The Psychosocial Themes of Children with a Congenital Heart Defect

by

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DECLARATION

Hereby I, Catharina Gerdina Pheiffer, declare that the Master's Degree research thesis that I herewith submit for the Magister Artium Degree in Clinical Psychology, at the University of the Free State is my independent work, and that I have not previously submitted it for a qualification at another institution of higher education. I am aware that the copyright is vested in the University of the Free State and that all royalties with regard to intellectual property that was developed during the course of and/or in connection with the study at the University of the Free State will accrue to the University.

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TERMINOLOGY

Bio-psychosocial Burden of a Disease: A commonly used term of the "burden of a disease" refers to the effect of a health problem as measured by financial cost, and psychological, social, and other indicators (Whiteford et al., 2013).

Cardiovascular Disease (CVD): Cardiovascular disease is the overarching term for a class of diseases that involve the heart or blood vessels. Amongst others, CHD is one type of CVD (GBD 2013 Mortality and Causes of Death Collaborators, 2014).

***Collective Feasibility Study*:** This term is used if a preliminary study has an element unique to a feasibility study as its primary objective but contains elements of a pilot study and familiarisation study.

Collective Pilot Study: This term refers to the combined utilisation of elements of three types of preliminary studies, with the pilot element being the primary objective given the focus on this objective during the **planning** phase of this study (i.e., when the protocol was compiled).

Congenital Heart Defect (CHD): CHD is defined as an anatomic malformation of the heart or great vessels, which occurs during the intrauterine developmental stage (Rao, 2012), affecting the normal flow of blood through the heart.

Ganzheitpsychologie: This school of thought promotes a holistic approach to enquiry and proposes that functional elements come to life when the whole is considered (Hermann, 1976, as found in Hanlon, 1991).

Middle Childhood: The middle childhood years (i.e., primary school years) are a developmental time when children undergo critical physical, cognitive, and social changes. During this time, children enter school, and their social context broadens beyond their families. Ideally, middle childhood gives children the opportunity to develop competencies, interests, and a healthy sense of confidence that they can master and control their worlds (Eccles, 1999, as found in Biehl, Park, Brindis, Pantell, & Irwin, 2002).

Millennium Development Goals (MDGs): The millennium development goals are eight goals with measurable targets and clear deadlines for improving the lives of the world's most disadvantaged people. To meet these goals and eradicate poverty, leaders of 189 countries signed the historic millennium declaration at the United Nations Millennium Summit in 2000.

Preliminary Study: This term includes a characteristic of a familiarisation study as its primary objective but it also includes elements of a feasibility study and a pilot study. In such a case, the term *collective familiarisation study* could be used. Depending on the objectives of a preliminary study, the terms *collective pilot study* or *collective feasibility study* could also be considered.

The Developmental Psychopathology Model (DPM): This multi-level model takes cognisance of emerging patterns of adjustment and tracks the child's developmental progression in various domains, namely biological, psychological, family, and social influences (Sameroff, 2000).

ABSTRACT

Children living with a congenital heart defect (CHD) carry the burden of a condition affecting their biological, psychological, and social functioning. The extent of influence depends on the unique and complex relationship between a wide range of developmental domains, outcomes, and life course trajectories. Children with CHDs are more vulnerable to experience psychological difficulties. Although there is a sound body of international research pertaining to the psychosocial themes of children with a CHD, South African research on this topic is non-existent. The aim of this study was to explore and describe the psychosocial themes of children with a CHD in the South African context.

Semi-structured interviews were conducted with nine children (six males and three females) in the middle childhood developmental stage between the ages of eight and fourteen years. All had a confirmed congenital cardiac lesion and received treatment for their condition. They resided in three geographical locations, namely the Free State, the Northern Cape, and Lesotho. Data were analysed by means of thematic analyses. To gain a comprehensive understanding of children with a CHD, psychosocial themes were contextualised in terms of the developmental psychopathology model.

Five main themes and thirteen subthemes emerged from the participants' narratives. The five main themes related to (a) understanding of cardiac status (i.e., *"I have a heart"*); (b) perceptions regarding post-operative cardiac status (i.e., *"Talking about my heart"*); (c) awareness of psychological experiences related to cardiac status (i.e., *"Talking from my heart"*); (d) social functioning and cardiac status (i.e., *"Heart to heart"*); and (e) understanding of cardiac status as a chronic condition with long-term psychological effects (i.e., *"Attached to my heart"*). Findings of this sample of children with a cardiac condition were that they have (a) an age-appropriate understanding of their cardiac conditions; (b) well-developed episodic memory, which holds inherent advantages for future intrapersonal management of the condition; (c) well-developed cognitive regulation; (d) a combination of misperceptions regarding post-operative cardiac status and more realistic outlooks on their post-cardiac status; (e) awareness of psychological experiences related to their cardiac statuses, including anxiety, fear, loneliness, sadness, anger, and resilience; (f) negative (e.g., peer rejection) and positive (e.g., support from caregivers, siblings, and teachers) experiences

in the functional social domain; and (g) an understanding of the unique attachment to their hearts; i.e., a chronic cardiac condition.

The clinical implications of the findings highlight that health care professionals and researchers need input from children with CHDs to enhance their professional understanding of the intra- and interpersonal experiences of these children and contribute to the provision of comprehensive high-quality health care. Recommendations regarding future research on CHD include considering sample size, type of cardiac conditions, and the question of quantitative versus qualitative research.

This study emphasises the importance of holistic management of paediatric cardiac conditions on a biopsychosocial level and serves as an aide-mémoire that a child with a CHD becomes an adult with a CHD.

Keywords: psychosocial themes, congenital heart defect, middle childhood, developmental psychopathology model, qualitative study

OPSOMMING

Kinders wat met ’n kongenitale hartgebrek (KHG) saamleef dra die las van ’n toestand wat hulle biologiese, sielkundige en sosiale funksionering beïnvloed. Die mate van invloed hang af van die unieke en ingewikkelde verhouding tussen ’n wye reeks ontwikkelingsdomeine, uitkomste, en lewensloopbane. Kinders met KHG’e is meer kwesbaar om sielkundige probleme te ondervind. Hoewel ’n sterk hoeveelheid internasionale navorsing ten opsigte van psigososiale temas van kinders met ’n KHG bestaan, bestaan daar geen Suid-Afrikaanse navorsing oor hierdie onderwerp nie. Die doel van hierdie studie was om die psigososiale temas van kinders met ’n KHG in die Suid-Afrikaanse konteks te verken en te beskryf.

Semi-gestruktureerde onderhoude is met nege kinders (ses seuns en drie meisies) tussen die ouderdomme van agt en veertien jaar in die middelkinderjare-ontwikkelingsfase gevoer. Almal het ’n bevestigde kongenitale hartletsel gehad en behandeling vir hulle toestand ontvang. Hulle het in drie geografiese gebiede gewoon, naamlik die Vrystaat, Noord-Kaap en Lesotho. Data is deur middel van tematiese analise ontleed. Om ’n omvattende begrip van kinders met ’n KHG te ontwikkel, is psigososiale temas in terme van die psigopatologiese ontwikkelingsmodel gekontekstualiseer.

Vyf hooftemas en dertien subtemas het uit die deelnemers se verhale na vore gekom. Die vyf hooftemas het verband gehou met (a) begrip van hartstatus (m.a.w. *“Ek het ’n hart”*); (b) persepsies ten opsigte van postoperatiewe hartstatus (m.a.w. *“Praat oor my hart”*); (c) bewustheid van sielkundige ervarings verwant aan hartstatus (m.a.w. *“Praat uit my hart”*); (d) sosiale funksionering en hartstatus (m.a.w. *“Hart tot hart”*); en (e) hartstatus is ’n chroniese toestand met langtermyn sielkundige uitwerkings (m.a.w. *“Geheg aan my hart”*). Bevindings uit hierdie groep kinders het ingesluit dat kinders met ’n harttoestand (a) vir hulle ouderdom ’n toepaslike begrip van hulle harttoestande het; (b) goed ontwikkelde episodiese geheue het wat inherente voordele vir toekomstige intrapersoonlike bestuur van die toestand inhou; (c) oor goed ontwikkelde kognitiewe regulering beskik; (d) ’n kombinasie van wanpersepsies oor postoperatiewe hartstatus en meer realistiese beskouings van hulle hartstatus toon; (e) bewus is van sielkundige ervarings verwant aan hulle hartstatusse, insluitende angs, vrees, eensaamheid, hartseer, woede en veerkragtigheid; (f) negatiewe (bv. verwerping deur portuur) en positiewe (bv. ondersteuning deur versorgers, broers en susters,

en onderwysers) ervarings in die funksionele sosiale domein het; en (g) ’n begrip van ’n unieke verbintenis met hulle harte, m.a.w. ’n chroniese harttoestand, het.

Die kliniese implikasies van die bevindings beklemtoon dat professionele gesondheidsorgwerkers en -navorsers insette van kinders met KHG’e benodig om hulle professionele begrip van die intra- en interpersoonlike ervarings van hierdie kinders te versterk en tot die voorsiening van omvattende hoëkwaliteit gesondheidsorg by te dra. Aanbevelings ten opsigte van toekomstige navorsing oor KHG sluit oorweging van steekproefgrootte, tipes harttoestande, en die vraag oor kwantitatiewe versus kwalitatiewe navorsing in.

Hierdie studie beklemtoon die belangrikheid van holistiese bestuur van pediatriese harttoestande op ’n biopsigososiale vlak en dien as ’n aide-mémoire dat ’n kind met ’n KHG ’n volwassene met ’n KHG word.

Sleutelwoorde: psigososiale temas, kongenitale hartgebrek, middelkinderjare, psigopatologiese ontwikkelingsmodel, kwalitatiewe studie

CHAPTER 1: INTRODUCTION

"Rhythm is a heartbeat. It is the first drum, a story in sound that reveals our imagination and celebrates our power. Rhythm is the multi-cultural common ground of the human family."

(Vacca, 2012)

1.1 Rationale and Aim of Study

The above-mentioned quote from Vacca (2012) provides a preview of the chapters to follow, which tells the story of the psychosocial themes of children with a congenital heart defect. Even though the physical heartbeats of these children might be inaudible and defective, their intra- and interpersonal "stories in sound" need to be heard, understood, and proclaimed.

A congenital heart defect (from here onwards referred to as a CHD) denotes an anatomic malformation of the heart or great vessels and ranges in complexity (Rao, 2012). The international incidence of moderate to severe CHD is 12/1 000 births (Hoffman, 2013). Of the one million children born annually in South Africa, 8 000 will have a CHD, of whom 4 500 will require surgery. Every year, 3 000 children either die of or remain affected by the symptoms of CHD (Paediatric Cardiac Services in South Africa, 2011). Therefore, CHD is classified as a prevalent chronic condition; i.e., a health problem that requires ongoing management (Department of Health, 2002).

The burden of supporting patients with a CHD falls heavily on South Africa, where the high fertility rate results in more CHD cases. Countries with the highest fertility rates tend to have the lowest incomes per capita (Hoffman, 2013) – a reality that exacerbates the economic burden of CHD. Furthermore, children with CHDs are at risk of associated diseases, such as infective endocarditis, and neurodevelopmental problems, which could result in morbidity, decreased longevity, lengthy and costly treatment (Hoffman, 2013), and psychosocial problems (British Cardiac Society, 2002).

The stress associated with a chronic condition, such as a CHD, could hamper normal development (World Health Organisation, 2007). Middle childhood and early adolescence pose various similarities (Eccles & Wigfield, 2000) and are characterised prominently by a psychological need to achieve competence, autonomy, and relatedness to peers (Connell & Wellborn, 1991). In contrast to the developmental milestones of their age, older children with

CHDs are at greater risk of internalising the associated psychological impact of a CHD (Karsdorp, Everaerd, Kindt, & Mulder, 2007). The development of a healthy body image could also be compromised (Officioso, Salerno, Bruzzesse, Alessio, & Di Maio, 2000). In addition, it has been found that family interaction is lower in young people with a chronic condition (Silver, Bauman, Coupey, Doctors, & Boeck, 1990), which might be because of the restrictions on lifestyle inherent in many chronic conditions. These restrictions might increase dependence on the family when it should be decreasing (Eiser & Berrenberg, 1995). The complex, multi-directional influences of a CHD on the functioning of paediatric patients require a conceptualisation framework to organise these influences.

The Developmental Psychopathology Model, or DPM (Achenbach, 1990), was used as a theoretical framework. This multi-level model takes cognisance of emerging patterns of adjustment and tracks the child's developmental progression in various domains, namely biological, psychological, family, and social influences (Sameroff, 2000). Given the interplay between the presence of a CHD and normal development, the DPM is well suited to categorise major themes that might arise from data analysis.

A better understanding of children's experience of a congenital heart defect requiring intervention will assist healthcare professionals to provide holistic treatment by considering the young patient's normal developmental needs, addressing some of their fears, and even restoring a certain degree of autonomy. A continuous EbscoHost search done from December 2014 to January 2016 found no study on this topic in the South African context, which confirmed the need for such a study.

Therefore, this study aimed to explore and describe psychosocial themes in children requiring intervention for CHD and to categorise these themes in accordance with the developmental domains of the DPM. The study is discussed in the first person to resonate the assertiveness, agency, and autonomy of the contributions that the participants made to this study, ensure clarity regarding the information provided, and to position myself in the study (The Writing Centre, 2014) not only theoretically where my findings and ideas build on or depart from the work of others, but also as an involved qualitative researcher. In addition, the first-person writing style underscores the qualitative narrative nature of the study (Dorit, 2005).

1.2 Research Process

To provide a comprehensive picture of the psychosocial themes of children with a CHD and to adhere to the above-mentioned aim, the research process included a literature review to identify and explain various concepts, theories, and previous findings related to CHDs, the developmental stage of the participants (middle childhood), and the theoretical framework that was used (the DPM). This was followed by a preliminary study, which evolved into the development of a novel and suitable type of preliminary study, namely a "collective pilot study". Based on an in-depth explication of apt methodology, including fundamental ethical considerations regarding research on children, the main study was conducted on nine participants aged between eight and fourteen years (six boys and three girls). All of them had been diagnosed with CHDs and were receiving medical treatment for their conditions. The research included semi-structured interviews and was analysed according to the DPM and its functional biological, psychological, and social domains.

The findings of the thematic analysis emerged into five main themes, namely "I have a heart" (understanding of cardiac status),"Talking about my heart" (perceptions regarding their post-operative cardiac statuses), "Talking from my heart" (psychological experiences related to their cardiac statuses), "Heart to heart" (the effects of living with a CHD on their social functioning), and "Attached to my heart" (CHD is a chronic cardiac condition). Thirteen subthemes emerged from the main themes. After discussing these findings, I critically reflected on the research process in terms of clinical implications and future research on the topic of psychosocial themes of children with a CHD.

1.3 Introductory Overview of Chapters

Chapter 1 (this introduction) introduces the research topic and provides the reader with a preview of what the research study and the rest of the chapters entail.

Chapter 2 demonstrates how I identified and merged important and relevant literature to form a framework of references for critical engagement with my research findings. The literature review focused on (a) the functioning of the normal heart; (b) congenital heart defects (definition, classification, aetiology, prevalence, and the biopsychosocial burden of CHDs); (c) the concept of a non-communicable disease; (d) developmental stage of middle childhood; and (e) the theoretical framework of the developmental psychopathology model (DPM).

Chapter 3 describes the preliminary study and includes definitions and types of preliminary studies. It introduces and explains the concept of a "collective pilot study". The chapter aimed at evaluating the three identified objectives, namely (a) feasibility to evaluate the criteria in terms of its age-range; (b) piloting the interview questions for their ability to yield rich data in answer to the research question; and (c) developing my degree of familiarity and comfort with the interview setting, the health care professionals, and administrative staff at the clinic and in the wards.

Chapter 4 explains the use of a qualitative research approach as the selected research methodology. It includes definitions of important qualitative methodological concepts, types and categories of research designs, sampling, and the proper use of a semi-structured interview. In addition, Ganzheitpsychologie as part of the theoretical backdrop is discussed briefly. Importantly, Chapter 4 provides a detailed framework of the ethical principles that were considered and adhered to throughout this research project.

Chapter 5 contains reports and critical discussions of the research findings, specifically how the findings were plotted on the DPM. These research findings comprise five themes, namely (a) the participants' understanding of their cardiac diagnoses; (b) perceptions regarding their post-operative cardiac statuses; (c) psychological experiences related to their cardiac statuses; (d) the effects of living with a CHD on their social functioning; and (e) a unique attachment to their hearts, i.e. chronic cardiac conditions.

Chapter 6, the conclusion to this study, illuminates the progression of the aims throughout the above-mentioned chapters. Chapter 6 concludes with a critical reflection on the research, makes recommendations based on the research findings, and highlights clinical implications and future research topics.

This study is the first of its kind in South Africa and, to build on Vacca's (2012) metaphor, the first drum with a rhythm that tells the story of the psychosocial themes of children with a CHD. Therefore, to add a consistent beat to the study, every chapter opens with an excerpt from a fairy tale tuning the narrative undertone of the dissertation and concludes with an African proverb to summarise the heart of the chapter. I trust that this dissertation will represent the proverbial heartbeat.

CHAPTER 2: LITERATURE REVIEW

The fairies now began to bestow their gifts. The youngest endowed her with surpassing beauty; another gave her wit; a third imparted grace; a fourth promised that she should dance to perfection; a fifth, that she should sing like a nightingale … It was now the old fairy's time to speak;… she declared the Princess would prick her hand with a spindle and die of the wound. This terrible sentence fell like damp upon all the company, and there was no one present but what shed tears. But just then the young fairy came out from behind the tapestry hangings, and said aloud, "Be comforted, O King and Queen … though I cannot prevent the Princess from pricking her hand with a spindle, yet, instead of dying, she shall only fall into a sleep, that will last a hundred years, at the end of which a king's son will come and wake her."

The Sleeping Beauty in the Wood (Nesbit et al., 1956, pp. 97-98)

2.1 Introduction

As illustrated in the children's fairy tale above, each child is born with a set of unique attributes. While some may be virtuous in nature, others may seem like a burden that permeates various areas of functioning. Children born and living with a congenital heart defect (CHD) carry such a burden, which does not only affect their biological functioning, but also their psychological and social functioning (Marino et al., 2012). The degree of influence that adversity has on a child's biopsychosocial functioning, also known as ecobiodevelopmental functioning (Shonkoff, 2010), depends on the unique and complex relationship between ecology of childhood and a wide range of developmental outcomes and life course trajectories (Mayes & Lewis, 2012). As health care practitioners and researchers, we are dependent on these children to enhance our understanding of their intra- and interpersonal experiences to move towards the provision of comprehensive high-quality health care.

Investing in the health and well-being of the children of South Africa is an investment in the future development of our country (Rees, Chai, & Anthony, 2012; United Nations International Children's Emergency Fund, 2013). The 5th South African Child Health Priorities Conference, hosted by the University of the Free State in 2014 (Saloojee, McKerrow, & Van der Vyver, 2015), is an illustration of movement towards investment in the health and well-being of the children of South Africa. The aim of this conference was to

review progress in child health in South Africa, more specifically to reflect on recent achievements and to set priorities for the near future.

A major topic included progress with regard to reaching the eight Millennium Development Goals (MDGs) identified in the United Nations (2000) declaration. The conclusion was that, in order to maintain the current momentum towards attaining the MDGs, sustained focus on maternal and child health care needs to be a priority. From a critical standpoint, Hoosen et al. (2011) are of opinion that much more work is required before South Africa can claim to be investing actively in the health and well-being of its children. They base their opinion on the fact that South Africa is yet to achieve adequate progress towards the MDG of reducing the under-5 mortality rate, doing far worse than many poorer countries. However, as Leblanc (2009) explains, even though paediatric heart diseases, such as congenital heart defects (CHDs) are not explicitly included in the MDGs, accomplishing some of the goals will have a direct effect on children with heart disease in developing countries. In turn, the effective management of cardiovascular diseases (CVDs),[1] such as CHDs, will contribute to attaining the MDGs. To endorse Lablanc's (2009) optimistic view, Figure 1 illustrates how the eight MDGs are linked to CVDs in general and CHDs in particular, and highlights the importance of making the effective management of CVDs a priority.

[1] Cardiovascular disease (CVD) is the overarching term for a class of diseases that involves the heart or blood vessels. Amongst others, congenital heart defect (CHD) is one type of CVD (GBD 2013 Mortality and Causes of Death Collaborators, 2014).

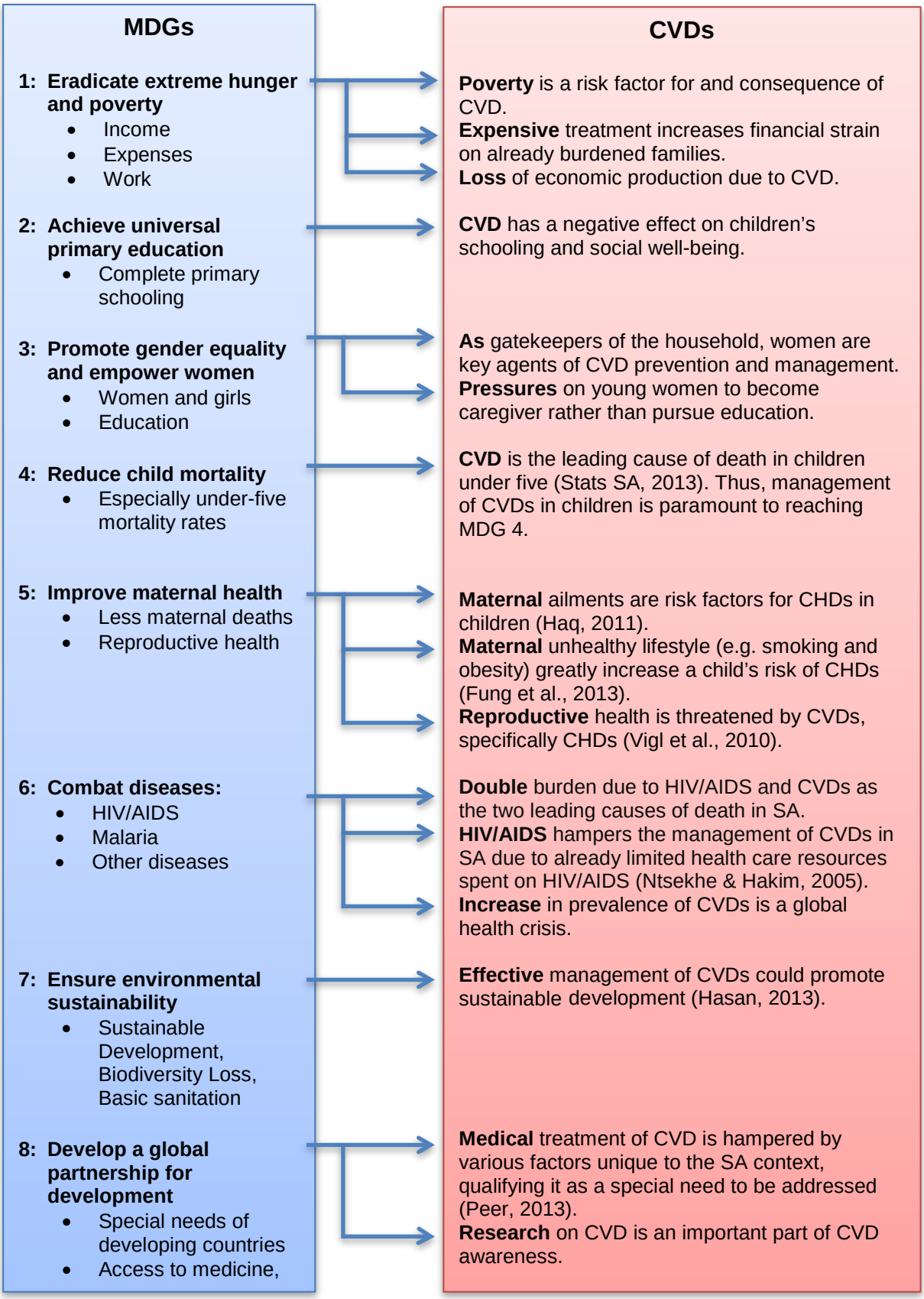

Figure 1. The effective management of CVDs, such as CHDs, will contribute to attaining the eight MDGs. Adapted from World Heart Federation (n.d.), and Fuster (2006).

This alternative view reflects the theme of the 5th South African Child Health Priorities Conference of "Closing the Gaps – Beyond Child Survival" (Saloojee, McKerrow, & Van der Vyver, 2015), where health care practitioners and researchers alike were encouraged to move away from traditional notions focussed on child survival and the absence of disease towards reflecting on how best to promote the well-being, resilience, and capability of children in South Africa. Three subthemes were highlighted, namely (a) local initiatives to take stock of and to enhance child survival; (b) an exploration of childhood development; and (c) a critical reflection on mental health.

This is an important shift given the fact that, with appropriate care, at least 85% of children with a CHD are expected to survive to adulthood (Warnes et al., 2001). Thus, a child with a CHD becomes an adult with a CHD, as indicated by the frequent continuation of childhood cardiac symptomatic patterns into adulthood (Thomas, Olusoji, & Awolola, 2013). Unfortunately, the psychosocial challenges that these children are likely to experience could also persist into adulthood (Kovacs & Utens, 2015). Thus, Dr Gerard Martin, co-director of the Children's National Heart Institute in Washington, DC, encourages health care practitioners to not only focus on repairing the congenital heart defect at the time that it is detected, but also to gain deeper understanding of the experience of the patient (Martin, 2014). Dr Martin understands that a CHD is a lifetime condition affecting various areas of the patient's functioning and thus far more than a mere structural abnormality of the heart.

In the light of the abovementioned argument, the health and well-being of children with a CHD needs to be a priority, a principle adopted through the ratification of the United Nations Convention of the Rights of the Child in 1989 (United Nations, 1989). In line with this convention, there is growing recognition that the input of children with regard to health-related decisions should be sought (Jamieson & Lake, 2013; Kendall, Sloper, Lewin, & Parsons, 2003).

This chapter aims to show the importance of exploring and raising awareness about the experiences of these children to promote and provide comprehensive treatment, specifically considering prominent psychological themes that are present in the lives of these patients. This aim is achieved by providing an overview of the functioning of the normal human heart, a detailed explanation of the concept of a CHD, the developmental stage of middle childhood, as well as a sound theoretical framework – the developmental psychopathology model (DPM).

2.2 The Functioning of a Normal Heart

"The human heart is a remarkable organ. It is the first organ to develop in the embryo, beating and pumping blood to the foetus at only seven weeks. Its resilience sustains us for a lifetime. For all that has been studied and written about the heart, it remains one of the most complex organs in the human body" ("The Heart of the Matter", 2014). To illustrate its complexity, the following section focuses on the functioning of a normal heart to support the understanding of a CHD.

The normal heart is a strong, hardworking pump made of specialised muscle tissue, which pumps blood through the blood vessels of the circulatory system (Taber & Venes, 2009). The heart has four chambers. The upper two chambers are the called the atria, and the lower two are the ventricles.

Figure 2 illustrates the four chambers of the heart. A wall of tissue, called the septum, separates the chambers. In a normal, healthy heart, blood is pumped through the chambers. This process is facilitated by four heart valves that open and close to let the blood flow in one direction. The four heart valves are the (a) *tricuspid valve*, located between the right atrium and the right ventricle; (b) the *pulmonary valve* between the right ventricle and the pulmonary artery; (c) the *mitral valve* between the left atrium and the left ventricle; and (d) the *aortic valve* between the left ventricle and the aorta.

Each valve has a set of "flaps" to prevent the backflow of blood. Normal, healthy blood flow is a circulation in series that flows in a pattern of *body-heart-lungs-heart-body*. As indicated in Figure 2-1, bluish blood low in oxygen (desaturated) flows back to the heart after circulating through the body. It returns to the heart through the systemic veins and enters the right atrium (Guyton & Hall, 2011). Figure 2-2 illustrates how the right atrium empties blood through the tricuspid valve into the right ventricle, which is dominantly a passive process. The right ventricle pumps the blood under low pressure through the pulmonary valve into the pulmonary arteries (Figures 2-3, 2-4). From there, the blood goes to the pulmonary microvasculature where gas exchange (oxygenation) takes place (Figure 2-5). After the red cell haemoglobin has taken up oxygen, the blood turns a bright red colour, after which it returns to the left heart through the pulmonary veins to the left atrium, as indicated in Figure 2-6 (Gordon Betts et al., 2013). Figures 2-7 and 2-8 illustrate how, from there, it passes through the mitral valve and enters the left ventricle. Figures 2-9 and 2-10 show how the left ventricle then ejects the oxygen-rich blood through the aortic valve into the aorta, which takes

blood to the general circulation of the body (American Heart Association, 2011). This circulation pattern of *body-heart-lungs-heart-body* is then repeated.

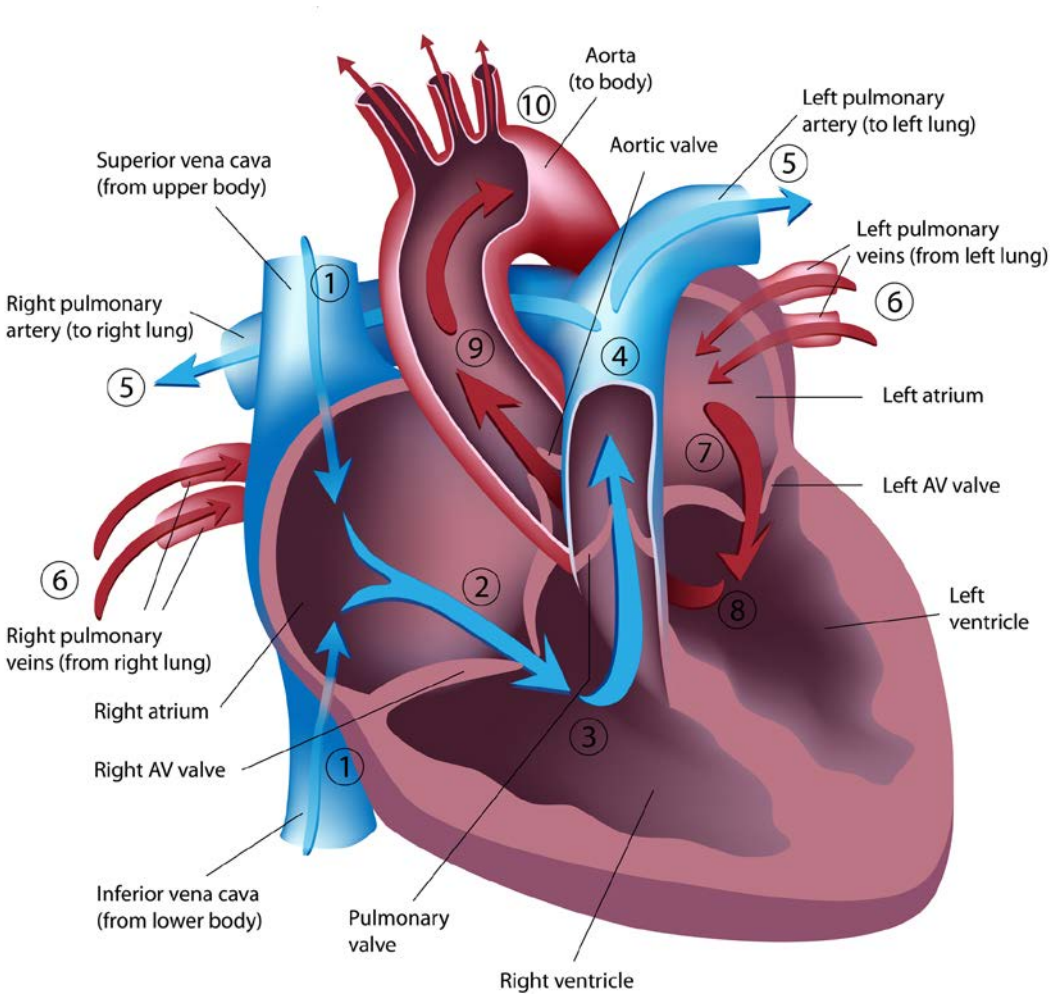

Figure 2. The pathway of blood flow sequence through the heart in a body (1) – heart (3) – lungs (5) – heart (6) – body (10) sequence. Reprinted from *Dreamstime* by ID 19337291, 2007, Retrieved from http://www.dreamstime.com/photos-images/blood-flow-human-heart.html#details19337291. Copyright 2007 by Alila. Reprinted with permission.

2.3 Congenital Heart Defect (CHD)

2.3.1 A non-communicable disease (NCD)

CVD, such as a CHD, is considered as a non-communicable disease, which is defined as a medical condition that is not mainly caused by infection, is non-transmissible between people, usually of long duration, and generally slow in progression. It results in long-term health consequences and often creates a need for long-term treatment and care (World Health Organization, 2015). Therefore, CHD is classified as a chronic condition – a health problem that requires ongoing management (Department of Health, 2002). Worldwide, NCDs

represent 63% of global deaths, of which 80% occur in low- and middle-income countries, and it is predicted that it will be responsible for 73% of all deaths by 2020 (World Health Organization, 2016b). CVDs, which include CHDs, are one of the leading NCDs globally, as they account for the largest fraction of deaths related to NCDs, followed by cancer, chronic obstructive pulmonary disease, and diabetes (Murray & Lopez, 2013). Moreover, sub-Saharan Africa has the challenge of dealing with what is called "a double burden of disease" (Peer, 2015, p. 2) in the sense that infectious diseases, such as HIV/AIDS and tuberculosis (TB), are high, while NCDs are rising rapidly. Therefore, CVDs such as CHDs are responsible for a considerable proportion of the burden of NCDs, as explained by Bloom et al. (2011). They label CVD as a dominant contributor to the global economic burden of NCDs. This finding can be extrapolated to the South African context, where 52% of total deaths in 2014 were due to NCDs, of which 35% were CVDs. Figure 3 illustrates this statistic as well as other fractions of NCD deaths in South Africa in 2014.

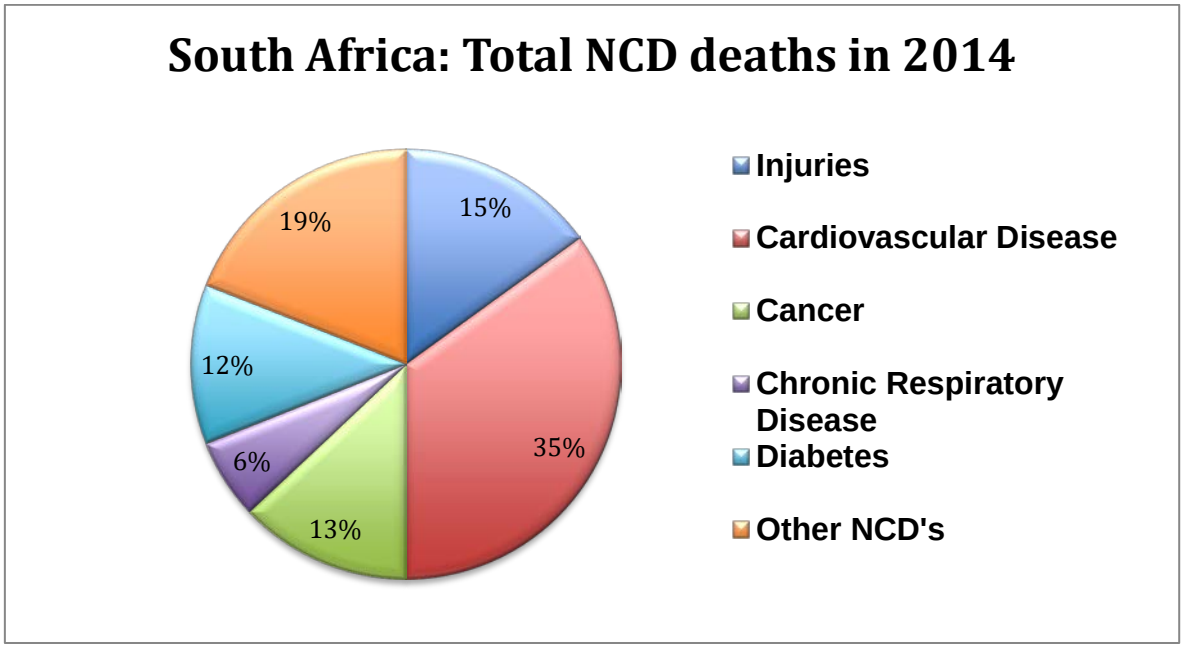

Figure 3. Cardiovascular Disease is the most common non-communicable disease that contributed to the total number of NCD deaths in South Africa in 2014. Adapted from "Noncommunicable Diseases Country Profiles 2014" by World Health Organization, 2014. Retrieved from http://www.who.int/nmh/countries/zaf_en.pdf. Copyright 2014 by the World Health Organization.

In South Africa, the major non-communicable diseases are CVDs, diabetes, cancer, chronic respiratory diseases, and mental illness (Mayosi et al., 2009). Furthermore, Day et al. (2014) provide statistics on the increase of mental illness as a prominent NCD in South Africa, by highlighting its increase in prevalence from 0.3% in 2008 to 1.4% in 2013. The growing awareness of mental illness as an NCD of note is an important part of the shift in focus from

communicable diseases to NCDs with a focus on longer lives lived with a disability (Whiteford et al., 2013).

Puoane, Tsolekile, Sanders, and Parker (2008) reviewed efforts for the prevention and management of NCDs in a South African context and highlighted the following shortcomings in the control of non-communicable diseases in South Africa:

- Awareness campaigns for non-communicable diseases do not reach the target audiences, especially the rural population, due to poor infrastructure and inadequate communication facilities.
- A lack of integration of health care programmes.
- The need for research, especially in impoverished areas of South Africa.

There is a need for the development of strong models for chronic care management (The NCD Alliance, 2011), as medical and nursing curricula emphasise curative care, rather than a comprehensive approach that encompasses prevention, promotion, and rehabilitative aspects (Steyn & Levitt, 2006). Importantly, despite the emphasis of the NCD Alliance (2011) that non-communicable diseases and their risk factors have a major effect on the health of children, there is an unfortunate misconception that non-communicable diseases do not affect children (The NCD Alliance, 2011). Childhood and adolescence are crucial times for the prevention of NCDs. A life-course approach to prevention, diagnosis, and management may result in significant gains in health outcomes, global productivity, and health care savings (Proimos & Klein, 2012). In general, chronic illnesses are known to affect the psychological and physical development of the child (Huff, McClanahan, & Omar, 2010). Moreover, the alarming statistics about the growing burden of NCDs in general and CVD and mental illness in particular, contributed to the motivation for the study on the psychosocial themes of children with a CHD.

2.3.2 Definition

CVDs can be categorised into six types, namely ischemic heart disease, cerebrovascular disease (stroke), peripheral vascular disease, heart failure, rheumatic heart disease, and CHDs ("Six Types of Cardiovascular Disease", 2010).

CHD is defined as an anatomic malformation of the heart or great vessels, which occurs during the intrauterine developmental stage (Rao, 2012), affecting the normal flow of blood through the heart. It is a childhood disease; yet, it is not preventable by vaccination. The birth defect causes the most infant deaths (Yang et al., 2006). However, it is not a noticeable one and therefore does not necessarily draw immediate attention (Children's Heartlink, 2015).

CHDs may involve problems with a valve, a chamber, the septa, an artery or blood flow (American Heart Association, 2011) and can either be simple or complex (Hundley et al., 2010). Certain types of heart defects, such as rheumatic heart disease, are not present at birth but acquired at a later stage (World Heart Federation, 2012). Therefore, heart defects are divided into congenital and acquired defects (Eze & Ezemba, 2007).

2.3.3 Classification

CHDs are classified into cyanotic and acyanotic, depending upon whether the patients clinically exhibit cyanosis – a physical sign of a lack of oxygen in the blood causing bluish discoloration of the skin and mucous membranes (and blood oxygen saturation of < 85%).

2.3.3.1 Cyanotic

Cyanotic heart disease refers to a group of heart defects that are present at birth and result in a low blood oxygen level ("Cyanotic heart disease", 2015). As explained above, in a normal heart, blood returns from the body and flows through the heart and lungs. Heart defects with which children are born can change the way blood flows through the heart and lungs which causes desaturated blood to be pumped out to the body. There is virtually continuously mixing of saturated and unsaturated blood, resulting in less oxygen delivered to the body. This causes the skin to appear blue, a condition named cyanosis – referred to as *systemic arterial desaturation* (Rao, 2012).

The most common cyanotic defects are Fallot's tetralogy and transposition of the great arteries. Some of these defects involve the heart valves. Heart valve defects that can cause

cyanosis include (a) the tricuspid valve (the valve between the two chambers on the right side of the heart) that might be absent or unable to open wide enough; (b) the pulmonary valve (the valve between the heart and the lungs) that may be absent or unable to open wide enough; and (c) the aortic valve (the valve between the heart and the blood vessel to the rest of the body) that might be unable to open wide enough.

In addition to the main symptom of cyanosis, children may present with dyspnoea (breathing problems/shortness of breath); that is, spells in which the body is suddenly starved of oxygen. During these spells, symptoms may include anxiety, hyperventilation, and a sudden increase in bluish discolouration of the skin. Infants may become tired or sweat while feeding and may not gain as much weight as they should. In addition, syncope (fainting) and chest pain may occur. Other symptoms depend on the type of cyanotic heart disease and may include feeding problems or reduced appetite, leading to poor growth, greyish skin, puffy eyes or face, and chronic tiredness (Webb, Smallhorn, Therrien, & Reddington, 2011).

2.3.3.2 Acyanotic

Acyanotic heart disease is a group of heart conditions where blood with oxygen mixes with blood with little oxygen in the heart, also referred to as left-to-right shunts (Khan Academy, 2016).

Acyanotic defects are subdivided into obstructive lesions and left-to-right shunt lesions. In the case of the latter, blood is shunted (flows) from the left side of the heart to the right side of the heart due to a structural defect (hole) in the interventricular or interatrial septum (Pillitteri, 2013). Lesions with left-to-right shunts include atrial septal defect, ventricular septal defect, and patent ductus arteriosus. Obstructive lesions include pulmonary stenosis (narrowing of the pulmonary valve), aortic stenosis (narrowing of the aortic valve), and coarctation of the aorta, which refers to the narrowing of a certain part of the aorta (Groenemeijer, Bakker, Slis, Waalewijn, & Heijmen, 2008).

These babies are a “pink” colour (not bluish as in the case of a cyanotic heart defect) and present with symptoms of congestive heart failure, which may include poor weight gain, feeding or exercise intolerance or prolonged recovery from respiratory infections (Rao, 2005).

2.3.4 Aetiology

The exact cause of CHDs is not known (American Heart Association, 2010). CHDs arise from various distinct aetiological risk factors, ranging from genetic or genomic variation to exposure to teratogens, which elicit diverse cell and molecular responses during cardiac development (Lage et al., 2012). Most CHDs can be explained by the *multifactorial inheritance hypothesis* – a theory that was originally developed by Nora (1968), as cited in Krishnamoorthy (2013). This hypothesis is supported by Payne, Johnson, Grant, and Strauss (1995) as well as by Blue, Kirk, Sholler, Harvey, and Winlaw (2012). According to this hypothesis, when exposed to a given environmental trigger (to which the foetus may be sensitive) during the critical period of cardiac morphogenesis, a predisposed foetus is likely to develop a heart defect. This genetic and environmental interaction, also referred to as *epigenetics*, is most likely to be the pathogenic mechanism of CHD (Hinton, 2013).

Reliable information about worldwide birth prevalence of congenital heart defects may lead to better insight into its aetiology (Van der Linde et al., 2011).

2.3.5 Prevalence

Birth defects such as Down's syndrome, foetal alcohol spectrum disorders, spina bifida, cleft lip, and neuromuscular diseases are often thought to be the most common birth defects. Generally, CHD is not considered as a common birth defect ("The Heart of the Matter", 2014). However, every fifteen minutes, a child is born with a CHD – a number that translates to 1% of the population worldwide (Reller, Strickland, Riehle-Colarusso, Mahle, & Correa, 2008). Therefore, CHD is viewed as a major global health problem (Dolk, Loane, & Garne, 2011).

Before the introduction of advanced echocardiography, a test that uses sound waves to create images of the heart (Stedman, 2000), incidence figures ranged from five to eight per thousand live births. However, better diagnosis has enabled the detection of milder forms of CHD, which brings current estimates to a range from eight to twelve per thousand live births (Hoffman, 2013). Van der Linde et al. (2011) found that, from 1930 to 2010, the reported total CHD birth prevalence increased substantially from 0.6 per 1000 live births to 9.1 per 1000 live births. With a worldwide annual birth rate around 150 million births, this corresponds with 1.35 million live births with CHD every year (Van der Linde et al., 2011). This statistic is indicative of a major public health issue.

Apart from infectious diseases, CHDs account for more deaths in the first year of life than any other condition (World Health Organization, 2011). The incidence is constant worldwide, across geographic and ethnic backgrounds, in spite of variations in socio-economic conditions ("Global Report on Pediatric Cardiac Disease – Linked by a common purpose", 2007; Wyszynski, Correa-Villaseñor, & Graham, 2010). Therefore, it is valid to extrapolate these estimates to developing nations.

In Africa, children's health issues are particularly prominent because of the large "youth bulge" in population distribution, with the bulk of African countries having a very young population (Mubila, 2012). Until recent years, a popular belief was held throughout the world that cardiac diseases were rare among Africans (Eze & Ezemba, 2007). This picture has changed dramatically. Hewitson and Zilia (2010) confirm that a third of African children affected by CHDs will die in their early years. Those who live longer are likely to be debilitated by the condition (Thakur, Negi, Ahluwalia, & Sharma, 1997). In African populations, the epidemiological data are still scarce. Some African studies released in countries like Nigeria, South Africa, Mozambique, and Angola showed prevalence of 2 to 12% (Mocumbi, Lameira, & Yaksh, 2011; Sadoh, Uzodimma, & Daniels, 2013).

Of the one million children born annually in South Africa, 8 000 will have a congenital heart defect, of whom 4 500 will require surgery. Every year, 3 000 children either die of or remain affected by the symptoms of a congenital heart defect (Hoosen et al., 2011).

Owing to better conditions in diagnosis and early medical and surgical treatment, patients have a much better chance of survival and a substantially increased life expectancy (Apers et al., 2013). However, these patients continue to face a variety of adversities, including physical, socio-economic, psychosocial, and other environmental challenges.

2.3.6 Biopsychosocial burden

Children with CHDs are biologically and physically at risk for associated diseases, more specifically infective endocarditis, which could result in considerable morbidity, decreased longevity, and lengthy and costly treatment (Hoffman, 2013). They also have an increased chance of associated defects in several other organ systems as well as neurodevelopmental problems. For example, Marino et al. (2012) posits that moderate to severe neurodevelopmental disabilities occur in over 50% of children with severe CHDs and 25% in those with less severe abnormalities.

The socio-economic burden of supporting patients with a CHD falls heavily on countries such as South Africa, where the high fertility rates, result in more cases of patients with CHDs ("Determinants and Consequences of High Fertility", 2010). High fertility rates result in higher birth rates, which in turn results in more children born with CHDs. This occurrence is influenced by the age structure of a given population in the sense that countries with high fertility rates have a higher proportion of younger people, as is the case with South Africa. The census of 2011 indicates a median age of 22 to 25. As mentioned earlier, the "youth bulge" and the high fertility rate in South Africa are the main contributing factors to the current population age structure (Lehohla, 2015). Countries with the highest fertility rates tend to have the lowest incomes per capita (Hoffman, 2013) – a reality that exacerbates the economic effect of CHD. For example, additional costs to CHDs beyond costly surgical treatment include medical treatment, cost of transport to hospital (a common challenge in many parts of Africa), and loss of parental working time when they have to take the children to a medical centre (Hewitson & Zilia, 2010).

In addition to the biological and socio-economic burden, a variety of psychosocial challenges are at play (British Cardiac Society, 2002), seeing that a major physical illness usually has an effect on the psychological well-being of any individual, regardless of age (Fischer & Collins, 2012). A summary of the research conducted by Johnson (2015), Johnson & Francis (2005) as well as Van Rijen & Utens (2010) confirm the fact that a major physical illnesses, such as a CHD, usually have an impact on the psychological well-being of any individual. An illness of early onset, that requires frequent diagnostic and therapeutic interventions can adversely affect the emotional functioning and behavioural adaptation of children and adolescents with a CHD.

Various studies confirm the fact that children with CHDs are considered to be at increased risk of psychological difficulties (Fekkes et al., 2001; Kovacs, Saidi, & Kuhl, 2009). For example, Spijkerboer, Utens, Bogers, Verhulst, and Helbing (2008) found that parents of children with a CHD reported higher levels of behavioural and emotional problems in their children, compared to the reference group. Masi and Brovedani (1996) describe specific psychological aspects present in children with a CHD. These include the inhibition of thoughts and emotions, anxiety, depressive reactions, feelings of loneliness, low self-esteem and inadequacy, impulsivity and weakness of self-identity. In addition, Yildiz, Savaser, and Tatlioglu (2001) found aggressive behaviour and somatic complaints present in children with a CHD.

Children with CHDs have more medical fears and more symptoms of anxiety than normal peers have (Gupta, Mitchell, Giuffre, & Crawford, 2001). In addition to a predisposition to develop low self-esteem and psychological distress, children with CHDs are at particular risk for poor school adjustment (Johnson, 2015). In contrast to the developmental milestones of their age, older children with CHDs are at greater risk for internalising their problems (Karsdorp et al., 2007). The development of a healthy body image could also be compromised (Officioso et al., 2000), which in turn could affect a child's self-esteem negatively.

Furthermore, Connolly, McClowry, Hayman, Mahony, and Artman (2004) found that children who had surgery for a CHD had clinically significant indicators of posttraumatic stress disorder following surgery. Medical intervention for CHDs usually involves open-heart surgery, cardiopulmonary bypass, cooling of the body, and post-operative intensive care in an intensive care unit (ICU). These are common major stressors related to the experience of a CHD (Menahem, Poulakis, & Prior, 2008). Latal, Helfricht, Fischer, Bauersfeld, and Landolt (2009) conducted a systematic review of long-term psychological adjustment of children with a CHD requiring open-heart surgery and found that a considerable proportion of children experienced psychological maladjustment.

Importantly, regardless of the intensity of medical intervention, children with a CHD are at risk and vulnerable to psychological difficulties and issues with other areas of functioning, which may jeopardise normal development (Biehl, Park, Brindis, Pantell, & Irwin, 2002). To illustrate, children exposed to strong, frequent, and/or prolonged adversity or toxic stress are at risk for cognitive impairment and stress-related illnesses. Toxic stress causes over-activation of the stress response system; therefore, the body is constantly in a heightened state of arousal, which disrupts normal brain and organ development and, consequently, damages neurological systems. The result could be poor academic performance, a lack of social competence, and an inability to regulate emotions, for example (Sandstrom & Huerta, 2013).

To highlight the coming of age and importance of a focus on the psychosocial themes in children with a CHD further, both retrospective and prospective research has shown that most mental disorders in adulthood begin in childhood and adolescence (Johnson & Francis, 2005; Kessler et al., 2007). It has been shown that even adult cognitive abilities have been impaired in part by elevated chronic stress during childhood (Evans & Schamberg, 2009). According to

Moore, Vandivere, and Ehrle (2000), children in middle childhood with three or more risk factors of "turbulence" (see para. 1) are twice as likely to develop behavioural and/or emotional problems. They define turbulence as two or more of six possible changes in residence, school, parental employment, or health.

Thus, it is evident that biopsychosocial factors play a significant role in children with CHDs, which might affect the child's developmental outcomes and prognosis. To conceptualise the interplay between CHD and normal development in children aged 8-14 accurately, it is important to be cognisant of normal developmental milestones of middle childhood, especially because children's understanding, perceptions, and attitudes about health behaviour develop rapidly during middle childhood (Biehl et al., 2002).

2.4 The Developmental Stage of Middle Childhood

Middle childhood and early adolescence pose various similarities (Eccles & Wigfield, 2000) as both are characterised prominently by a psychological need to achieve competence, autonomy, and relatedness to peers (Connell & Wellborn, 1991). It is a time of important developmental advances that establish a child's sense of self (Eccles, 1999).

These transformations in self-understanding have a major effect on children's self-esteem. A key contributing factor that accounts for these changes in self-concept is cognitive development, which affects the structure of the self. For example, children in middle childhood and early adolescence can better coordinate several aspects of a situation in reasoning about their physical world. Similarly, in the social domain, they combine typical experiences and behaviour into psychological dispositions, blend positive and negative characteristics, and compare their own characteristics with those of their peers (Harter, 2006).

Berk (2010) illustrates how a child's self-esteem is influenced by various developmental domains, including the biological, psychological, and social domains.

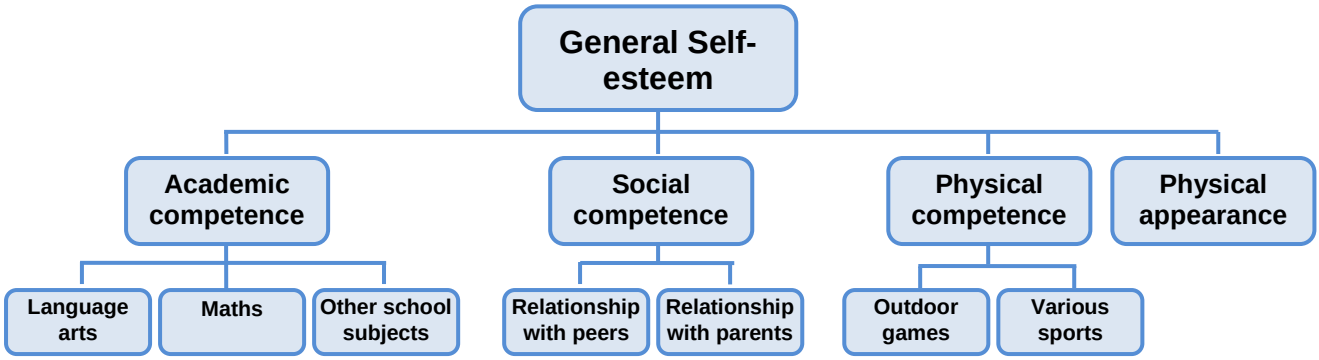

Figure 4. A child's self-esteem is influenced by various developmental domains, including the biological, psychological, and social domains. Adapted from *Development Through the Lifespan* (5th ed., p. 331), by L. E. Berk, 2010. Boston, MA: Allyn & Bacon. Copyright 2010 by Pearson Education, Inc.

According to Erikson (1968), the combination of adult expectations and children's drive toward mastery sets the stage for the psychological conflict of middle childhood, termed "industry versus inferiority". The ideal is for the child to develop competence (industry) rather than inferiority. This developmental milestone is resolved positively when children develop a sense of competence at useful skills and tasks. The failure to master trust, autonomy, and industrious skills may cause the child to doubt his or her future, leading to shame, guilt, and the experience of defeat and inferiority.

Schwartz, Gorman, Nakamoto, and Toblin (2005) provide an example of how difficulties in these domains of development can have negative implications for children's emerging self-concepts. They found that deficient academic performance is associated with depression and other forms of internalised distress.

Furthermore, children's behaviour in the peer group has proven to be a stable indicator of their social competence (Zeller, Vannatta, Schaffer, & Noll, 2003). A positive climate for social and moral growth is one that fosters peer interaction (Nucci, 2001). A sense of relatedness may function as a motivational resource when children face challenges or difficulties. Furrer and Skinner (2003) found that in times of stress, children who experience significant others as being supportive, respond with more vigour, flexibility, and constructive actions. A study conducted by Schwartz, Gorman, Duong, and Nakamoto (2008) highlights the fact that positive experiences in one domain could mitigate the risk for less desirable outcomes in another domain. For example, they found that depressive symptoms associated with poor academic performance were less in children who had positive peer relations. Based on this important finding, one can argue that possible problematic outcomes because of CHD

could be mitigated by the attainment of key developmental milestones during middle childhood, i.e. competence, autonomy, and relatedness to peers.

Shifting the spotlight from peer relatedness to family interaction, attachment theories explain the long-term effects of secure versus insecure attachments to caregivers (Ainsworth, 1979; Bowlby, 1969). From this theoretical viewpoint, relationship representations are referred to as *internal working models of attachment figures* (Crittenden, 1990). Secure attachments and their corresponding internal representations function as a safe psychosocial space, allowing children the freedom to explore and to engage constructively in activities and interactions with others. The fact that the presence of CHD can influence mother-infant interactions during a crucial period of the infant's psychological development and thus adversely affect the mental health of the child (Johnson & Francis, 2005) signifies the importance to explore the psychosocial themes of children living with a CHD.

In addition, Demby, Riggs, and Kaminski (2015) highlight the importance of the family system, especially parent-child attachment, in the determination of children's development. They examined the role of family interaction patterns in associations between parent-child attachment and psychological adjustment among eight- to eleven-year-old children. The results of this study highlight dyadic attachment (i.e. two attachment figures) and family interaction patterns as two important factors that foster positive emotional and behavioural outcomes in children. Even though recent studies indicate no significant difference in the family interactions of children with a CHD, there are some indications that it needs to be monitored (Herzer et al., 2010; McClellan & Cohen, 2007). However, earlier findings suggest that family interaction has been found to be lower in young people with chronic conditions (Silver et al., 1990), which might be due to the restrictions on lifestyle inherent in many chronic conditions. These restrictions might increase dependence on the family when it should be decreasing progressively from middle childhood to early adolescence (Eiser & Berrenberg, 1995). Rawatlal, Kliewer, and Pillay (2015) found that positive family interactions are predictive of a secure parent-child attachment relationship and reduce the risk of developing depression in the age group of 9-18 years. Children with secure attachment to their primary caregivers presented with emotional regulation and insight, which is labelled as a critical factor in psychological health (Barish, 2013). This is in line with Macklem's (2007) statement that children learn emotional regulation from their primary caregivers.

Clearly, middle childhood and early adolescence are stages during which important bio-psychosocial developmental advances take place. Based on this crucial time of multiple developmental changes and the interplay between the various areas of functioning, there was a need for a conceptual framework that would organise data accurately and extensively to make sense of and present the findings of this study (the psychosocial themes of children with a CHD) in a well-structured manner. Consequently, the DPM (Achenbach, 1990) was selected as a theoretical framework for this study.

2.5 Theoretical Framework: Developmental Psychopathology Model (DPM)

2.5.1 Rationale

Instead of attempting to resolve the well-known debate of nature versus nurture, advances in various disciplines such as neuroscience, molecular biology, developmental psychology, epidemiology, and sociology have contributed to an alternative perspective on the complex interactions between nature and nurture in development across the human lifespan (Sameroff, 2010). This multidisciplinary scientific perspective is the foundation to an important paradigm shift that has taken place regarding the understanding and conceptualisation of health and illness across the lifespan, which has come to be known as developmental psychopathology (Cicchetti, 2016).

Developmental psychopathology allows for the enhancement of life prospects of children with a cascading effect on other important aspects of society, such as its social and economic status (Shonkoff et al., 2012). Developmental psychopathology focuses on various domains of functioning, emerging patterns of adjustment, and the interplay between normality and pathology (Cicchetti & Cohen, 2006; Sameroff, 2000).

A developmental psychopathology approach is guided by developmental systems theory (Bronfenbrenner, 1977; Granic & Hollenstein, 2003), which proposes that human beings are living systems and part of a larger operating system of potential influences that shapes development. The systems that influence behaviour become increasingly complex and distal as the child ages (Sroufe, Egeland, Carlson, & Collins, 2005).

The idea of co-occurrence of multiple factors influencing adaptation refers to the idea that individuals who begin with similar behavioural patterns may end up at very different developmental outcomes (i.e. *multifinality*), while those with different initial behaviour can manifest very similar outcomes, a concept referred to as *equifinality* (Luyten, Vliegen, Van

Houdenhove, & Blatt, 2008). These outcomes may be within the range of normal development or abnormal development, i.e. pathology.

Sroufe (1990) explains the concept of normality and pathology by using the analogue of a tree: Normal development can be understood in terms of growth close to the trunk of the tree, whereas abnormal development is reflected in branches growing further from the tree. Thus, pathology is defined by successive and changing patterns of deviation from normality. Such deviation is a result of the interplay between intrapersonal processes and external forces. Regarding psychopathology, the value of the DPM lies in its usefulness to address multifaceted mental health issues by providing an important framework to inform clinical decision-making (Drabick & Kendall, 2010). The DPM has been found useful in the conceptualisation and management of a wide range of psychological conditions, including attention deficit/hyperactive disorder, conduct disorder, anxiety disorders, depressive disorders, bipolar disorders, autism, and schizophrenia (Drabick & Kendall, 2010).

An important intrapersonal factor that serves as a mediator for the emergence of possible psychopathology is resilience. The DPM makes provision for the fact that most children at risk for developmental difficulties still achieve positive developmental outcomes due to the possibility of multiple developmental pathways diverging from any specific starting point. Resilience can be defined as reduced vulnerability to risk experiences regardless of the source, the overcoming of a stress or adversity, or a relatively good outcome despite risk experiences (Rutter, 2012). Developmental psychopathologists use the term *resilience* to refer to children who develop competently and adapt successfully to life's challenges under adverse conditions and therefore have the ability to "bounce back" after adverse experiences. It is a complex process that may vary across context (e.g., subculture or culture), domain of functioning (e.g., academic, social, or emotional), and developmental stage (Cummings, Davies, & Campbell, 2000). The foundational premise of the DPM is the study of the basic mechanisms that cause developmental pathways to diverge toward pathological or typical outcomes (Wenar, Kerig, & Ludlow, 2012). Thus, the rationale of the DPM conceptual framework allows for exploration of children's experiences of a CHD (i.e., an abnormal biological factor) in their development across functional domains.

