And then due to some other severe flare-ups we now started on the Humira**.**

17. **S:** The biologic.

18. **J:** So hopefully this will actually work a bit better.

19. **S:** And she's been on that, what? Two months, three months?

20. **J:** Not yet. About a month and nearly a half.

21. **S:** Ok, so there's still a while to go.

22. **J:** Yeah yeah.

23. **S:** Because it's what, five, six months before you really notice.

24. No, no, no. Should be about six weeks to two months. So she started ...

25. **S:** She's a bit confused about that. She, she said to me five, six months before she'll know if it's really working.

26. **J:** Oh shame. You know what, I don't think there's any harm sometimes in giving a longer period.

27. **S:** Ja.

28. **J:** To patients in general.

29. **S:** Yes.

30. **J:** So they don't sit there and expect this sudden improvement.

31. **S:** The miracle.

32. **J:** The miracle cure. But now recently she had a particularly severe flare-up, and in February this year, March, she had also a very severe flare-up. That actually kept her home from school. In Feb, in March, she was home from school for four days or even a whole week. This time not as bad, about two days. So that's where we're at, at the moment.

33. **S:** So it's in comparison to what can happen in a fairly short period to get diagnosed.

34. **J:** I suppose. Although I think -- I think it may have been different were it not for the severe viral illness. You know, I mean obviously that triggered it. But I think if a child just suddenly develops joint pains in the swollen joint, they'll get diagnosed maybe a little bit quicker these days.

35. **S:** I think the problem's with the ones that I've interviewed has always been the ones that don't get the swollen joints.

36. **J:** Yes. That's always a problem. That's always a problem. Dr X was actually commenting on that.

37. **S:** Ja, that's a tricky one. But ja ...

38. **J:** And the swelling can be quite minimal. I mean ...

39. **S:** You might not even see it.

40. **J:** Absolutely. I've only become aware of it because she showed me what to look out for. It's certainly not something that a GP would notice, or even sometimes paediatrician that's inexperienced may not be aware of it. So a hundred per cent, I agree with you completely.

41. **S:** How -- How was it for you as a mom, as the mom [laughing], for, for her to get a diagnoses of JIA. For you and your husband?

42. **J:** So, I can't -- I can't speak on his behalf as such, but for me personally the diagnosis wasn't so hard to accept; the treatment was much harder to accept. I think, you know -- I think about the time I took her to the paediatric rheumatologist, I had come to terms with the treatment that she will need, because I knew that was the diagnosis. As Dr X said to me: you knew, right, you just came for a second opinion. [laughing]

43. **S:** [laughing]

44. **J:** And I said yeah, and for the treatment. Because I would never treat my own child like that, in that respect. So for me the hardest thing to accept was having to let my kid take these kind of medications. I think it's hard to accept for an adult, but even more so for a child. Much harder to accept.

45. **S:** Because?

46. **J:** Because of the potential side-effect of these drugs. And the long-term use of these drugs. And just, you know, everything that goes with it. And there, being a medical doctor, made it much harder for me I think.

47. **S:** What, what about being a medical doctor made it so much harder?

48. **J:** Because I know so much more about these medications. Their side effects and yes.

49. **S:** Consequences of them. Ja. And your husband, how ... Could you just, possibly ...

50. **J:** I think, you know, being a non-medical person, I think he was very upset to see her in pain and disabled and not being able to do the things she loves doing. Which, a lot of it's dancing, so ballet and modern, and that kind of thing.

51. **S:** So it actually has impacted on her ability to do physical things that she used to enjoy?

52. Yes, yes. Significantly. So last year she managed to do all of it and she even did the modern exam and it was fine. This year unfortunately, she hasn't been able to. She started off and then she had that bad flare-up in March, and she stopped.

[10 minutes]

53. And this whole year she hasn't been well enough to go back. And I'm hoping that with the Humira next year she will be able to.

54. **S:** She will be able to.

55. **J:** Yeah. Firstly because it's important to move, very important to move. Secondly I think it's, it's important for her self-esteem, for, just for being a kid, to do these fun things.

56. **S:** Do you think it's separated her out from her peer group in any way, or her friendship group?

