

**THE PREDICTION OF PSYCHOLOGICAL WELL-BEING IN CHILDREN
AND ADOLESCENTS WITH CHRONIC, LIFE THREATENING
ILLNESSES**

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STATEMENT

I, Brenda Denise Talbot, declare that the thesis submitted by me for the Philosophae Doctor (Child Psychology) degree at the University of the Free State is my own independent work and has not previously been submitted by me at another university/faculty. I furthermore cede copyright of the thesis in favour of the University of the Free State.

B D Talbot

Date

DEDICATION

This research is dedicated to my son Dylan Talbot (1984-2005) whose twenty one year journey with long term illness has taught me the true meaning of resilience, courage, hope and fortitude.

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Abstract

A life threatening illness has the potential to disrupt the child's world at a time when significant developmental changes are taking place. Extensive literature exists on the impact of illness on the developing child however current salutogenic research has provided evidence that psychological well-being is attainable regardless of disease status, and that children with life threatening illnesses like cancer can be as psychologically well-adjusted as healthy ones. There is a need to develop a better understanding of psychological well-being despite serious risks such as life threatening illnesses. The current study aims to identify factors that promote well-being in children with life threatening illnesses, as measured by life satisfaction as a component of well-being. A mixed method sequential explanatory design was used in this study. An availability sample of children aged 10-18 years ($N=44$) was recruited from oncology treatment centres in Durban and Bloemfontein, South Africa. The whole sample participated in the quantitative study using self-report measures. The objectives of the quantitative component of the study were to identify factors that explain the variance in life satisfaction and to investigate the differences in coping resources between children with high and low levels of life satisfaction. The following self-report measures were used to gather quantitative data: Satisfaction with Life Scale, Coping Resources Inventory, Fortitude Scale and Children's Hope Scale. Descriptive statistics were calculated for all scales and Pearson product moment correlation coefficients were determined between all subscales. A hierarchical regression analysis was used to determine the relationship between the predictor and criterion variables. The Mann Whitney U test was used to determine the significance of differences in children with high and low levels of life satisfaction. The quantitative findings suggested average levels of life satisfaction for the whole group even when compared to children without illness. Satisfaction with life correlated significantly with hope and social support (1% level of significance) and with cognitive coping (5% level of significance). The predictor variables accounted for 38.9% of the variance in life satisfaction. A strong interdependence was found between coping resources. The difference between children with high and low levels of life satisfaction was in their sense of hope and appraisal of social support. The goal of the qualitative component of the study was to explore the children's experiences of the impact of the illness on their well-being. For this component of the study, participants with high life satisfaction scores were recruited ($n=6$). Semi-structured interviews were conducted and analysed using

thematic content analysis. Insight into the significant impact of cancer was gained as well as the most frequently used coping resources and strategies that facilitate coping and well-being. The most frequently used coping resources included maintaining a sense of hope, utilising social support and gathering developmentally appropriate information, as well as cognitive coping which included cognitive reformulation, internal positive dialogue and finding meaning and purpose. Respondents also reported emotional, relational and spiritual coping. Concluding findings were that social support, hope and cognitive coping were the most powerful predictors of life satisfaction and that the difference between children with high and low levels of life satisfaction was related to sense of hope and appraisal of social support. A limitation of this study was the small sample size. Cultural variations were found in the information seeking behaviours and concept of family in terms of social support. Further investigation of these, especially for the South African context, is recommended. Knowledge of these well-being predictors for children with long term illnesses should be considered in health care policy formulations, and intervention programmes for enhancing well-being and identifying children at risk for adjustment difficulties.

Key words: children, adolescents, life threatening illness, life satisfaction, coping resources, coping strategies.

Abstrak

'n Lewensbedreigende siekte het die potensiaal om 'n kind se lewe te ontwig op 'n tydstep wanneer betekenisvolle ontwikkeling plaasvind. Omvattende literatuur bestaan oor die impak van siekte op die ontwikkelende kind, huidige salutogene navorsing dui egter daarop dat psigologiese welstand bereikbaar is ten spyte van die siektetoestand en dat kinders met lewensbedreigende siektes, soos kanker, psigologies net so goed aanpas soos gesonde kinders. Daar is egter 'n behoefte om die faktore wat psigologiese welstand bevorder ten spyte van lewensbedreigende siekte, beter te verstaan. Die huidige ondersoek poog om faktore wat die welstand bevorder van kinders met lewensbedreigende siektetoestande, te identifiseer. 'n Gemengde metode, opeenvolgende, verklarende ontwerp is in die ondersoek gebruik. 'n Beskikbaarheidsteekproef van 44 kinders tussen die ouderdomme 10 tot 18 jaar is gewerf by onkologie behandelingsentrums in Durban en Bloemfontein, Suid-Afrika. Die volledige steekproef het aan die kwantitatiewe ondersoek deelgeneem en het die selfrapporteringsvraelyste voltooi het. Die doelstellings van die kwantitatiewe komponent van die studie was om faktore te identifiseer wat die variansie in die deelnemers se lewenstevredenheid verklaar asook om verskille in die copinghulpbronne van respondente met hoë en lae vlakke van lewenstevredenheid te ondersoek. Die volgende meetinstrumente is gebruik om kwantitatiewe data in te win: Lewenstevredenheidskaal, Coping-hulpbronne opname, Fortaliteitskaal en die Hoopskaal vir kinders. Beskrywende statistieke is vir alle skale bereken en Pearson produkmoment-korrelasiekoëffisiënte tussen alle skale is bepaal. 'n Hiërargiese regressie-ontleding is uitgevoer om die verhouding tussen die kriterium- en voorspellingsveranderlikes te ondersoek. Die Mann Whitney U toets is gebruik om die beduidendheid van verskille tussen die groep met lae en hoë lewenstevredenheid te bepaal. Die kwantitatiewe resultate het getoon aan dat die totale groep respondente gemiddelde vlakke van lewenstevredenheid rapporteer selfs wanneer hulle met gesonde populasies vergelyk word. Lewenstevredenheid van die groep het beduidend gekorreleer met hoop en sosiale ondersteuning (op die 1% beduidendheidspeil) en met kognitiewe coping (op die 5% beduidendheidspeil). Die voorspeller veranderlikes het 38.9 % van die variansie in die groep se lewenstevredenheid verklaar. 'n Sterk mate van interafhanklikheid is tussen die copingveranderlikes gevind. Die kinders met hoë en lae vlakke van lewenstevredenheid het beduidend verskil ten opsigte van hulle gevoel van hoop en hulle beoordeling van sosiale ondersteuning. Die doel van die kwalitatiewe komponent van die ondersoek was om die

kinders se ervaring van die impak van die siektetoestand op hulle welstand te eksplorieer. Respondente met hoë vlakke van lewenstevredenheid ($n=6$) is gewerf vir die kwalitatiewe komponent van die studie. Semi-gestruktureerde onderhoude is gevoer en die inligting is met behulp van tematiese inhoudsontleding ondersoek. Insig is verkry ten opsigte van die impak van die siektetoestand op die kinders se welstand asook ten opsigte van die copinghulpbronne en copingstrategieë wat dikwels gebruik word en wat welstand en verhoogde aanpassing bevorder. Die algemeenste copinghulpbronne wat gerapporteer is, behels om 'n gevoel van hoopvolheid te behou, om sosiale ondersteuningsnetwerke te benut, om ouderdomsgepaste inligting te versamel en om kognitiewe coping te gebruik, insluitend kognitiewe herformulering, interne positiewe dialoogvoering en om sin en betekenis te vind. Respondente het die gebruik van 'n reeks emosionele, relasionele en spirituele copingstrategieë beskryf. Samevattende bevindings toon dat sosiale ondersteuning, hoop en kognitiewe coping die belangrikste voorspellers van die welstand van die kinders was. Die tekortkominge van die ondersoek hou veral verband met die klein steekproefgrootte. Kulturele variasies is gevind in die soeke na inligting en die konsep van gesinsondersteuning. Verdere ondersoek van hierdie aspekte, veral in die Suid-Afrikaanse konteks word aanbeveel. Kennis oor die voorspellers van die welstand van kinders met lewensbedreigende siektetoestande moet in ag geneem word in die formulering van gesondheidsorgbeleid asook in intervensieprogramme ter bevordering van die welstand van kinders asook in die identifisering van kinders wat moontlik 'n verhoogde risiko vir aanpassingsprobleme het.

Sleutelwoorde: kinders, adolessente, lewensbedreigende siekte, lewenstevredenheid, copinghulpbronne, copingstrategieë.

Resilience does not come from rare and special qualities, but from the everyday magic of ordinary, normative human resources in the minds, brains, and bodies of children, in their families and relationships, and in their communities (Masten, 2001, p.227).

TABLE OF CONTENTS

STATEMENT	ii
DEDICATION	iii
ACKNOWLEDGEMENT	iv
ABSTRACT	v
ABSTRAK	vii

CHAPTER 1: INTRODUCTION

1.1	ORIENTATION AND PROBLEM STATEMENT	1
1.2	OBJECTIVES AND RESEARCH QUESTIONS	4
1.3	RESEARCH METHOD	4
1.4	ETHICAL CONSIDERATIONS	6
1.5	CONCEPT CLARIFICATION	7
1.6	STRUCTURE OF THE THESIS	9

CHAPTER 2: STRESS, COPING AND HEALTH: MODELS

OF STRESS AND COPING

2.1	INTRODUCTION	11
2.2	THEORETICAL SHIFT IN STRESS AND COPING RESEARCH: AN HISTORICAL PERSPECTIVE	11
2.2.1.	Stress as a response	11
2.2.1.1.	Limitations of the response theory of stress	12
2.2.2.	Stress as a stimulus	13
2.2.2.1.	Limitations of the stimulus theory of stress	14
2.2.3.	Stress as a transaction between the person and the environment	15
2.2.3.1.	Limitations of the transactional model of stress	16

2.3.	PARADIGM SHIFT FROM PATHOGENESIS TO SALUTOGENESIS: THE EMERGENCE OF POSITIVE PSYCHOLOGY	16
2.3.1.	The shift from pathogenesis to salutogenesis	16
2.4.	THEORETICAL MODELS OF STRESS AND COPING	18
2.4.1.	Richard Lazarus	19
2.4.1.1.	Biographical information	19
2.4.1.2.	Lazarus' model of stress and coping	20
2.4.1.2.1.	Background to the model	20
2.4.1.2.2.	Explanation of Lazarus' model	21
2.4.1.2.2.1.	Causal antecedents of appraisal (person and environment factors)	22
2.4.1.2.2.2.	Mediating processes	23
2.4.1.2.2.3.	Adaptational outcomes	28
2.4.1.2.3.	Critique of Lazarus' model	29
2.4.2.	Aaron Antonovsky	30
2.4.2.1.	Biographical information	30
2.4.2.2.	Antonovsky's salutogenesis model of health	31
2.4.2.2.1.	Stressors	33
2.4.2.2.2.	Tension/tension management and stress	33
2.4.2.2.3.	Generalised resistance resources – resistance deficits (GRR-RD)	34
2.4.2.2.4.	Sense of coherence (SOC)	35
2.4.2.2.5.	Individual placement on the health ease/dis-ease continuum	37
2.4.2.3.	Critique of Antonovsky's model	38
2.4.3.	Rudolph Moos	39
2.4.3.1.	Biographical information	39
2.4.3.2.	Moos' integrated stress and coping process model	40
2.4.3.2.1.	Background to the model	40
2.4.3.2.2.	Explanation of Moos' model	41
2.4.3.3.	Critique of Moos' model	45
2.5	CONCLUSION	46

CHAPTER 3: THE CHILD WITH CANCER: A DEVELOPMENTAL PERSPECTIVE

3.1	INTRODUCTION	48
3.2	IMPROVED CANCER SURVIVAL RATES AND QUALITY OF LIFE ISSUES	48
3.3	UNDERSTANDING CANCER	49
3.3.1	The disease process	50
3.3.2	Incidence and types of cancer in children	50
3.3.3	Etiology and associated risk factors	52
3.3.3.1	Environmental exposure	53
3.3.3.2	Prenatal drug and substance exposure	53
3.3.3.3	Parental occupational exposures	54
3.3.3.4	History of maternal foetal loss	55
3.3.3.5	Biological factors	55
3.3.4	Diagnosis, treatment and side effects	55
3.3.5	Conclusion	57
3.4	UNDERSTANDING DEVELOPMENT	57
3.4.1	Middle childhood	58
3.4.1.1	Physical development	58
3.4.1.2	Cognitive development	58
3.4.1.3	Emotional and affective development	59
3.4.1.4	Social development	60
3.4.1.5	Moral development	60
3.4.2	Adolescence	61
3.4.2.1	Physical development	61
3.4.2.2	Cognitive development	62

3.4.2.3	Emotional and affective development	63
3.4.2.4	Social development and interpersonal relationships	65
3.4.2.5	Moral development	66
3.5	UNDERSTANDING CHILDHOOD CANCER IN THE CONTEXT OF DEVELOPMENT: BI-DIRECTIONAL IMPACT	67
3.5.1	The impact of cancer on the child	68
3.5.1.1	Diagnosis and prognosis	69
3.5.1.2	Adapting to the treatment and side effects	70
3.5.1.3	Relationships with others	71
3.5.1.4	Dealing with two worlds: illness and health	73
3.5.2	The impact on the family system	74
3.5.2.1	Medical stressor	77
3.5.2.1.1	Pre-diagnostic stage	78
3.5.2.1.2	Diagnosis	78
3.5.2.1.3	Remission and relapse	79
3.5.2.2	Personal and social stressors	79
3.5.2.2.1	Intellectual stress	79
3.5.2.2.2	Instrumental stress	80
3.5.2.2.3	Interpersonal stress	80
3.5.2.2.4	Existential stress	81
3.5.3	The impact on the siblings	81
3.5.4	The impact on the marital system	82
3.5.5	The impact on the parent-child relationship	82
3.5.6	Late effects of cancer and the cancer survivor	83
3.5.6.1	Cognitive late effects	84
3.5.6.2	Psychological late effects	84

3.6	CONCLUSION	87
CHAPTER 4: COPING AND WELL-BEING		
4.1	INTRODUCTION	89
4.2	UNDERSTANDING THE LINK BETWEEN COPING AND WELL-BEING	89
4.3	THE CONSTRUCT OF COPING	93
4.3.1	Coping resources	95
4.3.1.1	Internal coping resources	96
4.3.1.1.1	Spiritual/religious or philosophical belief systems and meaning/purpose in life	97
4.3.1.1.2	Hope	99
4.3.1.1.3	Self esteem	101
4.3.1.2	External coping resources	102
4.3.1.2.1	Social support	102
4.3.1.2.2	Information	105
4.3.1.2.3	Basic living conditions and services	107
4.3.2	Modes of coping	110
4.3.2.1	Coping strategies	110
4.3.2.2	Coping skills	111
4.3.2.2.1	Approach coping	112
4.3.2.2.2	Avoidance coping	112
4.3.2.3	Dimensions of coping	113
4.3.2.3.1	Problem-focused coping	114
4.3.2.3.2	Emotion-focused coping	114
4.3.2.3.3	Relational coping	115
4.3.3	Factors moderating coping	116

4.3.3.1	Age	116
4.3.3.2	Gender	118
4.3.3.3	Culture	119
4.3.3.4	Socio-economic factors	121
4.4	WELL-BEING AS A CONSTRUCT	123
4.4.1	The hedonic perspective on well-being	123
4.4.1.1	Life satisfaction	124
4.4.2	The eudaimonic perspective on well-being	126
4.4.3	Factors moderating well-being	127
4.4.3.1	Age and gender	128
4.4.3.2	Culture	129
4.4.3.3	Socio-economic factors	130
4.5	CONCLUSION	132
CHAPTER 5: RESEARCH DESIGN AND METHODOLOGY		
5.1	INTRODUCTION	135
5.2	RESEARCH DESIGN	135
5.3	THE OVERARCHING AIM OF THE STUDY	136
5.4	QUANTITATIVE STUDY	136
5.4.1	Research questions, objectives and hypotheses	136
5.4.2	Research participants	137
5.4.2.1	Demographic characteristics of participants	138
5.4.2.1.1	Age	138
5.4.2.1.2	Gender	139
5.4.2.1.3	Racial distribution of participants	139
5.4.2.1.4	Educational levels of participants	139
5.4.2.1.5	Medical diagnoses	140

5.4.2.1.6	Time lapse since diagnosis	141
5.4.2.1.7	Treatment centres	141
5.4.2.1.8	Parental employment status: Father	142
5.4.2.1.9	Parental employment status: Mother	142
5.4.3	The quantitative data gathering process	143
5.4.3.1	Universitas Hospital, Bloemfontein	144
5.4.3.2	Inkosi Albert Luthuli Central Hospital, Durban	144
5.4.3.3	Private patients, Durban	145
5.4.4	Practical problems associated with data gathering	145
5.4.5	Measuring instruments	146
5.4.5.1	Satisfaction with Life Scale	147
5.4.5.2	Coping Resources Inventory	148
5.4.5.3	Children's Hope Scale	149
5.4.5.4	Fortitude Scale	150
5.4.5.5	Biographical questionnaire	152
5.4.6	Statistical data analysis	153
5.5	QUALITATIVE STUDY	153
5.5.1	Aims and goals of the study	154
5.5.2	Research design	154
5.5.3	Research participants	154
5.5.4	Data gathering process	155
5.5.5	Interview process: semi-structured interview process	155
5.5.6	Method of data analysis	156
5.6	ETHICAL CONSIDERATIONS	157
5.7	CONCLUSION	158

CHAPTER 6: RESULTS AND DISCUSSION

6.1	INTRODUCTION	159
6.2	QUANTITATIVE RESULTS	159
6.2.1	Reliability coefficients and descriptive statistics	159
6.2.2	Intercorrelations	164
6.2.3	Hierarchical regression analysis	167
6.2.4	Significance of differences between groups with high and low life satisfaction	169
6.3	QUALITATIVE RESULTS	172
6.3.1	Theme 1: Cancer as a stressor: Impact of diagnosis and treatment	172
6.3.1.1	The emotional impact of cancer	172
6.3.1.2	Impact on physical abilities	176
6.3.1.3	Disruption of daily lives	177
6.3.1.4	The impact on significant relationships	178
6.3.1.5	Impact on education and mental/intellectual stimulation	181
6.3.1.6	Overview of the impact of diagnosis and treatment	182
6.3.2	Theme 2: Coping resources and coping strategies	183
6.3.2.1	Coping resources	184
6.3.2.1.1	Information as a resource	184
6.3.2.1.1.1	Overview of information as a resource	189
6.3.2.1.2	Social support as a resource	190
6.3.2.2	Modes of coping	196
6.4	SUMMARY AND INTEGRATION OF QUANTITATIVE AND QUALITATIVE RESULTS	204
6.5	CONCLUSION	207

CHAPTER 7: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

7.1	INTRODUCTION	209
7.2	SUMMARY AND CONCLUSIONS OF THE LITERATURE REVIEW	209
7.3	SUMMARY AND CONCLUSIONS OF QUANTITATIVE AND QUALITATIVE RESEARCH FINDINGS	212
7.4	LIMITATIONS OF THIS STUDY	215
7.5	RECOMMENDATIONS	217
	7.5.1 Recommendations for future research	217
	7.5.2 Recommendations for practice	217
7.6	CONTRIBUTIONS OF THIS STUDY	218
7.7	PERSONAL REFLECTIONS	219
	LIST OF REFERENCES	221

LIST OF FIGURES

Figure 1	A theoretical schematization of stress, coping and adaptation	21
Figure 2	Antonovsky's salutogenesis model of health	32
Figure 3	The integrated stress and coping process model	41
Figure 4	The incidence of childhood cancers	51
Figure 5	The widespread impact of childhood cancer	68
Figure 6	A model of the interplay between context, coping, and adaptation among youth	90
Figure 7	Age distribution of participants	138
Figure 8	Gender distribution of participants	139
Figure 9	Racial distribution of participants	139
Figure 10	Educational levels of participants	140
Figure 11	Medical diagnoses of participants	140
Figure 12	Lapse in time since initial diagnosis	141
Figure 13	Recruitment of participants from state and private treatment centres	142
Figure 14	Parental employment status: Father	142
Figure 15	Parental employment status: Mother	143

LIST OF TABLES

Table 1	Summary of participants' information – qualitative interviews	155
Table 2	Alpha-coefficients for subscales of measuring instruments	160
Table 3	Averages and standard deviations for the total investigated group	161
Table 4	Comparison of means and standard deviations of healthy and ill students and investigated group: Coping Resources Inventory	162
Table 5	Intercorrelations between predictor variables and the criterion variable ($N=44$)	165
Table 6	The contribution of the different variables to R^2	168
Table 7	Mann-Whitney U results on the scales for the two groups	170

APPENDICES

Appendix A	Ethics approval	263
Appendix B	Guardian consent form	264
Appendix C	Participant assent form	265
Appendix D	Biographical questionnaire	266
Appendix E	Semi structured questionnaire	269

CHAPTER 1

INTRODUCTION

1.1 ORIENTATION AND PROBLEM STATEMENT

A life threatening illness has the potential to disrupt a child's world at a time when extensive and rapid developmental change is occurring and important developmental tasks are being negotiated. In addition to the impact on the physical, cognitive, social and emotional development of the child, the impact on its family and other significant systems, of which it is a part, can be profound.

The biomedical model of medicine, which has as its framework the presence or absence of disease, has influenced psychological research and literature and thus the focus has been on the diagnosis and treatment of disease in both psychology (psychopathology) and medicine. Consistent with this perspective is the paradigm that a person who has a chronic life threatening illness cannot attain a state of psychological well-being in the presence of disease (Lyon, 2000).

The emergence of cognitive psychology in the 1980s brought with it the inclusion of concepts such as individual differences in coping (Lyon, 2000). Coping theories thus shifted to include the recognition that a person's coping skills and resources can potentially mediate the impact of life stressors. Theorists such as Lazarus (2000a) have provided an important theoretical framework, recognising the transaction between the individual and the life stressor. He incorporated the role of appraisal, which included the significance of the stressful event to the individual, as well as the individual's ability to deal with the event.

The extension and inclusion of such constructs challenged traditional thinking and brought with it a shift in research questions. Researchers such as Antonovsky (1987) argued that it was necessary to move beyond the biomedical model and its focus on disease and rather examine those factors that enhance the individual's capacity to cope (Horsburgh,

2000). Antonovsky's Salutogenesis model of stress and coping describes the process of maintaining well-being despite being exposed to a life stressor, such as a long-term illness. The recognition that psychological well-being can be experienced regardless of the improvement or deterioration of a chronic life threatening illness has made an important contribution to both psychology and medicine, and provides an alternative to the biomedical model which focuses on pathogenesis rather than salutogenesis (Horsburgh, 2000).