2.5.2 Domains

To organise the complex interactions among functional domains and integrate knowledge across scientific disciplines into a coherent, holistic view, a systematic multi-domain approach is required (Marshall, 2013).

Table 1 illustrates Cicchetti's (2006) summary of the DPM in general practice and examples of how I considered these principles relate to the study of the psychosocial themes of children with a CHD.

Table 1a

Use of the DPM in General Practice and in the Study of the Psychosocial Themes of Children with a CHD

General Practice	**The psychosocial themes of children diagnosed and living with a CHD**
Comprehension of and appreciation for the *developmental transformations* that occur throughout the human lifespan.	**This study is very specific in terms of the age range in the inclusion criteria, given the fact that information exchanged carries different meanings, interpretations, and perceptions, depending on the developmental stage.**
Continuous evaluation, consideration, and management of the *risk and protective factors* as the individual progresses through the various developmental stages.	**Any given number of children with the same type of CHD might experience life with the illness differently based on other biological, psychological, or social factors (risk or protective) that will influence their ability to deal with challenges related to the illness.**
Continuous evaluation, consideration and management of biopsychosocial processes *within and outside of the individual* in the course of development.	**This study included explorations of the child's intrapersonal (i.e., thoughts and emotions) as well as interpersonal functioning, such as their relationship with family and friends.**

Note. Adapted from "Development and Psychopathology" by D. Cicchetti (2016) in D. Cicchetti and D. J. Cohen, *Developmental Psychopathology: Theory and Method* (2nd ed.). Hoboken, New Jersey: John Wiley & Sons, Inc. Copyright 2006 by John Wiley & Sons, Inc.

Table 1b

Use of the DPM in General Practice and in the Study of the Psychosocial Themes of Children with a CHD

General Practice	**The psychosocial themes of children diagnosed and living with a CHD**
A strong focus on how the *developmental tasks unique to each developmental stage moderate the manifestation and onset of clinically significant signs and symptoms.*	**The successful attainment of industry (competence) could be compromised potentially, resulting in inferiority (poor self-esteem) if not monitored properly (Erikson, 1950).**
The recognition that a particular *stressor(s) may result in different biological, psychological, and/or social difficulties*, depending on the developmental stage of the individual at that point in time.	**A child in middle childhood with a CHD might develop the inability to take part in physical activities such as sport and may experience particular difficulties with relatedness to his or her peers.**

Note. Adapted from "Development and Psychopathology" by D. Cicchetti (2016) in D. Cicchetti and D. J. Cohen, *Developmental Psychopathology: Theory and Method* (2nd ed.). Hoboken, New Jersey: John Wiley & Sons, Inc. Copyright 2006 by John Wiley & Sons, Inc.

2.5.2.1 The biological domain

Adding to the already rich empirical evidence of the effects of early life experiences on normal development, there has been a remarkable advancement in the understanding of how human biological mechanisms affect development throughout the lifespan. In general, these advancements in the study of early experience and biology contribute towards the conceptualisation of many of the etiological complexities of mental health (Bush & Boyce, 2014).

Biological considerations as part of the DPM include (a) genetics; (b) neuropsychology (i.e. the development, structure, chemistry, and functioning of the brain); (c) medical factors such as illness and treatment thereof; and (d) the personality construct of temperament (Lewis & Rudolph, 2014).

2.5.2.1.1 Genetics

Genes can be defined as essential entities that direct the development and functioning of organisms by producing proteins that in turn regulate all the important cellular processes in

the human body; i.e., the “blueprint” for an organism. The concept of *genetic reductionism* concerns the idea that all biological phenomena are caused by genes and cause a variety of higher-level phenomena such as certain biological features (“Molecular Genetics”, 2007). O’Connor (2014) states that a discussion of the effect of genetics on developmental outcomes needs to emphasise molecular genetic findings. Molecular genetics is the field of biology and genetics that studies the structure and function of genes at a molecular level. The study of chromosomes and gene expression of an organism can provide insight into heredity, genetic variation, and mutations. This is useful not only in understanding and treating genetic diseases but also in developmental biology, as is relevant to the use of the DPM in this study (the psychosocial themes of children with a CHD).

2.5.2.1.2 Neuropsychology

In terms of neuropsychology, Gottlieb (2007) in his theory of probabilistic epigenesis argues that gene-environment interactions are fundamental to understanding development. Within this framework, the field that encompasses the neuroscience of developmental psychopathology must consider the multi-directional influences between genes, brain, behaviour, and environment. This process starts with the coding of genes for the synthesis of proteins that then influence brain development, organisation, structure, and function. However, the environment also influences neural development and alters the effect of genes through epigenetics (Meaney, 2010), a set of biological mechanisms that warrant the environment to modify genetic expression. Understandably, the brain is at the juncture of many of these genetic and environmental influences on mental health outcomes. In addition, the brain also acts as mediator of these reciprocal interacting influences and thereby provides a unique window into the development and treatment of psychopathology (Hyde, Bogdam, & Hariri, 2011).

Erikson (1968), a developmental psychologist, uses the term *epigenetic principle* to encompass the notion that we develop through an unfolding of our personality in predetermined stages (i.e., through genes), and that our environment and surrounding culture influence how we progress through these stages. In relation to our socio-cultural settings, this biological unfolding occurs in stages of psychosocial development, where progress through each stage is determined by our success, or lack of success, in all the previous stages (Boeree, 2006).

The brain undergoes selective pruning – a process in which some areas are enhanced, while others are diminished. This process is influenced by daily experiences that can result in new axonal projections and facilitate synaptic reductions and associations (Rappley & Kallman, 2009). Hence, despite any genetic predispositions for mental health or physical risk factors that a person may have, with proper nurturing and exposure to stimulating environments, it is possible to alter one's epigenetics and how one will perceive and interact with the world (Fish et al., 2004); thus, it relates to the importance of identifying psychosocial themes in children with a CHD.

2.5.2.1.3 Medical factors

Of specific interest in the context of exploring the psychosocial themes of children with a CHD is that medical complications occurring during pre- and perinatal developmental stages influence further developmental outcomes because many of the complications that affect premature infants reflect the immaturity of important biological systems (Blenner, Hironaka, Vanderbilt, & Frank, 2014). For example, the neurodevelopmental and psychosocial problems related to CHD often result in many of these patients not being able to attain otherwise possible achievements in various areas of functioning, including education, employability, insurability, and general quality of life (Kovacs et al., 2009; Van Rijen et al., 2003).

2.5.2.1.4 Temperament

Rothbart and Hwang (2005) provide a comprehensive definition of temperament by explaining that it is "constitutionally based individual differences in reactivity and self-regulation, displayed in the domains of emotion, activity, and attention" (p. 168). The authors of this definition of temperament use the word *constitutional* to explain that temperament systems are biologically based and influenced over time by genes, environment, and experience. Furthermore, *reactivity* refers to the onset, intensity, and duration of emotional, motor, and orienting reactions. The term *reactivity* can be used to describe broad behavioural dimensions, such as positive or negative emotional reactivity, as well as physiological reactions that are more specific, such as heart rate reactivity or fear-induced startle. According to Rothbart and Hwang (2005), temperament also includes *self-regulation*; that is, processes that serve to modulate reactivity.

Rettew and McKee (2005) provides a summary of Thomas and Chess's nine continuous dimensions of temperament in addition to three higher-order categories of "difficult", "slow-to-warm-up", and "easy", which include activity, regularity, initial reaction, adaptability, intensity, mood, distractibility, persistence, attention span, and sensitivity.

Research on temperament in children with a CHD indicates elevated emotional reactivity, which could possibly be an early indicator of continued emotional and behavioural problems (Stene-Larson et al., 2009).

2.5.2.2 The psychological domain

The psychological domain of the DPM consists of three subdomains, namely the cognitive, emotional, and behavioural subdomains. Cognitive processes involve the ways in which our memories, perceptions, thoughts, emotions, and motives guide our understanding of the world and our actions (i.e. behaviour). Therefore, emotion and motivation are intrinsic parts of cognitive processes (Wang, 2007). Thus, there is a reciprocal relationship between these three subdomains. Piaget's theory of cognitive development, developed in the 1950s, is a comprehensive theory about the nature of knowledge acquirement. According to Piaget, cognitive development is a progressive reorganisation of mental processes resulting from biological maturation and environmental experience. Piaget is of the opinion that children construct an understanding of the world around them, experience discrepancies between what they already know and what they discover in their environment, then adjust their ideas accordingly (McLeod, 2012). This theory substantiates the interplay between mental process, such as the three dimensions of the DPM psychological domain, namely the emotional, cognitive, and behavioural dimensions.

Sameroff (2010) proposes that contemporary theories of development require at least four models for understanding human psychological change, namely (a) a *personal* model, (b) a *representational* model, (c) a *regulation* model, and (d) a *contextual* model. Sameroff (2014) includes a fifth *evolutionary* model. Even though the focus of each of these models is different, all of them ultimately influence psychological developmental outcomes.

The *personal model* is necessary for understanding the progression of competencies. This is of special significance in the context of this study, given the notion that competency is an important developmental milestone during middle childhood (see Section 1.4). The personal model requires unpacking the changing complexity of the individual as he or she

moves from the sensorimotor functioning of infancy to increasingly intricate levels of cognition, from early attachments with primary caregiver(s) to relationships outside of the family system, e.g. with peers, teachers, and others in the world beyond home and school, and from the early differentiation of self and other to the multifaceted personal and cultural identities of adolescence and adulthood (Sameroff, 2010).

The *regulation model* adds a dynamic systems perspective to the relation between person and context. During early development, human regulation moves from the primarily biological to the psychological and social. What begins as the regulation of biological needs develops into the regulation of attention, behaviour, and social interactions (Sameroff, 2010). The regulation model needs to enjoy attention as part of the exploration of children with a CHD, seeing that the regulation of biological issues (CHD-related issues) play such a major role in their daily lives, that it might impede the ability to regulate other areas of functioning, such as attention and social interactions (Daliento, Mapelli, & Volpe, 2006; Gupta et al., 2001).

In the *representational model*, an individual's here-and-now experiences become encoded in cognition at abstract levels that form the interpretive "lens" for new experiences, as well as a sense of self and other (Sameroff, 2010). In the context of a child with a CHD, experiences related to the illness could determine how these children approach and deal with new experiences. This basic premise of the representational model is evident throughout the interview that was conducted as part of the exploration of psychosocial themes of children with a CHD, in the sense that questions included the topic of how these children think about and understand CHD.

The *contextual model* focuses on the multiple sources of experience that either boost or inhibit individual development. The growing child is increasingly involved with a variety of social settings and institutions that have a direct or indirect effect on their functioning, as explained by Bronfenbrenner's (1977) theory of social ecology. The contextual model is of particular importance in the social domain of the DPM (Sameroff, 2010). This model highlights the role of significant others such as primary caregivers, teachers, and even health care professionals in facilitating sources of experience for children with a CHD (Escudero, 2008).

Finally, Sameroff (2014) explains that the *evolutionary* model is necessary to explain the co-development of genetic polymorphisms and psychological and social functioning (as discussed in Section 1.5.2.1). Finally yet importantly, the evolutionary model confirms the choice of theoretical framework for the exploration of children with a CHD, namely the DPM, which encompasses biological, psychological, and social functioning.

Sameroff (2014) states that if these five models are combined, it offers a comprehensive view of the multiple parts, wholes, and interconnecting processes of human development, especially as they are related to psychopathology. The components of these five models are imbedded in the process to get a holistic picture in exploring the psychosocial themes in children with a CHD.

2.5.2.3 The social domain

The social domain of the DPM consists of two subdomains, namely *attachment* and *systems* (especially the family system). These two subdomains of social functioning form the overarching theme for a comprehensive definition of social processes, namely (a) the ways in which psychological functioning (emotions, cognition, and behaviour) are influenced by people outside of the individual; (b) the group(s) to which an individual belongs; (c) the individual's personal relationships with other people including parents, siblings, other family members, extra-familial individuals, and peers; (d) the influence of culture; and (e) the pressures an individual might experience from these social sources. Such pressure could translate into affected psychological processes. Thus, social and psychological processes (i.e., emotions, cognition, and behaviour) have intimate connections in the sense that social processes affect an individual not only when others are not physically present but also when others are present. Therefore, as mentioned earlier, an analysis of the social factors is important to gain insight into psychological processes in the social context (Bandawe, 2010). For example, research suggests that CHD can influence mother-infant interactions from the beginning, in a crucial period of the infant's psychological development and thus may affect the mental health of children and adolescents adversely (Johnson & Francis, 2005).

Two of the most prominent theories of culture and human development are the socio-ecological theory (Bronfenbrenner & Morris, 2006) and the socio-cultural theory (Vygotsky, 1978). Both these theories argue that culture influences socialisation, which in turn independently or in interaction with personal and social factors contributes to developmental outcomes. Culture may affect development through various processes such as facilitation and

subdual of specific behaviour (Weisz, Weiss, Suwanlert, & Chaiyasit, 2006). Furthermore, cultural norms and values may also provide a frame of reference for social evaluations of behaviour and thus result in certain cognitive perceptions of and emotional experiences to the behaviour (Chen, Fu, & Leng, 2014). For example, depending on the severity of CHD and subsequent surgical intervention, some children with a CHD might have a substantial scar on their chest because of cardiac surgery. Abnormal scars could cause unpleasant symptoms, including aesthetical distress, disfigurement, as well as psychosocial and functional disabilities (Bayat, McGrouther, & Ferguson, 2003), which suggests that in some social settings (i.e., cultures) scars might be perceived as a sign of weakness. This may have various implications for the biopsychosocial functioning of a child with a CHD. A few practical examples include reluctance to participate in social activities where the scar would be visible (such as swimming), the perception of being physically or psychologically "weaker" than others, with potentially detrimental effects on the child's self-esteem, which is an important psychosocial developmental aspect during middle childhood.

The developmental changes in the relationship between an individual and the context (i.e. the social domain of functioning) can be explained as an expanding cone in a cylinder, as illustrated by Figure 5.

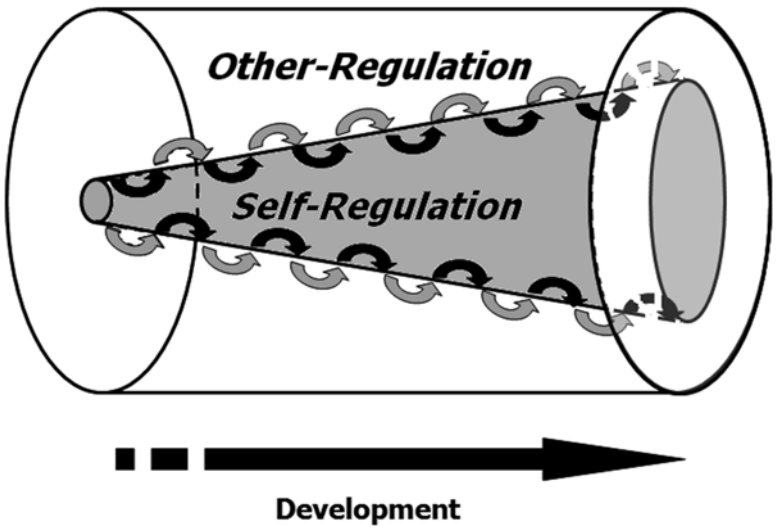

Figure 5. Transactional relations between self-regulation and other-regulation. Reprinted with permission from "A Dialectic Integration of Development for the Study of Psychopathology", by A. Sameroff, 2014, in *Handbook of Developmental Psychopathology* by M. Lewis and K. D. Rudolph. Copyright 2014 by Springer Science+Business Media.

As the child progresses through developmental stages, the balance between *other-regulation* and *self-regulation* shift, as the child is able to take on more and more

responsibility for his or her own well-being. Examples of *other-regulators* include parents (e.g., attend to their needs when they cry), peers (who contribute to knowledge about appropriate and inappropriate social behaviour), and teachers (who socialise children into group behaviour and contribute to cognitive-regulation skills). In the case of a child with CHD, an example includes the fact that other-regulators might constantly have to remind and assist children to take their medication, to keep their physical activity limited (in accordance with prescriptions from their medical doctors) and to provide guidance with regard to the way in which they understand and feel about their cardiac diagnoses and the related biopsychosocial restraints it places on their various areas of functioning. This regulation by others aids in the child's increased ability to self-regulate across the functional biopsychosocial domains.

Self-regulatory abilities are influenced strongly by the experience of other-regulation, especially the regulation provided by caregivers (Sameroff, 2014). This idea highlights the importance of consideration of attachment as part of the social domain of functioning of the DPM (Sameroff, 2014; Waters et al., 2010).

Given the interplay between the presence of a CHD (related to biological functioning) and other areas of development (i.e., psychological and social functioning), the DPM was the preferred theoretical framework for this study mainly because the DPM could be used to categorise major themes that arose from data analyses, which in turn aided in the conceptualisation of the influence of the presence of a CHD on other areas of development and vice versa, as illustrated in Figure 5.

2.6 Conclusion

James and Roberts (2009) advocate that research in clinical child and adolescent psychology should focus on investigating how various domains of functioning interplay in the development of psychopathology in children and adolescents. Furthermore, Allan and Fischer (2012) state that future research in the field of cardiac psychology should include the identification of psychosocial characteristics to maximise the physical and mental health of cardiac patients. They also promote a holistic view of an individual and the psychosocial factors unique to a given individual.

Therefore, the aim of this study was to explore the psychosocial themes of children with a CHD. Hence, the study is in harmony with the appeal of Allan and Fischer (2012) as well as

James and Roberts (2009) to promote the exploration of psychosocial characteristics present in individuals with a CVD, such as a CHD. It builds on the work of Baumeister and Härter (2007), namely to focus on aspects of psychosocial functioning to allow more effective intervention with regard to this patient population.

Ultimately, this study aims to contribute to the field of child and adolescent psychology also in a broader, comprehensive way by

- investing in the holistic well-being of the children of South Africa;
- providing comprehensive high-quality health care;
- moving towards achievement of MDGs in line with the principles of the United Nations Convention on the Rights of the Child; and
- building a scientific base for clinical psychological perspectives on this patient population.

Finally, the African proverb “Birds sing not because they have answers but because they have songs” (Dickson, 2013) encapsulates the aim of this research study, which, metaphorically speaking, is to learn the “lyrics and melody” of the “songs sung” by children living with a CHD.

CHAPTER 3: PRELIMINARY STUDY

First she tasted the porridge of the Great, Huge Bear and that was too hot for her. And then she tasted the porridge of the Middle Bear, and that was too cold for her. So she went to the porridge of the Little, Small, Wee Bear and tasted that, and that was neither too hot nor too cold, but just right, and she liked it so well she ate it all up … Then Goldilocks went upstairs into the bedchamber in which the Three Bears slept. And first, she lay down upon the bed of the Great, Huge Bear, but that was too high at the head for her. And next she lay down upon the bed of the Middle Bear, and that was too high at the foot for her. And then she lay down upon the bed of the Little, Small, Wee Bear, and that was neither too high at the head nor at the foot, but just right. So she covered herself up comfortably and lay there till she fell fast asleep.

– The story of The Three Bears (Nesbit et al., 1956, pp. 115-116)

3.1 Introduction

Similar to Goldilocks' search for a bed that would allow her to enjoy a peaceful, untroubled rest, a preliminary study is an opportunity for the researcher to refine various aspects of a research study to promote seamless execution of the main study. The main goal of conducting a preliminary study is to assess the viability of a research study in order to avoid potential adverse consequences of embarking on the main study that potentially could "drown" the entire research effort (Thabane et al., 2010, p. 1).

Sampson (2004) uses the analogy of a ship at sea, approaching the harbour, to highlight the importance of conducting a preliminary research study. In the same way a harbour pilot is responsible for navigating a large ship through dangerous waters into a port, a preliminary study can act as a pilot guiding the researcher through the "unpredictable waves" of the selected field of research. It can reduce the number of unanticipated problems during the main study markedly because of the opportunity to redesign parts of the study to overcome difficulties that might become evident because of the preliminary study. Such reworking of study elements could minimise problems associated with "unreflecting emersion" in the field under study (Gumbo, 2014, p. 386).

In addition, by conducting a preliminary study, the researcher receives useful insights that might otherwise not have been noted. Woken (2006) explains that such insights increase

the chances of getting richer and more accurate findings in the main study. It also has the innate quality of focusing the information gained during the research process. Sampson (2004) encourages researchers to keep a preliminary study objective-focused by warning that "immersion in the field without pre-exposure can provide a researcher with a feast of fascinating information but not knowing where to start" (p. 388-389). Such a showering of information diminishes the mystery of inquiry but leaves much unknown.

Furthermore, a preliminary study requires an account of what a researcher has learned during its process (Foster, 2013). Thus, it is imperative that the researcher must reflect on the research process, which in turn will increase the trustworthiness of the study and contribute to the knowledge base scientifically. Therefore, apart from the ability of a preliminary study to raise the quality of a research study by strengthening methodological rigour and exactitude, it also inherently holds an opportunity for reflection and reflexive preparation. It is an opportunity for reflection on the process by asking and answering critical questions about the methodology and "what ought to be" (Coghlan & Brannick, 2005, p. 7). In addition, it serves as a "study of the self", i.e. reflexivity, by allowing the researcher to reflect inward on how thoughts, feelings, and behaviour interact with external factors that have an inevitable influence on the phenomena under study. Sandelowski and Barrosso (2002) claim that reflexivity is the hallmark of excellent qualitative research and explains this concept by stating that "it entails the ability and willingness of researchers to acknowledge and take account of the many ways they themselves influence research findings and thus what comes to be accepted as knowledge" (p. 222). Therefore, reflexive practice nourishes reflection on the research process in the sense that introspection leads to heightened awareness for the detection of areas for growth and improvement, such as insights regarding the refinement of interview questions to meet the developmental level and needs of a participant best.

In addition, it contributes to adherence to ethical principles, as explained by Guilleman and Gillam (2004): Firstly, it allows researchers to reflect on how their research intervention might affect the research participants before any actual research is conducted. Secondly, it allows researchers to consider how they would respond in scenarios that they could envisage only during the initial stage of the research process. Thirdly, during the main study, the reflexive researcher will be better able to identify ethically important moments and will have a basis for responding in an ethically sound manner. Thus, reflexivity is interwoven with "ethical mindfulness" (Warin, 2011, p. 805) and is of special importance when conducting research with children (Phelan & Kinsella, 2013). A process of reflexivity heightens the

researcher's sensitivity for understanding the reciprocal relationships embedded in a research process, especially that between the researcher and the participant (Renold, Holland, Ross & Hillman, 2008).

Factors that played a major role in the process of reflection and reflexivity in this study were culture, language and age. They influenced the social interactions between the participants and me. For example, I observed that many of the participants were more comfortable to make eye contact with the translator than with me, seeing that they could understand what the translator said and therefore felt more comfortable to converse with her in their first language, which was Sesotho or Setswana. By being aware of my intrapersonal dynamics I was able to monitor my subjectivity, which had the potential to taint the data collection and analysis phases. Therefore, the preliminary study was an opportunity to refine the research methodology and the researcher's personal style. It was a crucial step towards unlocking the powerful implications that a preliminary study could have on the main research study.

In the light of Nunes, Martins, Zhou, Alajamy, and Al-Mamari's (2010) findings that the systematic use of preliminary studies is underreported, specifically in qualitative research literature, the goal of this chapter is threefold. First, a detailed reflection on the aims of and approach to the preliminary study that was conducted is provided as a demonstration of a systematic preliminary study. The second goal is to stimulate greater awareness about the importance of conducting a preliminary study. Last but not least, it is envisioned that, upon reading this chapter, fellow researchers will be encouraged to offer reflexive accounts of their own experiences during a preliminary study.

3.2 Aim

In exploring the psychosocial themes of children with a congenital heart defect in conducting the preliminary study, two overarching objectives were of particular significance, namely (a) testing the integrity (i.e. rigour) of the study protocol, which enabled refinement of procedures especially the inclusion/exclusion criteria of this research study, and (b) testing of data collection forms, which ensured that the interview questions were comprehensible, appropriate, well defined, clearly understood and presented consistently. Other forms, such as patient information documents as well as consent and assent forms were also tested.

Apart from the above-mentioned general objectives, I had the following specific questions regarding three different aspects of the research approach that served as the aims for this preliminary study:

(a) Are the inclusion criteria feasible and suitable?

(b) Are there interview questions that require refinement?

(c) How can I familiarise myself and become more comfortable with the research setting?

In the following section, three types of preliminary studies are discussed to illustrate the conceptualisation of these aims.

3.3 Types of Preliminary Studies

Conducting a preliminary study appears to be a balancing act between gaining as much as possible from the outcomes; yet, at the same time, keeping it focused on the objective (Lancaster, 2015; Moore, Carter, Nietert, & Stewart, 2011). Therefore, it is important that the researcher should have in-depth understanding of the theoretical principles, concepts, and terms related to a preliminary study. A point of departure that I found valuable was to differentiate between three prominent types of preliminary studies, termed (a) a feasibility study, (b) a pilot study, and (c) a familiarisation study. These three terms are often used interchangeably and incorrectly, but understandably so. Arain, Campbell, Cooper, and Lancaster (2010) state, “Authors should be aware of the different requirements of *pilot studies* and *feasibility studies* and report them appropriately. We found that in practice the definitions of feasibility and pilot studies are not distinct” (p. 6). As part of the literature study that I conducted, I found multiple definitions that required clarity on the differences and unique characteristics of each of these types of studies. Definitions that contributed to my initial confusion about these types of studies were vague, contained overlapping terms and used such terms interchangeably. A thorough grasp of the role and proper use of each of these types of studies is paramount to the optimisation of a research effort (Milne, 2012). Therefore, I aimed to become knowledgeable on the premises and unique qualities of these three types of studies – a process that led to a new level of understanding and application.

3.3.1 Feasibility study

According to Bowen et al. (2009), a feasibility study is used to determine whether an intervention is appropriate for further testing; in other words, it enables the researcher to assess whether or not the ideas and findings can be shaped to be relevant and sustainable. Such research may identify not only what, if anything, in the protocol or research method needs modification but also how changes might occur. They state that a feasibility study is undertaken to address the question of whether the planned evaluation can be made. This definition is problematic, given the fact that it refers to the testing of proposed research methods, which is a foundational objective of a pilot study rather than that of a feasibility study.

The National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (2014) provides an unambiguous definition of a feasibility study by stipulating its distinct features clearly. According to this definition, a feasibility study is a process during which "pieces of research are done before a main study in order to answer the question 'Can this study be done?' It is used to estimate important parameters required to design the main study" (para. 1).

Orsmond and Cohn (2015) integrated the findings of one of their studies with information from a literature review to identify the main objectives of a feasibility study. They identified follow-up questions for each objective, designed to assist researchers to understand possible barriers to the ultimate success of a research project. Table 2 provides a summary of Orsmond and Cohn's (2015) findings.

Table 2

Feasibility Study: Objectives and Follow-up Questions

Objective	Examples of follow-up questions
Evaluation of recruitment capability and sample characteristics	**How feasible and suitable are eligibility criteria e.g. too restrictive or over inclusive?**
Evaluation of data collection procedures and outcome measures	**Do the participants have the capacity to complete the data collection procedures?**
Evaluation of the acceptability and suitability of the study procedures	**Do the study procedures allow a reasonable amount of time or does it create a burden for the participant?**
Evaluation of the resources and ability to manage and implement the study	**Does the research team have the administrative and financial capacity, expertise, skills, space, and time to conduct the study?**
Preliminary evaluation of participant responses	**How do the findings correspond with the proposed theoretical model?**

Adapted from "The Distinctive Features of a Feasibility Study: Objectives and Guiding Questions" by G. I. Orsmond and E. S. Cohn, 2015, *Occupational Therapy Journal of Research: Occupation, Participation and Health, 35*, 7-8. Copyright 2015 by SAGE.

The most prominent limitation of a feasibility study is that it is indicated for use in studies that evaluate the efficacy of an intervention (Bowen et al., 2009; Dainty et al., 2014; Michelson et al., 2014). Therefore, reports of such studies tend to focus on efficacy potential but less on the examination of other elements of feasibility, such as practicality and the integration of various elements of the research process that are critical to decisions for proceeding with controlled efficacy testing (Wuest et al., 2015). The use of a feasibility study is further limited by the fact that, even though it can provide some insight into how the research phenomena could be approached, it does not specify how the objective is to be achieved. ("Project Management: The Start of the Project Journey", 2015). Furthermore, the single most important difference between a feasibility study and a pilot study is that a feasibility study is not an instrument that measures the outcome of interest and therefore should not be utilised as such (Arain et al., 2010).

3.3.2 Pilot study

Barley (2011) defines a pilot study as an examination of the feasibility of an approach that the researcher intends to use in the main study. According to this author, such an examination includes an evaluation of the feasibility of recruitment, randomisation, retention, assessment procedures, new methods, and implementation of the novel intervention. This definition is confusing, seeing that it uses the terms *pilot study* and *feasibility* interchangeably when it is in fact two different types of studies with different aims.

The National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (2014) provides a more demonstrative definition of the premises of a pilot study by stating that, in a pilot study, "a smaller version of the main study is used to test whether the components of the main study can all work together. It is focused on the *processes* of the main study" (para. 3). These processes refer to the proposed methodology. Thus, when the time comes for a pilot study to be conducted, the researcher would already have a good idea of what he/she is searching for and would have narrowed the methodological approach down to the point where it can be tried, tested, and altered if need be. A pilot study helps to ensure that the main study runs smoothly (Schade, 2015; Van Teijlingen & Hundley, 2001). Thus, a pilot study can ensure a "soft landing onto the runway" of the main study.

The value of conducting a pilot study is embedded in its pragmatism, as it gives the researcher a "license to adapt" any aspect of the research study through a process of an experimental and exploratory trial of the main study. It allows not only an evaluation of the research methods but also an evaluation of *the self* (Wray, 2015). It is an opportunity for reflecting on questions, such as "What did I learn about myself?" and "How can I improve?" Thus, a pilot study facilitates a process of reflection and reflexivity and ultimately adds to the quality of the main study and substantiates the viewpoints of Guilleman and Gillam (2004) and of Coghlan and Brannick (2005).

Conversely, a pilot study could be "misused … and misrepresented" (Lancaster, Dodd, & Williamson, 2004, p. 307). Table 3 depicts Foster's (2013) illustration of how easily a pilot study could be misused but, more importantly, better utilised if the core characteristics of a pilot study is understood.

Table 3

The Core Characteristics of a Pilot Study

What a Pilot Study Is	What a Pilot Study Is Not
A methodological preface to a larger study.	**Not a hypothesis study.** **Not synonymous with a small sample size.**
Designed to refine methods and/or to provide evidence for calculating sample size in future research (Hopkins, 2000).	**Use of the term *"pilot study"* is inappropriate unless the study was designed to test research methods and to report useful insights gained regarding methodology.**
Allows the researcher to try out methods before committing to the level of accuracy required in the main study.	**Does not provide a meaningful effect size estimate for subsequent studies due to the imprecision inherent in data from small samples.**

Adapted from "What a pilot study is and what it is not" by R. L. Foster and R. N. Faan, 2013, *Journal for Specialists in Pediatric Nursing, 18,* p. 1. Copyright 2013 by Wiley Periodicals, Inc. and "The Role And Interpretation of Pilot Studies in Clinical Research" by A. C. Leon, L. L. Davis, and H. C. Kraemer, 2011, Journal of Psychiatric Research, 45, p. 3-4. Copyright 2011 by NIH Public Access.

In line with Sampson's (2004) proposition of an objective-focused preliminary study, Lancaster et al. (2004) recommend that a pilot study should have a well-defined set of aims and objectives to ensure methodological rigour and scientific validity.

Leon, Davis, and Kraemer (2011) explain two critical limitations to the role and interpretation of a pilot study. Firstly, because a pilot study is not a hypothesis-testing study, its use is not indicated for studies that evaluate safety and efficacy. Secondly, a pilot study can examine only research elements of the sample type included in the study; i.e., the results do not necessarily generalise beyond the inclusion and exclusion criteria of the pilot (Leon et al., 2011).

3.3.3 Familiarisation study

According to Barley and Bath (2014), a familiarisation study is a process of becoming familiar with the research context. Whiteley and Whiteley's (2005) definition is more detailed. They claim that a familiarisation study entails three elements, namely procedures, content, and theory. The *procedures* element assesses the physical procedures for data collection. The *content* element evaluates suitable data collection methods, and the *theory* element aims to identify the theoretical approach best suited for the process of familiarisation; for example,

phenomenological, symbolic interactionist, or ethno-methodological. At first sight, this definition overlaps with the characteristics of a pilot study, namely a critical evaluation of the proposed research methodology. However, Whiteley and Whiteley (2005) also highlight that a familiarisation study addresses the momentous bridging from theory (e.g., planning of a research study such as finding a "gap" in literature, writing a research proposal, and attaining ethical approval) to context – "adapting to the situation on the ground" (p. 3). Thus, the main goal of a familiarisation study for the researcher is to become aware of and familiar with data that can be accessed only from the participant's point of view (Barley & Bath, 2014).

Therefore, a familiarisation study is a valuable exercise for the researcher to become acquainted with the "language" of the research setting to identify opportunities for networking with significant figures in the setting and to learn as much as possible about the operational style of the setting. This allows the researcher to become knowledgeable on how to collect and record data unobtrusively (Barley, 2011). Additionally, a familiarisation study can assist the researcher in learning how to structure and focus his/her observations efficiently by taking cognisance of the interview setting and use of the space (Berg, 2009). Conversely, Whiteley and Whiteley (2005) warn researchers that a familiarisation study requires much time and effort due to the level of thinking, planning, and research activity required in the research context.

The core of the different types of studies can be summarised as follows: A feasibility study focuses on *what could be designed and investigated*, a pilot study focuses on testing *what has already been designed* and a familiarisation study *prepares the researcher for the research context*. In the next section, I describe my conceptualisation of a preliminary study based on these three types of studies.

3.4 Conceptualisation

In the conceptualising process, I reflected on the value of each type of preliminary study in preparing for the main study. The first step was to reflect on the role and function of a feasibility study, then a pilot study, and finally, a familiarisation study. This process ensured that all spheres of the research process were "screened" for elements that potentially could act as hindrances during the main study. Eventually, I could integrate the three types of preliminary studies meaningfully and plot my expectations of the preliminary study, which resulted in the identification of three specific objectives (see Figure 6).

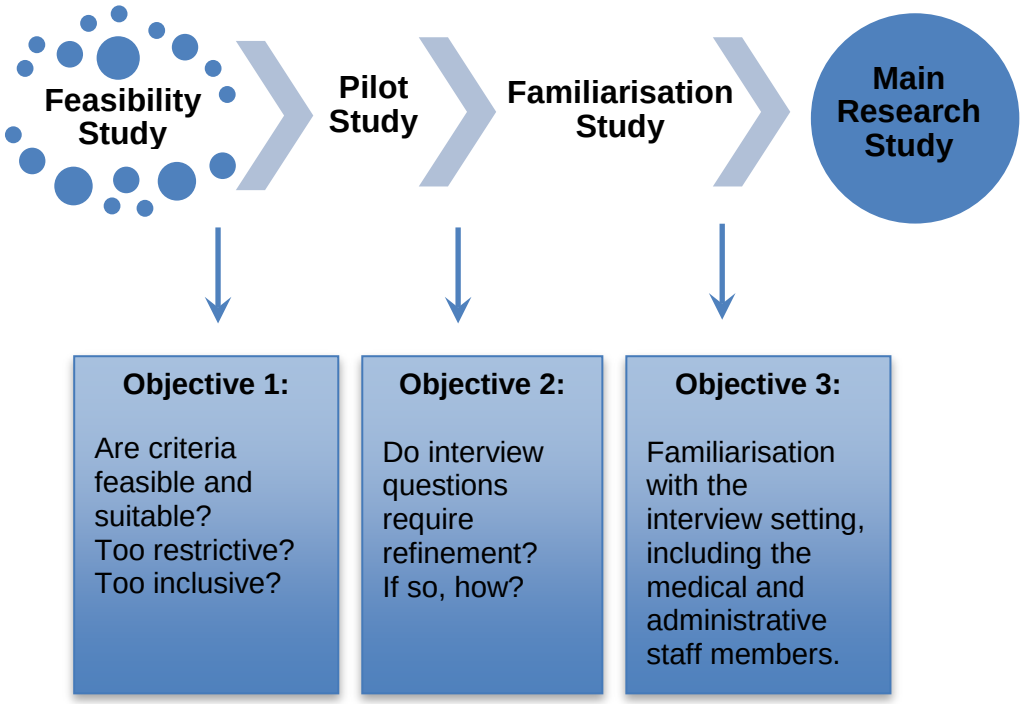

Figure 6. Conceptualisation Model: The process of developing objectives for the collective pilot study.

3.5 Collective Pilot Study

Strictly speaking, this preliminary study could be termed a pilot study, seeing that one of the major objectives was to assess the semi-structured interview questions and modify them if I deemed it necessary to do so. However, as is evident in Figure 6, I used elements of a feasibility study (assessing the feasibility and suitability of inclusion criteria), a pilot study (trying out the interview questions to determine whether modifications are needed) and a familiarisation study (becoming familiar with the interview setting) to assist in the refinement of study elements. To prevent theoretical confusion, the combination of these elements required the generation of a new term. I therefore coined the term *collective pilot study* to refer to the combined utilisation of elements of all three types of preliminary studies mentioned previously, with the pilot element being the primary objective, given the focus on this objective during the **planning** phase of this study (i.e. when the protocol was compiled). Similarly, the term *collective feasibility study* could be used if a preliminary study has an element unique to a feasibility study as its primary objective but contains elements of a pilot study and a familiarisation study. The same goes for a preliminary study, which has a characteristic of a familiarisation study as its primary objective but also includes elements of a feasibility study and a pilot study. In such a case, the term *collective familiarisation study*

could be used. Hence, for the remainder of this dissertation, I will use the term *collective pilot study* when referring to my preliminary study.

3.5.1 Aim

As mentioned earlier, the aim of the collective pilot study was threefold, namely (a) to assess the feasibility and suitability of the inclusion criteria; (b) to refine the interview questions if needed; and (c) to familiarise myself and become more comfortable with various aspects of the research setting.

3.5.2 Participant

I conducted a collective pilot study on one participant. In view of the objective to assess the age range for inclusion, I selected this specific participant because of his age at the time of the interview, which was 8 years and 6 months. The participant was recruited from the Universitas Hospital in Bloemfontein in collaboration with the Department of Paediatric Cardiology at the hospital. On the day of the interview, one of the collaborating paediatric cardiologists introduced me to the participant and his mother in the hospital ward, where he received medical care at that time. Prior to the interview, I asked the participant's mother to complete (a) the informed consent form and (b) a demographic information sheet, for administrative purposes. The informed consent form as well as the drawing activity and the semi-structured interview were conducted in the participant's first language (Setswana) with the assistance of a qualified translator (qualified language practitioner).

3.5.3 Research method

Qualitative inquiry was the interpretive approach guiding this descriptive explorative study. Qualitative research methods are appropriate to use when describing a phenomenon about which little is known and are particularly suited when describing a phenomenon from the emic, i.e. individual, perspective (Yin, 2011). Therefore, a qualitative research approach was the approach of choice to explore the psychosocial themes of children with a congenital heart defect. With regard to data collection, human figure drawing, a drawing activity was employed to build rapport (Bakken, Obiakor, & Rotatori, 2012), and the semi-structured interview was conducted personally and was audio recorded.

The semi-structured interview extended over three consecutive sessions. Halfway through the first session – without prior notice to me, the participant, or his mother – the

participant was transferred to the intensive care unit (ICU). The participant's health care professionals informed me that he urgently needed to receive intravenous fluids. Even though this was not how I initially envisioned the interview procedure, it provided me with more opportunities to familiarise myself with the research setting. Because of this unanticipated event, the first session was conducted in the general ward, and the last two sessions in the ICU ward to accommodate the participant's medical treatment at that time. During the second session, the participant grew tired and requested that we return later that day to complete the interview.

The questions of the semi-structured interview were designed in accordance with the domains of the developmental psychopathology model (DPM), namely the biological, psychological, and social domains (Achenbach, 1990). Questions revolved around the participant's functioning in these domains (see Appendix B for the English version and Appendix C for the Sesotho version). The interview commenced with questions related to the participant's biological functioning. Examples of questions asked in the biological domain are "Tell me what is going on with your heart?" and "How does your heart tell you when you are feeling ill?" This led to a description of the events surrounding the diagnosis of a heart defect and the subsequent procedures and treatments.

From there, my questions moved into the psychological domain (emotional, cognitive, and behavioural). For example, the participant was asked how he felt about his ill heart (emotional), if he had three wishes that would come true what he would wish for (cognitive) and which activities he was unable to do due to his ill heart (behavioural).

The third domain of the DPM, the social domain, included questions such as "Who looks after you? Tell me more about that person" and "Tell me a story of a time when you and your family travelled together." Questions were kept open-ended, and probes were used to clarify what was said. Interviews were transcribed and analysed directly after data collection.

It is important to note that I did not stick to the structure of the questions in a rigid fashion, primarily due to the fact that flexibility in this regard aided in moving more into the world of the participants for a better understanding of their experiences. In addition, such flexibility answers to the ethical principle of justice, whereby flexibility regarding how the questions were asked allowed for the collection of data that is accurate. In turn, accurate data collection strengthened the trustworthiness of the study.

The six phases of thematic analysis (Braun & Clarke, 2006) were utilised to analyse the data. Braun and Clarke (2013) emphasise the theoretical flexibility of thematic analysis. They state that thematic patterning does not require adherence to one specific theory or explanatory framework and can therefore be applied within a variety of theoretical frameworks (as is evident from the use of the DPM in this study). Some of the pioneers in the establishment of thematic analysis as a robust framework for qualitative data analysis advocate the development of coding frames to facilitate the generation of measures, such as inter-rater reliability (Boyatzis, 1998; Guest, MacQueen, & Namey, 2012; Joffe, 2011). However, Braun and Clarke (2013) find this concept problematic in relation to qualitative research. Woods and Dempster (2011) endorse Braun and Clarke's (2006) viewpoint of analysing recursively and not to view the six phases of analysis as a linear process.

The results of a preliminary study should be interpreted with caution. Such results should be reported overtly and unambiguously as *preliminary findings*. (Bowie, Halley, Blamey, Gillies, & Houston, 2016). The intention of such reports should be limited to informing future research and reports by highlighting potential pitfalls for other researchers (Foster, 2013). Barley (2011) recommends that the researcher should refrain from including data generated from a pilot study in the data set of the main research study because possible modifications to methods, as a result of a pilot study, could risk the presence of additional sources of variation. However, there are instances when data from before and after protocol changes can be combined. For example, Leon et al. (2011) explain that the presence of a well-specified research design could serve as motivation for combining data.

3.5.4 Results

3.5.4.1 Objective 1: Feasibility – Are criteria feasible and suitable?

This objective focused on the *feasibility* of the inclusion criteria. The initial inclusion criteria for this study were (a) children between the ages of nine and fourteen; (b) children who had been formally diagnosed with a CHD, with at least one surgical procedure performed relating to the condition; and (c) children from both genders. The exclusion criteria were (a) a child with an illness that falls outside a diagnosis of a CHD (e.g. HIV/Aids); (b) a child who may not be medically fit or well enough to engage in the interview process at the time; and/or (c) a child with a physical disability. Children with a physical disability were not included because of the potential for confusion between psychosocial themes because of living with a

congenital heart defect and psychosocial themes due to living with a physical disability. Such confusion could have resulted in inaccurate reporting of research findings.

The participant understood the research process well and was able to follow instructions, converse constructively, and provide meaningful data related to the research question of this study.

An additional observation was that the participant mentioned getting tired during the interview process, which appeared to be related to his medical status at the time of the interview. From a critical viewpoint, this observation related to exclusion criterion *b*, namely a child who may not medically be fit or well enough to engage in the interview process at the time. However, the context of this particular interview (being part of the preliminary study) enabled me to explore ways in which to deal with such an instance and to clarify the strategy that I would follow in future if faced with a similar scenario rather than exclude this participant without further consideration. I concluded that, if faced with such a scenario in future interviews, my strategy would be to (a) explore the reason for the participant expressing tiredness; (b) explore the severity of tiredness; and (c) keep ethical conduct in mind by discussing the situation with the participant in that moment, respecting his/her autonomy and acting accordingly. In this case, the child wanted to continue with the interview and requested that the translator and I return later to continue with the interview.

After careful consideration of information gathered, I decided that the age range of the inclusion criteria could be broadened to include children aged 8 years, which finalised the age range for inclusion to be eight to fourteen years. This decision is supported by experts on human development and middle childhood, such as Eccles (1999), Ozretich and Bowman (2001), and Mah and Ford-Jones (2012), who include children aged 8 years in the middle childhood developmental stage.

3.5.4.2 Objective 2: Pilot – Do the interview questions require refinement?

Piloting of the semi-structure interview highlighted three interview questions that needed refinement to be understood better by the participant and to ensure the yielding of rich data, namely questions 2, 8, and 9.

3.5.4.2.1 Question 2: Tell me what is going on with your heart?

This question falls under the biological domain of the DPM. It proved to be vague and challenging for the participant to answer. The preceding question, "Why are you here at hospital today?" was similar to this question, which could have contributed to the challenge of deciding how to answer it. I considered a slightly different approach, such as "Why do you have to visit the doctor and hospital from time to time?" It is more definitive in content yet still suitable to form part of the biological domain of the DPM.

3.5.4.2.2 Question 8: Name some things that you like about yourself.

This question falls under the psychological domain of the DPM. The participant did not understand the question and thought that he had to name things that he was good at. This response could be ascribed to the fact that children of this age might still have difficulty with sharing their inner worlds on an abstract level, which this question required (Knoetze, 2012). It is important to note that children in middle childhood are in a process of developing emotional awareness, emotional regulation, and accurate transcribing of their intrapersonal functioning (Saarni, 2011). Therefore, by rephrasing the question as "Name some things about yourself that you are proud of" would facilitate an emotion-focused response by means of subtle probing, which might be necessary for this age group. However, after much consideration, I decided to keep the question in its original format. The alternative option, namely "Name some things about yourself that you are proud of" would be used as a probing question if I were to realise that the participant had difficulty to provide a rich response. I realised that, depending on the participant's level of cognitive functioning, I might have to use the probing question.

3.5.4.2.3 Question 9: Name some things that you don't like about yourself.

Like Question 8, this question related to the psychological domain of the DPM. The participant did not understand the question and thought he had to name things that he did not like. Similar to question 8, the participant's response could be ascribed to the fact that children of this age might still have difficulty with sharing their inner worlds on an abstract level, which this question required (Knoetze, 2012). An alternative way of stating the question could be "Name some things in your life that you are not proud of". As with question 8, I decided to pose the question in its original form and to use the alternative form of the question if it was necessary to gain more information.

3.5.4.3 Objective 3: Familiarisation – Mapping the setting

The procedural element of a familiarisation study (Whiteley & Whiteley, 2005) can be a useful tool for all studies that are working with a specific community or researching a particular place regardless of the methods that they are employing (Barley, 2011). The familiarisation study confirmed my viewpoint that it was important to get to know the professional staff at the interview sites, which were the Paediatric Cardiology Outpatient Clinic as well as the paediatric wards at Universitas Hospital. It was also necessary to acclimatise to the clinical setting in the hospital and to explore ideas for making the setting more conducive to authentic and heartfelt dialogue.

As part of this re-familiarisation process, I was confronted with the realisation that when I asked for silence and privacy at the participant's bedside in order to conduct the interview, that I would literally be asking the health care professionals to step out of their "consulting rooms" to accommodate me. This highlighted the importance to liaise with the participant's team of health care professionals and to build a collaborative working relationship with them. Such an effective working relationship would prove to enhance the efficiency of the main study.

3.6 Conclusion

The theoretical underpinnings of a preliminary research study necessitated me to develop a customised set of aims and objectives. A combination of theoretical knowledge, my expectations, queries and concerns resulted in a systematic preliminary study. This approach yielded valuable information that strengthened the scientific rigour of the main research study.

The first objective, aimed at *feasibility*, was to evaluate the criteria in terms of age range. The inclusion criteria were expanded to include children aged 8 years. The second objective aimed to *pilot* the interview questions for their ability to yield rich data in answer to the research question. Three interview questions were altered carefully so that they remained theoretically sound but ensured better understanding from the participant and therefore a stronger contribution to data. Finally, the third objective aimed to develop my degree of *familiarity* and comfort with the interview setting, the health care professionals, and administrative staff at the clinic and in the wards. This goal was achieved successfully.

By utilising techniques from different types of preliminary studies, namely the feasibility study, the pilot study, and the familiarisation study, my expectations for the

preliminary study were met sufficiently. In addition, the term "*collective pilot study*" was created to describe a pilot study that contains elements of a feasibility study, a pilot study, and a familiarisation study.

This account of reflection on the approach to and aims of the preliminary study also aimed at stimulating greater awareness about the importance of conducting a preliminary study and encouraging fellow researchers to adopt a similar practice. In addition, the important contribution of reflection and reflexivity to ethical conduct during a research project was illuminated.

As Sampson (2004) explained, in the same way that the harbour pilot guides a ship through stormy waves to safety, this preliminary study contributed to anchoring the main study in solid scientific methodology. I critically engaged with various aspects of the research approach to prepare for a "smooth landing onto the runway" of the main study. The following African proverb accurately encapsulates the importance of a preliminary study: "*You never test the depth of a river with both feet"* (Okupa, 2014).

CHAPTER 4: METHODOLOGY

And so the duckling was admitted on trial for three weeks; but no eggs came. The tomcat was master of the house, and the hen was the lady, and always said, "We are the world." The duckling thought one might have a different opinion, but the hen would not allow it.

"Can you lay eggs?" she asked [the Ugly Duckling].

"No."

And the tomcat said, "Can you curve your back, and purr?"

"No."

"Then you cannot have any opinion of your own."

And the duckling sat in the corner and was melancholy.

"You don't understand me," said the duckling [to the hen].

"We don't understand you? Then pray who is to understand you?"

– The Ugly Duckling (Nesbit et al., 1956, pp. 108-109)

4.1 Introduction

Understanding is at the core of any research effort – a process of collecting information to increase understanding about a specific phenomenon in order to expand a given scientific knowledge base (Cresswell, 2008). An important step for the researcher in a research endeavour is to select the most appropriate methodology; i.e., an approach that would answer the research question best, whether it would be qualitative, quantitative, or a mixed-method approach. For example, to find quantitative differences in children's behaviour or attitudes, a quantitative method might be more appropriate, but to find and illuminate meanings related to these differences, a qualitative method would need to be employed ("FAQ 1: When is it better to do qualitative or quantitative research?" 2010). Therefore, one methodological approach is not superior to another but rather complementary. As Cresswell (2002) explains, quantitative research often builds on findings from qualitative research. For example, this qualitative study of the psychosocial themes of children with a congenital heart defect (CHD) could be used in

future as the foundation of a quantitative study to categorise psychosocial themes in accordance with severity of CHD and type of medical intervention.

Whereas quantitative research aims to understand distribution by means of statistical estimation, qualitative research aims to understand diversity by illuminating uniqueness (Jansen, 2010). Such in-depth understanding is facilitated by the distinct characteristics of qualitative research, namely (a) consideration of context; (b) a focus on meaning; (c) flexibility; (d) the plausibility of interpretation rather than one absolute "truth"; (e) the unique researcher-participant relationship, (f) the unique set of skills required by the researcher; and (g) an inductive and "messy" approach to data analysis (Roller & Lavrakas, 2015).

These core concepts remain evident throughout this chapter, as the appropriateness of a qualitative research approach and subsequent methodology to the exploration of the psychosocial themes of children with a CHD are described.

4.1.1 Definition

Given its dynamic and controversial nature, multiple definitions of qualitative research exist. These definitions display variance in how they are articulated and are influenced largely by the distinct theoretical principles of each author's discipline of practice and research approach of choice.

In qualitative research, the aim of the research shapes the approach – whether it is for the purpose of understanding, emancipation, or deconstruction of a given phenomenon (Lather, 1992). If the purpose is to understand, an interpretive approach is usually followed. If the purpose is to emancipate, for example by clarifying a misperception about a phenomenon, a critical approach is indicated, and if the purpose is to deconstruct or "unpack" a phenomenon, the researcher would most likely approach the phenomenon from a post-modern stance (Merriam, 2009).

In the discipline of psychology, an interpretive view of qualitative enquiry is common, where the aim is to understand the subjective meanings of persons in the studied domain and to translate such meaning into scientific knowledge. For example, Peltzer and Promtussananon (2003) explored black South-African children's understanding of health and illness. The results contributed to the design of developmentally appropriate and effective educational programmes on health and preventing HIV/AIDS.

Conversely, in the medical disciplines, a critical approach to qualitative research is used widely. To illustrate, Hardcastle, Usher, and Holmes (2006) highlight the value of critical qualitative research in the nursing field by outlining Carspecken's (1996) five-stage critical qualitative research method. The first stage involves comparison of initial findings with subsequent findings and illuminates important cultural themes. During the second stage, the researcher identifies key themes that require further exploration by a description of the cultural and social context at play. Stage three facilitates in-depth understanding of the participant's cultural and social experiences through emergence of the self in the participant's cultural and social world. Stages four and five focus on theorising by linking it to theory that critically addresses the functional patterns of an individual.

Within the discipline of education, a postmodern approach is indicated because of the shared purpose of broadening knowledge by challenging ways of thinking and generates alternative views of a given phenomenon (Lichtman, 2010). For example, Zeeman, Poggenpoel, Myburgh, and Van der Linde (2002) illustrate the value of discourse analysis (as a post-modern research approach) to educational research as a reflexive, productive process that is directed at change and progress.

Even though definitions may differ because of variance in style, most definitions of qualitative research highlight its core characteristics (Yin, 2011). Many definitions focus on the importance of context. Flick (2007) includes the main difference between quantitative and qualitative research: Whereas a quantitative approach is conducted in a specialised research setting (e.g. a laboratory), a qualitative approach to enquiry meets the participants "in their worlds" in a quest to understand, describe, and explain social phenomena. This is done by analysing (a) experiences of individuals or groups; (b) interactions and communications; or (c) documents. All three of these routes seek to understand how people make meaning of the world around them.

Flick's (2007) viewpoint thus relates to Flick, Von Kardorff, and Steinke's (2004) definition that gaining insight necessitates "placing oneself in the participant's shoes". Flick et al. (2004) state that a qualitative research approach aims to gain insight into the life worlds of the participants "from the inside out" (p. 3). Thus, meeting the participants "in their worlds" requires a reflective, interpretive, descriptive, and usually reflexive effort to describe and understand actual instances of human action and experience from the perspective of the participants who are living through a particular situation (Fischer, 2006). Reflection focuses

on the accuracy when reporting participants' accounts of reality. Reflexivity, on the other hand, is an explicit evaluation of the self and involves reflecting one's thinking back to oneself (Shaw, 2010). In this study, I report on the processes in the participants and in myself to understand the phenomenon of living with a CHD better.

Baxter and Jack's (2008) concise definition of a qualitative research effort also focuses on its contextual nature by describing it as "an approach to research that facilitates exploration of a phenomenon within its context using a variety of data sources" (p. 544). Schank and Villella's (2004) definition of qualitative research highlights its inquisitive nature and therefore the importance of meaning, implying better understanding of the social realities of participants by illuminating aspects of a phenomenon that would otherwise have been "left in the dark" with researcher and participant alike unaware of its potential value.

Cresswell's (2007) view of qualitative research is a popular definition in literature pertaining to qualitative health research (Miller, 2010). This definition focuses on the methodological nature, the complexity of the end product and the nature of its naturalistic inquiry. The popularity of this definition is possibly due to its pragmatic stance that reflects action, intervention, and constructive knowledge (Goldkuhl, 2012) and is therefore understandably attractive to the field of medicine.

Clearly, most if not all definitions of qualitative research involve an interest in subjectivity and the authenticity of human experiences (Silverman, 2013). This definition reflects the premise that qualitative researchers prefer findings that result from interpretation of different realities rather than a single "truth". Therefore, the core of qualitative research lies in understanding the meanings that people attach to actions, decisions, beliefs, and values in their social world.

An EbscoHost search (an international online research engine) conducted on 9 February 2016 found no study related to the topic of the psychosocial themes of children living with a CHD in the South African context. This finding confirmed the need for this study to be conducted. Consequently, I aspired to explore the psychosocial themes of children with a CHD by capturing the perspectives of the child participants. A qualitative research approach was the most suitable choice, as this topic of enquiry required a flexible, circular and inductive research method that would allow a reflexive process throughout the study (Maxwell, 2012). This was done by searching for concepts related to how these children

experience life with a chronic illness, specifically a CHD, and to consider how it influenced various areas of their functioning. Through interpretation, while considering the conditions in which the participants live, I was able to identify meaningful themes and thus adhered to the core features of qualitative research (Yin, 2011).

4.1.2 Advantages

Academics and clinicians alike increasingly recognise the benefits of a qualitative approach to health care research (Brookes, 2007; Pope & Mays, 2013) with its use in a clinical setting increasingly appearing in prominent medical journals (Abrams, Siegfried, & Geldenhuys, 2011; Kuper, Reeves, & Levinson, 2008; Yoong et al., 2013).

In the past, qualitative and quantitative research were viewed as "opposing research camps" (Dholakia, 1985, p. 3). A possible explanation for this dichotomy is that physicians and clinical researchers may be unfamiliar with qualitative research or may be uncertain how it relates to their field of expertise (Poses & Isen, 1998). However, there is growing awareness and agreement that qualitative research and quantitative research are similar in the sense that both are methods of enquiry and merely differ in their methodological approaches (Crowe & Sheppard, 2010). As Al-Busaidi (2008) explains, the consideration of both quantitative and qualitative research approaches will ensure that the correct methodology is used for answering the proper questions. The most appropriate methodology to answer a research question expands a given scientific knowledge base, which eventually is the main purpose of any research effort, regardless of its methodology.

A number of authors believe that qualitative research can answer research questions about biopsychosocial functioning better than a quantitative approach can do. For example, Mays and Pope (1995) claim that qualitative research is an essential part of health care research because it can explore complex phenomena (e.g. behaviours and attitudes) in a way that a quantitative research approach might not be able to do. Consequently, it has proven to be useful for examining clinical decision-making. Bowen, Purdy, Lyttle, and Heawood (2014) illustrate this fact with their qualitative study, which explored clinical decision-making for children under five with minor respiratory conditions who were attending the emergency department.

Berkwits and Aronowitz (1995) argue for the broad clinical applicability of qualitative research by explaining that qualitative research is particularly useful in the study of a health-

related phenomenon that has both social and clinical dimensions. Ballinger and Payne (2000), as well as Pope, Van Royen, and Baker (2002) support Berkwits and Aronowitz's (1995) statement by emphasising that qualitative methods could make an important contribution to understanding how to improve the quality of health care.

The study of psychosocial themes in children with a CHD called for a qualitative approach due to the reciprocal influence between the clinical condition, namely a CHD, and the participants' functioning – both in intrapersonal and interpersonal domains. By following a qualitative methodology, this study might subsequently contribute to the provision of comprehensive, high-quality health care to paediatric cardiac patients.

4.1.3 Ganzheitspsychologie

Given the focus of the study on psychosocial development during the developmental stage of middle childhood, I reflected on insights from the Ganzheitspsychologie tradition (Hermann, 1976, as found in Hanlon, 1991). This school of thought promotes a holistic approach to enquiry and proposes that functional elements come to life when the whole is considered. For example, the way in which a child with a CHD relates to his/her peers reveals the child's cognitive perceptions about the self and established patterns of social interactions, which could be traced back to the primary attachment style between child and primary caregiver (Clark, 2009). Whereas quantitative researchers often focus on measuring the parts in an issue, qualitative studies prefer to create a full picture. This supports the use of a qualitative approach in this study, seeing that a combination of various elements contribute to overall functionality, which is a critical component of mental health (Anderson & Bellfield, 1999).

According to Ganzheitspsychologie, a researcher should adhere to four central guidelines of qualitative research effort. These four tenets are holism, structure, development and feelings. Rudolph (2013) explains that, in the realm of human life, the whole (first tenet) encompasses a living structure (second tenet) that is open to development (third tenet). The experiences of the whole are manifested in feeling states (fourth tenet). The experiences of the whole can be unconscious, in which case it is referred to as emotion. However, if experiences of the whole are conscious, it constitutes the use of the term *feelings* – an omnipresent state that is bound to the living structure's biology and subjective relation to its environment (Prinz, 2005).

Diriwächter and Valsiner (2011) state that the process of arriving at the whole should include developmental aspects and processes from biological to abstract; for example, how the presence of a physical illness affects psychological functioning. It was paramount for this study to include and maintain emphasis on developmental processes due to the multi-level and reciprocal influence of experiences on a child's development. The developmental psychopathology model, also referred to as the DPM (Achenbach, 1990), was utilised, as this model provides a framework for the conceptualisation of a child's functioning across various domains, including the biological, psychological, and social domains.

4.2 Research Design

4.2.1 Definition

The research design refers to the selected strategy employed to achieve the research aims logically and unambiguously. It constitutes the blueprint for collecting, measuring, and analysing data. The research problem determines the type of design to be used (De Vaus, 2001).