57. **J:** So that's something that did concern me. I think -- Look, obviously I'm looking at it from the outside as a parent, but I certainly think her friends have actually been quite supportive and understanding. So no, I don't -- I don't think it's excluded her. Sometimes -- I don't know if, if sometimes she's excluded herself, not they've excluded her, because of it. Because that I really don't ... I haven't seen. But I wonder if sometimes she felt that she couldn't keep up, so she said no, she won't take part in something.

58. **S:** Sort of managing her illness?

59. **J:** Yeah.

60. **S:** And the fatigue side of things? How do you think that impacted on her?

61. **J:** No, that's a very big problem. That is a huge problem, and I wasn't aware of how much of a factor that is in, in arthritides. And I discussed it at length with Dr X and realised that it's a huge part of the disease. And that really is a huge problem. Huge problem. I have no doubt that it's impacted on her very severely. What it has also done ... It's almost like she has to drag herself around some days. Which is horrible.

62. **S:** Forces herself.

63. **J:** Yes. Yes. Look, it's good that she does, because God forbid she should just lie in bed and do nothing. But, but it's not nice to have to do that. And, and it certainly has impacted on her doing her doing extra murals, because she's so exhausted.

64. **S:** Having said what you've just said there, do you think that she protects the people around her by not sharing her level of fatigue or her level of ...

65. **J:** Yes, I think she does.

66. **S:** Pain.

67. **J:** Yes. Yes. I have no doubt that's true.

68. **S:** I was just wondering about that because of some of the things that she said.

69. **J:** Yes.

70. **S:** And I was like, hmm. [laughing]

71. **J:** Ja, I have no doubt.

72. **S:** She's a little, she's a little protector. She doesn't want to burden others with things.

73. **J:** That's very true.

74. **S:** Ja. Ja. The biological, it's Humira she's on, the injection.

75. **J:** Ja.

76. **S:** How's that impacting on her?

77. **J:** Look, she's not ... I don't know any child that's keen on needles or injections, but the fact that she doesn't have to do it herself, I think she's quite relieved about that. I think she was quite happy that the nurse was so nice and she came and showed what to do and did her whole thing. It was very sweet. It was -- She's great that nurse from the company. And, and gave her some confidence, I guess, in the medication, in the way it's administered. Look, I think she still worries the, like on the day that we have to do it, but it gets better, you know, with following injections.

78. **S:** Yes, ja. Ja. I suppose you eventually just become accustomed to something. It becomes the norm.

79. **J:** But I think we also get better at how to ... How to administer it so it's less uncomfortable, so it's, you know ... Like we've learnt that we have to leave it out for so long so that it's at room temperature.

80. **S:** Ah. Ok.

81. **J:** She told us to leave it out, but it's hard to judge, you know. Now we get a better idea what works.

82. **S:** So it's a learning process?

83. **J:** Yeah, it's a bit of a learning curve, absolutely. Diabetic patients that have to inject insulin will also tell you that it's a learning process. Pretty much any procedure you have to do.

84. **S:** But now Humira is horrendously expensive. I mean ...

85. **J:** Ja. So that's been a big issue, because our medical aid refused to pay for it.

86. **S:** They’re very naughty aren’t they.

87. **J:** [laughing] Is that what you call it? Ok. That’s very kind of you to put it that way. I have a few other choice words for that.

88. **S:** [laughing]

89. **J:** Which I shared with them actually. Not that they care, but it made me feel better about it. Yeah so, you know what, my feeling is: for my kids, for education, for health, we do what we have to do.

90. **S:** Do you know Karen at all? Her ...

91. **J:** Why does the name sound familiar?

92. **S:** I’ll chat with you after the interview about that.

93. **J:** Ok.

94. **S:** Ja. Ok.

95. **J:** Has she got a daughter? Is her name Mary? Right, so yes I do.

96. **S:** Cool. Ja. I just want to share something with you, just later.

97. **J:** Sure.

98. **S:** And how do you think it’s impacted on the family as a whole?

99. **J:** That’s quite an interesting question. So I think that my oldest daughter, who is currently in Israel doing a postgraduate degree, is very understanding, very supportive, very kind. Tanya like tries to spoil her, being the big sister. My middle daughter initially had a hard time accepting that. Firstly because I think because she’s studying medicine, she knew a little bit more about it, as all medical students think they do. [laughing]

100. **S:** It’s the same as the psychology students.