As a result of the biomedical focus, stressors had little importance as a construct in psychology. Following the shift in thinking, the field of stress and coping has become the most vigorously researched area of psychology in the past two decades. In the period 1982–1992, psychology literature (PsycINFO) reflected 46 000 references to stress and coping with a further 136 000 in the five-year period between 2003 and 2008 (Frydenberg, 2008). While the increase in stress and coping research has been significant, the focus has been on adult studies. On the one hand, the knowledge gained from adult studies that psychological well-being can be attained despite the improvement or deterioration of a medical condition, is important and is conceptually applicable to children. On the other hand, the social, cognitive and physical realities of children differ significantly from those of adults. Historically, stress-coping theories for children and adolescents have been adapted from adult models even though appraisal and cognition are central to the more recent theories and these processes are likely to differ between children and adults (Ryan-Wenger, Sharrer, & Wynd, 2000). There is a need not only for increased differentiation in stress constructs and measures, but also differentiation and coherent frameworks for understanding the differences between the adult and child in terms of these processes (Wertlieb, 1991).

Antonovsky (1979, 1987) wrote that stressors are omnipresent but it is the availability of resources that determines the adjustment outcomes. While it is important to recognise the impact that a long-term illness can have on children, the knowledge that it is possible to attain psychological well-being in its presence, is equally important. This makes the identification of the factors that can promote coping and psychological well-being, and that are unique to children, important not only on an academic level but also on an individual level in terms of quality of life and providing intervention for the child.

The relationship between stress, coping and well-being is complex but there is convincing evidence (Antonovsky, 1979, 1987; Kobasa, 1979; Lazarus & Folkman, 1984;

Moos & Holahan, 2002, 2003) that the linear, reductionist models of causality between stress and well-being are no longer supported and that coping mediates the impact of stressors and determines well-being.

This research will specifically explore factors that predict psychological well-being, as measured by life satisfaction, in children who have diagnoses such as cancer. It serves to identify those factors that have the potential to mediate the impact of the stress of a life threatening illness regardless of its medical progression and have the potential to influence psychological well-being. While the knowledge gained will be specific to children with cancer, leukaemia and haemophilia, the knowledge gained will be applicable to those with all life threatening illnesses, and will therefore make an important contribution to the knowledge base in psychology, medicine, and related fields, such as nursing.

An EBSCOhost search (using the CINAHL, Academic Search, MEDLINE and Africa-Wide Information data bases) conducted on 18/06/2012 investigating the number of local and international studies on the psychological well-being of seriously or chronically ill children, found limited international and local studies that focused specifically on factors predicting or enhancing psychological well-being. Of seven international studies, four investigated the impact of an illness on well-being, one was a literature review on illness and well-being, one an investigation of the impact of maternal well-being and one a study of physical activity on the child's well-being. One African study was found, focusing on the role of socioeconomic status and well-being in an epileptic population. A single South African study was found focusing on the development of an intervention programme to enhance the well-being of children with HIV-Aids. A further EBSCOhost search for international and local studies predicting the well-being of children with cancer, revealed no identified studies in South Africa. Fifteen studies were found internationally of which five were pathogenically orientated, looking at the impact of cancer on well-being, while nine explored specific dimensions in relation to well-being, including goals and hope. Only one study investigated the prediction of well-being in terms of specific factors such as self-esteem and locus of control, with a salutogenic focus.

The above statistics provide evidence of a need for studies, with a salutogenic orientation, focusing on the psychological well-being of children both locally and internationally. In addition, in South Africa, with the HIV-Aids pandemic and the high

prevalence of other life threatening illnesses, there is increasing urgency for information on psychological well-being, which is unique to children and is also culturally relevant. This study will make an important contribution not only from an academic perspective, but also on a human level in terms of promoting quality of life for the affected children and their families.

1.2 OBJECTIVES AND RESEARCH QUESTIONS

The purpose of this mixed method study is to investigate the factors that predict life satisfaction, as a measure of well-being in children, with life threatening illnesses such as cancer. In particular, the researcher aims to investigate what enables some children to have higher levels of psychological well-being, using life satisfaction as a measure, despite the impact of the illness on self and the systems that support them. The personal experiences of their illness as well as the strategies they use to cope with the challenges they face, will be explored.

The researcher will attempt to answer the following research questions:

- What are the factors that predict and explain the variance in the life satisfaction of children with life threatening illnesses and enable them to attain a state of psychological well-being?
- Do the levels of fortitude, coping and hope of children with life threatening illnesses significantly relate to their levels of life satisfaction?
- To what extent do children with high and low levels of life satisfaction differ with regard to fortitude, coping resources and sense of hope?
- How do children experience living with a life threatening illness?
- What coping strategies and/or resources are used by children living with life threatening illnesses who have higher levels of life satisfaction?

1.3 RESEARCH METHOD

The research study consists of both a quantitative and qualitative component. The first three research questions will be answered by the quantitative component of this study and the last two questions by the qualitative component.

For the quantitative component, participants were recruited from three sources:

- The Oncology and Haematology Unit at the Universitas Hospital, Bloemfontein, Free State.
- The Oncology and Haematology Unit at Inkosi Albert Luthuli Central Hospital, Durban, KwaZulu-Natal.
- Oncology Unit - Private Hospital and Private Oncology Patients, Durban, KwaZulu-Natal.

Data was gathered using the following questionnaires:

- Satisfaction with Life Scale (Diener, Emmons, Larsen & Griffin, 1985).
- The Coping Resources Inventory (Hammer & Marting, 1988).
- The Children's Hope Scale (Snyder et al., 1991).
- The Fortitude Questionnaire (Pretorius, 1998).
- Self-compiled biographical questionnaire.

Well-being (satisfaction with life) served as the criterion variable, while coping, hope and fortitude were used as predictor variables.

Qualitative data was gathered by selecting participants with high scores on measures of life satisfaction. Participants were interviewed by the researcher, in a one-on-one setting, using a semi-structured interview with translators used as required. The researcher's aim was to gather information on the participants' experiences of living and coping with a long-term illness.

The purpose of using both quantitative and qualitative research methods was to provide both objective and subjective information which would meet scientific criteria but without losing the personal experience of living with a long-term illness. Although the concept of the “illness experience” implies universality, studies of illness have shown that it is unique for each individual therefore the qualitative methodology enables the distinctiveness of each diagnosed individual’s experience to be noted (Menne, 2006).

1.4 ETHICAL CONSIDERATIONS

Due to the special circumstances of the participants it was important to meet the following ethical requirements in this study:

- Ethical permission was obtained from the Ethics Committee: Faculty of Health Sciences, University of Free State - Ethics Application ETOVS NR 80/07 (Appendix A).
- Permission to conduct the study was obtained from the Department of Health, KwaZulu-Natal Province; Department of Health, Free State Province; Department of Paediatrics and Departments of Haematology and Oncology at the Universitas Hospital, Bloemfontein, Free State; Departments of Haematology and Oncology at Inkosi Albert Luthuli Central Hospital, Durban, KwaZulu-Natal Province.
- Research participants and their guardians were fully informed about the nature of the research both in writing and verbally. Consent was obtained from guardians (Appendix B) and assent from the research participants (Appendix C). They were informed that their participation was voluntary and that they were free to withdraw from the study at any stage without recrimination.
- All questionnaires and communication were in the mother tongue of all participants/guardians, and were conducted by translators who were language proficient.

- The privacy of all participants was and shall be respected. They were assured that all information would be kept confidential.
- All participants were treated equally.
- Consideration was given to the psychological well-being of all participants and their guardians. Counseling was offered to all participants and guardians following their participation in the study, should the need arise.

1.5 CONCEPT CLARIFICATION

The following concepts and terms in this study are clarified as follows:

- Reference to the female gender (she/hers/herself) is included in reference to the male gender (he/his/himself) unless otherwise stated.
- **Child:** the term 'child' refers to the legal definition according to the Constitution of South Africa. The term is used to refer to all children under the age of 18 (Louw, D., & Louw, A., 2007). In this study, the term includes children from 10 to 18 years of age.
- **Cognitive appraisal:** an evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful (Lazarus & Folkman, 1984).
- **Coping:** the constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984).
- **Fortitude:** the strength to manage stress and stay psychologically well, derived from an appraisal of self, the family and support from others (Pretorius, 1998; Pretorius & Heyns, 2005).

- **Health:** is not only the absence of disease and infirmity, but a state of complete well-being in a physical, mental and social meaning (United Nations, 1948).
- **Hope:** hope in children is conceptualised as a cognitive set involving the beliefs in one's capabilities to produce workable routes to goals (pathways) as well as the self-related beliefs about initiating and sustaining movement towards these goals (agency) (Snyder et al., 1997).
- **Psychological stress:** a particular relationship between the person and the environment appraised as taxing or exceeding resources and endangering well-being (Lazarus & Folkman, 1984).
- **Resilience:** the capability of individuals and systems (families, groups and communities) to cope successfully in the face of significant adversity (Smith, Perrin, Yule, & Clarke, 2009).
- **Resources:** the necessary means to ensure the attainment of a goal (George, 2009; Hobfoll, 1988).
- **Satisfaction with life:** the cognitive component of subjective well-being. It refers to a personal judgment about the acceptability of the individual's life (Diener et al. 1985; Diener, 2000).
- **Sense of coherence (SOC):** defined as the capacity to perceive that one can manage in any situation. It is characterised by: a) comprehensibility - the degree to which a situation is predictable and explicable; b) manageability - the availability of sufficient resources (internal and external) to meet the demands of the situation; c) meaningfulness - the degree to which life's demands are worth the investment of energy (Antonovsky, 1987).
- **Stressor:** a stimulus, event or state that causes physiological or psychological arousal and that is appraised as taxing or exceeding the resources of the individual (Lazarus & Folkman, 1984).

- **Well-being:** optimal psychological functioning and experience (Springer & Hauser, 2006).

1.6 STRUCTURE OF THE THESIS

The thesis is divided into seven chapters delineated as follows:

Chapter 1: This chapter serves as an introduction to the study. It provides an orientation to the potential a life threatening illness has to disrupt the child's world at a time when important concurrent developmental tasks are taking place. It highlights the theoretical shifts in stress and coping research as well as the paradigm shift from pathogenesis to salutogenesis and how these have led to the recognition that, in spite of a life threatening illness and regardless of its progression, it is possible to attain a state of psychological well-being. It outlines the purpose of this research, which is to investigate factors that predict psychological well-being, as measured by life satisfaction, unique to children and adolescents. A brief outline of ethical considerations, research methodology and concept clarification is given.

Chapter 2: The aim of this chapter is to present three theoretical models and discuss how they have contributed to the researcher's conceptual understanding of well-being. The models of Richard Lazarus, Aaron Antonovsky and Rudolph Moos are presented. Each of these models has made a significant contribution to the understanding of the relationship between stress, coping and well-being. The Integrated Stress and Coping Process Model (Moos & Schaefer, 1993) was selected as the guiding theoretical framework for this study. The concept of salutogenesis, which is a paradigm shift from the traditional biomedical model reflecting pathogenesis, is also discussed.

Chapter 3: This chapter provides an understanding of childhood cancer and the developmental tasks of the middle childhood and adolescent phases of development. It discusses the impact of cancer on the child and its supporting systems. The emphasis is on the bi-directional relationship between the impact of cancer and the developmental context, both requiring adjustment in the developing child. The psychological adjustment and

challenges of the childhood cancer survivor, and potential late effects of cancer, are also discussed.

Chapter 4: The aim of this chapter is to provide a general conceptual understanding of the constructs of coping and well-being, and the link between them. Variables that moderate coping and well-being are discussed. Coping resources, both internal and external, as well as modes of coping are discussed. Moos' (2002) revised model, which is adapted for youth and applicable to those with chronic disorders, is presented.

Chapter 5: In this chapter, the research design and methodology of this mixed method study are discussed, including details of the participants, data gathering process, measuring instruments and data analysis procedures. Ethical issues involved in the research study, including the process of obtaining ethical approval and dealing with the data gathering in an ethically responsible manner are presented.

Chapter 6: In this chapter the research findings of the quantitative study are reported, followed by a presentation of the qualitative research findings. The chapter is concluded through integration (triangulation) of the quantitative and qualitative findings.

Chapter 7: This concluding chapter will present a summary and conclusion of the literature review. Subsequently, a summary and conclusions of the quantitative and qualitative components of the study will be presented. Finally, limitations and contributions of the study, recommendations for future research will be made, as well as personal reflections will be given.

In the following chapter, the theoretical shift that has occurred in stress and coping research, as well as the paradigm shift from pathogenesis to salutogenesis will be discussed. In addition, three theoretical models of stress and coping will be discussed.

CHAPTER 2

STRESS, COPING AND HEALTH: MODELS OF STRESS AND COPING

2.1 INTRODUCTION

The purpose of this chapter is to provide an orientation to the theoretical shift that has occurred in stress and coping research as well as the paradigm shift that has occurred in psychology and related disciplines, from a pathogenic model (based on diagnosis and pathology) to a salutogenic model that focuses on what enables individuals to stay psychologically healthy in spite of adversity. The theoretical models of three theorists (Richard Lazarus, Aaron Antonovsky and Rudolph Moos) are presented, each of which has made a significant contribution to the understanding of stress, coping and well-being, and to positive psychology.

2.2 THEORETICAL SHIFT IN STRESS AND COPING RESEARCH: AN HISTORICAL PERSPECTIVE

Early research initially conceptualised stress as a response to environmental stressors then shifted to viewing it as a stimulus to which individuals responded. Later research work viewed stress as a transaction between the person and the environment. The following outline traces the evolution of the conceptualisation of stress.

2.2.1 Stress as a response

Stress was considered a response to noxious stimuli or environmental stressors and was viewed as a dependent variable in research. The concept was pioneered by the work of researchers, such as Selye in the 1950s, but still accounted for approximately 24% of the stress studies between 1974 and 1984 (Lyon & Werner, 1987). Stress was not considered an

environmental demand but a universal set of physiological reactions and processes created by such a demand (Lazarus & Folkman, 1984). As a result, the stress response was not considered dependent on the nature of the stressor, and Selye's concept of the General Adaptation Syndrome reflected this thinking (Hobfoll, 1989; Lazarus & Folkman, 1984). Three well defined stages to stress were considered i.e., alarm, resistance and exhaustion, resulting in disease states if severe and prolonged. The alarm phase reflected the first phase of the stress response, with body temperature and blood pressure lowering (shock), followed by an increase in adrenal cortical secretions that produced a rise in blood pressure and often in body temperature. A stage of physiological resistance would follow, characterised by adrenal enlargement, shrinkage of the thymus gland and gastrointestinal ulceration. Finally, following long exposure to severe stress, exhaustion occurred and would produce diseases of adaptation such as arthritis and even death (Insel & Moos, 1974; Lazarus & Folkman, 1984).

2.2.1.1 Limitations of the response theory of stress

Hobfoll (1989) criticised the response theory of stress, stating that in this conceptualisation

the term stress is loosely borrowed from the field of physics. Humans, it is thought, are in some ways analogous to physical objects such as metals that resist moderate outside forces but that lose their resiliency at some point of greater pressure. The analogy to humans is obvious, albeit inexact (p. 514).

Hobfoll (1989) extended his criticism by stating that theorists such as Selye had employed illogical deductive reasoning, depicting stress in terms of outcome, such that an organism could be seen as under stress only when a phase of the general adaptation sequence was occurring. This viewpoint, Hobfoll noted, precluded the possibility of prospectively identifying the cause of stress, because one is forced to wait until the outcome before knowing when it will occur.

Lazarus and Folkman (1984) also criticised Selye's theoretical conceptualisation, for not defining the degree to which homeostasis was disturbed, nor recognising cognitive variables or individual differences in the coping process (Lyon, 2000). For Lazarus and Folkman (1984), models such as Selye's hold that all demands are more or less qualitatively

equivalent in producing physiological mobilisation, and this increased susceptibility to all diseases. They emphasised that generality models cannot easily explain individual differences, while appraisal processes provided a common pathway through which variables (person and environment) modified psychological responses and hence emotions and their biological concomitants.

2.2.2 Stress as a stimulus

Later research work saw a shift in thinking to conceptualising stress as a stimulus. The stimulus based approach saw life events as the stressor to which a person responds. Stress was therefore the independent variable in research.

The central premise of this model was that too many life changes increased one's vulnerability to illness. The primary theoretical propositions were that life changes were normative but that they resulted in the same readjustment demands for everyone; that change was stressful regardless of the desirability to the individual and that there was a common threshold beyond which illness resulted. The person was viewed as a passive recipient in the stress process (Lazarus & Folkman, 1984; Hobfoll, 1989).

The work of researchers such as Holmes and Rahe reflected the above premise (Hobfoll, 1989; Lyon, 2000) and led to the development of the Schedule of Recent Life Events and the Social Re-adjustment Rating Scale (Kobasa, 1979; Antonovsky, 1979, 1987). Their premise was that a cluster of events that required change in ongoing life adjustment is significantly associated with illness onset, and that the greater the change or adaptive requirement, the greater the vulnerability to and consequences of disease. They were thus postulating that the concept of life change appeared to have relevance to the causation of disease, time of onset and severity.

Research in the 1950s on the effects of stress on performance, stimulated by World War II and the Korean War, resulted in convincing evidence that performance was not uniformly impaired or facilitated. It became clear that there were important individual differences in response to stress and that performance could not be predicted by reference to stressful stimuli. It became evident that, in order to predict performance outcomes, it was

necessary to pay attention to the psychological processes that created individual differences in reactions, such as motivation and coping (Lazarus & Folkman, 1984).

The concept of stress as a stimulus was falling out of favour by the late 1980s as a result of the work of researchers such as Antonovsky (1987) and Kobasa (1979). Yet approximately 30% of nursing research on stress between 1974 and 1984 continued to reflect the stimulus based paradigm (Lyon & Werner, 1987). It is possible that this was a reflection of the continued orientation towards the medical/pathogenic model (in a field such as nursing) and the possible lack of recognition of the moderating potential of psychological processes, as well as the lack of identification of psychological well-being as an important health outcome.

2.2.2.1 Limitations of the stimulus theory of stress

A shift away from the stimulus based approach began to occur as researchers began to investigate the possible effect of mediating or moderator variables and the processes intervening between stressful demands and outcomes (Lazarus & Folkman, 1984). Researchers such as Kobasa (1979) and Antonovsky (1987) disconfirmed the theoretical conceptualisation of stress as a stimulus. Kobasa introduced the concept of hardiness as a moderating personality variable between stress and illness. Antonovsky's sense of coherence construct, seen as the individual's capacity to perceive that he can manage in any situation, was also considered a powerful mediator between life event stress and illness (Lyon, 2000).

Antonovsky (1979) challenged the stimulus theory of stress. He agreed that while there is a relationship between stress and his construct of sense of coherence, people with the same life events score, with different strengths of sense of coherence, would manifest different health outcomes. Conversely, he anticipated that people with the same level of sense of coherence but different life event scores would be equally healthy. He further stated that it would not surprise him if a moderately high life events score even became salutary.

Hobfoll (1989) too criticised the stimulus theory of stress stating that few studies who adopt this view of stress have compared reactions to different categories of stressful events and even if they did, it is very clear that the stimulus would only be one facet of the stress phenomena.

2.2.3 Stress as a transaction between the person and the environment

In 1966, Lazarus described stress as follows: “stress is not a variable but a rubric consisting of many variables and processes” (Lazarus & Folkman, 1984, p. 12). He further noted that when considering stress, it is important to “adopt a systematic theoretical framework for examining the concept at multiple levels of analysis and to specify antecedents, processes and outcomes” (Lazarus & Folkman, 1984, p. 12).

The work of researchers, such as Lazarus (Lazarus & Folkman, 1984; Lazarus, 2000a, 2000b) and Moos (1984, 1986, 2002; Moos & Holahan, 2003) viewed stress as a transaction between the person and the environment. Lazarus, for example, presented a theoretical framework to explain the complex phenomenon of stress, emphasising the important role that “appraisal” plays in how a person reacts, feels and behaves (Lazarus & Folkman, 1984). Appraisal was considered the primary mediator of person-environment transactions and determined emotions and coping behaviours (Lazarus, 2000a).

This shift in thinking was a major impetus for the field of cognitive psychology and unlike the unidirectional, static, antecedent-consequent models which included response based or stimulus based orientations to stress, the transactional model explicitly included coping efforts. Transactional models of stress and coping view the person and the environment in a dynamic, mutually reciprocal, bi-directional relationship (Lazarus & Folkman, 1984). These authors emphasised that the term transaction implied a newly created level of abstraction in which the person and the environment elements are joined together to form a new relational meaning. They noted that this was different from interaction, as in this process interacting variables retained their separate identities. From a transactional perspective, the characteristic of the separate entities is subsumed. Lazarus and Folkman’s (1984) approach to stress emphasises cognitive appraisal which does not refer to the environment or the person alone but to the integration of both in a given transaction. The transactional view of stress sees coping as a process orientated phenomenon and emphasises that such effort is different from automatic adaptive behaviour that has been learned. Coping also involves managing the stressful situation and does not necessarily mean mastery.

2.2.3.1 Limitations of the transactional model of stress

Hobfoll (1989) argued that only a weak link exists between current stress models and the actual research that is conducted. In addition, he argued that “current models are tautological and so can do little to move stress investigators toward new horizons of research. Yet, because they are tautological, they can never be rejected either” (p. 514).

Apart from the shift to more complex explanations of the stress process, the following section outlines a shift from pathogenesis to salutogenesis, and the emergence of positive psychology.

2.3 PARADIGM SHIFT FROM PATHOGENESIS TO SALUTOGENESIS: THE EMERGENCE OF POSITIVE PSYCHOLOGY

2.3.1 The shift from pathogenesis to salutogenesis

Psychology embraced the scientific principles of the modernist paradigm where knowledge about human behaviour was assumed to be attained in the same way as other sciences, applying the concepts of reductionism, linear causality, objectivity and empiricism (Avis, Pauw & Van der Spuy, 2004). Psychology’s adoption of the pathogenically oriented biomedical model resulted in a focus on diagnosis and psychopathology. It was inevitable then that the focus of research and clinical practice would reflect this (Antonovsky, 1979; 1987).