4.2.2 Types

The six most common qualitative research designs include phenomenological, ethnographic, grounded theory, historical, case study, and action research (Ritchie & Lewis, 2003).

Phenomenological studies examine human experiences through the descriptions provided by the people involved (Patton, 2002). Ethnography is the study of social interactions, behaviour, and perceptions that occur in groups, teams, organisations, and communities (Reeves, 2008). Action research is a type of qualitative research that aims to improve practice and then to study the effects of the action that has been taken (Streubert & Carpenter, 2002). In grounded theory studies, data are collected and analysed, and then a theory is developed that is grounded in the data (Jacelon & O'Dell, 2005). Historical studies concern the identification, location, evaluation, and synthesis of data from the past and aim to relate these past happenings to the present and to the future. Case studies are in-depth examinations of people or groups of people. Jacelon and O'Dell (2005) propose the use of case studies to explore real clinical situations in depth.

In four instances, a case study research design should be considered as the research design of choice (Yin, 2003), namely when answering “how” and “why” questions; when the researcher is unable to manipulate the behaviour of participants; if the contextual conditions are deemed a significant aspect of the phenomenon under study; and if the boundaries between the phenomenon and the context are unclear.

Kay (2012) illustrates the use of a case study research design in health psychology. The aim of Kay’s (2012) study was twofold. The first aim was to explore and describe the experiences of a child suffering from a somatic symptom and related disorder, for instance a mental illness characterised by physical symptoms such as pain not due to a general medical condition but rather by psychological factors (American Psychiatric Association, 2013). Secondly, the study aimed to establish guidelines that would strengthen the child’s ability to cope with the challenges and thereby prevent comorbid mental illnesses. Kay’s (2012) study is deemed a qualitative, explorative, and contextual research design with a single case study approach, seeing that the study was conducted from the paediatric participant’s viewpoint with the understanding that the participant is the best source to provide information about his or her experiences.

In summary, three core features of a case study research design convinced me to use this type of research design for the study of children with a CHD, namely its particularistic, heuristic, and descriptive nature (Merriam, 2009). Its appropriateness for utilisation in this study can be motivated in more detail as follows:

- This study aimed to explore and describe the psychosocial themes in children with a CHD by asking how the presence of a CHD affects the psychosocial functioning of a child.

- I was unable to manipulate the behaviour and experiences of the participants due to the intrapersonal nature of the phenomenon under study, i.e. the “inner world” of the child.

- A case study research design would be able to organise and make sense of the inevitable, reciprocal, and enmeshed relationship between the child participants’ contexts (external forces) and their psychosocial functioning (intrapersonal state).

4.2.3 Categories

A case study research design can be categorised based on (a) a disciplinary perspective; (b) a function; (c) an attribute; and (d) a type (Hancock & Algozzine, 2006).

Figure 7 provides an outline of these four categories.

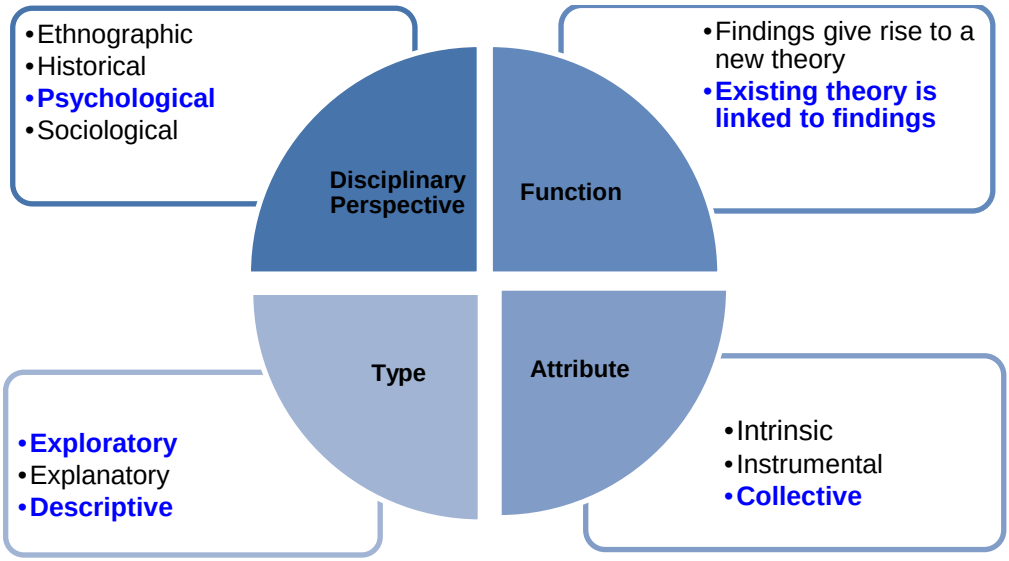

Figure 7. A case study research design can be categorised according to (a) a disciplinary perspective; (b) a function; (c) a characteristic; and (d) a type, with subcategories for each of the four main categories. The categories applicable to the study of psychosocial themes in children with a CHD are indicated in pink boldface. Adapted from "Doing Case Study Research" (pp. 31-33), by D. R. Hancock and B. Algozzine, 2006, New York, NY: Teachers College Press. Copyright 2006 by Teachers College, Columbia University.

With regard to the disciplinary perspective, Merriam (2001) suggests that case study research may be founded in ethnographic, historical, psychological, or sociological orientations. In the psychology discipline, case study research typically revolves around aspects of human behaviour often by using theories and concepts generated by existing research in psychology. For example, Piaget (1953) developed a theory of cognitive development that has had a major effect on instruction over the years. Piaget's theory focuses on (a) the process of children's thinking; (b) the recognition of the crucial role of children's self-initiated learning; (c) active involvement in learning activities; and (d) acceptance of individual differences in developmental progress (Berk, 2010). Thus, a psychological case study of a learner might draw upon Piaget's theory to help conceptualise children's understanding of illness (Koopman, Baars, Chaplin, & Zwinderman, 2004). Another example is that of a local study conducted by Cooke (2009), who explored children's experiences of

their obesity by using Erikson's (1959) theory of psychosocial development to indicate how important domains of functioning, such as psychosocial functioning, were affected by the participants' obesity. In a similar fashion, I utilised the theory of developmental psychopathology (Achenbach, 1990) to plot the psychosocial themes of children with a CHD in various domains of these children's functioning.

The function of a case study research design is to capture the essence of a phenomenon under study in such a rich way that the researcher will be able to see either (a) if it gives rise to a new theory, or (b) if and how an existing theory is linked to the research findings (Yin, 2004). For example, Andersen (2009) used the SHIP® Model of Projection (Steenkamp, 1991) as a theoretical premise in her qualitative study of the viability of using non-standardised thematic projection media with young adolescents (early adolescence). According to the SHIP® Model of Projection (Steenkamp, 1991), projection can be regarded as activated stress, and the individual's whole system reacts because of external stress working in on the system. Andersen (2009) was able to build on this model by providing guidelines to practitioners regarding the use of non-standardised thematic projection media with young adolescents. In this study on psychosocial themes in children with CHD, the theoretical framework, namely the DPM (Achenbach, 1990), clearly highlights that various aspects of a child's functioning interact with a variety of aspects from the child's context. Therefore, the DPM (Achenbach, 1990) was utilised as (a) the method of enquiry, i.e. a semi-structured interview; and (b) the method of analysis of the psychosocial themes of children with a CHD. The DPM guided the interview questions, and themes identified in the various domains (biological, psychological, and social) of the DPM were plotted.

In addition to its disciplinary orientation and function, a case study research design may also be classified according to attributes as intrinsic, instrumental, or collective (Stake, 2005). Researchers engaging in an intrinsic case study want to know more about one particular individual, group, and event and are not necessarily interested in generalisation of their findings (Abma & Stake, 2001). For example, Skär and Prellwitz (2008) explored how a child with obesity perceives his participation in play activities. This is an example of an intrinsic case study research design, seeing that the researchers needed information from only one participant to answer the research question sufficiently.

When the theoretical explanation that underpins a phenomenon is of greater interest than the phenomenon itself, the use of an instrumental case study research design is indicated

(Stake, 1995). For example, in Lineham's (2010) instrumental case study on a 16-year-old female with muscular dystrophy, the primary research aim was to raise awareness around some of the issues associated with complex illness during adolescence, taking special cognisance of the service needs unique to the adolescent developmental stage versus the adulthood developmental stages. Even though this study (the psychosocial themes of children with a CHD) has a strong theoretical presence in the DPM (Achenbach, 1990), the study merely used the DPM to explore the phenomenon of children living with a CHD. The phenomenon was not studied to expand on the underlying theoretical model. Thus, the instrumental case study research design would not have been an appropriate choice.

Finally, collective case study research attempts to address an issue in question while adding to the literature base that helps to conceptualise a theory better. This design usually involves several instrumental cases performed to enhance our ability to theorise about some larger collection of cases. For example, a researcher may engage in a series of studies designed to explore one of the eight forms of intelligence contained in Gardner's (1999) theory of eight (and later nine) types of intelligence (TEDx Talks, 2015). Findings from these studies may substantiate the theory while providing insights into how people think and behave in a particular situation. To illustrate, a study conducted by Gleason (2011) shows how intrapersonal intelligence can be implemented to develop learners" writing skills. I aimed to explore and describe psychosocial themes in children with a CHD through the lens of theoretical constructs by utilising the DPM of conceptualisation (Achenbach, 1990). Therefore, I aimed to provide new insights into a particular group of children – those who are suffering from a CHD. Thus, collective case study research was employed for this study.

Case study research designs can also be categorised according to type (exploratory, explanatory, and descriptive). An exploratory design is used to explore situations in which the phenomenon of interest has no clear, single set of outcomes (Yin, 2003). For example, Lotzkar and Bottorff (2001) conducted an observational study of the development of the nurse-patient relationship. Logic would argue that a relationship such as that between a nurse and a patient cannot be confined to a specific set and quality of interactions. Consequently, Lotzkar and Bottorff (2001) followed an observational approach to explore how the nurse-patient relationship naturally unfolds to bring forth a unique combination of interactions.

Explanatory designs seek to establish cause-and-effect relationships. The primary purpose is to explain, rather than describe, how events occur by isolating the influence of

specific variables on the outcome (Porta, 2008). To illustrate, Schneider (2012) explains how bibliotherapy affects the anxiety levels of children diagnosed with cancer.

Finally, descriptive designs attempt to present a complete description of a phenomenon in its context (Merriam & Tisdell, 2015). This type of design is illustrated by Ndile and Kohi (2011), who explored and described parents' knowledge about their children's CHD, their medication, and the prevention of complications. They found that parents lacked knowledge about their children's CHD, medications, and prevention of associated complications, especially endocarditis.

The type of research design that was implemented in the study to explore the psychosocial themes of children with a CHD can be categorised as an exploratory and descriptive case study research design. This classification is based on (a) the fact that this study has no clear, single set of outcomes – before data collection and analysis, I did not know exactly how the psychosocial functioning of children with a CHD is affected and (b) it aims to describe the nature of and extent to which the presence of a CHD affects the psychosocial functioning of the child.

4.3 Sampling

Sampling involves the art of skilfully selecting a small part of a group as a sample for inspection (Merriam-Webster, 2015). In qualitative research, sampling contributes to trustworthiness by maximising the efficiency and validity of a research study (Morse & Niehaus, 2009). Because the choice of a sample strategy should be geared towards answering the research question (Palys, 2008), sampling can follow different approaches, from a flexible way of sampling to a purposeful approach (Flick, 2007).

Theoretical sampling is an example of a sampling strategy that is more flexible. It functions as a feedback loop; i.e., insights generated because of data analysis provide feedback regarding further sampling (Charmaz, 2006). Therefore, it cannot be planned in detail before the primary data collection process. For example, Amidi-Nouri (2008) investigated how families of children in the terminal phase of an illness experienced this phase and how the families transitioned to life (i.e. how they continued with life) after the child's death. A theoretical sampling approach informed Amidi-Nouri (2008) regarding the most suitable sources for continued data collection.

Conversely, in purposive sampling, the number of cases is defined in advance and includes a collection of specific, predetermined features. This focus on specificity explains why purposive sampling is common in qualitative research (Curtis, Gesler, Smith & Washburn, 2000). To illustrate, in their study of the health perceptions of homeless young people, Flick and Röhnsch (2007) had to find out where people living under these circumstances can be met, where they hang out, meet peers, or turn to institutional help.

Palys (2008) divides purposive sampling into nine subtypes, including stakeholder sampling, extreme (or deviant case) sampling, typical case sampling, paradigmatic case sampling, maximum variation sampling, criterion sampling, theory-guided sampling, critical case sampling, and disconfirming (or negative case) sampling.

To explore the psychosocial themes of children with a CHD, I decided to follow a purposive criterion method of sampling (Tongo, 2007). As with any form of purposive sampling, criterion sampling enables the researcher to compare and contrast, and to identify similarities and differences in the phenomenon of interest (Palinkas et al., 2013). Moreover, criterion sampling has strong quality assurance (De Vos, Strydom, Fouché, & Delport, 2002). This is evident in the criteria that were outlined distinctly at the beginning of the study. The inclusion criteria for this study consisted of (a) children between the ages of eight and fourteen; (b) children who have been diagnosed formally with a CHD, with at least one surgical procedure performed relating to the condition; and (c) children from both genders. The exclusion criteria included (a) a child with an illness that falls outside a diagnosis of a CHD (e.g. HIV/Aids); (b) a child who may not medically be fit or well enough to engage in the interview process at the time; and/or (c) a child with a physical disability. Children with physical disabilities were not deemed eligible for the study because of the undue influence of the disability on the child's experience of living with a CHD.

Regarding sample size in qualitative research, the question is whether a sample size is informationally representative rather than statistically representative (Barnett, Vasileiou, Thorpe, & Young, 2015). Experts in the field of qualitative research agree that sample size depends on (a) research objectives; (b) epistemological and theoretical underpinnings; (c) type of analysis; (d) practical considerations such as access to participants; and (e) the criteria of data (thematic) saturation, i.e. when no new insights about the phenomenon/theoretical category are found by adding new cases (Baker & Edwards, 2012). All of these considerations merge to the conclusion that an appropriate sample size for a qualitative study is one that

answers the research question adequately (Charmaz, 2006). In line with this principle, the study of the psychosocial themes of children with a CHD initially aimed to include 15 to 20 children with CHDs of varying degrees of complexity. This estimate was in accordance with the average number of eligible patients serviced by the Department of Paediatric Cardiology at the University of the Free State. An attempt was made to consult similar South African studies for arguments and guidelines regarding sample size, but no similar studies could be found. The criterion of thematic saturation was used to guide the final number of participants, which was nine, namely six boys and three girls. Data saturation became evident with the realisation that there was enough information to replicate the study, the ability to obtain additional new information had been attained, and when further coding was no longer feasible (Fusch & Ness, 2015).

4.4 Instrument for Data Collection: Semi-structured Interview

4.4.1 Aim and structure

An interview is "a process during which a researcher and participant engage in a conversation focused on questions related to a research study" (DeMarrais, 2004, p. 55). Interviewing is the vehicle that transports the researcher to the participant's world of relating to the self and others, both from past and present experiences (Merriam, 2009).

The structure of an interview varies from highly structured, questionnaire-driven interviews to unstructured, open-ended, conversational formats. For the most part, however, interviewing in qualitative investigations is more open-ended and less structured because the qualitative researcher is interested in each participant's unique definition of him- or herself, other people, and situations. In the semi-structured interview, questions are structured but flexible in that the researcher is allowed to elaborate on a question if it is deemed necessary (Whiting, 2008).

Galletta (2013) explains that an interview consists of three segments. During the *first segment* of the interview, the researcher listens attentively to the participant's telling and probes for more information deemed necessary for rich data. Information that could enhance the richness of data includes details, events, observations, insights, and emotions that are relevant to the topic and worthy of revisiting later in the interview. The *middle segment* should contain questions that will ensure that the research topic is explored adequately; in other words, the researcher delves deeper into the information provided in the first segment.

The *final segment* benefits from and builds on the data emerging from earlier questions in the interview and explores abstract concepts that are more complex, such as meaning embedded in metaphors and contradictions. As the interview progresses, the researcher's awareness and indications of thematic saturation need to play a more prominent role (Ando, Cousins, & Young, 2014).

Gallettas's (2013) three-segment principle helped me to organise the questions across the DPM domains to ensure the emergence of rich data. The questions were designed to be domain specific yet simultaneously build on previous questions in more depth. For example, Question 2 ("Tell me what is going on with your heart") is categorised under the biological domain. However, Question 7 ("How do you feel about your sick heart?") and Question 10 ("What is happening to your heart?") fall under the psychological domain, but it was useful to delve deeper into Question 2 from the biological domain. Question 20 ("Who cares for you when you feel sick/sad/hungry/scared?") forms part of the social domain but also added depth to the child's responses to questions 2, 7 and 10.

4.4.2 Types of questions

A high-quality, semi-structured interview contains six types of questions (Patton, 2002). Table 4 provides an outline of the development of interview questions that would elicit rich responses through the integration of these types of questions with the domains of the DPM. Table 4 also illustrates distinct characteristics of a semi-structured interview, such as the fact that the questions were open-ended, specific yet used flexibly, and included more and less structured questions (Merriam, 2009).

Table 4a

Semi-structured Interview: Integration of Question Types and DPM Domains

Type	Question	DPM Domain
Experience & Behaviour	**Do you have to take medication? Tell me more.**	**Bio**
	What do you enjoy doing? Tell me more.	**Bio**
	Who looks after you? Tell me more about that person.	**Soc: Attachm**
	What are your favourite activities?	**Psych: Behav**
	Name the things that you cannot do because of your heart problem. Does it bother you? How?	**Psych: Behav**
	Tell me more about your friends.	**Soc: System**

Note. Bio = Biological; Soc = Social; Attachm = Attachment; Psych = Psychological; Behav = Behaviour; Cogn = Cognitive; Emo = Emotional. * Some types of questions can be included in more than one domain of the DPM, depending on the content of the answer; e.g., "Tell me what is going on with your heart" might relate not only to the child's CHD (i.e. biological domain) but also to the child's knowledge and perception of his/her CHD (i.e. Psych: Cogn. domain). Adapted with permission from "Qualitative research and Evaluation Methods" (3rd ed.) by M. Q. Patton, 2002, Thousand Oaks, CA: Sage Publications, Inc. Copyright 2002 by Sage Publications, Inc.

Table 4b

Semi-structured Interview: Integration of Question Types and DPM Domains

Type	Question	DPM Domain
Opinion & Values	**Why are you here at the hospital today?***	**Bio**
	Tell me what is going on with your heart*.	**Bio**
	Tell me more about the health of your family members.	**Bio**
	What do your parents/caregivers say to you?	**Psych: Cogn**
	What do your siblings say to you?	**Psych: Cogn**
	What do your friends say to you?	**Psych: Cogn**
	What do your teachers say to you?	**Psych: Cogn**
	If you could be any animal, what animal would you want to be? Why?	**Psych: Cogn**
	Who understands you the best?	**Soc: Attachm**
Feeling	**How do you feel about your ill heart?**	**Psych: Emo**
	Name some things that you like about yourself.	**Psych: Emo**
	Name some things that you do not like about yourself.	**Psych: Emo**
	If you had 3 wishes that would come true, what would you wish?	**Psych: Cogn**
Knowledge	**What is happening to your heart?**	**Psych: Cogn**
	How does your heart tell you when you are feeling ill?	**Bio**
	What does the doctor say to you?	**Psych: Cogn**
Sensory	**Tell me about a time when you and your family travelled together.**	**Soc: System**
Background	**Who cares for you when you feel sick/sad/hungry/scared?**	**Soc: Attachm**

Note. Bio = Biological; Soc = Social; Attachm = Attachment; Psych = Psychological; Behav = Behaviour; Cogn = Cognitive; Emo = Emotional. * Some types of questions can be included in more than one domain of the DPM, depending on the content of the answer; e.g., "Tell me what is going on with your heart" might relate not only to the child's CHD (i.e. biological domain) but also to the child's knowledge and perception of his/her CHD (i.e. Psych: Cogn. domain). Adapted with permission from "Qualitative research and Evaluation Methods" (3rd ed.) by M. Q. Patton, 2002, Thousand Oaks, CA: Sage Publications, Inc. Copyright 2002 by Sage Publications, Inc.

4.5 Data Collection and Analysis

For data analysis, I followed the six phases of thematic analysis (Braun & Clarke, 2006). During the first phase, I familiarised myself with the data. This involved the transcription of the data (in written form), reading and re-reading the data, and noting down initial ideas. I approached this phase open-mindedly in the sense that I overincluded rather than underincluded ideas that carried potential for further analysis. The second phase of data analysis involved the generation of initial codes, namely coding interesting features of the data systemically across the entire data set and organising data relevant to each code. During the third phase, I moved closer to definitive themes by organising potential themes and gathering all data relevant to each potential theme. The fourth phase involved a review of the themes, such as checking the work in relation to the coded extracts (referred to as Level 1) and the entire data set (referred to as Level 2). During this phase, a thematic map of analysis

was generated. During the fifth phase, the themes were defined and named. After the proceedings of the first five phases had been followed closely, the final sixth phase provided me with the opportunity for a final analysis. The selection of vivid, compelling extract examples and their analysis was important during this phase. This was related back to the research question and literature to ensure that the research question had been answered successfully and that the data were plotted accurately onto the theoretical framework – the DPM.

Table 5 illustrates Braun and Clarke's (2006) 15-point checklist, which provides pointers with regard to transcription, coding, analysis, reporting on the results, and other overall guidelines. By using this checklist, I enhanced the quality of the thematic analytic process.

Table 5a

15-point Checklist for High-quality Thematic Analysis

Process	No.	Criteria
Transcription	**1**	**Data were transcribed to an appropriate level of detail, and the transcripts were checked against the tapes for accuracy.**
Coding	**2**	**All data items received equal attention in the coding process.**
	3	**Coding process was thorough, inclusive, and comprehensive.**
	4	**All relevant extracts for each theme were collated.**
	5	**Each theme was compared and organised.**
	6	**Themes are internally coherent, consistent, and distinctive.**

Note. Adapted from "Using thematic analysis in psychology" by V. Braun and V. Clarke, 2006, *Qualitative Research in Psychology, 3,* p. 96. Copyright 2006 by Edward Arnold (Publishers) Ltd.

Table 5b

15-point Checklist for High-quality Thematic Analysis

Process	No.	Criteria
Analysis	**7**	**Data were analysed and interpreted, not merely described.**
	8	**Analysis and data match; the extracts illustrate the analytic claims.**
	9	**Analysis tells a motivated, organised story about the data and topic.**
	10	**Good balance between analytic, narrative, and illustrative extracts.**
Overall	**11**	**Enough time was allocated to complete all phases of the analysis adequately, without rushing a phase.**
Written report	**12**	**Assumptions about and specific approach to thematic analysis are explicated clearly.**
	13	**Described method and reported analysis are consistent.**
	14	**Language and concepts used are consistent with the epistemological position of the analysis.**
	15	**Researcher played an active role in the identification of themes**

Note. Adapted from "Using thematic analysis in psychology" by V. Braun and V. Clarke, 2006, *Qualitative Research in Psychology, 3,* p. 96. Copyright 2006 by Edward Arnold (Publishers) Ltd.

4.6 Ethical Considerations

Conducting research with children raises special ethical issues due to their vulnerable status. Children are vulnerable in two ways. Firstly, they are inherently vulnerable due to certain age-related characteristics, including limited knowledge and understanding as well as physical weakness. These factors render them dependent on adults. Secondly, they are structurally vulnerable because of lack of economic and political power (O'Reilly, Ronzoni, & Dogra, 2013).

These principles endorse the equal provision of quality health care to all patients, beneficence in providing evidence-based care, and non-maleficence in avoiding harmful therapies (e.g., without scientific evidence). Therefore, research on children should be viewed as a moral duty based on ethical principles (Neill, 2005).

In preparing for the research and to adhere to ethical principles, I reflected on the primary ethical principles and articles of O'Reilly et al. (2013) and Allan (2011), as well as

the ethical principles of the UNICEF office of research (Graham, Powell, Taylor, Anderson, & Fitzgerald, 2013). Table 6 provides a conceptualisation of ethical conduct by summarising the ethical principles, considerations, and examples of some questions on which I reflected.

Table 6

Conceptualisation: Ethical Conduct

Principle	Consideration/s	Question/s*
Beneficence	**Measures of benefit**	**What is the research question and aim of the study?**
		How will children with CHD benefit from the research?
		How will the research endorse their development and care?
		Why does this research topic speak to me?
		Who is responsible for responding and/or acting on its findings?
Non-maleficence	**Distress and fear minimisation**	**How will I ensure that participants are protected from harm, e.g. unforeseen emotional upset, during the interview?**
	Debriefing	**What do I need to do in the case of emotional upset during an interview with a child participant?**
	Sensitive issues	
	Power relation	**How will I prepare the participants (including understanding what research is and how to carry it out ethically)?**
	Individual data protection	**How will I ensure that research data are held confidentially and securely?**
	Confidentiality (anonymity)	
	Availability to public	
Respect	**Autonomy**	**How will the children exercise informed consent to participate in research?**
	Informed assent	
	Informed consent	**How will parents be informed of their children's participation in the research project?**
	Right to withdraw	
	Developmental aspects	**How will I ensure the parents and participants have the right to withdraw?**
	Inducements vs. compensation	**Will the research setting allow the participants to express their views freely?**
		How will I take cognisance of a possible language barrier?
		If the child participant asks to take the crayons (used for the drawing exercise) home, how should I respond?
Justice	**Distributive justice**	**What process am I going to follow to ensure that data recording, analysis and reporting are accurate?**
	Coercion	
	Proportionality	**How will I ensure equality in selecting research participants?**

Note. Adapted from "Research with children: Theory & Practice" by M. O'Reilly, P. Ronzoni, and N. Dogra, 2013. Thousand Oaks, CA: SAGE Publications Inc. Copyright 2013 Michelle O'Reilly, Pablo Ronzoni and Nisha Dogra; "Law and Ethics in Psychology: An international perspective" (2nd ed.) by A. Allan, 2011. Somerset West: Inter-Ed Publishers. Copyright 2011 by Inter-Ed Publishers; "Ethical Research Involving Children" by A. Graham, M. Powell, N. Taylor, D. Anderson, & R. Fitzgerald, 2013. Florence, Italy: UNICEF

Office of Research – Innocenti. Copyright 2013 by UNICEF Office of Research. *Some principles and considerations inevitably overlapped in the questions I had to ask myself.

The Health Research Ethics Committee of the University of the Free State gave me permission to conduct this research (see Appendix A). Informed consent from the parents/guardians and informed assent from each child were gained prior to data collection. The guidelines provided by the World Health Organisation (2016a) were followed to design the informed consent form (see Appendix D and E) and the informed assent form (see Appendix F and G). The participant's autonomy was respected by the informed assent process, during which the research process was explained in detail. The participants were also provided with the option to withdraw from the project at any time, thus adhering to the ethical principle of justice, seeing that the participants were not coerced into any activity related to the research project.

I gained knowledge of the development stage, the cultural background, and the heart condition of the participants before data collection took place. This was done to adhere to the ethical principles of beneficence, non-maleficence, respect, and justice. I accomplished this by reviewing literature on normal development during middle childhood and early adolescence, conversing with individuals from the same cultural background as the participants, and consulting with a participant's medical doctor to understand the participant's heart defect in more depth.

During qualitative research, language is the vehicle that delivers a participant's sense of self. Therefore, a translator was present during contact sessions with the participant to ensure accuracy of information exchanged. The translator contributed towards beneficence, non-maleficence, respect, and justice for the participant, as they were able to share their intrapersonal experiences in their language of choice, which in turn made them feel comfortable and understood. Squires (2008) explains that translator neutrality is an important aspect of ethical conduct in qualitative research. Consequently, the appointment of the translator was based on the following three criteria: (a) her qualifications as language practitioner (see Appendix I); (b) her ability to relate to and converse appropriately with children in the developmental stage of middle childhood; and (c) a strong recommendation from a reputable language practitioner with whom I had worked in the past. Furthermore, this translator signed an agreement of confidentiality to protect the participants' privacy. Additionally, back-translation (Brislin, 1970) of the interview protocol was done to ensure that the words of the participants did not create evidence that misrepresented the phenomenon

under study (Weeks, Swerissen, & Belfrage, 2007). The back-translation was done by two different translators at two different locations to strengthen the trustworthiness in general (Shenton, 2004) and translator neutrality in particular (Squires, 2008).

The qualitative research tradition holds that a research enquiry should be made with minimal intrusion. I viewed this premise as an ethical consideration of non-maleficence and respect, which are evident from various aspects of the study, including the choice of research setting and the nature of the data-collection instruments. For example, preparations have been made for when a participant might experience significant emotional upset (either reported by a participant or observed by the researcher). If that were to happen, that participant would be referred to an appropriate mental health care professional. Privacy and confidentiality were ensured by interviewing the child participant in a quiet, private space, with no other individuals other than the translator present. A “do not disturb” sign was also used. In addition, health care staff members were briefed on the importance of no disturbance during the interview.

Francis et al. (2010) propose a model to ensure thematic saturation. To adhere to the principle of justice, I familiarised myself with the model by critically engaging with the content to strike a balance with regard to reaching thematic saturation. The first phase of this model requires the researcher to use his/her intuition while conducting an interviewing in order to get a sense of whether anything new is emerging in relation to the research objectives. Secondly, a researcher should be able to continue interviewing until a “stopping criterion” has been reached. O’Reilly et al. (2013) state that only the researcher will be able to identify the point at which repetition occurs. Therefore, in this study, the onus was on me to find a fine balance between working towards thematic saturation without compromising the ethical principles of beneficence, non-maleficence, respect, and justice for the child participant. I strove to remain sensitive to verbal and non-verbal messages from a child participant that indicated discomfort with or unwillingness to continue, even though I might have wanted to continue with the process of ensuring thematic saturation (i.e. the repetition of themes).

To ensure justice, I focused on trustworthiness, namely transferability, credibility, dependability, and confirmability (Shenton, 2004). In terms of transferability, I made use of a reputable, evidence-based research method. The methodology of the project reflected the ethical principles of beneficence and non-maleficence by the implementation of child-friendly instruments such as age-appropriate interview questions and drawings. Regarding credibility,

triangulation was applied by using different methods (e.g. observation, the semi-structured interview, and discussion with my supervisors). Tactics to ensure honesty in participants also played a key role in ensuring credibility; for example, a variety of conversational techniques such as the skilful use of statements (Geldard, Geldard, & Yin Foo, 2013) was utilised to promote honesty in the participants without disrespecting their sense of self. In addition, iterative questioning (rephrased questions pertaining to matters previously discussed) was utilised.

Dependability formed an important part of the ethical conduct to ensure accurate understanding of the participants, also as part of respect for their intrapersonal functioning. Dependability included member checking (an opportunity for the participants to review their responses) by means of summarisation of information and restatement of questions took place (Sharpe, 2006). To strengthen dependability, my supervisor did peer reviewing (Shenton, 2004).

Research transparency ensures confirmability and contributes to ethical conduct throughout a research project (Carcary, 2009). Research transparency was maintained by an audit trail throughout the project. In developing an audit trail, I recorded an account of all research decisions and activities throughout the study. I made all decisions taken about theoretical, methodological, and analytical choices explicit (Koch, 2006). This process was done by keeping a log of all research activities. I also kept a journal of my own experiences.

Thus, because of my reflection on the ethical principles and how to align them in accordance with the aim of this study, I was able to ensure that ethical conduct permeated every aspect of the study. It was also clear to me that ethical principles were interwoven and could not be compartmentalised rigidly. To meet my participants “in their worlds” indeed required reflection and reflexivity.

4.7 Conclusion

The core characteristics of a qualitative research approach (Roller & Lavrakas, 2015) remained evident throughout this chapter. It served as motivation to explore the psychosocial themes of children with a CHD, and can be summarised as follows:

- Data collection did not take place in a vacuum but rather in a context; therefore, the information gained was the product of various situational factors by means of an in-depth interview with each child participant.

- Along with the emphasis on context, meaning, and the potential for researcher subjectivity, qualitative research is distinguished by the fact that it places the researcher at the centre of data collection. The research space that I shared with the participants facilitated in-depth understanding of the meaning that they attach to living life with a CHD.

- This qualitative research effort required a unique set of skills that goes beyond the usual qualities of organisation, attention to detail, and analytical abilities that are necessary for all researchers. For example, I had to employ techniques to build rapport with the participants and active listening skills.

- Qualitative researchers also need a special class of analytical skills that can meet the demands of "messy analysis". In addition, flexibility was built into the research design. For instance, I had to apply discernment with regard to topics that needed further exploration with specific follow-up (probing) questions as part of the semi-structured interview. I also had to make allowance for flexibility regarding sample size, which depended on various factors, such as saturation – a characteristic that is unique to qualitative research.

- Given the sensitive nature of the phenomenon under study, i.e. the psychosocial themes of children with a CHD as well as the vulnerable age group, ethical conduct infused every aspect of the study. Throughout the study, I held myself accountable to the words of Potter Stewart, who states that ethical practice involves an understanding of the difference between knowing what one *should do* (i.e. from a legal point of view) and what is the *right thing to do*; that is, keeping the best interest of the participants as first priority (Stone & Ukleja, 2009). I continuously reminded myself to deal with the participants in the same way that I would want another researcher to deal with me and my own children.

It is clear that qualitative research follows a multi-layered, circular process that continually builds upon itself until the beauty of meaningful interpretation and in-depth understanding is achieved.

Ragin, Nagel, and White (2003) explain that users of social science research might criticise qualitative research for its small sample sizes. However, if the purpose and usefulness of a qualitative research approach is understood and appreciated fully, it will be evident that a

small sample size is in fact paramount to a focus on diversity rather than distribution. Thus, the contribution of qualitative research findings to a given scientific knowledge base is substantial in its own right. This idea is reflected in the African proverb stating that “if you think you are too small to make a difference, try sleeping in a closed room with a mosquito” (“Africa’s proverb of the day”, 2016).

CHAPTER 5: FINDINGS AND DISCUSSION

"Here they are, the very beans themselves," he went on, pulling out of his pocket a number of strange-looking beans. "Ah! You don't know what these beans are," said the man. "If you plant them overnight, by morning they grow right up to the sky."

"Right," says Jack, and hands him over Milky-white's halter and pockets the beans. Back goes Jack home and, as he hadn't gone very far, it wasn't dusk by the time he got to his door.

"What!" says Jack's mother. "Have you been such a fool as to give away my Milky-white, for a set of paltry beans? And as for your precious beans, here they go out of the window. And now off with you to bed."

When he woke up, the room looked so funny. The sun was shining into part of it, and yet all the rest was quite dark and shady. So Jack jumped up and dressed himself and went to the window. And what do you think he saw? Why, the beans his mother had thrown out of the window into the garden had sprung up into a big beanstalk, which went up and up and up till it reached the sky…

– Jack and the Beanstalk (Nesbit et al., 1956, pp. 118-123)

5.1 Introduction

Jack's curiosity, perseverance, patience, and courage, against all odds, led him to the discovery of gold, which made him a rich young man. Jack's journey to riches served as inspiration for this chapter, which illustrates the meticulous process of thematic analysis that led to rich discoveries regarding the psychosocial themes of children with a congenital heart defect (CHD).

To explore the psychosocial themes of children with a CHD, nine participants with ages ranging between eight and fourteen were interviewed. The interviews were transcribed and analysed to identify recurring themes. Five prominent themes evolved from the participants' responses. These themes related to (a) the participants' understanding of their cardiac diagnoses; (b) perceptions regarding their post-operative cardiac statuses; (c) psychological experiences related to their cardiac statuses; (d) the effects of living with a CHD on their social functioning; and (e) a unique attachment to their hearts, i.e. chronic cardiac conditions.

Within each of these overarching themes, thirteen subthemes were noted. The full-text transcriptions of the interviews (in English, Sesotho, Setswana, and Afrikaans) are included in Appendix H. In the discussion of the above-mentioned themes, excerpts from the full text transcriptions will be presented in English.

A brief overview of the participants is presented first, followed by a discussion of the themes.

5.2 Description of Participants

The sample consisted of nine participants: six boys and three girls aged between eight and fourteen years. The mean age of the sample was twelve years. They were Sotho-, Tswana-, Zulu-, and Afrikaans-speaking and were all diagnosed with a form of CHD. They came from the Northern Cape, Lesotho, and the Free State and were treated by a team of paediatric cardiologists at Universitas Hospital. Table 7 outlines this background for the reader of the participants' experiences of CHD. To protect the participants' identities, reference is made to code names (A to I).

It should be noted that, even though participant G has an additional diagnosis of HIV/AIDS (technically an exclusion criteria), she was included in this study based on the fact that she was clearly able to identify between symptoms and experiences ascribed to the CHD and those ascribed to the HIV/AIDS. This decision resulted from a critical reflection on this case - similar to the process implemented during the preliminary study (see section 3.5.4.1). In adherence to the ethical principle of beneficence and non-maleficence, participant H was identified with a need for psychotherapy and was referred accordingly. This emphasises the importance of a professional support system in providing comprehensive and high quality care.

Table 7

Participants: Biographic Information

		GENDER		AGE	LANGUAGE		DIAGNOSIS
		M	F		Education	Home	
	A	✔		**8:6**	**Tswana**	**Tswana**	**Ventricular Septal Defect. Aortic Valve Regurgitation.**
	B	✔		**12:1**	**Sotho**	**Zulu**	**Partial Abnormal Pulmonary Venous Drainage. Atrial Septal Defect Type 2.**
	C	✔		**13:2**	**Tswana**	**Tswana**	**Tetralogy of Fallot, with a right-sided aortic arch.**
	D	✔		**13:10**	**Afrikaans**	**Afrikaans**	**Aortic Valve Stenosis of the bicuspid aortic valve.**
	E		✔	**13:11**	**Sotho**	**Afrikaans**	**Double Outlet of the Right Ventricle. Transposition of the Great Arteries. Atrial Septal Defect Type 2. Patent Ductus Arteriosus. Peripheral Pulmonary Stenosis.**
	F	✔		**12:6**	**Afrikaans**	**Afrikaans**	**Double Outlet Right Ventricle. Pulmonary Stenosis.**
	G		✔	**12:10**	**Sotho**	**Sotho**	**Atrial Septal Defect Type 2.**
	H		✔	**14:9**	**Afrikaans**	**Afrikaans**	**Tetralogy of Fallot.**
	I	✔		**8:8**	**Afrikaans**	**Afrikaans**	**Tricuspid Valve Atresia.**
Average		**6/9**	**3/9**	**12**	*	**	

* Afrikaans: 4/9, Sotho: 3/9, Tswana: 2/9

** Afrikaans: 5/9, Tswana, 2/9, Sotho: 1/9, Zulu: 1/9

5.3 Thematic Analysis

Figure 8 illustrates how the five main themes and the thirteen subthemes were plotted in accordance with the DPM domains.

Figure 8. The main and subthemes identified cut across the biological, psychological, and social DPM domains.

5.3.1 Theme 1: *I have a heart*: Understanding of cardiac diagnoses

Eight of the nine participants had a fair understanding of their cardiac diagnoses and were able to explain, to some extent, what the matter with their hearts was.

Understanding is a complex, multi-layered, psychological process, which represents the relationship between an individual and a given phenomenon or object (Bereiter, 2002). Cognitive-emotive integration is an important aspect of understanding. Thus, the process of understanding starts with the acquisition of knowledge that is integrated with affect, resulting in a series of psychological processes, such as perception of and attitudes about a given idea or object. Logically, the extent of cognitive integration is mediated by the individual's level of cognitive functioning, which differs from one developmental stage to the next. The

participants were all in the developmental stage of middle childhood (between the ages of eight and fourteen years of age), and according to Piaget (1951/1995), they were in the *concrete operational stage* of cognitive development. Cognitive characteristics of this stage are evident in the concrete manner in which the participants shared their understanding of their cardiac diagnoses, which represented the first subtheme: *I have a hole in my heart.*

5.3.1.1 Sub-theme: I have a hole in my heart

A: *"There is a hole [in my heart]."*

C: *"The doctor then checked me and then said that I have a hole in my heart. [Before the operation] my heart was not in a good condition … there is an opening in my heart."*

E: *"There is a hole in my heart and the hole is still open. The hole in my heart is now busy closing because I take tablets."*

G: *"My heart has a hole in it, so they took something like an umbrella to close it up."*

As children enter middle childhood, they become mature enough to use logical thought, but it is limited to physical objects in the *here-and-now* (hence referred to as *concrete* operational). This principle is evident in the data set, with four of the nine participants understanding that the holes in their hearts could be closed.

Another observation from the data set that also resonates theoretical findings on cognitive development during middle childhood is the principle of *continuum of acquisition* (Berk, 2010) i.e. a gradual mastery of logic. Older participants presented with a slightly more abstract understanding of their cardiac conditions:

B: *"My vein is pumping blood into the wrong pipe of the heart … they [the doctors] said that they were going to close the wrong vein that was pumping blood to the heart."*

D: *"There is a big problem with my heart – the valve does not function the same as other people's … it is narrowed. At birth, there is a flap that is meant to tear but the flap in my heart did not tear. The valves work like doors that open and close. The valve doesn't open as it should and it leaks blood."*

F: *"There is a vein [in my heart] that constantly calcifies … this makes the valve weak … With each operation, they remove the lime but this time round they [the doctors] put a*

stent in … it's a little metal thing … at first it is small but when they inserted it into me it opened. It is made of metal."

H: *"The valve moved/pulled away from the heart and then they stitched or closed it. During the previous operation, they told Mom that they are going to replace the valve with a new one."*

Participant I was the only one who was not able to describe his cardiac condition – not even on a concrete level:

I: *"I don't know [what is going on with my heart]. I think there is a problem with my heart but I don't know what."*

Information provided by Participant I, e.g. *"My teacher says that I am shy"*, as well as collateral information from the parents, provides a possible reason for the participant's response. The parents described this participant as a slow-to-warm-up child with an introverted temperament. When probed, the participant stated that he wanted to know what was going on with his heart, but it seemed as though he had not asked his doctor or parents about what the matter with his heart was.

Thus, it can be said that eight of the nine participants (with the exception of Participant I) exhibited an age-appropriate cognitive understanding of their cardiac conditions. However, although still within the average range, the levels of intellectual functioning of children with a CHD were found to be lower than those of their age-matched controls (Donofrio & Massaro, 2010). These findings suggest that the participants' understanding of their cardiac conditions – although found to be age-appropriate – might be limited due to the presence of a CHD and therefore could be even better.

The multidirectional influences among the functional domains of the DPM are of special importance, considering the role that the environment (e.g., social and educational settings and influences) can play in cognitive functioning; hence, the children's understanding of their cardiac diagnoses. Examples of such influences include health care professionals and the paediatric patients' significant others.

5.3.1.2 Sub-theme: I remember what happened to my heart

Memory development during middle childhood shifts from recollection by familiarity toward the increased ability to encode, decode, and recall detailed components of episodes. Thus, episodic memory is a specific memory ability that improves markedly during middle childhood (Ghetti, Mirandola, Angelini, Corndoli, Ciaramelli, 2011). Episodic memory involves *subjective remembering*, also referred to as *autonoetic consciousness* (Chen, McAnally, & Reese, 2013), which refers to the ability to mentally place our sense of self in the past. Our sense of self affects our behaviour and relates to how we reflect on our own past behaviour as well as how we feel about it.

This type of memory is of special importance in children with a chronic illness, such as CHD, because events that are recorded into episodic memory may trigger episodic learning, i.e. behaviour that occurs because of an event (Terry, 2006). Therefore, this memory skill has a significant influence on the child with a CHD and illness-related events. Episodic memory enables these children to play an integral part in their own treatment. To illustrate, episodic memory can assist the child with a CHD to attain cognitive-emotive integration, which will result in health-promoting behavioural changes, for example, refraining from or engaging in activities for the sake of health promotion. If this happens, it can be said that episodic memory resulted in episodic learning.

Eight of the nine participants displayed well-developed episodic memory, as reflected in the detail of the following responses:

B: *"Yes, I was taking pills. I came here on the 9th of November then left on the 25th of November 2015. They [the doctors] said that there was something wrong with me so they gave me pills as a result and said that they will later on treat me … they were writing tests at school so they did not want me to miss school … The main reason [for the pills] was to try and prevent the illness not to damage him [my heart] any further."*

C: *"My mother took me to the doctor for a check-up and then the doctor said that I had a hole in my heart, so he wrote a letter to transfer me to Kuruman Hospital. At Kuruman Hospital, they said that they will not be able to help me so they transferred me to Kimberley [hospital] and there they also said that they were unable to help me, so they transferred me here [Universitas Hospital]."*

D: *"Yes, the tablets [medication] help my heart to beat slower (in the normal range). There was once an incident when my heart was beating fast because I was walking a lot – I was playing golf and the medication slows down my heartbeat, so there was a 'clash' and I got dizzy."*

E: *"I have had two operations [for my heart]. When I needed a third operation, Mom refused the operation because she was scared that I might die. I am also scared, because at the time of the second operation the doctor said that I might die during that operation."*

F: *"The one time, they [children at school] almost took me to the office (I ran and fell), there was this purple spot on my leg. At first, they thought that I had pulled a muscle but nothing actually happened. As far as I know, it seems as though they care about me because as far as I know I am the only one who gets crowded [by other children] when I get injured. I think it is due to the heart problem or something."*

G: *"And what I pride myself in is that I do my school work. When I grow up I want to be a doctor … Because I saw that the doctors are the ones who helped me a lot. When I was still a child I wanted to be a policewoman but now, growing up, I see that doctors are important. My father says, 'The truth is that doctors saved your life.' …. When I went to Pelonomi they told me that I had a lung problem. They said that my lung was too small and when I arrived here at the hospital, they said that I do not have a small lung – the problem is that there is a hole in my heart. And then the doctor said that it is supposed to be operated and closed … 29th of March last year. It was on a Wednesday."*

In addition, the influence of episodic memory on various functional domains of the DPM was noted. For example, Participant H shared how she cherished memories of her friends and family, especially her deceased grandfather. In a sense, her episodic memory skills allowed her to keep her beloved grandfather in remembrance and she made choices in life based on the example that he set for her when he was still alive, regardless of the fact that she had a potentially life-threatening illness (CHD):

H: *"It was at my grandfather's funeral. It was a big funeral because my grandfather was a good golfer. He knew Ernie Els*. My auntie has also been on TV for golf … we have photos of her and Ernie Els* and a jacket that Ernie Els* gave her. She lives in Durban*. Many people in my family play golf."*

In the case of Participant I, he was also able to "talk from his heart" about the emotion of anger by means of episodic memory. When asked to name some things that he could not do because of his heart problem, he responded as follows:

I: *"I should not get angry much [but there are things that make me angry], for example, my cousin, when we play, then he wants to play with us but he doesn't know how to play [the rules of the game]; because [when we play] he would play with us but then he would run into the house when we have to search for him [during hide-and-seek]."*

Furthermore, Tracy and Shergill (2013) posit that episodic memory plays a role in visual or auditory *misperception.* In the case of Participant H, episodic memory appears to be a double-edged sword: On the one hand, it aids in reliving positive emotional experiences of her grandmother. However, on the other hand, it may result in a negative emotional experience for this participant.

H: *"My mother [takes care of me when I feel sick/sad/hungry/scared]. It used to be my grandmother but now she is gone. I dream about her everyday. I dreamt that her funeral was at four o'clock in the morning. The people were getting ready and the body only arrived at four o'clock in the afternoon. Then I went there to look at her … she was blue … then I was in the field at my uncle's funeral, with the ambulance and police driving past to our house. When we arrived at home, I thought they brought my uncle's body … but the body had changed … it was my grandmother's body. Then I stood at the door and cried … I just heard [the participant's mother calling], 'Sarah* [my mother's name], the child is crying, come and help her!' Then Granny woke up, she grabbed my hand and I begged her to leave my hand and I went and stood at the door."* and *"When my other grandmother scolds me, then I think about this granny … then I ask myself why did she have to die … why not someone else? She died on Karabo's* mom's birthday, last year. Sometimes, I hear someone talk then I ask, 'Who is talking?' but no-one talks – everybody is sleeping. Or, I would hear footsteps in the house then I ask again. Last year my uncle and us were home alone. His child went and fetched water, came back and placed the water on the cupboard. I heard [a noise] in the kitchen … I saw that the glass (with water) was upside-down but the water was still in the glass."*

This sub-theme is a clear example of the reciprocal relationship between the three sub-domains of the psychological domain of the DPM: The cognitive process of memory (a

component of cognition) and emotions work together to guide the child's world-view (a component of cognition) and subsequent behaviour (see Section 2.5.2.2). Nelson (2014) explains that memories mediate the presence of negative affect because of a sense of loss of control and that children whose lives are interrupted markedly by negative memories (such as memories related to life with a chronic illness, such as a CHD) require sensitive therapeutic intervention.

Participant D's response is an example of this theoretical statement:

D: *"For example, every year we have a school trip to Ramsgate*. All the schools from the district go on the same day. I couldn't slide down the Slide of Courage. My mom said I shouldn't because I will panic and it would have placed too much stress on my heart. I went down once before, though … I was quite scared and panicked."*

In contrast to all the other participants, Participant A, who is the youngest participant (8 years old), did not exhibit well-developed episodic memory. However, it should be noted that Participant A was interviewed while in the Intensive Care Unit (ICU) of the hospital. His treatment status at the time of the interview may have hindered his ability to share elaborately to give a clearer picture of his episodic memory.

5.3.1.3 Subtheme: Healthy for my heart

Linked to the previous cognitive-oriented subtheme, which revolves around episodic memory, the next subtheme focuses on the reciprocal relationship between cognition and behaviour – two of the three psychological subdomains of the DPM. Cognitive regulation refers to the ability of the human brain to utilise cognitive skills such as attention, language, and executive control to influence decision-making, which in turn should result in adaptive behavioural outcomes. Therefore, it is a process of redirecting unsuccessful efforts toward behaviour that is healthy for one's heart (Hutcherson, Plassmann, Gross, & Rangel, 2012; Janssens et al., 2016).

From a developmental psychopathological point of view, this realisation poses a challenge, seeing that children in the developmental stage of middle childhood typically are not yet good at cognitive self-regulation (Berk, 2010). However, the data set at hand presented with a strong indication of high levels of cognitive self-regulation that are not typical of the developmental stage of middle childhood:

B: *"Yes, I was taking pills … to try and prevent the illness not to damage him [my heart] any further."*

C: *"I take pills … I take them after meals … since 2011."*

In response to "Why do you take the medication?" C answered, "*They said that they will help me."*

In response to "How does your heart tell you when you are feeling sick?" C answered, *"I can't play, talk or eat … because I would be in pain."*

D: *"My ribs push in, it feels like needle pricks, I have pain, I get nauseous and my heart starts to beat very fast when I do exercise. That is why I don't do strenuous fitness exercises anymore. I still train with the rest but I don't do the serious fitness exercises"* and *"It is not nice for me to have this [heart] illness. I cannot play touch rugby with the other children. I so badly want to play with them but then I think about the possible consequences … if they were to tackle me in a certain way, maybe too hard, then it is not good for my heart. My heart can't handle contact like that."*

E: *"The hole in my heart is now busy closing because I take tablets."*

F: In response to the question of how other children at school will know when he is feeling ill, F answered, *"Yes, usually with Open Gate* [game], *I will sit down and then they know that they shouldn't choose me. If I get up, then they can choose me."*

G: In response to "Why are you here at hospital today?" G answered, *"I have to come to the hospital from time to time because I have to know how I am doing with regard to the problem of my heart. And I take care of my heart very well and even at school when I play with other learners and they want to hit me somewhere on my body where I know I have a heart problem I say, 'No, don't hit me there.' because I know that I have a heart problem. So I try by all means to protect my heart."*

H: Referring to the fact that medical treatment could markedly change her cardiac condition for the better, H shared that *"I want to live to see where I end up in life."*

I: *"Yes [I have to take medication] to heal my heart."*

Even the youngest participant, Participant A (8:6), exhibited cognitive regulation:

A: *"[The doctor] says that I should drink water and milk … [it] will help me."*

These findings of an appreciation for the "plan behind the pills", so to speak, are also in dissonance with recent studies on social cognition of children with a CHD (Bellinger, 2008; Cassidy, White, DeMaso, Newburger, & Bellinger, 2015). They found that children with a CHD are at a greater risk for difficulties with cognitive self-regulation. Their findings are in line with those of Donofrio and Massaro (2010), who highlight the lower levels of intellectual (i.e. cognitive) functioning of children with a CHD.

Conversely, my findings support the research findings of Perricone, Polizzi, and De Luca (2013), who found that children with a CHD have sufficient cognitive abilities that enable them to redefine their self-images and face the risk condition. To illustrate the multi-directionality between DPM domains, the findings of Barsalou (2008) suggest that perception and cognition are mediated by the biological domain of the DPM at the source of illness perception, i.e. the body. The bodily state, combined with increasing *abstract reasoning* as children progress through middle childhood (see Section 5.3.1.1), enables them to perceive themselves not in terms of a mere sick body, but rather in terms of a child with a potentially able body. In addition, the cognitive skill of *perceptive organisation* allows the child to redefine the representation of his/her own body and his/her interaction with the world. Thus, a child with well-developed cognitive abilities, such as abstract reasoning and perceptive organisation skills, could have a greater chance of understanding what his/her health care practitioner tells him/her about the treatment and would be more susceptible to adhere to therapeutic intervention.

5.3.2 Theme 2: *Talking about my heart*: Perceptions regarding post-operative cardiac status

Perception, as a crucial cognitive component that permeates various functional domains, was demonstrated clearly in the participants' responses about their post-operative cardiac status, which formed the foundation for the following two subthemes:

5.3.2.1 Sub-theme: My heart is fixed!

Even though post-operative functioning can indeed be improved markedly, children with a CHD may have prolonged cardiac symptoms even after surgical or interventional treatment with recommended lifelong treatment (Roos-Hesselink, 2004). The participants' responses indicated a misperception about their post-operative cardiac statuses, which could

potentially have a negative effect on their psychosocial functioning. In DPM terms, such a misperception is actually a normal concrete cognitive characteristic during middle childhood (Ylvisaker, 2006): Some participants indicated that, as long as the hole in their heart was fixed, they were healed and would be free of symptoms. When asked how they knew when their hearts were feeling sick and what was going on with their hearts, these participants responded as follows:

A: *"[My heart] is in a good condition (sharp)."*

B: *"Being unable to inhale … it hurts me … but now I think that it will never happen [again] because I have been operated."*

C: *"[Before the operation], my heart was not in a good condition and there was an opening in my heart. [Now], nothing [is happening to my heart]."*

E: *"[The hole] in my heart is now busy closing because I take tablets"*.

G: *"It is a strong pain on my heart. Something like nails when they are stabbing you … that kind of pain and I would tell my Mom that I have this severe pain and my mother would ask if I am sure it's my heart and I would say, 'Yes, I am sure.'[Now] it's beating well, I can run now because I have been operated and I can do a lot of things. Yes, [my heart is fixed and it works the same as any other child of my age]."*

I: *"I'm all right."*

These responses support the notion that logical thinking increases as the child progresses through middle childhood. According to the "common sense model" (CSM), patients create their own models or representations of their illness to make sense of their illness, which, in turn, influence their coping strategies and health outcomes (Hagger & Orbell, 2003). The above-mentioned participants have a linear understanding of their illness – they had physical symptoms because of their illness, which was eliminated by the operation. Thus, the CSM highlights an important limitation of the concrete operational thinking stage coined by Piaget in 1954 (Berk, 2010): Children think logically only when dealing with concrete information they can perceive directly. From a DPM perspective, concrete cognition combined with medical intervention in the biological domain (i.e. cardiac surgery) creates a healthy positive emotion of hope, which could serve as a protective factor against future unhealthy negative emotions. However, it could also present as a risk factor: In the case of the

participants mentioned above, their health status and subsequent biological functioning had indeed improved because of medical intervention, but they were unaware of the physiological intricacies that might continue to affect their health in future.

5.3.2.2 Sub-theme: My heart is fixed, but…

In contrast to the above-mentioned findings, three of the nine participants had a more realistic outlook regarding their post-operative (i.e. future) cardiac status:

D: In response to the question "Why are you here at hospital today?" D answered, *"To see if my heart condition got worse or not."* The interviewer then asked whether there was a possibility that it could in fact get worse. D responded by saying, *"Yes, it has happened before."*

F: *"There is a valve in my heart that constantly calcifies. With every operation they remove the lime, but the last time, they put in a stent."*

H: *"I felt happy, because they can fix the problem … [it is not totally fixed but] still a bit sick."*

Interestingly, these three participants are three of the older participants. Typical development during middle childhood predicts that misperceptions regarding illness are likely to dissolve and to be replaced by understanding that is more rational. One of the fundamental premises of the DPM (typical vs. atypical development) explains the "flip side of the development coin": If the child has difficulty to reach the cognitive milestone of increased logical thinking, misperception of illness might be maintained or even worsened, with clinically significant negative effects (i.e. pathology) on the child's functioning in other domains, such as in the psychological domain. The ideal is for the child to rather have a rational perception of his/her health status, which will "save him/her in the later", by facilitating a process of cognitive-emotive integration and resultant adaptive behaviour. Children who have a misperception about their future cardiac health status might seem psychologically well adjusted in the "now", but might have trouble in the "later" when rationality dawns on them. Conversely, children who have a clear perception about their future cardiac health status might present with psychological complaints that are more acute. However, the "sting in the now" might be the key for rational, well-adjusted future expectations and resultant functioning.

5.3.3 Theme 3: *Talking from my heart:* Awareness of psychological experiences related to cardiac status

5.3.3.1 Sub-theme: I am not OK … I feel nervous, scared, sad, lonely, frustrated, and angry

My findings contribute to the already existing body of research that found psychological distress in children living with a CHD, as outlined in Chapter 2 (Section 2.3.6). Most of the participants highlighted the fact that they were experiencing some form of psychological distress because of the diagnosis of CHD. However, the type and degree of psychological distress varied across the data set.

A: It was evident that Participant A felt a great degree of frustration because of the fact that he has to monitor his food intake constantly because of his CHD: *"[I like] food. [I don't like it that I am] not eating … I am unable to eat because of this hole in my heart … [I wish] to eat."*

B: In response to the type of illness that he has, Participant B shared that *"it started when I was playing with my friends. So we were running and then a car that was coming with a lot of speed actually passed me in close range and I was very scared so I fell down. So they took me to the clinic."*

"[The symptoms get worse] if I were to be scared or frightened. It can happen anytime."

When asked how he felt about his ill heart, the participant answered, *"When I first heard I became frightened because they [the doctors] told me that had I not come to them in time, I would be left with ten days to live. The doctor advised me not to get too frightened because if I become too frightened then I will become more sick again."*.

C: *"My heart pains."* [In response to *"How does your heart feel when you can't feel play, talk or eat?"*]

D: *"I feel nervous because I am worried that he [the doctor] might say that I should not play any sport anymore. [Sometimes I feel] lonely and sad … when, [for example,] they call the rugby players out of class over the intercom, then I am almost the only boy that stays behind [because I am not allowed to play rugby]."*

E: *"I am also scared because at the time of the second operation, the doctor said that I might die during that operation. ... I is hurtful - the children tease me … they say that I have heart problems and they tease me because I receive an 'adult' grant."*

F: *"I'm OK with it but also not OK with it."*

G: *"[Before the operation] it was hurtful because other children laughed at me."*

H: *"I wish that I could do well at my schoolwork … I feel weak at school due to my heart. ... The children tease me about my heart ....the teachers treat me in the same way as they handle the other children ... but I want them to be more sensitive with me ... It is hurtful [when children tease me] … Sometimes I feel OK but sometimes not."*

I: *"I am not allowed to be angry; for example, my cousin, when we play, then he wants to play with us but he doesn't know how to play [the rules of the game]; because [when we play] he would play with us but then he would run into the house when we have to search for him [during hide-and-seek] … that makes me angry"* and *"[Kids at school] hurt me and they didn't apologise … it made me sad."*

The interview questions were designed according to the developmental stage of middle childhood. They were also designed to elicit abstract thinking. For example, Question 17 was designed to elicit more abstract responses by taking a concrete stance: "If you could be any animal [concrete], which animal would you want to be and why [abstract]?" However, the responses related more to the emotional and behavioural domains of the DPM. A significant observation is that the participants (with the exception of participants G, H, and I) identified with animals that represent strength and authority ("383. African Elephant", n.d.). This is possibly linked to the physical vulnerability with which children with a CHD present.