101. **J:** [laughing] And I think by the nature of her personality and her choice of career, she wanted to solve it, which she couldn’t. And she’d come up with suggestions and ideas that really aggravated Charlotte and they ended up fighting about it. And I tried to explain to her, but you know, there are some things that only come with experience and some of it’s also her personality.

102. **S:** So what kind of suggestions would she come up with?

103. **J:** That, no, no, she must go to biokinetics. No, she must do -- She must do her exercises because it’s not good for her to just lie there. But when she’s in acute pain she really can’t do her exercises. No, she must go to hydrotherapy, which incidentally Dr X suggested. And I mentioned it. The truth is, it’s very very far away. The only facility available is very far away, and she really doesn’t like being in water like that, doing exercises in water, or physio in water. So you know, I’ve always said to her that I’m happy for her to try whatever treatments are available. And in fact I've taken her for quite alternative stuff. She goes to BodyTalk, she went to reflexology. To me, if something doesn't harm and can help, I'm all for it.

104. **S:** Ja. So you use the complimentary medicines?

105. **J:** I -- Everything. Everything. Everything possible. I, I strongly believe in it for my patients, for me, for ... So I think there's a place for conventional medicine in all diseases, but I think there's a place for alternative medicine too. And sometimes to work together if possible. So no I, as I said to my patients, I don't think your burst appendix should not be treated by your homeopath, right?

[both laughing]

But your allergies can, because I have so little to offer you for that. [laughing] So I think there's a place for things and I'm quite open to that. And I've even had one or two patients that insisted on treating their arthritis homeopathically, much to my horror, but I said I'd rather monitor them than have them completely unsupervised with their ... They happen to have quite significant ocular presentations.

106. **S:** Like uveitis?

107. **J:** Actually, they had a scleritis. So on the uveitis I'm quite non-negotiable**.** Quite non-negotiable on the uveitis. On the scleritis I may tolerate the combination.

108. **S:** The uveitis can become permanent though, can't it?

109. **J:** The uveitis is so destructive. It's so destructive to vision and to the structures in the eye. And that left untreated will cause blindness, which is terrible.

[20 minutes]

And I don't think there's a place there for homeopathy.

110. **S:** And is must be so scary for the kids suddenly to get. One day I'm fine and the next day I can't see ... I know some of them get blurry vision.

111. **J:** Yes. So exactly. There's actually one of the little patients that sticks in my mind was a little boy of seven. He was then seven. Who presented after he'd been treated for pink eye for like a month or six weeks, or who knows how long. He had bilateral roaring uveitis. Roaring. He had sore knees, sore ankles. His father kept shouting at him that he couldn't play soccer properly. It was a disaster. I sent them to Dr X like immediately. So him I actually had to treat with injecting cortisone in, behind both his eyes and drops and that. And I sent him to Dr X and his parents refused to accept the diagnosis. And wouldn't take him back. So once his eyes were fine, there was nothing I could do anymore about that. But it was really quite horrendous.

112. **S:** And I think that's something that is, it's very hard for parents to get that ... Some parents to get that, all parents to get that diagnosis, no matter how well informed you are, to know that your child is now very ill. You mentioned that your daughter had difficulty coming to the terms with the fact that she couldn't fix it. How about you?

113. **J:** I think by the time I went to Dr X, I'd gotten to that point where I realised I couldn't fix it. [laughing]

114. **S:** Because I think the JIA's incredibly tricky, because in some kids they do get, they do go into ...

115. **J:** Remission, ja.

116. **S:** Remission. And some carry it on into adulthood, and it's that not knowing that you've to hold. It must be very draining for you as parents? Or not?

117. **J:** So that it is. That it is. There's no doubt about it. I'm also the kind of personality that takes on my kids' worries and stressors and you know, and my patients and you know, everyone around me.

118. **S:** Everyone.

119. **J:** I, I'm working on that. But it has been. It has been really really, at times, more than just draining. It's been quite overwhelming at times. To, to watch her in pain, and it's limited to what we can do and what I can give her, and how much medication, you know, you want to give a kid. Or, or anyone for that matter.