Critics such as Gergen (1990) expressed their dissatisfaction with the mental health professions for following the medical model in the need to be scientific. They noted that, within this framework, psychology had created a language of deficit by focusing on diagnostic labels and categories. Gergen cautioned that once a language of deficit has been created, a culture of dependency on these terms within the discipline is created. Once actions are translated into a professional language of deficit, the culture constructs itself in these terms. Another critic of psychology, Sloan (2000), noted that in order for a critical review of theory and practice to take place, it must be pursued until the discipline is radically transformed, rendered obsolete or totally transcended. Huitt (2003) challenged this view by

stating that times of theoretical dissonance are opportunities to develop new understandings or to integrate previous understandings in new ways.

The recognition of individual differences in coping and the role of factors mediating the outcome between stress and well-being has made an important contribution to psychology. Antonovsky (1979, 1987, 1991; Antonovsky & Sagy, 2001) recognised that, in spite of exposure to extreme adversity, there were some people that were able to stay psychologically healthy. This led him to question the pathogenic thinking which was pervasive in medicine, psychology and related fields. He shifted his focus to salutogenesis and investigated factors that enabled this. This shift in thinking had significant implications for well-being as a construct as it meant that stress did not necessarily impact upon well-being but that there were other mediating processes operating.

Antonovsky's work (Antonovsky, 1979; 1987) enabled him to see that pathogenesis categorised people in an artificially dichotomous way (Langeland et al., 2007), either as patients or non-patients, and that the question of pathogenesis in research and clinical practice 'why do people get this disease?' reinforced such categorisation (Horsburgh, 2000). Antonovsky (1979) challenged the pathogenic orientation as it is by definition "a model that postulates a state of disease that is qualitatively and dichotomously different from a state of nondisease. The individual is sick or well. The organ is diseased or nondiseased. The condition is pathological or nonpathological. Dichotomisation blinds us to a conceptualisation made possible by a salutogenic model - a multidimensional health-illness continuum between two poles that are useful only as heuristic devices and never found in reality: absolute health and absolute illness" (p. 37). He stated that pathogenesis only asks the question - why does this person enter this state of pathology but never asks the salutogenic question which is - what are the factors pushing this person towards either end of the continuum. Antonovsky (1987) stated that salutogenic thinking compels us to devote our energies to the formulation, and the advancement, of the theory of coping.

By shifting the research question and asking a different question - what are those factors that promote health and allow people to stay healthy in spite of disease or trauma, Antonovsky (1979, 1987, 1991; Antonovsky & Sagy, 2001) contributed to a radical transformation in the field where health and illness were no longer viewed as dichotomies but were rather seen on a multidimensional health-illness continuum. This contributed to the

development of new understandings about health and a conceptual transformation in psychology and disciplines such as medicine, as it seeks to explain factors that move individuals towards the healthy end of the health-illness continuum (Horsburgh, 2000). It has also resulted in a significant move away from the language of deficit (Antonovsky, 1979).

Relevant to this study, positive psychology has provided another health outcome: psychological well-being. It is not just the absence or presence of disease in children with life threatening, long term illnesses that confirms wellness. Psychological well-being is a dimension that is not only relevant but essential to the individual regardless of the presence of an adverse life experience/stressor such as a life threatening illness, or its progression. The relationship between stress, coping and well-being is complex but there is convincing evidence that the linear model of causality between stress and well-being is no longer supported and that coping mediates the impact of stressors and determines well-being.

The theoretical models of stress and coping, which have also contributed to the field of positive psychology, will be presented in the next section.

2.4 THEORETICAL MODELS OF STRESS AND COPING

The following is a presentation of Lazarus' **Model of Stress and Coping** (Lazarus & Folkman, 1984), Antonovsky's **Salutogenic Model** (Antonovsky, 1979) and Moos' **Integrated Stress and Coping Process Model** (Moos & Schaefer, 1993). Lazarus and Moos are associated with stress and coping theory, while Antonovsky is associated with positive psychology.

2.4.1 Richard Lazarus

“No one is surprised that plants have developed complex and essential protein discriminating mechanisms or that animals have wired-in mechanisms for distinguishing dangerous predators. Why then should it surprise anyone that a species as advanced neurologically as Homo sapiens should have developed a highly symbolic set of cognitive processes for distinguishing among experiences that harm, threaten, challenge, or nurture? Indeed, successful adaptation and the human sense of well-being rest on the ability to make such evaluative perceptions” (Lazarus & Folkman, 1984, pp. 23-24).

2.4.1.1 Biographical information

Born in 1922 in New York, Richard Lazarus (Professor of Psychology - University of Berkley, California) enjoyed a distinguished academic career, receiving numerous prestigious awards for his contribution to science and psychology (University of California, 1996).

Lazarus’ work and ideas on stress began in the early 1950s. His transitional views, which included his work on appraisal, were reflected in the 1960s and 1970s. His later work in the 1980s and 1990s reflected themes flowing from his increasing recognition that stress and emotion were two interdependent themes which should be combined as one. Following his retirement in the late 1990s, Lazarus made a case for stress being a broader area of emotion. In his later writings, Lazarus incorporated the concept of appraisal and its relevance for understanding culture and emotion, emotional development and psychopathology (Lazarus, 2000a).

2.4.1.2 Lazarus' Model of Stress and Coping

2.4.1.2.1 Background to the model

Lazarus' research in the early 1950s in the military services led him to conclude that the arousal and the effects of stress were dependent on how different individuals evaluated and coped with the personal significance of what was occurring (Lazarus, 2000a). This was at a time when stress as a construct had little, if any, place in social science and there was minimal interest in stress or emotion, except on the part of the military. In the late 1950s, Lazarus began a series of investigations using motion picture films to arouse stress and emotion. He used instructional sets to change the way the film affected the viewer, both subjectively and psychophysiologically. By documenting how this changed the way that participants evaluated the meaning of film events (lowering or raising levels of stress), he was able to effectively demonstrate the power of appraisal to influence a person's emotions, as well as their means of coping with emotional stress (Lazarus & Folkman, 1984; Lazarus, 2000a). Following Lazarus' influential monograph in 1966, *Psychological Stress and the Coping Process*, it became apparent that emotion and stress were important, not only to the military, but for all academia. When dealing with stress and coping theory and research, Lazarus emphasised that appraisal was the centerpiece (Lazarus, 2000a).

Lazarus' concept of appraisal had at its roots the work of Magda Arnold (first theorist to develop appraisal theory). Appraisal emerged as the main mediational construct of psychological stress and emotion, and later became a principal rationale for cognitive-behaviour therapy. In his early writings, Lazarus acknowledged that he erroneously used the word "perception" instead of appraisal, which did not explicitly indicate an evaluation of the personal significance of what was happening for well-being (Lazarus, 2000a, 2000b).

Lazarus and Folkman (1984) emphasised that the way people cope with stress influences their physical, social and psychological well-being. Stress and coping were considered reciprocals of each other. When coping is effective, stress is usually controlled. When coping is ineffective stress mounts, and if out of control, can lead to physiological disturbance, subjective stress and impaired social functioning. Appraisal is central in mediating subsequent thought, feeling and action. Stress is not viewed as maladaptive as it can cause people to draw on adaptive resources and gain strength, which could be used as a

resource in future crises. They noted that the question should not be whether stress is good or bad but rather “how much, what kind, at which times during the life span and under what social and personal conditions it is harmful or helpful” (Lazarus & Folkman, 1984, p. 182).

2.4.1.2.2 Explanation of Lazarus’ model

The following is a diagrammatic representation of Lazarus’ model:

Causal Antecedents		Mediating Process Time 1... T2... T3... Tn Encounter 1... 2... 3... n		Adaptive Outcomes	
Person variables	Environment	Appraisal	Coping	Immediate Effects	Long term Effects
Values- commitments beliefs, existential sense of control	(situational) demands, constraints resources (e.g., Social network) ambiguity of harm imminence of harm	Primary Secondary Reappraisal	Problem- focused Emotion- focused Seeking, obtaining and using social support Resolutions of each stressful encounter	Physiological changes Positive or negative feelings Quality of encounter	Somatic health/illness Morale (well-being) Social functioning

Figure 1. A theoretical schematization of stress, coping and adaptation (adapted from Lazarus & Folkman, 1984, p. 350)

The main conceptual elements of the model are Causal Antecedents which include person and environment factors, Mediating Processes which include primary and secondary appraisal, reappraisal and coping (emotion and problem-focused coping), and Adaptational Outcomes.

2.4.1.2.2.1 Causal Antecedents of Appraisal (Person and Environment Factors)

Consistent with the relational analysis of stress in any transaction, environment and person factors are the two main variables which influence whether appraisal is that of a threat or a challenge (Lazarus, 2000a). Person and situation factors are interdependent components of a dynamic person-situation relationship. They can be considered antecedents of appraisal but only in terms of their meaning with respect to the balance between demands and resources within the person, within the environment, and between the person and the environment (Lazarus & Folkman, 1984).

- a) **Person factors:** Important person factors which determine appraisal are commitment and beliefs. The deeper a person's commitment or belief, the greater the potential for threat and challenge. At the same time, the depth of commitment or belief can also push a person toward ameliorative action and help sustain hope. Beliefs reflect what is important to people and underlie the choices they make, thus they contain a motivational quality. They guide people into or away from situations by shaping cue sensitivity and influence appraisal through their impact on vulnerability (Lazarus & Folkman, 1984).

Personality dispositions (e.g., self-confidence, self-efficacy or feelings of inadequacy) influence whether a person is more prone to threat or to challenge (Lazarus, 2000a; Lazarus & Folkman, 1984).

- b) **Environment factors:** Some environmental circumstances impose too great a demand on a person's resources whereas others provide considerable latitude for available skills and persistence (Lazarus & Folkman, 1984; Lazarus, 2000a). Situation factors such as novelty, predictability and event uncertainty are important. A completely novel situation will result in appraisal of threat only if some aspect has been previously connected with harm. Such stimuli are processed through pre-

existing systems of schematised and abstracted knowledge (Lazarus & Folkman, 1984). Event uncertainty (e.g., waiting for news of a medical investigation) introduces the notion of probability (e.g., chance of relapse). It is considered a major adaptive task as it has the potential to immobilise anticipatory coping processes (Lazarus & Folkman, 1984; Moos, 1986).

The concept of time may be one of the most important environment factors and parameter of stressful situations (Lazarus & Folkman, 1984). Imminence is important, as the more imminent an event is, the more urgent and intense the appraisal. There is evidence that the relationship between imminence and arousal is different for threat and challenge, as threat elicits greater coping complexity. Historically, the duration of the stressful event has been considered a major factor in disease and psychopathology. The assumption is that chronic stressors wear down the individual, both physically and psychologically. Lazarus and Folkman (1984) challenge this premise in that, according to the fundamental principles of their model, chronic stressors do not inevitably lead to disease and psychopathology, due to the processes of coping and appraisal as being mediatory. They acknowledge however, that chronic intermittent patterns give the individual “time off”, while chronic persistent patterns or chronic sequential stressors (e.g., illness and death) present a more persistent level of threat. Temporal uncertainty refers to not knowing when an event will occur and is often associated with avoidant coping. Uncertainty is influenced by ambiguity (when the information necessary for appraisal is unclear or insufficient). The greater the ambiguity the more person factors shape the meaning of the situation which has a greater risk for threat appraisal if the person’s disposition exists to be threatened. The timing of stressful events or the timing of stressful events in relation to each other over the life cycle is significant, and relevant for appraisal (Lazarus & Folkman, 1984).

2.4.1.2.2.2 Mediating Processes

- a) **Appraisal:** Lazarus and Folkman’s (1984) concept of appraisal refers to the evaluative cognitive processes that intervene between an encounter and the reaction (Lazarus, 2000a). It is phenomenological in that it is based on the individual’s subjective interpretation of the transaction. The premise of appraisal theory is that

people are constantly evaluating relationships with the environment with respect to the implications for personal well-being (Lazarus & Folkman, 1984; Lazarus, 2000a). Appraisals are usually dependent on many subtle clues in the environment, previous experience and a host of personality variables such as goals, beliefs, personal resources and liabilities (Lazarus, 2000a). Lazarus and Folkman (1984) emphasise that appraisal is not just information processing. It is evaluative, focused on the meaning or personal significance of the information that is constructed by the person (Lazarus & Folkman, 1984). It is this that gives an appraisal its emotional quality (Lazarus, 2000a).

Lazarus and Folkman (1984) emphasise that appraisal “goes far beyond immediate and indeliberate cognitive-affective responses” (p. 26) and that little is known about how the process works. At the psychological level, this means that when there are threatening events we are enabled to respond quickly and automatically to an adaptational crisis, even without awareness of the process, as a result of what has already been learned (Lazarus & Folkman, 1984; Lazarus, 2000a).

Lazarus distinguished between primary and secondary appraising (Lazarus & Folkman, 1984; Lazarus, 2000a). The following is a discussion of these two important components of his theory:

Primary appraisal: Lazarus and Folkman (1984) identified three kinds of primary appraisal. When an encounter has no implications for the person’s well-being it is appraised as irrelevant. When an encounter is construed as positive (preserves/enhances well-being or has the potential to do so) it is appraised as benign-positive. When an encounter is appraised as including harm or loss/threat or challenge, it is considered a stress appraisal. Threat and challenge call for the mobilisation of coping efforts. Challenge appraisals focus on the potential for gain or growth (characterised by pleasurable emotions). Threat centers on potential harms and is characterised by negative emotions. Threat and challenge can occur simultaneously and are not poles of a single continuum. They are related constructs. Challenge as opposed to threat has important implications for adaptation because the person is usually more able to draw on available resources. Lazarus (2000a) identified three main components influencing appraisal. Goal relevance is whether an

encounter is viewed by the person as relevant to well-being. Goal congruence is whether the conditions of the encounter facilitate or thwart what a person wants. Ego involvement is whether the encounter taps into self-esteem, moral values, meaning, the well-being of others and life goals.

Secondary appraisal: Is a complex evaluative process that focuses on what can be done about a troubled person-environment relationship (Lazarus & Folkman, 1984; Lazarus, 2000a). The evaluation of coping options as well as a decision as to which one to choose, and how to set them in motion, must take place. Social and intrapsychic constraints against acting them out also influence appraisal (Lazarus, 2000a). Lazarus (2000a) identifies three basic judgments which are involved in secondary appraising. Blame or credit for the outcome requires a judgment as to who or what is responsible for a harm, threat, challenge or benefit or if it was something that could have been avoided. The attribution of a malevolent or benign intention on the part of others is considered. Coping potential arises from the judgment that one can/cannot act successfully to ameliorate or eliminate harm/threat, or bring to fruition a challenge or benefit. Future expectations influence appraisal. These can be positive or negative depending on how the troubled person-environment relationship is viewed by the individual.

Primary appraisal does not operate independently of secondary appraisal (which is needed to obtain an understanding of the overall situation), thus there is an active interplay of both. The adjective “secondary” does not imply a process of less importance (Lazarus & Folkman, 1984; Lazarus, 2000a). Lazarus (2000a) emphasises that the distinctly different contents of each type of appraisal justifies treating them separately but that each should be regarded as integral meaning components of a more complex process (Lazarus, 2000a).

Re-appraisal: This refers to a changed appraisal on the basis of new information from the environment. The two-way transactions between the person and the environment are complex (Lazarus & Folkman, 1984). When re-appraisal occurs, alteration of emotion takes place by constructing a new relational meaning of the stressful encounter. When this process occurs, it is often difficult to distinguish it from an ego defense (e.g., denial) however when the personal meaning of what is happening fits

the evidence, it is not an ego defense but according to Lazarus (2000a), is “one of the most durable and powerful ways of controlling destructive emotions” (p. 205). Re-appraisal therefore has an adaptive coping function. Lazarus noted the tendency in psychology to distinguish between negative and positive emotions and to polarise them. In his view, this distorts their individually substantive qualities and the complex meanings inherent in each discrete emotion. It also negates the fact that emotions are interdependent (and therefore not positive or negative) and does not take into account that re-appraisal can transform one emotion into another (Lazarus & Folkman, 1984; Lazarus, 2000a). The construction of a new relational meaning leads to an outcome which includes emotion and also determines morale/well-being, social functioning and health (Lazarus & Folkman, 2000a).

- b) Coping:** Lazarus and Folkman (1984) noted that coping as a concept was typically equated with adaptational success but that for progress to be made, coping must be viewed as efforts to **manage** stressful demands, regardless of outcome. Accordingly, no strategy should be considered inherently better or worse than any other and judgments as to the adaptiveness of a strategy must be made contextually. They emphasised that coping should not be equated with mastery over the environment as many sources of stress cannot be mastered. Effective coping under these conditions is that which allows the person to tolerate, minimise, accept or ignore what cannot be mastered. They define coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. Coping is the effort to manage psychological stress” (Lazarus & Folkman, 1984, p. 141).

Lazarus’ process view of coping includes the fact that there is no universally effective (or ineffective) coping strategy. The efficacy of coping is dependent on the type of person, threat and stage of the stressful encounter. When threats are re-appraised, emotions are altered by constructing a new meaning of the stressor. The choice of coping strategy usually varies with the adaptational significance and requirements of each threat (Lazarus & Folkman, 1984; Lazarus, 2000a). Evidence suggests substantial variations among persons in the ordering and duration of kinds of coping across, and even within, particular types of stressful encounters.

According to Lazarus and Folkman (1984), coping serves two overriding functions. The first is to manage/alter the problem with the environment causing distress by obtaining information and mobilising actions for the purpose of changing the reality of the troubled environment. The coping action may be directed at self or the environment. This is termed problem-focused coping. In the case of a medical diagnosis or illness, seeking out the opinions of different medical specialists would be an example of problem-focused coping (Lazarus, 2000a). Regulating the emotional response to the problem is termed emotion-focused coping. Problem- and emotion-focused coping influence each other throughout a stressful encounter and can both facilitate and impede one another (Lazarus & Folkman, 1984). Making a distinction between the two types of coping can lead to an oversimplification of how coping works (Lazarus, 2000a). An example is taking medication prior to an examination for severe performance anxiety. This would be an illustration of both functions, providing evidence that the same act may have more than one function. Lazarus (2000a) emphasised that, while it would be a legitimate question to ask which coping strategy produces the best adaptational outcome under different sets of conditions, this thinking fails to recognise that in nearly all stressful encounters, the person draws on both functions. Both are essential parts of the total coping effort (Lazarus, 2000a). Lazarus noted that coping should not be thought of as an either/or term but as “a complex of thoughts and actions aimed at improving the troubled relationship with the environment - a process of seeking the most serviceable meaning available in the situation, one that supports realistic actions while also viewing the situation in the most favourable way possible” (Lazarus, 2000a, p. 206).

In Lazarus' model, the cognitive and motivational underpinnings of coping originate with the first recognition of one's trouble or good fortune. The resulting coping thoughts and actions serve as bridges between the relational meanings of the encounter and how the person acts and feels. In effect, appraisal unites coping with the emotion process (Lazarus & Folkman, 1984). Emotions are considered complex, organised subsystems consisting of beliefs, motives, meanings, subjective experiences and physiological states (Lazarus, 2000a).

Lazarus (2000a, 2000b) noted that conceptually, appraisal and coping go hand in hand and overlap which results in academic uncertainty about whether a stress related

thought or action is an appraisal, a coping process or both. The uncertainty stems from the fact that cognitive coping is basically a re-appraisal, which is difficult to distinguish from the original appraisal, except for its history (Lazarus, 2000a). Coping is determined by personal constraints that mitigate the use of resources, such as internalised cultural values and beliefs, which proscribe certain ways of behaving (Lazarus & Folkman, 1984).

2.4.1.2.2.3 Adaptational Outcomes

The importance of appraisal and coping as processes is that they affect adaptational outcomes. Lazarus and Folkman (1984) identified three kinds of adaptational outcomes. Social functioning is determined by the effectiveness with which one appraises and copes with day to day living, influenced by the match of appraisal and the event. Effective coping depends on the match between secondary appraisal (coping options, coping demands) and a selected coping strategy. Social functioning over the long term is an extension of coping effectiveness in specific encounters over the life course. Morale, a multi-dimensional concept associated with dimensions such as life satisfaction, and closely related to affect or emotion, relates to well-being. Positive and negative experiences in a stressful encounter reflect only the momentary evaluation of current well-being. Long term morale is likely to reflect a background affective state that is enduring. From a stress and coping perspective, the key question concerns how appraisal and the coping process affect subjective well-being in a specific encounter (short term), as well as the relationship between well-being in the short term and morale over the long term. Somatic health has historically been associated with stress, emotion and coping. These factors were considered causal factors in somatic illness. The relationship between social functioning, morale and somatic health is complex. Good functioning in one area does not however necessarily mean that the person is functioning well in all areas (Lazarus & Folkman, 1984; Lazarus, 2000a).

Lazarus' model of Stress and Coping was revised in 1991 and replaced the original model which was formulated by Lazarus and Folkman in 1984. In the revised model, Lazarus (2000a) referred to his cognitive-motivational-relational theory of emotions because motivation, cognition and the meanings constructed about the person-environment were conjoined in the emotion process and were considered crucial concepts. He viewed

cognition, motivation and emotion as parts of a larger integrated subsystem (the mind), which in turn were embedded in larger systems such as the family, social group and society.

Following his retirement in the late 1990s, Lazarus made a case for stress being a broader area of emotion. He emphasised the importance of “daily hassles” as a source of stress and argued that these typically caused more human suffering than major life events, although they could be interrelated. Appraisal was considered important when dealing with either of these. This was an important shift away from the prevalent view about the significance of major life stressors (Lazarus, 2000a).

2.4.1.2.3 Critique of Lazarus’ model

Lazarus’ model is viewed as seminal work in the field of stress and coping. His concept of appraisal has made a unique contribution to the shift in the theoretical orientation from linear models of stress and coping. This has had a profound effect on research and has contributed to the development of other transactional theories and models. His concept of appraisal, with his distinction between primary and secondary appraisal, has made an important contribution to a greater understanding of the processes that serve as moderators between an event and the outcome. Of relevance to the field of health and illness, and to this study in particular, it has allowed an understanding that the cognitive appraisal processes of what a diagnosis of a long term illness means to a child, can determine the impact and outcome. Apart from the implication for well-being, it has positive implications for intervention. His distinction between types of coping also allows a further understanding both in terms of the processes and their implications for understanding coping behaviours.

Lazarus’ theory has been criticised by Hobfoll (1989) who acknowledges that, while it can be argued that Lazarus and Folkman (1984) have, in their transactional model of stress, emphasised the interaction between the environment and the individual, what they have termed the environment is actually the individual’s appraisal thereof. Hobfoll alleged that this has led to a circularity of their approach which follows from their overemphasis on perception as well as their lack of emphasis on environmental contingencies. It is Hobfoll’s opinion that the overemphasis on Lazarus’ concept of appraisal has downplayed the impact of social circumstances and demands.