A: *"Elephant [and a] tiger … because it's a big animal."*

B: *"I would choose to be a monkey because I climb trees and people are [will be] afraid of me. I don't know [if other people are scared of monkeys] but I am scared of a monkey [because] I am not used to it. People would be afraid of me and the good thing is I won't even have to go to school. I do love school but when I am sitting by myself I think to myself that school is irritating."*

C: *"Cow … because it has milk … it can produce milk … it can produce, like give birth."*

D: *"I would want to be a dog – a white German shepherd because they are the most beautiful dogs and they are big - they don't have to be scared of others [or what others think]."*

E: *"I would like to be an elephant because I like elephants – they make me laugh (I like joking). I would also like to be a zebra because they chase the others around and [at home] I chase the older ones out … easily!"*

F: ***"****I would say a fish, but there is one thing [about me] that doesn't fit with a fish and that is that they are usually not that fast and that is the same as me … I don't know how to put it … it fits in with the rest … but I want to fit in more [with the other children]."*

The responses from participants G and H may seem concrete on face value; however, abstract thinking is embedded in these responses. For Participant G, penguins are a symbol of positive emotional experiences, also referred to as *representation* (Sameroff, 2010):

G: *"I would like to be a penguin ... [because] the shape of their mouths when they cry makes me laugh!"*

Participant H was able to draw a similarity between her own interests and that of butterflies:

H: *"A butterfly because I love flowers as butterflies do."*

Interestingly, Participant I (aged 8:8), who could not explain his understanding of CHD, also identified a butterfly as his animal of choice. Participant I's response possibly revealed how he thought about his introverted temperament and possible underlying wish to be more extrovert:

I: *"A butterfly ... because it is colourful. It shines outwards … [and it] likes to fly around."*

The DPM explains that different levels of thinking are found in the different domains of functioning. For example, if we were to plot Participant D's response on the DPM, his way of thinking about a German shepherd dog varies across the DPM domains. His idea of a German shepherd being a physically big dog will fall within the biological domain. However, Participant D also related to a German shepherd on a psychological level (i.e., the DPM psychological domain), with his idea that a German shepherd is fearless and does not care about the opinion of others.

The rational-emotive behaviour school of thought (Dryden & Branch, 2008) suggests that there is a difference between *healthy* negative emotions and *unhealthy* negative emotions. Some of the above-mentioned responses (e.g., participants B, D, and I) may appear to be of clinical significance, where others appear to be a healthy degree of negative emotion as contextually appropriate (e.g., participants A and F). Regardless of severity of psychological distress, children with CHDs who do not present with psychological adjustment problems are still at risk for covert physiological anxiety, medical fears, depression, and behavioural problems (Dulfer, Helbing, Duppen, & Utens, 2013).

This theme of psychological experiences related to CHD links to the DPM not only in terms of conceptualisation of development but also provides a framework for preventative measures, i.e. to reduce risk factors for the development of unhealthy negative emotions (pathology) and the enhancement of protective factors against the development of pathology. If a psychological vulnerability is detected in a child with a CHD, a thorough DPM conceptualisation will assist the team of health care practitioners to identify areas of functioning that can be utilised for preventative purposes. During middle childhood the development of *industry* (Erikson, 1968) is an important developmental task. If not mastered, it could lead to significant psychological distress, which in turn sometimes could affect the self-esteem of the child (Johnson, Galambos, & Krahn, 2015). From the data, the next three subthemes on self-esteem emerged, namely (a) *"I am not OK…I cannot run, walk, play";* (b) *"Others are not OK too";* and (c) *"But I will be OK."*

5.3.3.2 Subtheme: I am not OK … I cannot run, walk, play

Recalling Berk's (2010) explanation of self-esteem during middle childhood and Erikson's (1968) psychosocial theme of *"industry versus inferiority"* (see Chapter 1, Section 2.4), the capacity of children to view themselves in terms of stable dispositions of competence (i.e. academic, social, and physical) creates a platform for children in middle childhood to create a general psychological image of themselves, i.e. an overall sense of self-esteem (Harter, 2003). Two of the most prominent indicators of a healthy self-esteem are physical competence and approval by peers, i.e. social competence (Klomsten, Skaalvik, & Espnes, 2004 as found in Berk, 2010; Sveningsson, 2012). In response to Question 19, "Name the things that you cannot do because of your heart problem. Does it bother you? What does it do to you?" all but one of the participants gave responses that indicate vulnerability in terms of the perception of their physical competence and hence their self-esteem:

B: *"Not being able to run fast … [it bothers me] because I am not like other people when it comes to running."*

C: *"[I was] unable to carry heavy loads or things."*

D: *"For example, every year we have a school trip to Ramsgate. All the schools from the district go on the same day. I couldn't slide down the Slide of Courage. My mom said I shouldn't because I will panic and it would have placed too much stress on my heart. I went down once before, though … I was quite scared and panicked."*

E: *"It is not nice that I can't play on the 'spider' because it makes me dizzy and I can also not play on the swings."*

G: *"Before the operation I couldn't run. I could run only for a short distance and then I would be sweating and would tell them that I am tired ... I would ask myself, when I go to bed at night, "Why did God create me to be this way?"*

H: *"I can't play 'riem-spring' and skipping rope … most of the things I can't do, such as netball, but I try to do it."*

F: *"I wish I could … be more popular at school … such as when children like me and want to be my friend."* When asked what he would want to change about himself, he responded, *"The fact that I am short [and] I also don't like my eye problem."* Note: Participant F's mother shared that he was smaller than his peers and siblings due to his heart condition.

Participant F's response is significant, especially when the link between physical activities and appearance is considered. Owing to his cardiac diagnosis, this participant is unable to participate in many physical activities that would make him physically bigger and/or stronger (e.g. rugby), which in turn has implications for his self-esteem and social competence.

A: *"[I don't like the fact that I am] not eating [here at hospital]."* (This child was fed intravenously because of cardiac surgery, and it became a significant issue for him).

Physical growth and development have a direct link to nutrition. Even though this participant received proper nutrition intravenously, it was clear that he enjoyed eating as an

important activity in his daily programme. Eating as an activity relates to the behavioural aspect of the psychological DPM domain.

5.3.3.3 Subtheme: Others are not OK too

Even though self-esteem during middle childhood is shaped mostly by the child's own academic, physical, and social competencies, other social factors might also hinder the development of a healthy self-esteem, including culture, gender stereotyping, "warm" relations with extended family members, and child-rearing practices (Berk, 2010). In this regard, four of the nine participants expressed cognisance about significant others who also were "not OK":

D: In response to the question "Who understands you the best?" Participant D answered: *"My father, because my grandmother who were also sick … they couldn't do everything for her and my grandpa worked away from home. The same with my dad and I … My dad doesn't attend my sport events much and that is how my grandfather was with my dad."*

E: *"I wish that mom wouldn't chase my friends away in the way that she does now … I wish that my mom wouldn't lie to my friends when they ask if I am at home … Mom gives hidings and she likes to pretend in front of other people."*

G: *"My grandfather passed away. When he passed away, he couldn't talk or see ... when the drips were inserted in his body he just took them out by force ... It was February 2014 ... I think if he had agreed for the blood to be donated to him he would still be alive. I believe he is the one person who loved me more than any other person."*

H: *"[It angers me when] when my granny scolds my mother and says that my mom sleeps around but she doesn't … and Granny swears at me."*

5.3.3.4 Subtheme: But I will be OK

As a part of typical development, it is expected that self-esteem might decline during the first few years of middle childhood but then increases as children's appraisal of their competencies and characteristics refines (Berk, 2010). At this point, the development of a healthy self-esteem might become challenging for the child living with a CHD. Several protective factors mitigate this psychosocial vulnerability for a poor self-esteem through a DPM concept, namely *compensating activities* (Utens & Levert, 2015). This concept

facilitates resilience. The absence or presence of compensating activities sets the tone for this subtheme titled *"But I will be OK"*.

As is evident from the discussion in Chapter 2 (Section 2.5.1), resilience is a complex process that may vary across context (e.g., culture, family), domain of functioning (e.g., temperament, academic, social, emotional), and the developmental stage of individuals, such as children versus adolescents (Cummings and Davies 2002). Resilience is understood best as a dynamic and interactive process (Rutter, 2012). Often, it is assumed mistakenly to be an innate trait of the individual when, in fact, most research now shows that resilience is the result of external forces such as the ability to interact with their environments and the processes that either promote well-being or protect individuals against the influence of risk factors (Zautra, Hall, & Murray, 2010). A core premise of the DPM is the identification of *protective factors* that account for healthy outcomes despite an encounter with adverse factors. Protective factors serve as buffers that either dilute or counteract the negative effects of risk factors, which could also vary across context, domain of functioning and developmental stage, as mentioned above.

The findings are similar with those of Marino et al. (2012), who found that children with a CHD are markedly resilient. I took my findings a step further by analysing the various sources of resilience in line with the DPM premise that resilience has multiple sources of origin.

A thematic analysis of the data set at hand revealed protective factors from various sources that cut across the DPM domains. Table 8 provides a summary of these sources and nature of these protective factors. It is important to remember that some responses carry significance in **more than one functional domain** and was therefore mentioned accordingly in Table 8.

Table 8a

Summary of Sources and Nature of Protective Factors

Domain	Sub-domain	Quote
<u>Biological</u>:	**Genetic inheritance of tempera-ment and shared interests.**	**D:** ***"We are the same … the relationship that I have with my grandmother is unique because we have a special bond [the heart illness]."***
		H: ***"I like to play golf … my grandfather was a good golfer … my auntie has also been on TV. for golf."***
		E: ***"My grandmother … she knows what "truth" is and she also doesn't like people who lie [the same as me]."***
	Positive feedback regarding cardiac (health) status	**F:** ***"Usually Dr Smith* would say that I look better than usual."***
	Temperament – determination	**C:** ***"[I wish to] build a house and buy myself a car … a five-room house … it would be a big house and it would be my house and I will be staying alone. I wish to have sheep, cows and goats. [If I could be any animal, I would want to be a] cow, because it can produce milk."***
	Temperament	**G:** ***"They say that I am a very talkative person who loves jokes. My friends love my jokes."***
<u>Psychological:</u> **Cognitive**	**An age-appropriate psycholo-gical focus on the materialistic aspects of his dream to become rich one day.**	**C:** ***"[I wish to] build a house and buy myself a car … a five-room house … it would be a big house and it would be my house and I will be staying alone. I wish to have sheep, cows and goats. [If I could be any animal, I would want to be a] cow, because it can produce milk."***
	Intellectual interests	**F:** ***One of the best times was when we visited my cousin in Johannesburg*. I think we were there for six days and during the six days we visited a museum, the zoo and an aquarium … I don't know its [the museum] name but it is about history. When you walk in there is a big elephant statue and outside there are dinosaurs – their bones."***
		F: ***"I think that they [parents] think that I am much better than usual."***
	Perception	**F:** ***"I fell behind with my school work … tomorrow I can't borrow the other child's book again, but my cousin said that she will make copies for me."***
	Problem-solving skills	**F:** ***"I am quite proud of … the good marks that I receive for my schoolwork … I have started to notice a difference [in my friend's marks] ever since Mr Engelbrecht* put him next to me in the Match class [since I started to support him with his Maths]."***
	Pride	**G:** ***"I like to talk to my mother about how I feel about my heart and about school. I talk to my father as well" and "I like to see where I end up in life."***
Emotional	**Social sharing of emotion**	
	Positive future expectations	**D:** ***"When I play golf, I forget about everything that had happened during the day … I am a good golfer … a 14 handicap."***
Behavioural	**Hobbies, i.e. fun activities**	**H:** ***"When I have something fun to do."***
		E: ***"I like to cook … I can cook meat. I can also bake cake … I like it when my grandmother teaches me to make, for example, 'vetkoek'."***

Note: *Pseudonyms are used to adhere to confidentiality.

Table 8b

Summary of Sources and Nature of Protective Factors

Domain	Sub-domain	Quote
Social:		
Attachment Systems	**Close relationship with mother and deceased grandmother i.e. strong maternal attachments**	**H:** ***"My mother [understands me the best … sjo, sjo, she [my grandmother] was like a mother to me."***
	Relational bond due to shared illness	**D:** ***"We are the same. The relationship that I have with my grandmother is unique because we have a special bond [the heart illness]."***
	Support from significant others	**E:** ***"My grandfather doesn't think I am silly … he says it is only the older ones that are silly … my grandmother [also] takes my side."***
	Social sharing of emotion (Rimé, 2009)	**G:** ***"I like to talk to my mother about how I feel about my heart and about school. I talk to my father as well."***
	The cultural system of being a Zulu	**B:** ***"I am proud because I am Zulu … I love the Zulu language … at home we are all Zulus and people say that to be a Zulu you have to be strong like Shaka Zulu … [I am strong like Shaka Zulu]"***
	Close relationship with family	**D:** ***"But the nicest trip was when we went to Yzerfontein*. My father doesn't like to party … he prefers to relax with us at home. My dad enjoyed [that trip] a lot. The water is very cold there, but it is still nice to play there. It is nice because it was family bonding time."***
	Spending time with friends	**E:** ***"I like to play with the other children such as playing 'touch', to walk around, to sit around and play on the phones with them under the trees. We talk about school and about the other children at school. I also like to go to town … .I go to town with my friends … we buy drinks, go to the park and to the mall, we play games and we sit under the tree and take pictures … [but my phone is gone] and I don't like it. Buhle* is my best friend … she likes me. We have been friends since we were little … we are very close."***
	Shared interests with friends.	**D:** ***"… if I play the sports that I do [with the other children] then I think that we are the same and then I feel included."***
	Support from peers	**F:** ***"… as far as I know, they seem to care about me … "***
	Positive feedback from medical practitioner	**F:** ***"Usually Dr Smith* would tell me that I look better than usual."***
	Trustworthy significant others	**F:** ***"[If I have a problem, I can speak to] my cousin … [and Ruan*] … he listens to you when you talk to him and he tries to help you when you have something that you are stressed about."***
	Birth order	**G:** ***"I am proud to be the big sister … Karabo* [younger sister] is silly … she takes people's bags, hides behind me for protection because she knows that her big sister will protect her."***
	Communication	***H: "I like to have good talks with other people."***
	Medical Care	**G:** ***I want to become a doctor when I grow up … the doctors help me a lot … 29 March 2015 [the doctors] at Pelonomi Hospital said they think there was something wrong with my lungs, they sent me to Universitas Hospital where they [the doctors] saw that I have a hole in my heart. At first, I wanted to become a police officer when I grow up but after the heart problem, I realised that doctors are important. My dad says the doctors saved my life."***

Note: *Pseudonyms are used to adhere to confidentiality.

Building on the previous subtheme of the variety of sources of resilience, Mari, Cascudo and Alchieri (2016) highlight the important role that *other regulators* (see Section 2.5.2.3) i.e. social support, specifically family support, play in this regard.

5.3.4 Theme 4: *Heart to heart*: Social functioning and cardiac status

Some of the participants expressed difficulties with regard to social functioning. From a DPM point of view (see Section 2.5.1), a child's intrapersonal functioning is influenced greatly by external forces that are a combination of various experiences and interactions. This powerful influence of social interactions serves as motivation for the following subtheme, namely *"They don't like me"*.

5.3.4.1 Subtheme: They don't like me

E: *"… the other children tease me [about my heart]."*

F: *"I wish that I could be more popular at school (more children like them [popular children])."*

G: *"It was hurtful because other children laughed at me"* and *" What hurts me the most is that they [the other children] keep saying that I am not punished like them, knowing very well what my condition is … I also wish to be punished like them, like other children."*

H: *"There is no-one at school who would be a good friend for me"* and *"He [biological father] said that he will come but he hasn't yet visited me … I don't think that he will ever come … they told him that I was in hospital and they sent him pictures but he didn't come to visit me."*

When asked whether I could arrange for her to consult with a psychologist to discuss her psychological challenges further, Participant H replied, "No, my other dad [stepfather] will give me a hiding. He even scolds me when I go visit my friend but I don't even walk around … we just stay at the house" and "When my [step-] grandmother scolds me, I think about my [maternal] granny and then I ask myself why did she have to die … why not someone else?"

The above-mentioned findings raise serious concern when seen in the light of typical development as explained by Furrer and Skinner (2003), namely that a sense of relatedness may function as a motivational resource when children are faced with challenges or difficulties.

Two alleys of mitigation are at play. Firstly, inter-domain mitigation refers to the fact that even though most of the participants referred to challenges regarding socialisation, especially with their peers, they seem to function on an adaptive level in various other functional domains. Based on my findings explained in 5.3.3.3, I present the concept of **intra**-domain mitigation, which argues that other "in-house" healthy social interactions, apart from social interactions with peers, serve as mitigating factors for adaptive functioning. From this theoretical viewpoint, relationship representations are referred to as internal working models of attachment figures (Crittenden, 1990). As explained in Chapter 2, secure attachments and their corresponding internal representations function as a safe psychosocial space, allowing children the freedom to explore and to engage constructively in activities and interactions with others.

5.3.4.2 Subtheme: But there are those who care

The idea of intra-domain mitigation motivates the following subtheme, namely "But there are those who care".

All of the participants indicated significant others that they perceive as loving and caring:

A: "*Daddy [looks after me] … he is a good person … he buys me morning shoes [slippers], shoes … All Star label … as well as two track suits … Mommy [cares when feeling sick. sad, hungry or scared]."*

B: *"[Mom says that] she will not get tired of coming to the hospital because she loves me … [My siblings] say that I should get better so that I can stop coming to hospital because they love me … [They say] the void is felt when I am not there at home."*

C: *"They [the doctors] are going to help me [and] heal my heart … they [the doctors] did an operation because they wanted to be sure that the opening is healed, so they checked me and found that it is not healed so they had to do another one [operation]"* and *"Mom [is] a good person … early in the morning when we go to school my mother warms water for us to bath … my mother's mother and daddy [also] cares for me."*

D: *"My mother is a housewife and she does almost everything (she has two sets of hands) … In the morning, when I get to the kitchen, my medication will be ready; all we have to do is to pour our own cereal."*

E: *"My grandfather takes my side because I am his favourite."*

F: *"[If I have a problem, I can speak to] my cousin … [and Ruan*] … he listens to you when you talk to him and he tries to help you when you have something that you are stressed about."*

G: *"[The fact that] my parents support me [are things that I like about myself]"* and *"I want to build my parents a big house because it's because of them that I am here on earth"* and *"my mother was crying her eyes out when all this was happening [when I fell ill]"*, and referring to her perception of how much her grandfather cared for her, *"I believe that my grandfather died because of me."*

H: *"My mother [understands me the best] … Sjo, sjo, she [my grandmother] was like a mother to me."*

I: *"My mother [looks after me] … she likes to cook … [her food is] tasty"* and *"Dad [says that I shouldn't get angry a lot as it is not good for my heart]."*

Linking with the above-mentioned findings, my experience and interactions with the participants' caregivers indicate that they love and care for their children and only want the best for their children. Examples include the fact that even when they did not have money to pay for transport to attend the interview, they made some or the other plan to make sure that their children would participate in this research project. Also, parents were aware of the fact that their children were missing school when they (the children) were admitted to hospital or had to miss school due to a medical appointment. Furthermore, many parents travelled very far distances to ensure that their children could participate in this study, i.e. by putting their own comfort second to put their children's well-being first.

5.3.5 Theme 5: *Attached to my heart*: Understanding of cardiac status as a chronic condition with long-term psychological effects

More than in the case of adults, children depend on and are attached to human beings. Given the extent of their dependency on their primary caregivers, children's family relationships greatly influence their experiences in health and illness. Attachment can be understood as being the enduring emotional closeness that prepares children for independence in later life (Rees, 2007). As mentioned earlier, Bowlby (1969) suggests that early attachment experiences create "internal working models" (p. 10), i.e. lifelong templates for the manner in

which children will grow up to perceive, value, and rely on relationships. Healthy attachment provides children with a "secure base" necessary to explore, learn and relate, and with the well-being, motivation, and opportunity to do so. Healthy attachment is also important for safety, stress regulation, adaptability, and resilience.

Seen in the above-mentioned light, it can be expected that the child's internal working model, based on earlier attachment patterns, might serve as a blueprint not only for future relationships with other people but also the attachment of children with a CHD to their chronic cardiac condition, which refers to a different form of attachment. To have a healthy attachment to their chronic cardiac conditions, two elements of preconception are important for these children, namely (a) relatedness and (b) acceptance (Rees, 2007). These two elements set the scene for the following two subthemes namely (a) "It is more than my heart" and (b) "I will always have a heart".

5.3.5.1 Subtheme: It is more than my heart

Referring to the concept of relatedness (see Section 2.4), a healthy sense of "belonging" to a primary family structure is the departure point for a sense of relatedness to other structures such as relatedness to peers. In addition, we now know that peer relatedness plays a major role in the development of a healthy self-esteem (Berk, 2010). We also know that a sense of relatedness serves as a motivational source for children facing difficulties (Furrer & Skinner, 2003). This idea highlights the importance that children with a CHD should feel a sense of relatedness not only to social structures outside of themselves but also to **internal** relations, of which their chronic cardiac conditions are one of the most prominent relations. In addition, they should also feel a sense of relatedness to their specific population group i.e. other children with CHDs. However, the participants in my data set did not present with a prominent sense of relatedness to their special populations group. The focus remained on how they were different from their peers because of their cardiac conditions:

A: *"[I like] food. [I don't like it that I am] not eating … I am unable to eat because of this hole in my heart … [I wish] to eat … there are [things that other kids can do but not me] when it comes to eating, they can eat and I cannot."*

B: *"I don't want to be a Sotho … I [would] ask my mother where do I come from because at home there are only Zulus."*

C: *"I can't sleep, eat, play, walk and I can't even take myself to the toilet [when I become very sick because of my heart]"*. Note that the activities mentioned are basic daily activities that the norm group of children of this age are able to do. Furthermore, in response to the question *"Are there others who have problems with their hearts?"* Participant C answered, *"No, it's only me."*

D: *"It is not nice for me to have this [heart] illness. For example, I cannot play touch rugby with the other children ... I so badly want to play with them …"*

E: *"My teacher says that my heart problem is the reason why I fail [at my school work]."*

F: When asked what he would want to change about himself, Participant F responded, *"The fact that I am short [and] I also don't like my eye problem."* and *"I want to play rugby but I can't …"*

G: *"[Before the operation], it was hurtful because other children laughed at me [because of my heart illness]."*

H: *"I would walk in the street and then the others will gossip about me and tease me as though they don't like me."*

I: When asked to name some things that he cannot do because of his cardiac condition, Participant I responded by saying that *"[I am not allowed to] run too much and [I am also not allowed to] get angry much [because of my heart condition]."* This response highlights how this participant is different from his peers, seeing that running and feeling upset from time to time are typical behaviour as part of daily life.

The above-mentioned findings highlight the importance of social support groups for children who suffer from chronic cardiac conditions.

5.3.5.2 Subtheme: I will always have a heart

The second subtheme revolves around the second important element of preconception related to attachment, namely acceptance.

Low et al. (2012) explored the role of acceptance in rehabilitation in life-threatening illnesses. Their findings suggest that it may be possible to reduce psychological morbidity and improve physical mobility by increasing patients' acceptance using an approach to patients

with chronic illnesses based on acceptance and commitment therapy (ACT) . Seen in the light of this theoretical finding, children with a CHD need to reach a point of acceptance to promote future psychological and physical well-being.

Responses from my data set indicate that all the participants were at different locations on the continuum of acceptance of their chronic cardiac conditions. The placements of the data set on the acceptance continuum can be categorised as follows:

(a) Lower end of the acceptance continuum due to a lack of sufficient insight into the intricacies of their cardiac condition:

A: *"I don't know [whether there is something wrong with me and why I have to take medication]."*

C: *"I don't know [what it means that there is a hole in my heart]."*

B: In response to "*How does your heart tell you when you are feeling sick?*" and "*How often does this happen?*" Participant B answered, *"It hurts me. But now I think that it will never happen [again] because I have been operated."*

(b) Low to higher point on the acceptance continuum:

E: *"It is hurtful … the children tease me … they say that I have heart problems and that I receive an adult grant."*

(c) On the higher end of the acceptance continuum:

D: In response to the question, *"Why do you have to come to hospital from time to time?"* Participant D answered, *"To see if my heart condition got worse or not … it has happened before …"*

F: *"I am OK with it but also not OK with it [having a heart illness] … I would like to play rugby but I am not allowed to [because of my ill heart]. I do [play] … cricket."*

G: *"I have to come to the hospital from time to time because I have to know how I am doing with regard to the problem of my heart."*

H: *"[My heart] is still a bit sick."*

I: *"[I feel] happy [about my ill heart] because then they [the doctors] look after you]."*

The above-mentioned two subthemes related to relatedness and acceptance highlight the ideal for children with a CHD to progress from a focus on the "hole" in their hearts to being "whole" individuals. Functional elements come to life when the whole is considered (see Chapter 4, Section 4.1.3).

5.4 Conclusion

The results highlight five psychosocial themes that are present in children with a CHD. The first theme that emerged was titled "I have a heart", i.e. the participants' understanding of their cardiac diagnoses. Subthemes that emerged from this main theme include (a) "I have a hole in my heart", which resonated the level of cognitive development of the participants; (b) "I remember what happened to my heart", which described the development of the participants' episodic memory; and (c) "Healthy for my heart", which discussed cognitive regulation in terms of choosing to engage in "heart-healthy" behaviours.

The second main theme that emerged was titled "Talking about my heart". This theme revolved around the participants' perceptions regarding their post-operative cardiac statuses. The two subthemes that emerged here are (a) "My heart is fixed!" and (b) "My heart is fixed but …"

The third main theme that arose is "Talking from my heart". This theme illuminated psychological experiences related to the participants' cardiac statuses. The first subtheme under this main theme is (a) "I am not okay … I feel nervous, scared, sad, lonely, frustrated and angry" and (b) "I am not OK … I cannot run, walk, play like others". The third subtheme is (a) "Others are not OK too" and (b) "But I will be OK".

The fourth main theme identified is that of "Heart to heart". This theme explored the effects of living with a CHD on the participants' social functioning. Two subthemes were identified, namely (a) "They don't like me" and (b) "But there are those who care".

The fifth main theme is that of "Attached to my heart", which highlighted the unique attachment that these participants had to their hearts, i.e. chronic cardiac conditions. Two subthemes emerged, namely (a) "It is more than my heart" and (b) "I will always have a heart".

Thus, the semi-structured interviews facilitated the process of making rich discoveries regarding the psychosocial functioning of children with a CHD and the cascading effects of the themes. For example, the participants had well-developed episodic memory, which was particularly valuable in dealing with their perception of their cardiac conditions and in approaching other psychosocial challenges.

One of the most significant revelations as part of thematic analysis of my data set is the fact that children with a CHD present with contrasting experiences, such as

- a concrete versus an abstract understanding of their cardiac conditions;
- misperceptions versus realistic perceptions about their cardiac conditions;
- healthy negative psychosocial experiences versus unhealthy psychosocial experiences;
- discouragement versus hope regarding their cardiac statuses; and
- social rejection versus social acceptance and support.

Regardless of the above-mentioned contrasts, the golden thread of resilience was evident throughout the entire process of thematic analysis. Although the participants demonstrated markedly varying degrees of awareness regarding attachment to their cardiac conditions (i.e. relatedness and acceptance), resilience emerged as a prominent feature that could assist in movement on the continuum of acceptance.

If I were Jack, the participants were the “magic beans”, their diagnosis of CHD resembled Jack’s sceptical mother, and the information and experiences the participants shared were indeed the beanstalk to rich discoveries regarding the psychosocial themes of children with a CHD. As the African proverb so accurately describes, “Wisdom is like a baobab tree; no one individual can embrace it” (Koutonin, 2013).

CHAPTER 6: CONCLUSION

6.1 Overview

The primary aim of this research study was to explore the experiences of children diagnosed and living with a congenital heart defect (CHD). This was done by means of semi-structured interviews with six boys and three girls aged between eight and fourteen years and diagnosed with a CHD. Thematic analysis of the collected data set yielded rich information regarding the psychosocial themes of children with a CHD. Secondly, I critically discussed and illuminated the identified themes in terms of the developmental psychopathology model (DPM) and the link between the themes and the participants' cardiac status. Thirdly, I *identified* recommendations for health care professionals in practice as well as for future research on the topic of children with a CHD.

Chapter 1 introduced the reader to the research study and provided a preview of all the subsequent chapters by highlighting the fact that every heartbeat forms part of a story.

The dissertation continued with **Chapter 2**, a literature review, starting with the famous fairy tale of Sleeping Beauty in the Woods (Nesbit et al., 1956). A child is born with a compilation of gifts, some being welcoming gifts while others being burdens that cannot necessarily be prevented or eradicated completely. However, health care practitioners can assist those children in the management of their challenges. To do so, we need proverbial songs. In the literature review, I listened to songs – from songs about recent academic literature on the biopsychosocial burden of a congenital heart defect (CHD), to songs about the medical and psychological theories aiming to describe the child's biopsychosocial functioning. The literature review concluded with the African proverb, "Birds sing not because they have answers but because they have songs" (Dickson, 2013).

Chapter 3, the preliminary study and the story of Goldilocks and the three bears (Nesbit et al. 1956), followed. As I progressed, the wisdom of a well-known African proverb dawned on me. This proverb heeds to "never test the depth of a river with both feet" (Okupa, 2014). Goldilocks was uncomfortable and wanting. However, she was also brave and opportunistic. These qualities inspired me. I utilised the three main types of preliminary studies, studied them, and combined them to suit the needs of this research project. This exercise resulted in a set of clear guidelines as to how I had to go about conducting the preliminary study so that the questions and areas of concern could be resolved properly. In

addition to the courage that Goldilocks displayed, she was also very systematic in her actions. If she had arrived while the bears were at home, she might never have reached her goals; i.e., she did not test the depth of the water by putting both her feet in the river. I conducted the preliminary study similarly by familiarising myself with the appropriate and applicable literature and identifying what needed to be evaluated during the preliminary study. I also took a few chances and "broke a few chairs" but reflected on the outcome and how I could adapt it as part of preparing for the main study. Eventually, I reached my goals and ended up confident and comfortable to take the preliminary study into the main study. I also coined the concept of a *collective pilot study,* assessed the feasibility and suitability of the inclusion criteria, refined the interview questions as necessary, and familiarised myself with various aspects of the research setting.

After my insights regarding the life of Goldilocks, the Ugly Duckling (Nesbit et al., 1956) entered **Chapter 4**, the methodology. The Ugly Duckling emphasised the circular nature of qualitative research methodology and the importance of trustworthiness. In this process, I realised the veracity of the African proverb, which states that *"If you think you are too small to make a difference, try sleeping in a closed room with a mosquito"* ("Africa's proverb of the day", 2016). The Ugly Duckling longed to understand and expand a given knowledge base. He needed someone to appreciate his uniqueness by considering his context, his own understanding of the world, someone who would not merely label him as the "Ugly Duckling" but who would interpret and verbalise his needs. This would be possible only if he had someone who would take the time and dedication and put in an effort to listen to his unique worldview. After a taxing journey, the Ugly Duckling found what he was looking for when he reached the swan pond. For the first time in his life, he felt understood, accepted, liberated, and valued, (which are important components of feeling wholesome). The Ugly Duckling felt small and insignificant until he experienced how important and beautiful he actually was when surrounded by "mosquitoes" at the swan pond.

Chapter 4 illuminated the value of a qualitative research approach by providing an elaborative definition of qualitative research, the benefits of a qualitative research approach, and the link between qualitative research and a holistic view of a research subject, i.e. Ganzheitpsychologie. This chapter also outlined the different types and categories of research design as well as the use of purposive sampling to maximise trustworthiness. Furthermore, the aim, structure, and types of questions were discussed in detail, seeing that the interview represented the swans that approached the Ugly Duckling to release a completely new world

of understanding. In the same way that the Ugly Duckling's perceptions were challenged by the swans' interpretation of what they saw in him, Chapter 4 highlighted the steps that were taken to analyse the findings from the data collection thematically. Last, but not least, when the swans saw the Ugly Duckling, they bowed before him as a sign of respect for his young age and beauty. Chapter 4 concluded with a similar gesture by highlighting the ethical considerations that would be adhered to throughout the research endeavour in working with young and fragile participants.

Finally, after my encounters with Sleeping Beauty, Goldilocks, and the Ugly Duckling, the research steered me into discussing the findings in **Chapter 5**, Jack and the Beanstalk (Nesbit et al., 1956). The initial African proverb of "Birds sing not because they answers but because they have songs" cascaded into "Wisdom is like a baobab tree; no one individual can embrace it" (Koutonin, 2013). Chapter 5 resonates with Jack's perseverance and patience that led to rich discoveries. However, it was not as easy as it would appear – he had to wait patiently for the right moment to exchange the milk cow for the "magic beans". When he saw the beans, he knew that it held promise. Similarly, I engaged in a patient process of searching for the "magic" in the data set. Five main themes emerged, namely, *"I have a heart"*; *"Talking about my heart"; "Talking from my heart"*; *"Heart to heart";* and *"Attached to my heart"*. Thirteen subthemes emerged, namely *"I have a hole in my heart"*; *"I remember what happened to my heart"*; *"Healthy for my heart"*; *"My heart is fixed!"*; *"My heart is fixed, but …"*; *"I am not OK … I feel nervous, scared, lonely, sad, and angry"*; *"I am not OK … I cannot run, walk, play"*; *"There are others who are not OK too"*; *"But I will be OK"*; *"They don't like me but …"*; *"There are those who care"*; *"It's more than my heart"*; and *"I will always have a heart"*.

The riches belonged to Jack, but his journey to the gold involved more than one individual, including the strange-looking old man, the milk cow, Jack's sceptical mother, the giant's wife, and the giant himself. The rich knowledge and wisdom that emerged from thematic analysis is much like the thick, giant beanstalk and a baobab tree: I needed a dedicated team of research assistants and, most importantly, the children with their CHDs to embrace it – I could not have done it alone.

6. 2 Clinical Implications

The thematic analysis of the psychosocial themes of children with a congenital heart defect (CHD) accentuates clinical implications regarding the children's cognitive functioning, psychosocial support and broader conceptualisation and application of the DPM.

Firstly, health care professionals need to be encouraged to consider children's level of cognitive functioning when they explain diagnoses to their paediatric cardiac patients. Communicating with the child on an age-appropriate level, without coming across as being condescending, is paramount; for example, by asking the child to repeat what he/she has just heard (to ensure an understanding of his/her cardiac condition, treatment, etc.). Furthermore, the child's temperament needs to be considered when a cardiac diagnosis and treatment for the paediatric patient is explained. The reason for this is the determining influence that temperament has on a child's way of relating and responding across functional domains, more specifically including his/her affect, attention, behaviour and social functioning (Calkins, 2012). Caregivers also need to be encouraged to promote the cognitive development, more specifically that of abstract reasoning, in the child with a CHD. Increased and well-developed abilities to reason abstractly would assist greatly in the child's perception of his/her physical body, cardiac illness, and how these perceptions will play out in everyday interactions and experiences. This is such an important point, seeing that a child's perceptions regarding his/her cardiac illness have implications for the child's self-esteem and future psychosocial functioning.

Secondly, health care practitioners and significant others alike need to be cognisant of any emotional and/or behavioural upset at a given time. The children may benefit from an opportunity to discuss their intrapersonal functional world with an appropriate mental health care professional. Children with a CHD are in need of continuous motivation and communication about their hearts. Therefore, creating a safe space for these children to externalise their inner psychosocial challenges and not to internalise it, may be complementary and supportive to their psychosocial functioning. Children with CHDs may benefit from support groups to address psychosocial stressors that they might be experiencing. Raising awareness, especially in schools, to ensure that children living with a CHD is not ostracised by their cardiac condition, may improve social support and understanding. The responsibility to encourage a comprehensive understanding of a child's cardiac condition is

on the entire treatment team and the paediatric patient's support system, such as the child's primary caregivers.

Thirdly, the theme of psychological experiences associated with CHD not only relates to the DPM in terms of conceptualisation of development but also provides a framework for preventative measures; i.e., to reduce risk factors for the development of unhealthy negative emotions (pathology) and develop protective factors against the development of pathology. If a psychological vulnerability is detected in a child with a CHD, a thorough DPM conceptualisation may assist the team of health care practitioners to identify areas of functioning that can be utilised for preventative purposes. With the DPM in mind, constant reassessment for possible risk and protective factors could contribute to healthy functioning across functional domains, specifically with regard to psychosocial functioning.

6.3 Future Research

Future research on CHD may benefit from considering samples size, type of cardiac conditions and the question of quantitative versus qualitative research.

Although thematic saturation was reached, rich data were generated, and the aim of the study was reached, the sample size of the study was small. Therefore, the use of findings for the purpose of generalisation for the special population of children with a CHD is limited. Furthermore, even though the data set included Tswana-, Sotho-, Zulu-, and Afrikaans-speaking participants, they were all recruited from the Northern Cape, Free State, and Lesotho region. Thus, a larger sample size that is more diverse should ideally include participants from other areas in South Africa. This could add to the generalisation of research findings.

Given the fact that this was an exploratory study, it did not focus on the severity and type of cardiac illnesses and how they correlated with certain psychosocial themes that arose. Further research is necessary in this regard, such as a quantitative study on the types of cardiac conditions versus the types of psychosocial themes that are present. Such a study could assist in refining and identifying psychosocial themes that are specific to different types of cardiac illnesses. In turn, this will add to the ability of the entire support system (including health care professionals, caregivers, teachers, and so forth) to provide even more specialised care in accordance with the psychosocial needs of the child.

Finally, qualitative interpretations may be affected by the perceptions, biases, and assumptions of the researcher, despite the rigorous efforts taken to avoid this in the

methodology. However, the potential benefit of these interpretations outweighs the inherent risks associated with qualitative methodology to support and illustrate the findings of the present study.

Some of the results differ from that of existing literature and warrant research, too. For example, my findings indicate that children with a CHD exhibit sufficient cognitive regulation to understand; e.g., why they need to engage in behaviours that will be beneficial for their cardiac health. This finding is in dissonance with recent studies on social cognition of children (in middle childhood and adolescence) with a CHD (Bellinger, 2008; Cassidy et al., 2015; Donofrio & Massaro, 2010), who postulate that children with a CHD are at a greater risk for difficulties with cognitive abilities in general and self-regulation in particular.

As scientific practitioners, we face the challenge to integrate the clinical implications and the recommendations for future research skilfully to build on the findings from the research project.

6.4 In Conclusion

This study, exploring and describing the psychosocial themes of children with a CHD, is the first of its kind conducted in the South African context. It contributes to the existing body of knowledge involving comprehensive, high-quality care for children with a CHD in South Africa. A unique contribution of this study is that the insights that were gained were provided by the child directly; i.e., not by a third person (e.g., a sibling, parent, or health care professional).

Children with a CHD should be able to understand that they have ill hearts, talk about their ill hearts, understand why it is important for them to adhere to treatment regimes, talk from their hearts to a trusted significant other about their intrapersonal experiences of living with a CHD, have the necessary support structure (including individuals outside of the immediate family system) to deal with social challenges in a healthy manner, and understand and assimilate the fact that they are whole persons – more than just an ill heart and someone with a bright future filled with opportunities for success. Rhythm is indeed more than a heartbeat.

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APPENDIX A: ETHICAL APPROVAL LETTER

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA

UFS·UV
HEALTH SCIENCES
GESONDHEIDSWETENSKAPPE

IRB nr 00006240
REC Reference nr 230408-011
IORG0005187
FWA00012784

20 October 2015

MRS CG PHEIFFER
C/O DR HP VAN DER WATT
DEPARTMENT OF PSYCHOLOGY
FACULTY OF HUMANITIES
UFS

Dear Mrs Pheiffer

ECUFS NR 114/2015
MRS CG PHEIFFER
DEPARTMENT OF PSYCHOLOGY
PROJECT TITLE: THE PSYCHO-SOCIAL THEMES OF CHILDREN WITH A CONGENITAL HEART DEFECT

1. You are hereby kindly informed that, at the meeting held on 15 October 2015, the Ethics Committee approved the above project after all conditions were met.

2. Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

3. A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.

4. Kindly use the ECUFS NR as reference in correspondence to the Ethics Committee Secretariat.

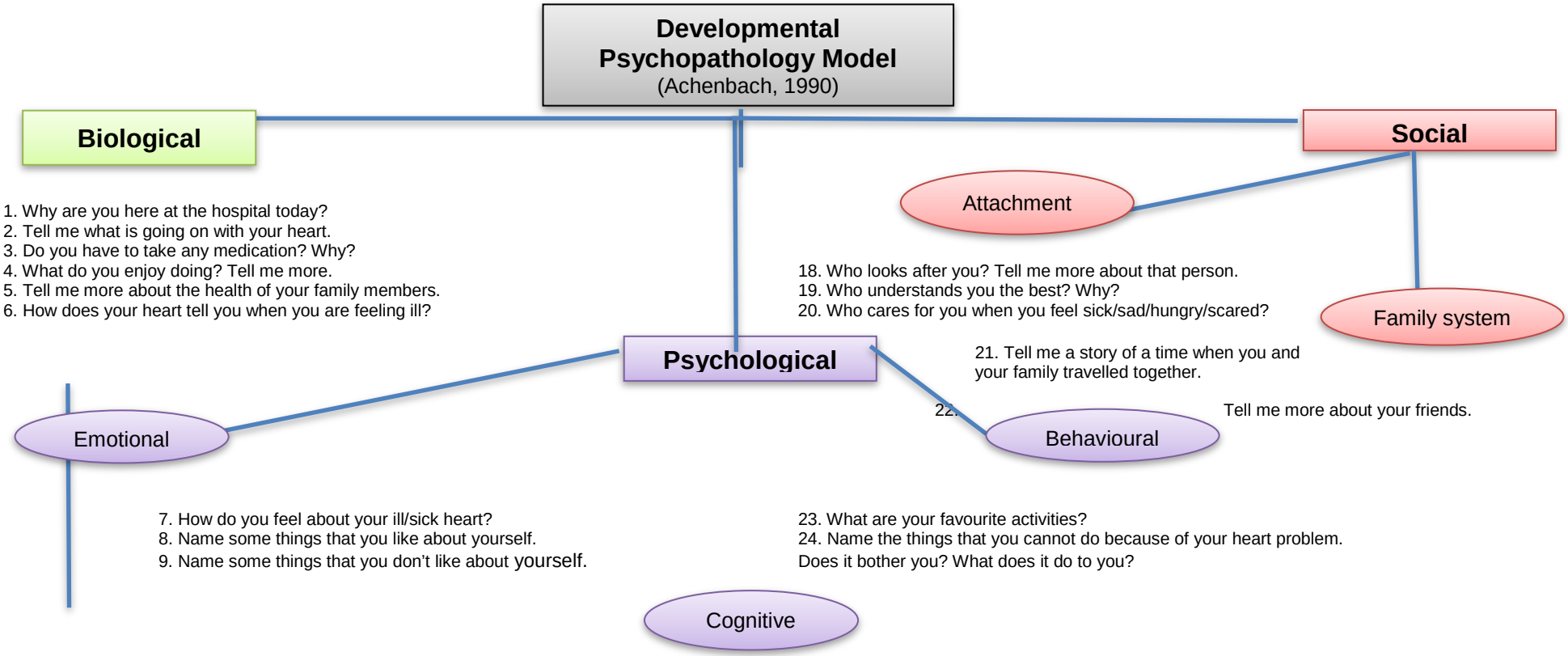
5. The Ethics Committee functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the Ethics Committee of the Faculty of Health Sciences.

Yours faithfully

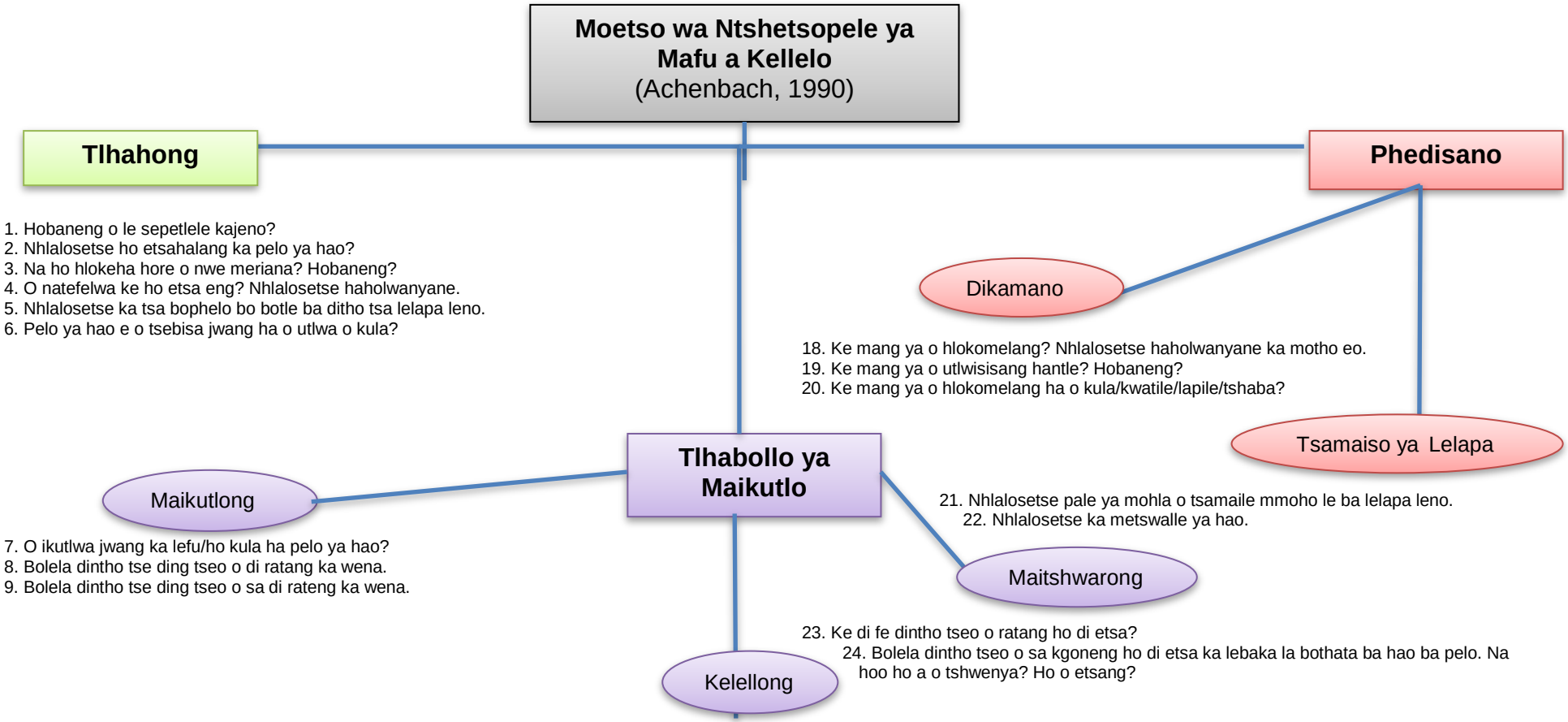
DR SM LE GRANGE
CHAIR: ETHICS COMMITTEE

Cc: Dr R vd Watt

APPENDIX B: INTERVIEW QUESTIONS ON THE *DEVELOPMENTAL PSYCHOPATHOLOGY MODEL* (ENGLISH VERSION)



APPENDIX C: INTERVIEW QUESTIONS ON THE *DEVELOPMENTAL PSYCHOPATHOLOGY MODEL* (SOTHO VERSION)



1. Hobaneng o le sepetlele kajeno?
2. Nhlalosetse ho etsahalang ka pelo ya hao?
3. Na ho hlokeha hore o nwe meriana? Hobaneng?
4. O natefelwa ke ho etsa eng? Nhlalosetse haholwanyane.
5. Nhlalosetse ka tsa bophelo bo botle ba ditho tsa lelapa leno.
6. Pelo ya hao e o tsebisa jwang ha o utlwa o kula?

18. Ke mang ya o hlokomelang? Nhlalosetse haholwanyane ka motho eo.
19. Ke mang ya o utlwisisang hantle? Hobaneng?
20. Ke mang ya o hlokomelang ha o kula/kwatile/lapile/tshaba?

21. Nhlalosetse pale ya mohla o tsamaile mmoho le ba lelapa leno.
22. Nhlalosetse ka metswalle ya hao.

7. O ikutlwa jwang ka lefu/ho kula ha pelo ya hao?
8. Bolela dintho tse ding tseo o di ratang ka wena.
9. Bolela dintho tse ding tseo o sa di rateng ka wena.

23. Ke di fe dintho tseo o ratang ho di etsa?
24. Bolela dintho tseo o sa kgoneng ho di etsa ka lebaka la bothata ba hao ba pelo. Na hoo ho a o tshwenya? Ho o etsang?

10. Ho etsahalang pelong ya hao?
11. Haeba o ne o ena le ditakatso tse tharo tse ka phethahalang, o ne o tla itakaletsa eng?
12. Ngaka e reng ho wena?
13. Batswadi/bahlokomedi ba hao ba reng ho wena?

14. Bana beno ba reng ho wena?
15. Metswalle ya hao e reng ho wena?
16. Matitjhere a hao a reng ho wena?
17. Haeba o ne o ka ba phoofolo, o ne o tla batla ho ba phoofolo e fe? Hobaneng?

APPENDIX D: INFORMED CONSENT FORM (ENGLISH VERSION)

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA

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HEALTH SCIENCES
GESONDHEIDSWETENSKAPPE

Informed Consent Form for the parent/guardian of a child with a congenital heart defect (CHD).

This informed consent form is for the parent/guardian of a child who qualifies for participating in the research titled: "The psycho-social themes of children with a congenital heart defect."

Name of Principle Researcher: **Mrs C. G. Pheiffer**
Name of Organization: **University of the Free State**
Name of Sponsor: **Paediatric Cardiology research entity**

This Informed Consent Form has two parts:

Part 1: Information Sheet (to share information about the study with you).
Part 2: Informed Consent (for signatures if you agree that your child may take part).

Note: You will receive a copy of the full Informed Consent Form

Part 1: Information Sheet

Introduction
I am Carina Pheiffer - a Master's student at the University of the Free State. I am doing research, which can assist children with a heart defect to be better understood and helped by the professionals treating them. I am also a member of Prof Brown's team who take care of children with heart problems. In my research, I will talk to girls and boys, and ask them some questions. However, I will first ask the parent's/guardian's permission. I will need both you and your child's permission before I can begin. Before you make a final decision, you can talk to anyone that you want to. You are welcome to stop me as we go through the information if you want to ask a question.

Why am I doing this research?
I am doing this research because I want to understand how a child with a heart defect thinks and feels about his/her heart defect and other areas of his/her life. This information can help the professionals who treat these children, to understand their child patients' physical and emotional needs better. If they understand their child patients better, they can take care of them in a very good way.

How am I going to do this research?
I will have an interview with your child and ask some questions about how he/she thinks and feels about his/her heart defect and other areas of his/her life.

Who is going to take part in the research?
I want to talk to many children about how they think and feel about their heart defects and other life experiences. I would like to ask your child to participate because he/she has a diagnosis of a congenital heart defect.

Is it your decision?
Yes. You do not have to agree that your child can talk to me. You can choose to say no and any services that you and your family receive at this centre will not change. We know that the decision can be difficult when it involves your child. And it can be especially hard when the research is about a sensitive topic such as your child's health. You can ask as many questions as you like and I will answer them.

What will happen?
I will interview your child by asking some questions. If it is necessary, a translator will also be there to make sure that your child understands questions well and is able to answer in the language that he/she feels comfortable with.

The interview will take place at the Outpatient facility of the Department [1] *of Paediatric Cardiology at Universitas Hospital. The information that I will receive is confidential. This means that no one else except for myself, Dr R. van der Watt (my research supervisor) and Prof S. Brown (my co-supervisor) will work with the information that your child shares with me.*

The interview will take about 2 hours and will include the following activities:

- *Your child will draw a picture of himself/herself and talk about it with me.*
- *Your child will answer questions that I will ask about his/her life.*

Your child does not have to answer any question or take part in the discussion/interview/ survey if he/she doesn't wish to do so, and that is also fine. Your child may choose to tell you about the interview and the questions but does not have to do this. I am not going to share with you neither the questions we ask nor the responses that your child gives me.

If your child feels upset during the interview and I observe this, I will talk to your child about it. If I make the decision that a referral to a mental health care professional is necessary to help your child further, it will be discussed with your child and also with you.

Even though there will be no direct benefit for you or your child, the information that I get from this study will help to meet more needs of many children with a heart defect. I would like to publish the results of the research so that other interested people may learn from my research.

Remember, it is your choice whether your child can participate in this study and your child does not have to take part in this research if she/he does not wish to do so. Your child may stop participating in the interview at any time. Choosing to participate or not will not affect either your own or your child's future treatment in any way.

Who to Contact?
If you have any questions, you may ask them now or later or you may contact the following people:

- *Myself, Mrs. C. Pheiffer, via e-mail: cgpheiffer@gmail.com*
- *My research supervisor, Dr. R. van der Watt telephonically: 051 401 9682*
- *My research co-supervisor, Prof. S. Brown telephonically: 051 405 3241*

The Ethics Committee of the Faculty of Health Sciences at the University of the Free State has approved the research. This is a committee whose task is to make sure that the people who take part in a research study are protected from harm.

Part 2: Informed Consent

- *I have been asked to give consent for my child to participate in this research study, which will involve my child completing one interview and to draw a picture.*
- *I have read the information on the previous pages and it has been read and explained to me.*
- *I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction.*
- *I consent voluntarily for my child to participate in this research study.*

Child's name:……

Name of Parent/Guardian: _____

Signature of Parent/Guardian: _____

Date: _____

Day/month/year

(If parent/guardian is illiterate, see next page)

If parent/guardian is illiterate:

I have witnessed the accurate reading of the consent form to the parent/guardian of the potential participant, and the individual has had the opportunity to ask questions.

I confirm that the individual has given consent freely.

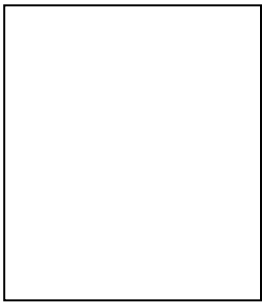
Print name of witness: _____

Signature of witness _____

Date _____

Day/month/year

Thumbprint of the parent/caregiver:



Statement by the researcher/person taking consent

I have accurately read out the information sheet to the parent/guardian of the potential participant, and to the best of my ability made sure that the person understands that the following will be done:

1. Their child will be interviewed on the day that they come to hospital for medical intervention.
2. That the child will be asked to draw a picture of themselves and talk about the picture as a means to get comfortable with the interview setting and interviewer.
3. That the child will have to answer questions about his/her heart defect and other life experiences.

I confirm that the parent was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the parent or guardian of

the participant _____

Name of researcher taking the consent: _____

An Informed Assent Form will be completed: Mark YES____ or NO_____

APPENDIX E: INFORMED CONSENT FORM (SESOTHO VERSION)

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA

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GESONDHEIDSWETENSKAPPE

Foromo ya Tumello e nang le kutlwisiso ya motswadi/mohlokomedi wa ngwana ya hlahileng ka bothata ba popeho ya pelo (CHD).

Foromo ya Tumello e nang le kutlwisiso ena ke ya motswadi/mohlokomedi wa ngwana ya dumeletsehang ho nka karolo diphuphutsong tsa: "Meokotaba ya ntshetsopele ya tlhabollo ya maikutlo a bana ba hlahileng ka bothata ba popeho ya pelo" (*The psyho-social themes of children with a congential heart defect*").

Lebitso la Mofuputsi ya ka sehloohong: **Mrs C. G. Pheiffer**

Lebitso la Mokgahlo: **Yunivesithi ya Freistata**

Lebitso la Motsihetsi wa tsa ditjhelete: **Tjheleteng ya diphuphutso tsa Bongaka ba bana ba nang le Mahloko a Pelo**

Foromo ya Tumello e nang le kutlwisiso ena e na le dikarolo tse pedi:

Karolo ya 1: Leqhepe la Tlhahisoleseding (ho arolelana tlhahisoleseding ya diphuphutso le wena).

Karolo ya 2: Tumello e nang le kutlwisiso (ho tekenwa haeba o dumela hore ngwana wa hao a nke karolo).

Ela hloko: O tla fumantshwa khopi ya Foromo ya Tumello e nang le kutlwisiso e feletseng.

Karolo ya 1: Leqhepe la Tlhahisoleseding

Selelekela

Ke Carina Pheiffer – moithuti wa Masters Yunivesithing ya Freistata. Ke etsa diphuphutso tse ka thusang hore bana ba nang le bothata ba pelo ba utlwisiswe le ho thuswa hantle ke ditsebi tse ba phekolang. Ke boela ke le setho sa sehlopha sa Moporofesara Brown se hlokomelang bana ba nang le bothata ba pelo. Diphuphutsong tsa ka, ke tla buisana le banana le bashanyana, mme ke ba ba botse dipotso tse itseng. Ho sa le jwalo, ke tla qala pele ka ho kopa tumello ya motswadi/mohlokomedi. Ke tla hloka tumello ya hao le ya ngwana wa hao pele nka qala. Pele o nka qeto, o ka buisana le motho e mong le e mong eo o batlang ho buisana le yena. O amohelehile ho ka nthiba ha ntse re hlalosa tlhahisoleseding ena haeba o batla ho botsa potso.

Hobaneng ha ke etsa diphuphutsong tsena?

Ke etsa diphuphutso tsena hobane ke batla ho utlwisisa hore na ngwana ya nang le bothata ba pelo o nahana le ho ikutlwa jwang ka bothata ba hae le dikarolo tse ding tsa bophelo ba hae. Tlhahisoleseding ena e ka thusa ditsebi tse phekolng bana ba na, le ho utlwisisa ditlhoko tsa mmeleng le maikutlong tsa bana ba kulang. Haeba ba utlwisisa bakudi ba bona ba bana hantle, ba ka kgona ho ba hlokomela ka tsela e hantle.

Ke tlo etsa diphuphutso tsena jwang?

Ke tlo ba le inthaviyo le ngwana wa hao mme ke botse dipotso tse itseng ka hore o nahanang le ho ikutlwa jwang ka bothata ba hae ba pelo le dikarolo tse ding tsa bophelo ba hae.

Ke mang ya tlo nkang karolo diphuphutsong tsena?

Ke batla ho buisana le bana ba bangata ka hore ba nahanang le ho ikutlwa jwang ka bothata ba ba bona ba pelo le dikarolo tse ding tsa maphelo a bona. Nka thabela ho kopa ngwana hao hore a nke karolo ka ha o na le bothata ba popeho ya pelo.

Na ke qeto ya hao?

Ee. Ha o a qobeletseha ho dumela hore ngwana wa hao a buisane le nna. O ka kgetha ho re tjhe mme ditshebeletso tseo le di fumantshwang setsheng sena wena le ba lelapa la hao di ka se fetohe. Re a tseba hore ha ho bobebe ho nka qeto haholoholo ha e amana le ngwana hao. Mme ho thatafala le ho feta ha diphuphutso di shebane le ntlha e hlokolotse ha kaale, e jwalo ka bophelo bo botle ba ngwana wa hao. O ka botsa dipotso tse ngata ka mokgwa oo o batlang ka teng mme ke tla di araba.

Ho tlo etsahalang?

Ke tlo inthavoya ngwana wa hao ka ho botsa dipotso tse itseng. Ha ho hlokeha, toloko e tla ba teng ho netefatsa hore ngwana wa hao o utlwisisa dipotso hantle mme o kgona ho araba ka puo eo a phuthulohileng ho e bua.

Inthaviyo e tla nka sebaka mane Bakoding ba sa robatsweng sepetlele (Outpatient) Lefapheng la Mahloko a Pelo, Sepetleleng sa Universitas. Tlhahisoleseding eo ke tla ifumantshwa e tla ba lekunutu. Hona ho bolela hore ha ho motho ntle le nna, Dr R. van der Watt (motshwari wa diphuphutso tsa ka) le Prof S. Brown (motshwari-mmoho wa diphuphutso tsa ka) ya tla sebedisang tlhahisoleseding eo ngwana wa hao a tla e arolelanang le nna. Inthaviyo e tla nka dihora tse 2 mme e tla kenyeletsa dintho tse lateng:

- *Ngwana wa hao o tla tshwantsha setshwantsho sa hae mme a buisana le nna ka sona.*
- *Ngwana wa hao o tla araba dipotso tseo ke tla mmotsa tsona ka bophelo ba hae.*

Ngwana wa hao ha a qobeletseha ho araba kapa ho nka karolo dipuisanong/inthaviyong/dipalong tsa dipatlisiso, haeba a sa batle ho etsa jwalo, ha ho phoso. Ngwana wa hao a ka kgetha ho o jwetsa ka inthaviyo le dipotso empa ha ho hlokehe hore a etse jwalo. Ha ke tlo o tsebisa dipotso esitana le dikarabo tseo ngwana wa hao a tla mphang tsona.

Haeba ngwana wa hao a ka halefa nakong ya inthaviyo mme ke be ke elelwa sena, ke tla buisana le ngwana wa hao ka sena. Haeba ke nka qeto ya hore ho iswa setsebing sa

tlhokomelo ya bophelo le mahloko a kelello ho bohlokwa ho thusa ngwana wa hao, qeto ena etla sikasikwa le wena ha mmoho le ngwana wa hao.

Le ha ho sena kuno e tobileng wena le ngwana wa hao, tlhahisoleseding eo ke tla e fumana diphuphutsong tsena e tla thusa ho fihlella ditlhoko tsa bana ba bangata ba nang le bothata ba pelo.Nka rata ho phahlalatsa sepheto sa diphuphutso tsena hore batho ba bang ba nang le kgahleho ba ithute ho tswa diphuphutsong tsena.

Hopola, ke kgetho ya hao hore ngwana wa hao a ka nka karolo diphuphutsong tsena le ngwana wa hao ha a qobeletsehe ho nka karolo diphuphutsong tsena haeba a sa lakatse ho etsa jwalo. Ngwana wa hao a ka emisa ho nka karolo dinthaviyong nako e nngwe le e nngwe. Ho kgetha ho nka karolo kapa ho se nke karolo ho ka se ame phekolo ya kamoso ya hao esita le ya ngwana wa hao.