120. **S:** And what are your feeling around all that?

121. **J:** About the pain? The control of pain?

122. **S:** Not necessarily from a medical perspective, within yourself as a mom.

123. **J:** From a parent's perspective. *Sjo*. Obviously I really think that the earlier we manage the pain, the better. It's a lot harder to get rid of it when it's become very severe. One of my hardest things has been to teach Charlotte that. Because she would not want to take anything.

124. **S:** What does she take for pain?

125. **J:** She, she really just takes an anti-inflammatory, like a Nurofen. Even Panado sometimes helps her. But mostly a Nurofen, sometimes Mypaid. That's about it right now. That's been hard to teach her. That she mustn't wait until it's unbearable. It's a lot harder to manage and the pain receptors get reset and it makes it harder the next time.

126. **S:** What, what do you mean by that?

127. **J:** So in neurology, the current thinking is that if you let your headache become unmanageable, you're going to have to take half a bottle of whatever.

128. **S:** Because a normal dose is just not going to work.

129. **J:** Yes. Because it is just so terrible. Whereas if you take it in the beginning, you'll need a smaller amount, it will work faster, it won't become so bad. Now the next time you get a headache, it just applies specifically to that, but I think it applies to all pain really. So the next time your body will sense it earlier, almost, so your, your threshold becomes different.

130. **S:** Ok. But that's an interesting thing for me to explore, because part of the thing that I'm asking the kids is about pain management. How do they live with their pain. So ok, that's very helpful for me.

131. **J:** So currently, for example, in orthopaedic surgery, in any surgery for that matter, we tell the patients: if I've given you painkillers, specifically for the next three days, I don't want you to wait until you have pain to take them. I want you to take them irrespective of whether have pain or not, in order so that you don't develop that kind of cycle of pain. So ...

132. **S:** And of course, she doesn't like to take meds?

133. **J:** No. Which is, which is good on the one hand, it really is. But on the other hand, it makes it difficult with the pain management. Ja. So that's where I think these other methods do help.

134. **S:** Like with reflexology? Because that's good for pain control as well.

135. **J:** The BodyTalk she really likes. She likes the lady very much.

136. **S:** Does she have good relationships with her doctors?

137. **J:** She seems to have a really good relationship with Dr X. She's a lovely woman and the kids seem to really like her, and I think parents do to. I mean, I don't know, because I'd been working with her much for longer than my daughter has been a patient. So our relationship is maybe slightly different.

138. **S:** Different, yes. And her other medical ... Like biokinetics.

139. **J:** Oh she loves her biokineticist. She loves her. And what I love about the biokineticist, she's not one of these people that says, oh you must come every month, so I can make money. She'll say, ok, we're over the acute episode, do your exercises, come back when you need me again. She loves our physio and he's very good with her. And he's understood her condition from the beginning. He treats a fare amount of adult with arthritis and I'm sure some of the kids as well. She enjoyed the reflexologist but lately she asked me to take a break, because she found that, and I agree with her because I also go to the same reflexologist, her own emotional luggage became an issue. The ...

140. **S:** She was placing it ...

141. **J:** She was passing it onto the patient.

142. S: Ok.

143. J: Yes. And I totally understood and I didn't want Charlotte to be exposed to that. It's not necessary. It's inappropriate actually.

144. S: And, and this is a very personal question. You don't have to answer it. How has it impacted on the relationship between you and your husband?

145. J: That's an interesting one. I"ve never thought about it. Thinking about it now to to answer you, I think that my husband kind of just relies on me to manage all of it. That ... I don't know if it's only because I'm the mom or also because I have the medical knowledge. I wouldn't know, because I don't know what happens in other families. I think -- But if I look at my own patients, 99.9 per cent of the time the moms come with the kids. They know the medicines, they know what's going on, they fill in the forms, they do the applications. So I think from that point of view, it's probably a common thing and it's not because I'm a doctor. I think it just makes it maybe easier because I'm a doctor. So he, he genuinely does know that I know what I'm doing, I hope. [laughing]

146. S: So you basically manage the illness. That's your job, sort of thing.

147. J: Yeah. I think he finds it really hard to watch her be in pain and not be able to do anything about it. I think men in general's approach ... I mean, think about it, you complain to your husband you had a bad day; all you really want to do is just complain, he wants to fix your day. I mean seriously. [laughing]

148. S: And Dad can't fix her problem either.

149. J: No, unfortunately not.

150. S: So how does that impact on the two of you? Or does it? I mean, I'm just exploring with a child with chronic illness, is there, is there a dynamic that changes? Is there a change?