Matsumoto and Ekman (1994) criticised Lazarus' focus on the individual in his theory of appraisal and emotion. They are of the opinion that transactions include the interrelationship between persons and their dual and simultaneous appraisals. They suggested that interconnections among people are facts of life and that the focus on the individual ignores the sociocultural milieu, neglecting the richness of information that exists in the transaction.

Matsumoto and Ekman (1994) further criticised Lazarus' concept of appraisal, noting that one of the problems inherent in the process is that inevitably a judgment about the inner workings of a person's mind is made and it assumes that emotion as a construct means the same thing and includes the same components for different kinds of people. They find this assumption untenable.

The writer agrees that while the value of the concept of appraisal cannot be negated, Lazarus' emphasis has been on internal processes and there has been a diminished value placed on the impact of social and environmental factors. In South Africa, extreme poverty, child-headed households and limited resources are what many children in South Africa face, in addition to their diagnoses of long term illnesses.

The second model to be presented is that of Aaron Antonovsky, who drew on the work of Lazarus and Folkman (1984) regarding cognitive appraisal.

2.4.2 Aaron Antonovsky

“The question became one of seeking to understand the rarity, almost the miracle of those who did not break down. The question was so unusual that it had no name...this led me to coin the concept of salutogenesis – the origin of health” (Antonovsky, 1991, p. 2).

2.4.2.1 Biographical information

Antonovsky (1923-1994), an American-Israeli medical sociologist, held the position of Professor of Medical Sociology at Ben Gurion University in Israel (Antonovsky, 1979). He introduced his salutogenic theory “Sense of Coherence (SOC)” as a global orientation to

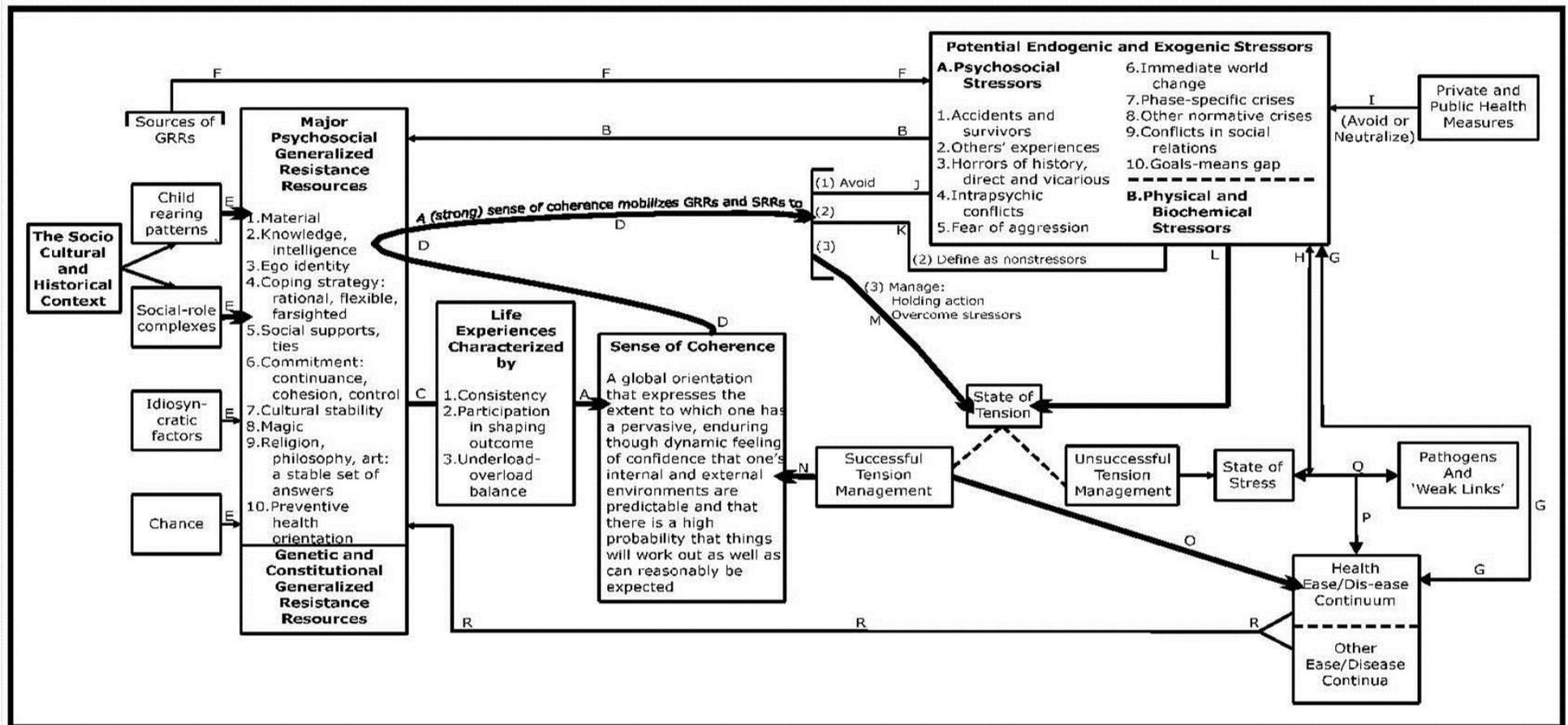
view the world, claiming that the way that people view their lives has a positive influence on their health (Lindstrom & Eriksson, 2006). The salutogenic orientation was developed in terms of systems theory conceptualisation, which was similar to the thinking from which the SOC construct evolved (Antonovsky, 1991).

Initially Antonovsky (1979) focused his research interest on social class and health and later on the impact of stress and health. Historically, it was at a time when the mainstream paradigm in public health focused on disease and risk factors and searched for causal relationships between them. Stress was seen as a negative event that increased susceptibility and risk for individuals and Antonovsky's early research reflected this paradigm. Gradually this thinking changed when he started to research psychological breakdown as a dependent rather than an independent variable (Antonovsky, 1987). Antonovsky (1979) recognised that stressors are omnipresent and occur continuously, and noted that it was surprising that organisms could survive the constant mass exposure. He began to explore the concept of adaptability in psychological, social and cultural spheres as a major key to the successful management of stressors (Antonovsky, 1979, 1987). This led him to ask the question as to what it was that enabled individuals to survive. He saw health on a continuum and stated that the most important research question was what caused health and not what were the reasons for disease.

The origins of salutogenesis (saluto = health; genesis = origin) derived from qualitative research conducted by Antonovsky with Israeli women who were coping well in spite of their traumatic experiences in the concentration camps (Lindstrom & Eriksson, 2006). In his 1971 study, Antonovsky wrote "what is, however, of greater fascination and of human and scientific import ... is the fact that a not-inconsiderable number of concentration camp survivors were found to be well-adapted ... what, we must ask, has given these women the strength, despite their experiences, to maintain what would seem to be the capacity not only to function well, but even to be happy" (Van Breda, 2001, p. 14).

2.4.2.2 Antonovsky's Salutogenesis Model of Health

The following is a diagrammatic representation of Antonovsky's Salutogenesis Model:



Arrow A: Life experiences shape the sense of coherence.

Arrow B: Stressors affect the generalized resistance resources at one's disposal.

Line C: By definition, a GRR provides one with sets of meaningful, coherent life experiences.

Arrow D: A strong sense of coherence mobilizes the GRRs and SRRs at one's disposal.

Arrow E: Childrearing patterns, social role complexes, idiosyncratic factors, and chance build up GRRs.

Arrow F: The sources of GRRs also create stressors.

Arrow G: Traumatic physical and biochemical stressors affect health status directly; health status affects extent of exposure to psychosocial stressors.

Arrow H: Physical and biochemical stressors interact with endogenic pathogens and 'weak links' and with stress to affect health status.

Arrow I: Public and private health measures avoid or neutralize stressors.

Line J: A strong sense of coherence, mobilizing GRRs and SRRs, avoids stressors.

Line K: A strong sense of coherence, mobilizing GRRs and SRRs, defines stimuli as nonstressors.

Arrow L: Ubiquitous stressors create a state of tension.

Arrow M: The mobilized GRRs (and SRRs) interact with the state of tension and manage a holding action and the overcoming of stressors.

Arrow N: Successful tension management strengthens the sense of coherence.

Arrow O: Successful tension management maintains one's place on the health ease/dis-ease continuum.

Arrow P: Interaction between the state of stress and pathogens and 'weak links' negatively affects health status.

Arrow Q: Stress is a general precursor that interacts with the existing potential endogenic and exogenic pathogens and 'weak links'.

Arrow R: Good health status facilitates the acquisition of other GRRs.

Note: The statements and arrows in bold are the core of the salutogenic model.

Figure 2. Antonovsky's Salutogenesis Model of Health (Antonovsky, 1979, pp. 184-185).

The main conceptual elements of the model are Stressors; Tension and Tension Management and Stress; Generalised Resistance Resources (GRR) and Sense of Coherence (SOC) which includes the components of comprehensibility, manageability and meaningfulness.

2.4.2.2.1 Stressors

Stressors are viewed as endemic to the human condition (Antonovsky, 1979). They upset the individual's homeostasis, present demands on the individual to which there are no readily available responses and result in a state of tension (Horsburgh, 2000). Stressors are subjectively experienced and interpreted phenomena, which can occur on both an individual and/or group level (Antonovsky, 1979).

Antonovsky (1987) reconceptualised stressors by differentiating between chronic stressors, major life events and daily hassles. Chronic stressors were noted to be enduring, relatively permanent and continuous. The relevance of chronic stressors is the extent to which they provide life experiences characterised as being conducive to a strong or weak SOC. Chronic-resources/chronic-stressors are generalised and long lasting and therefore are the primary determinants of one's SOC level. The importance of major life events for example, death, divorce or a diagnosis of a serious illness is not so much the event but the consequences and sequence of events that follow. The strength of the SOC of the person determines whether the outcomes will be noxious, neutral or salutary. Daily hassles refer to a demand to which there are no automatic adaptive responses for example, a minor accident. Antonovsky (1987) did not assign too much importance to these. He described the above differentiation as "conceptual enrichment" (p. 32), as previously all stressors were considered potentially negative.

2.4.2.2.2 Tension/tension management and stress

Antonovsky (1979, 1987) described tension as the load/strain that stressors (physiological and emotional) place on people. This can be accompanied by either or both positive and negative affect. The term stress is reserved for the strain that remains when the tension is not successfully overcome. The nature of the outcome depends on the ability of the individual to manage the tension. If tension management is effective, stress does not ensue

and the impact on health is then neutral or even salutary. The individual's ability to manage tension and avoid or manage stress is influenced by factors known as GRRs (Antonovsky, 1979; Horsburgh, 2000). A strong SOC mobilises available GRRs and determines how the state of tension is responded to (Antonovsky, 1979). Antonovsky (1979) emphasised that tension must be distinguished from stress. Tension can be salutogenic but it can also lead to stress. The crucial question is what determines whether a state of tension will be transformed into a state of stress or will have neutral or even salutary consequences.

2.4.2.2.3 Generalised Resistance Resources - Resistance Deficits (GRR-RD)

GRRs are defined by Antonovsky (1979) as “(physical, biochemical, artifactual-material, cognitive, emotional, valuative-attitudinal, interpersonal-relational, macrosociocultural) characteristic of an (individual, primary group, subculture, society) that is effective in (avoiding, combating) a wide variety of stressors and thus preventing tension from being transformed into stress” (p. 103). In essence, a GRR is what provides one with meaningful, coherent life experiences. GRRs have a complex relationship to each other and to the SOC. They are shaped by specifiable social conditions (child rearing patterns, sub cultural and cultural patterns of social organisation). These factors provide continuous experiences that build up the GRRs crucial to the SOC. Antonovsky noted individual differences in the response to GRRs (Antonovsky, 1979, 1987).

Typical GRRs are financial resources, knowledge and experience, self-esteem, the extent to which one is embedded in a social network and social support, commitment and cohesion to culture and tradition, intelligence and view of life (including religion and philosophy). Antonovsky (1979, 1987) viewed knowledge and intelligence, culture, religion and spirituality as the most decisive and powerful GRRs. He also included coping strategies as GRRs. The higher they are in utilising the variables of rationality, flexibility and farsightedness, the more effective they are considered as GRRs. In the medical setting, with reference to the treatment of illness and of relevance to this research, Antonovsky viewed the doctor/medical team as a potential GRR. If the encounter with the doctor/health care system is systematically characterised by consistency, participation in shaping the outcome, and an underload-overload balance of stimuli, the SOC is maintained or reinforced. However, systematic negative experiences can weaken the SOC (Antonovsky, 1979).

Antonovsky (1979) recognised that the absence or low levels of GRRs had implications. This resulted in him merging GRRs and his notion of stressors into one concept: generalised resistance resources-resistance deficits (GRR-RDs). Each GRR was ranked on a continuum. The higher the person was on the continuum, the more likely it was that he would have consistent, balanced life experiences and high participation in decision making. The converse applied if a person was low on the continuum. According to Antonovsky (1979), more important than the resources themselves, was the ability to use them, as GRRs lead to life experiences that promote a strong SOC - a way of perceiving life and the ability to successfully manage complex stressors, while the converse applies for GRDs. Both contribute to the development of the SOC (Antonovsky, 1987).

2.4.2.2.4 Sense of coherence

The SOC is the central concept of Antonovsky's Salutogenesis Model of Health which emphasises the process of staying healthy in spite of stress (Antonovsky, 1979, 1987; Sandell, Blomberg & Lazar, 1998). Referring to the research he was conducting at the time, Antonovsky (1979) wrote "one resource was not only more highly correlated with our measure of overall health status but also seemed to be the intervening variable between other resources and health. This was not just another generalised resistance resource; it was a way of looking at the world. We came to call it the sense of coherence" (p. 8). He further stated "It is the core of my answer to the problem of salutogenesis" (p. 183).

SOC is a construct defined by Antonovsky (1987) as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; that the resources available to one are to meet the demands posed by the stimuli and that these demands are challenges worthy of investment and engagement" (p. 19). The SOC is thus the capacity to perceive that one can manage in any situation.

Influenced by the work of Lazarus and Folkman (1984), Antonovsky (1987) suggested the SOC was a cognitive and emotional appraisal style which is associated with effective coping, health enhancing behaviours and better social adjustment (Strümpfer, Viviers, & Gouws, 1998). In terms of these components, people with a weak SOC would

perceive/experience internal and external stimuli as inexplicable, chaotic and unpredictable (Antonovsky, 1987). By contrast, people with a strong SOC are likely to define stimuli as non stressors or view them as having low relevance and feel shorter lived tension. When confronted with a formidable stressor, they are more likely to feel a sense of engagement and a willingness to cope. They usually have a repertoire on which to draw, to deal with the stressor in terms of the behavioural aspects of coping and the emotional regulation. They are better able to judge the efficacy of their behaviours to manage tension, cope with stress or both, and are more likely to discern the need for and to make use of alternative actions (Horsburgh, 2000).

The SOC is a crucial element in the basic personality structure of an individual in the context of a subculture, culture or historical period. It is shaped, tested, reinforced and modified not only in childhood but throughout life (Antonovsky, 1979; Antonovsky & Sagy, 2001). From birth, the child goes through constant situations of challenge and response, stress, tension and resolution. The more experiences that are characterised by consistency, participation in shaping outcome, and an underload-overload balance of stimuli, the more the world is perceived as coherent and predictable. Paradoxically, a measure of unpredictable experiences is essential for a strong SOC. When all of the experiences are predictable, the SOC can be weakened. In adolescence, as the crucial stage is for ego identity, the tentative SOC becomes more definitive. If the life experiences are similar to that of childhood, the SOC is reinforced, however like other adolescent characteristics, it may be more labile (Antonovsky & Sagy, 2001). According to Antonovsky (1979, 1987), change is possible as the adolescent has greater options in selecting or encountering experiences that enhance or weaken SOC. Young adulthood is entered with a tentative SOC. Commitments regarding work, life style and relationships further serve to cement the SOC over time. Once a considerable degree of permanence of the SOC is established in adulthood, it serves as a guide to the individual to select and interpret experiences congruent with the established level of SOC (Antonovsky, 1979, 1987).

In a wider analysis of SOC, Antonovsky described its key components as comprehensibility, manageability and meaningfulness (Antonovsky, 1979, 1987). The following is an explanation of these components (Antonovsky, 1979, 1987; Lindstrom & Eriksson, 2005, 2006; Makola, 2007):

Comprehensibility is the cognitive component. This refers to the extent to which individuals perceive internal or external stimuli as clear, ordered, structured and consistent information, and on the basis of which they can expect these stimuli to be so in the future. Manageability is the behavioural component which refers to the extent to which individuals perceive their life events to be bearable, can be coped with or challenges that can be met. Available resources include those perceived to be within the person's own control but may also be under the control of legitimate others (e.g., spouse, relatives, doctor, organisation, God) who have the capacity/power to assist. For the child and adolescent, the demands are determined not only by the internal resources but also the suprasystems (first and foremost the family) and whether they place such resources at the individual's disposal (Antonovsky, 1979; 1987; 1991). Antonovsky (1979; 1991) emphasised that manageability should not be confused with sense of mastery or an internal locus of control. Rather, it is the belief that one has adequate resources at one's disposal to meet the demands that is significant. Meaningfulness is the motivational component. This refers to the extent to which the person feels that life makes sense emotionally rather than cognitively. Antonovsky (1991) viewed meaningfulness as being the most central of the three components, followed by comprehensibility. Without meaning, comprehensibility or manageability are likely to be temporary. He noted that in his writings in 1979 he made reference to the three components but presented them as a unitary concept (SOC) neglecting the issue of how they were interrelated. He noted that a high level in one does not imply a high level in another. The SOC as a whole has a strong correlation with perceived health, mental well-being and quality of life (Eriksson & Lindstrom, 2005). Antonovsky (1987) acknowledges the influence of the work of Viktor Frankl in naming the meaningfulness component.

2.4.2.2.5 Individual placement on the health ease/dis-ease continuum

Antonovsky's (1979) proposed conceptualisation of the health ease/dis-ease continuum is that of a multifaceted state or condition of the human organism. Health ease explains movement to the salutary end of the (health) breakdown continuum. An individual's placement on the health ease/dis-ease continuum is indicated by pain, functional limitations, prognostic implications and action implications. It is both an objective and subjective phenomenon and it embraces the notion of causality, the interpretation of which is culturally determined (Antonovsky, 1979, 1987). Antonovsky (1979) noted that traditionally, one's location on the health ease/dis-ease continuum was viewed as a dependent variable. It was

seen as the final outcome of a long chain of phenomena. However, he stated that it should also be seen as having the potential to be an independent variable as it can affect the extent to which one is exposed to stressors. It can be a significant GRR as it can foster meaningful life experiences and it can facilitate the acquisition of other GRRs. Antonovsky (1987) stated “I am quite persuaded, until data compel me to modify or change my position, that the sense of coherence is a very major determinant of maintaining one’s position on the health ease/dis-ease continuum and of movement towards the healthy end” (p. 15). Antonovsky noted that whatever one’s location at any given point of time is, the extent to which the GRRs are available plays a decisive role in determining movement toward the healthy end of the continuum or at least, not moving towards the dis-ease end (Antonovsky,1979).

2.4.2.3 Critique of Antonovsky’s model

Antonovsky’s (1987) three components of the SOC are seen as comparable with the theoretical models of reputable theorists such as Kobasa (1979) and Moos and Schaefer (1993). For example, Moos’ relationship component (involvement, support and motivation) is comparable in concept to his meaningfulness component. Moos’ system maintenance component (clarity, organisation and consistency) is seen as comparable to his comprehensibility component and Moos’ goal orientation component (independence, work, pressure load) is seen as similar to his manageability component (Antonovsky, 1987).

With reference to their analysis of Antonovsky’s theory, concepts, and the operationalisation behind his SOC Scale, Flensburg-Madsen, Ventegodt and Merrick (2005) concluded that Antonovsky's basic idea of sense of coherence, as the basis for the salutogenic orientation is outstandingly good, in spite of the lack of statistical evidence. They rated the key explanatory concepts of comprehensibility, manageability, and meaning as fair. They were of the opinion that Antonovsky's theory was unfortunately much less clear, as Antonovsky assumed predictability to be very important for the sense of coherence, especially for comprehensibility and manageability.

Antonovsky’s salutogenic model has played an important role in the shift from the biomedical model with its health outcome as the presence or absence of disease to the incorporation and extension of psychological well-being as a further health outcome in response to illness. The systems orientation of his model recognises that the individual lives

within the context of various systems. This allows for the exploration of social and cultural factors in adaptation to life crises such as long term illness. While his model recognises that stressors are subjectively interpreted on an individual or group level, the systems orientation implies that an stressors such as the diagnosis of illness in an individual is likely to have impact on other systems and vice versa. This has important implications for intervention as the individual and its systems need to be considered. The development of the sense of coherence has provided a dispositional component to his model which is shaped during the developmental process in the context of culture and history. The sense of coherence mobilises what Antonovsky refers to as resistance resources or resistance deficits. These are important conceptual extensions and allow for a greater understanding of what contributes to the individual's ability to withstand the impact of life stressors such as a long term illness. The components of his theoretical model have important implications for the well-being of the individual.

The final model to be presented is Rudolph Moos' Integrated Stress and Coping Process Model.

2.4.3 Rudolph Moos

"I learned that many people are remarkably resilient and even thrive in the face of adversity. They manage to confront and transcend the most profound life crises and lead apparently productive lives ... at the same time there are often profound hidden personal costs ... I set out to try and understand the personal and social factors that shape these outcomes" (Moos, 2010).

2.4.3.1 Biographical information

Rudolph Moos, a Jew born in Germany, experienced the period pre, during and post World War II. He described his early childhood as chaotic as, for most of the war, he was separated from his parents. Post war, his family relocated to the United States of America. Moos observed the attempts and challenges of his and other families in a foreign land attempting to regain their existence and sense of self following the persecution they had suffered. This inspired him to translate and adapt his grandfather's memoirs in order to understand more about his origins and how Jews experienced Germany pre and post war, and

how they confronted its aftermath. Moos (2010) stated that his career in psychology enabled him to explore the questions that he needed to ask which included why some individuals are able to overcome severe life crises and live apparently normal lives and others are not. He was intrigued by the idea that life crises are turning points, times of opportunity as well as risk.

Apart from his Stress and Coping Process model, Moos developed the Life Stressors and Social Resources Inventory for both adults (LISRES-A) and youths (LISRES-Y). They were developed to assess chronic stressors, measure social resources and coping efforts (cognitive and behavioural) (Moos, 2002). Moos is currently Professor of Psychiatry and Behavioural Sciences at Stanford University.