O ka ikopantsha le mang?

Haeba o na le dipotso tse itseng, o ka di botsa ha jwale kapa wa ikopantsha le batho ba latelang ha mmamorao:

- *Nna, Mrs. C. Pheiffer, ka imeili: cgpheiffer@gmail.com*
- *Motshwari wa diphuphutso tsa ka, Dr. R. Van der Walt, mohaleng: 051 401 9683*
- *Motshwari-mmoho wa diphuphutso tsa ka, Prof. S. Brown, mohaleng: 051 401 3241*

Komiti ya Boitshwaro bo botle ya Lefapha la Bophelo bo botle le Saense, Yunivesithing ya Freistata e dumeletse diphuphutso tsena. Komiti ena e ikarabella ho netefatseng hore batho ba nkang karolo diphuphutsong ba tshireletsehile.

KAROLO YA 1 E FELLA MONA (Sheba leqhepe le latelang bakeng sa KAROLO YA 2)

Karolo ya 2: Tumello e nang le kutlwisiso

- *Ke kopuwe ho fana ka tumello ya hore ngwana wa ka a nke karolo diphuphutsong tsena, tse tla kenyeletsang hore ngwana wa ka a nke karolo inthaviyong le ho tshwantsha setshwantsho sa hae.*

- *Ke badile tlhahisoleseding e maqhepeng a fetileng mme ka boela ka e ballwa ka ba ka e hlalosetswa.*

- *Ke bile le monyetla wa ho botsa dipotso ka yona mme dipotso tseo ke ileng ka di botsa di arabilwe ka mokgwa o nkgotsofatsang.*

- *Ke dumela ka boithaupi hore ngwana wa ka a nke karolo diphuphutsong tsena.*

Lebitso la ngwana: .....

Lebitso la Motswadi/Mohlokomedi: _____

Tekeno ka Motswadi/Mohlokomedi: _____

Letsatsi: _____

Letsatsi/kgwedi/selemo

(haeba motswadi/mohlokomedi a sa tsebe ho bala le ho ngola, sheba leqhepe le latelang)

Haeba motswadi/mohlokomedi a sa tsebe ho bala le ho ngola:

Ke ile ka elahloko ho balwa ha foromo ya tumello e nang le kutlwisiso ya motswadi/mohlokomedi wa eo a ka nkang karolo, mme le motho o ile a fumantshwa monyetla wa ho botsa dipotso. Ke a dumela hore motho eo o fane ka tumello ka boithaopi.

Hatisa lebitso la paki: _____

Tekeno ka paki: _____

Letsatsi: _____

Letsatsi/kgwedi/selemo

Kgatiso ya monwana wa motswadi/mohlokomedi:

Setatemente ka mofupotsi/motho ya nkang tumello

Ke baletse motswadi/mohlokomedi wa ya ka nkang karolo leqhepe la tlhahisoleseding ka ho nepahala, mme ho ya ka moo ke kgonang ka teng ke ile ka netefatsa hore motho eo o utlwisisa se latelang se tla etsa:

1. *Ngwana wa hae o tla inthaviyowa letsatsing leo ba tletseng ho phekolwa sepetlele.*
2. *Hore ngwana o tla kopuwa ho tshwantshise setshwantsho sa hae mme re buisane ka tsona e le tsela ya ho leka ho phuthuloha inthaviyong le ho motho ya etsang inthaviyo.*
3. *Ngwana o tla tlameha ho araba dipotso tse mabapi le bothata ba hae ba pelo le dintho tse ding tsa bophelo ba hae.*

Ke dumela hore motswadi o ile a fumantshwa monyetla wa ho botsa dipotso ka diphuphutso, mme dipotso tsohle tseo a ileng a di botsa di arabilwe ka ho nepahala, le ka moo ke kgonang ka teng. Ke dumela hore motho enwa ha a qobelwa ho fana ka tumello, tumello e fanwe ka boithaopi le mahala.

Khopi ya Foromo ya Tumello e nang le kutlwisiso ena e fuwe motswadi/mohlomokedi wa ya nkang karolo _____

Lebitso la mofuputsi ya nkang tumello: _____

Foromo ya Tumello e nang le kutlwisiso e tlatsitswe: Tshwaya EE_____kapa TJHE_____

APPENDIX F: INFORMED ASSENT FORM (ENGLISH VERSION)

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA

UFS·UV
HEALTH SCIENCES
GESONDHEIDSWETENSKAPPE

Informed Assent Form for children with a congenital heart defect.

This informed assent form is for children who are invited to participate in a study on the psycho-social themes in children with a congenital heart defect. These children:

- Are between the ages of 9 and 14;
- Have been formally diagnosed with a congenital heart lesion, with at least one surgical procedure performed relating to the condition;
- Are currently patients of the Department of Paediatric Cardiology at Universitas Hospital in Bloemfontein;

Principle Investigator: Mrs Carina Pheiffer

Name of Organisation: University of the Free State

Name of Sponsor: Paediatric Cardiology research entity

This Informed Assent Form has two parts:

Part 1: Information Sheet (gives you information about the study).
Part 2: Form of Assent (this is where you sign if you agree to take part).

You will be given a copy of the full Informed Assent Form.

Part 1: Information Sheet

Introduction

My name is Carina Pheiffer. I am a student at the University of the Free State. I want to learn more about your heart condition and how you think and feel about your heart condition. This means that I am doing research on this topic. I want to understand how children with a heart condition experiences different parts of their lives and I think this research could help tell me that.

I am inviting you to be part of this research study. You can decide whether or not you want to take part. Your parent(s)/guardian know that I am also asking you for your agreement. If you are going to take part in the research, your parent(s)/guardian also have to agree. But if you do not wish to take part in the research, you do not have to, even if your parents have agreed.

You may discuss the information that I share with you with anyone you want to help you decide if you want to take part in this research study or not.

Let me tell you more about the research project. Please ask me to stop and I will take time to explain.

Why am I doing this research?

I want to understand how children with a heart defect experience their lives. If I can understand how these children think and feel about living life with a heart defect, then people treating them can understand how these children think and feel about living life with a heart defect and then treat their heart defect very good. Because you also have a heart defect, I would like you to tell me about your life and how it feels to live life with a heart defect. I want to hear from many children with a heart defect who are between the ages of 9 and 14 years.

You don't have to be part of this research if you don't want to be. If you decide not to be in the research, it's okay and nothing changes - everything stays the same as before. Even if you say "yes" now, you can change your mind later and it is still okay. No one will be upset with you if you decide that you don't want to talk to me anymore.

If I decide to take part, what is going to happen to me?

If you decide to be part of the research, I am going to ask you some questions on how you experience different things in your life, for example, things that you like and don't like.

If you decide that you want to do this, there will be three things that will happen:

1. On the same day that you come to the hospital to see your doctor, I will also be there. I will then ask you to go with me to one of the rooms at the hospital where it is nice and quiet and where you will feel comfortable to talk to me. There might also be a lady who will help us with language – to make sure we understand each other well.

2. Then, I will ask you to draw me a picture of yourself and we will talk about your picture. Remember that this will not be a test – there is no right or wrong way of doing it. We will do this fun activity to get to know each other better before we talk about your heart defect and how you experience life.

3. After you have drawn your picture and we have talked about your picture, I will ask you some questions about different events in your life. I have pictures here to show you what will happen. You can ask me to stop and explain again at any time and I will do that. Please look at the cards and listen to what I explain to you.

If you decide to take part in the research and you start to feel upset while we are talking, you can tell your parent/guardian or me. If you need to talk more about your upset feelings, then I will arrange that a professional person, who knows a lot about feelings, can help you further. I will just need to tell your parent/guardian as well, so that they can know we are making plans to help you feel better.

Is there anything good that happens to me?

If you decide to take part in this research study, your heart defect will not go away. You will also not receive money to take part. But, in a way, it will make you feel better because you will know that your doctor will understand how you think and feel about living your life with heart defect and how the heart defect may affect different parts of your life.

I will not tell other people that you are in this research and I won't share information about you to anyone who does not work in the research study. This is called 'confidentiality'. It will not be shared with or given to anyone except my helpers who are Dr. van der Watt and Professor Brown.

When we are finished with the research, I will write a report about the things I learned that could help the people who treat your heart defect as well as other children who have heart defects.

You do not have to be in this research. No one will be angry or disappointed with you if you say no. You can say "yes" now and change your mind later and it will still be okay.

You can ask me questions now or later. I have written a number and address where you can reach us or, if you are nearby, you can come and see us. If you want to talk to someone else that you know like your teacher or doctor or auntie, that's okay too.

If you choose to be part of this research I will also give you a copy of this paper to keep for yourself. You can ask your parents to look after it if you want.

END OF PART 1 (See next page for PART 2).

Part 2: Form of Assent

I understand that:

- *The research is about explaining how I think and feel about my heart defect*
- *and different things that I experience in my life.*
- *The research results will be used for other professional people to learn more*
- *about how children with a heart defect think and feel.*
- *I understand that I will be asked to draw a picture, talk about my picture and*
- *answer some questions about my heart defect and other events in my life.*
- *I know when this will take place.*
- *I know where this will take place.*
- *I can say no at any time if I don't want to take part or talk to the researcher.*
- *I can get help if I feel upset during the research.*
- *I will receive no money to take part.*
- *I know whom to contact if I have any questions and I have the number.*

I have read all the information on the previous pages (or had the information read to me). I have had my questions answered and know that I can ask questions later if I have them. I understand all the information. I agree, out of my own free will, to take part in the research.

OR

*I do not wish to take part in the research. I have not signed the assent below.*_____ *(initialed by child)*

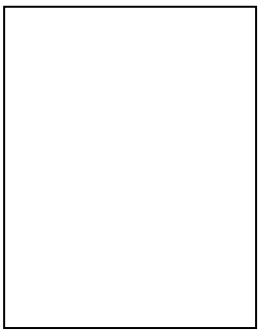
Only if child assents:

Print name of child _____

Signature and thumbprint of child: _____

Date:_____

Day/month/year



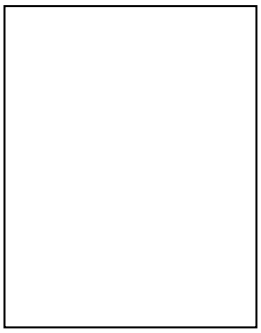
If the child is illiterate:

I have witnessed the accurate reading of the assent form to the child, and the child has had the opportunity to ask questions. I confirm that the child has given consent freely.

Print name of witness (not a parent) _____

AND

Thumbprint of child



Signature of witness _____

Date _____

Day/month/year

Declaration of the Researcher:

I have accurately read the assent form to the potential participant, and the child has had the opportunity to ask questions. I confirm that the child has given assent freely.

Print name of researcher_____

Signature of researcher_____

Date _____

Day/month/year

Statement by the researcher/person taking consent:

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the child understands that the following will be done:

1. *The child will be interviewed on the day that they come to hospital for medical intervention.*
2. *That the child will be asked to draw a picture of themselves and talk about the picture as a means to get comfortable with the interview setting and interviewer.*
3. *That the child will have to answer questions about his/her heart defect and other life experiences.*

I confirm that the child was given an opportunity to ask questions about the study, and all the questions asked by the child have been answered correctly and to the best of my ability. I confirm that the child has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this assent form has been provided to the participant.

Print Name of Researcher/person taking the assent_____

Signature of Researcher /person taking the assent _____

Date _____

Day/month/year

Copy provided to the participant _____ (initialed by researcher/assistant).

Parent/Guardian has signed an informed consent ___Yes ___No _____ (initialed by researcher/assistant).

APPENDIX G: INFORMED ASSENT FORM (ENGLISH VERSION)

Foromo ya Tumello e nang le kutlwisiso ya bana ba hlahileng ka bothata a pelo.

Foromo ya Tumello e nang le kutlwisiso ena ke ya bana ba memelwang ho nka karolo diphuphutsong tsa meokotaba ya ntshetsopele ya tlhabollo ya maikutlo a bana ba hlahileng ka bothata ba popeho ya pelo (*The psyho-social themes of children with a congential heart defect*). Bana ba:

- Dipakeng tsa dilemo tse 9 le 14;
- Bao dingaka di fumaneng ba e na le leqeba ka lebaka la bothata ba pelo, bonyane le opareishini e le nngwe e entsweng ka lebaka la bothata bona;
- Ke bakudi ba Lefapha la Bongaka ba bana ba nang le Mahloko a pelo a, Sepetleleng sa Universitas, Bloemfontein.

Lebitso la Mofuputsi ya ka Sehloohong: **Mrs C. G. Pheiffer**

Lebitso la Mokgahlo: **Yunivesithi ya Freistata**

Lebitso la Motsihetsi wa tsa ditjhelete: **Tjheleteng ya diphuphutso tsa Bongaka ba Mahloko a pelo a bana**

Foromo ya Tumello e nang le kutlwisiso ena e na le dikarolo tse pedi:

Karolo ya 1: Leqhepe la Tlhahisoleseding (ho arolelana tlhahisoleseding ya diphuphutso le wena).

Karolo ya 2: Tumello e nang le kutlwisiso ena (mona ke moo o tla tekenang haeba o dumela ho nka karolo).

O tla fumantshwa khopi ya Foromo ya Tumello e nang le kutlwisiso e feletseng.

Karolo ya 1: Leqhepe la Tlhahisoleseding

Selelekela

Lebitso la ka ke Carina Pheiffer – ke moithuti waYunivesithi ya Freistata. Ke batla ho ithuta haholwanyane ka bothata ba hao ba pelo le hore o nahana le ho ikutlwa jwang ka bothata ba hao ba pelo. Hona ho bolela hore ke tlo etsa diphuphutso ka ntlha ena. Ke batla ho utlwisisa hore bana ba nang le bothata ba pelo ba pheladi karolo tse fapafapaneng tsa maphelo a bona jwang mme ke nahana hore diphuphutso tsena di ka nna thusa ho tseba sena.

Ke o memela ho ba karolo ya diphuphutso tsena. O ka kgetha ho nka karolo kapa tjhe. Batswadi/mohlokomedi wa hao o a tseba hore ke kopa tumello ya hao. Haeba o tlo nka karolo diphuphutsong tsena, batswadi/mohlokomedi o tla tlameha ho fana ka tumello. Empa haeba o sa lakatse ho nka karolo diphuphutsong tsena, ha o a qobeletseha, le haeba motswadi wa hao a dumetse.

O ka arolelana tlhahisoleseding lena le mang kapa mang eo o batlang hore a o thuse ho nka qeto ya hore o batla ho nka karolo diphuphutsong tsena kapa tjhe.

E re ke o hlalosetse haholwanyane ka diphuphutso tsena. Ka kopo nthibe nako e kgolo le e nyane mme ke tla nka nako ya ho o hlalosetsa.

Hobaneng ha ke etsa diphuphutsong tsena?

Ke batla ho utlwisisa hore na bana ba nang le bothata ba pelo ba phela maphelo a bona jwang. Ha nka ka utlwisisa hore bana ba na ba nahana le ho ikutlwa jwang ka ho phela ka bothata ba pelo, batho ba ba phekolang ba tla kgona ho utlwisisa hore bana ba na ba nahana le ho ikutlwa jwang ka ho phela ka bothata ba pelo mme ba phekolo bothata ba bona hantle. Ka hobane le wena o na le bothata ba pelo, ke rata ha o nqoqela ka bophelo ba hao le hore o ikutlwa jwang ka ho phela ka bothata ba pelo. Ke batla ho hlalosetswa ke bana ba bangata ba nang le bothata ba pelo ba pakeng tsa dilemo tse 9 le 14.

Ha o a qobeletseha ho nka karolo diphuphutsong haeba o sa batle. Ha o ka nka qeto ya ho se nke karolo diphuphutsong, ha ho phoso mme ha ho se tla fetoha – tsohle di tla dula ntse di le jwalo ka pele. Le ha o ka re "ee" ha jwale, o ka na wa fetola monahano wa hao ha mmamorao mme le teng ho tla be ho ntse ho lokile. Ha ho motho ya tla o halefela haeba o sa batle ho bua le nna ho ya pele.

Ha ke nka qeto ya ho nka karolo, ho tlo etsahalang ka nna?

Ha o ka nka qeto ya ho ba karolo ya diphuphutso, ke tlo o botsa dipotso tse itseng ka hore o phela ka dintho tse fapaneng jwang bophelong ba hao, ho etsa mohlala, dintho tseo o di ratang le tseo o sa di rateng.

Ha o ka nka qeto ya hore o batla ho etsa sena, ho tla ba le dintho tse tharo tse tla etsahalang:

1. *Mohla letsatsi leo o tlileng sepetlele ho tla bona ngaka, ke tla be ke le teng. Ke tla o kopa hore o tsamaye le nna ho ya phaphosing e nngwe ya diphaphosi tsa sepetlele e ntle moo ho thutseng, moo o tla phuthulohang ho bua le nna. Ho ka na ha eba le mosadi ya tla re thusang ka puo – ho netefatsa hore re utlwisisana hantle.*

2. *Mme, ke tla o kopa hore o ntshwantshisetse setshwantsho sa hao mme re tla buisana ka setshwantsho sa hao. O hopole hore hona e tla be e se teko – ha hona tsela e lokileng kapa e fosahetseng ya ho tshwantshisa. Re tla etsa papadi ena e le hore re tsebane ha ntle pele re ka bua ka bothata ba hao ba pelo le tsela eo o phelang ka yona.*

3. *Ka mora hore o tshwantshise setshwantsho sa hao mme re buisane ka sona, ke tla o botsa dipotso tse itseng ka diketsahalo tse fapaneng bophelong ba hao.*

Ke na le ditshwantsho mona ho o bontsha hore ho tla etsahala eng. O ka nkopa ho emisa le ho o hlalosetsa hape nako e nngwe le nngwe mme ke tla etsa jwalo. Ke kopa o shebe dikarete mme o mamele seo ke o hlalosetsang sona.

Ha o ka nka qeto ya ho nka karolo diphuphutsong tsena mme wa halefa ha re ntse re buisana, o ka bolela motswa/mohlokomedi wa hao kapa nna. Haeba o hloka ho bua haholwanyane ka se o halefisitseng, ke tla kopa setsebi, se tsebang haholo ka tsa maikutlo, ho o thusa ho ya pele. Ke tla hloka feela ho tsebisa motswadi/mohlokomedi wa hao, hore re tsebe ho fumana tsela ya ho o thusa hore o ikutlwe hantle.

Ho na le ho lokileng ho tla ntlhahelang?

Ha o nka qeto ya ho nka karolo diphuphutsong tsena, bothata ba hao ba pelo bo ka se fele. Ha o tlo lefelwa ho nka karolo. Empa ka mokgwa o itseng, o tla ikutlwa o le hantle hobane o tla be o tseba hore ngaka ya hao e tla utlwisisa hore na o nahana le ho ikutlwa jwang ka ho phela le bothata ba pelo le hore bothata ba pelo bo ama dikarolo tse ding tsa bophelo ba hao jwang. 3

Nka se bolelle batho ba bang hore o nka karolo diphuphutsong tsena mme nka se fane ka tlhahisoleseding ka wena ho motho ya sa sebetsaneng le diphuphutso tsena. Tsohle di tla ba „lekunutu". Di ka se fuwe mang kapa mang ntle le bathusi ba ka e leng Dr. van der Walt le Moporofesara Brown.

Ha re qetile ka diphuphutso, ke tla ngola tlaleho ka dintho tseo ke ithutileng tsona tse ka thusang batho ba phekolang bothata ba hao ba pelo le bana ba bang ba nang le bothata ba pelo.

Ha o a qobeletseha ho ba karolo ya diphuphutso tsena. Ha ho motho ya tla o halefela kapa a swabe ha o ka re tjhe. O ka na wa re "eya" ha jwale mme wa fetola monahano wa hao ha mmamorao le teng ho tla be ho ntse ho lokile.

O ka mpotsa dipotso ha jwale kapa ha mmamorao. Ke ngotse nomoro le aderese moo o ka re fumanang teng, haeba o le haufinyana, o ka tla re bona. Haeba o batla ho bua le motho e mong eo o mo tsebang jwalo ka titjhere ya hao kapa ngaka kapa mmangwane, ho ntse ho lokile.

Haeba o kgetha ho ba karolo ya diphuphutso tsena ke tla o fa khopi ya pampiri ena o ipehele yona. O ka na wa kopa batswadi ba hao hore ba o hlokomelle yona ha o batla.

KAROLO YA 1 E FELLA MONA (Sheba leqhepe le latelang bakeng sa KAROLO YA 2).

KAROLO YA 2: Foromo ya Tumello

Ke a utlwisisa hore:

- Diphuphutso tsena ke tsa ho hlalosa hore ke nahana le ho ikutlwa jwang ka bothata ba pelo le dintho tse ding tse fapaneng tsa bophelo ba ka.
- Sepheto sa diphuphutso se tla sebediswa ke ditsebi ho ithuta haholwanyane ka hore bana ba nang le bothata ba pelo ba nahana le ho ikutlwa jwang.
- Ke a utlwisisa hore ke tla kopuwa ho tshwantshisa setshwantsho, ho bua ka setshwantsho le ho araba dipotso tse itseng ka bothata ba pelo ya le diketsahalo tse ding tsa bophelo ba ka.
- Ke a tseba hore sena se tla etsahala neng.
- Ke a tseba hore se tla etsahalla ho kae.
- Nka re tjhe nako e nngwe le nngwe haeba ke se ke sa batle ho nka karolo kapa ho buisana le mofuputsi.
- Nka fumantshwa thuso ha nka halefa nakong ya diphuphutso.
- Ha ke tlo fumantshwa tjhelete ha ke nka karolo.
- Ke a tseba hore nka ikopantsha le mang haeba ke na le dipotso mme ke na le dinomoro.

Ke badile tlhahisoleseding e maqhepeng a fetileng (kapa ke ile ka balwa tlhahisoleseding). Dipotso tsa ka di ile tsa arabelwa mme ke a tseba hore nka botsa dipotso ha mmamorao haeba ke na le tsona. Ke utlwisisa tlhahisoleseding.

Ke dumela, ka boithaopi , ho nka karolo diphuphutsong.

KAPA

Ha ke dumele ho nka karolo diphuphutsong. Ha ke a tekena tumello e latelang. _____ (ditlhako tsa mabitso ka ngwana)

Haeba ngwana a dumela:

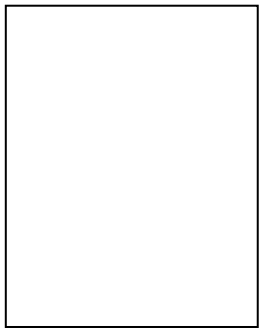
Haeba ngwana a sa tsebe ho bala le ho ngola:

Ke ile ka elahloko ho balwa ha foromo ya tumello ho ngwana, mme ngwana ya nkang karolo o ile a fumantshwa monyetla wa ho botsa dipotso. Ke a dumela hore ngwana eo o fane ka tumello ka boithaopi.

Hatisa lebitso la paki (e seng motswadi): _____

LE

Kgatiso ya monwana wa ngwana



Tekeno ka paki: _____

Letsatsi: _____

Letsatsi/kgwedi/selemo

Boitlamo ka Mofuputsi:

Ke ile ka balla ya tla nkang karolo foromo ya tumello ka ho nepahala, ngwana o bile le monyetla wa ho botsa dipotso. Ke dumela hore ngwana o fane ka tumello ka boithaopi.

Lebitso la Mofuputsi _____

Tekeno ka Mofuputsi _____

Letsatsi_____

Letsatsi/kgwedi/selemo

Setatemente ka mofupotsi/motho ya nkang tumello

Ke baletse motswadi/mohlokomedi wa ya nkang karolo leqhepe la tlhahisoleseding ka ho nepahala, ho ya ka moo ke kgonang ka teng ke ile ka netefatsa hore motho eo o utlwisisa se latelang se tla etsahalang:

1. *Ngwana wa hae o tla inthaviyowa letsatsing leo ba tletseng ho phekolwa sepetlele.*

2. *Hore ngwana o tla kopuwa ho tshwantshise setshwantsho sa hae mme re buisane ka tsona e le tsela ya ho leka ho phuthuloha inthaviyong le ho motho ya etsang inthaviyo.*

3. *Ngwana o tla tlameha ho araba dipotso tse mabapi le bothata ba hae ba pelo le dintho tse ding tsa bophelo ba hae.*

Ke dumela hore motswadi o ile a fumantshwa monyetla wa ho botsa dipotso ka diphuphutso, mme dipotso tsohle tseo a ileng a di botsa di arabilwe ka ho nepahala, le kamoo ke kgonang ka teng. Ke dumela hore motho enwa ha a qobelwa ho fana ka tumello, tumello e fanwe ka boithaopi le mahala.

Khopi ya Foromo ya Tumello e nang le kutlwisiso ena e fuwe motswadi/mohlomokedi wa ya nkang karolo _____

Lebitso la mofuputsi ya nkang tumello: _____

Foromo ya Tumello e nang le kutlwisiso e tlatsitswe: Tshwaya EE_____kapa TJHE_____

APPENDIX H: FULL-TEXT TRANSCRIPTIONS OF PARTICIPANTS (A-I)

Participant A
Boy, 8 years; Setswana
Note:

- The questions reflect the DPM-interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of a term at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**Researcher**	**Translator**	**Setswana**	**English**
1	**Quickly tell me, why are you at the hospital today?**	Ke kopa o njwetse ka potlako, hobaneng o le sepatala kajeno?	Ho tswala pelo.	To close the heart.
	What is the problem with the heart?	Bothata ke eng ka pelo?	Go na le leshoba.	There is a hole.
2	**So tell me, what is going on with your heart?**	Jwale mpolelle, ho etsahala eng ka pelo ya hao?	Ha ke itsi.	I don't know.
	So tell me, why do you have to be at the hospital?	Jwale mpolelle, hobaneng o tlameha hore o be sepatala?	Ke sepatala hore bat lo tswala lesoba mo pelong yame.	I am at the hospital so that they can close the hole in my heart.
	So do you know anything else about your heart or that hole? Tell us more.	Ekaba ho na le ho hong o ho tsebang ka pelo ya hao kapa lesoba leo? Re jwetse haholonyana.	Eya. Ha ke itsi.	Yes. I don't know.
3	**Do you have to take any medication?**	Ekaba ho na le moriana ofe kapa ofe oo o tlamehang ho o nwa?	Eya.	Yes.

	Why do you have to take medication?	Hobaneng o tlameha hore o nwe moriana ena?	Ha ke itsi.	I don't know.
	Is there something wrong with you? Why do you have to take medication?	Ekaba ho na le ho hong ho phoso ka wena? Hobaneng o tlameha ho nwa meriana?	Ha ke itsi	I don't know
4	**Quickly tell us, what do you enjoy doing?**	Re kopa o re jwetse, ke eng seo o thabelang ho se etsa?	[Ha ona karabo]	[No response]
	You said you like to watch TV and soccer. What else?	O itse wena o rata ho shebella TV le bolo, ke eng hape eo wena o ratang ho e etsa?	Ho shebella dimovie.	Watching movies.
	What is your favourite movie?	Ke ofe Movie o o oratang?	Ha ke itsi leina la movie oo.	I don't know the name of the movie.
	What else? You said also that you like playing. What sort of games do you play? Do you guys wrestle or do you watch it on TV? Can you tell me more about when you get home after a school day, what do you do? And then?	Ke eng hape? O itse o rata go tshameka. Ke mofuta ofeng wa digame o di bapalang? Le bapala wrestling ena kapa le e shebella TV? Ke kopa o njwetse haholonyana ka ha o fihla hae o tswa sekolong, o etsa eng? Ha o qeta? Ke kopa o njwetse haholonyana ka ha o fihla hae o tswa sekolong, o etsa eng?	Bolo, *Lanta photo***, *wrestling*. TV Ke apara dikhai tse ding ha ke hetsa be ke ja. Ha ke hetsa ke ya go tshameka.	Ball, *Lanta photo*** and wrestling. TV I change my clothes and then eat. When I am done I go outside to play.

	Do you do your homework?	Mmereko wa hae wa o etsa? Oo le o filweng sekolong?	Eya.	Yes.
5	**Tell me about your family and their health.**	Njwetse ka ba lelapa leno le hore ba phetse jwang?	Ha ke itsi.	I don't know.
	Are they healthy? Mom and dad - and I see you have three sisters. Do they look after you?	Mpolelle ka maphelo a bona, mama le papa le bo ausi ba hao, ba phetse hantle? Ha ba kuli bona? Ba o hlokomela?	Ba siame. Eya.	They are in good health. Yes.
6	**Before coming to the hospital, how did you and Mom know that there was something wrong with your heart?**	Wena le mama le tsibile jwang hore ho na le bothata ka pelo ya hao? Pele le ka tla sepetlele?	Eya.	Yes.
	What was that?	E ne e le eng? Ho ne ho etsahala eng?	Pelo e ne e sa betse sentle.	My heartbeat was not right.
	Did you feel it yourself or did the doctor tell you?	Doctor ke yona e o jwetsitseng hore pelo ya hao ha e betse sentle kapa wena o ikutlwetse?	Ngaka.	The doctor.
7	**How do you feel about the fact that your heart is sick?**	O ikutlwa jwang ka taba ena yah ore pelo ya hao e na le bothata?	Sepe.	Nothing.
	How did you feel when the doctor said that you need to have an operation of the heart?	O ile wa ikutlwa jwang ha ne doctor e re o tlameha ho tla a tlo operata pelo ya hao?	[Ha ona karabo]	[No answer]

	Did you feel good, bad, angry, scared or worried?	O ile wa ikutlwa jwang a na o ile wa ikutlwa o le hantle kapa o kwatile, o kgenne, o tshohile kapa o ngongoreile? O ile wa ikutlwa jwang?	Sentle hela.	Just OK.
8	**What things about yourself do you like?**	Ke dife dintho ka wena tseo o di ratang?	Dijo.	Food.
	About yourself for example: I love to paint and I am very good in art so I like the fact that I like art. I like that about myself that I am good in art.	Ka wena mohlala: Ke rata ho penta hape le ho taka jwale ke rata ntho eo ka nna hore ke tseba ho taka. Nqoqele ka wena.	Ke kgona ho drawya, ho tshameka.	I can draw and play.
	What are you good at?	Ke eng ntho eo o kgonang ho e etsa hantle?	Go tshameka bolo ya *rugby*.	To play rugby.
	With whom do you play rugby? At school or with your friends at home or what?	O tshameka rugby le bo mang? Sekolong kapa le ditsala tsa hao hae kapa jwang?	Hae.	At home.
	What else are you good at?	Ke difeng dilo tseo o kgonang ho di etsa kantle le ho tshameka *rugby*?	Ke yona eo hela.	It's the only one.
	So you can play rugby very well?	O kgona ho bapala bolo ya *rugby* hantle?	Eya.	Yes.
9	**What things about yourself don't you like? I will give an example: sometimes I bite**	Ke dife dintho tseo o sa di rateng ka wena? Ho etsa mohlala: Ka nako tse ding ke loma manala aka jwale	Ho sa je.	Not eating.

	my nails and I don't like the fact that I bite my nails.	ha ke rate sena ka nna ... taba ena yah ore ke loma manala aka. Wena ke eng ntho eo o sa e rateng ka wena?		
	What else? Can you think of something else?	Ke eng enngwe? O ka kgona ho nahana ka ntho enngwe?	Yona eo hela.	That is the only one.
	Explain to me a bit when you say you don't like when you are not eating.	Ntlhalosetse ha nyane ha o re ha o rate ha o sa je.	Ke hobane ke ka mona jwale ha ke kgone ho ja ka baka la lesoba le mo pelong.	It's because I am in here so I am unable to eat because of this hole in my heart.
	Is it because you are that you do not like that you can't eat? When you are at home, do you eat a lot of food or only a little bit?	Ekaba ke ka lebaka la hore o mona hore ha o kgone ho ja. Ha o le hae o ja dijo tse ngata kapa tse nyane?	Eya. Tse di nyane.	Yes. A small bit.
10	**What is happening to your heart now?**	Ho etsahala eng pelong ya hao?	Sepe.	Nothing.
	Did they fix your heart?	Ba lokisitse pelo ya hao?	[Ha ona karabo]	[No response]
	Is your heart still ill or in good condition now?	Pelo ya hao e hantle nou kapa e ntse e na le bothata?	E shap.	It's in a good condition (sharp).
11	**If you had three wishes and they would come true. What three things would you wish for?**	Hoja o ne o ka labalabela dintho tse tharo mme be di phethahala. Ke dilo dife tseo o ne oka lakatsa gore di diragale?	Ho ja, sheba *TV* le ho tshameka.	To eat, watch television and play.

	Let us say you are done here and you go home healthy. What three things will you then wish for?	Ha re re o qetile mona mme o ya hae o fodile. Ke dintho dife tse tharo o ka lakatsang gore di diragale?	Dijo, *TV* le go tshameka.	Food, television and playing.
12	**What do doctors say to you?**	Doctor e re eng ka wena?	ke tshwanetse ke nwe metsi le mashi.	That I should drink water and milk.
	Why do you think the doctor thinks you should drink water and milk; what will they do?	Hobaneng o nahana hore doctor e ka re jwalo ho wena hore o nwe mashi le metsi?	Di lo go nthusa.	They will help me.
	How will they help you?	Di tla o thusa jwang?	Sentle.	Very well.
	What will they do to you?	Di tla o etsa eng ho wena?	Hela.	Just.
13	**So what do Mommy and Daddy say about you?**	Mama le papa ba re eng ka wena?	Papa o re pelo ya me e betsa sentle.	Dad says that my heartbeat is good.
	And Mommy?	Mama yena o reng feela ho wena?	Mama o re papa o tlo go nthekela dibuka ke kgone go drawya.	Mom says that Dad is going to buy me books so that I can draw.
	Did you ask for a book to draw?	Jwale o ile wa kopa papa hore a o rekele buka hore o kgone ho drawya?	Aa ke mama a mo kopileng.	No, my mom asked my dad to buy a book for me to draw.
	Would you like that when Dad buys you a book?	O ka rata seo ha papa a ka o rekela buka hore o tlo drawya?	Eya.	Yes.
	And you think Daddy will do that for you?	O nahana hore papa o tla o etsetsa seo?	Eya.	Yes.

14	**What do your sisters say about you?**	Bo ausi ba hao bona ba reng ka wena?	Sepe.	Nothing.
15	**What do your friends say about you?**	Ditsala tsa hao di re eng ka wena?	Sepe.	Nothing.
	What is your best friend's name?	Lebitso la motswalle wa hao wa hlooho ya kgomo ke mang?	Khabane*.	Khabane*.
16	**What do your teachers say about you?**	Matitjhere a hao a reng ka wena?	Sepe.	Nothing.
	If I had to ask the teachers, what kind of learner you are, what would they say?	Hoja ne ke tlameile ho botsa matitjhere a hao hore wena o mofuta a jwang wa moithuti ba ne ba ka re eng?	Sepe.	Nothing.
	Think of something: Just one thing you think they would say about you. Would they say that you are a naughty boy, quiet in class … What will they say about you? Who is your favourite teacher? What is the name of your school again?	Nahana ka ho hong. Ntho e lenngwe eo o nahanang ba ka e bua ka wena. Ba ka re wena o mosimanyane a seleng, a thotseng ka classing ... ba ka reng feela ka wena? Ke titjhere e feng eo o e ratang haholo? Nhopotse lebitso la sekolo sa lona?	Ha ke itsi. Ha ke itsi leina la hae. Httbdidi	I don't know. I don't know the name of that teacher. Httbdidi

17	**If you could choose to be an animal, what animal would you choose, and why would you choose to be that animal?**	Ha o ne o kgetha ho ba phoofolo, o ne o ka kgetha ho ba phoofolo e feng? Hobaneng?	Elephant.	Elephant.
	Elephant … why?	Hobaneng *Elephant*?	Hobaneng ke e bone.	Because I saw it.
	So you like elephants?	Jwale o rata *Elephants*?	Eya, ke ile ka bona le *Tiger*.	Yes, I also saw a tiger.
	Wow ... What is it about those two animals that you like? Do you think that an elephant is strong?	Ke eng ka diphoofolo tseo tse pedi o e ratang? O nahana hore *Elephant* e na le matla?	Hobane *elephant* e kgolo. Eya.	Because it's a big animal. Yes.
18	**What are the favourite things that you like to do? Remind me.**	Ke eng dintho tseo o thabelang ho di etsa? Kopa o nkgopotse.	Ke ho ja, sheba *TV* le go tshameka *rugby*.	Eating, watching television and playing rugby.
	What do you like playing with your friends?	Ke eng eo o ratang ho e tshameka le ditsala tsa hao?	*Rugby*.	Rugby.
19	**Are there things that you cannot do because of your heart problem?**	Ekaba ho na le dintho tseo o sa kgoneng ho di etsa ka lebaka la bothata ba hao ba pelo?	Sepe.	Nothing.
	Are there some things that other kids can do and that you cannot do because of the heart problem?	Ho na le dintho tseo bana ba bang ba kgonang ho di etsa tseo wena o sa kgoneng ho di etsa ka baka la bothata ba pelo?	Eya, go na le ba gona go ja nna ha ke kgone.	Yes, there are when it comes to eating, they can eat and I cannot.

	The problem of eating - is it only at the hospital or at home as well?	Bothata bona ba ho sa je ba teng sepatala feela kapa le hae hape.	Ke a kgona go ja sepatala le gae mara e seng nou yana.	I can eat both at home and at the hospital, just not at the moment.
	What will happen if you can't eat?	Ho tlo etsahala eng ha o sa kgone ho ja?	Ha ke itsi.	I don't know.
	Why do we have to eat?	Hobaneng re tlameha ho ja?	Hore re be shap.	So that we can be OK (sharp).
20	**Who is the person who looks after you?**	Ke mang motho a o hlokomelang?	Papa.	Daddy.
	Tell me about Daddy, what sort of person is he?	Njwetse ka papa wa hao, ke mofuta ofe wa motho?	Ke motho o shap.	He is a good person.
	What makes him a good person?	Ke eng se mo etsang motho a lokileng?	O nrekela dimorning shoes le ditlhako ... white *All star***, di tracksuit tse pedi.	He buys me morning shoes, shoes ... *All star*** label and they are white in colour as well as two tracksuits.
21	**Which person knows and understands you the best?**	Ke mang a o tsebang a bile a o utlwisisa ho feta?	Papa.	Daddy.
22	**And who cares for you when you feel sick, scared or hungry or tired?**	Ke mang a o hlokomelang ha o ikutlwa o kula, o tshohile, o tshwere ke tlala kapa o lapile?	Mama.	Mommy.
23	**I want you to think of a time when you and your family travelled together. Maybe went on a**	Ke batla o nahane ka nako moo wena le ba lelapa la heno le ileng la tsamaya ha mmoho kapa le nka leeto hammoho kapa le ya ho leloko	Ke na le family tse pedi. Enngwe e dula Pretoria* enngwe yona e dula Kroonstad*. Ke tla o jwetsa ka pale ya ha ne re ile Pretoria* ho	I have two relatives. One stays in Pretoria* and the other one in Kroonstad*. We went to Pretoria* and we arrived there at

	holiday or went to another family member. Anything. Tell us a story.	le leng la lelapa? Ntho enngwe le enngwe. Re jwetse pale.	rakgadi. Ha ne re fihla moo ntate waka o ile a shebella bolo ka nako eo nna ke shebelletse dipopo le bana ba rakgadi. Batswadi ba ka ba ne ba nwa kofi rona re ile raj a papa. Ho ne ho le monate. Ke ile ka thabela ho ba moo. Ke ne ke ile moo le mama le papa le nnake ya monyane. Boausi baka bona ba ne ba se ba ile Pretoria* jwale re ba thotse ho na moo. Ha re ne re kgutla re ile ra kgutlela hae re le kaofela.	my aunt's place. My dad watched soccer while I watched cartoons with my aunt's kids. My parents were having coffee. And it was very nice and I enjoyed it. We also ate porridge. I went there with Mom, Dad and my other sibling and we all returned at once. The two sisters went to Pretoria* first, we had to go join them.
24	**Tell us a bit about your friends.**	Re jwetse ha nyane ka ditsala tsa hao?	Re tshameka ka *bicycle* le Tau*. Tsala enngwe ya me ke Kabelo* re ya habo re fihle re je mmoho ha re fetsa be re lo tshameka. Re etsa tsohle hammoho. Bokang* ke tsala ya boraro ya me re tshameka *wrestling* hammoho mara ha re lematsane ha re fetsa be re lo ja. Ha nna le Bokang* re tshameka oo a bonang e mong pele o a matha a be a mo raha ke ka hoo re tshamekang ka teng.	We play with a bicycle together with Tau*. My other friend is Kabelo*. I usually go to his home and when we arrive there we do everything together including eating. My third friend is Bokang*, we play wrestling together but we do not hurt each other like the one on TV. When we are finished, we go to eat. Bokang* and I enjoy playing with each other at school – the one who sees the other one first kicks him. That is how we play.
	Why did you choose Tau*, Kabelo* and	Hobaneng o kgethile Tau*, Kabelo* le	Hela.	Just.

	Bokang* to be your friends? Why do you like playing with them?	Bokang* hore e ebe tsala tsa hao? Hobaneng o thabela ho bapala le bona?		
	Maybe it's because they like the things that you like.	Mohlomong ke hobane ba rata dintho tseo o di ratang.	Eya.	Yes.
	Thank you.	Ke a leboga.		

Explanation of specific terms used:
Question 4: *Lanta photo*** refers to a game that involves photos.
Question 20: *All star*** is a shoe brand.

Participant B
Boy, 12 years; Sesotho & isiZulu
Note:

- The questions reflect the DPM interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of a term at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**Researcher**	**Translator**	**Sesotho**	**English**
1	**Quickly tell us, why are you at the hospital today?**	Re qoqele hore hobaneng o le sepetlele kajeno?	Ke i le ka kula, ka ya *clinic* ba fumana hore ke tlameha ho ya Manapo ha fumanwa hore ha ba kgone ho nthusa ke ha ba nromella mona ba kgonne heh.	I got ill, so I was taken to the clinic. So there at the clinic they referred me to Manapo Hospital. Then, the hospital transferred me here to Universitas, so here is where I was assisted.
	So when you say "ill" - what is that about? What is wrong?	Ha o ne o kula jwalo re hlalosetse, ho kula hoo ke eng?	Ke i le ka qala ha ne ntse ke matha ke ha koloi e feta pela ka ke ile ka tshoha haholo ke ha ke wela fatshe. Ke ha tla be ba nkise *clinic*. *Clinic* ba re ke tshohile haholo ebile ke na le lefu la pelo ke ha ba nromela sepetlele.	It started when I was playing with my friends. So we were running and then a car, that was coming with a lot of speed, actually passed me in close range and I was very scared so I fell down. So they took me to the clinic. At the clinic they said that I was too terrified and that I have a heart problem so that is when I was referred to the hospital.
	And how old were you when this happened?	O ne o na le dilemo tse kae ha ne sena se etsahala?	Ke ne kena le 10 years.	I was ten years old.
2	**Tell me what is going on with your heart.**	Ho na le meriana eo o tlamehang ho enwa bakeng sa bothata ba pelo?	Mothapo waka o pompela madi phipheng e wrong ya pelo.	My vein is pumping blood into the wrong pipe of the heart.

3	**Do you have to take any medication?**	Ho na le ditlhare tseo o tlamehang hore o di nwe?	Eya, ke ne ke nwa dipidisi.	Yes, I was taking pills.
	Why?	Hobaneng?	Ke fihlile mona ka di 29 tsa *November* ke ha ke kgutlela morao ka di 25 *November* 2015 ba re ho na le ntho e sa lokang ke kgutlele hae batla boela ba nsebetsa ba ile ba nnea dipidisi ka lebaka la seo.	I came here on the 9th of November then left on the 25th of November 2015. They said that there was something wrong with me so they gave me pills as a result and said that they will later on treat me.
	What was that "something" that was wrong?	Ke eng ntho eo ban eng ba re ha e a loka ho wena?	Ba re re tlo ngola ditest sekolong jwale ha ba batle ke dule hae ke sa ngole ditest.	They were writing tests at school so they did not want me to miss school.
	Okay, so is that why they sent you home first and said that they would treat you later?	Jwale ke lona lebaka le entseng hore ba o romele hae ba be ba re batla o sebetsa ka morao?	Eya.	Yes.
	But now when you think back, what was wrong? Why did they give you those pills?	Ha jwale ha o nahana ... o kgutlela morao, phoso e ne e le eng? Hobaneng ba ne ba o neha dipidisi tseo?	Hobane akere ha ba ntreata jwale ntho eo e tlo tswela pele jwale ba ne ba leka ho e thibela hore e seke ya senya le ho feta pele ba ka ntreata. Hobane e ne e tlo ndamaga hore ke sa hlole ke loka nakong eo ba ntreatang.	The main reason was to try and prevent the damage for the illness not to damage him any further so that he can be treated.
	And what was the illness?	Ho kula hona ke eng?	Ke lefu la pelo.	The problem of the heart.
4	**What do you enjoy doing?**	O thabela ho etsa eng?	Ke rata ho drawya.	I love to draw.

	Really?	Ka nnete?	Eya, ke tlile le dibuka tsa ho drawya mona di teng. Ke di late?	Yes, I came with my drawing books here. Should I fetch them?
	Yes, you can quickly fetch them.	Eya, o ka di lata.	-	[The participant went to fetch his drawing book and then returned to the interview room]
	Wow … look at that, is it OK if I take a picture? I am going to add it to our things here.	Tjo … bona seo hlena, ekaba ho lokile ha nka dinka senepe? Ke tlo di Kenya ho dintho tsa rona mona.	Eya.	Yes.
	Is it a book from school or your own book from home?	Ekaba ke buka ya sekolong kapa ke buka ya hao ya hae?	Ke e sebedisa feela hae.	I am only using it at home.
	What else do you like?	Ke eng enngwe eo o e ratang?	Ke rata ho bapala bolo.	I love playing soccer.
	Are you good at drawing and playing soccer?	O kgona ho drawya hantle le ho bapala bolo?	Eya.	Yes.
5	**I want you to tell me a bit about your family. Specifically about their health. How is the health of your family?**	Ke batla o njwetse hanyane ka ba lelapa la hao. Haholoholo ka hore ba phetse jwang. Jwale njwetse hore ba phetse jwang?	Nkgono waka yena ke yena a ne a kula. O hlokahetse 2013 ka lebaka la stroke. Ba bang ha bana nix. Ngwaneso a nang le 6 *years* ke yena a nang le allergy. Le oo wa 9 *years* o ile a tjhaiswa ke koloi nou tje ha a kwatile ho ba bohloko mona pelong.	My granny passed away in 2013 because of a stroke. The six-year-old sibling has an allergy. And the nine-year-old was once hit by a car so now when he is angry he feels pain in his chest - in his heart.
	Does the nine-year-old get angry often?	O na a nang le dilemo tse 9 o na le ho kwata kapa ho kgena hangata?	Tjhe, ha a bapala yena ha a kwate empa feela ha a batle o mo bapadise ha	No, she doesn't get angry most of the time. She doesn't want other kids to play with her in a rough manner. She

			bohloko kapa o mo jwetse dintho tseo a sa di batleng. Mohlala: ha a tshwere pene o be o re mphe pene eo o mo lwantsha. Ke tse ding tsa dintho tse mo kwatisang.	only wants to play in harmony together. Let us say, she is holding a pen then you say harshly, “Give that pen.” Those are one of the things that make her angry.
	And you said when she gets angry she gets a pain? Where is the pain?	O itse ha a kwatile o ba le pain. O ba le *pain* kae?	Mona.	Here.
	OK. And you said your grandmother passed away because she had a stroke. Do you know what a stroke is?	O ile wa re jwetsa le ka nkgono a hao hore o ile a hlokahala ka *stroke*. O a tseba hore *stroke* ke eng?	Aa ha ke se tsebe.	No I don’t know it.
	And other family members are they OK?	Ditho tse ding tsa lelapa bona ba shap ha ba kuli?	Eya ba shap.	Yes, they are OK (sharp).
6	**How does your heart tell you when you are feeling sick?**	Pelo ya hao e o bontsha jwang ha o kula?	Ha ke kgone ho hula moya.	Being unable to inhale.
	How often does this happen?	Sena se etsahala ha kae mohlomong?	Le nou tje ha nka tshoha feela e tlo etsahala.	Even now if I were to be scared or frightened, it will happen.
	So can you give us an example of something that would frighten you and you will be unable to inhale?	O ka re fa mohlala wa ntho e ka o tshosang mme o be o sa kgone hula moya?	Ha motho a ka re o tlo nlahlela ka *venster nou* hape le ho bona batho ba lwana. Tsena di ka ntshosa.	When someone says that they are going to throw me out of the window right now and seeing people fight. These would frighten me.
	How does it feel when you can’t inhale?	O ikutlwa jwang ha o sa kgone ho hula moya?	Ke utlwa ho le bohloko.	It hurts me.

	And how often does that happen? That you get frightened and struggle to inhale?	Sena se etsahala ha kae? Hore o tshohe mme o ska kgona ho hula moya?	E ka etsahala neng kapa neng. Mara nou tje ha ke nahane hore e tla etsahala hobane ke tswa operationing.	It can happen any time. But now I think that it will never happen because I have been operated.
	This operation, what did they do?	Operationing moo ba entse eng?	Ba ile ba njwetsa hore batlo kwala mothapo oo o pompang madi lesobeng la pelo e wrong.	They said that they were going to close the wrong vein that was pumping blood to the heart.
7	**How do you feel about your ill heart?**	O ikutlwa jwang ka taba ya hore pelo ya hao e na le bothata?	Ha ke ne ke qeta ho tshoha ke ile ka tshoha hobaneba ile ba njwetsa hore hoja ka seke ka tla ho bona ka nako nka be ke salletswe ke 10 days ya ho phela.	When I first heard I became frightened because they told me that had I not come to them in time, I would be left with 10 days to live.
	Who told you that? Can you remember?	Ke mang a o jwetsitseng ntho eo? A na o santsana o hopola?	Ke doctor wa Manapo Hospital. O ile a jwetsa mme waka. Mme wa ka a jwetsa batho ba heso le nna.	It was the doctor at Manapo Hospital. He told my mother. My mother then told my siblings and me.
	And you said that made you feel frightened?	O itse sena se ile sa o tshosa?	Eya, mara eseng haholo hobane doctor o ile a re ke ska tshoha haholo hobane ke tla tsoha ke ho kula.	Yes, I was frightened but the doctor advised me not to get too frightened because If I become too frightened then I will become more sick again.
	Why were you frightened?	Hobaneng o ne o tshohile?	Hobane ne ke batla ho ba *artist nou* tje nkebe ke sa ba yona.	Because I wanted to be an artist but because of that I was never going to be one.
	Why not?	Hobaneng?	Hobane ne nka be ke shwele.	Because I would die.

	And now? How do you feel now?	Ha jwale o ikutlwa jwang?	Ke ikutlwa ke thabile hobane seke qetile.	I am very happy because I am finished [with being ill].
8	**Name some things that you like about yourself. Some things that you are proud of.**	Mpolelle dintho tseo o di ratang ka wena. Dintho tse etsang hore o be motlotlo ka wena.	[In isiZulu]***: Ngiyaziqhenya ngokuba wuMzulu, futhi nginesiphiwo sokudweba.	I am proud because I am Zulu and that I know how to draw.
	And what is it about being a Zulu that makes you so proud?	Ke eng ntho ka ho ba Mozulu e etsang hore o be motlotlo?	Hobane ke a e rata *language* ya isiZulu.	Because I love the Zulu language.
	What is it about the language?	Ke eng ka puo ena ya isiZulu?	Ke a e rata hobane heso re Mazulu feela hape ba re Mozulu wa tiisetsa that is why ke le motlotlo ka boZulu. Jwale ka Shaka Zulu.	I love it because at home we are all Zulus and people say that to be a Zulu you have to be strong like Shaka Zulu.
	Are you strong?	O ka re o tiile?	Eya.	Yes.
9	**Now I want you to name some things that you don't like about yourself. Things that you are not proud of.**	Jwale mpolelle dintho tseo o sa di rateng ka wena. Dintho tseo o seng motlotlo ka tsona.	Ha ke rate ho ba setlokotsebe hape ha ke rate ho ba Mosotho hobane hae ha hona Basotho.	I don't want to be a criminal and I also don't want to be a Sotho because at home there are Sothos.
	If you were Sotho and were the only Sotho speaking, what would that mean for you? What would happen?	Ho ja e ne e le wena feela Mosotho mme e le wena feela a buang Sesotho … e ne e tla bolela eng ho wena ntho eo?	Ne ke tla botsa mme waka hore ke tswa kae hobane ke Mazulu feela hae.	I was going to ask my mother that where do I come from because at home there are only Zulus.
	You also said that you do not like to be a criminal. So what is a criminal?	O itse hape ha o rate ho ba setlokotsebe. Jwale setlokotsebe ke eng?	Ke batho ba bolayang batho ebile ba tshwara poho.	Those that kill people and rob.

	Are you a criminal?	A na o setlokotsebe?	Tjhe.	No.
	I wanted you to name some things about you that you don't like. Things that are a part of you that you don't like.	O batla hore o mo jwetse ka wena dintho tseo e leng ho wena tseo o sa di rateng ka wena.	Nna ha ke rate hore ke be mona ka lebaka la ho kula.	I don't like being here because I am ill.
10	**Tell me again what is happening to your heart now?**	Ke kopa o njwetse hore ho etsahala eng pelong ya hao ha jwale.	Ho na tje ke right ene ke a thaba le hore le kgethile nna hore ke tle mona.	I am fine right now and I am happy that you chose me to come here.
	We are also happy that you are here. We love listening to you.	Le rona re thabile hore o mona. Re rata ho o mamela.	[Ha ona karabo]	[No response]
	Is this different from how you felt before you had the operation?	Ekaba ho fapane le pele ha ne o operatuwa ka tsela eo o ile wa ikutlwa ka teng?	Eya.	Yes.
	How?	Jwang?	Ha ne ke sa etsa *operation* ne ke sa heme hantle *nou* tje se ke le shap.	Before the operation I couldn't breathe properly, but after the operation, that was no longer the case.
	So there was a big difference?	Jwale ho ile ha e ba le phapang e kgolo?	Eya.	Yes.
11	**If you had three wishes and you could wish anything and it would come true, what would you wish for?**	Hoja o ne o ka labalabela dintho tse tharo. Dintho tseo o lakatsang hore di ka etsahala ho wena o ne o ka labalabela eng?	Nka labalabela ho bapala soccer be ke hlahella moo TV jwale ka mmapadi wa bolo.	I would wish to play soccer and appear on the television as a soccer player.
	What else?	Eng hape?	Ho ba *artist*. Hore batho ba nrate.	To be an artist. For people to love me.

	Who are you thinking of when you are saying that you would wish for people to love you?	O nahanne ka mang ha o re o ne o ka labalabela hore batho ba o rate?	Batho ba sa nrateng.	Those that don't like me.
	Are there people like that?	Ba teng batho ba jwalo?	Ke nahana jwalo hobane o ka se tsebe se ka pelong ya motho.	I think so because you can never know what is in a person's heart.
12	**What does the doctor say to you?**	Ngaka e reng ho wena?	Ha jwale?	At the moment?
	What does the doctor say to you or say about you?	Ngaka e reng ho wena kapa e reng ka wena?	E ile yare ke se ke fodile *nou* ke salletswe ke *check-up* ka mora kgwedi tse 6.	The doctor said that I am now healed. I only have to come for a check-up after six months.
13	**So what does Mom say about you?**	Mama o reng ka wena?	O re a nkebe a kgathala ho tsamaya tsela ena ya sepetlele hobane wan rata.	She says that she will not get tired of coming to the hospital because she loves me.
	How does that make you feel?	Seo se etsa hore o ikutlwe jwang?	Ke thaba hobane o a nrata.	I become very pleased because she loves me.
	What does Dad say about you? When Daddy talks about you, what does he say?	Ntate wa hao o reng ka wena? Ha papa a bua ka wena o reng?	Le yena o re wan rata.	He also says that he loves me.
	Do you have siblings?	O na le bana beno?	Eya, ke na le ngwaneso wa moshemane a dilemo tse 6 ke oo a nang le allergy, ke na le ausi a dilemo tse 18 o na le bitso ya badimo le ausi o mong waka a sebetsang *guest house*.	Yes, I have a little brother who is six years old. He is the one who has an allergy. I have a sister who is eighteen years old and she has a calling from the ancestors. And my elder sister, who is working at the guest house, she cleans and

				cooks for guests.
	Does she enjoy her job?	O a o thabela mosebetsi oo wa hae?	Eya ke nahana hore o a o thabela hobane o ile a kena 2013 le *nou* o ntse a sebetsa teng.	Yes, I think that she is happy with her job because she started working there in 2013 until now. She is still working there.
	At some stage you said you have a nine-year-old in your family. Who was that?	O ile wa re ho na le ngwana a dilemo tse 9 heno ... ke mang oo?	Ke ngwana ausi waka a nang le 24.	That is the child of the twenty-four-year old sister. She is my niece.
14	**What do your brother and two sisters say to you?**	Ngwaneno wa moshemane le boausi ba hao bar eng ho wena?	Ba re ke fole ke tlo tlohela ho tla mona sepetlele.	They say that I should get better so that I can stop coming to the hospital.
	Why do you think they say that?	O nahana hore hobaneng ba re jwalo?	Hobane ba nrata. Ha ba kgone ho dula ha monate ha ke le siyo. Ho ba monate ha ke le teng.	Because they love me. The void is felt when I am not there at home. So when I am around them we are all happy together.
15	**What do your friends say to you?**	Metswalle ya hao yona e reng ka wena?	Ha ne ke tswa sepetlele ba ile ba mpotsa hore ne ke le kae ka mora nako e telele tje.	When I came back from hospital, they asked me where I was all along.
	Why do you think they ask you that?	O nahana hore hobaneng ba o botsa seo?	Hobane ba batla ke kgutle re tlo bapala.	Because they want me to come back so that we can play together.
16	**What do your teachers say to you?**	Matitjhere a hao a reng ka wena?	Le bona ba re ke fole.	They also say that I should get better soon.
	Why do they say that?	Hobaneng ba re jwalo?	Hobane ke se ke ka loser ke mosebetsi.	Because they don't want me to lose a lot of work at school.
	If you have to guess, what do	Hoja o ne o tlameha ho nahana	Ba re ke stoutu mara ke a o etsa	They say I am silly but I do my school work.

	your teachers think about how you perform at school?	feela, matitjhere a hao a nahana eng ka tsela eo o sebetsang ka yona sekolong?	mosebetsi waka wa sekolo.	
	Can you give us an example of when you are "silly"?	O ka nehelana ka mohlala wa ha o le "stoutu"?	Re a bua haholo ka classing. E seng nna feela.	We talk a lot in class – not only me but my classmates as well.
	Who starts it usually?	Ke mang a qalang ha ngata?	Ke oo ke dulang le yena ka classing, Piti*.	Piti*.
	What does he start to talk about?	O qala a bua ka eng?	A be a bua ka eng kapa eng.	He talks about anything.
17	**If you could be an animal, what animal would you like to be?**	Ho ja o ne o ka ba phoofolo o ne o ka rata ho ba phoofolo efeng?	Nka kgetha hore ke be *monkey*.	I would choose to be a monkey.
	Why?	Hobaneng?	Hobane ke palama difate ene batho ba a ntshaba.	Because I climb trees and people are afraid of me.
	Are people scared of monkeys?	Batho ba tshaba ditshwene?	Ha ke tsebe mara nna ke a e tshaba.	I don't know but I am scared of a monkey.
	What is it about a monkey that you are scared of?	Ke eng ka tshwene eo o e tshabang?	Ya tshabeha tje.	Its frightening.
	Why?	Hobaneng o re ya tshosa?	Ha ka e tlwaela.	I am not used to it.
	Is it because of its sharp teeth or is it because it's so fast and they swing or is it because they make a funny noise?	Ke ka lebaka la lerata leo ditshwene di le etsang kapa ke ka lebaka la meno a teng a mutsu kapa mohlomong hobane di na le lebelo?	Kaofela ha ntho tseo.	All of them.

	Why?	Hobaneng?	Hobane batla ntella. Batho batlo ntshaba ebile ha ke no ya le sekolong.	Because they would disrespect me. People would be afraid of me and the good thing is I won't even have to go to school.
	Why won't you have to go to school?	Hobaneng ho sa tlo hlokahala hore oye sekolong?	Ke a se rata sekolo mara ha ke dutse ke le mong ke a nahana hore sekolo sa tena ... nkabe ke dutse hae *nou*.	I do love school but when I am sitting by myself, I think to myself that school is irritating. I would have just stayed at home. I am better off at home.
	So will people respect you when they are scared of you?	Batho ba ka o hlompha ha ba o tshaba?	Eya.	Yes.
	What is it about school that irritates you?	Ke eng ka sekolo e o tenang?	Ba nnatha botitjhere ... re tsoha hoseng.	We wake up early in the morning to go to school and teachers punish us.
	Like how?	Jwang?	Ha re baka lerata.	When we are making noise.
	How do they punish?	Ba le natha jwang?	Ba re natha matsohong.	They hit us on the hands.
	How should a teacher deal with a noisy class? If you were a teacher, how would you deal with a noisy class?	Tijhere e tlameha ho sebetsana jwang le class e lerata? Hoja o ne o le titjhere o ne o tla sebetsana jwang le class e lerata?	Ne ke tla ba jwetsa hantle hore le dira lerata.	I will tell them in a nice manner that they are making noise.
	Are you scared of the teachers?	O tshaba matitjhere?	Eya.	Yes.
18	**Tell us again, what are your favourite activities?**	Re jwetse hape ke eng dintho tseo o ratang ho di etsa?	Ke rata ho bapala bolo le ho drawya.	I love playing soccer and drawing.