151. J: I think maybe for a while, like maybe my middle daughter, he had a hard time accepting the chronicity of the diagnosis.

[30 minutes]

And also tried to encourage her to, don't know, play netball or whatever, when that really was not an option.

152. S: So then did you -- Did the two of you sometimes disagree on the advice he was giving?

153. J: I just -- I just explained to him that hopefully once the medication has started working, she can resume her activities, but both him and my daughter must realise that there are times when she really just can't do it. And it's difficult for another person to understand the degree or level pain of that disability. So I"ve tried to explain to them that this is not just a, you know, I sprained my ankle it's a bit sore, kind of situation. [laughing] And unfortunately she's got so many joints involved. Her lower back is severely involved.

154. **S:** The sacroiliac.

155. **J:** Ja, both sacroiliacs; one more than the other. Both knees, both ankles, her hands and her feet. Her temporomandibular joints, one more than the other. And intermittently the costochondral joints, which is horrible. Yeah, it's between the breastbone and the ribs. And that's terrible, because every time you take a breath, it's sore. And that's really debilitating. And the truth is, how would someone else know what you're talking about unless they've experienced it? You know, it, it really is hard. But I think they've come to understand a little bit more, accept a bit more.

156. **S:** So it sounds to me that you're all working together. So that hasn't actually brought in conflict and a lot of discord. Maybe disagreements, but it hasn't caused too much divisiveness or ...

157. **J:** No, no. I don't -- I mean, you know, there are times when everyone feels like they want to have their say about something or they think they can fix it or do better. But all in all it's, it's ok.

158. **S:** And then the other thing that I was wondering about is have you and your husband adjusted your parenting technique with Charlotte?

159. **J:** Compared to what it was before she was ill? That's interesting. I have to give that some thought. [laughing] I think I have. I think I have. In as far as maybe giving her so much more support for whatever she needs.

160. **S:** Can you ...

161. **J:** Like for example, her anxiety has always been an issue for her in terms of writing exams, in terms ... Just in general. She's a very anxious kid. And I think the disease has perhaps exacerbated that anxiety. And I realised that we actually weren't managing it anymore sufficiently, so we've actually gone and consulted a paediatric psychiatrist, who agreed that it required a small amount of treatment. Which I thought was a good idea.

162. **S:** Is it just performance anxiety treatment or generalised anxiety treatment?

163. **J:** It's probably a bit of generalised, but definitely the performance anxiety has been there for a very long time.

164. **S:** So has she been placed on an antidepressants or ...

165. **J:** It's an anti-anxiety.

166. **S:** Ok. So is it a permanent one or does she just take it on the days when she needs it?

167. **J:** No. So she needs to take it now for, to build up a dose, and then I suppose she'll see.

168. **S:** It will be interesting, because I'll be coming up hopefully to get, to see her again, to see if the reduced anxiety impacts on her pain.

169. **J:** So that's always been my feeling that ...

170. **S:** Because sometimes it's stress related.

171. **J:** Stress exacerbates auto-immune diseases. There's no doubt in my mind about that. And that ...

172. **S:** And do you think -- Do you see a pattern with Charlotte with regards to ...

173. **J:** No. In her the pattern's very much in keeping with flare-up of allergies, which Dr X feels very really strongly about. And she actually refuses to change kids' mediations for arthritis during allergy seasons.

174. **S:** Ok, that's very interesting.

175. **J:** Ja. So with her there's no doubt there's a relationship there. That the allergies flare up, the arthritis flares up.

176. **S:** So then the big change ...

177. **J:** But not the anxiety, no.

178. **S:** So in the one area that you've changed the way you manage her as an adolescent, is that you've put more support systems in place?

179. **J:** I've tried, yes.