2.4.3.2 Moos' Integrated Stress and Coping Process Model

2.4.3.2.1 Background to the model

The shift to psychological research focusing on the influence of social context on development and coping was in part a reaction to the dissatisfaction of the trait conceptualisation of personality (Kiritz & Moos, 1974). A growing body of research evidence had demonstrated that substantial differences could occur in the behaviours of the same persons when they were in different settings (Insel & Moos, 1974). Moos (2002) noted that this evidence had provided a clearer understanding of the underlying characteristics of life contexts and coping strategies, and about stress and coping processes. Moos' model (1993) was thus informed by stress and coping theory which focused on life stressors and social resources as two key sets of contextual factors associated with well-being. It was further informed by a systems orientation. The model provides a conceptual framework regarding both the dispositional and contextual perspectives of coping and how adaptive coping can moderate the influence of acute and chronic stressors on health and well-being (Moos, 2002; Moos & Holahan, 2003).

Insel and Moos (1974) identified dimensions that characterise a wide variety of social climates. Relationship dimensions include involvement, cohesion and support, the personal growth/goal orientation dimensions include autonomy, task orientation and work pressure

and the system maintenance/change dimensions include clarity, control and physical comfort (Insel & Moos, 1974; Antonovsky, 1987).

2.4.3.2.2 Explanation of Moos' model

The following is a diagrammatic representation of Moos' model

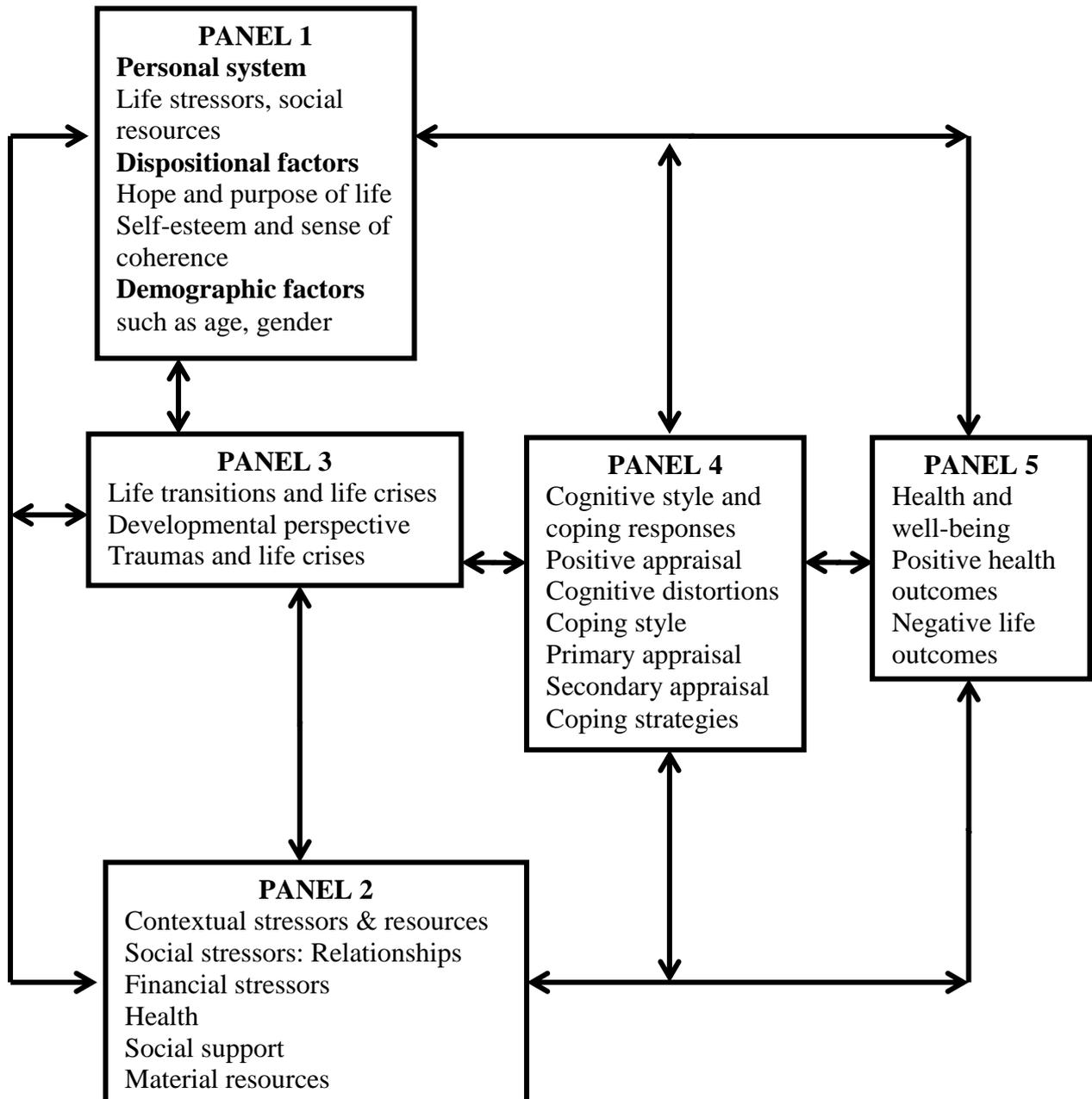


Figure 3. The Integrated Stress and Coping Process Model (Moos & Schaefer, 1993, p. 237).

The model consists of five panels. This includes: Personal System, Environmental System, Life Transitions and Crises, Coping Style and Appraisal and Health and Well-being.

The bi-directional paths in the model indicate that the processes are transactional and that reciprocal feedback can occur at each step (Moos & Schaefer, 1993). The model is an attempt to understand the development and outcome of life transitions and crises. It is based on the premise that through a cognitive appraisal of the significance of the crisis, basic adaptive tasks are set forth (Moos, 2002; Moos & Schaefer, 1993). A life crisis typically presents a set of related tasks and requires a combination or sequence of coping skills (Moos, 1986, 2002; Moos & Schaefer, 1993). The relative importance of the adaptive tasks varies depending on the personal characteristics of the individual, the nature of the stressor and the unique set of circumstances. The individual's appraisal, task definition, selection and effectiveness of coping skills are influenced by three sets of factors: demographic and personal characteristics, aspects of transition or crisis and features of the physical and social environments. These factors jointly affect the resolution of the initial phase of the crisis (Moos, 2002).

The following is an explanation of the five panels of the model:

The model proposes that ongoing environmental and personal factors foreshadow the transitory conditions and three factors (Panels 1, 2 & 3) shape cognitive appraisal and coping skills (Panel 4) and in turn, health and well-being (Panel 5) (Moos, 2002; Moos & Holahan, 2003).

Panel I: The Personal System includes biogenetic characteristics. In addition, dispositional factors and personal resources such as cognitive/intellectual abilities, social competence, self-confidence, optimism and extroversion are included (Moos, 2002; Moos & Holahan, 2003). These factors are considered enduring characteristics (Moos, 2002). Prior crisis and coping experiences are also considered important (Moos, 1986). Demographic factors include age, gender, ethnicity and socio-economic status. A combination of these factors defines the psychosocial crises as well as their resolution. Developmental factors are influential.

Panel 2: The Environmental System is composed of relatively stable conditions in specific life domains, which include the family climate, ongoing life stressors and social resources. Moos (2002) proposed that the nuclear family climate is the key context that sets the stage for adolescent development for example, and affects adolescents' reactions to life crises and transitions. He conceptualised the family environment in three dimensions which have important effects on psychological processes (Insel & Moos, 1974; Moos, 2002). The relationship dimension (the extent to which individuals, families and communities are involved and are supportive of each other) is a crucial dimension of the psychosocial environment, especially during the maturation process of the child (Insel & Moos, 1974). This dimension taps into areas such as cohesion, expressiveness, conflict and family affect (Moos, 1985). The personal growth dimension refers to the underlying goals towards which a particular setting is oriented (Moos, 1985) such as independence, achievement, culture, recreation and religion (Moos, 2002). The system maintenance dimension deals with the degree of structure, clarity and openness to change that characterises that setting and taps into family control or structure (Moos, 2002).

Panel 3: Life transitions and life crises: these include transitory conditions while Panel 1 reflects enduring characteristics (Moos, 2002). Moos and Schaefer (1986) view life transitions and crises as turning points which can result in personal growth and an expanded repertoire of coping skills or which may result in impaired adjustment and problem solving, which will impact upon future transitions and crises. The characteristics of life transitions and crises (type and context) define the nature of adaptive tasks the individual and his social network (e.g., family members) face, and consequently their adaptive responses. In view of the potential for growth, Moos and Schaefer (1986) positively view prevention programs and interventions which expand coping skills and can teach individuals to recognise and reduce the sources of stress helping them to strengthen their personal competence, coping skills and social resources as a means to personal growth.

Panel 4: Cognitive Appraisal and Coping Skills: Moos and Schaefer (1986) recognise that people respond differently to life crises/transitions. Factors determining their appraisal of the events as well as their choice and progression of coping strategies include a combination of personal and demographic factors, event related factors and available social resources. Social resources are primary and affect the selection and use of coping responses in specific stressful situations. The framework is consistent with the process/integration

model that considers coping in terms of the degree of integration among a person's values and beliefs, behaviour and emotions, social system and demands raised by specific stressors (Moos & Holahan, 2003).

Five major sets of adaptive tasks are required when managing a life transition or crisis (Moos & Schaefer, 1986). These include establishing the meaning and personal significance of the situation, confronting the reality and responding to the requirements of the external situation. It also involves sustaining relationships with family members, friends and other individuals who may help in resolving the crisis and its aftermath (in the case of an illness, it is often medical personnel or other patients). Maintaining an emotional balance by managing upsetting feelings aroused by the situation is important (e.g., the diagnosis and treatment of a long term illness evokes feelings such as uncertainty). The final task is preserving a satisfactory self-image and maintaining a sense of competence.

Major sets of coping skills are employed to deal with the adaptive tasks outlined above. These skills can be used individually, consecutively or more likely, in various combinations. They are not inherently adaptive or maladaptive but skills that are efficient in one situation may not be effective in another (Moos & Schaefer, 1993). These include cognitive appraisal and coping skills which reflect two main conceptual approaches to classify coping responses (Moos 2002, Moos & Holahan, 2003). Moos and Schaefer (1986) organise coping skills into three domains according to their primary focus and coping responses. The three domains are appraisal-focused coping, problem-focused coping and emotion-focused coping. Appraisal-focused coping (appraisal and re-appraisal) entails attempts to understand and find patterns of meaning in a crisis. The process is a form of coping as it serves to modify the meaning and therefore comprehend the threat aroused by the situation. Associated coping responses include logical analysis and mental preparation, cognitive re-definition and cognitive avoidance or denial. Problem-focused coping seeks to confront the reality of a crisis and its aftermath by dealing with tangible consequences and trying to construct a more satisfying situation. Associated coping responses include seeking information and support, taking problem-solving action and identifying alternative rewards. Emotion-focused coping aims to manage the feelings provoked by crisis and to maintain effective equilibrium. Associated coping responses include affective regulation, emotional discharge and resigned acceptance.

Panel 5: Health and well-being: With respect to the association between situation-specific coping responses and adaptive outcomes, individuals who rely more on approach coping rather than avoidance coping responses tend to adapt better to life stressors and experience fewer psychological symptoms (Holahan & Moos, 1991) while avoidant coping is a significant risk factor (Holahan & Moos, 1986, 1987a; 1987b; Moos & Holahan, 2003). The adaptive value of different coping skills depends on the interaction between the personal and social resources and the requirements of the particular situation (Moos & Holahan, 2003). Feelings of self-confidence, an easy going disposition, a disinclination to use avoidance coping and the availability of family support operate jointly to protect individuals from negative psychological consequences of life stress (Holahan & Moos, 1986, 1987a; Moos & Holahan, 2003) and are associated with health and well-being.

2.4.3.3 Critique of Moos' model

The basic assumption of Moos and Schaefer's Integrated Stress and Coping Process Model (1993), is that risk and protective factors interact with one another and with life-crises and developmental transitions. The combined impact of these three elements determines the coping strategies utilised by the individual and ultimately results in either a negative or positive health outcome. An advantage of this model is that there are flexible bi-directional pathways between stressors, resources and coping processes which influence one another (Kruger, 2010). This also implies that the way that the individual responds to a particular life transition or crisis is not static but is dependent on the nature of the interacting variables and the context he is in and developmental stage.

Recognising that the individual brings to any situation a range of personal, dispositional, demographic and contextual factors and that these are set in the context of a developmental and systemic perspective, makes a unique contribution to the field of stress and coping. It is a combination of these factors which influences the individual's response to the life transition or crisis (such as a long term illness). It also determines the individual's response to the crisis and determines the outcome such as psychological well-being.

The recognition by Moos and Schaefer (1993) of contextual stressors and resources is important and is especially relevant to this study. There are few models that recognise that the same factors can be a stressor or a resource depending on how they are experienced or

perceived by the individual and depending on their availability and nature. Information to a child with cancer, for example, can be a stressor or a resource depending on how much information is given, its appropriateness and its timing. Similarly, a medical professional or a family member can be a stressor or a resource depending on the availability and quality of the relationship.

The participants of this study are children who are moving through the middle childhood and adolescent phase of their development (Panel 3) and are part of a family, educational, religious, cultural and social system (Panel 2). At the time of diagnosis of a life threatening illness (Panel 3), they bring to the situation, a range of dispositional and demographic factors (Panel 1). The interaction of these variables, including their cognitive styles and coping responses (Panel 4) determines the outcome, the goal of which is psychological well-being (Panel 5) regardless of the status of the medical condition.

2.5 CONCLUSION

The theoretical shift from pathogenesis to salutogenesis has had a major impact on research, and disciplines such as medicine and psychology. This has resulted in a change in the focus of research from asking what it is that causes disease to what it is that enables individuals to stay healthy. In addition, the concurrent shift in the conceptualisation of stress from being a stimulus or a response, to a transaction between the person and the environment has led to the realisation that psychological well-being may be an outcome despite adversity. These concepts have been incorporated in the stress and coping models of theorists Antonovsky (1979), Lazarus and Folkman (1984) and Moos (Moos & Schaefer, 1993) which were presented in this chapter. Common to these theorists is the notion is that there is not a linear relationship between the stressor and the outcome but that the individual brings to the stress situation a number of person or environmental variables, which in combination with factors which mediate the stressor (such as appraisal), determine the outcome which is psychological well-being.

These conceptual elements have important implications for children with cancer. In essence, they imply that despite the fact that they are dealing with a stressor which is cancer, at a time when concurrent developmental processes and tasks are taking place, it is possible

to attain a state of well-being. As Moos' Integrated Stress and Coping Process Model (1993) includes a developmental perspective and recognises the interaction of internal and external factors contributing towards coping in the face of a life crisis when developmental transitions are taking place, it will be used as the guiding theoretical framework for this study.

In the next chapter, childhood cancer in terms of the disease process, etiology, incidence and treatment is discussed. As cancer in children occurs in a developmental context, an overview of the developmental tasks and challenges of children in the middle childhood and adolescent phases of their development is presented. The bi-directional relationship between the impact of cancer and developmental context is emphasised. Lastly, the psychological adjustment and challenges of the childhood cancer survivor and potential late effects, as well as quality of life issues are discussed.

CHAPTER 3

THE CHILD WITH CANCER: A DEVELOPMENTAL PERSPECTIVE

3.1 INTRODUCTION

The purpose of this chapter is to provide an understanding of childhood cancer in terms of the disease process, etiology, incidence and treatment. As the experience and impact of cancer in children occurs in the context of development, the chapter also provides an overview of the developmental tasks and challenges of children in the middle childhood and adolescent phases of their development. The emphasis is on the bi-directional relationship between the impact of cancer and developmental context. The psychological adjustment and challenges of the childhood cancer survivor, potential late effects of cancer, as well as quality of life issues are discussed.

3.2 IMPROVED CANCER SURVIVAL RATES AND QUALITY OF LIFE ISSUES

Previously thought to be fatal, childhood cancers are now considered treatable and potentially curable with an overall survival rate of over 70% (Patterson, Holm, & Gurney, 2004; Pogany et al., 2006). This is a result of multimodal therapy which includes multi-drug chemotherapy regimens, radiation and surgery (Benaim & Sorrentino, 1996; Long & Marsland, 2011; Ostroff & Steinglass, 1996; Poole, 2003). Dramatic improvements in disease free survival and a subsequent dramatic decline in cancer mortality have been achieved by increased research efforts directed towards epidemiologic studies of potential causes and risk factors for individual childhood cancers. In addition, greater knowledge of tumour biology, improved methods of detection and diagnosis, treatment and supportive care interventions have been contributory (Moore, 2002; Ostroff & Steinglass, 1996; Patterson et al., 2004).

Internationally the death rate for all major chronic illnesses has fallen. In Canada, for example, the death rate decreased from 794 per hundred thousand in 1984 to 622 per hundred thousand in 2001 (Samson & Siam, 2008). A primary consequence of this evolution is that, rather than preparing individuals to die, they need to be prepared to adapt over the long-term. Poole (2003) noted that in 2000, 1 in 1000 adults was a survivor of childhood cancer and that these statistics were on the increase. In view of this trend, there are more children living with cancer than are dying from it and there is thus an urgency to ensure **quality of life** (QOL). The extent to which life can be prolonged increases the importance of concern with the meaningfulness and effectiveness of living (Chesler & Barbarin, 1987; Insel & Moos, 1974).

According to Bleyer (1990), the dramatic improvement in survival is worthwhile only if the QOL justifies the increased prolongation of that life. It is for this reason that QOL issues for paediatric oncology patients have become increasingly important. The following definition of QOL was put forward by participants in an American Cancer Society workshop on QOL in children's cancer. QOL is multi-dimensional. It includes, but is not limited to, the social, physical and emotional functioning of the child and adolescent and when indicated, his or her family. Measurements of QOL must be from the perspective of the child, the adolescent and the family, and must be sensitive to the changes that occur throughout development. Chesler and Barbarin (1987) write that the impact of cancer must be judged, not only by the children's physical survival, but also by the extent to which they can resume pre-illness activities.

3.3 UNDERSTANDING CANCER

As the majority of the participants in this study had diagnoses of various types of cancer ($n=41$), the focus will be on cancer. A few of the participants were diagnosed with haemophilia ($n=3$) and were included in this study as they were treated in the oncology and haematology units, and it is assumed that their illness experience, albeit different, parallels that of children with cancer.

The following information provides an understanding of the disease process of childhood cancer, incidence, etiology and treatment.

3.3.1 The Disease Process

Cancer refers to the process in the body in which a cell or group of cells has developed the ability to grow in an abnormal and uncontrolled fashion. Although the single term cancer is used, it refers to a variety of different diseases affecting different tissues and organs (Chesler & Barbarin, 1987). The disease process includes malignant transformation which is a multistage process. **Initiation** involves the inappropriate activation of normal growth promoting genes to genes that encode for aberrant cellular growth (oncogenes) and proliferation, or inactivation or deletion of suppressor genes that normally inhibit cellular proliferation. **Promotion** is the second event in carcinogenesis that stimulates transformed cells to proliferate. **Progression** refers to tumor invasion of surrounding tissues and involves the accumulation of additional genetic alterations. **Metastasis** is the final stage of carcinogenesis and involves the spread of cancer cells to distance sites. This is often accompanied by the development of drug resistance (Moore, 2002).

The genetic alterations may be inherited or sporadic, and interact with poorly understood environmental factors. The two broad categories of genes involved in the development of paediatric cancers are dominant oncogenes and recessive suppressor genes (Rubinitz & Crist, 1997). There is compelling evidence that chromosomal translocations are often the initiating event in leukaemia, which occurs prenatally (Greaves, 2002; Lightfoot, 2005). The development of cancer in children closely parallels normal tissue development whereas adult malignancy is superimposed on pre-existing tissue. The implication of this biology is the increased responsiveness to treatment, especially chemotherapy (Poole, 2003).

3.3.2 Incidence and types of cancer in children

In developed countries, malignant disease is the most common non-accidental cause of death in children (Chesler & Barbarin, 1987; Poole, 2003; Wong & Chan, 2006) while in South Africa infectious respiratory and nutritional causes are the most common, including HIV (Poole, 2003). Although accurate published statistics on the incidence of childhood cancer in South Africa are not available, preliminary data suggested an annual incidence of 70-80 children per million (500-600 children) (CHOC 2006; Poole 2003) compared with the worldwide incidence of 150 children per million. It is estimated that a further 500 children

die of childhood cancer each year in South Africa due to a lack of diagnosis and treatment. Contributory factors include poor access to specialised medical services, especially in rural or poor communities or where families do not have the financial resources to seek medical help. Lack of awareness of childhood cancer is also a factor (CHOC, 2006). In addition, presenting symptoms of cancer can be varied and non-dramatic (such as low grade fever of long duration) and cancer may develop in the child for some time before it is recognised (Chesler & Barbarin, 1987). It is estimated that only half to two thirds of malignancies in black children in South Africa are diagnosed and that 80% of these children present at an advanced stage of the disease, thus contributing to poorer survival rates (Jithoo, 2010) and possibly a prevalence underestimation. In addition, the reality of the situation in South Africa is that children have to cope with inadequate medical service provision, especially mental health interventions (Richter, 2000).

The types of cancer are distinguished by the part of the body or organ system they attack and are often associated with the age of the child (Chesler & Barbarin, 1987). The relative incidence of the various childhood cancers (Poole, 2003), is represented below in figure 4.