19	**Are there things that you cannot do because you have an ill heart?**	Ana ho na le dintho tseo o sa kgoneng ho di etsa hobane o na le bothata ba pelo?	Ke ska kgona ho matha haholo le hore ke ska tshoha.	Not being able to run fast and I am not supposed to be afraid.
	So you used to be frightened?	Jwale o ne o hlola o tshoha?	*Sometimes* ne ke tshoha ha ke bona ntho e tshosang.	I used to be frightened when I see something scary.
	Can you give us an example of something that you have seen and was horrific?	O ka re fa mohlala wa ntho eo o kileng wa e bona e tshosa?	Kei le ka bona ba bolaya motho ha ne ke ya shopong ka *bicycle*.	I saw someone being killed when I was on my way to the shop riding a bicycle.
	How did you know that he was being killed?	O tsibile jwang hore ba ne ba mo bolaya?	Ba ne ba mohlaba ka thipa.	They were stabbing him.
	When was this?	Sena se etsahetse neng?	E ne e le 20h30 bosiu last year.	It was 20h30 at night last year.
	Have you told this to anyone? Who have you shared it with?	O kile wa jwetsa motho ka sena? O bolelletse mang?	Eya. Ke ile ka bolella batho ba heso le bakgotsi baka.	Yes. I told people at home as well as my friends.
	You said that you cannot run as fast as other kids and that you are not supposed to get frightened. Does this bother you?	O itse ha o kgone ho matha ka potlako jwalo ka bana ba bang le hore ha o a tlameha ho tshoha. Sena se a o tshwenya?	Eya.	Yes.
	Why does it bother you?	Hobaneng sena se o tshwenya?	Hobane ha ke tshwane le bana ba bang ka taba ya ho matha.	Because I am not like other children when it comes to running.
20	**Who looks after you?**	Ke mang a o hlokomelang?	Ke family yaka.	My family.
	Who is also part of your family besides those that you already mentioned?	Ke bo mang ba bang bao e leng ditho tsa lelapa leno kantle ho bao o seng o buile ka	Ke malome waka le bana ba malome waka le bo aunty baka.	My uncle and his children as well as my aunts.

		bona?		
	Are you a big family?	Lelapa leno le leholo?	Eya.	Yes.
	What would you tell us about your family?	Ke eng seo o ka re jwetsang sona ka family ya hao?	Hore ke a ba rata.	That I love them.
	Why?	Hobaneng?	Hobane ba nsireletsa.	Because they protect me.
	Do you also protect them?	Le wena wa ba sireletsa?	Eya.	Yes.
21	**Who understands you the best?**	Ke mang a o utlwisisang haholo?	Ke mme waka.	It's my mother.
	Why do you say that?	Hobaneng o re jwalo?	Hobane ke yena ya kgethileng ho tla mona.	Because she is the one that chose to come here.
	So, if you had secrets, who would you trust?	Jwale hoja o ne o na le diphiri o ne o tla tshepa mang?	Ausi waka ya nang le 18 years.	My eighteen-year-old sister.
22	**Who cares for you when you feel sick/sad/hungry/ scared?**	Ke mang a o hlokomelang ha o ikutlwa o kula, o hloname, o lapile kapa o tshohile?	Ke mme waka le ntate waka le boausi baka ba babedi.	My mother, father and two sisters.
23	**I want you to tell us a story about a time when you and your family travelled somewhere.**	Ke batla o re jwetse pale ka nako moo wena le family ya hao ne le etela kae kae.	Re ne re tjhakela ha malome waka. Ne re tsamaya ka koloi ya ntate wa ka. Ha ne re fihla ba ne ba re thabetse. E ne ele ka di 25 tsa *December* ra kgutlela ka *new year* bosiu. Ho ne ho le monate. Malome o na le bana ba bararo. Ne	We went to my uncle's place. He stays in Gauteng. We drove there using my father's car. And we were very happy. It was on the 25th of December. We stayed there until the 1st of January. It was very nice. Especially during new year's eve they were there shooting crackers and

			re bapala. Ka *new year* ngwana a monyane wa malome o ile a lematswa ke *crackers*. Ba ile ba mo potlakisetsa sepetlele. Ka *new year* re ile ra kgutlela hae bosiu. Moo ne re ile teng e ne e le Gauteng.	fireworks and then unfortunately one of the crackers hurt the younger child of my uncle and the child had to be rushed to hospital. I don't remember the date when the child came back. But now she is healed. But she lost her nail. After that we had to drive back home. It was nice being there.
24	**Tell us anything about your friends.**	Re kopa o re jwetse ntho enngwe le enngwe ka metswalle ya hao.	Ba rata ho bapala. Ba nrata. Ke na le bakgotsi ba 3, ke Seretse*, Molapo* le Lebona*. Re bapala kaofela ntho enngwe le enngwe. Ke di next door tsa ka. Ke batho ba right. Lebona* ke yena a nrutileng ho drawya.	They love playing. They love me. I have three friends: Seretse*, Molapo* and Lebona*. We play anything together. They are my neighbours and they are good people. Lebona* is the one who taught me how to draw.
	Thank you.	Re a leboha.		

Participant C
Boy, 13 years; Setswana/ Sesotho
Note:

- The questions reflect the DPM-interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of a term at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**Researcher**	**Translator**	**Sotho**	**English**
1	**Please tell us why are you at the hospital today?**	Ke kopa o re jwetse hore hobaneng o le sepatala kajeno?	Hobane ne ke bobola.	Because I was sick.
	What was wrong?	Bothata e ne e le eng?	Mama o ne a nkisitse ngakeng ke bobola.	My mother took me to the doctor because I was sick.
	What was the matter?	Lerobong jwale ka lesoba?	E na o ile a ncheka ene a re ke na le lerobong pelong Eya.	The doctor then checked me and then said that I have a hole in my heart.
	When was this?	Sena se diragetse neng?	Kgale ka 2011.	A long time ago, in 2011.
2	**What was going on with your heart? Explain to us.**	Go diragala eng ka pelo ya gago? Re hlalosetse.	Sepe.	Nothing.
	And before you went into operation at the hospital?	Pele o tla sepatala o tlo etsa operation?	Ba re ha ya siama mme e bulegile.	They said that my heart was not in a good condition and that there is an opening in my heart.
	What does that mean?	Seo se bolela eng?	Ha ke itsi.	I don't know.
3	**Do you have to take medication?**	Ho na le ditlhare tseo o tlamehang hore o di nwe?	Ke nwa dipidisi.	I take pills.

	When do you take the pills? In the morning or in the afternoon or before you go to sleep?	O di nwa neng hoseng kapa mantsiboya pele o robala?	Ke di nwa ha ke hetsa ho ja.	I take them after meals.
	Have you started to drink these pills now or have you been drinking them since 2011?	Dipidisi tsena o qadile ho di nwa ha jwale kapa haesale o ntse o di nwa ho tloha selemong sa 2011?	Eya, ho tloha 2011.	Yes, since 2011.
	Why do you take the medication? What does it do?	Hobaneng o tlameile hore nwe meriana ena kapa dipidisi tsena, di etsang ho wena?	Ba ne ba re di lo ho nthusa.	They said that they will help me.
	How will they help you?	E tlo ho o thusa jwang?	E ya ho fodisa lesoba le pelong ya me.	They are going to help me with the pain. They are going to heal my heart.
4	**What do you enjoy doing?**	Ke eng seo o thabelang ho se dira?	Go raga bolo, go tshameka *karate*.	To kick the ball, to play karate.
	Where did you learn karate?	O ithutile kae *karate*?	Ha hona moo ya re rutileng re e tshameka hela.	Nobody taught us, we are only just playing karate.
	What else do you like to do?	Ke eng ntho enngwe o ratang ho e etsa?	Ya go taboga. Ho tshameka brikfolo.	Running. Playing a game of making flips.
	Who is the best at that among your friends?	Ditsaleng tsa hao ke mang a kgonang ho etsa brikfolo ena hantle haholo?	Ke Tsepo*	Tsepo*.
	And yourself?	Wena?	Ke a e kgona.	Yes, I can do it.
	How do you feel when you have done a good flip?	O ikutlwa jwang ha o entse brikfolo e ntle haholo?	Ke siame.	I feel good.

5	**Tell us a bit more about the health of your family members.**	Re jwetse ka bophelo bo botle ba lelapa leno?	Ba siame kaofela.	They are all healthy.
	Are there others who have problems with their hearts?	Ekaba ho na le ba bang ba nang le bothata ba pelo?	Aa ke nna hela.	No, it's only me.
6	**How does your heart tell you when you are feeling sick?**	Pelo ya hao e o tsebisa jwang hore o a bobola?	Ha ke kgone go tshameka, go bua le go ja.	I can't play, talk or eat.
	Does it happen often?	Sena se diragala gantsi?	Aa.	No.
	How does your heart feel when you can't feel play, talk or eat?	O ikutlwa jwang pelong ya hao ha o sa kgone go tshameka, go bua kapa go ga?	Pelo yaka e tla be e le bohloko.	My heart pains.
7	**How do you feel about the fact that your heart is sick?**	O ikutlwa jwang ka hore wa bobola ka ntlha ya pelo ya gago?	Ha ke kgone go robala, go ja, go tshameka le ho tsamaya, ha ke kgone le ho ikisa *toilet*.	I can't sleep, eat, play, walk and I can't even take myself to the toilet.
	Why can't you do these things?	Hobaneng o sa kgone go dira dilo tseo kaofela?	Hobane be ke na le *pain*.	Because I would be in pain.
	And when you are in pain, how do you deal with it?	Ha o le bohlokong o sebetsana le bohloko kapa *pain* eo jwang?	Ke a patjama.	I lie on the bed.
	Was that before you had the operation?	Sena se ne se diragala pele o ya operationing?	Eya.	Yes.
	Before you had the operation, how did you know when your heart was ill?	Pele o ya operationing o ne o tseba jwang hore wa bobola le pelo	Ne ke le sentle hela.	I was just OK.

		ya hao ya bobola?		
	So was it only when the doctor told you that you have a hole in your heart that you knew something was wrong?	Ke ha o tla be o tsebiswa ke *doctor* kgetlo la ntlha hore ho na le moo ho buleileng pelong ya hao ke ha o tla be o tsebe hore o na le bothata ba pelo?	Eya.	Yes.
	And Mommy told us that in December they also did an operation, last year December?	Mama o ile a re jwetsa hore a re jwetsa hore ba ile ba o etsa operation selemo se fitileng ka December?	Eya, ba ntirile.	Yes, they operated on me.
	Why did they have to do another one now?	Hobaneng ba ne ba tlameha hore ba dire operation enngwe ha jwale?	Ba ne ba batla go bona pelo yame e siame, hore lesoba le kwaleile na ... ke ha ba ncheka mme ba thola hore pelo yame ha e so siame jwale ke ha ba tlameha ho dira enngwe hape.	They did an operation because they wanted to be sure that the opening is healed so they checked me and found out that it is not healed so, they had to do another one.
	So, this time they were just checking to see if the hole had healed?	Ba ne ba hlahloba feela hore lesoba le fodile?	Eya.	Yes.
8	**Name some things that you like about yourself.**	Re bolelle dintho tseo o di ratang ka wena tseo o leng motlotlo ka tsona ka wena?	Ke rata bolo.	I love soccer.
	Are you good at soccer?	O kgona go tshameka bolo sentle?	Eya le go taboga le *karate*.	Yes, and running as well as karate.
9	**What things about yourself don't you like?** For example:	Ke dife dintho ka wena o sa di rateng? Mohlala:	Sepe.	Nothing.

	Carina bites her nails and I hate that I bite my nails. I get so angry when I bite my nails. I don't like it. I want to change it. I don't want to bite my nails. So, what things about you don't you like? If there is something.	Carina o rata ho loma manala a hae ene o hloile seo. Ha a rate hore o loma manala a hae o batla hore a fetohe. Ke dife dintho tseo o sa di rateng ka wena?		
	And which things are you proud of – things that you have done or things that you can do?	Ke dife dintho tseo o leng motlotlo ka tsona, dintho tseo o di thabelang, mohlomong tseo o ileng wa di etsa tse etsang hore o di thabele.	Go bereka.	Working.
	What kind of work?	Mofuta o feng wa mmereko?	Wa go kga metsi.	Going to get water.
	Anything else that you want to add?	Ho na le ho hong o batlang ho re jwetsa hona, ho tlatsa seo o qetang ho se bua?	Sepe.	Nothing.
10	**Quickly tell me again. I forgot. What is happening to your heart at the moment or now?**	Ke kopa o njwetse hape, ke lebetse. Ho diragala eng pelong ya gago ha jwale?	Sepe.	Nothing.
	And before?	Pele?	Sepe.	Nothing.
	Before the operation?	Pele ho operation?	Ho ne ho sa diragale sepe.	Nothing was happening.
	What was the problem with your heart before you had an operation?	Bothata e ne e le eng ka pelo ya hao pele o dira operation*?	Mme waka o ne a nkisitse ngakeng *for check-up*. *Doctor* e be re kena le lesoba pelong a be a kwala	My mother took me to the doctor for a check-up and then the doctor said that I have a hole in my

			lekwalo ho ntransfera ho sepatala sa Kuruman. Ko Kuruman ba be ba re ha ba kgone jwale ba ntransfera Kimberley. Kimberley ba itse le bona ha ba kgone ke ha ba ntransfera mona.	heart, so he wrote a letter to transfer me to Kuruman Hospital. At Kuruman Hospital, they said that they will not be able to help me so they transferred me to Kimberley [hospital] and there they also said that they were unable to help me, so they transferred me here.
	So were they able to help you here?	Jwale mona teng ba kgonne ho o thusa?	Eya.	Yes.
11	**If you had three wishes and you could wish anything and it would come true, what would you wish for?**	Haeba o ne o ka labalabela dilo tse tharo, hore o ne oka di labalabela mme be di etsahala, o ne o ka rata go diragale eng?	Go aga ntlo le ho ithekela koloi.	To build a house and buy myself a car.
	Who would the house belong to and what would it look like? How many rooms would the house have, and who would live in that house?	Ntlo eo e ne e tlaba ya mang? Mme e ne e tlaba jwang, e ne e tlaba le dikamore tse kae hape ke mang a ne a tla dula ka ntlong eo?	Dirumu tse 5. Ntlo e tonna. E le ntlo ya me. Ke tla be ke dula ke le 1.	A five-room house. It would be a big house and it would be my house and I will be staying alone.
	Then you said you would like to have a car and then said a car?	O itse o ka batla ho ba le koloi o itse e *silver*.	Eya, ke be le dinku, dikgomo le dipodi.	Yes, and sheep, cows and goats.
	So you are going to be a rich man?	So o tlo ba monna wa mohumi?	Eya.	Yes.
	So what would people say when you have this big house, own car and	Batho ba ka re eng ha o na le ntlo e tonna, koloi e leng ya, dinku,	Sepe.	Nothing.

	a lot of sheep, cows and goats?	dikgomo le dipodi tse ngata, batho ba ka re eng ka wena?		
	What do you think they would say?	O nahana hore ba ka re eng ka wena?	Ba go ntoya.	They are going to bewitch me.
	Why would they do that?	Hobaneng ba ka etsa seo?	Ke honne ke tla be ke le mohumi.	Because I will be rich.
	And what would you say to them when they tell you that they want to bewitch you?	Wena o ka re eng ho bona ha ba o jwetsa hore ba tlilo go o loya?	Go siame.	It's OK.
	So why would they want to bewitch you when you are rich?	Hobaneng ba ka batla ho o loya ha o le mohumi?	Ke ya go ya kerekeng.	I will go to church.
	But why would other people say that they want to bewitch you?	Empa hobaneng ha batho ba bang ba ka re ba batla ho o loya?	Batla be ba batla go tsaya madi ame.	Because they would want to take my money.
	What do you think they would want to do with your money?	O nahana hore ba ka batla ho etsa eng ka madi a hao?	Ba ka batla go tsaya madi ame ba be ban ka dinku, dikgomo le dipodi tsa me.	They would want to take my money as well as my sheep, cows and goats.
	Do they also want to be rich?	Le bona ba batla hore e be barui?	Eya, le bona ba batla hore e be barui.	Yes, they would also want to be rich.
12	**What do doctors say to you?**	Dingaka di re eng ho wena?	Ba re ka mosho ke ya hae.	They are saying that tomorrow I am going home.
	Are you excited?	O thabile haholo?	Eya.	Yes.
	You said you have a mommy and a daddy?	O itse o na le mama le papa?	Eya.	Yes.
	Do all of you live in the same house?	Le dula ntlong e le nngwe?	Eya.	Yes.

13	**So what does Mommy say about you?**	Mme wa hao o re eng ka wena kapa ho wena?	O nthoma shopong ho lo mo rekela.	She sends me to the shop to buy her something.
	What does she tell people about her son?	O jwetsa batho eng ka mora wa hae?	Sepe.	Nothing.
	What do you think she says about you?	O nahana hore o re eng ka wena?	Dilo tse dintle.	Good things.
	Are you a good boy?	O mosimanyana ya siameng?	Eya.	Yes.
	And what does daddy say about you?	Ntate wa hao o re eng ka wena?	O re ke mosimanyane ya siameng.	He says that I am a good boy.
	Why are they saying that?	Hobaneng ba re jwalo?	Ha ba nthoma shopong ke a itlhaganela.	When they send me to the shop I don't take my time. I go there immediately.
	Do you have siblings?	O na le bana beno?	Eya, baka ba babedi hela ba banyane ho nna.	Yes, I have two.
	Are you the eldest?	Ke wena ya motonna?	Eya.	Yes.
	Are your siblings boys or girls?	Bonnake ba hao ke banana kapa basimanyane?	O mo *one* ke mosimanyane.	One is a boy.
14	**What do they say about you? Do they talk yet?**	Ba re eng ka wena? Ba se ba tseba ho bua?	Eya, ha ke na le madi ba re ke ba nehe madi.	Yes, when I have money they say I should give them.
	So do they know that you, as their older brother, can take care of them?	Jwale ba a tseba hore wena jwale ka abuti wa bona o ka kgona ho ba hlokomela?	Eya.	Yes.
	Is that true? Will you look after them?	Ekaba ke nnete, O ka ba hlokomela?	Eya.	Yes.

15	**What do your friends say about you?**	Ditsala tsa hao di re eng ka wena?	Ba re sentle hela.	They only say good things.
	What are those things? Tell us.	Ke eng tseo? Re jwetse.	Ba ile ba re ha ke tla mona ke tsamaye sentle.	They told me to have a safe trip when I came here.
	Why do you think they chose you to be their friend?	O nahana gore ke goreng ba kgethile wena hore o be tsala ya bona?	Ke ra ha re rekelana. Ha ke na le madi ke a ba rekela le bona ba nrekela.	We buy things for each other. When I have money I buy for them and they also buy for me.
16	**What do your teachers say about you?**	Matitjhere a hao a reng ka wena?	Sentle hela.	Good things.
	What good things?	Ke dintho dife tse ntle?	Ba hlola ba mpotsa hore ke dira sentle.	They usually tell me that I am doing well.
17	**If you could be an animal, what animal would you like to be?**	Ho ja o ne o ka ba phoofolo o ne o ka rata ho ba phoofolo efeng?	Kgomo.	Cow.
	Why?	Hobaneng?	Hobane e na le mashi, e kgona go dira mashi.	Because it has milk. It can produce milk.
	And why would that cause you to choose a cow?	Hobaneng sena se ka o etsa hire o kgethe kgomo?	E a tswala.	It can produce like give birth.
	So that you can even have more cows?	Hore ho be le dikgomo tse ngata?	Eya.	Yes.
18	**Who looks after you?**	Ke mang a o hlokomelang?	Mama.	Mom.
	What sort of mom is your mom? What sort of person is she?	Mama wa hao ke mofuta o jwang wa motho? Re hlalosetse ka mama wa hao?	O siame hela.	Just a good person.

	What makes her a good person?	Ke eng se dirang hore o re ke motho ya siameng?	Hoseng ha re ya sekolong mama wa tsoha a ba re futhumaletsa metsi a ho hlapa.	Early in the morning, when we go to school, my mother warms water for us to bath.
	What else? Why is she a good mommy?	Ke eng enngwe? Hobaneng o re ke mme ya lokileng?	Ha re ya sekolong o re phehela motoho.	When we go to school, she also cooks soft porridge for us.
	Anything else that makes her a good mommy?	Ekaba ho na le senngwe se etsang hore o re mme wa hao ke motho ya siameng?	O re hlatswetsa dihempe ha re tswa sekolong.	She washes our shirts when we come back from school.
19	**Who understands you the best? Who knows you the best?**	Ke mang a o tlhaloganyang haholo? Ke mang a o tsebang sentle?	Mama.	Mom.
20	**Who cares for you when you feel sick, sad, hungry or scared?**	Ke mang a o hlokomelang ha o ikutlwa o bobola, o hloname, o tshwerwe ke tlala kapa p tshohile?	Mama wa mme wame.	My mother's mother.
	And Daddy - doesn't he care for you?	Ntate wa hao yena ha a o hlokomele na?	Wa ntlhokomela.	He cares for me.
	How does Dad care for you?	Ntate wa hao oo hlokomela jwang?	Sentle.	Just okay.
	What sort of things does he do to care for you?	Ke mofuta wa dintho difeng a di etsang hore o re wa o hlokomela?	O ile a fihla ke robetse tlasa setlhare antsaya a lo nrobatsa ka tlung.	He arrived when I was asleep under the tree; he carried me to the house to sleep.
21	**Tell us a story when you and your family members travelled together on a trip to somewhere.**	Re bolelle pale moo wena le ba lelapa leno le ile la nka leeto ha mmoho le ileng la etela sebakeng se	Ne re ya toropong e le papa le mama, nna le bonnake, papa a lo re rekela dikhai kaofela. Sena se diragetse ka	Last year I went with my parents and siblings to town and my father was going to buy clothes for us.

		itseng ... wena, mama, papa le bonnake ba hao.	*December* selemo se fitileng.	
	Which town did you go to? Was it the one in Upington*?	Ke toropo e fe le ne le ile ho yona? Ekaba e ne e le e Upington* kapa jwang?	Upington*.	Upington*.
	How was that trip for you?	Leeto leo le ne le le jwang?	Go ne go le monate.	It was nice.
22	**Tell me about your friends.**	Njwetse ka ditsala tsa hao?	Ke batho ba shap.	They are good people (sharp).
	Tell us again, why would they want to be your friend?	Re jwetse hape hobaneng ba batla ho ba metswalle ya hao?	Hobane re dula tafoleng e one re le bararo sekolong.	There at school we share a table, the three of us.
	Why do you enjoy being their friend?	Hobaneng o thabela ho ba motswalle wa bona?	Mohapi* ke wa lesika, Neo* ha ho kwadiwa re dula re le two be re thusana.	Mohapi* is family, Neo*, when we are writing, we sit together and help each other.
	During the test? Or Before?	Ha le ntse le ngola test? Kapa pele le ka ngola test?	Pele.	Before.
	Are they funny?	Ke batho ba qabolang?	Eya**.**	Yes.
23	**What are your favourite activities?**	Ke eng dintho tseo o ratang ho di etsa?	Bolo, *karate*, go taboga le go tshameka di game.	Soccer, karate, running and playing games.
	What sort of games?	Mofuta o fe wa di *game*?	E seng tsena tsa motjhini mara tsa lebala tseo re di tshamekang.	Not machinery games but playing actual games outside.
	What sort of games?	Mofuta ofe wa di *game*?	*Skotch*.	The jumping game called *Skotch*.
	Do you enjoy school?	O natefelwa ke sekolo?	Eya, ke thabela ho ba sekolong.	Yes, I enjoy school.

	And what are your favourite things at school?	Ke dintho di feng tseo o di ratang sekolong?	*Maths*, Setswana, *English* le *Natural Science*.	Maths, Tswana, English and Natural Sciences.
	And your marks? Are you doing good?	Dimarks tsa hao di jwang? O ntse o ya hantle?	Eya, key a hantle sekolong ebile ke kgona ho pasa.	Yes, I go to school very well and I am able to pass.
	Have you ever failed a grade?	O kile wa pheta grade sekolong?	Ke ile ka pheta *grade* 4 ka lebaka la batho ba ntsi ba ne ba kgwanta ba re thibela ho ya sekolong hoba ba ne ba tlo se tjhesa.	I repeated grade 4 because there were protestors who were stopping us from going to school or, if so, they were going to burn the school.
	Was it last year or the year before that?	Sena se ne se le neng? Selemo se fitileng kapa selemo Pele ho seo?	Selemo se fitileng.	Last year.
	What were the protestors threatening you with?	Ba ne ba le tshosetsa ka eng batho ba neng ba kgwanta?	Dithipa le Spitkgarafu.	Knives and a spade.
	What did they say they were going to do with them?	Ba ne ba itse ba tlo etsa eng ka tsona?	Ba ne ba itse ba tlo tjhesa sekolo so ha ho ka ba le motho a sa ba mameleng ba tlilo go mo hlaba.	They said they were going to burn the school and whoever went against them, they were going to stab them.
	Were you the only one who had to repeat the grade, or were there other kids as well?	E ne e le wena feela a ne a tlameha ho pheta grade kapa ho ne ho na le bana ba bang?	Le bana ba bang.	Other children as well.
24	**Before the operation, what couldn't you do because of the heart problem?**	Pele ho *operation* ke eng seo o ne o sa kgone ho se dira ka baka la bothata ba pelo?	Ke ho tjhuletsa, go sa kgone ho jara dilo tse di boima.	Unable to carry heavy loads or things.

	Does it bother you?	Sena se a o tshwenya kapa ha se o tshware hantle?	Eya.	Yes.
	How does it bother you?	E o tshwenya jwang taba ena ya gore ha o kgone go jara dilo tse boima?	Hobane ha ke tshwara dilo tse boima ha ke kgone ho tsamaya.	I am unable to walk as well when I carry these heavy loads.
	How does it make you feel?	E o etsa o ikutlwe jwang?	Sehuba sa ka se ba bohloko.	My chest pains.
	How do you feel about this? Angry, sad, just OK, or happy?	O ikutlwa jwang ka hore ha o kgone ho dira dilo tse ding ka baka la bothata ba pelo, tsena di etsa o thabe, o kgene, o kwate?	Sentle hela.	Just okay.
	Thank you.	Re a leboha.		

Participant D
Boy, 13 years; Afrikaans
Note:

- The questions reflect the DPM-interview , although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of a term at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**English Translation**	**Researcher**	**Afrikaans**	**English**
1	**Why are you here at hospital today?**	Hoekom is jy vandag hier by die hospitaal?	Om te kyk of my hartprobleem erger geraak het of nie.	To see if my heart condition got worse or not.
	Is there a possibility that it could get worse?	Is daar 'n moontlikheid dat dit erger kan raak?	Ja, dit het al in die verlede gebeur: Vir twee jaar in 'n ry het die spier dieselfde gebly (45)**. Maar, in die derde jaar het dit erger geword (54)**.	Yes, it has happened before: For two years in a row the muscle stayed the same (45)**. But in the third year, it got worse (54)**.
2	**Tell me what is going on with your heart.**	Vertel vir my wat met jou hart aangaan.	Daar is 'n groot probleem met my hart – die klep werk nie soos ander mense s'n nie – dit is dunner. Wanneer 'n mens gebore word is daar 'n flap wat moet skeur, maar die flap in my hart het nooit geskeur nie. Die kleppe werk soos deure wat oop en toe gaan.	There is a big problem with my heart – the valve does not function the same as other people's … it is narrowed. At birth, there is a flap that is meant to tear but the flap in my heart did not tear. The valves work like doors that open and close.

3	**Do you have to take any medication? Why?**	Moet jy enige medikasie gebruik? Waarom?	Ja. Die pille help my hart om stadiger te klop (normaal). Daar was ‘n keer wat my hart vinnig geklop het, want ek het baie geloop – ek het gholf gespeel. Omdat die medikasie maak dat my hart stadiger klop, was daar ‘n *clash* en toe raak ek duiselig.	Yes, the tablets help my heart to beat slower (in the normal range). There was once an incident when my heart was beating fast because I was walking a lot – I was playing golf and the medication slows down my heartbeat, so there was a *clash* and I got dizzy.
	For how long have you been taking the medication?	Hoe lank neem jy al die medikasie?	Ek het voorheen ander medikasie gebruik, maar toe maak hule dit nie meer nie, so ek is nou al vir so maande op nuwe medikasie.	I used to take different medication, but then it was discontinued, so I have been on new medication for about a month now.
4	**What do you enjoy doing? Tell me more.**	Wat is jou gunsteling aktiwiteite? Vertel my meer.	Om gholf te speel. Ek speel graag gholf saam met my vriende. Wanneer ek gholf speel, vergeet ek van alles wat deur die dag gebeur het. Ek is ‘n goeie gholfspeler (ek is ‘n 14 *handicap***). Ek hou ook daarvan om krieket te speel.	To play golf. I play golf with my friends. When I play golf, I forget about everything that had happened during the day. I am a good golfer (a 14 *handicap***). I also like to play cricket.
	What activities do you enjoy doing during school holidays?	Watter aktiwiteite geniet jy om tydens skoolvakansies te	Om saam met my vriende te speel. Ons speel *Xbox***	To play with my friends. We play *Xbox*** …

		doen?	Ek is goed daarmee.	I am good at it.
5	**Tell me more about the health of your family members.**	Vertel vir my ‘n bietjie meer van jou familielede se gesondheid.	My ma, pa en suster (sy is 16 jaar oud) is normaal en hulle het geen gesondheidsprobleme nie. My boetie wat sewe jaar oud is, het ernstige *diabetes***. My ma is ook ‘n diabeet, maar sy hoef nie insulien-inspuitings te kry nie.	My mother, father and sister (who is 16 years old) are normal with no health problems. My brother, who is seven years old, has severe *diabetes***. My mother is also diabetic, but she doesn’t have to get insulin injections.
	Do any of them have heart illnesses?	Het enige van hulle hartprobleme?	My ouma het dieselfde hartprobleem as wat ek het.My aorta-klep is ‘n probleem, maar twee van my ouma se hartkleppe het probleme.	My grandmother has the same heart illness as me. My aorta valve is a problem but two of my grandmother’s valves have problems.
	What goes through your mind when you think of Granny having the same health condition as you?	Wat gaan deur jou gedagtes wanneer jy dink aan Ouma wat dieself hartprobleem as jy het?	Ons is dieselfde. Die verhouding wat ek met my ouma het is uniek omdat ons soort van ‘n *special bond* het (ons hartprobleme).	We are the same. The relationship that I have with my grandmother is unique because we have sort of a special bond (the heart illness).
6	**How does your heart tell you when you are feeling sick?**	Hoe sê jou hart vir jou wanneer dit siek voel?	My ribbes druk so in. Dit voel soos naaldprikke. Ek	My ribs push in. It feels like needle pricks, I

			het pyn, ek raak naar en my hart begin baie vinnig te klop wanneer ek oefening doen. Dit is die rede hoekom ek nie meer harde oefening doen nie. Ek oefen nog steeds saam met die ander [kinders], maar ek doen nie die harde oefeninge nie.	have pain, I get nauseous and my heart starts to beat very fast when I do exercise. That is why I don't do strenuous fitness exercises anymore. I still train with the rest but I don't do the serious fitness exercises
	Do other people know about your ill heart?	Is daar ander mense wat weet dat jou hart siek is?	Ja. Dit is nie vir my 'n probleem om vir ander mense te vertel nie (veral kinders en onderwysers by die skool). Party kinders by die skool weet nie dat ek 'n hartprobleem het nie. Die sportafrigter en onderwysers weet dat ek 'n hartprobleem het en hulle is *fine* daarmee – hulle verstaan dit bietjie beter as die kinders.	Yes, it is not an issue for me to tell other people (adults and children at school). Some children don't know that I have a heart illness. The coach and teachers know about my heart problem and they are fine with it. They understand it a bit better than the children.
	Do the teachers treat you differently because of your heart problem?	Hanteer die onderwysers jou anders omdat jy 'n hartprobleem het?	Nee.	No.
7	**How do you feel about your ill heart?**	Hoe voel jy oor die feit dat jou hart siek is?	Dit is nie vir my lekker om hierdie hartprobleem te hê nie. Byvoorbeeld, ek kan nie *touch rugby*** saam met	It is not nice for me to have this heart illness. For example, I cannot play *touch rugby***

			die ander kinders speel nie. Ek wil so graag saam met hulle speel, maar dan dink ek aan die nagevolge. As hulle my op ‘n sekere manier sou *tackle*, dalk te hard (wat maklik kan gebeur), dan sal dit nie goed wees vir my hart nie. My hart kan nie sulke soort van kontak hanteer nie.	with the other children. I so badly want to play with them but then I think about the possible consequences. If they were to tackle me in a certain way – maybe too hard (which could easily happen) then it is not good for my heart … my heart can’t handle contact like that.
	How do you feel then?	Hoe voel jy dan?	Ek voel dan ontsteld, want al my vriende speel.	I would then feel upset because all of my friends play.
8	**Name some things that you like about yourself.**	Noem ‘n paar dinge van jouself waarvan jy hou.	Ek het talent vir gholf en krieket.	I am talented in golf and in cricket.
	Where, do you think, does the talent come from?	Waar, dink jy, kom die talent vandaan?	Ek oefen [gholf en krieket] baie.	I practise [golf and cricket] a lot.
9	**Name some things that you don’t like about yourself.**	Noem ‘n paar dinge van jouself waarvan jy nie hou nie.	Ek kan nie *rugby* speel nie. Ek kyk meer gholf en krieket saam met my pa op die TV (nie *rugby* nie), want ek het nooit eers die reëls van *rugby* geleer nie.	I cannot play rugby. I watch more golf and cricket on TV with my dad (not rugby) because I have never even learned the rules of rugby.
	What is it about rugby that you like?	Wat is dit van *rugby* waarvan jy hou?	Om iemand te *tackle*.	To tackle someone.

10	**What is happening to your heart?**	Wat is aan die gang met jou hart?	Die klep werk nie reg nie. Die flap het nie geskeur nie, so dit maak nie oop soos wat dit moet nie en dit laat bloed deur.	The valve is not working properly. Tthe flap didn't tear, so it doesn't open as it should and it leaks blood.
	Who explained this to you so nicely?	Wie het dit vir jou so mooi verduidelik?	Dr Smith*. Elke keer wanneer ek na hom toe gaan, dan wys hy vir my prentjies en 'n model van die hart.	Dr Smith* Every time, I visit him, he shows me pictures and a model of the heart.
11	**If you had three wishes and you could wish anything and it would come true, what would you wish for?**	As jy drie wense gehad het, wat sou waar word, waarvoor sou jy wens?	Dat my hart gesond sal word. Dat ek uiteindelik sal kan *rugby* speel, iemand sal kan *tackle* en ge-*tackle* sal kan word.	That my heart would be healed. For once, that I would be able to play rugby, tackle and be tackled.
	It sounds like you have thought about this a lot in the past."	Dit klink of jy al baie in die verlede hieroor gedink het.	Ja, ek dink baie daaroor. Ek sal ook graag aan die Nedbank Million Dollar Golf Challenge** wil deelneem.	Yes, I think about it a lot. I also want to take part in the Nedbank Million Dollar Golf Challenge**.
12	**What does the doctor say to you?**	Wat sê die dokter vir jou?	Wat hy gewoonlik sê. Hy verduidelik vir my hoe my hart was en hoe dit nou is.	What he usually says. He explains to me how my heart was before and how it is now.
	How is that experience for you?	Hoe is die ervaring vir jou?	As my hart minder lek (m.a.w. as dit beter raak), dan	If the leak in my heart is less (when it gets

			voel ek gelukkig. Maar ek voel *nervous*, want ek is bang dat die dokter sal sê dat ek geen sport meer mag doen nie.	better), then I feel happy but I feel nervous because I am worried that he might say that I should not play any sport anymore.
13	**What do your parents say to you?**	Wat sê jou ouers vir jou?	Hulle sien my as ‘n normale kind. Hulle hanteer my op dieselfde manier as my suster en broer.	They see me as a normal child. They treat me the same as my sister and my brother.
	Are you different from other children?	Is jy anders as ander kinders?	Partykeer voel ek anders. Byvoorbeeld, oor die feit dat ek nie rugby mag speel nie [oor my hart wat siek is]. Maar, wanneer ek die sporte speel wat ek speel [saam met die ander kinders], dan dink ek dat ons dieselfde is en dan voel ek dat ek deel is van die groep.	Sometimes I feel different. For example, the fact that I am not allowed to play rugby [because of my ill heart]. But if I play the sports that I do [with the other children] then I think that we are the same and then I feel included.
14	**What do your siblings say to you?**	Wat sê jou suster en broer vir jou?	My broer verstaan nie my hartprobleem so goed soos my suster nie, maar ek kan *touch rugby*** saam met hom speel, want ons het ‘n klein erf.	My brother does not understand my heart condition as much as my sister does, but I will play *touch rugby*** with him because we have a small yard.

	Is there anyone who thinks that you are different from other children?	Is daar enige iemand wat dink dat jy anders as ander kinders is?	Nee, want ek het nog nie vir al my vriende hier [van my hartprobleem] vertel nie.	No. because I haven't told all of my friends here [about my heart condition].
	Do you experience bullying?	Word jy geboelie?	Nee, nooit.	No, never.
15	**What do your friends say to you?**	Wat sê jou vriende vir jou?	Meeste van hulle speel nie *rugby* nie – hulle is swemmers. Hulle doen ander sporte soos *squash*. Hy ['n vriend] het my eenkeer gevra om saam met hom *squash* te speel, maar my ma het nee gesê, omdat ek te moeg sal word. Ek pas in by my groep vriende.	Most of them, they don't play rugby … they are swimmers … they do other sports like squash. He asked me to play with him but mom said no because I would get too tired. I fit in with my group of friends.
	Have you ever felt pressure to play rugby?	Het jy al ooit druk ervaar om rugby te speel?	Nee, nie regtig nie.	No, not really.
16	**What do your teachers say to you?**	Wat sê jou onderwysers vir jou?	Ek weet nie regtig nie. Hulle sal sê dat ek soms deur moeilike tye gaan, byvoorbeeld, wanneer die kinders wat rugby moet gaan speel uit die klas geroep word oor die interkom, dan is ek omtrent die enigste seun wat in die klas bly en dan moet ek eers wag totdat hulle terugkom voor ek weer met hulle kan	I don't really know. They would say that I go through difficult times, for example when they call the rugby players out of class over the intercom, then I am almost the only boy that stays behind and then I have to wait for them to return before I can talk to

			gesels.	them again.
	How does that feel? Is it embarrassing?	Hoe voel dit? Is dit vernederend?	Alleen en hartseer. Nee.	Alone and sad. No.
17	**If you could be an animal, what animal would you like to be? Why?**	As jy kon kies om enige dier te wees, watter dier sal jy wil wees? Hoekom?	Ek sal 'n hond wil wees – a wit *German Shepherd***, want hulle is die mooiste honde en hulle is groot – hulle hoef nie bang te wees vir ander (of wat ander sal dink) nie. My suster is bewus van wat ander mense van haar dink. Maar, ek gee nie om wat ander mense van my dink nie. Byvoorbeeld, wanneer my suster 'n hokkiewedstryd speel dan skree ek en my pa kliphard: "*Go*, Adri*!" Sy haat dit!	I would want to be a dog – a white German Shepherd** because they are the most beautiful dogs and they are big – they don't have to be scared of others (or what others think). My sister is concerned with what others think of her. But I don't care what other people think of me. For example, when my sister plays a hockey game, my dad and I would yell at the top of our lungs:"Go, Adri*!" She hates it!
	But don't you think that you are also going to be like that (self-aware) when you turn 16 [like your sister]?	Maar, dink jy nie dat jy ook so self-bewus gaan raak wanneer jy 16 word [soos jou sussie] nie?	Nee! Ek gee nie om wat ander mense van my dink nie … ek plant my naam.	No! I don't care what other people think of me … I plant my name.
18	**What are your favourite activities?**	Wat is jou gunsteling aktiwiteite?	Krieket , gholf en *Xbox***.	Cricket, golf and *Xbox***.

19	**Name the things that you cannot do because of your heart problem. Does it bother you? What does it do to you?**	Noem die dinge wat jy nie kan doen nie as gevolg van jou hartprobleem. Pla dit jou? Wat doen dit aan jou?	Byvoorbeeld, elke jaar is daar ‘n skool-uitstappie *Ramsgate** toe. Al die skole in die distrik gaan op dieselfde dag. Ek kon nie by die *Slide of Courage* afgly nie – my ma het gesê ek moet dit nie doen nie, want ek sal paniekerig raak en dit sal te veel stres op my hart sit. Ek het al eenkeer voorheen by die *Slide of Courage* afgegaan, maar ek was nogal bang en paniekerig.	For example, every year we have a school trip to Ramsgate*. All the schools from the district go on the same day. I couldn’t slide down the *Slide of Courage.* My mom said I shouldn’t because I will panic and it would have placed too much stress on my heart. I went down once before, though … I was quite scared and panicked.
20	**Who looks after you? Tell me more about that person.**	Wie sorg vir jou? Vertel my meer van daardie persoon.	My ma is ‘n huisvrou en sy doen omtrent alles (sy het twee stelle hande). Byvoorbeeld, in die oggende wanneer ek in die kombuis ingaan, dan is my medikasie alreeds gereed vir my om dit te drink. Al wat ons hoef te doen, is om ons eie pap in te skep. My pa is nie baie by die huis nie.	My mother is a housewife and she does almost everything (she has two sets of hands). For example in the morning, when I get to the kitchen, my medication will be ready. All we have to do is to pour our own cereal. My dad is not home much.
	And how is that for you?	Hoe is dit vir jou?	Partykeer raak dit maar alleen, maar ek raak gewoond daaraan, want hy	Sometimes it gets lonely but I get used to it because he

			[my pa] werk gereeld op ander plekke (weg van die huis af).	works away from home quite often.
	And when he's at home over weekends, what would you two do together?	En wanneer hy oor naweke by die huis is, wat doen julle twee saam?	As ons gelukkig is, sal ons op 'n Vrydagaand na 'n restaurant gaan. Maar, op Sondae wil hy net rus voor die volgende werksuitstappie, want hy slaap net vier ure op 'n slag.	If we are lucky, we would go to a restaurant on a Friday night, but on Sundays he just wants to rest for the next work trip because he only sleeps four hours at a time.
	Would you like to spend more time with your dad?	Sal jy daarvan hou om meer tyd saam met jou pa te spandeer?	Ja, gholf en krieket, maar hy [my pa] is baie besig.	Yes, golf and cricket – but he [my dad] is very busy.
	How is that for you?	Hoe ervaar jy dit?	Teleurgesteld, maar ek verstaan hoekom hy so moeg is – a.g.v. sy werk. Hy het dit vir ons verduidelik.	Disappointing but I understand why he is so tired because of his work. He has explained it to us.
	What job would you want to do one day?	Watter tipe werk sal jy eendag wil doen?	Óf 'n boer, óf 'n seviele ingenieur.	Either a farmer or a civil engineer.
21	**Who understands you the best?**	Wie verstaan jou die beste?	My pa, want met dié wat my ouma ook so siek was, kon hulle [oupa en pa] nie alles vir haar doen nie. My oupa het ook weg van die huis gewerk. Dit is dieselfde met my en my pa (hy werk ook weg van die huis).	My father, because with my grandmother who was also ill, they couldn't do everything for her, and my grandfather worked away from home. The same with my dad and me

				(also working away from home).
	So, why would you say he [father] understands you the best?	So, hoekom sê jy dat hy [pa] jou die beste verstaan?	My pa woon nie baie my sportbyeenkomste by nie en dit is ook hoe my oupa met my pa was.	My dad doesn't attend my sport events much and that is how my grandfather was with my dad.
	Say, for example, you had a major problem and you needed to talk to someone about it, who would you talk to?	Sê nou jy het 'n groot probleem en jy het nodig om met iemand daaroor te praat – met wie sal jy daaroor praat?	Ek sal met my nefie praat. Hy is vyftien jaar oud en ons is baie naby aan mekaar.	I would talk to my cousin. He is fifteen years-old and we are very close.
22	**Who cares for you when you feel sick/sad/hungry/ scared?**	Wie sorg vir jou wanneer jy siek/hartseer/honger/ bang voel?	My ma.	My mother.
23	**Tell me a story of a time when you and your family travelled together.**	Vertel vir my van 'n keer toe jy en jou familie iewers heen gegaan het [vir 'n uitstappie].	Dit was vir my OKSH** krieketproewe. My pa, ma en suster het saamgegaan. Maar die lekkerste uitstappie was toe ons Yzerfontein* toe gegaan het. My pa hou nie daarvan om te kuier nie … hy verkies om net rustig by die huis saam met ons te wees. My pa het daardie vakansie baie geniet. Die [see]water daar is baie koud, maar dit is nogsteeds lekker om daar te rond te speel. Dit was lekker, want dit was *family bonding time.*	It was for my OKSH** cricket trials. My father, mother and sister went with me. But the nicest trip was when we went to Yzerfontein*. My father doesn't like to party … he prefers to relax with us at home. My dad enjoyed [that trip] a lot. The water is very cold there, but it is still nice to play there. It was nice because it was

				family bonding time.
24	**Tell me more about your friends.**	Vertel my meer van jou vriende.	Riaan* is net soos ek – hy gee nie om wat ander van hom dink nie. Hy is snaaks. Hy hou daarvan om *squash* te speel. Shaun* is die kind met die grootste kuif wat ek al in my lewe gesien het! Hy is 'n swemmer. Cobus* is 'n "tough guy", byvoorbeeld hy dink hy is die sterkste en so aan. Hy is kort. Ek is vriende met hulle want ek kan op hulle staatmaak en hulle ondersteun my.	Riaan* is just like me – he doesn't care what others think. He is funny. He likes to play squash. Shaun* is the child with the biggest fringe that I have ever seen! He is a swimmer. Cobus* is a "tough guy", for example he thinks that he is the strongest and so forth. He is short. I am friends with them because I can rely on them, and they support me.

Explanation of specific term/s used:

Question 1: 45** and 54** refers to a measurement, in percentage, regarding the functioning of the heart muscle.

Question 4: handicap** refers to a term used to explain one's level of skill in golf.

Question 4 & 18: *Xbox*** is a video gaming brand and respresents a series of video games.

Question 5: *Diabetes*** refers to an illness related to blood-sugar levels.

Question 7 & 14: *touch rugby*** refers to a type of game that involves running and physical touch.

Question 11: *Nedbank Million Dollar Golf Challenge*** refers to an annual golf competition held at Sun City in South Africa, during which professional golf players from around the world compete for one million dollars.

Question 17: *German Shepherd*** refers to a specific breed of dogs.

Question 23: OKSH** is the acronym used for a specific group of cricket trials.

Participant E
Girl, 13 years; Afrikaans
Note:

- The questions reflect the DPM-interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of terms at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**English Translation**	**Researcher**	**Afrikaans**	**English**
1	**Why do you have to go to hospital from time to time?**	Hoekom moet jy van tyd tot tyd hospitaal toe gaan?	Hulle sê daar is 'n gat in my hart en hy is nog nie toe nie.	There is a hole in my heart and the hole is still open.
	Anything else that you want to add?	Enigiets anders wat jy wil bysit?	Nee.	No.
2	**What is happening to your heart now?**	Hoe is jou hart nou?	Die gat gaan nou bietjie toe, want ek drink pille.	The hole in my heart is now busy closing because I take tablets.
	So is it the tablets that cause the hole to start closing up?	So is dit die pille wat maak dat die gat nou begin toegaan?	Dis die pille.	It's the tablets.
	How do you know that it is the tablets?	Hoe weet jy dit is van die pille?	Hulle het vir my ma gesê as ek nie my pille drink nie dan sal die hart nie toegaan nie. Ek moet baie pille drink.	They told my mother that if I don't drink my tablets then the heart will not close. I have to take lots of tablets.
	And how do you feel about your heart? Why?	En hoe voel jy oor jou hart, en hoekom?	Dit maak seer – die kinders koggel my.	It is hurtful – the children tease me.
	Can you give an example?	Kan jy 'n voorbeeld gee?	Hulle sê ek het hartprobleme en koggel my want ek kry 'n "grootmens-*grant*"**.	They say that I have heart problems and they tease me because I receive an "*adult grant*"**.

	What do you do when they do things like that?	Wat maak jy as hulle sulke goed vir jou sê?	Ek gaan sê vir die juffrou, maar sy vat dit nie kop toe nie.	I go and tell the teachers but they don't take it to heart.
	What would you like her to do about it?	Wat sal jy wil hê moet sy vir jou doen?	Sy moet die kinders keer.	She must stop the children.
	How often does it happen that they tease you about your heart?	Hoe gereeld gebeur dit dat hulle vir jou koggel oor jou hart?	So een keer by 'n maand … daar is een kind … hy boelie ons … 'n ander juffrou jaag hom weg, maar hy luister nie vir hulle nie. Hulle sê hy is te laf.	Once a month. There is one child … he bullies us … another teacher chases him but he wouldn't listen to them. They say that he is silly.
3	**And you say that you have to take tablets?**	En jy sê jy moet pille drink?	Ja.	Yes.
	Which tablets?	Watter pille moet jy drink?	Ek ken nie die naam nie.	I don't know the name.
	What do they look like?	Hoe lyk die pille?	Hulle is rond en wit en gesny in die middel.	They are round, white and cut in the middle.
	And you say that you have to take a lot of those tablets? How many?	Jy sê jy moet baie van hulle drink? Hoeveel?	Ja, ek drink ook kleintjies. In die oggend, in die middag en in die aand.	Yes, I also drink small ones. In the morning, afternoon and in the evening.
	Does Mommy give you the tablets to drink, or do you have to remember it yourself?	Gee Mamma vir jou die pille of moet jy self onthou?	Partykeer.	Sometimes.
4	**What do you enjoy doing?**	Wat *like* jy om te doen? Wat is vir jou lekker om te doen?	Om te speel met die kinders. Ons speel *touch***, dan loop ons rond, dan sit ons op die foon onder die boom.	I like to play with the other children such as playing *touch***, to walk around, to sit around and play on the phones with them under the trees.

	Do you have a phone?	Het jy ‘n foon?	Ja, maar hy’s weg. Ek weet nie wie dit gevat het nie.	Yes, but it is gone. I don’t know who took it.
	Will you be able to get another one later?	Sal jy later weer een kan kry?	Mamma sal nie weer een vir my koop nie.	Mommy wouldn’t buy me one again.
	What do you then talk about?	Wanneer julle so gesels, waaroor gesels julle?	Ons praat oor die skool en ons vriende en dis lekker by die skool. En ons praat oor een meisie wat hulle nie *like* nie.	We talk about school and about the other children at school.
	What does she do?	Wat maak sy?	Ek weet nie.	I don’t know.
	What else do you like?	Wat *like* jy nog?	Ek *like* dit om dorp toe te gaan.	I also like to go to town.
5	**Tell me, your family members, are they sick? Healthy?**	Vertel my bietjie, die ander mense in jou familie, is hulle siek? Gesond?	Hulle is gesond. Dis net my ouma wat siek is … sy het suiker [*diabetes*].	They are healthy, except for my grandmother – she has sugar problems [*diabetes*].
	So it’s only you and Granny that are sick?	So dis net jy en Ouma wat siek is?	My ma ook … sy is *diabetic**.	And my mother … she is a diabetic.
6	**How does your heart tell you when you are feeling sick?**	Hoe sê jou hart vir jou as hy nie reg is nie?	Hy klop vinniger. As ek draf (resies) doen by die skool dan klop dit van die binnekant af.	When I do sports, it beats faster and it beats from the inside.
	Are you allowed to do sports?	Mag jy sport doen?	Dokter sê ek moet nie sport doen nie, maar ek moet dit doen want ek moet punte kry by die skool.	The doctor says that I should not do sports but I have to because I have to get marks at school.
	Why don’t you stay in class with the other sick children when the rest has to go and run?	Hoekom bly jy nie in die klas saam met die ander siek kinders as die res moet gaan hardloop nie?	Ek bly meeste van die tyd in die klas … ek hardloop net bietjie.	I stay in the class most of the time and only run a bit.

7	**How do you feel about your ill heart? Tell me more.**	Hoe voel jy oor jou hart wat siek is? Vertel vir my meer.	Ek voel nie lekker nie. Ek voel seer, want hulle sê dis die hartprobleem wat maak dat ek 'n *slow learner* ** by die skool is en druip. Juffrou sê so.	I feel hurt because the teacher says that my heart problem is the reason why I am a *slow learner*** and the reason why I fail [at schoolwork].
	If your heart were healthy, do you think that it would have been better?	As jou hart gesond was, dink jy dit sou beter gegaan het?	Ja.	Yes.
8	**Name some things that you like about yourself.**	Noem 'n paar goed van jouself waarvan jy hou.	Om te speel met die ander kinders, om TV te kyk, om te werk by die huis. Ek werk baie by die huis. Ek kyk mooi na myself. Ek luister wanneer my ma met my praat.	I like to play, watch TV and to do work [chores] around the house. I am an eager worker at home. I look after myself well. I listen to my mother.
9	**Name some things that you don't like about yourself.**	Noem 'n paar goed van jouself wat jy nie *like* nie.	Ek *like* nie dat ek skinder nie of wanneer ek ander kinders afmaak nie.	I don't like it when I gossip and when I put other children down.
10	**What is happening to your heart?**	Wat gaan aan met jou hart?	Ek het twee operasies gehad. Toe hulle die derde wou maak, toe het Mamma gesê sy wil dit nie hê nie, want sy was bang dat ek sou doodgaan. Die tweede keer (operasie) het die dokter gesê ek kan dalk doodgaan. Ek is ook bang.	I have had two operations [for my heart]. When I needed a third operation, Mom refused the operation because she was scared that I might die. I am also scared because at the time of the second operation, the doctor said that I might die during that operation.

11	**If you had three wishes and you could wish anything and it would come true, what would you wish for?**	As jy vir drie goed kon wens wat sal waar word, waarvoor sal jy wens?	Ek sal vir die kind sê om my goed by die huis gaan haal, dan gaan slaap ek by my suster, Lisebo*; sy is 21. My ma wil nie hê ek moet by my suster gaan slaap nie. Ek gaan kuier by haar in die *holidays*. Ek is allenig by die huis. My ander suster, sy is 18, gaan kuier vir Lisebo*. Mamma moet nie my vriende so wegjaag nie … sy sê hulle kom te veel daar. My suster sy is 18, mag doen wat sy wil en Mamma maak niks nie. Oupa vat my kant want ek is sy *favourite*. Mamma sê ek *like* te veel van lê. Mamma moet nie vir my vriende jok as hulle vra of ek by die huis is nie. Mamma slat my te veel en hou daarvan om hoog te sit met ander mense, dat die mense sien alles is *oraait*.	I would send one of the young ones to go and fetch all of my things at home and then I would go and live with my sister, Lisebo,*who is 21. My mother doesn't want me to live with my sister. I visit her during holidays because I feel lonely at home. I have two sisters. My sister who is 18 years old is allowed to go and visit Lisebo*. I would wish that Mom wouldn't chase my friends away in the way that she does now … she says that they visit our place too often. My sister (who is 18) is allowed to do whatever she wants. My grandfather takes my side because I am his favourite. I like to relax and hang around. I wish that my mom wouldn't lie to my friends when they ask if I am at home. Mom gives me hidings and she likes to pretend in front of other people.

12	**What does the doctor say to you?**	Wat sê die dokter vir jou?	Hy vra werk ek reg by die skool? Hy het vir my ‘n brief gegee, maar die brief is nou weg, toe se hulle, hulle sal ander brief skryf dat ek na ‘n ander skool toe gaan. Die dokter vra my drink ek my pille en dan sê ek ja. Hulle vra my of ek moeg raak by die skool en of ek te veel speel want hulle sê my hart klop te veel … hulle kan dit sien.	The doctor asks me whether I do my school work properly and whether I am coping with my school work. He said that he would write a letter for me to be placed in another school. He wrote the letter. But the letter got lost. The doctor also asks me whether I still take my medication then I answer *“yes”*. The doctor also asks me whether I get tired. Then I say when I run I get tired. Then the doctor says that my heartbeat shows that I am very (too) active.
13	**What do Mommy and Daddy say to you? And your grandfather and grandmother?**	Wat sê Mamma en Pappa van jou? En jou oupa en ouma?	Hulle sê ek *like tjommies* en sit en dat ek laf is ... ek doen wat my sussie doen. Pappa stuur nie geld nie, Mamma wil die polisie laat kom. Oupa sê nie ek is laf nie en dat dit net die grotes is wat laf is. Ouma vat ook my part.	They say that I like to be with my friends and to just sit around. They say that I am silly and that I do what my sister does. My dad doesn’t send us money, so my mom wants to get the police involved. My grandfather doesn’t think that I am ; he says it is only the older ones that are silly. My grandmother also takes my side.

14	**What do your sisters say to you?**	Wat sê jou susters vir jou?	Lisebo* sê ek maak haar naar, maar niemand *like* haar nie. Haar vriende sê hulle mag nie so maak nie - so lelik wees met my nie. Sy knou my af. Lisebo* skinder van my by haar vriende oor *"die jong een wat die geld kry"*. Sy sê ook ek laat hom lag.	Lisebo* says that I make her nauseous, but no one likes her. Her friends say that she should not be nasty towards me. Lisebo* gossips to her friends about me – about *"the young one that gets money"*. I also make him laugh.
15	**What do your friends say about you?**	Wat sê jou vriende van jou?	Hulle *like* my en is lief vir my en hulle skinder nie van my nie.	They like me and love me and do not gossip about me.
	What else?	Wat sê hulle nog?	Hulle sê dat ek 'n regte vriend is.	They say that I am a real friend.
	What makes you a real friend?	Wat maak van jou 'n regte vriend?	Ek koop byvoorbeeld vir hulle *chips* en hulle deel ook met my.	I would, for example, buy chips for them. They share with me.
16	**What do your teachers say about you?**	Wat sê die onderwysers van jou?	Hulle sê ek is laf by die skool en ek kan nie skryf nie oor my hart en dat ek te veel van speel hou.	They say that I am silly at school. They say that my heart problem is the reason why I cannot write properly. They say that I like playing too much.
17	**If you could be an animal, what animal would you like to be? Why?**	As jy kan kies om enige dier te wees, watter een sal jy kies en hoekom?	'n *Elephant because* ek hou van dit, hulle maak vir my grappe (laat my lag). 'n Sebra want hulle jaag rond. Ek jaag die grotes uit … enigentyd!	I would like to be an elephant because I like elephants – they make me laugh (I like joking). I would also like to be a zebra because they

				chase the others around – I chase the older ones out … easily!
18	**What are your favourite activities?**	**Waarvan hou jy om te doen?**	Om te kook. Ek bak vleis. En om koeke te maak. Om te gaan leer by my ouma om *vetkoek* te maak. En om buitekant skoon te maak.	I like to cook … I can cook meat. I can also bake cake. I like it when my grandmother teaches me to make, for example, *vetkoek.* I enjoy cleaning the yard.
19	**Name the things that you cannot do because of your heart problem. How is that?**	Noem ‘n paar goed wat jy nie kan doen nie, omdat jou hart siek is. Hoe voel dit?	Ek kan nie op die *spider*** speel nie, want dit maak my duiselig en ek kan nie op die *swing* klim nie … dit is nie lekker nie.	It is not nice that I can’t play on the *spider*** because it makes me dizzy and I can also not play on the swings.
20	**Who looks after you? Tell me more about that person.**	Wie kyk na jou? Vertel my meer van daardie persoon.	My mamma. Sy’s reg … sy baklei vir my dat kinders my nie koggel nie.	Mommy. She’s right … she fights for me so that other children won’t tease me.
21	**Who understands you the best?**	Wie ken en verstaan vir jou die beste?	My ouma … sy weet wat is “waarheid”, sy *like* nie mense wat lieg nie.	My grandmother … she knows what “truth” is and she also doesn’t like people who lie.
22	**Who cares for you when you feel sick/sad/hungry/ scared?**	Wie sorg vir jou wanneer jy siek voel of hartseer voel of honger is of bang is?	My mamma.	My mother.

23	**Tell me a story of a time when you and your family travelled together.**	Vertel my van ‘n keer wat jy en jou familie saam iewers heen gegaan het.	Doringbaai* – ek, my sister, my oupa, mamma, ander kinders en my *auntie.* Ons het geswem, gespeel (*touchies***). Ons het gebraai en pap geëet.	One time, we went to Doringbaai* - me, my sister, my grandfather, mommy, other children and my auntie. We swam and we played (*touch***), we had a barbeque and porridge.
24	**Tell me more about your friends.**		Ons gaan dorp toe dan koop ons vir ons koeldrank dan gaan sit ons by die park en dan gaan ons *mall* toe, speel *games*, sit onder die boom en vat *pictures*. Motle* is my beste beste vriend, van kleins af. Ek *like* dit nie dat my *phone* so weg is nie.	I go to town with my friends … we buy drinks, go to the park and to the mall, we play games and we sit under the tree and take pictures … [but my phone is gone] and I don’t like it. Motle* is my best friend, she likes me. We have been friends since we were little … we are very close.
	Thank you.	Dankie.		