180. **S:** You're trying to put more support systems in place to manage her, to help her manage her illness.

181. **J:** And to acknowledge what she's telling us, you know. That she has pain, that she has anxiety, that ... You know, if she's coming out and admitting it to me, I feel that I need to do something about it.

182. **S:** So, so you're getting -- You're encouraging her to talk to you openly about what she's experiencing.

183. **J:** I've tried to encourage all of my kids to do that. Always.

184. **S:** Always. So it's not just -- So that's not actually something you have changed then. So that you have been doing all the time. Yes. And then, adolescents, being adolescents, sometimes it's necessary for consequences and discipline and things.

185. **J:** Sure.

186. **S:** Has that changed in any way since her diagnosis, the way in which you react?

187. **J:** Interestingly, she's actually pretty hard on herself. So I've never really had to discipline her that much. In fact, none of my kids. They -- They're pretty -- In, in fact, at times, with my other two, I've almost had to say to them, let go a bit. Like relax a bit. The world won't come to an end if you don't get a hundred per cent or whatever. Because of her anxiety, I've actually ... I've actually tried to stop my husband or my older daughters from putting her in that situation, because it only makes it worse.

188. **S:** When they try to give her advice?

189. **J:** Yes. Like, why aren't you studying now, you've got a test tomorrow. Or, you know, why are you procrastinating? So I feel like punishing a kid like that actually achieves nothing. First of all, how do you punish them anyways? But it just increases their anxiety level and doesn't have a beneficial response.

190. **S:** So, with the way in which you manage your kids, you've actually not really needed to use the negative ...

191. **J:** So I've been fortunate enough not to. Been fortunate enough not to.

192. **S:** Discipline consequences.

193. **J:** Of course the once or twice we've told them you can't go to this or this place because it's inappropriate or whatever, and you can have a tantrum, but you still can't go. But that's kind of ... I mean, thank God it's never been a huge issue.

194. **S:** A huge issue in your family. Which brings me onto another question of adolescence being a time period of asserting your independence and wanting to go places. With Charlotte, have you found perhaps in comparison to your other two, has the illness impacted on her independence in any way from a sort of developmental perspective?

195. **J:** No, I don't think so. I think she's always been the kind of kid that loves to be at home. So she's never loved sleeping out at friends. She'll sleep out at friends, but it's not her favourite thing. She's never really loved going to camp. She's gone to camp, but it's not the best thing being away from her home comfort.

[40 minutes]

196. **S:** I mean, I think particularly within your community, the, the camp experience is something we could possibly just discuss on how that impacts on her. Because she goes for quite long camps now.

197. **J:** Yeah, they camped about three weeks.

198. **S:** Three weeks, ja. And I know all about the trommels and the camp beds, and the ...

199. **J:** Yes. So you know what, last year she went and funnily enough her friend, in her tent, and her were both on similar medications. So they reminded ...

200. **S:** Both for the same illness?

201. **J:** Yes. So they reminded each other to take their medicines. And she wasn't on injections, so it wasn't an issue.

202. **S:** Yes, because you have to be kept cold don't they, when you travel.

203. **J:** Yes, it's a huge performance. Yes.

204. **S:** Ja. Ja.

205. **J:** They have to be kept in a fridge. Yeah, it's a business.

206. **S:** So will she go on camp this year now?

207. **J:** She doesn't want to actually. She was undecided and she's decided she actually really doesn't want to. One of her best friends is going and one isn't going. And she just said, you know, to be perfectly honest, sleeping in a tent full of sand and sharing bathrooms is really not her thing. Which I totally understand, because I've never been a fan of that personally. I came to South Africa when I was already in Grade 11, so camp wasn't really a thing so much anymore. But when I lived overseas I once went on camp; that really was not my scene.

208. **S:** So you don't think that's got to do with the medication now, or the illness?

209. **J:** Oh no, I don't think so.

210. **S:** So it's actually more of a personal preference? It's just important for me to differentiate that. Is she limiting herself because ...

211. **J:** No, no.

212. **S:** So, so that is just preference.

213. **J:** Yes.

214. **S:** Ok, cool.