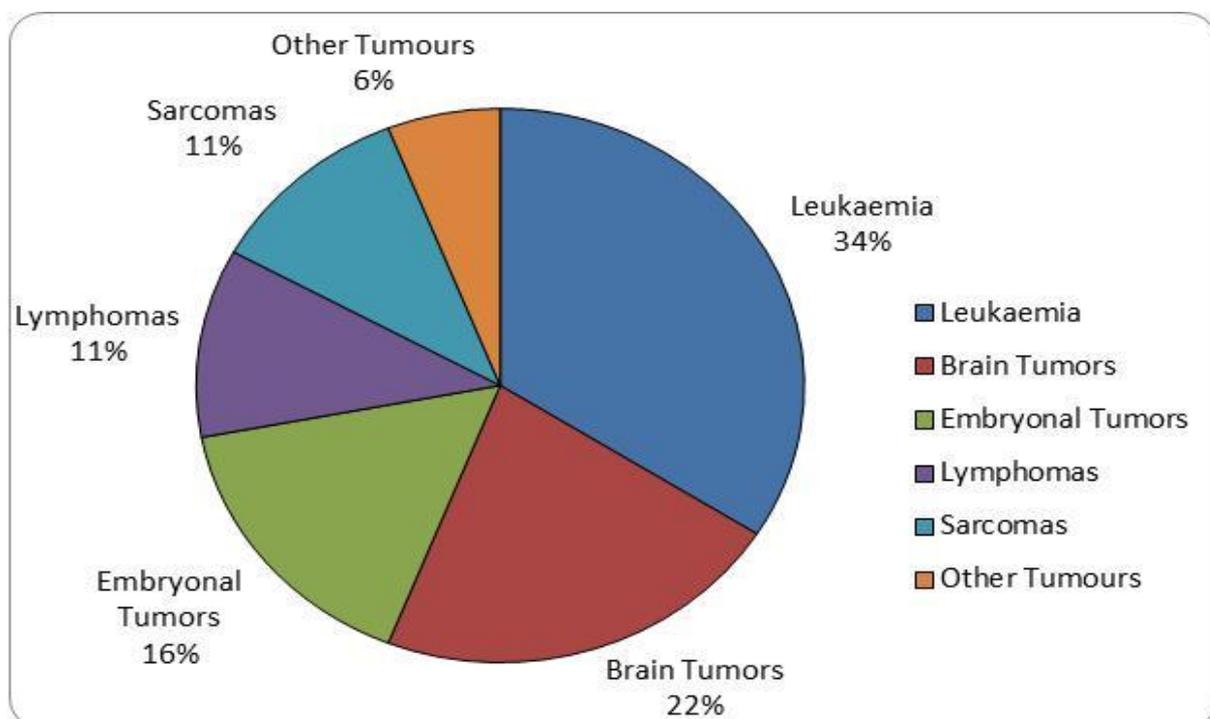


Figure 4. The incidence of childhood cancers.

Leukaemia (cancer of the blood system) originates in the bone marrow where blood cells are formed. An overgrowth of leukaemic cells crowds out healthy blood cells and infiltrates the bloodstream and other organs (Chesler & Barbarin, 1987). The incidence of 34% suggests that it is the most common form of childhood cancer (Ostroff & Steinglass, 1996). Leukaemia is made up of acute lymphoblastic leukaemia (ALL) - 27% and acute myeloid leukaemia (AML) - 7% (Poole, 2003). Most children diagnosed with leukaemia are between 2 and 12 years of age (Chesler & Barbarin, 1987). **Brain tumours** (22%) (Poole, 2003) occur with greatest frequency in the 5-10 year old group (Chesler & Barbarin, 1987). **Lymphomas** (11%) are cancers of the lymph system and include Hodgkin's lymphoma (7%) and Non-Hodgkin's lymphoma (4%) (Poole, 2003). They occur mostly in prepubescent children and adolescents (Chesler & Barbarin 1987). **Sarcomas** (11%) involve cancer in the soft tissue (6%) and in the bone (5%) (Poole, 2003). They also occur most frequently in prepubescent children and adolescents (Chesler & Barbarin, 2003). **Embryonal tumours** (16%) are made up of Wilms tumour (kidneys) (6%), neuroblastoma (6%), retinoblastoma (eye) (3%), and hepatoblastoma (liver) (1%) (Poole, 2003). They usually occur in very young children with a median age of less than 3 years (Chesler & Barbarin, 1987). Prognosis is determined by the type and stage of cancer.

3.3.3 Etiology and associated risk factors

An important question is whether childhood cancers are caused by something specific or are just tragic random events (Anderson, 2006). Recent advances in the treatment of childhood cancer have not been matched by similar advances in the understanding of etiology and associated risk factors (Anderson, Diwan, Fear, & Roman, 2000; Matteo & Pierluigi, 2008). Findings from reported studies are mostly inconclusive and controversial and there have been methodological concerns (Belson, Kingsley, & Holmes, 2007; Lightfoot, 2005; Zahm & Devesa, 1995), such as parental recall and small sample sizes (Zahm & Devesa, 1995). In addition, the short latency period between conception and early age of occurrence for most paediatric tumours narrows the window time for investigating the carcinogenic effects of environmental exposures (Anderson et al., 2000; Moore, 2002). Causation of at least some children's cancers is however suggested by direct and indirect evidence, including epidemiological data and animal studies. These predict early life sensitivity of humans to carcinogenic effects (Anderson, 2006). The literature broadly views the following associated risk factors:

3.3.3.1 Environmental exposure

The association between prenatal and post natal environmental exposures such as hydrocarbons, paints, benzene and pesticides and risk of childhood cancer has only been recently investigated (Moore, 2002). Exposure before birth and early in life has long been thought to be an important determinant of leukaemia, and the list of suspected chemical, physical, and biological agents continues to increase (Lightfoot, 2005). The literature notes that the investigations into environmental exposure have not been without methodological challenges in terms of confirming and quantifying exposures (Belson et al., 2007). Maternal exposure to hydrocarbons such as benzene, petroleum, coke, pitch, tar and soot has been associated with an elevated odds ratio (OR) of 1.9-3.3 in relation to total cancers (Castro-Jiménez & Orozco-Vargas, 2011; Feingold, Savitz & John, 1992). An odds ratio of greater than one means that the exposure may increase the risk of cancer (National Cancer Institute, 2010).

Epidemiological evidence has suggested that ionising radiation (Anderson et al., 2000; Belson, Kingsley & Holmes, 2007; Greaves, 2002) may play a role in the development of leukaemia and lymphomas (Greaves, 2002) and that paternal exposure (particularly pre conception) has been associated with an increased risk of infant leukaemia (Shu et al., 1994). Some authors have, however, concluded that no reliable support exists for this association (Wakeford, 1995). According to Shu et al. (1994), the risk of ALL increased with the number of X-rays to the upper and lower gastrointestinal tract and lower abdomen and chest. The highest risk for ALL was related to two or more X-rays (OR=3.78). Higher risks were also linked to exposures closer to conception. X-ray exposure in the month prior to conception of the index child was related to an increased risk (OR=4.5) of infant leukaemia. The findings could not be attributed to differences in underlying diseases that required x-ray or medications. Shu et al. (1994) further noted that the link between preconception x-ray exposure and infant ALL indicates a potential role of mutation or genomic instability in the development of cancer in young children.

3.3.3.2 Prenatal drug and substance exposure

The link between maternal prenatal drug and substance exposure and childhood cancer has also been recently investigated (Buffler, Kwan, Reynolds, & Urayama, 2005;

Moore, 2002). Diuretics for hypertension, amphetamines, tranquilisers, and non-prescription pain relievers have been associated with an increased risk of neuroblastoma (Schwartzbaum, 1992). There is modest evidence that maternal alcohol and drug consumption (especially during second and third trimesters) have been associated with increased risk of leukaemia (2.28 fold risk for ALL, 10.48 elevated risk for AML). A positive association was found for total amount of alcohol consumed during the pregnancy (Moore, 2002). An 11 fold risk of AML has been associated with the use of drugs, particularly marijuana, just prior to the pregnancy. Parental use of marijuana and cocaine significantly increased the risk for rhabdomyosarcoma (Robison, Buckley & Bunin, 1995).

3.3.3.3 Parental occupational exposures

Parental occupational exposures have been associated with an increased risk of childhood cancer (Belpomme et al., 2007; Buffler et al., 2005; Castro-Jiménez & Orozco-Vargas, 2011; Feingold et al., 1992). Paternal exposure to substances such as creosote adjusted the OR to 2.0 or greater for any childhood cancer. Paternal exposure to aniline (benzene derivative) and anthracene (coal tar derivative) were associated with an increased risk of ALL. Exposure to creosote and beryllium (toxic metal) was associated with an increased risk of brain tumours, with an OR=3.7 and 2.1 respectively (Castro-Jiménez & Orozco-Vargas, 2011; Feingold et al., 1992).

Bunin et al. (1990) reported that paternal occupations in the metal industry/military were associated with sporadic heritable retinoblastomas and that employment as welders/machinists before conception was associated with the non-heritable form of the disease with an OR of 4.0 (post conception risk higher-5.0). In the non-heritable form of retinoblastoma, post-conception exposures were important. Significantly more cases than controls in the non-heritable group had maternal grandfathers who were farmers (OR=10). One possible explanation is that women whose fathers were farmers would have been exposed to pesticides while growing up (stored in body fat), resulting in a higher body burden of pesticides that could adversely affect the foetus after conception.

3.3.3.4 History of maternal foetal loss

A history of maternal spontaneous abortion/miscarriage has also been investigated as a risk factor for ALL in the two to four year old groups, the risk being greater in the younger group. The risk increased with the number of foetal losses. Hypothesised explanations include genetic factors predisposing to an early onset of ALL and parental exposure to environmental agents. The latter not only increased the risk of foetal loss (Yeazel, Woods, Robison, Buckley, & Ruccione, 1995) but was also associated with childhood ALL (Belson et al., 2007; Yeazel et al., 1995).

3.3.3.5 Biological factors

Genetic factors are considered important in terms of etiology of childhood cancer. ALL and AML for example, are characterised by chromosomal translocations (Buffler et al., 2005) involving over 200 genes which are found in up to 80% of all cases. There is strong evidence that rearrangements involving specific genes or specific gene fusion can originate in utero. As with most other cancers, the mechanism by which leukaemia arises is thought to involve gene-environment interactions (Buffler et al., 2005; Lightfoot, 2005). Although there might not be a single or exclusive postnatal cause, an abnormal immune response to common viral and bacterial infection(s) in the child has emerged as a plausible etiological mechanism in the development of leukaemia and lymphomas (Greaves, 2002, 2006). In equatorial Africa, for example, Burkitt's lymphoma is most common in children and accounts for about 74% of all childhood malignancies (30% in the United States). There is emerging evidence that the link between Epstein-Barr virus and a specific virus for malaria accounts for the high incidence in Africa (Drisdelle, 2010).

3.3.4 Diagnosis, treatment and side effects

In order to establish a diagnosis of the specific type and subtype of cancer, upon which treatment and prognosis are based, tissue must be obtained (Chesler & Barbarin, 1987; Poole, 2003). Patients assigned to a good prognostic group are treated with the minimum of therapy whereas patients who fall in the poor prognostic group are treated aggressively (Poole, 2003). The therapeutic goal is to maximise damage to cancerous cells and to cure the patient with

minimum long-term effects. Therapeutic modalities for childhood cancer are chemotherapy, surgery, radiotherapy and biologic therapy including bone marrow transplantation. Disfiguring surgery is avoided if possible and less radiotherapy is used to avoid its effect on bone growth of the developing child (Poole, 2003). Once a diagnosis is made, the child usually spends a few days to several weeks in hospital, if there are complications. Active outpatient treatment usually takes place over a period of one to two years (Long & Marsland, 2011). If a relapse occurs, intensive treatments are reinitiated and extended and may involve readmissions to hospital (Chesler & Barbarin, 1987).

The nature of the cancer determines whether surgery, radiation and/or chemotherapy are required. Treatments usually have a toxic effect on the body and most children experience physical discomfort which are often associated with fear and anxiety. Drugs effective against cancer are especially targeted for fast growing tumour cells but they often have potent effects on other fast growing cells in the body such as mucous membranes and hair (Chesler & Barbarin, 1987). The loss of hair is usually of greatest impact to adolescents in view of their developmental phase, where identity formation and appearance are important. All children treated for cancer are likely to experience suppression of the immune system and blood counts, rendering them more vulnerable to infection and haemorrhage. During such periods, isolation is required and disruption of schooling and social activities is common. Fatigue, nausea and loss of appetite are frequently experienced. Although many of these side effects are temporary, there are important cosmetic, emotional, behavioural and health impacts. More permanent side effects can be secondary to surgery. Brain surgery has the potential for cognitive and motor sequelae or amputations in the case of bone cancer. Removal of an eye in retinoblastoma has obvious cosmetic, physiological and psychological consequences (Chesler & Barbarin, 1987). Nutritional problems are a common concern for paediatric cancer patients. Taste changes, nausea and vomiting and behavioural/environmental factors such as learned food aversions are common problems that contribute to poor oral intake and malnutrition, which have been associated with decreased tolerance of chemotherapy, increased incidents of infection and reduced prognosis (Tyc, Vallelunga, Mahoney, Smith, & Mulhern, 1995). Effective treatment of drug resistance and highly aggressive tumours continue to be a challenge (Chesler & Barbarin, 1987).

Advances in the management of disease and treatment related symptoms have also been important. Drugs used to hasten the recovery of bone marrow cells from the

suppressing effects of chemotherapy decrease the risk for sepsis. New classes of drugs are particularly effective in decreasing nausea and vomiting associated with chemotherapy regimens (Moore, 2002). These pharmacological advances have decreased the morbidity associated with aggressive cancer treatment. Gene therapy, defined as the insertion of genetic material into somatic cells with therapeutic intent, is the most recent innovation in the treatment of childhood cancers (Benaim & Sorrentino, 1996). There is evidence that children treated in large specialised treatment centres do better than in other centres (Chesler & Barbarin, 1987; CHOC, 2006; Poole, 2003) as they have the latest research results on treatment modalities and protocols. These centres have intensive care units suitable for children, advanced laboratories for critical disease markers and other such specialised facilities (Chesler & Barbarin, 1987).

3.3.5 Conclusion

The preceding section provides an understanding of cancer in terms of disease process, types of cancer, treatment and incidence. It notes the importance of quality of life issues in view of the improved survival rates of childhood cancer. It also highlights the fact that currently the link between etiology and cancer remains inconclusive and controversial but that there is evidence to support the link between biological and environmental factors.

The impact of childhood cancer takes place within a developmental context. An understanding of the bi-directional interaction between these two factors is crucial. The following section provides an understanding of the developmental tasks and challenges of children in the middle childhood and adolescent phases of their development.

3.4 UNDERSTANDING DEVELOPMENT

Children in this study are in the late middle childhood and adolescent phases of their development. Middle childhood is demarcated from 6-12 years and adolescence at between 11 and 13 years and ending between 17 and 21 years (Louw, D., & Louw, A., 2007).

The following information provides an overview of middle childhood and adolescence and the developmental tasks that are taking place.

3.4.1 Middle childhood

The middle childhood phase is an important developmental phase in which rapid cognitive, social, emotional and self-concept development is taking place. Relative to this, physical development is slower (Louw, D., & Louw, A., 2007). The middle childhood phase is an important developmental phase as it is the preparation for adolescence and is a time when self-esteem and sense of mastery are in a critical stage of development.

3.4.1.1 Physical development

An important characteristic of the middle childhood period is the slower rate of physical growth in comparison with the earlier preschool period and later adolescence. However, within this period, an outstanding feature is the rapid growth of the arms and legs relative to the torso. It is also a time when the girl:boy ratio in terms of growth is different, with girls developing at a faster rate than boys. As a result of increased strength, muscular control and co-ordination, the acquisition and refinement of psychomotor skills are the most prominent developmental characteristics of middle childhood. The brain also reaches its adult size and weight (Louw, D., & Louw, A., 2007).

3.4.1.2 /Cognitive development

The middle childhood stage represents significant cognitive gains. In Piagetian terms, the child moves from the pre-operational phase and enters the concrete operational phase. This allows for the development of thinking which includes concepts such as reversibility (Louw, D., & Louw, A., 2007), and thus by implication, irreversibility. It is in this phase of development that the child begins to acquire the theoretical concepts required for an understanding of death for the first time. Concepts commonly referred to in the literature include universality/inevitability (understanding that all things die); irreversibility/finality (understanding that when a living thing dies, its physical body cannot be made alive again); non functionality/cessation (understanding that all life defining functions cease on death) and causality (understanding that things die as a result of biological function). Irreversibility and universality are the first components to develop and are believed to be prerequisites for the other concepts. Non-functionality and causality then follow sequentially (Cuddy-Casey & Orvaschel, 1997). It is not unreasonable to consider that an understanding of concepts such

as causality and irreversibility will influence the child's thinking about his diagnosis of cancer.

During this stage of development, cognitive decentring takes place. This allows for less egocentric thinking and is associated with a decrease in egocentric behaviour. Other changes that become evident are in information processing, executive functioning and memory (Louw, D., & Louw, A., 2007). In particular, there is a marked improvement in working memory capacity (the ability to work with information and ignore competing information) in this developmental phase (Kesek, Zelazo, & Lewis, 2009). Children in this phase of development also have an improved "theory of mind" and thus are able to understand their own behaviour and thoughts as well as that of others. In terms of language development, not only are they able to use and understand language at a higher level, they also display a greater use and understanding of facial expressions and gestures to read into the language of others (Louw, D., & Louw, A., 2007). It is the writer's opinion that the cognitive development, the conceptual development and the associated awareness that take place at this time makes this group of children particularly vulnerable to the information, implications and associations of a diagnosis of cancer.

3.4.1.3 Emotional and affective development

As a consequence of cognitive changes, significant shifts are seen in emotional development. There is an increased ability to understand complex emotions such as guilt (Eisenberg, 2000) and shame (Basson, 2008; Eisenberg, Morris, & Vaughan, 2009). These are self-conscious emotions following an appraisal/evaluation of a situation (Eisenberg et al., 2009). Guilt can enhance social relationships in that it motivates people to treat others fairly and equally. Shame, however, involves a negative evaluation of the self and can cause avoidance of others (Eisenberg, 2000; Eisenberg et al., 2009). During this stage of development these emotions become internalised and integrated and manifest behaviourally. An increased understanding that more than one emotion can be experienced in a particular situation, as well an increased tendency to take into account events and situations leading to emotional reactions, is seen in middle childhood. There is also an improvement in the ability to conceal negative emotional reactions and the use of self-initiated strategies for redirecting feelings (Basson, 2008).

The increased ability for the understanding of self and others allows for comparison of self in relation to others. Self-esteem development involves judgments about one's worth and is often based on feedback from others, and achievements relative to others (Louw, D., & Louw, A., 2007; Eisenberg et al., 2009). As a result of the increased ability for comparison in relation to others, an increase in sibling rivalry may be seen at this time (Louw, D., & Louw, A., 2007).

3.4.1.4 Social development

In the middle childhood phase the parent-child relationship shifts. Children are less dependent on their parents and spend relatively less time with them although they still have a high need for them. Peer acceptance is important. Greater solidarity and cohesion develops within the peer group and there is often gravitation towards children of the same gender and age. Friendships remain fairly stable and provide an important context in which skills such as tolerating criticism, resolving disputes and emotional commitment are learnt (Louw, D., & Louw, A., 2007).

3.4.1.5 Moral development

Moral development takes place concurrently with the other areas of development. One of the most important developmental tasks to be mastered in the middle childhood phase is the ability to differentiate between right and wrong. During the late middle childhood phase, the view that rules should be obeyed at all times (moral realism) and that no mitigating circumstances should be taken into account (moral absolutism) has lessened and a phase of moral relativism is entered, where the child realises that rules can be questioned and the intentions can be taken into account. A realisation that bad things do not happen because of naughty behaviour also emerges (Louw, D., & Louw, A., 2007). Moral emotions such as empathy and sympathy become more sophisticated and are presumed to play an important role in socio-emotional development and social behaviour (Eisenberg, 2000; Hoffman, 2000). Empathy involves a degree of self-other differentiation and cognitive perspective taking and involves both cognitive and emotional responses, while sympathy involves only the latter (Eisenberg et al., 2009). Although rudimentary forms of empathy are present early in life (Hoffman, 2000; Roth-Hanania, Davidov, & Zahn-Waxler, 2011), it is in early and middle childhood that the ability to decipher own and others' emotional states becomes more

developed, as does the cognitive understanding of the processes of experiencing empathy (Hoffman, 2000).

3.4.2 Adolescence

Adolescence is a period of multidimensional development with rapid and extensive developmental change and physical, sexual, cognitive, emotional and social maturation (Basson, 2008; Frydenberg, 2008; Larson & Sheeber, 2009; Louw, D., & Louw, A., 2007). Movements towards independence and explorations of identity are significant developmental tasks (Frydenberg, 2008). Adolescence is characterised by increases in negative emotionality, greater sensitivity to peer-related social interactions, greater reward seeking, greater engagement with long-term goals (Nelson et al., 2005) and experimentation (Basson, 2008). These changes contribute to the image of adolescence as a period of life fraught with stress (Aneshensel & Gore, 1991). While there is extensive debate in the literature as to whether adolescence is a period of “storm and stress” or a normative transition into adulthood, there is general agreement that adolescence has a number of significant adjustment hurdles and that a complex set of external and internal stressors are thus part of the adolescent experience (Frydenberg, 2008).

The very nature of adolescence as a period between childhood and adulthood means that most teens encounter numerous life change events with the potential to evoke stress (Aneshensel & Gore, 1991) and that adolescent concerns generally reflect the developmental tasks of their own age and of early adulthood (Frydenberg, 2008). Life stressors in adolescence (such as a long-term illness) have been shown to contribute to an increased risk of emotional, cognitive and behavioural difficulties such as depression, behaviour problems, anxiety disorders and academic failures (Frydenberg, 2008), although most children with cancer are as psychologically normal as physically healthy children (Chesler & Barbarin, 1987).

3.4.2.1 Physical development

Unlike the middle childhood phase, this developmental stage is characterised by major physical changes. Adolescents’ growth spurts involve sudden increases in height and weight (Pinyerd & Zipf, 2005). For girls, this is usually at 10.5 years with peaks by age 12.

This returns to a slower rate at about age 13. Boys usually begin their growth spurt by age 13 with a peak at 14 years. Rapid muscle development makes both boys and girls noticeably stronger and physically more capable than they were as children (Seger & Thorstensson, 2000). For most girls, sexual maturation starts at age 9 to 11, with first menstruation at age 12. For boys, puberty starts at age 11 to 12 and peaks at age 13 to 14.5 (Pinyerd & Zipf, 2005). The impact of these physical changes on the psychological state of adolescents can be profound. Each adolescent experiences a variety of individual differences, with some moving through adolescence quickly and graciously whilst others are confronted with more challenging transitions (Louw, D., & Louw, A., 2007). The differences in the developmental rate contribute to adolescents' self-consciousness about their appearances (Basson, 2008). Girls often experience a mixture of positive and negative feelings about puberty (Moore, 1995). Negative feelings are thought to be mediated by body dissatisfaction. Boys, on the other hand, usually have positive associations with the weight gain, decreases in body fat, increases in lean muscle (DeRose & Brooks-Gunn, 2009) and voice changes that accompany puberty. Boys can become preoccupied with their physical and athletic appearance and abilities (Benjet & Hernández-Guzman, 2002; Rosenblum & Lewis, 1999).