Explanation of specific term/s used:

Question 2: “*Adult grant*”** refers to financial support provided by the government.

Question 4 & 23: *Touch*** or *touchies*** is a game that involves running.

Question 5: *Diabetes*** refers to an illness related to blood-sugar levels.

Question 7: *Slow learner*** is a term commonly used to describe a child with learning difficulties.

Question 19: *Spider*** is a steel-structured game often found in play parks.

Participant F
Boy, 12 years; Afrikaans
Note:

- The questions reflect the DPM-interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of terms at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**English Translation**	**Researcher**	**Afrikaans**	**English**
	Before we begin I would like to know: today was your first day back at school, right? And? How was that for you?	Voor ons begin wil ek eers hoor … vandag was jou eerste dag terug by die skool, nè? En? Hoe was dit vir jou?	Wel, dit was lekkerder as gewoonlik. Vir eens was die kinders vriendeliker met my as gewoonlik.	Well, it was nicer than usual. For once the children were nicer to me than usual.
1	**Why did you have to go to hospital?**	Hoekom moes jy hospitaal toe gaan?	Daar is 'n aar in my hart wat heeltyd verkalk en dit maak die klep swak. Met elke operasie haal hulle die kalk uit en hierdie keer het hulle net 'n *stent*** in gesit.	There is a vein in my heart that constantly calcifies. This makes the valve weak … With each operation, they remove the lime but this time round they [the doctors] put a stent in.
	What is a *stent*?	Wat is 'n *stent*?	Dis so yster dingetjie … eers so klein maar toe hulle dit in my sit toe maak dit oop. Dit is van yster gemaak.	It's a little metal thing … at first it's small but when they inserted it into me it opened. It is made of metal.
	And you say that it weakens the valve. What does "weaken" mean?	En jy sê dit maak die klep swak. Wat beteken	Ek dink die bloeddruk is te laag.	I think the blood pressure is too low.

		"swak"?		
	And what is "calsify"?	En wat is "verkalk"?	Ek weet nie. Dit is heeltyd in een aar wat dit verkalk. Ek weet nie presies nie.	I don't know. It constantly calsifies in one vein. I don't know exactly.
	But you know a lot! Is it dr Smith* who explained it to you so nicely?	Maar jy weet baie, hoor! Is dit dr Smith* wat dit so mooi vir jou verduidelik het?	Ja.	Yes.
2	**Tell me what is going on with your heart.**	Vertel vir my wat met jou hart aangaan.	Daar is 'n aar wat verkalk en dit maak die klep swak want die bloeddruk is te laag.	There is a vein that calcifies and it weakens the valve because the blood pressure is too low.
	I still want to know what "calcify" means.	Ek wil nog steeds weet wat "verkalk" beteken.	Ek weet nie. Hulle praat net heeltyd van my aar wat verkalk.	I don't know. They just constantly talk about my vein that calcifies .
3	**Do you have to take any medication?**	Gebruik jy enige medikasie?	Ja. Ek moes altyd bloeddrukpille drink, maar nou nie meer nie. Verder drink ek *Prosydin***.	Yes. I used to take tablets for blood pressure, but not anymore. Other than that I only drink *Prosydin***.
	What is that [*Prosydin*]?	Wat is dit [*Prosydin*]?	Hulle sê dit word van *Grapeseed Extract* gemaak en dit maak dat hy stadiger verkalk.	They say it's made of grape seed extract and causes the vein to calcify at a slower rate.
	Do you know the name of your heart problem?	Weet jy wat is die naam van die probleem met jou hart?	Nee.	No.

4	**What do you enjoy doing? Tell me more.**	Wat is jou gunsteling aktiwiteite/ dinge om te doen? Vertel my meer.	Ek hou van baie goed. Ek hou van speletjies speel op my foon, met my vriende rondhardloop by die skool en saam met hulle te speel.	I like many things. I like to play games on my phone, to run around with my friends at school and to play with them.
	Such as?	Soos?	Ons speel meestal *Open Gate***.	Mostly, we play *Open Gate***.
	What is that [Open Gate]?	Wat is dit [Open Gate]?	Jy moet aan die ander kant van die rugbyveld kom sonder dat jy ge-*touch* word. As jy daar kom, dan skree hulle: "*Open Gate*!"	You have to get to the other side of the rugby field without anyone touching you. If you get there, then they yell: "*Open Gate*!"
	And what is your favourite electronic game?	En wat is jou gunsteling elektroniese game?	Meestal speel ek op my foon en *Xbox*** – niks anders nie.	I mostly play on my phone and play *Xbox*** – nothing else.
	How often do you play *Xbox*?	Hoe gereeld speel jy *Xbox*?	Nie baie nie, want ek mag nie.	Not a lot because I am not allowed to.
	What else do you enjoy?	Waarvan hou jy nog?	*Sweets*! Verder weet ek nie eintlik nie.	Sweets! Other than that I don't know.
	Do you and your friends spend a lot of time together over weekends?	Kuier of speel jy en jou vriende baie oor naweke by mekaar?	Nee, net by die skool en so een of twee keer in vakansie.	No, only at school and maybe once or twice during holidays.
	So, what do you do over weekends?	So, wat doen jy oor naweke?	Oor naweke speel ek maar op my foon en lê, want daar is niks anders om te doen nie.	During weekends I play on my phone en I lay down because there is nothing else to do.
	And you and your brother?	En jy en jou broer?	Hy wil nie meer speel nie … net op sy foon want hy is nou al groter. Verder jaag hy my uit sy	He doesn't want to play anymore … only on his phone because he is older

			kamer as ek by hom wil wees.	now. Other than that he chases me out of his room when I want to be with him.
5	**Tell me more about the health of your family members?**	Vertel my meer oor die gesondheid van jou familielede.	Almal is nogal gesond. Dit is net my sussie wat so elke nou-en-dan siek word. Verder is alles reg. Partykeer kry sy verkoue. Sy het al twee keer longontsteking gehad.	Everyone is quite healthy. It's only my sister that falls ill every now and then. Other than that, everything is OK. Sometimes she gets the flu. She has had lung infection twice.
6	**How does your heart tell you when you are feeling sick?**	Hoe sê jou hart vir jou wanneer dit siek voel?	Gewoonlik kry ek 'n borspyn of iets en dit gebeur omtrent so partykeer een keer 'n maand.	Usually I would get a pain in my chest or something and it happens about once a month.
	How do you experience that?	Hoe voel dit vir jou?	Nogal seer. [the participant indicates the exact location of pain on heart area]. Partykeer as ek baie hardloop, dan voel dit of my borskas so ruk. Ek dink dis van die baie hardloop, maar nie een van die ander kinders kan dit eers begin sien nie [hoe erg dit is nie]. Gewoonlik wil die kinders my dan kantoor toe vat dat hulle die ambulans bel en alles (die eerste paar kere), maar toe word hulle daaraan gewoond.	It's quite sore. [The participant indicates the exact location of pain on heart area]. Sometimes when I run a lot it would feel as though my chest shakes. I think it is because of all the running, but not one of the other children can see it [how bad it really is]. Usually the children then want to take me to the office so that they can phone the ambulance and so forth (the first few times) but then they got used to it.

	So how will they know? For example, would you say, "Wait, stop!" Or what?	So, hoe sal hulle weet? Bv., sal jy sê: "Wag, stop 'n bietjie." Of hoe?	Ja, gewoonlik met *Open Gate*** gaan sit ek en dan weet hulle, hulle moet my nie kies nie. As ek opstaan, dan kan hulle my maar kies.	Yes, usually with *Open Gate*** I go and sit and then they know that they shouldn't choose me. If I get up, then they can choose me.
	How do you experience the fact that they tend to be so concerned about you and checking to see if you're OK?	Hoe voel dit vir jou as hulle so oor jou is en vra of jy *OK* is?	Eenkeer het hulle my amper kantoor toe gevat (ek het gehardloop en geval), toe was daar so pers kol hier oor my been. Hulle het eers gedink ek het my spier gerek, maar toe het niks eintlik gebeur nie. Sover soos wat ek sien, lyk dit asof hulle omgee vir my, want sover is ek die enigste een wat almal rondom my *crowd* as ek seerkry. Ek dink dis te danke aan die hartprobleem of ietsie.	The one time, they almost took me to the office (I ran and fell), there was this purple spot on my leg. At first they thought that I had pulled a muscle, but nothing actually happened. As far as I know it seems as though they care about me because as far as I know, I am the only one who gets crowded [by other children] when I get injured. I think it is due to the heart problem or something.
7	**How do you feel about your ill heart?**	Hoe voel jy oor die feit dat jou hart siek is?	Ek weet nie eintlik nie. Ek is *OK* daarmee, maar ook nie *OK* daarmee nie. Daar is klompie sporte wat ek so graag wil speel, maar ek mag nie want ek mag nie kontaksport speel nie. Sulke goed waar hulle jou tackle.	I don't really know. I am OK with it but also not OK with it. Tthere are a few sports that I would like to play, but I'm not allowed to play sports that involve physical contact.
	Such as?	Soos?	Rugby. Ons het met karate begin maar toe stop my ma dit.	Rugby. We started with karate but then my mom stopped it .

	Why can't you play that?	Hoekom kan jy dit nie speel nie?	Dr Smith* sê dat die sny op my bors kan oopgaan.	Dr Smith* says that the wound on my chest could open up.
	So, which sports do you play?	So, watter sporte doen jy?	Ek doen maar net een sport waarmee ek gewoonlik in kom en dis krieket.	I only do one sport that I usually get selected for and that is cricket.
	Do you enjoy cricket?	Geniet jy krieket?	Ek geniet dit nogals maar gewoonlik sit hulle my op die *bench* so as iemand beseer word dan kan ek inkom.	I kind of enjoy it but usually they put me on the bench so I only play when someone gets injured.
	And how is that for you?	En, hoe is dit vir jou?	Dit is nogals lekker om te kyk hoe speel hulle, maar ek wil ook partykeer speel, dan kan ek nie.	It is quite fun to watch them play but sometimes I also want to play but then I can't.
	Do you know what the reason is?	Weet jy wat die rede daarvoor is?	Nee.	No.
8	**Name some things that you like about yourself.**	Noem 'n paar dinge van jouself waarvan jy hou.	Ek is nogal trots op hoe aktief ek kan wees en die goeie punte wat ek kan kry by die skool. Daar is een vak waarmee ek nogal sukkel … dis Engels, want as jy een dingetjie mis of een ding verkeerd het dan verloor jy 'n punt. Maar die res doen ek nogal goed.	I am quite proud on how active I can be as well as the good marks that I receive for my schoolwork. There is one subject that I struggle with and that is English because if you miss one little thing or have one thing wrong then you lose that mark. But I do well in the other subjects.

	And regarding how active you are?	En rondom hoe aktief jy is?	Ja. Pouses sê die kinders ek is een van die moeilikstes om te vang met *Open Gate***, maar ek weet nie eintlik hoekom nie. Ek is nie vinnig nie, maar hulle kry my nog steeds nie gevang nie. Ek is nogal goed in Open Gate**. Hulle sê ek *side-step* hulle en ek draai te vinnig vir hulle.	Yes. During break time, the children say that I am one of the most challenging ones to catch when we play *Open Gate***, but I don't really know why. I am not fast, but they still can't catch me. I am quite good at *Open Gate***. They say that I side-step them: I turn too fast for them.
9	**Name some things that you don't like about yourself.**	Noem 'n paar dinge van jouself waarvan jy nie hou nie.	My kortgeid.	The fact that I am short.
	What about being short bothers you?	Wat van dit [om kort te wees] pla jou?	Gewoonlik dan … ek weet nie … ek hou net nie van so kort wees nie.	Usually then … I don't know … I just don't like being so short.
	Is your dad or brother perhaps also short?	Is jou pa of broer ook dalk kort?	Nee, my pa is lank en my boetie is nog langer as my pa.	No, my father is tall, and my brother is even taller than my father.
	Why do you think you are short?	Hoekom dink jy is jy kort?	Ek weet nie. My ma sê een kant van my pa se familie was kort. My oom is amper so lank soos ek. My ma sê dis dalk hoekom.	I don't know. My mother says that my father's side of the family are short people. My uncle is almost as short as me. My mom says that's possibly why [I am short].
	Anything else?	Enigeiets anders?	Ek hou ook nie eintlik van my oogprobleem nie.	Actually, I also don't like my eye-problem.

	Can you tell me a bit more about that?	Kan jy my bietjie meer daarvan vertel?	Uhm … ek kan nog sien, maar ek kan nie vêr sien nie … ek kort ‘n bril om op die bord te sien en om af te skryf en dit.	Uhm … I can still see, but I am near-sighted … I need my glasses to see the blackboard and to copy from the blackboard and so.
	Since when have you had to wear glasses?	Van wanneer af dra jy ‘n bril?	Ek het laasjaar hom gekry, dink ek.	I think I got it last year.
10	**What is happening to your heart?**	Wat is aan die gang met jou hart?	Daar is ‘n aar in die hart wat verkalk dan affekteer dit een van my kleppe.	There is a vein in the heart that is calsifying and affecting my valves.
11	**If you had three wishes and you could wish anything and it would come true, what would you wish for?**	As jy drie wense gehad het wat sou waar word, waarvoor sou jy wens?	Dis ‘n moeilike een … ek kan maar net aan twee dink. Ek wens ek kon – soos wat hulle in Engels sê – *popular* wees by die skool, en ek wens ons kry nie soveel werk by die skool nie.	That’s a tough one … I can only think of two. I wish that I could – as they say in English – be more popular at school, and I wish that I did not get so much school work.
	So quickly tell me … if you were a dictionary and you had to tell someone what the meaning of the word “popular” is, how would you explain it?	So sê gou vir my … as jy ‘n woordeboek was en jy moes vir iemand sê wat *popular* beteken, hoe sal jy dit verduidelik?	Soos as kinders van my hou en my vriend sal wil wees.	Such as when children like me and would want to be my friend.
	What would make you more popular?	Wat sal maak dat jy meer *popular* is?	Ek weet nie.	I don’t know.
	And those children who are more popular than you, what is it that you	En, kinders wat meer *popular* is as jy? Wat van dit	Baie meer kinders hou van hulle.	Many more children like them.

	like?	*like* jy?		
	Why?	Hoekom?	Ek weet nie.	I don't know.
	And the second one … less work at school or less homework?	En die tweede een … minder werk by die skool of minder huiswerk?	Minder as in totaal.	Less of everything in total.
12	**What does the doctor say to you?**	Wat sê die dokter vir jou?	Gewoonlik sê dr Smith* ek lyk beter as wat ek gewoonlik doen.	Usually Dr Smith* would say that I look better than usual.
13	**What do your parents say to you?**	Wat sê jou ouers vir jou?	Hulle sê nie eintlik iets oor dit nie [hoe dit nou gaan].	They don't really say much about that [about how I am at this stage].
	And if you had to guess, what do you think they think of you?	En as jy moet raai, wat dink jy dink hulle van jou?	Ek dink hulle dink dat ek nogal baie beter is as gewoonlik.	I think that they think that I am much better than usual.
	Why?	Hoekom?	My ma sê toe ek nog klein was kon ek net so twee treë vat dan moes ek sit om asem te kry.	My mother says when I was still a baby I would take two steps and would then have to sit down to catch my breath.
	And your father … what does he say about you?	En jou pa … wat sê hy van jou?	Nie eintlik baie nie.	Not much.
	Suppose I were to phone your father and ask him to describe what kind of a child you are, what would he tell me?	En as ek nou jou pa sou bel en vir hom sou vra watter tipe kind jy is, wat sou hy vir my sê?	Ek weet nie.	I don't know.

14	**What do your siblings say to you?**	Wat sê jou suster en broer vir jou?	[Geen respons]	[No response]
	So you said when you enter your brother's room then he chases you out?	So, jy't gesê as jy in boetie se kamer is, dan jaag hy jou uit?	As ek te lank daarbinne is.	If I stay in there too long.
	What would be "too long"?	Wat sal "te lank" wees?	So tien minute.	About ten minutes.
	What would your brother say about you?	Wat sal hy [boetie] van jou sê?	Hy sê ek is irriterend.	He says that I irritate him.
	And your sister?	En sussie?	Sy sê nie veel van my nie … sy's so-so oor my.	She doesn't say much about me … she is so-so with me .
15	**What do your friends say about you?**	Wat sê jou vriende vir jou?	Ek weet nie eintlik wat sê hulle van my nie.	I don't really know what they say about me.
	What do you think do they say or think about you?	Wat dink jy sê of dink hulle van jou?	Partykeer sê hulle ek is vriendelik en dit, maar nie nog iets nie.	Sometimes they say that I am friendly but not much else.
16	**What do your teachers say about you?**	Wat sê jou onderwysers vir jou?	In elke klas dink ek is dit ietsie anders.	I think it is different in each class.
	Let's then take your favourite teacher and your least favourite teacher … what would they say about you?	Kom ons vat dan jou *favourite* juffrou en jou minste *favourite* juffrou … wat sê hulle van jou?	Ek is bly my minste *favourite* juffrou het ek nie meer by klas nie ... dit was verlede jaar … en hierdie jaar is my gunsteling 'n meneer … hy sê nogals ek's aktief en ek konsentreer op my werk.	I am glad that my least favourite teacher don't teach me anymore … that was last year … and this year my favourite teacher is a male … he says that I am quite active and that I

				concentrate on my work.
	And one other teacher?	En nog een ander onderwyser?	Haar opinie van almal is maar dieselfde … sy sê sy's baie lief vir kinders, maar dit lyk regtig nie so nie. Sy's die een wat kinders van hulle stoele afgooi met 'n borsel. Niemand hou van haar nie en is bietjie bang vir haar. Sy het al haar stok op 'n kind gebreek. Verder is daar nog een onderwyser wat kwaai is, maar sy's half vriendelik … sy is net kwaai om jou in toom te hou. Sy slaan nie aan iemand of iets nie … sy bel jou ouers.	Her opinion is the same for all the children … she says that she loves children but it really doesn't show. She's the one who throws board brushes at children and then they fall off their chairs. No one likes her and is a bit scared of her. Once she broke a stick on a child. Furthermore, there is one other teacher who is harsh but fairly friendly … she is only harsh to keep you focused. She doesn't hit you or anything like that … she phones your parents.
	What would she say about you?	Wat sal sy van jou sê?	Ek is so-so by haar. Sy is partykeer kwaai met my en partykeer vriendelik met my … so in die middel.	I am so-so with her. Sometimes she is harsh with me and sometimes she is friendly … somewhere in the middle.
	Can you give me an example of when she would be angry towards you?	Kan jy vir my 'n voorbeeld gee van wanneer sy kwaai is met jou?	Sy's kwaai as jy die kleinste stukkie huiswerk uitgelos het, soos een vraag. Maar sy skree ten minste nie. Die enigste klas wat hulle nie skree nie is die vêrste klas – dit is my gunsteling klas.	She is harsh when you had left out the smallest piece of homework, such as one question. But at least she doesn't yell. The only class in which they don't yell is the one that is

				furthest away – that is my favourite class.
	In general, what do you think of your teachers?	Oor die algemeen … wat dink jy van jou onderwysers?	Daar is goeies en slegtes.	There are good ones and bad ones.
	How do you feel about going to high school?	Hoe voel jy daaroor om hoërskool toe te gaan?	My boetie sê dis baie lekkerder as die laerskool, so ek is half opgewonde.	My brother says that it is much more fun than primary school so I am sort of excited.
17	**If you could be an animal, what animal would you like to be? Why?**	As jy kon kies om enige dier te wees, watter dier sal jy wil wees? Hoekom?	Ek wil sê 'n vis, maar een ding pas nie by 'n vis nie, want gewoonlik is visse nie te vining nie maar hulle is so-so. Dis half soos ek en hulle … ek weet nou nie hoe om dit uit te spreek nie … hy meng in saam met die ander.	I want to say a fish, but there is one thing that doesn't fit with a fish and that is that they are usually not that fast and that is the same as me … I don't know how to put it … it fits in with the rest.
	What allows him to be able to fit in?	Wat maak dat hy kan inmeng?	Ek weet nie, ek weet net dat ek sien altyd visse dan swem hulle so baie saam.	I don't know. I do know that I see that fish always swim together.
	Do you feel like you're fitting in or do you want to fit in more or what would you say?	Voel dit vir jou of jy inpas of wil jy meer inpas of hoe?	Ek pas in, maar ek wil meer inpas.	I do fit in but I want to fit in more.
	So if we consider a school of fish … where do you swim?	So as dit 'n skool visse is … waar swem jy?	Omtrent hierso rond [deelnemer wys op die prentjie na die agterste deel van die skool visse].	Somewhere around here [shows on picture in the back bundle of the school of fish].

18	**What are your favourite activities?**	Wat is jou gunsteling aktiwiteite?	Dis mos speletjies speel, aktief wees, saam met vriende speel en gesels met my vriende.	It's playing games, to be active, and to talk to and play with my friends.
	What do you and your family do together that you enjoy?	Wat doen julle as gesin saam wat lekker is vir jou?	Nie baie goed nie. Net besig by die huis.	Not much. Only busy at home.
	And what is your favourite Xbox** game?	En wat is jou gunsteling *Xbox*** game?	'n Kar-*game*. Sy naam is *Need for Speed Rivals*. Daar's nog 'n *game* wat ek wil hê … my nefie het hom, maar ek mag hom nie kry nie, want hy is 18 [beperk].	A car game. Its name is *Need for Speed Rivals.* There's another game that I want, but I am not allowed to have it because it is rated 18.
	And do you perform in *Need for Speed*?	En hoe doen jy in *Need for Speed*?	So-so, maar daai [ander] *game* … my nefie sê jy *fight* vir die wat nie hulleself kan beskerm nie, maar die naam klink half nie so nie … dis *Assasins Creed* … hulle is *assasins* en dan beskerm hulle die mense … in Afrikaans is dit die tempeliere.	So-so, but that other game … my cousin says it's about fighting for those who cannot fight for themselves even though the name doesn't sound like that … it's *Assasins Creed* … they are assasins and they protect the people … in Afrikaans they are called *tempeliere.*
	So, what is an assassin?	So, wat is 'n *assassin*?	Jy maak mense dood. Daar [in die *game*] betaal hulle jou nie om 'n sekere person dood te maak nie … kom ons sê julle is *Batman*: Julle is in die skaduwees en julle word so min as moontlik gesien en as julle mense sien wat ander mense seermaak wat dit nie	You kill people. There [in the game]; they don't pay you to kill people … let's say you are *Batman*: You are in the shadows and you are seen as little as possible and when you see people

			verdien nie, dan stap julle in. Julle is ‘n geheime groep … *The creed* … julle is ‘n klein groepie teen ‘n klompie koninkryke wat *evil* is. Op daai een is dit mense wou nie die belasting wat hoër is betaal nie, toe begin hulle die mense skiet en nou veg julle teen hulle.	who hurt other people who don’t deserve it then you step in. You are in a secret group … *The creed* … you are a small group against quite a few kingdoms that are evil. In that one specific version it is about people who refused to pay the higher taxes and then they started to shoot people and now you fight against them.
19	**Name the things that you cannot do because of your heart problem.**	Noem die dinge wat jy nie kan doen nie as gevolg van jou hartprobleem.	Rugby.	Rugby.
	Does it bother you?	Pla dit jou?	Nie eintlik nie. Ek wil rugby speel, maar ek weet ek kan nie en ek glo nie ek sal so goed daarin doen nie.	Not really. I want to play rugby but I know that I can’t so I don’t think that I would be good at it.
	Why not?	Hoekom nie?	Die kinders sê ek sal goed wees met die hardloop – nie met die *tackle* nie.	The children say that I will be good with the running – not with tackling.
	When you think about the fact that you will never be able to play rugby, what feeling do you experience?	As jy nou dink aan die feit dat jy nooit sal kan rugby speel nie, wat se gevoel kom by jou op?	Ek’s nie hartseer nie, maar ek’s ook nie bly nie … ek weet nie hoe om dit te verduidelik nie.	I’m not sad but I’m also not happy … I don’t know how to explain it.

20	**Who looks after you? Tell me more about that person.**	Wie sorg vir jou? Vertel my meer van daardie persoon.	My ouers.	My parents.
	Can you describe Mom in a few sentences?	Kan jy vir Mamma beskryf in ‘n paar sinne?	Sy’s vriendelik, maar jy moet haar nie “*rev*”** nie, anders kan sy moeilik wees en sy is nie ‘n ma wat jou sommer by die huis laat bly as dit skool is nie.	She is friendly but you shouldn’t “rev”** her because then she can get difficult and she is also not a mother who will let you stay home and not go to school.
	What “revs” Mom?	Wat “*rev*” vir Mamma op?	As sy vir jou ‘n werk gee en jy gaan doen dit nie onmiddellik nie of as sy ‘n oproep van die skool kry dat ietsie fout is, so iets	If she gives you a task and you don’t go and do it immediately or when she receives a call from school that something is maybe wrong, stuff like that.
	Has it happened in the past that the school phoned Mom?	Het dit al met jou gebeur dat die skool vir Mamma gebel het?	Een keer.	Once.
	What happened?	Wat het gebeur?	My boeke het agter geraak en so ver ek probeer inhaal het en so ver ek [boeke] geleen het, wou hulle [die kinders] dit onmiddellik terug hê, want dan gee die onderwyser nog werk en toe word ek te ver agter.	I fell behind with my books and the more I tried to catch up by lending others’ books, they wanted it back again and the teacher just gave more work and then I fell way behind.
	Why were your books behind?	Hoekom was jou boeke agter?	Dit was die Engels. Sy [die juffrou] gee omtrent so drie bladsye werk vir	It was in English. She [the teacher] gives about three

			‘n periode. Sy *check* nie elke dag ons boeke nie – daar is party dae wat sy te besig is. Die laaste ruk wat ek by die hospitaal was, het sy ietsie nuuts begin … sy is nou vriendelik met my vandat ek terug is van die operasie af en sy sê sy verskoon my en more moet die boeke in en ek’s ‘n week agter.	pages of homework during one class period. She doesn’t check our books everyday – there are days when she is too busy. Recently, when I was at hospital, she started a new thing. She is friendly with me since I came back from the operation. She says that she pardons me regarding school work even though the books need to be handed in tomorrow and I am a week behind.
	What now? What is the plan? How are you going to catch up the work?	So wat nou? Wat is die plan? Hoe gaan jy die werk inhaal?	Ek weet regtig nie, want more gaan ek nie die boek by die kinders kan kry nie, want dis by juffrou. Sy sê ek moet dit net verkieslik voor volgende week Maandag ingee. Ek dink my niggie gaan fotostate maak, maar ek weet nie.	I don’t really know, because tomorrow I won’t be able to borrow books from the other children seeing that it will be with the teacher. She said I should just hand it in by next week Monday. I think my cousin will make photocopies but I don’t know.
	Is your cousin in your class?	Is jou niggie in jou klas?	Ja, maar ek weet nie hoe ons bymekaar pas nie: Sy is langer as ek en sy’s altyd [nommer] een of twee in die graad en ja, ek is ook nogal goed, maar ek kom nooit in die top tien eers nie. En gewoonlik het sy baie	Yes, but I don’t know how we fit together: She is taller than me and she is usually number one or two in the class. I am also good but I never even reach

			meer vriende as ek. Ons is teenoorgesteldes, maar ons kom baie goed oor die weg … ons is vriende.	top ten. And usually she has much more friends than me. We are opposites but get along very well … we are friends.
	So when you think about your book that is behind, how does it make you feel?	So, as jy dink aan jou boek wat so agter is, hoe laat dit jou voel?	Bietjie *nervous*. Ek het eers gedink ek moet die hele week se werk vandag inhandig – toe begin ek eers stres, want ek dink ons is in een week dertien periodes by haar en op die minste, gee sy twee bladsye per periode. Toe begin ek wonder hoe ek alles vandag gaan regkry en ek het nog ander huiswerk ook.	A bit nervous, At first I thought that I had to hand in the entire week's work today – then I started to stress because I think in one week, we see that teacher for thirteen class periods and at the very least she will give two pages of work during each period. Then I started to wonder how I am going to have everything ready for today and I have other homework as well.
	How often do you have to miss school to visit the doctor?	Hoe gereeld is dit wat jy skool moet mis om die dokter te gaan sien?	Gewoonlik elke ses maande.	Usually every six months.
21	**Who understands you the best?**	Wie verstaan jou die beste?	Ek dink my niggie.	I think my cousin.
	So, when you have a problem and you urgently have to talk to someone about it, who would you go to?	So, as jy 'n probleem het en jy moet dringend met iemand praat, na wie toe sal jy gaan?	Gewoonlik na haar toe.	Usually to her.

	How so?	Hoe so?	Ons praat maar baie in die klas wanneer ons kan, want as gevolg van die register wat ons alfabeties moet sit, sit ons in baie klasse langs mekaar.	We talk a lot in class when we can because due to the reason that we are alphabetically seated, we sit next to each other in many of the classes.
22	**Who cares for you when you feel sick/sad/hungry/scared?**	Wie sorg vir jou wanneer jy siek/hartseer/honger/bang voel?	Hang af watse gevoel dit is. Vir hongerte is dit gewoonlik my ma. Vir bang, praat my niggie en my vriende met my baie. Hartseer praat ek gewoonlik net met my niggie. Siek gewoonlik ook met my ma.	It depends on what the feeling is. For hunger, it is usually my mother. For feeling scared my cousin and friends would talk to me a lot. For sadness I usually only talk to my cousin. For feeling sick, usually also with my mother.
	This story regarding your heart … what is your feeling about it?	Die hart-storie van jou … wat is jou gevoel rondom dit?	Ek weet nie eintlik nie. Gewoonlik is ek *fine* daarmee, maar ek's half kwaad omdat ek nie kan rugby speel en *tackle* nie.	I don't really know. Usually I am fine with it but I am kind of angry because of the fact that I cannot play rugby and cannot tackle.
	And then, how do you deal with it?	En dan, hoe hanteer jy dit?	Ek begin net aan ietsie anders dan dink.	I just start to think of something else.
23	**Tell me a story of a time when you and your family travelled together.**	Vertel vir my van 'n keer toe jy en jou familie iewers heen gegaan het [vir 'n uitstappie].	Een van die lekkerstes was, ons het Johannesburg* toe gegaan om by my nefie te gaan kuier. Ek dink ons was daar vir ses dae en binne die ses dae was ons na 'n museum toe, die dieretuin toe en akwarium toe.	One of the best times were when we visited my cousin in Johannesburg*. I think we were there for six days and during the six days we visited a museum, the zoo and an aquarium.

	Which museum?	Watter museum?	Ek ken nie sy naam nie, maar hy het geskiedenis. As jy instap is daar so groot olifant-beeld en buitekant is daar so beelde van *dinosaurs*, maar nie hulleself nie - hulle bene.	I don't know its name but it is about history. When you walk in, there is a big elephant statue and outside there are dinosaurs – their bones.
	When was this?	Wanneer was dit gewees?	Ek dink twee jaar terug … almal [was saam].	I think two years ago … everyone [went with].
	What was the highlight of that week for you?	Wat was vir jou die hoogtepunt van daardie week?	Die akwarium.	The aquarium.
	How so?	Hoe so?	Daar was baie visse wat ek nog nooit gesien het nie en die enigste ding wat ek nie van hom [die vakansie] hou nie is dat dit te vining verbygegaan het.	There were fish that I have never seen before and the only thing that I didn't like [about the trip] is that it went by too quickly.
	Where do you usually go during December?	Waarheen gaan julle gewoonlik in Desembers?	Partykeer gaan ons … ons moet elke Desember Pretoria* toe gaan … dis of die Desember of die Januarie … of ons gaan rivier toe (amper elke keer 'n ander een!) of ons gaan kuier by die familie.	Sometimes we go … we have to go to Pretoria* every December … it's either December or January … or we go to the river (almost every time a different one!) or we go and visit the family.
24	**Tell me more about your friends**	Vertel vir my meer van jou vriende.	Party van hulle kan ek na toe draai as ek in die moeilikheid is en dit, maar party … ek vertrou hulle, maar eintlik vertrou ek hulle nie eintlik nie.	I can turn to some of them when I am in trouble but some … I trust them but also actually don't trust them.

	Is there someone that you would say is your best friend?	Het jy iemand wat jy sal sê jou beste vriend is?	Ja, maar ek is meer vriende met almal.	Yes but I am more friends with everyone.
	Like the fish swimming in the group … who is friends with this one and that one?	Soos die vis wat in die bondel swem … wat vriende is met hierdie en daardie een?	Ek's reg daarmee. Ek het omtrent drie wat soos beste vriende is: Johan*, Ruan* en Edward*. Johan* is een van die enigste vriende wat ek het wat nie goed doen nie [met skoolwerk], maar ek kan sy probleem verstaan: Sy ouers het geskei en dis net hy, sy ma en sy boetie en dan moet hy by die huis help en sy skoolwerk *juggle* en alles. Maar al verskil wat ek begin sien het is vandat meneer Engelbrecht* hom langs my gesit het om hom te help met sy Wiskunde, maar verder niks.	I'm fine with it. I have about three who are like best friends to me: Johan*, Ruan* and Edward*. Johan* is almost the only one of my friends who struggles with his school work. But I can understand his problem: His parents got divorced and it's now only him, his mother and his brother and so he has to help at home and he has to juggle that with his school work and so forth. However, I have started to notice a difference ever since Mr Engelbrecht* put him next to me in the Math class but other than that, nothing.
	So, since you have started to support him with the Maths he is doing better?	So, vandat jy hom bietjie support met die Wiskunde doen hy beter?	Ja, van die somme verstaan hy net nie. As hy dit eers snap dan doen hy goed. Ek dink sy gewone gemiddeld is agt-en-vyftig [persent] en laas kwartaal was sy Wiskunde twee-en-vyftig [persent] en nou's dit agt-en-sewentig [persent]. Ek dink nou's sy gemiddeld van agt-en-	Yes, some of the Math he just doesn't understand. Once he grasped it then does well. I think his usual average is fifty-eight [percent] and for the last quarter it increased to fifty-two [percent] and

			vyftig [persent] af na een-en-sewentig [persent] toe.	now it is seventy-eight [percent]. I think his average increased from fifty-eight [percent] to seventy-one [percent].
	How long have you been friends?	Hoe lank is julle al vriende?	Omtrent so vir vier jaar, maar met Edward* is ek al die langste vriende – van kleuterskool af.	About four years, but I have been friends with Edward* for the longest time – since creche
	What is the reason for still having the same type of friendship?	Wat is die rede dat julle nog steeds die dieselfde vriendskap het?	Ons hou daarvan om mekaar besig te hou en te gesels en dit. Al probleem wat ek nou het, is ander vriende begin nou inskop, nou kry hy net tyd vir ander kinders, want hulle wil die heeltyd met hom wees en dit.	We like to keep each other busy by talking and so forth. I have one problem though – other friends are starting to interfere and now he only has time for other children because they want to be with him all the time.
	How so?	Hoe so?	Ek weet nie. Dis die graad sessies, want dit het so met my niggie ook gewerk: Sy het al hoe meer met leerlingraad gekom, want hierdie jaar is die verkiesing vir leerlingraad.	I don't know. It is the grade sixes because the same thing happened with my cousin: She hung around more with prefects because this year is prefect selection.
	So you are saying that you feel a bit neglected because of her friendships with other children?	So sê jy dat jy bietjie afgeskeep voel omdat sy meer met ander kinders kuier?	Ja, maar my niggie … ek dink nie sy het laasjaar begin nie … met party van hulle was sy al van graad drie af vriende.	Yes, but my cousin … I don't think that she started that last year … with some of them she has been friends since Grade 3.

	And Ruan*?	En Ruan*?	Ruan* … hy kan irriterend wees, maar hy is ook nogals ‘n goeie vriend.	Ruan* … he can be irritating even though he is quite a good friend.
	What makes him a good friend?	Wat maak hom ‘n goeie vriend?	Hy luister altyd as jy praat en hy probeer jou help as jy iets het waaroor jy stres.	He listens to you when you talk to him and he tries to help you when you have something that you are stressed about.
	We are done now, thank you. I just want to ask one more thing: When you heard that you have to go for another operation, how did you feel?	Ons is nou klaar, dankie. Ek wil net gou nog iets vra: toe jy nou hoor jy moet weer vir ‘n operasie gaan, hoe het jy gevoel?	Ek het effens gestres, maar ek was ook half minder bang as gewoonweg, want ek het geweet hulle hoef nie weer oop te sny nie.	I was quite stressed but I was also less scared than the previous time because I knew that they weren’t going to cut me open again.

Explanations of specific terms used:

Question 1: ** A *stent* is a medical device that keeps a tubular structure, in this case the heart valve, open.

Question 3: ** *Prosydin* is an anti-oxident that consists of high-quality grapeseed extract, vitamin E and vitamin C. It improves blood circulation.

Question 4, 6 & 8: ** *Open Gate* is a game that involves running and preventing members of the opposite team to reach a certain place on the demarcated area where the game is played.

Question 4 & 18: ** *Xbox* is a video gaming brand and respresents a series of video games.

Question 20: ** *“rev”* is derived from the word *revolution* and is often used to describe a person who becomes increasingly upset – similar to the increasing revolutions of a running motor engin.

Participant G
Girl, 12 years; Sesotho
Note:

- As explained in chapter 5 (see section 5.2), Participant G was included in the study, even though she meets an exclusion criteria (diagnosed with HIV/AIDS).
- The questions reflect the DPM-interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of terms at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**Researcher**	**Translator**	**Sesotho**	**English**
1	**Why do you have to come to the hospital from time to time?**	Hobaneng nako le nako o tlameha hore o sepetlele mona?	Mohlena le mohlena ha ke tla sepatala ke tlameha ho tlo sheba hore na pelo yaka e ntse e ya hantle hobane nna ke hlokomela pelo yaka. Ke a tseba hore ke na le bothata le sekolong ha bana ba sekolo ba batla ho nkotla moo ke nang le bothata ba pelo ke re aa ska nkotla moo.	I have to come to the hospital from time to time because I have to know how I am doing with regard to the problem of my heart. And I take care of my heart very well and even at school when I play with other learners and they want to hit me somewhere on my body where I know I have a heart problem I say, "No, don't hit me there." because I know that I have a heart problem. So I try by all means to protect my heart.
2	**Tell me, what is going on with your heart?**	Bothata ke eng hantle ntle ka pelo ya hao?	Pelo yaka e na le lesoba jwale ba nkile ntho enngwe ekare umbrella so ba be ba e Kenya moo.	My heart has a hole in it, so they took something like an umbrella to close it up.
3	**Do you have to take any medication? Why?**	Ho na le meriana e fe ka e fe eo o tlamehang ho e	Ke nwa *Disprins*. Ba mpha *Disprins* feela.	I take *Disprin*. They gave me *Disprin* only.

		nwa?		
	Okay, so what does the *Disprins* do? Why do you think they gave you the *Disprins*?	Ha o nahana hobaneng ba o neha *Disprins*? O nahana hore e etsang kapa e o thusa jwang?	Ba itse e tlo nthusa ho lesoba lena mona ba kentseng ntho ena hore le kwalehe ene le ntse le kwaleha hanyane hanyane.	The *Disprins* actually help with regard to the wound to be closed. I can see that the wound is closing up little by little.
	When did they do that operation?	Ba e entse neng operation eo?	11 September.	11 September.
	Last year?	-	***	Yes.
4	**What do you enjoy doing?**	ke eng seo o thabelang ho se etsa?	*******	I like to play with my sister.
	Oh,you have a sister?	-	*Yes*, ke nna a moholo ha rona.	Yes, I am the eldest at home.
	What else?	Ke eng hape?	***	I like to play with my friends and go to the shops and talk about stuff of school.
	And what stuff at school do you usually talk about?	Ke mofuta o few a dintho tsa sekolo tseo le hlolang le bua ka tsona?	***	Maths, Geography and History.
	Oh..so you talk about the subjects at school?	Oh..le bua ka mosebetsi wa sekolo?	***	Yes.
	Are your friends also clever? Because you look like a clever girl.	Metswalle ya hao le yona e hlalefile na, hobane o bonahala o le ngwanana ya hlalefileng?	***	Yes.

	What else do you like to do that is really fun?	Ke eng enngwe eo o thabelang ho e etsa?	Ke rata ho bua le mme waka haholo. A be a mpotsa hore na ke phetse jwang le hore sekolong ke ntse ke ya jwang ... le ntate waka ke rata ho bua le yena.	I like to talk to my mother and tell her how I feel about my heart. I love to talk to my mother mostly because we talk about what happened at school. I enjoy talking to my mother. My father as well.
	Do you have other siblings?	O na le bana beno ba bang?	Aa.	Yes.
	It's you and your younger sister?	-	***	Yes ... Lebohang*.
	But I am confused because in the picture you drew you said that the mother of this girl (Whitney) is dead.	Ke iphumana ke lahlea jwale..o itse mme wa Whitney oo o mo drawyileng moo o hlokahetse.	Akere ke bua story.	I was just making up a story.
5	**OK, thank you. Is your family healthy or do they have problems with their health?**	Ho lokile. Ke a leboha. Ba lelapa leno ba phetse hantle kapa ba na le bothata le bona ba ho kula?	***	My mother and father have problems; they have *HIV* and I also have *HIV* and my grandmother had *HIV*. My grandfather died on 28 February the year before last and had high blood, he didn't have *HIV*.
	And Lebohang*?	-	***	Lebogang* is healthy.
	How old is Lebogang*?	Lebogang* o na le lemo tse kae?	***	Six years.
	Is she in school yet?	-	***	Yes.

6	**How does your heart tell you when you are feeling sick?**	Pelo ya hao e o tsebisa jwang hore o a kula? O utlwa ka eng hore pelo ya hao e na le bothata?	*Sometimes* ke ntho ekareng lehlaba ntho tse ka reng dinalete di a o hlaba, mme waka ke be ke mo bolella hore mama pelo yaka e ba bohloko a be a re o sure ke pelo be ke re eya ke sure.	It is a strong pain on my heart. Something like the nails when they are stabbing you ... that kind of pain and I would tell Mom that I have this severe pain and my mother would ask if I am sure its my heart and I would say, “Yes, I am sure.”
	How often do you feel that pain?	Bohloko bona bo tla neng ... lehlaba lena le tla ha kae ... mohlomong ha nngwe bekeng kapa ka kgwedi..ha kae?	Ha nngwe ka beke. *Nou* ha le ntshware nix ha ke tsebe le ntshwara ha ho etsahetse eng.	Once a week. But recently I have not experienced this pain.
	Is it after the operation that it is better?	-	Pele ho *operation* ha ne ke bapala le bana ba bang ne ke kgathala ka pele. Ha ke ne ke matha ne ke fufullelwa nou ke matha ho fihlella. Ke a kgona sfapano.	Yes. I am much better. After the operation, I am much better.
	And you play netball?	-	-	Yes.
7	**How do you feel about your ill heart?**	O ikutlwa jwang ka pelo ya hao e kulang kapa bothata ba hao ba pelo?	Ha ke ikutlwe ke le terrible. Ke ikutlwa ke le hantle. Ha ke itshwabele le ho itshwabela. *When I was a child* ne ke kula ke hore ke kula haholo mme waka a sa tsebe hore na ke eng.	I feel much better. I don’t feel terrible at all. I feel good. I am not even ashamed at all. Because when I was a child I used to be sick regularly and my mother did not know what was wrong.
	Before the operation when you used to get	Pele ho operation ha o ne o ntse o kula	Bana ba bang ba ne ba ntsheha ba sa batle ke dule pela bona mme	It was hurtful because other children laughed at me and did not want me

	sick a lot. How did you feel then?	haholo. Teng o ne o ikutlwa jwang?	ntho eo e ne e nkutlwisa bohloko.	to sit next to them. So it was painful.
	Because of the heart?	-	***	Yes.
8	**I want you to name things about yourself that you like ... things about you that you are proud of?**	Re kopa o re jwetse dintho tseo o di ratang ka wena ... dintho ka wena tseo o leng motlotlo ka tsona?	Nka nna ka bua le ka ntate waka?	Can I also talk about my dad?
	Yes, of course.	Eya o ka etsa jwalo.	Ntate waka wa nsupporta o a nrata wa nhlokomela le mme waka. Le hore ngwaneso o mpitsa ausi wa hae. Ke ntho eo ke e ratang eo. Le hore hape nna ke etsa mosebetsi wa ka wa sekolo ke yona ntho eo ke e ratang ka bophelo ba ka eo.	My parents love and support me and are always by my side. And my little sister always call me “my sister” so I feel very proud that I am her sister. And what I pride myself in is that I do my school work. When I grow up I want to be a doctor.
	And you said when you grow up you want to be a doctor? So it’s something you take pride in already?	-	***	Yes.
	Why do you want to be a doctor?	Hobaneng o batla ho ba ngaka?	Hobane ke bone hore didoctor di nthusitse haholo. Ha ntse ke hola ne ke batla ho ba leponesa jwale ha ntse ke hola ka bona hore didoctor di important. Ntate waka a re ho bua nnete feela didoctor di savile bophelo ba hao.	Because I saw that the doctors are the ones who helped me a lot. When I was still a child I wanted to be a policewoman but now, growing up, I see that doctors are important. My father says, “The truth is that doctors saved your life.

	When did they find out about your heart problem?	Ba thotse neng ka bothata ba hao ba pelo?	Ha ne ke ile *Pelonomi* ba sa e bone ntse ba re letshwafo yaka e nyane. Ha ne ke fihla mona ba re aa ngwana ona letshwafo la hae ha le lenyane empa feela e le pelo ya hae e nang le lesoba ke ha fihla Doctor a re re tlameha ho e etsa *operation* ho kwala lesoba leo.	When I went to *Pelonomi* they told me that I had a lung problem. They said that my lung was too small and when I arrived here at the hospital, they said that I do not have a small lung – the problem is that there is a hole in my heart. And then the doctor said that it is supposed to be operated and closed.
	And when was this?	Sena se ne se le neng?	Ka *march* laboraro ka di 29 selemo se fitileng.	29th of March last year. It was on a Wednesday.
9	**Name some things that you don't like about yourself. Things that you are not proud of.**	Nehelana ka dintho tseo o sa di rateng ka wena. Dintho tseo o seng motlotlo ka tsona.	Moriri wa ka.	My hair.
	What about your hair?	Ke eng ka moriri wa hao?	Ke batla ho o kuta moriri waka. Ha ke o rate.	I want to cut my hair. I don't like it.
	Why do you want to cut your hair?	Hobaneng o batla ho kuta moriri wa hao?	***	Mom doesn't want me to cut my hair because it's winter.
	And why do you think that Mom doesn't want you to cut your hair?	Hobaneng ha o nahana hore mama hobaneng a sa batle hore o kute moriri wa hao?	Mme waka o rata ho judga batho.	My mom likes to judge people.
	What is wrong with cutting it short then?	Ke eng se phoso ka ho kuta?	Nna ke a batla ho o kuta mme waka ha a batle.	I do want to cut it but my mother doesn't want me to.
	OK, what else?	Ho lokile, ke eng ho hong?	Ngwanarona o rata ho nshapa ene nna ha ke	My little sister likes beating me and I don't

			rate ho shapuwa . Ha ke mo otla mme waka a be a mo thusetsa ene nna ntho eo ya ntena eo ha ke e rate ... ke yona ntho eo ke sa e rateng.	like that. When I want to hit her back my mother reprimands me. That is what I don't like.
	How does that make you feel?	Sena se o etsa o ikutlwe jwang?	***	I feel bad.
	Tell me a bit more. It feels bad, how?	Ho ntse ho thwe Lebohang* o monyane mara yena ha a nkotla mona ha a monyane.	***	They keep saying that Lebohang* is the youngest but when she hits me she is not young anymore.
	And you say your mom likes to judge people?	-	***	Yes.
	Can you give me and example?	O ka mpha mohlala wa seo?	*When I wash the dishes she will tell me not like this but like that and I do not like that****. And I say**** mama ntlohelle hl eke hlatswe dijana. O rata ho judga batho wa ntena mme waka hle.	My mother will keep on saying "You can't do dishes like this ... you will have to do them this way." and I don't like that. And I would tell her: "Mom, please leave me alone so that I can do the dishes."
	Is it the same with your hair? She wants it to be this way and you want it to be that way?	Ekaba ke ntho e tshwanang le ka moriri wa hao? Yena oo batla o be ka tsela e itseng ene wena o o batla ka tsela e itseng?	Eya.	Yes.
	Anything else that you don't like about yourself?	Ekaba ho na le ntho enngwe eo o sa e rateng ka wena?	***	No.

10	**Quickly tell me, what is happening with your heart now?**	Re jwetse heh ho etsahala eng ka pelo ya hao ha jwale?	***	It's beating well, I can run now because I have been operated and I can do a lot of things.
	Is your heart fixed?	Pelo ya hao e lokisitswe?	Eya.	Yes.
	Does it work the same way as any other child of your age?	E sebetsa ka tsela e tshwanang le ngwana a dilemong tsa hao?	***	Yes.
11	**If you had three wishes and you could wish anything and it would come true, what would you wish for?**	Ha ne o na le ditabatabelo tse tharo ... dintho tseo o ne o ka di labalabela ho be ho kgonahala hore di etsahale, e ne e tla ba difeng?	Ke batla ho etsetsa mme waka ntlo e kgolo, ke mo ahele ntlo hobane ke yena le ntate wa ka ba nthusitseng hore ke fihle ke le mona. Ho ja e se ka bona ekaba ke le siyo lefatsheng.	I want to build my parents a big house because it's because of them that I am here on earth. They are the ones who brought me here so if it was not because of them, I would not be here.
	And if you are a doctor one day you will be able to build them a big house.	Ha o se o le ngaka ka leleng la matsatsi o ka kgona ho ba ahela ntlo eo e kgolo.	Eya. *I want to have money so I can**** ke ba rekele dijo something like that, ke batla nkgono waka ha a hlokahala be ke se ke le moholo ... ha a hlokahala a ska hlokahala jwalo ka ntate moholo waka.	Yes. I want to have money so that I can buy my family food and I want my grandmother to pass away when I am already old because I do not wish for her to pass away the way my grandfather did.
	What are you referring to when you say that you do not want your grandmother to pass away the same as your grandfather?	O bolela jwang ha o re ha o labalabele hore nkgono wa hao a hlokahale ka tsela e tshwanang le ntatemoholo wa hao?	Ntatemoholo wa ka o hlokahetse a sa tsebe ho bua, mohlang a hlokahalang o ne a batla ho re bona ke ha a sa kgone, a sa batle ho ja . Nkabe a ntse a phela le kajeno hoja a sa hana ho fiwa madi	My grandfather passed away. When he passed away, he couldn't talk or see. He wished to see us and then when they wanted to donate blood for him, he refused and when the drips were inserted in his body he

			o ile a hana . Le di dripi o ne a dintsha … ha ya ndula hantle ntho eo yah ore ntatemoholo waka o hlokahetse hobane ke yena a ne a nrata ho feta batho bana kaofela.	just took them out by force because I think if he had agreed for the blood to be donated to him he would still be alive. So, that thing did not sit well with me - the death of my grandfather, because I believe he is the one person who loved me more than any other person.
	When did your grandfather pass away?	Ntatemoholo wa hao o ile a hlokahala neng?	Ka di 13 tsa *February*.	On the 13th of February.
	I am very sorry to hear that.	Ke taba tse seng monate.	-	-
	Was it this year?	Ke selemong sena?	Selomo se ka pele ho se fitileng.	The year before last.
	What type of grandfather was he for you when he was still healthy?	E ne ele ntatemoholo a jwang ho wena ha a ntse a phetse hantle?	O ne a rata hore ha a ne a kgotse a re rekele dintho tse monate, ne re dula re tsamaya le yena *everyday* a ntse a re ke bana baka bana. *Nou* re a mo hoopla hle. Zone eo kaofela ya mo tseba. E ne ha hona motho a sa mo hopoleng.	Whenever my grandfather had received his salary he would buy us the nicest of things and would go with us around telling people: "These are my children." And he loved us very much and there is not even a single person who doesn't miss him because everyone, even in the neighbour-hood, they know him and do miss him.
	So there are many people who are missing him?	-	***	Yes.
12	**What do the doctors say to you when you**	Ha o ntse o tla mona nako le nako o tlo bona	Ba re nou ha ne ke tlile ka di 11 tsa *March* ke ha ba fihla	When I was here on the 11th of March, the doctors told me that my

	come here to see the doctor from time to time? What do they tell you?	dingaka di re eng ho wena?	ba re pelo yaka e ntse e tla hantle, ke ha fihla *doctor* eo e ne enketsa *scan* ka yona ke ha ba ntshetsa yona ba re ke lo bontsha ntate waka akere o ne a sat la ne ke tlile le mme waka so ke ha ba fihla ba re pelo yaka e hantle ke healthy, ke hantle ntse ke ithlokomela.	heart is in the right condition, its fixed, I am healthy and I am taking good care of myself. They even did a scan and made a printout of the scan because my father did not come with us; I only came with my mother. They said that I should take the scan to show it to my father that I am doing very well. My heart is doing very well and I am healthy.
13	**Let us start with your mom, what does your mom say about you?**	Ha re qale ka mama hore yena o reng ho wena?	Batho ba ne ba mpona ke otile *nou* batho ba mpona hore ke fodile. Bakgotsi ba hae ba re ngwana wa hao o fodile ka nnete abe a re eya o fodile ka lebaka la di *doctor* tsa ne en ke a ba leboha. *First time* ke ile ka akgeha ka ya *Pelonomi* ha keya ntate waka akere ha a tsebe nix ... a nkenya kgaba ka hanong, ngwanarona a le teng ha ne ke fihla sepatala, mme waka o ne a lla en mme waka ha a lla. Mme wa ka wa re rata hle le ntate waka ha hona motho ya ka nketsang letho. O a nrata.	There came a time when I was very skinny and had lost a lot of weight and people could see that I was sick but right now when they look at me, they tell my mother that I am indeed healed. And I remember the first time when I collapsed and had to be taken to *Pelonomi*, my father inserted a spoon in my mouth when I had fainted and was bleeding and had to go to *Pelonomi* and all this happened in the presence of my little sister. So they had to take me to *Pelonomi* and my mother was crying her eyes out when all this was happening because she loves us very much as her children.
	Was this because of your heart that this happened or was it because of the	Sena se etsahetse ka lebaka la bothata ba hao ba pelo kapa ka lebaka	Pele ne ke say a sekolong ke tshwerwe ke mpa ke sa kgone ho robala ntate waka a ntlela *Eno* ... ka sala le	It started as stomach cramps and then my father gave me *Enos* to drink and then my grandfather sent me to

	HIV?	la *HIV*?	ntatemoholo waka yena a re ke lo beha welese kganthe ke lo wa, ha ne ke feta ka mane ka kamoreng a utlwa se ke wetse fatshe ke ha a re wena o ptjhatla radio yaka. Ha ne a tla a bona. Ntatemoholo waka o hlokahetse ka lebaka la ka a re ho kampa ha shwa nna eseng ngwana waka..eseng setloholo saka.	go put his radio in the room and then when I was on my way there I collapsed, then my grandfather did not know what was happening – he only heard the sound of the radio falling down and then said, "You are breaking my radio." When he arrived there, he found me on the ground and I believe that my grandfather died because of me because he said that he might as well die and not me.
	And when did this happen?	Sena se etsahetse neng?	E ne e le ka di 18 of *February* 2014	It was on the 18th of February in 2014.
	So what do you think Mom thinks about you?	O nahana hore mme wa hao o nahana eng ka wena?	O nahana hore ha nka ntshetsa dithuto tsaka pele ka sebetsa ka ba motle, ka itshebeletsa ka ba ahela ntlo o tla bona hore o hodisitse kannete, yena heh o rata tjhelete.	I believe that when my mother looks at me, her wish is for me to continue with my studies, study hard, work for myself, be independent and have a lot of money because she loves money very much.
	What does Dad say about you? What does Dad think about you?	O nahana hore Papa yena o reng ka wena?	O nahana hore ke tla sebetsa, ke ithate, ke be le bana ba batle mara o re aa ha a batle ke nyalwe.	Dad thinks that I can work, love myself, have beautiful children but he says that he doesn't want me to get married.
	Why? Is he too protective?	Hobaneng o o tshireletsa haholo?	Eya, ha a batle nix ka nna.	Yes, he doesn't want anything when it comes to me.
14	**What does your sister say about you? What do you think she**	Ngwaneno o reng ka wena? Kapa o nahana hore ngwaneno o nahana eng ka	A ba re ke mo thuse ka di *homework* tsa hao, nako tse ding re a bina a ba re ausi waka ke kopa o nrute ho	She would say that I should help her with her homework. Sometimes we sing and then she asks me again to help

	thinks about you?	wena?	ngola be ke moruta ho ngola. Nakong enngwe akere o rata ho qala batho sekolong jwale ha ba mo qala a be a tla ho nna and then nna ha ke batle ho otlwuwa en yena o rata ho qala batho yena le bakgotsi ba hae.	her write. She is very naughty; she usually starts with people like taking their school bags and running around with the school bags and afterwards hides behind me, seeking protection. So, as the *"big sister"* I have to fight the battles for her and she doesn't want to get beat up so she always does that.
	How does this make you feel?	Sena se o etsa o ikutlwe jwang?	***	Feel better.
	So, do you think she knows that you will protect her?	Jwale o nahana hore o a tseba hore o tla mo tshireletsa?	Eya wa tseba.	Yes, she knows.
15	**What do your friends say to you?**	Metswalle ya hao yona e nahana eng ka wena?	Akere nna sekolong ke motho a buang haholo so ba rata dijokes tsaka. Ba rata hore ke itshwere hantle. Ha ke rate bashemane. Ke ngwana a itshwereng hantle. Ba a tseba hore ke na le bothata ba pelo. Sekolong ha ke shapuwe. *Mistress* le yena o a tseba ha a batle ho nshapa hape ha a batle ho nkwatisa.	I am a very talkative person and I also love making jokes and my friends love my jokes. I think they like me because I am a well mannered girl and I don't run around with boys. Even at school my teachers do not beat me. They say, "We are not going to punish you because we don't want to make you angry." because even at school they know I have a heart problem.
	And what do you think about that - that they don't punish you because you have a heart problem?	O nahanang ka seo hore matitjhere ha a o shape hobane o na le bothata ba pelo?	Bana ba ka classing ba rata hore yena ha a shapuwe ha a kule o shap en ntho eo e nkutlwisa bohloko nakong tse ding be ke e ngola diaring yaka, e nkutlwisa bohloko.	Learners in my class would say, "No, she has to be punished as well, why can't you punish her because she is healthy, she is OK." And that hurts me very much. Sometimes I write about it in my diary.

	Tell us a bit more about what the learners say, "No, she should also be punished." How does that make you feel?	Re jwetse haholonyana ka hore ba re aa le yena ha a shapuwe, sena se o etsa o ikutlwe jwang?	E nkutlwisa bohloko hobane le nna be ke batla ho shapuwa jwalo ka bona so ntho e nkutlwisang bohloko le ho feta ke hore ba re ha ke etsuwe nix ene le nna be ke batla ho shapuwa ha ke tshabe thupa. Ke na le ho ba tsheha ha ba shapuwa ba be ba re wena ska tsheha hobane ha o shapuwe. Be re aa ha se nna a itseng a ska nshapa nna. Ntho e nkutlwisang bohloko ke hore ba re nna ha ke shapuwe ba ntse ba tseba bothata baka.	What hurts me the most is that they keep saying that I am not punished like them, knowing very well what my condition is, because sometimes I laugh at them when they are being punished and they will come to me and say, "You are not punished so don't laugh." I also wish to be punished like them, like other children. I usually tell them that it isn't my choice. I am not the one who said I shouldn't be punished. It is the situation that I find myself in.
	Do the kids at school and the teachers know about the *HIV* or only about the heart problem?	Matitjhere le bana mane sekolong ba tseba hape le ka *HIV* kapa ka bothata ba hao ba pelo feela?	Ka bothata ba ka ba pelo feela.	They only know about the heart problem.
16	**I have heard a little bit about what your teachers say to you or think about you, is there anything else that they say about you?**	Ke utlwile hanyane ka hore matitjhere a hao a nahana eng ka wena kapa ba nahana eng ka wena, ekaba ho na le seo o ka se tlatsang?	*Sometimes* ba utlwa bohloko ha ba mpona hore *nou* ntse ke theoha ho dimarks tsaka. Nna ke rata ho etsa mosebetsi waka haholo. Ho na le ngwana a bohlale ka classing a ratang ho ba thopa ka *maths* so be ke re nako enngwe ke batla ho tshwana le yena ngwana oo. Ke batla ho mo feta tseleng *en nou* ke tlo tiisa ho feta moo.	My teacher usually becomes hurt when they see me because my marks are degrading, but I am working very hard in order to fight that. Like, there is a boy in class who is very good at maths and he is always at the top of the class and I wish to be like that learner. Even right now I told myself that in June I am going to work very hard to even exceed or reach the position of that learner.