215. **J:** It's because she really would rather stay at the Radisson than in a tent. [laughing] And I can't really blame her for that. [laughing]

216. **S:** No, no. Each to their own when it comes to that.

217. **J:** Yes.

218. **S:** Is there anything that you've found that's either been very challenging or very helpful through this whole experience either for you or for her?

219. **J:** So I think it's been extremely helpful that her tutor has been so supportive. So let me explain to you a little bit about the system at King David. Each group of kids has a tutor. Almost like a reg teacher. Because they don't really have reg anywhere because they go to different classes for different subjects. So they meet in his or her classroom in the morning and they take reg and fill them in on announcements or whatever. They collect things, whatever they need to do. And this gentleman has been absolutely amazing from the beginning. So from the beginning of Grade 8, he helped me to get whatever she needed for exams, extra time or rest time or whatever. He has been so understanding. If she doesn't come to school he messages me, if I forgot to message him, I usually do. Is she ok, what's wrong, do you know what's happening? Don't worry, I'll help ... He happens to be her Hebrew teacher, so. I'll fill her in, I'll catch her up, don't worry about it. And her -- And then, every number of tutors have a director, so it's like another teacher who's usually a head of department, they kind of helps or supervises or assists with more major issues. And her director this year has been also amazing, amazing, amazing. She's helped with stuff, she's given her notes to leave school early if she was unwell.

220. S: Wow.

221. J: Which happened quite a bit during this last bout of flare-ups.

222. S: Flare-ups.

223. J: I say to he, you know what, at least try and go for a couple of hours. You don't miss so much work. And if you can't stay go to the director and explain to her and I'm sure she'll let you go. Which she did. Which was fantastic. So she's been very supportive and very nice. I think that's made a difference. It really has made a big difference.

224. S: A supporting school environment is very significant.

225. J: So there's a big problem with our schools I think in general. Firstly, that the kids schlep around a bag that weighs three times what she does, which I horrendous and everything is up and down stairs and up and down hills. So some days she may have been able to go to school, but she couldn't carry her bag up the stairs or she couldn't go up the stairs. Then what could she do at school?

226. S: Then she has to stay at home.

227. J: Ja. So that to me is a huge issue. Really a huge issue.

228. S: And obviously King David hasn't moved onto the e-books yet?

229. J: They tried that and abandoned it at some point because it wasn't working. And the kids hated it and the teachers even more. So this year I think we downloaded one. [laughing] One e-book. That's a -- That's really a problem. I think what's been very helpful is that there are more children with this condition, so the schools have learnt to understand and to, you know, make allowances. So the IEB has also learnt I guess. I think that's -- That's as far as that's concerned. For me personally I feel very strongly that, that she has a normal life and everyone treats her normally.

230. S: And does that happen?

231. J: I think to a large extent it does. Because ... not a disease, it's a condition as far as I'm concerned. It's a condition that you learn to manage and carry on with. I think it's very detrimental if people see themselves as being identified by this condition, making it into an illness that takes over their whole life. I mean I've seen that in adult patients. And I think it's very detrimental.

232. **S:** So it's a case of, Charlotte happens to have JIA, Charlotte is not JIA.

233. **J:** Hundred per cent. Absolutely. It's like kids with diabetes and a multitude of other chronic conditions.

234. **S:** You're not a diabetic, you're a person who happens to have diabetes.

235. **J:** Yes. Yes. Correct. And I think that's really important and I mean, that perhaps there's more enlightenment about these days.

236. **S:** So that's been a big help, the fact that there's more awareness?

237. **J:** To me it has. Yes.

238. **S:** Do you think awareness has been an issue in the past or, and still can be an issue?

239. **J:** Yes. Yes. Definitely. And I think in some socio-economic groups it still is more than others, maybe in some population groups more than others. I think maybe education levels affect that, impact on that.

240. **S:** Ja. I know -- I know I have -- Ok, a lot of kids that I've seen and a number of them have had growing pains and the paediatrician has just said no, it's fine, it's growing pains. It will go away.

241. **J:** Yes. Yes. Yes.