3.4.2.2 Cognitive development

Adolescence is characterised by distinct stages in brain maturation with the development of the frontal lobes (Louw, D., & Louw, A., 2007) and core executive and self-regulatory skills that continue into early adulthood (Allen & Sheeber, 2009). This maturation is thought to be associated with significant remodelling in brain regions associated with social cognition, response inhibition, emotional regulation and the capacity for reflective and hypothetical thinking (Allen & Sheeber, 2009b; Nelson et al., 2005). In Piagetian terms, the adolescent has now entered the formal operational stage of cognitive development (Louw, D., & Louw, A., 2007).

With the development of the prefrontal cortex and executive function, adolescents are better able to manage their own actions, focus on alternative appraisals of strategies, disengage from distressing cues and inhibit impulses; however, the development of executive function follows a protracted course that mirrors the slow development of the prefrontal cortex. Executive function can be fragile and complex and vulnerable to disruption from various sources, which include stressors (Kesek, Zelazo, & Lewis, 2009).

The adolescents' newly acquired ability to reason abstractly also signifies that they are starting to question many existing beliefs and values (Schaffer & Kipp, 2007; Sigelman & Rider, 2009). The ability to think hypothetically and question often results in what is commonly perceived as argumentativeness (Louw, D., & Louw, A., 2007). The adolescent requires more intellectual stimulation than in previous stages of development. While the ability to have the perspective of "other" broadens to beyond that of another individual to that of society, a new kind of egocentric thinking occurs in adolescence. As adolescents reflect their own thoughts, their combined physical and psychological development often results in the belief that they are the focus of others. This results in an intense awareness of appearance, sensitivity to criticism from others and an exaggerated sense of how others perceive them, which leads to a high level of self-conscious thoughts and behaviours (Louw, D., & Louw, A., 2007).

3.4.2.3 Emotional and affective development

Affective development is inextricably linked with cognitive, biological, sexual and interpersonal processes which are also undergoing rapid and marked development during the adolescent period (Allen & Sheeber, 2009b). The most important developmental changes during adolescence involve the process of identity formation and self, and a progression towards a sense of independence (Basson, 2008; Frydenberg, 2008). The defining neurobiological change and developmental event of early adolescence is puberty (Allen & Sheeber, 2009b; DeRose & Brooks-Gunn, 2009). Although biological researchers have traditionally viewed puberty from an endocrine perspective, more recent developments have emphasised the neural control of hormone secretion and the extensive brain remodelling that is associated with it (Sisk & Foster, 2004).

Until recently, examination of brain structure and function depended on autopsy and lesion work and it was therefore difficult to study the adolescent brain (Casey, Giedd, & Thomas, 2000). Recent technological advances, such as functional magnetic resonance imaging, have allowed unprecedented opportunities to track developmental changes in the brain both structurally and functionally (Kesek et al., 2009). In particular, brain regions associated with affective processing are densely innervated by gonadal steroid receptors (Nelson et al., 2005; Sisk & Foster, 2004) which play a role in regulating many of the neurotransmitter systems associated with affective and social responsiveness and mood

(Osterlund & Hurd, 2001; Sundermann, Maki, & Bishop, 2010). Animal and human studies support a link between gonadal hormones such as testosterone and sensitivity to social status (Rowe et al., 2004). The influence of physical development and especially hormonal changes in adolescence can lead to moodiness, bouts of depression and lower or more uneven energy levels (Sigelman & Rider, 2009). In addition, how well adolescents cope with the physiological changes of puberty depends on how well they cope with stress in general, their pre-pubertal psychological vulnerability and the frequency and types of stressors during the pubertal transition. Puberty is thought to accentuate the effects of psychosocial factors that existed prior to its onset (DeRose & Brooks-Gunn, 2009).

Strong evidence exists that, relative to adulthood, adolescence is a time of wide emotional swings with both strong negative and positive emotions, with positive states more frequent than negative ones for most adolescents (Larson & Sheeber, 2009). Emotional regulation of feelings, impulses and appraisals is one of the most important developmental processes of this phase of development. The capacity for emotional regulation increases throughout adolescence as does the intensity of the emotions; however these changes do not always occur in parallel. Many theorists consider it typical for regulatory capacities to lag behind the increases in the intensity and range of emotions, as the ability to regulate emotions and behaviour depends to a large degree, on cognitive capacities that do not reach maturity until early adulthood (Kesek et al., 2009). This neurobiological mismatch is exacerbated by the substantial and rapid changes in the adolescent's social environment and by the normative withdrawal of parental regulatory controls (Allen & Sheeber, 2009c).

In adolescence, a gender differential was noted, in terms of depressive disorders and anxiety incidence, which continues through adulthood. Rates of depression in boys and girls are indistinguishable until the pubertal transition and by mid-adolescence the gender difference is 2:1 for girls to boys (Allen & Sheeber, 2009c) for the incidence of anxiety (de Matos et al., 2008). Research by DeRose and Brooks-Gunn (2009) found that pubertal hormones accounted for a small portion of the variance in outcomes when investigating affect, with social factors having the stronger effect. Ultimately, the impact of the physical changes and the concurrent psychological development determines whether the adolescent becomes a well-adjusted adult (Basson, 2008).

3.4.2.4 Social development and interpersonal relationships

The social world that the child encounters during the transition to adolescence is increasingly broad, hierarchical, and complex (Allen & Sheeber, 2009a). During adolescence, significant changes begin to occur in the nature of family and social relations. These transitions in school life, peer and family relationships often result in increases in conflict within the family, characteristically with parents (Louw, D., & Louw, A., 2007). These conflicts are more marked in the early and middle adolescent years and are generally superseded in late adolescence, when parent/child relationships become more settled (Frydenberg, 2008). One of the primary developmental tasks for families of adolescents is renegotiating relationships such that the necessary asymmetrical power structure between children and their parents becomes more balanced, as the adolescent is increasingly allowed more autonomy and input into family and personal decision making (Allen & Sheeber, 2009a; Larson & Sheeber, 2009). The successful accomplishment of the psychosocial developmental tasks demands changes in numerous established social relationships, for example, when parents and child negotiate changing responsibilities and privileges (Aneshensel & Gore, 1991). These changes in the parent-adolescent relationship, however, mean that the external contributors to adolescent affective and behavioural regulation in the form of parental support and structure are reduced at a time when increased emotionality and reward-seeking create additional regulatory demands (Allen & Sheeber, 2009b; Larson & Sheeber, 2009).

Adolescents are substantially more sociable than younger children (Steinberg & Sheffield Morris, 2001) spending up to one third of their waking hours in the company of their peers (Hartup & Stevens, 1997), with the amount of time spent with family members decreasing by half and an increase by 50% spending time alone (Larson, Richards, Moneta, Holmbeck, & Duckett, 1996). In adolescence, close peers surpass parents as the primary source of social support and contribute to the adolescent's self-concept and well-being (La Greca, Davila, & Siegel, 2009). Adolescents are more likely to report being in a good mood when with friends or when recreating (Buchanan, Eccles, & Becker, 1992; Steinberg, 1999). Peer relationships in this period have several distinct features that influence affective experiences. Relationships with peers are relatively egalitarian in nature whereas in their relationships with adults an imbalance exists in the distribution of power and knowledge. A primary component of adolescent friendships is intimate self-disclosure. Thoughts and

feelings are expressed within these friendships and mutual co-rumination of problems about adverse experiences, both real and hypothetical, is frequent (Furman, McDunn, & Young, 2009; Allen & Sheeber, 2009c). The tenuousness and complexity of adolescent relationships occur in the context of adolescents' increased sensitivity and rejection by their peers (Nelson et al., 2005). This makes adolescence a period of particularly high interpersonal stress associated with the establishment and maintenance of the kind of social reputation that will enhance social acceptance and reduce the likelihood of rejection and ostracism (Allen & Sheeber, 2009a).

The emergence of romantic relationships is common during this period of development (Furman et al., 2009; La Greca et al., 2009), thus there is often a growing interest in dating. Physical attractiveness and popularity become critical issues which have implications for personal self-esteem and the development of relationships (Basson, 2008).

3.4.2.5 Moral development

One of the most important life skills that adolescents have to acquire is a set of values and an ethical system that operates as a guide to behaviour (Louw, D., & Louw, A., 2007). The increased ability to experience moral emotions such as empathy and sympathy in middle childhood continues into adolescence. There is some evidence of a neural basis for this changing ability and that the surge of gonadal steroids at puberty induces changes within the limbic system that alters the adolescent's emotional attributions about social stimuli. At the same time the maturation of the prefrontal cortex enables increasingly complex and controlled responses to social information (Nelson et al., 2005). As in middle childhood, the development of self-conscious emotions such as guilt continues through adolescence, with the increasing ability of adolescents to think abstractly and to judge themselves in comparison to others (Eisenberg et al., 2009). There is a concurrent shift away from dualistic thinking that something can be right or wrong to relativistic thinking (Louw, D., & Louw, A., 2007).

The preceding two sections of this chapter have focused on an understanding of cancer and the developmental tasks of middle childhood and adolescence respectively. The following section will focus on the impact of cancer on the child and its supporting systems, while concurrent developmental tasks are taking place.

3.5 UNDERSTANDING CHILDHOOD CANCER IN THE CONTEXT OF DEVELOPMENT: BI-DIRECTIONAL IMPACT

The impact of childhood cancer is widespread. From a General Systems Theory perspective, the child who has cancer is an individual which is part of many other systems. The theoretical assumption that underlies General Systems Theory is that living systems are organised in a hierarchy wherein complex higher systems emerge from lower ones. The following subsystems are present: (Janosik & Green, 1992; Schlebusch, 1990).

- National system
- Community/Society
- Organisation (e.g., school)
- Groups (e.g., family)
- Organism (e.g., child)
- Biological level (e.g., cancer)

A change in one level impacts upon systems on another level either positively or negatively. The impact on systems is bi-directional. In the case of childhood cancer, a diagnosis has its greatest impact on the child and systems closest to it. However, even systems which are furthest from the child can impact significantly for example, the impact on the child of the national system is powerful in terms of the resources and policies regarding health. Figure 5 (below), illustrates the widespread impact of cancer on the child.

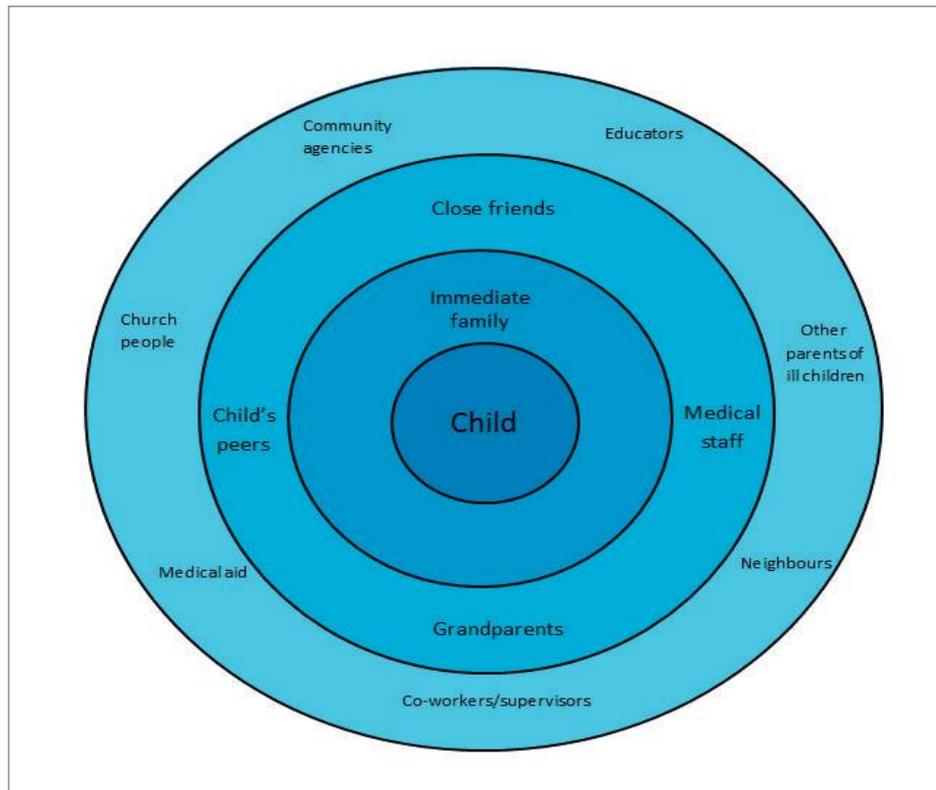


Figure 5. The widespread impact of childhood cancer (Chesler & Barbarin, 1987, p. 270).

3.5.1 The impact of cancer on the child

Cancer is a disease which has many facets. Apart from the impact of the diagnosis on the child, the child has to contend with the treatment and its side effects. The disruption to the child's world and all that is familiar is profound. All of this takes place while concurrent developmental changes are occurring. Recent literature on children's and adolescents' experiences with cancer has put to rest earlier concerns about psychological abnormality. Studies indicate that most children with cancer are as psychologically normal as physically healthy children but that some do have psychological and emotional problems, as do healthy ones (Chesler & Barbarin, 1987; Zebrack et al., 2007). There is however a growing body of evidence that family factors may contribute to adjustment outcomes. These include family risk or protective factors that can precede and/or result from the child's diagnosis. Cancer can also impact the family system at multiple levels, from individual family members to disruptions of relationships between family members and functioning within the whole family system (Long & Marsland, 2011).

Although childhood cancer is hard for the family and is a shared stress, the illness affects the child differently from other family members (Chesler & Barbarin, 1987). In the late middle childhood and particularly the adolescent developmental periods, the growing need for autonomy and independence competes with parents' concerns for controlling the illness regimen (Engel & Melamed, 2002). The developmental tasks of middle childhood and adolescence present a particularly trying time for the child and having cancer at the same time makes it especially hard (Chesler & Barbarin, 1987). In this developmental period, changes in hormones can make the medical regulation of the disease processes difficult, even with excellent compliance.

An understanding of the impact of cancer from the child's perspective is important. Chesler and Barbarin's (1987) research with adolescents ($N=17$) indicated that they experienced diagnosis, surgery and relapse as potent stress events. Hair loss and school re-entry were identified as powerful events. Adolescents, in particular, listed the important stressors they experienced as related to medical stresses and managing the external social world. The following discussion provides an understanding of how cancer impacts upon the child.

3.5.1.1 Diagnosis and prognosis

At diagnosis, children may experience stress regarding understanding the seriousness of the condition and dealing with the uncertainty of the situation. Some parents share the information directly but there are times when information may be incomplete or delayed. Based on the child's cognitive abilities at this time, conclusions may be drawn using cues such as parental distress and reading between the lines of what is said and what is whispered out of earshot (Louw, D., & Louw, A., 2007). Many children notice and read into the rapidity with which they are hospitalised and notice that siblings are allowed to stay at home and some relatives travel long distances to come to the hospital. Children's initial anxiety is exacerbated when they are not allowed to be active participants in discussions of their illness. In the absence of adequate information, children may fantasise an even worse scenario. It is for this reason that an early and full disclosure of the diagnosis, in clear and supportive ways to the child, is recommended (Chesler & Barbarin, 1987).

At the time of diagnosis, information seeking and denial seem to be the most common coping strategies used by adolescents, with younger children using denial more successfully (Koocher & O'Malley, 1981). Both strategies represent efforts to deal with information and its emotional meaning (Chesler & Barbarin, 1987). Information seeking is a psychological defence mechanism closely related to intellectualisation. This is an attempt to manage stress by cognitive mastery to establish a sense of intellectual control. The function of denial as a coping strategy involves the avoidance of information or experiences that may unnecessarily increase anxiety about the illness. Intellectualisation is a common coping strategy which leads to many of the children diagnosed with cancer becoming interested in biology and psychology (Chesler & Barbarin, 1987).

3.5.1.2 Adapting to the treatment and side effects

Adapting to the treatment for cancer is a potential stressor (Engel & Melamed, 2002) and includes pain and fears of death (Chesler & Barbarin, 1987). As treatment progresses, the seriousness of the situation is brought home to the child by drastic medical procedures such as surgery, chemotherapy, radiation, repeated hospitalisations, tests and injections. Each of these has the potential to debilitate the child physically and emotionally and to disrupt family life, school attendance and friendships.

Younger children, especially describe the illness and treatment in terms of needles, infusion pumps, scans, bone marrow aspirations and complex machinery (Chesler & Barbarin, 1987). The treatments sometimes make them feel as if their bodies are not their own. Even for children who are treated on an outpatient basis, the experience is stressful. Hockenberry-Eaton, Kemp and Dilorio (1994) investigated the relationship between acute and chronic cancer stressors, protective factors and the physiological and psychological responses experienced during treatment. Mean epinephrine levels (a physiologic measure of stress) were elevated above normal levels during clinic visits.

Changes in body image stem from the physical effects of treatment and a feeling that there is an internal battle going on between the good cells and the bad cells (Farrell & Hutter, 1980). For some adolescents the changes in their appearance, such as hair loss are even more troublesome than the pain of treatments. This appears to be more traumatic for girls than for boys (Orr, Weller, Satterwhite, & Pless, 1984). Amputation, although considered a life-

saving medical procedure, is a significant stress for the adolescent, especially with the cosmetic implications. Fatigue is an important symptom experienced by most children with cancer. Hockenberry-Eaton et al. (1998) conducted focus groups to define and describe fatigue experienced by the children. Younger groups described both physical and mental symptoms such as weakness, being tired, feeling upset and not being able to participate in sports. Adolescent descriptions of fatigue included changes in their body, feeling sorry for themselves, physical symptoms such as dizziness, nausea, hot and cold flushes and falling asleep anywhere (Moore, 2002).

Of all the treatment related issues, the unremitting, continuous, prolonged course of treatment with no respite was the most debilitating. Frequent hospitalisations or confinement was experienced as social isolation. Although most children received a great deal of attention in the initial stages, many felt forgotten and eventually isolated. Over time, the cumulative impact of prolonged treatment and gradual isolation from friends has the potential to lead to hopelessness and despair. It is not uncommon for depression, anger and rebelliousness to be common reactions (Chesler & Barbarin, 1987; Li, Chung, & Chiu, 2010).

Although 90% of children with cancer enter a state of remission, almost half suffer a relapse at some time. As the amount of time increases from diagnosis, children inevitably experience the deaths of other children who they have befriended. These deaths bring home very clearly the life threatening nature of their own illness (Chesler & Barbarin, 1987; Jithoo, 2010) and they are confronted with the issues of their own mortality.

3.5.1.3 Relationships with others

Having to relate to others is recognised as a potential stressor by many theorists (Chesler & Barbarin, 1987; Engel & Melamed, 2002), however from the perspective of Moos and Schaefer (1993), any relationship can be a resource or a stressor. For adolescents, as they spend so much time with their doctors and other medical staff such as nurses, these relationships have the potential to be stressors or resources. Many adolescents expressed the desire to have more personal and interactive relationships with the medical staff. They expected their doctors to be open, honest, and non-judgmental and to include them in the formulation of treatment plans. They expected them to protect their privacy and modesty.

This was especially important to them as many of them felt that they were being assaulted by the disease and its treatments (Chesler & Barbarin, 1987).

Relating to family and peers is also a potential resource or a stressor. For younger children, the diagnosis of cancer results in an extension of pre-existing dependency on their family, while for adolescents it may involve regression of their new found independence into a prior dependent relationship. The research literature suggests that children who are seriously ill become more dependent upon their parents, at least temporarily (Chesler & Barbarin, 1987). The symmetry or compatibility of coping strategies between parent and child was noted to be an important factor in parent-child interactions (Chesler & Barbarin, 1987; Hägglöf, 1999). Parents may, for example, want to discuss issues with their children who may not want to do so, or vice versa. Some children with cancer may want to protect their parents as they can see that the situation is upsetting for them (Chesler & Barbarin, 1987).

Relationships outside of the family are often a source of stress. Frustration and pain from social isolation and stigmatisation by peers is often a reality and issues in peer rejection can often arise as early as diagnosis (Chesler & Barbarin, 1987). It is important for the ill child to have friends, even one (Orr et al., 1984). When loss of opportunities for social interaction with peers is severe, it is experienced as a major deprivation that multiplies the other stresses of the illness. When a positive interaction with peers occurs it helps to ease the stress of coping with the illness and renews the child's adaptive capacities (Chesler & Barbarin, 1987). Just as parents have to decide what to tell their children, children with cancer must decide what and how much to tell their peers (Chesler & Barbarin, 1987). Orr et al. (1984) emphasise that it is also part of the ill child's responsibility to reach out to peers and to create opportunities for positive interaction. If the child with cancer is awkward about relating to former peers about his illness it will influence the peer response. Thus the child with cancer needs to guide the peer interaction.

3.5.1.4 Dealing with two worlds: illness and health

As a consequence of dealing simultaneously with normal social situations and with a unique medical situation, the experience of children with cancer is that they are living in two social worlds. There is a world of health and a world of medicine and illness, each of which has different rules. Even children who are doing well medically enter the world of medicine and illness for checkups and treatments (Chesler & Barbarin, 1987).

At home and school, ill children try to be normal and live according to the same rules as everyone else as they attempt to grow up and master the many challenges of everyday existence. In the medical setting they see people struggling with life and death and see sickness and pain. In this world they relate to doctors and nurses. They may see their friends die and have to confront their own mortality. In their other world they relate to parents, teachers and friends (Chesler & Barbarin, 1987). Children with cancer unanimously report that their primary goal in relation to these two worlds is to resume a normal life as soon as possible. At the root of this quest is a concern and resistance about being different or being treated differently than others. They would want to avoid an identity as a person with cancer (Engel & Melamed, 2002).

Children who have been in lengthy remissions and who are ready to come off treatment make more permanent transitions between these two worlds, from the medical world to the normal world. However, for many, getting better comes with its own stresses and strains. Koocher and O'Malley (1981) make reference to "The Damocles Syndrome" to dramatise the fragile thread by which even recovered or cured children live. Continuing attention to lumps or symptoms that might indicate the return of the illness and heightened reactions to anniversaries of diagnosis or treatment cessation are reminders of the ill world, even in the midst of health and recovery (Chesler & Barbarin, 1987).

School attendance is an important part of life and provides vital social opportunities and developmental activities. It is a way in which children with cancer can maintain normalcy despite their struggle with their illness. For these reasons, children with cancer are encouraged to participate in school activities as fully as possible. There are some difficulties, however, that pose challenges to re-entry to school (Chesler & Barbarin, 1987; Engel & Melamed, 2002). These include physical discomfort and fatigue, frequent absences, falling

behind academically, peer teasing and avoidance and difficulties relating to the school staff. Although teasing is typical school age behaviour, children with cancer are inappropriate targets for such teasing in view of their psychological vulnerability. Psychological and psychosocial consequences of the treatment and the situation can also affect the student's attitude towards school and achievements. Even with good students, it sometimes takes time to catch up to pre-existing levels of achievement and for children with pre-existing academic difficulties, this is compounded. An often overlooked component in the child's world is the personal-emotional issues that confront school staff when having to deal with children with cancer. In response to dealing with a child with cancer, they often experience feelings of sadness, fear and anxiety or experience an existential grappling with the meaning of life. Staff often report uncertainty as to how to relate to the child, knowing how demanding to be and how to discipline the child (Chesler & Barbarin, 1987).