	Why do you think that your marks have gone down?	Hobaneng o nahana hore marks tsa hao di theohile?	*Because* ha ke ngola ditest ha ke kgone ho utlwisisa *mistress*. *Mistress* o bala ka spit en nna be ke sa kgone ho utlwisisa, ba re hlalosetse hantle ... *slowly* ke kgone ho utlwisisa.	The way that the teachers read the instructions of the test. How this test needs to be done. Usually I don't understand them because they speak very quickly and I would need them to be more slower in order for me to understand exactly what has been expected of me in class.
	Do they talk too fast?	-	***	Yes.
17	**If you could be an animal, what animal would you like to be? Why?**	Ha ne o ka kgona hore o be phoofolo o ne o ka kgetha ho ba phoofolo e feng le hobaneng?	Ne ke batla ho ba *penguin*.	I would like to be a penguin.
	What is your reason?	Lebaka la hao?	Hobane di na le docolour tse ngata tse ntle ke hore dicolour tse o tse ntle ke tsona tse etsang ke nahane hore ke be tsona le molomo wa tsona wa nqabola haholoholo ha di lla.	I love them because they have very beautiful colours, that is what attracts me to them and also the shape of their mouths when they cry makes me laugh.
	What are the colours of a penguin?	Ke mebala e feng ya penguin?	*Red, orange, blue, yellow, green, white, brown* … ke dicolour tse ngata tse fapaneng.	Red, orange, blue, green, yellow, white, brown … they are many different colours.
	I did not know that you get different colours of penguins; I know that a Penguin is white and black. So are we sure that we are talking	Ne ke sa nahana hore *Penguin* e na le mebala e mengata rona re tseba e mmala o mosweu le botsho feela. Ekaba re bua ka *Penguin* mona?	Eya. Ke hlola ke e bona le *textbook* yaka e teng.	Yes. I usually see it and even in my textbook it is there.

	about a penguin?			
18	**Quickly tell me what are your favourite things to do?**	Kopa o njwetse hore ke dintho dife tseo o ratang ho di etsa?	Ho loha mme waka, ke hlola ke mo loha ke mo kama. Le ho bapala *netball* be ke ya ke lo bapala bolo le bashemane. Ke rata ho bapala le bashemane ba *class* ya rona le papadi ya di ulu.	I love combing and styling my mother's hair and going to netball practice, playing soccer with the boys, usually my classmates. I love playing soccer with them. And there is this game of wool that we like playing.
	So you play soccer with the boys? And are you good at it?	-	***	I am trying.
	What do they say about your soccer skills?	Ba re eng ka tsela eo o bapalang bolo ka teng?	Ba re wa leka re tla nne re o rute. Mara nna ha ke e tsebe so ba ntse ba nruta.	They say, "You are trying and we will keep on teaching you how to play soccer." I don't know it very well but they are still teaching me.
19	**Name the things that you cannot do because of your heart problem. If there are some things.**	Re jwetse dintho tseo o sa kgoneng ho di etsa ka lebala la bothata ba hao ba pelo. Haeba ho na le dintho tse itseng.	Ne ke sa kgone ho matha, ne ke tsamaya *distance* e nyane be se ke kgathetse ha ke bapala ne ke sa bapale haholo pele ho *operation* mara ka mora yona se ke kgona ho bapala nako e telele. Mme waka a be a re se ka bapala haholo hobane o tla e tshirimaka.	Before the operation I couldn't run. I could run only for a short distance and then I would be sweating and would tell them that I am tired. I couldn't play for a long time but after the operation there is nothing that I cannot do. I can run like any other child. My mom would say, "Don't play too much because you might hurt yourself."
	And back then when you couldn't run and so on, did it bother you?	Ha o ne o sa kgone hore o mathe seo se ne se sa o tshware hantle?	Eya.	Yes.

	How did it bother you?	Se ne se sa o tshware hantle jwang?	Ne ke ipotsa ke le mong ha ke lo robala hore hobaneng ke sa kgone ho matha, bana ba bang ba bapala ha monate nna ke sa kgone ... ke eng ho Ntate Modimo e leng ke e entse hore ke be jwalo mara *nou* ke shap *nou*.	I would ask myself, when I go to bed at night, "Why did God create me to be this way? Why don't I play like other children?" but right now the situation is different. I am good.
	So you would ask God why did you have the difficulties of the heart?	Jwale o be o botsa Ntate Modimo hore hobaneng o na le bothata ba pelo ?	Eya. Ne ke botsa Ntate Modimo hore hobaneng o nketse ke seke ka tshwana le bana ba bang. Hobane ka nako eo ne ke sa tsebe hore ke na le bothata ba pelo.	Yes. I would ask God, "Why did you create me like this not to be like other children?" Because at that time I did not know that I had a heart problem.
20	**Who looks after you?**	Ke mang a o hlokomelang?	***	My father, my granny and my mother.
	Tell me a little bit about your granny.	Njwetse hanyane ka nkgono wa hao.	Nkgono waka ke motho ya kgopo. Ha a batle nix ka rona. Ha motho a ka re otla o tla mo lata a ba jwetse hore ke bana ba ngwana waka bana. Ke tla le shapa.	My granny is very strict and protective of us. Whenever someone hits us or has done something wrong to us, she goes there and tells that person, "These are my grandchildren and you will not do this to them."
	Anything else that you can tell me about your father?	Ekaba ho na le ho hong o ka re jwetsang ka papa?	***	No.
	Anything else about your mom?	Ekaba ho na le ho hong o ka re jwetsang ka mama?	Mme waka onrata haholo. Ha ngata ke robala nako e telele haholoholo hobane *nou* ke *holiday* ke ka lebaka la moriana wa *HIV* so wa nrobatsa. Ke ka ho o ke	My mother loves me a lot. I usually sleep for a long period, especially now that it is a holiday. It is because of the medication of *HIV* so it drugs me so I sleep for a very long time and my

			robalang nako e telele … mme waka a be a ntse a ntsosa a re ke tsohe ke lo kgolo maka. Mme waka wa nrata hle. Ke tsohe ke lo kolomaka. Mme waka o nrata haholo.	mom will keep on waking me and telling me to wake up and clean. Basically my mother loves me.
21	**Who understands you the best?**	Ke mang a o utlwisisang haholo ?	***	Lebohang*.
	Why Lebohang*?	Hobaneng Lebohang*?	Lebogang* ha bashemane ba nkemisa seterateng o a ba jwetsa hore aa ke ausi waka oo motlohelleng.	When I walk down the street with her and boys want to propose love to me, Lebohang* shouts at them and tell them this is her sister so they must leave her alone.
	And you also said when your grandfather was alive, he also understood you well?	-	***	Yes.
	So where is Lebohang* now that you are here?	Jwale Lebohang* o kae ha le le mona?	Lebohang* o rata ho bapala a kampa a bapala mme a ska ja ... o ntse a bapala re mo siile ho Nkgono.	Lebohang* likes playing. She prefers to play rather than to eat. We left her at my Granny's place.
22	**Who cares for you when you feel sick/sad/ hungry/scared?**	Ke mang a o hlokomelang ha o ikutlwa o kula, o hloname, o tshohile kapa o lapile?	Nkgono waka.	My granny.
	Where does Granny live?	-	***	Kimberley*.
	How often do you see Granny?	O mmona ka mora nako e kae?	Ke ya *Saturday* le sontaha. Le ha dikolo di kwetswe.	I go there on Saturdays and Sunday. Even during school holidays.

23	**Tell me a story of a time when you and your family travelled together.**	Ke kopa o njwetse ka pale ya moo wena le ba lelapa leno le ile la eta ha mmoho.	Ne re ile ho rakgadi wa ka ne re ile Kestell*. Ne re nkile *bus* ya 14h30. E ne e le mme waka, nna, Lebohang*, nkgono. Re tjhakela ngwana bo nkgono waka. Ha re fihla moo ba ne ba re phehetse dijo tse ngata le *drink* re bapala le bana ba moo ho le monate. Mara *nou* mama o re o batla re ye Lesotho ha bona. Ho tlo etswa mokete ka December.	A time when we went to Kestell* and we took a bus of 14:30. It was me, my mother, Granny and Lebohang*. There was a celebration at my granny's sister's place and they invited us there. There were a lot of food and drinks. It was fun. We played a lot but my mother says that in December there is going to be a celebration there in Lesotho because that is where my mother comes from.
24	Who would you say are good friends of yours, and why would you say they are good friends?	Re jwetse ka bao o reng ke metswalle ya hao le hore hobaneng o re jwalo?	Bonolo*, Dineo*, Mariha*, Nthabi* ke metswalle ya ka e 4. Bonolo* ntho enngwe le enngwe ke e etsang wa nunderstanda ha ke sa tsebe nthong tsa sekolo wa mpontsha. Ke motho a rwalang diborele ebile o mokgutshwane. Ha ntho e etsahetse ho nna ke yena wa pele le ha mistress a ne a nshapa ke ha a re mistress ha a shapuwe. Ke ha a re hobaneng le ne le sa mpolelle.	Bonolo*, Dineo*, Mariha* and Nthabi* are my four friends. Bonolo* is a very supportive friend even in school work she is the one who assits me and even when something is happening to me, she is the first one to find out. Just yesterday, when a teacher wanted to punish me she is the one who stopped the teacher and said, "You are not supposed to punish her." And then [she] explained the situation to the teacher and then the teacher said that she was glad that she told her because she had no idea.
	Do you sometimes feel like you have to be punished? Do you sometimes do things that	-	***	Yes.

	you feel you need to be punished for?			
	What does it do to you when the teacher just lets it go?	Mme sena se o etsa eng ho wena ha matitjhere a kgaohana le wena feela ba sa o shape ha ba tlameha ho o shapa?	Ke ikutlwa hampe hobane bana ba bang ba shapuwa nna ha ke shapuwe en ha ke e rate ntho eo.	I feel bad because other learners are punished and I am not punished, so I do not like that.
	Why is it necessary for the teachers to punish the learners?	Bohlokwa ba matitjhere hore a shape bana ke eng?	Ba bang ha ba etse di Homework ba bang ba sele ba rohakana.	Others do not do their homework while others are very naughty because they even swear.
	So you think that punishment can help a person?	O nahana hore ho a thusa ho shapa motho.	***	No.
	So its more like you feel bad for the other kids.	-	***	Yes.
	Next is Nthabi*.	A latelalang le Nthabi*.	Nthabi* ke motho wa ne ne ke bua ka yena a tsebang *maths*. Ha ke sa tsebe ho etsa ntho wa nthusa. Maobane ne re dutse tafoleng e 1 a nthusa ho etsa mosebetsi wa sekolo. Re ja re le 4. Le ka *break*. Nthabi* wan rata le yena *not like* Bonolo*.	Nthabi* is that person I was talking about who is very good in mathematics. Just yesterday we were sitting there at the table and she was helping me with mathematics showing me where I do not understand so she supports me in my studies. She loves me and we all eat together and she would ask what do I need and then she would buy that for me. Nthabi* does love me but not the same as Bonolo*.

	Tell me a bit about Dineo*	Njwetse ha nyane ka Dineo*	Ha ke lla wa nthudisa *just like* maobane le ha ke satla ka dijo ke di lebetse ha rona a ba ja le nna re le babedi. Maobane ne re bapala re le babedi. Dineo* le yena ke best friend yaka.	Dineo* I can also say that she is my best friend because we play together. When I cry she comforts me. She is always there for me even when I forget my lunchbox at home she asks me if I am hungry and then we eat together.
	And Mariha*?	Mariha* yena?	Mariha* le yena ke *bestfriend* so yena ha a sena *homework* o ya ha rona a lo ncheka hore ntse ke le shap na … le ha ne ke le *Pelonomi* o ile a tla a tlo nsheba a na le Bonolo*. Le ka mora *operation* o ile a tlo nsheba hae.	Mariha* is also my best friend. When I was in hospital she asked her mother to come and see me there in hospital. She came to see me there at Pelonomi together with Bonolo*. And even when I missed out on homework she would bring homework for me at home. After the operation she came to visit me at home.
	What would make you say that you are a good friend to them?	Ke eng se ka etsang hore o re o motswalle a lokileng?	Hobane le nna ke a ba supporta. Bonolo* o ne a hlokahalletswe ke ntate so ke ha a fihla a lla ... bana ba bang ba rata ho mo teaser ba re ntate wa hae so ke a mo supporta le yena jwale ka ha nsupporta le yena.	They support me and I also support them. Like when Bonolo's* father passed away, I also supported her because other students would tease her about her father, so when she cries I will be there to comfort her.
	Anything else about your friends that you left out?	Ha hona letho leo o le siileng ka metswalle ya hao?	E mong ke moshemane, Thabo*. He is my best friend.	The other one is a boy name Thabo*. He is my best friend.
	OK, so what makes him your friend?	Ke eng se mo etsang mokgotsi wa hao?	Thabo* ke motswalle waka. Mme waka wa mo tseba hore ke mokgotsi waka. Nakong enngwe ha re tswa sekolong re ya ha bona re lo thusana ka	Thabo* is my best friend. My mother knows him. Usually we do our homework together. And he comes at home and accompany me to go home and drop

			dihomework ha re qetile be re ya ha rona a lo nthusa hore ke beye dibag ke kolomake.,	my bag then clean.
	Is he in the same school as the rest of you?	-	***	Yes.
	Does the *HIV* make you feel sick sometimes?	-	***	No, as long as I take my medication, I am fine.
	So, it is only the heart that made you feel like you are tired and so on?	Jwale ke pelo feela e ne e etsa o ikutlwe ekare o a kgathala jwalo jwalo?	Eya.	Yes.
	How do you feel about the fact that you have *HIV*?	O ikutlwa jwang ka hore o na le *HIV*?	-	I feel much better … it was not my decision because it comes from my mother through breastfeeding.

Participant H
Girl, 14 years; Afrikaans
Note:

- The questions reflect the DPM-interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See an explanation of terms at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**English Translation**	**Researcher**	**Afrikaans**	**English**
1	**Why are you here at hospital today?**	Hoekom is jy vandag hier by die hospitaal?	Ek het gehoes en toe ken ek nie wat dit is nie, want ek het 'n steek gekry. En toe sê my ma ons moet *clinic* toe gaan en toe sê die *clinic* ons moet hospitaal toe gaan. Toe kom die dokter en toe kyk hy my en toe wys hy my wat gebeur met my hart.	I coughed and I didn't know what was going on. I also experienced stabbing pain and so my mother took me to clinic and then they sent me to hospital and then the doctor examined me and told my mother what was going on with my heart.
	So what was going on with your heart?	So wat het met jou hart aangegaan?	Ek weet nie.	I don't know.
	When did this happen?		Dit was in Februarie.	It was in February.
	Since when have you known that you have a heart problem?	Van wanneer af weet jy dat jy 'n hartprobleem het?	Ons het hiernatoe gekom toe ek sewe maande oud was. Hulle het my al twee keer geopereer. Toe ek sewe maande was, die eerste een. Ek het 'n *stroke* gehad na die tweede operasie toe ek nege-en-'n-half was. Ek kan nie rerig met die hand [links] werk nie. Die voet sleep. Ek kan voel, maar	I have had two previous operations. The first one was when I was seven months old and the second operation was when I was nine-and-a-half years old. I had a stroke during the second operation and ever since I have difficulty moving the left side of my body and

			nie so lekker beweeg nie. My been is reg, maar partykeer pyn hy. My arm pyn ook partykeer.	sometimes I experience pain in my left arm and left foot.
	So why did you have to come to hospital again this time round?	Hoekom is jy nou weer by die hospitaal?	Ek weet nie. Hulle het die kleppie toegemaak … die kleppie het weggeskuif van die hart af.	I don't know … the valve moved/pulled away from the heart and then they closed it.
	Do you know the name of that valve?	Ken jy daai kleppie se naam?	No.	No.
2	**Tell me what is going on with your heart.**	Wat is aan die gang met jou hart? Wat is die probleem?	Ek weet nie. Die kleppie het weggeskuif van die hart af en hulle het hom nou net weer ge-*stitch* … toegemaak. Met die vorige operasie het hulle vir mamma gesê hulle gaan 'n nuwe een [klep] insit.	I don't know … the valve moved/pulled away from the heart and then they stitched or closed it. During the previous operation, they told Mom that they are going to replace the valve with a new one.
	Do you think that your heart is now fixed?	Is jou hart nou gesond of is hy nog siekerig?	Nee dis nog bietjie siek.	No, it is still a bit sick.
3	**Do you have to take any medication? Why?**	Moet jy medisyne drink en hoekom?	Toe ek hier was het hulle gesê ek moet *Disprin* drink, maar nie vir die hart nie.	Yes, they said I must take *Disprin* but no medication for my heart.
4	**What do you enjoy doing? Tell me more.**	Wat is vir jou lekker om te doen?	As ek iets lekkers het om te doen.	When I have something fun to do.
	Such as?	Soos?	Soos, as iemand na my toe kom en lekker met my praat.	Like good company or conversation.

	So you like to chat and to make jokes?	So jy hou van gesels en grappies?	Ja.	Yes.
	Which people's company do you enjoy?	Met watter mense maak jy lekker geselsies?	Met ons [ander] kinders.	The other children.
	What else do you enjoy?	Wat is nog vir jou lekker om te doen?	As ons iewers gaan na waar dit lekker is en niemand vir my kwaad maak nie.	To visit nice places [and] when no-one makes me angry.
	Are there people who anger you?	Is daar mense wat vir jou kwaad maak?	Partykeer is dit my ma, my pa, my broer, en my ma se kinders en my oompie en my ouma en my *auntie* se kinders en ander familie ook. Dit voel ek kan net weghardloop van hulle af.	Sometimes my mom, dad, my brother, my mother's other children, my uncle, my grandmother, my aunt's children and other family members. I feel like I want to run away from them.
	Can you give me an example of something that they do that might anger you?	Kan jy aan 'n voorbeeld dink van iets wat hulle doen of sê wat jou kwaad maak?	As my ouma my ma skel en sy sê my ma … my pa bly in Kaapstad*, so my ouma sê hoe slaap my ma rond, maar my ma slaap nie rond nie … en sy vloek my ook.	When my granny scolds my mother and says that my mom … my [biological] father stays in Cape Town* so Granny would say that my mother sleeps around but she doesn't … and Granny swears at me.
	Would you want me to arrange for you to talk to someone about these things? Someone who is also a psychologist, like me.	Sal jy wil hê dat ek moet reël dat jy oor die goed kan praat met iemand wat dieselfde werk as ek doen, 'n psychologist*?	Nee, sjo, my ander pa [stiefpa] sal my slaan. Hy skel my net as ek na my *tjommies* toe gaan en ek gaan nie rerig speel nie – ek sit in die huis.	No, my other dad [stepfather] will give me a hiding. He even scolds me when I go visit my friends but I don't even walk around – I just stay at home.
	Does Dad give you a tough time?	Gee Pappa jou 'n harde tyd?	Ja.	Yes.

5	**Your family, how is their health?**	Jou familie, hoe is hulle gesondheid?	My ouma sy het *high blood*. Mamma se ma het verlede jaar gesterf.	Grandmother has high blood. My grandmother on my mother's side passed away last year due to high blood … her feet were swollen.
	Did you know her well?	Het jy haar goed geken?	Sjo, sjo, sjo, daai was my ma daai. Sy was 'n reg mens … sy het nie baie geskel nie … sagte mens … sy slaan nie, sy's net sag. Voor sy afgesterf het, het sy my ma gehelp om my goed te betaal. Sy het vir my skoolgoed ook gekoop.	Sjo, sjo, she was like a mother to me … she was a soft-spoken person … she didn't scold and didn't hit. She also helped with money and bought me things for school.
	What illness did she have?	Watter siekte het sy gehad?	Sy't ook *high blood* gehad. My pa (wat in ons huis bly) het ook *high blood*.	She also had high blood. My dad (who lives in our house) also has high blood.
	And your Cape Town* dad … have you ever met or spoken to him?	En jou Kaapstad*-pa … het jy al ooit met hom gepraat?	Hy het gesê hy gaan kom, maar hy't nog nie gekom nie … hy sal nie kom nie. Toe my ma hom sê hy het 'n kind saam met haar, toe loop hy weg en van daar het hy nog nooit gekom nie. Hy bel my nie. Sondag het hy die familie gebel en toe sê hulle vir hom dat ek in die hospitaal is en toe neem hulle foto's van my en toe sê hy dat hy gaan kom, maar toe kom hy nie.	He said that he will come but he hasn't yet visited me … I don't think that he will ever come … they told him that I was in hospital and they sent him pictures but he didn't come to visit me.

	How does that make you feel?	Hoe voel dit vir jou?	Sleg.	Bad.
	What type of person do you think he is? Friendly?	Wat dink jy, watter tipe mens is hy?	Nie vriendelik. Partykeer gaan hy Kroonstad* toe, dan gaan hy nie na sy familie toe nie.	No. When he is in Kroonstad*, he doesn't even visit his family.
6	**How does your heart tell you when you are feeling sick?**	Hoe sê jou hart vir jou wanneer jy siek is?	As ek steke kry. Of as ek nie reg kan hoes nie en nie asem kan kry nie.	I get stabbing pain, I struggle with coughing, and I struggle to breathe.
	How often do you experience those symptoms?	Hoe gereeld voel jy so?	Een keer in maande.	Once in months.
7	**How do you feel about your ill heart?**	Hoe voel jy oor jou siek hart?	Dis seer … soos as ek in die straat loop en kinders skinder van my en maak my na soos wat ek maak, amper soos mense wat my nie *like* nie. Dit voel so.	It hurts, for example, I would walk in the street and then the others will gossip about me and tease me as though they don't like me. I feel that they don't like me.
	What would they say to you?	Wat sal hulle vir jou sê?	Hulle koggel my oor my hand. My broer koggel my ook as hy kwaad is vir my.	They tease me about my hand. My brother would also tease me when he is angry with me.
8	**Name some things that you like about yourself.**	Noem 'n paar dinge van jouself wat jy *like*.	As hulle so baklei, dan *like* ek om hulle te help om dit uit te sort. Soos, my *tjommie* vry mos al, so haar *boyfriend* het haar hart gebreek en toe maak ek hulle weer bymekaar.	When people fight or argue, then I like to help them to sort things out. For example, when my friend and her boyfriend argued, I helped them to get back together.

9	**Name some things that you don't like about yourself.**	Noem 'n paar dinge van jouself wat jy nie *like* nie	Ek wil baie *change*. Dat daar nie weer 'n operasie sal wees nie en dat die hand kan regkom.	I want to change many things. I don't want another operation and my hand … it needs to be fixed.
	How did you feel when the doctor said that you need another operation?	Hoe't jy gevoel toe die dokter sê dat jy nog 'n operasie moet kry?	Ek het bly gevoel [omdat hulle dit kan regmaak], want hulle het gesê as hulle nie die operasie doen nie, dan gaan ek doodgaan.	I felt happy because they can fix the problem because they said if they don't do this operation that I would die.
	How did that make you feel?	Hoe het dit jou laat voel?	Ek wil leef dat ek kan sien waar ek gaan eindig in die wêreld. Hier, toe die susters my pype uithaal, jo, ek het gevoel ek gaan doodgaan van seergeid.	I want to live to see where I end up in life. When the nurses took out the pipes, I thought that I was going to die because the pain was so bad.
10	**What is happening to your heart?**	Wat gaan aan met jou hart?	Ek weet nie.	I don't know.
11	**If you had three wishes and you could wish anything and it would come true, what would you wish for?**	Sê nou jy kan drie goed wens en dit sal waar word, waarvoor sal jy wens?	Om my pa te sien.	To see my [biological] father.
	What would you say to him?	Wat sal jy vir hom sê?	Ek ken nie as hy kom wat ek sal sê nie, maar vir my *tjommies* lieg ek … ek sal maak laat hy betaal! Dan lag ek. Ek wens ek kan skool oorvat – dat ek kan goed leer soos die ander kinders … meeste van die tyd	I don't know … will laugh when I see him. I lie to my friends and say that I will make him pay! I wish that I could do well at my schoolwork … I feel weak at school due to my heart. Most of the time I

			kom ek nie deur nie … [ek voel] swak en siekerig, asof dit die hart is wat so maak.	fail … I don't know why … it seems to be my heart that makes me feel weak.
	Do the teachers and children know about your heart problem and how do they deal with it?	Weet die onderwysers en die ander kinders dat jou hart siek is en hoe hanteer hulle dit?	Partykeer is hulle nie reg met my nie. Die kinders skel hulle my … die onderwysers hanteer my soos 'n gewone skoolkind … hulle skel my ook soos die ander … [ek wil hê] hulle moet meer versigtig met my wees.	The children tease me about my heart … the teachers handle me in the same way as they handle the other children … I want them to be more sensitive with me.
12	**What does the doctor say to you?**	Wat sê die dokter vir jou?	Die dokters sê niks vir my nie … hulle sê my net as hulle goeters uithaal en wanneer moet ek uitgaan – die goed wat hulle op my doen.	The doctors say nothing to me … they only talk to me when they take things out and when I can go out – the things that they do.
13	**What do your parents/guardian say about you?**	Wat sê mamma van jou?	Partykeer sê sy ek is dom … ek ken nie of is dit die waarheid nie … ek dink sy speel saam met my … sy praat niks van my hart nie. Sy sal sê ek is lui om skottelgoed te was … ander mense is lief vir my soos my oompie wat my uitgevat het. Hy't gesê as die skole sluit gaan hy my Margate* toe vat.	Mom says that I am stupid … I think she only jokes … she says nothing about my heart. She will say that I am lazy to wash the dishes … other people love me such as my uncle. He said that he will take me to Margate* on holiday.

14	**What do your siblings say about you?**	Wat sê sussie en boetie van jou?	Die kleintjie praat niks nie, maar sy vloek ook soos die ouma, dan lag ek haar uit, want sy's klein. My broer pla my, hy praat sleg van my. Partykeer pla ons mekaar en op die einde kom huil iemand dan word ons altwee geslaan … ons speel saam *ball* (sokker).	The little one says nothing but she swears like her grandmother and then I laugh at her because she is still small. My brother talks bad about me and bothers me. Sometimes we play and tease each other and then both of us get a hiding … we also play ball (soccer) together.
	What other sports do you play?	Watter ander sporte speel jy nog?	Ek *like* gholf maar daar is nou nie gholf nie, daar is net sokker en netbal … dis 'n Sotho skool, so daar's nie hokkie nie. Daar is ook 'n ander ene wat hulle saam met juffrouens oor skoolgoed praat.	I like to play golf but they don't have golf at school. I play netball … it is a Sotho school so they don't have hockey but other activities.
	Who plays golf with you?	Saam met wie't jy al gholf gespeel?	Saam niggies en neefs en my oompie wat in Upington* bly. Hy speel ook gholf, hy het al geld gewen vir gholf. My oupa kon ook goed gholf speel. Hy is in 2008 dood … was ek vyf of wat? ... kom ek kyk … [counts] … sjo het daai oompie my geslaan!	My cousins and my uncle who lives in Upington* has won money for golf. My grandfather was also a good golfer. Grandpa passed away in 2008 … how old was I … let me count … sjo, he gave me a hiding!
15	**And what about your friends?**	En wat van jou vriende?	Ek het nie eintlik vriende nie.	I don't really have friends.
	Why not?	Wat is die rede daarvoor?	Ek ken rerig nie. By die skool het ek ook nie baie vriende nie. Ek loop saam hulle	I don't know. At school I don't have friends. They see the other children

			en as hulle ander sien dan loop hulle saam met die ander. Dan loop ek maar allenig. Ek is nie skaam om te praat nie, maar ek het nie baie vriende nie. Ek het een vriend gehad wat bietjie vêr bly. En die ene [vriend] wat naby my huis bly. Nou't ek net twee vriende. Dis Karabo* en Lerato* (sy bly nou in Bethlehem*). Learto* se ma het gesê miskien kan Lerato* by ons kom bly. Haar ma het my skoolfonds betaal en alles gedoen. Lerato* se pa, toe sy klein was dan gaan ek saam dan gaan ons WIMPY toe. Hy het ons ge-*treat* en *casino* toe gevat en gemaak dat Lerato* haar ou foon vir my gee, maar toe raak dit weg by Oupa se begrafnis. Iemand het dit gevat. My ma het gesê sy sal kyk of sy 'n nuwe een kan koop. Ek wil dit nie sê nie, maar my ma het daai iemand gevloek! Daar was baie mense. [My oupa] het baie mense geken want hy het goed gholf gespeel. En ken vir Ernie Els*. My *auntie* was ook al op die TV en sy speel ook gholf … ons het *photos*	and then they would rather walk with them and then I walk alone. I am not shy to talk but I don't have many friends. I had one good friend. Now, I have two friends Karabo* in my school and Lerato* (she lives in Bethlehem* now); she used to live close by. Lerato's* mother said that maybe Lerato* can come and stay with us. She also used to pay my school fees and did everything for me. When Lerato* was little, then we would go with her father to the WIMPY and he took us to the casino. He also told Lerato* to give me her old phone, but it is gone now. I don't want to say it, but my mom swore at the person who took my phone; it was at my grandfather's funeral. It was a big funeral because my grandfather was a good golfer. He knew Ernie Els*. My auntie has also been on TV for golf … we have photos of her and Ernie Els* and a jacket that Ernie Els* gave her. She lives in Durban*. Many people in my family

			waar sy saam met Ernie Els* staan en ‘n baadjie wat sy by Ernie Els* gekry het. Sy bly in Durban*. Hulle is baie wat gholf speel.	play golf.
	So, what would Karabo* and LERATO* say about you?	Wat sal Karabo* en LERATO* van jou sê?	Partykeer dan baklei ek en Karabo* in die klas, dan skel ons mekaar, dan is ons weer reg. Lerato* se niggie het gesê dat ons al ons geheime moet uithaal en toe haal ek Lerato* s’n uit, (want sy het gesê sy vry saam Tlali*). Toe bel Lerato* haar pa en toe vloek Lerato* se pa my. Die dag daarna toe vra Lerato* askies.	Sometimes, Karabo* and I would argue or fight, then we scold each other but then we make peace shortly after. Lerato’s* cousin said that we should share our secrets with each other … so then I shared Lerato’s* secret (that she is dating Tlali*). Then Lerato* phoned her father who phoned me and scolded me. The next day, Lerato* apologised.
	How did you deal with Lerato’s* apology?	Hoe het jy dit hanteer toe sy askies gesê het?	Ek het dit reg hanteer.	I handled it well.
16	**What do your teachers say about you?**	Wat sê die onderwysers van jou?	Hulle sê ek is net reg.	They say that I am just right.
	What would the teachers tell me about you – what kind of a learner are you?	Wat sal die onderwysers vir my van jou vertel – watter tipe leerder is jy?	Ek is baie stout. Partykeer maak ek nie huiswerk nie, want ek vergeet. By die skool *like* ek om toilet toe te gaan, lyk my dat my blaas nie reg is nie … hulle hanteer my goed.	They would say that I am naughty. Sometimes I forget to do my homework. At school, I go to the toilet often but the teachers are fine with that … they treat me well.

17	**If you could be an animal, what animal would you like to be? Why?**	As jy ‘n diertjie kon wees, watter dier sou jy wou wees en hoekom?	‘n *Butterfly*, want ek *like* blomme en hy *like* ook blomme … pers [is my *favourite* blomme]. Soos my *auntie* maak blomme mooi vir *parties*.	A butterfly because I love flowers as butterflies do … my favourite colour is purple flowers. My auntie arranges flowers for parties.
18	**What are your favourite activities?**	Wat is jou *favourite* goed om te doen?	Ek *like* om te kook … soos as … die Sotho’s kook buite in swart potte en ek help my ma. Partykeer *like* ek om skottelgoed te was. Maar, as iemand my sê om iets te doen, dan kan ek dit nie dadelik doen nie. Toe ek klein was het ek altyd ses uur in die oggend opgestaan dan vee ek buitekant … nou is ek lui.	I like to cook … I help my mother to cook in the black pots (like the Sothos do). Sometimes I like to wash dishes. But when someone tells me to do something, I might not do it immediately. When I was little, I got up at six in die mornings and cleaned outside. Now I am too lazy.
19	**Name the things that you cannot do because of your heart problem. Does it bother you? What does it do to you?**	Is daar iets wat jy nie kan doen nie, omdat jy ‘n hartprobleem het en wat is dit?	Ek kan nie riem spring nie en *skipping rope* … Meeste van die goed kan ek nie doen nie soos netbal, maar ek *try* om dit te doen.	I can’t play *“riem-spring”* and skipping rope … most of the things I can’t do, such as netball, but I try to do it.
	And athletics? Are you allowed to take part in athletics?	En atletiek? Mag jy atletiek doen?	Nee.	No.
20	**Who looks after you? Tell me more about that person.**	Wie kyk agter jou?	My ma en my pa.	My mother and my father.
	Tell me more about your mother.	Vertel my paar sinne oor jou ma.	Sy’s ‘n regte ma, maar partykeer skel sy, sy’s iemand wat slaan. Sy skel net as dit nodig is. En as jy	She is a good mother but sometimes she scolds and hits. She only scolds when it

			haar iets vra sal sy dit doen (wat ek *short*). As daar nie kos is in die huis nie dan leen sy geld en betaal dit net weer terug.	is necessary. And when you ask her something, she will do it or get it for me (what I need). If there is no food at home, she will borrow money to get food for us.
	And your [step] dad?	En jou [stief] pa?	Hy is ook reg, maar jo, as hy dronk is dan is hy stil, maar as hy nugter is en hy is by die huis … as hy sien daar staan een koppie dan skel hy.	He is also good, but jo … when he is drunk he is silent (and sleeps) but when he is sober … jo, jo, jo … he scolds.
	Are you scared of him?	Is jy bang vir hom?	Partykeer, soos as hy my slaan dan lag ek hom uit. As my ma my slaan dan lag ek ook, want dis net vir ‘n rukkie seer en more is dit weer gesond.	Sometimes, like when he gives me a hiding I laugh at him. Even my mother hits me I laugh because it is only sore for a short while … tomorrow it is all better.
21	**Who understands you the best?**	Wie verstaan jou die beste?	My ma.	My mother.
22	**Who cares for you when you feel sick/sad/hungry/ scared?**	Wie kyk na jou as jy siek of bang of honger of hartseer voel?	My ma. Meeste was my ouma, nou is sy weg. I droom elke dag van haar. Ek het gedroom haar *funeral* was vier uur in die oggend. Die mense was iewers om reg te maak en die lyk het eers vier uur in die middag gekom. Toe gaan kyk ek na haar en gaan weer uit … sy was blou … toe is ons in die veld om	My mother. It used to be my grandmother but now she is gone. I dream about her everyday. I dreamt that her funeral was at four o’clock in the morning. The people were getting ready and the body only arrived at four o’clock in the afternoon. Then I went there to look at her … she was

			na my oompie se *funeral* toe te gaan en hier gaan die *ambulance* en die polisie net verby – ons het gedink hulle kom help vir ons. Toe ons daar kom, was die lyk daar. Ek het gedink dis my oompie se lyk maar toe het die lyk ge-*change* … toe is dit ouma. Toe gaan staan ek by die deur en toe huil ek. Ek hoor net: "Sarah* [my ma se naam], die kind huil, kom help!". Toe ek kyk, hier is my ouma wakker en toe gryp sy my hand en toe smeek ek haar om my hand te los en toe gaan staan ek weer by die deur.	blue … then I was in the field at my uncle's funeral, with the ambulance and police driving past to our house. When we arrived at home, I thought they brought my uncle's body … but the body had changed … it was my grandmother's body. Then I stood at the door and cried … I just heard, "Sarah* [my mother's name], the child is crying, come and help her!" Then Granny woke up, she grabbed my hand and I begged her to leave my hand and I went and stood at the door.
	So, you still think about your granny a lot?	So jy dink nog baie aan Ouma?	So, wanneer my ouma [ander ouma] my skel, dan dink ek baie aan haar … dan vra ek myself hoekom is dit sy wat oorlede is? Hoekom nie iemand anders nie. Sy het op Karabo* se ma se verjaarsdag gesterf laas jaar. Partykeer hoor ek iemand praat dan wonder ek wie praat dan is daar niemand nie – almal slaap. Of dan hoor ek voete stap in die huis in. Soos laasjaar toe is ons alleen by die huis saam met my oompie. Sy kind	When my other grandmother scolds me, then I think about this granny … then I ask myself why did she have to die … why not someone else? She died on Karabo's* mom's birthday, last year. Sometimes, I hear someone talk then I ask, "Who is talking?" but no-one talks – everybody is sleeping. Or, I would hear footsteps in the house then I ask again. Last year my

			het water gaan skep, toe sit hy die water op die kas en die piering is op die kas. Ek hoor toe net [geraas] in die kombuis en toe is die glas omgekeer, maar die water is nog in die glas, maar die water loop nie uit nie.	uncle and us were home alone. His child went and fetched water, came back and placed the water on the cupboard. I heard [a noise] in the kitchen … I saw that the glass (with water) was upside-down but the water was still in the glass.
	Did this really happen – it was not a dream?	Het dit regtig gebeur – was dit nie ‘n droom nie?	Nee, dit het rerig gebeur.	No, it really happened.
	So, sometimes you hear things like footsteps then there’s nothing and are you sure nobody else heard it?	So partykeer hoor jy iets soos voetstappe en dan is daar niks nie en is jy dan seker dat niemand anders dit gehoor het nie?	Ja, dan bly ek net stil.	Yes, then I just keep quiet.
	Do you sometimes see things that others don’t see?	Sien jy partykeer dinge wat ander mense nie sien nie?	Partykeer sien ek net iets blou wat so vinnig verby gaan … voor my ouma gesterf het, toe gaan iets blou verby my … toe sê hulle dis my oupa [wat oorlede is]. Toe huil ek toe lag hulle my uit.	Sometimes I see something blue moving past … it was before my grandma passed away … then they would say it was my [deceased] grandfather. Then I would cry and they would laugh at me.
	Since then, have you seen that blue motion again?	Het jy dit ooit weer gesien?	Ja, soos ‘n mens wat so loop en verbygaan. Toe vra ek: “Hoekom gaan jy kombuis toe?” Hy sê toe: “Jou oupa het nie ge-*like* as die kombuis so vuil is nie en dis hoekom ek kombuis toe gaan” … hulle het gesê dis	Yes, like a person walking past. I asked him why is he walking to the kitchen … he said that my grandfather never liked it when the kitchen was dirty … they said it was my grandfather … only I saw it.

			my oupa … net ek sien dit.	
	When last have you seen/heard something that others did not see/hear?	Wanneer laas het jy iets gesien of gehoor wat ander nie gesien of gehoor het nie?	Hierdie jaar, maar ek ken nie wanneer nie. Daar is mos iemand wat op die hoek wat ook al doodgesteek is. Sy't hakskoene ge-*like* nou loop sy met die hakskoene vier-uur in die oggend … ons hoor net as haar hakskoene lui dan weet ons sy is daar … sy kom na ons toe … net ek hoor.	This year, but I don't know when. Also, someone was stabbed to death at the corner near our place. She used to wear high heels and now she walks past with her high heels … we hear her high heels at four o'clock in the mornings ... the footsteps in the house – only I hear them.
23	**Tell me a story of a time when you and your family travelled together.**	Vertel vir my 'n regte storie van 'n keer wat jy saam met jou familie iewers heen gegaan het.	Toe ons in Margate* was … ek, my oupa, my ouma, my ma, my *auntie*, my oompie Nero* en Olson*. Ons het vir *Auntie* Anne* gaan kuier. Toe speel ons elke oggend in die see. Daar is mos daai *Anaconda*-ding … ek het op hom ge-*slide* (in die park). Net om te speel [was die lekkerste deel!] My oompie het gesê hy gaan my weer vat, maar ek ken nie of dit die waarheid is nie … hy is altyd besig of hy sê sy oog is seer.	We went to Margate … me, my grandfather, my grandmother, my mother, my auntie, my uncle, Nero* and Olson*. We went to visit Auntie Anne*. We went to the beach every day, we went on the slides (at the park) and we played a lot [it was the best thing about the trip]! My uncle said he will take me again but he is always busy or he would say that his eye is sore.
24	**Tell me more about your friends.**	Wat kan jy my nog vertel van jou vriende?	Karabo* is nie rerig my *tjommie* nie – partykeer loop sy nie saam met my nie, saam ander kinders. Ek wil baie *tjommies*	Karabo* is not really my friend – sometimes she doesn't walk with me – she would rather walk with

			hê, soos my ma. By die skool, as ek iets het dan loop hulle saam met my (daar is niemand by die skool wat ‘n goeie vriend vir my sal wees nie).	other children. I want many friends, like my mother. At school, when I have something then children pretend to be my friend. There is no-one at school who would be a good friend for me.
	How do you feel most of the time?	Hoe voel jy meeste van die tyd?	Partykeer voel ek reg, maar partykeer voel ek nie reg nie, as ek nie reg voel nie, as ek iets dink soos as ek nou iets gaan doen dan word die en die gedoen dan voel ek sleg. As ek sê mammie kom ons gaan iewers om te … dan sê ek maar *once*: “Dit gaan nooit gebeur nie.”	Sometimes I feel OK but sometimes not, especially when I think of something that I am going to do and then I would think that it might become an issue and then I feel bad. For example, if I ask my mom if we can go somewhere or do something and then I would think that maybe it would never happen.
	Thank you.	Dankie.		

Participant I
Boy, 8 years; Afrikaans
Note:

- The questions reflect the DPM-interview sheet, although not necessarily in the same order, but all the questions were covered.
- Keys: * Pseudonym.
  ** See the explanation of terms at the end of the transcript.
  *** Participant mixed language.

Question			Participant's response	
No	**English Translation**	**Researcher**	**Afrikaans**	**English**
1	**Why do you have to come to hospital from time to time?**	Hoekom moet jy partykeer hospitaal toe kom?	Om te kyk na my hart.	To look at my heart.
	Why does he [the doctor] need to check your heart?	Hoekom moet hy [die dokter] na jou hart kyk?	Om te kyk of ek *oraait* is.	To check if I'm all right.
	What do you say [about your heart]?	Wat sê jy [oor jou hart]?	Ek's *oraait*.	I'm all right.
	Why then do you have to visit the doctor?	Hoekom moet jy dan na die dokter toe kom?	Om te kyk of daar nie moeilikheid is nie.	To check if there isn't trouble.
	Has there been trouble with your heart in the past?	Was daar al moeilikheid met jou hart?	Ek weet nie.	I don't know.
2	**What is going on with your heart?**	Wat is nou aan die gang met jou hart?	Ek weet nie.	I don't know. I think there is a problem with my heart but I don't know what.
	Has the doctor explained to you what the matter with your heart is?	Het die dokter al vir jou verduidelik wat aan die gang is met jou hart?	Nee.	No.
	Would you like to know what the matter with your heart is?	Sal jy wil weet wat aan die gang is met jou hart?	Ja.	Yes.

3	**Do you have to take any medication, such as pills?**	Moet jy medikasie drink, soos byvoorbeeld pille?	Ja.	Yes.
	Why?	Hoekom?	Om my hart gesond te maak.	To heal my heart.
	So then, is there a problem with your heart?	So, is daar iets fout met jou hart?	Ek weet nie.	I don't know.
4	**What do you enjoy doing?**	Wat *like* jy om te doen?	Tennis speel en swem.	To play tennis and to swim.
	How good are you?	Hoe goed is jy?	Baie goed.	Very good.
	What else?	Wat nog?	Teken.	Drawing.
	What else?	Wat nog?	Speel.	Playing.
	Which games are your favourites?	Watter speletjies is jou gunstelinge?	Wegkruipertjie.	Hide-and-seek.
	With whom do you play hide-and-seek?	Saam met wie speel jy wegkruipertjie?	My niggies en nefies.	My cousins.
5	**Tell me more about the health of your family members.**	Vertel my bietjie van jou familie se gesondheid.	[Geen antwoord]	[No answer]
	First tell me, who lives with you in the house? Who is your family?	Vertel eers vir my, wie bly saam met jou in die huis, wie's jou familie?	My boetie en my ma en pa.	My brother and my mother and father.
	Now tell me more about the health of your family – are some of them ill?	Nou vertel my bietjie meer van jou familie se gesondheid – is daar van hulle wat siek is?	My ouma.	My grandmmother.
	What is wrong with Grandmother?	Wat is fout met ouma?	Ek weet nie.	I don't know.
	How do you know that she is ill?	Hoe weet jy dat sy siek is?	Sy het my gesê.	She told me.

	What did she tell you?	Wat het sy vir jou gesê?	Sy het net gesê sy is siek.	She only told me that she is ill.
	When did she tell you?	Wanneer het sy dit vir jou gesê?	Ek kan nie onthou nie.	I can't remember.
	Let's pretend that she did not tell you and you were just looking at her – how would you know that she is ill?	Sê nou sy het nie vir jou gesê nie en jy kyk haar net so – sou jy dan sê sy is siek? Hoe sal jy weet?	Haar oë is partykeer opgeswel.	Her eyes are sometimes swollen.
6	**How does your heart tell you when you are feeling sick?**	Hoe vertel jou hart vir jou as jy siek voel?	As ek "oorbring". Opgooi.	When I vomit.
	How often does it happen that you vomit?	Hoe gereeld gebeur dit dat jy opgooi?	Nie baie nie.	Not often.
	Anything else?	Nog iets?	Nee.	No.
7	**How do you feel about your ill heart?**	Hoe voel jy oor jou hart wat bietjie siek is? Hoe laat dit jou voel?	[Geen antwoord]	[No answer]
	How does it make you feel when someone tells you that your heart is ill?	Hoe laat dit jou voel as iemand vir jou sê jou hart is siek?	Gelukkig.	Happy.
	Why?	Hoekom?	Want dan kyk hulle [die dokters] na jou.	Because then they [the doctors] look after you.
8	**Name some things that you like about yourself.**	Watter dinge van jouself *like* jy?	Swem.	Swimming.
	Tell me more.	Vertel my meer.	Om te swem in die water en speel.	To swim in the water and to play.

	I want to know what is it about you that you are proud of or that you love?	Ek wil weet wat is daar van jouself waarop jy trots is of waarvoor jy baie lief is?	Ek hou van speel.	I like to swim.
9	**Name some things that you don't like about yourself that you want to change?**	Wat is daar van jouself wat jy nie *like* nie of wil verander?	Niks nie.	Nothing.
10	**What is happening to your heart?**	Wat is aan die gang met jou hart?	Ek weet nie.	I don't know.
	If you had to guess? Let's pretend that I am your doctor and I ask you, "What do you think is wrong with your heart?" – what will you tell the doctor?	As jy moet raai? Sê nou ek was die dokter en ek vra vir jou: "Wat dink jy gaan aan met jou hart?" – wat sal jy vir die dokter sê?	Niks nie.	Nothing.
	And what do you think will the doctor then tell you?	En wat dink jy sal die dokter dan vir jou sê?	Hy sal vir my sê wat aangaan.	He will tell me what is going on.
	How would you feel if he tells you what the matter with your heart is?	Hoe sal jy voel as hy vir jou verduidelik wat aangaan met jou hart?	[Geen antwoord]	[No answer]
	What would you tell him?	Wat sal jy vir hom sê?	Niks.	Nothing.
11	**Do you know what the word "wish" means?**	Weet jy wat die woord "wens" beteken?	Ja.	Yes.
	Tell me more.	Vertel my bietjie meer.	Ek weet nie.	I don't know.
	A wish is something that a person really wants or something that he really	'n Wens is iets wat mens baie graag wil hê of wil	Vir 'n tennisbaan en 'n swembad.	For a tennis court and a swimmingpool.

	wants to happen and then it happens. **If you had three wishes that would come true, which three things would you wish for?**	hê moet gebeur en dan gebeur dit dalk so. Sê nou jy het drie wense en daardie drie wense sal waar word, watter drie goed sal jy wens?		
	Where do you want the tennis court and the swimming pool?	Waar wil jy die tennisbaan en swembad hê?	Agter in die erf.	In the back of the yard.
	What else would you wish for?	Waarvoor sal jy nog wens?	Klere.	Clothes.
	Why would you wish to have clothes? Tell me more.	Hoekom sal jy vir klere wens? Vertel my bietjie.	Om aan te trek.	To wear it.
	I see that you are wearing nice clothes. Do you like to wear nice clothes? And Mommy, Daddy and your brother?	Ek sien jy het *nice* klere aan. *Like* jy *nice* klere? En Mamma, Pappa en boeta?	Ja.	Yes.
	So, why would you wish for more clothes?	So, hoekom sal jy vir nog klere wens?	Om dit op *Christmas* dag aan te trek.	To wear it on Christmas day.
	What happens on Christmas day? Why would you want to wear your new clothes on Christmas day?	Wat gebeur op *Christmas* dag? Hoekom wil jy jou nuwe klere op *Christmas* dag aantrek?	Ek weet nie.	I don't know.
12	**When you come to hospital and visit the doctor, what does he say to you?**	Wanneer jy hier by die hospital na die dokter toe kom, wat sê hy vir jou?	Hy sê hy is gelukkig om my weer te sien.	He says that he is happy to see me again.
	What else does he tell you?	Wat sê hy nog vir jou?	Niks nie.	Nothing.
13	**And what does Mommy say about you? What**	En wat sê mamma van jou? Wat sal	Ek weet nie.	I don't know.

	would she tell me about you?	sy vir my van jou sê?		
	I want you to take a guess. What does mommy say about you? Anything that you can think of.	Raai bietjie. Wat sê mamma van jou? Enigiets waaraan jy kan dink.	Dat ek hou van speel.	That I like to play.
	And if I were to ask your dad, "Tell me more about your son [Participant I]" – what would he say?	En sê nou ek vra vir Pa: "Vertel my bietjie van jou seun [Participant I]." – wat sal hy sê?	Dat ek hou van speel en swem.	That I like to play and to swim.
	Which type of "play" do they refer to?	Van watter "speel" praat hulle?	Wegkruipertjie.	Hide-and-seek.
	Do they sometimes play with you or only your cousins?	Speel hulle partykeer saam of net die nefies en niggies?	Ja [net die nefies en niggies].	Yes [only the cousins].
14	**What does your brother say about you?**	En wat sê jou boetie van jou?	Niks nie.	Nothing.
	What does your brother think of you?	Wat dink boetie van jou?	Ek weet nie.	I don't know.
	And when he is a grown-up, what would he say about you?	En wanneer hy groot is, wat sal hy van jou vertel?	Ek weet nie.	I don't know.
15	**What do your friends say to you?**	En jou maatjies? Ek sien jy is in Sterre* skool. Vertel my bietjie van die skool.	Ek geniet dit.	I enjoy it.
	Why do you enjoy it?	Hoekom geniet jy dit?	Speel.	Playing.
	What do you play at school?	Wat speel julle by die skool?	Tennis.	Tennis.

	So, what would your friends tell me about you?	So, wat sal jou maatjies vir my van jou vertel?	Ek weet nie.	I don't know.
	How so?	Hoe so?	[Geen antwoord]	[No answer]
	Help me to understand, what would your friends say about you?	Help my dat ons bietjie dink, wat sal jou maatjies van jou sê?	Dat ek van speel hou.	That I like to play.
	And what "play" do they talk about?	En van watter "speel" praat hulle?	Tennis.	Tennis.
	Who plays tennis with you?	Wie speel saam met jou tennis?	My maatjies.	My friends.
	Who are your good friends?	Wie is jou goeie maatjies?	Brandon*.	Brandon*.
	Are there other friends as well or only Brandon*?	Is daar nog maatjies of net Brandon*?	Net hy.	Only him.
	Tell me, why are you friends with him?	Hoekom is jy maatjies met hom, vertel my bietjie.	Hy hou ook van speel.	He also likes to play.
	Does he sometimes go and play at your house or are there other friends who go and play at your house?	Kom speel hy partykeer by jou huis of is daar ander maatjies wat partykeer by jou huis kom speel?	Nee, net die een langsaan … dis 'n dogtertjie … haar naam is Judy*.	No, only the one next door … it's a girl … her name is Judy*.
	What would she say about you?	Wat sal sy van jou vertel?	Dat ek hou van rondhardloop.	That I like to run.
16	**What do your teachers say about you?**	Wat sal Juffrou of Meneer van jou sê?	Ek weet nie.	I don't know.
	Let's pretend that I ask your teacher, "What kind of a child is he [participant I]?" what would she tell me?	Kom ons speel-speel dat ek vir jou juffrou vra: "Wat se tipe kind is hy [participant	Dat ek skaam is.	That I am shy.

		I]?" wat sal sy vir my vertel?		
	What else would she say?	Wat sal sy nog sê?	Niks nie.	Nothing.
	What would she say about your school work?	Wat sal sy sê oor jou skoolwerk?	Ek weet nie.	I don't know.
	Will the teacher say that you are a good child or a naughty child or what would she say?	Sal juffrou sê jy's 'n goeie kind of stoute kind of wat sal sy sê?	Goeie kind.	[A] good child.
	What is this teacher's name?	Wat is jou juffrou se naam?	Rose*.	Rose*.
	How does teacher Rose* talk with you, tell me more.	Hoe gesels juffrou Rose* met jou, vertel my 'n bietjie.	Sy gesels baie.	She talks a lot.
	What does she say to you?	Wat sê sy vir jou?	Sy maak net grappies.	She only makes jokes.
	How do you feel about teacher Rose*?	Hoe voel jy oor juffrou Rose*?	Bly … sy's goed.	Happy … she's good.
17	**If you could be an animal, what animal would you like to be? W**	Sê nou jy kan kies om enige dier te wees, watter dier sal jy kies en hoekom?	'n Skoenlapper.	A butterfly.
	Wow! Why?	*Wow*! Hoekom?	Want dis vol kleure.	Because it is colourful.
	What is it about the colours that is nice for you?	Wat is dit van die kleure wat vir jou *nice* is?	Dit skyn uit.	It shines outwards.
	What are your favourite colours?	Wat is jou gunsteling kleure?	Blou en groen.	Blue and green.
	What are the colours of butterflies?	Watter kleure is skoenlappers?	Ek kan nie onthou nie.	I can't remember.

	What does it [the colours] say about a butterfly?	Wat sê [die kleure] van ‘n skoenlapper?	Dat dit [‘n skoenlapper] hou van rondvlieg.	That it [a butterfly] likes to fly around.
	What does it do when flying around?	Wat gaan doen dit as dit so rondvlieg?	Ek weet nie.	I don’t know.
18	**Quickly name your favourite activities again.**	Noem gou weer die goed wat vir jou lekker is om te doen.	Speel (wegkruipertjie) en swem en teken.	Playing (hide-and-seek) and swimming and drawing.
	Anything that you want to add?	Enigiets wat jy wil bysit?	Nee.	No.
20	**Name the things that you cannot do because of your heart problem.**	Noem ‘n paar dinge wat jy nie kan doen nie, omdat jy ‘n probleem met jou hart het.	Te veel hardloop. Ongelukkig wees.	Running too much. Being unhappy.
	Tell me more about the “unhappy”, so that I would understand what you mean.	Vertel bietjie meer oor die “ongelukkig”, dat ek mooi verstaan wat jy bedoel.	Ek mag nie baie kwaad wees nie.	I should not get angry much.
	Why should you not become angry?	Hoekom mag jy nie baie kwaad wees nie?	Ek weet nie.	I don’t know.
	Do you sometimes become angry?	Raak jy partykeer kwaad?	Ja.	Yes.
	For? What angers you?	Vir wat? Wat maak jou kwaad?	My neef, as ons speel, dan wil hy saam met ons kom speel, maar hy weet nie hoe om dit [die speletjie] te speel nie.	My cousin, when we play, then he wants to play with us but he doesn’t know how to play [the game].

	What about that angers you? What would he [your cousin] say?	Wat is dit wat jou dan kwaad maak? Wat sal hy [jou neef] sê?	Want hy speel saam en dan hardloop hy in as ons hom moet loop soek [tydens wegkruipertjie].	Because he would play with us but then he would run into the house when we have to search for him [during hide-and-seek].
	Who told you that you should not become angry?	Wie het vir jou gesê dat jy nie baie mag kwaad raak nie?	My pa.	My dad.
	How do you feel about the fact that you should not run too much?	Hoe voel jy daaroor dat jy nie baie kan hardloop nie?	Niks nie.	Nothing.
	What does it mean – how does it make you feel?	Wat beteken dit – hoe laat dit jou voel?	Bly.	Happy.
20	**Who looks after you? Tell me more about that person.**	Wie sorg vir jou?	My ma.	My mother.
	What do you say about your mommy?	Wat sê jy van jou mamma?	Sy hou van kos maak.	She likes to cook.
	How does her food taste?	Hoe proe haar kos?	Lekker	Tasty.
	Have you told her that she makes tasty food?	Het jy al vir haar gesê dat sy lekker kos maak?	Nee.	No.
	What else about Mom?	Wat nog oor Ma?	Niks.	Nothing.
21	**Who understands you the best?**	Wie verstaan en ken jou die beste?	My maatjies.	My friends.
	Which friends?	Watter maatjies?	By die skool.	At school.
	What are their names?	Wat is hulle name?	Net Brandon*	Only Brandon*

	How does he know you so well?	Hoe ken hy jou so goed?	Want ons speel baie tennis.	Because we play a lot of tennis together.
	What if you have a problem and you need to talk to someone about it, who would you talk to?	Sê nou jy't 'n probleem en jy moet nou met iemand gaan praat oor die probleem, met wie sal jy gaan praat?	Met juffrou.	With teacher.
	Which teacher?	Watter juffrou?	Juffrou Rose*	Teacher Rose*
	Why would you spak to her if you have a problem?	Hoekom sal jy met haar gaan praat as jy 'n probleem het?	Sy gaan my help.	She will help me.
22	**Who cares for you when you feel sick/sad/hungry/scared?**	Wie kyk na jou as jy siek of hartseer of honger of bang voel?	My ma en pa.	My mother and father.
23	**Tell me a story of a time when you and your family travelled together.**	Vertel my bietjie van 'n keer wat jy en jou gesin iewers heen gegaan het.	Ons het gaan uiteet toe wil my neefs by SPUR gaan eet. Toe gaan ons en toe wil hulle weer gaan.	We went and ate at SPUR with my cousins. Then they wanted to go again.
	Do you think that you will go to SPUR again?	Dink jy julle sal weer SPUR toe gaan?	Ek weet nie.	I don't know.
	Who went with you to SPUR?	Wie was almal saam by SPUR?	My twee neefs en my een niggie [en Pappa, Mamma, broer en ek].	My cousins [and my dad, mom, brother and me].
	What was the nicest part of that time when you went to SPUR?	Wat was vir jou die lekkerste van daardie keer by die SPUR?	Om te speel.	To play.

	Also tell me about a time when you and your family travelled to some place (destination) together.	Vertel my ook van ‘n keer wat julle saam iewers heen gery het.	Winburg*.	Winburg*.
	Where is that?	Waar is dit?	Naby [aan ons].	Close [to us].
	Why did you go there?	Hoekom het julle soontoe gegaan?	Vir my pa se lisensie.	For my father’s licence.
	What type of licence?	Watse lisensie?	Kar.	Car.
	Who went with you? Daddy, you and who else?	Wie’t saamgegaan? Pappa, jy, en wie nog?	My ma en my boetie.	My mother and brother.
	What did you do while dad was getting his licence?	Wat het julle gedoen terwyl pappa vir sy lisensie gegaan het?	Gewag.	Waited.
24	**What more can you tell me about your friends?**	Wat kan jy my nog van jou maatjies vertel?	Hulle hou van lees.	They enjoy reading.
	Which friends enjoy reading?	Watter maatjies hou van lees?	Andy*.	Andy*.
	Do you like to read?	Hou jy van lees?	Ja.	Yes.
	What types of books do you read?	Watter tipe boeke lees jy?	Engels.	English.
	Why is Andy* a good friend to you?	Hoekom is Andy* ‘n goeie maatjie vir jou?	Hy hou van deel.	He likes to share.
	What does he share with you?	Wat deel hy met jou?	Lekkers.	Sweets.
	What kind of a friend do you think you are to him?	Watse tipe maatjie dink jy is jy vir hom?	Goeie [maatjie].	Good [friend].
	What makes you a good friend?	Wat maak jou ‘n goeie maatjie?	Ek deel.	I share.

	Anything else that you can tell me about your friends?	Enigiets anders wat jy nog van jou maatjies kan vertel?	Nee.	No.
	Quickly tell me, are there children at school who are sometimes nasty towards you?	Sê gou vir my, is daar kinders by die skool wat partykeer lelik is met jou?	Ja.	Yes.
	Tell me more about that.	Vertel my ‘n bietjie meer daarvan.	Hulle het my seer gemaak en toe sê hulle nie *sorry* nie.	They hurt me and they didn’t apologise.
	Why did they hurt you?	Hoekom het hulle jou seergemaak?	Ek weet nie.	I don’t know.
	How did they hurt you?	Hoe het hulle jou seergemaak?	[My] geslaan.	Hit [me].
	How did that make you feel?	Hoe het dit vir jou gevoel?	Ongelukkig.	Unhappy.
	Thank you.	Dankie.		

APPENDIX I: STATEMENT BY THE TRANSLATOR

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Greetings

This serves as a statement that I am a qualified language practitioner in the Free State, South Africa. Language Services offered to Mrs Carina Pheiffer by me for her Master's research dissertation were of high quality and professionalism. I translated all responses from participants during the interviews as well as the verbatim transcriptions from Sesotho, Setswana and isiZulu to English.

Thembasi Yvonne Mkhumbeni

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APPENDIX J: STATEMENT BY LANGUAGE EDITOR

Hereby I, Jacob Daniël Theunis De Bruyn STEYL (I.D. 5702225041082), a language practitioner accredited with the South African Translators' Institute (SATI), confirm that I have language edited the following thesis:

Title of thesis: The Psychosocial Themes of Children with a Congenital Heart Defect

Author: Ms Catharina Gerdina Pheiffer

Yours faithfully

J.D.T.D. STEYL
PATran (SATI)
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