242. **S:** And then they don't. So I think there is a lack of awareness out there. But ok, I'm now giving my ideas and this is not what this is about. Are there -- Is there any -- Big question is what lessons have you learnt as a parent that you could share with other parents whose children have been recently diagnosed? And if that meant doctor parent, that's also fine. [laughing]

243. **J:** So I think -- I think the first step probably is as a parent to come to terms with the fact that there is a, a lot lot unknown about this condition. Nobody can promise you when it will remit, or if it will remit, or you know, what the story is with its natural history. Which is hard for a parent to accept; I think it's hard for a person to accept. I think the parent has to come to terms with the medications that the child has to take, and the side effects of those medication, or possible side effects, so that they don't burden the child with their own luggage and their own issues. Because I do believe the kids pick upon that. So as hard as it may be, I think the parents need to come to terms with it before they can help their kids. And --

[50 minutes]

And you know what, I think that to a layperson it's quite scary, because it's very hard to really understand what this is about. Very very hard to understand what an auto-immune disease is. I guess it's quite scary too. And inevitably parents feel ... So this's where fortunately my knowledge saved me, because generally the parents feel that it's their fault somehow and they're responsible somehow, that they did something wrong somehow. I spend so much of my time when I do make a variety of diagnoses on kids, explaining to the parents they didn't do anything wrong. That because the child has a squint at the age of six months, the mother didn't eat something wrong when she was pregnant or do something bad, or, you know? Because I think that's probably a big issue for parents that are told their child has this condition. And I know some, as you said, sometimes it gets diagnosed late, so parents will blame themselves. There's really very little point in that. You've now got it, you diagnosed it, you're treating it. And if it was treated five months earlier, ok , well, you know. There's no real point in blaming yourself about it. I think that for a lot of parents that's a huge financial burden. And it really is a huge financial burden, because all these therapies ...

244. **S:** Ja, it's not just the meds.

245. **J:** No. So meds are a cost in their own right; the therapies are a cost in their own right. So it becomes a very serious financial investment, this condition. And -- And that's something that I think it might be useful for, for perhaps all parents to fight together against the medical aids and that. Not easy, but might be worthwhile.

246. **S:** Because I don't think it is recognised currently as a chronic condition, is it?

247. **J:** So it is recognised as chronic, but it depends how the rheumatologist puts it. So what, what code they are using. What ICD10.

248. **S:** As to whether they'll pay for the biologics or not?

249. **J:** No. So the, the biologics is a whole other problem. On certain schemes they won't consider paying for them.

250. **S:** Even if it's on the minimum prescribed list?

251. **J:** Yeah. Yeah. And then they've got their own agendas of what they think is the right treatment for a particular arthritides.

252. **S:** Because they've got their own doctors and things to advise.

253. **J:** Yeah, if you call them doctors. I have opinions on that. Oh, Dr X and I agree on that. It was quite funny. Because I didn't say a word, she just told me that, and I though that's funny, that's what I told one of them when they phoned me.

254. **S:** What did you tell him?

255. **J:** No so, so the problem is the majority of their panels of doctors are people that qualified, didn't want to practice, didn't want to do their community service. They have absolutely no clinical experience. And they phone you and say, my literature search suggests that this is a presentation of this. And I'm going, your literature search is right, no, it's not feature of that, so why do you want me to motivate for it? [Laughing] Or, or the opposite. Yeah, it's just bizarre. And the other lot that they employ are retired GP's. Who, I don't know how much they've kept up with what. And then occasionally, if you're fortunate, they have the one or two part-time advisors who still practice medicine and advise part-time. But the problem is that they're very few and they don't sit on all the meetings for all the cases and, you know. Those ones actually know what they're doing, but there are very few of those.

256. **S:** So the medical aids are quite a huge impact. They are a crucial aspect of having an adolescent with JIA.

257. **J:** Yes. Yes. I would say yes. I would definitely say yes.

258. **S:** Alrighty. And is there anything that you haven't shared with me today, or I haven't thought to ask? Anything that stands out for you that you think would be very important? Or that I need to know. Not very important. It's just something that you might have reflected on.

259. **J:** No, I think you've covered all the options here. [laughing] No, I can't think of anything really.

260. **S:** Ok, then shall we just stop now? Thank you so much.

261. **J:** It's a pleasure.

262. **S:** Let me just ...

[recording ends]