In spite of the many challenges and significant impact on their lives, many children report that their lives have changed for the better (Orr et al., 1984). Adolescents with cancer often suggest that they have become more serious about life, cherishing each minute. There are suggestions that many develop a sense of mastery, knowing that if they have conquered cancer they can conquer anything. A greater sensitivity to other people has also been reported (Chesler & Barbarin, 1987).

3.5.2 The impact on the family system

The definition of family varies from culture to culture. The family is a unique group which is defined by individual, ethnic and cultural influences that can be represented by many configurations of its members (Visher, E., & Visher, J., 1995). It is important that the impact of a long-term illness needs to be seen within this context, especially in South Africa with its diverse ethnic and cultural groups. Variations in family structure do not necessarily mean weaker families, although variations do require greater awareness and sensitivity to differences within individual families and within society. Relationships within the family, rather than structure or type of family, are much greater predictors of outcome for children (Visher, E., & Visher, J., 1995).

Cultural factors are key variables, along with life experiences and socio-economic status. These affect the meaning of cancer for families and how they cope (Gotay, 1996;

Thibodeaux, 2007). Burkett (1991) stated that culture, as a meaning system, is not an optional factor that only sometimes influences health and illness, it is prerequisite for all meaningful human experience, including that of being ill.

The diagnosis of a chronic condition is a stressful time, often causing disequilibrium within families (Chesler & Barbarin, 1987; Peek & Melnyk, 2010) and so seriously diverting the life course of the family. The threat of cancer depends on its meaning to a particular family (Weihs & Reiss, 1996). Parents are likely to grieve the healthy child they envisioned (Peek & Melnyk, 2010; Slate & Scott, 2009) but may also experience relief when the diagnosis is made as it relieves some of the uncertainty. The initiation of the treatment plan is often accompanied by a sense of relief as the attention and resources towards coping enables a temporary distancing from the longer term implications of the illness (Dolgin & Phipps, 1996). Some of the factors that affect the responses of the parents and others include the visibility of the condition, functional limitations (Silver, Westbrook, & Stein, 1998), associated cognitive deterioration (as in a brain tumour), the expectation of pain for the child and the uncertainty about changes in the condition (Chesler & Barbarin, 1987). According to Weihs and Reiss (1996), cancer poses a risk of separation and loss for the family, which is best contained in relationships which are secure. Normal family relationships include communication patterns, rituals, affection and roles attributed to family members and the diagnosis of cancer limits family functioning in these areas (Gotay, 1996; Dolgin & Phipps, 1996). Adaptability and cohesiveness are important aspects of how well a family can adjust to stress.

The literature on the impact of childhood illness/injury on the family was reviewed by de Almeida, Ly, Landon, Groft, Jenkins and Nicholson (2006). These studies ($N=115$) suggested that childhood illness/injury was stressful for the entire family and that the needs of family members for example, rest, nutrition and communication were largely unmet in many of the studies. With the exception of AIDS, no disease evoked greater insecurity and fear for a family than cancer (Jithoo, 2010). Matteo and Pierluigi (2008) explained that this fear resonates because of the association of cancer with the idea of death, pain, uncertainty and powerlessness.

Many families perceived the early diagnostic period and the acute exacerbations of the child's illness as times of crisis, which challenged family coping. The family's appraisal

of the situation, their problem solving strategies, coping repertoires, and usual patterns of functioning determined or moderated their ability to adapt. A family's functional level is not static and may fluctuate over time and these changes relate to the myriad of stressors that impact on the system and their ability to cope (McCubbin, M., & McCubbin, H., 1993). According to Moos (1986), families perceive a chronic condition, its effects and its implications in a variety of ways. Some families are able to integrate the condition as part of the daily routine, whereas others perceive it as a feared intrusion into their lives and the prognosis of the condition affects family response. If a condition is perceived to be life threatening, fear about the child's possible or impending death is likely to pervade initial reactions.

There is evidence that different families experiencing similar circumstances report variations in the way that they experience and react to cancer (Long & Marsland, 2011). Different personal and family backgrounds, available resources and the child's developmental stage place families in different circumstances and any attempts to describe the experience of childhood cancer as common or universal overlook these differences. Parents' gender, income, education and religion do not appear to result in different reports. The commonalities of the experience cut across status and education. The stresses of childhood cancer show no respect for typical social distinctions (Chesler & Barbarin, 1987). Family structure, previous experiences, managing stressful events, requirements of the child's condition, and other factors unique to each family will influence the family experience of cancer (Shephard & Mahon, 2002). The quality of the family environment influences family coping (Weihs & Reiss, 1996) and the potency of the problems they face may be linked to the ways family members are able to meet the demands by working as a team. Weihs and Reiss, (1996) noted that an open communication style within the family promotes joint problem solving. Family closeness has been reported as a positive outcome following childhood cancer (Long & Marsland, 2011; Spinetta, Swarner, & Sheposh, 1981).

The diagnosis of childhood cancer results in family members facing several complex tasks (Moos, 1986). The stresses of childhood cancer are exemplified in key family coping tasks. Managing internal emotional relationships is an important family task and includes managing the "special status" of the child, managing sibling jealousy and concern, coping with parental pain of the diagnosis (Peek & Melnyk, 2010) and coping with limited spousal time and individual exhaustion. Families also need to adapt to practical tasks associated with

the illness (Chesler & Barbarin, 1987; Moos, 1986). They need to cope with their lack of skill in their new role (Peek & Melnyk, 2010) and manage the financial demands of the situation (Chesler & Barbarin, 1987; Moos, 1986). Finally they need to manage external relationships by withdrawing from social contact (Chesler & Barbarin, 1987) and forming adequate relationships with health care professionals (Moos, 1986). While having a child with a chronic condition is stressful, families do not suffer a noticeable excess of dysfunction relative to other families (Hostler, 1991). Parents need to maintain a sense of inner mastery of their divergent feelings and try to preserve a satisfactory self-image, for example, helping their child as much as possible but not feeling overwhelmed by guilt when they cannot do everything the child asks. They also have to conserve family resources and their relationship with the ill child. Their primary task is to try and sustain hope in the face of uncertain prognosis (Moos, 1986).

Families face a number of stressors in their journey with childhood cancer. These include medical stressors, personal and social stressors. The following discussion provides an understanding of these areas.

3.5.2.1 Medical Stressors

For most families, the course of childhood cancer is a series of medical events or benchmarks that signal important movement towards or away from recovery. Family accounts of their experiences with the illness are often structured around the disease-related markers. Medical issues were described as the most potent stresses experienced by parents and, in particular, treatment related issues (Chesler & Barbarin, 1987). In comparison to other chronic medical conditions, childhood cancer demonstrated significantly higher impact scores in all domains due to the intensity of hospital-based treatments and degree of uncertainty, as cancer based treatments rarely settle into predictable routines (Heath, Lintuuran, Rigguto, Tikotlian, & McCarthy, 2006).

The adjustment of the family to childhood cancer is linked to the dynamic nature of the illness. The illness course is not linear but is characterised by peaks and ebbs in the different phases of illness (Dolgin & Phipps, 1996). The pre-diagnostic period, diagnosis, surgery, treatment side effects and relapse were the most common parental concerns. Each of these stages has its own impact and providing different kinds of help and support are

indicated (Chesler & Barbarin, 1987). The following discussion provides an understanding of the nature of the medical stresses experienced by the family during different stages of their experience with cancer.

3.5.2.1.1 Pre-diagnostic stage

The pre-diagnostic stage is described by many parents as a stressful period, as for some families, contradictory diagnoses and inadequate treatment systems need to be negotiated. The diagnostic period and the processes the child has to undergo are potent events as this is a period when life is ripped from its normal context. Parents' prior reality is shattered and it is a time that they enter a new reality with new definitions of themselves and others. At some level of consciousness, they know they are embarking on a long and difficult struggle and, although they are hopeful for a good outcome, they are aware that their lives will never return to what they were before (Chesler & Barbarin, 1987). Dominant themes of shock, disbelief and occasionally anger run through parents' comments about diagnosis (Chesler & Barbarin, 1987; Koocher & O' Malley, 1981). The combined impact of a diagnosis and news of poor prognosis heightens the stress. In most cases there are a few choices about treatment but when parents have to make choices such as amputations, there is additional stress and parental guilt is often high, especially when it involves painful procedures (Chesler & Barbarin, 1987).

3.5.2.1.2 Diagnosis

At diagnosis, the highest levels of stress were reported by parents and the feelings of confusion and emotional pain arising at diagnosis continue throughout treatment (Chesler & Barbarin, 1987). Chesler and Barbarin (1987) emphasise that "cancer is not a one-time event, it is a chronically life threatening disease" (p. 27). Every cold or sore that does not heal quickly, every headache or bout of influenza may carry a dangerous message. Since cancer is diagnosed at the microscopic level, even minor symptoms must be confirmed or disconfirmed by a visit to the clinic or hospital. An apparently healthy child may be discovered in microscopic examination to be in very serious condition, thus each visit to the doctor presents parents with a serious threat. Parents thus live on "pins and needles of hope and fear" (Chesler & Barbarin, 1987, p. 27).

3.5.2.1.3 Remission and relapse

In periods of remission, parents may however “forget” about the illness and a period of adaptation and normalisation and an attempt to return to a new equilibrium begins. Relapse occurs when the disease reasserts itself. It is described as the most stressful time, following the initial diagnosis (Chesler & Barbarin, 1987). Hope built up during remission is threatened and a new and long journey lies ahead for the family. It is often associated with a loss of confidence in a cure, creating a roller coaster of emotions. While going off treatment marks remission, the cautious pronouncement of a cure often carries the risk of relapse and of late side effects of treatment. Checkups continue, as does some of the stress associated with remission. Whereas some children and their parents have fears about going off treatment, others overreact in the other direction, assuming that if they have beaten cancer they can take other risks. Many acting out experimental behaviours that were denied or shelved for the years of treatment become quite attractive as well as feasible for the child, especially during the adolescent phase (Chesler & Barbarin, 1987).

The death of the child is not the end of pain and sadness for the parents but often marks the beginning of a period when sickness and hospitalisation no longer dominate the family’s life (Chesler & Barbarin, 1987).

3.5.2.2 Personal and social stressors

The psychosocial challenge of childhood cancer has its origin not in the disease itself but in the personal and social contexts within which the illness occurs. Childhood cancer raises personal and emotional issues with which the parents must deal and significantly affects parents’ and children’s networks of social relationships. Each person who may be a source of support may also be a potential source of stress. Personal and social stressors may be further differentiated into intellectual stress, instrumental stress, interpersonal stress and existential stress (Chesler & Barbarin, 1987).

3.5.2.2.1 Intellectual stress

Intellectual stress is created by the massive amounts of technical information and the unfamiliar culture of the medical system. The shock and surprise at diagnosis for parents is

partly a product of their ignorance of cancer and the lack of immediate understanding of the meaning of the diagnosis and prognosis. Parents experiencing intellectual stress may encounter a medical professional that exacerbates their feelings of inadequacy. Stress is increased when medical information is withheld or information is presented in a way that is confusing. Having to explain it to others is also a source of stress for many parents (Chesler & Barbarin, 1987).

3.5.2.2.2 Instrumental stress

Families have to face many concrete problems in terms of juggling multiple roles and responsibilities, such as holding down a job, being at the hospital and parenting the siblings of the child on treatment. Many parents have to make significant life style changes in order to cope with the financial demands. The stress of work is particularly potent for parents who need to work outside of the home. Parents who live a distance away from the hospital reported increased levels of stress. When children are treated on an outpatient basis, parents often become the front-line caretakers. They need to be proficient in terms of providing practical medical care and the need for information becomes even more critical when the child returns home (Chesler & Barbarin, 1987). The non-medical costs of living with cancer are significant in terms of food, travel and loss of income (Dockerty, Skegg, & Williams, 2003) especially in the first year of treatment (Heath et al., 2006). For families who do not have medical aid and are from low income groups the impact of cancer can be exacerbated (Chesler & Barbarin, 1987; Weihs & Reiss, 1996).

3.5.2.2.3 Interpersonal stress

Interpersonal relations can be stressful for the family. Relating to the sick child who is adjusting to the diagnosis and treatment can be a challenge to the family on many levels. Adjusting to the demands in the child's illness may create interpersonal stress in the marital relationship. Siblings feel conflicting feelings of concern about the illness and then are often resentful for the time and attention given to their sick sibling. Despite many reports of increased closeness to friends and family, there are also reports of distress in these relationships (Chesler & Barbarin, 1987). Meeting the needs of other family members, coping with friends' reactions, behaving in public as a parent of an ill child and coping with the stigma are further challenges for the family (Chesler & Barbarin, 1987).

3.5.2.2.4 Existential stress

Many parents find it hard to fit the experience of childhood cancer into their prior understanding of the nature and purpose of life (Chesler & Barbarin, 1987) and there is ubiquitous parental searching for causation and meaning (Dolgin & Phipps, 1996). Serious and chronic childhood illnesses are a challenge to the ways in which most people understand and organise their views of the world (Chesler & Barbarin, 1987; Spinetta et al., 1981). In the face of such a challenge, questions are asked as to why this has happened. It requires grappling with the meaning of one's own existence and often challenges prior religious beliefs and practices (Chesler & Barbarin, 1987). The threat to the life of a child disrupts one's image of normal. It challenges the sense of right and wrong. In their search for meaning, parents will often identify religious, philosophical, or scientific reasons for the child's condition (Holaday, 1984).

3.5.3 The impact on siblings

While the psychosocial impact on siblings is poorly researched relative to the child with cancer (Alderfer et al., 2010), there is evidence that siblings are directly and immediately affected by the diagnosis of a chronic condition but often lack the ability to control or affect the many significant changes within the family (Chesler & Barbarin, 1987). Siblings of children with cancer are the most left out and unattended to of all family members (Spinetta et al., 1981). From their research, Spinetta et al. (1981) reported that siblings' emotional needs were met at a level of significance less adequate than that of other family members and that they are also under substantial stress. This may result in substantial anxiety, an increased sense of isolation, and fears about their own health problems (Alderfer et al., 2010; Houtzager, Grootenhuis, & Last, 2001). It is likely that cancer related stressors and their variable manifestations in siblings are also related to the interaction of risk/protective factors within the family system (Long & Marsland, 2011).

Some siblings complain that the child with the chronic condition is treated more leniently and they often perceive that their mothers are overprotective and overindulgent of their sibling with cancer. Parents may be unaware they are treating their children with different standards (Chesler & Barbarin, 1987), leading to sibling feelings of anger, neglect and alienation (Chesler & Barbarin, 1987; Dolgin & Phipps, 1996). Siblings are usually

aware of their negative feelings and as a result may experience guilt (Houtzager et al., 2001). Fears of causality or contagion may also be present (Chesler & Barbarin, 1987). Assuming increased responsibility in daily routines while experiencing frequent separations from parents may result in accelerated emotional development (Dolgin & Phipps, 1996). In spite of the challenges, some siblings have described many positive effects of having a sibling with a chronic condition. These include greater maturity, supportiveness and independence (Barbarin et al., 1995).

3.5.4 The impact on the marital system

It is often assumed, that secondary to the stress of a diagnosis of childhood cancer, that the rate of family dissolution is greater. Carefully controlled studies have indicated no differences in marital functioning or in the rate of divorce in families of children with chronic conditions (Cadman, Rosenbaum, Boyle, & Offord, 1991). While significant stresses are placed on the marital subsystem, 65% of their sample reported their spouse as being the most helpful. When compared with parents of healthy children, parents of children with chronic conditions were at no greater risk for psychosocial problems or marital distress (Chesler & Barbarin, 1987). These findings however do not diminish the significant impact on the marital system or the significant adjustments it requires. There is evidence to suggest that a subset of families report persistent marital problems secondary to the marital strain placed on the relationship. Differences in the parents' emotional responses to cancer are also considered as contributory (Long & Marsland, 2011).

3.5.5 The impact on the parent-child relationship

As a child approaches middle childhood and adolescence, parents must gradually yield control and permit autonomy and freedom to make choices about personal, educational and social goals. The typical childrearing process is complicated by illness and treatment (Chesler & Barbarin, 1987) and aspects of some chronic conditions are frequently viewed by the parents as disruptive to their relationship with their child (Anderson, Riesch, Pridham, Lutz, & Becker, 2010; Goldberg & Simmons, 1988). Parents reported that the demands placed on them were time-consuming and often found meeting the emotional needs of the child difficult (Svavarsdottir, 2005). Parenting a child with a chronic condition involves qualitatively different work than parenting a child without. The diagnosis of an illness thus

disrupts the parenting process and the writer notes numerous parental reports on ambivalence about discipline and the consequences thereof in maintaining healthy parent-child boundaries.

3.5.6 Late effects of cancer and the cancer survivor

In contrast to the acute side effects of treatment which are caused by the effects of radiation and chemotherapy on proliferative cells, late effects may become observable months to years after the completion of treatment. These may be due to different mechanisms of injury and can range in severity from mild to life threatening. Late effects of cancer have been identified as affecting almost every organ system. The risk for a particular late side effect is dependent upon the type and total dose of chemotherapy or radiation received, the developmental stage of the organ at the time of treatment and sometimes gender (Moore, 2002; Velensek et al., 2008). Survivors of childhood cancer may also be at increased risk of second cancers (Korenjak, Sajko, & Jereb, 2011; Wilson, Cohn, Johnstone, & Ashton, 2010).

Five year survival rates for childhood cancer have increased from 56% (1974 to 1976) to 75% (1989 and 1995) (Pogany et al., 2006). For ALL, the most common paediatric cancer, survival rates have increased from 53% to 81% during the same time interval (Greenlee, Murray, Bolden, & Wingo, 2000). It is predicted that by 2010, 1 in 250 individuals between ages of 15 to 45 years will be a long-term survivor of childhood cancer (Hayman, Mahon, & Turner, 2002). Using an average age of six years at the time of cancer diagnosis, and a further 66 years as the projected length of life, approximately 72 years of every childhood cancer survivor's life is influenced by the late effects of the disease and treatment (Hayman, Mahon, & Turner, 2002; Zeltzer et al., 2009). There is emerging evidence that the transition from cancer patient to cancer survivor can be challenging in terms of receiving risk-based survivorship care to evaluate for physical and psychological late effects (Aziz & Rowland, 2003; Casillas et al., 2010).

3.5.6.1 Cognitive late effects

Treatment of the central nervous system (CNS) with radiation and chemotherapy can result in cognitive impairments which include declines in general intelligence and academic achievement scores, as well as deficits in visual spatial skills, verbal fluency, memory and speed of information processing (Moore, 2005; Pogany et al., 2006). There is evidence that higher doses of radiation are associated with more serious late effects (Anderson et al., 2000; Butler, Hill, Steinherz, Meyers, & Finlay, 1994; Kingma, Rammeloo, van der Does-van den Berg, Rekers-Mombarg, & Postma, 2000). Dose of cranial radiotherapy and age at diagnosis are the most important variables in education-related risk factors (Haupt et al., 1994; Pogany et al., 2006). There is increasing evidence that systemic treatment with high doses of drugs that cross the blood brain barrier and chemotherapy can also result in impairments that are serious enough to affect neurocognitive function and school performance adversely (Anderson et al., 2000; Butler et al., 1994; Kingma et al., 2000). Results from a large retrospective cohort study of 593 survivors of ALL and 409 sibling controls demonstrated that ALL survivors were significantly more likely than sibling controls to enter a special education or learning disabled programme. (Haupt et al., 1994). This confirmed an earlier study by Sawyer, Toogood, Rice, Haskell and Baghurst, (1989) where leukaemic children performed significantly lower than a matched control group. Lower scores on ratings of concentration and academic progress were found in a group of five year survivors of childhood cancer when compared with a group of healthy school peers (Sloper, Larcomb, & Charlton, 1994).

3.5.6.2 Psychological late effects

Early studies suggested that childhood cancer had an adverse impact on the psychological adjustment of children and their families (Koocher & O'Malley, 1981) and that children with cancer have significantly more psychological problems than other children in the community (Mulhern, Wasserman, Friedman, & Fairclough, 1989; Sawyer, Crettenden, & Toogood, 1986; Sawyer et al., 1989). The risk of emotional late effects is thought to be influenced by the age at the time of cancer treatment, type of treatment received, any residual effects of treatment and the amount and type of support received by peers and family (Moore, 2002).

Mulhern et al. (1989) observed a significantly higher incidence of deficiencies in social competence and an increased frequency of behavioural problems amongst cancer survivors compared to general population norms. The most frequently observed problems included poor school performance and somatic complaints (Sawyer, Antoniou, Toogood, & Rice, 1997). Sloper et al. (1994) described psychosocial adjustment of five year survivors of childhood cancer compared with a group of healthy school peers. Cancer survivors had significantly higher scores on parent and teacher rating scales of behavioural problems. It was proposed that a possible reason for these results was that at the time, a substantial number of children with cancer died as a result of their illness. In light of this, it is possible that the psychological problems exhibited by these survivors reflected their stress related to the high mortality rates of childhood cancer (Sawyer et al., 1997). There is evidence that the prevalence of problems experienced by children with cancer of different ages may vary, and it is also possible that the number of problems experienced by children varies at different points in time (Sawyer et al., 1995). The length of time since cancer diagnosis is associated with a negative influence on psychological outcomes. It also correlates negatively with the children's perceptions of self-worth (Hockenberry-Eaton, Dilorio, & Kemp, 1995). The negative correlation was greater for children who had experienced a relapse.

More recently, there have been differing findings regarding the prevalence of psychological problems experienced by children who were treated for cancer. Mackie, Kondryn and McNally (2000) reported that there was not a higher incidence of psychiatric disorders but higher rates of psychosocial problems amongst childhood cancer survivors. Their sample of 102 survivors with childhood leukaemia or Wilms tumour, and 102 unrelated healthy controls, completed standardised measures of interpersonal and social role performance and intellectual ability to assess past and current functioning. Forsbach and Thompson (2003) also suggested that all cancer survivors showed poor functioning in the domains of relationships, friendships, non-specific social contact and day-to-day functioning. Problems in close relationships were associated with more recent cancer treatment. Poorer coping was associated with lower intelligence (Mackie et al., 2000; Forsbach & Thompson, 2003)

Other researchers found that children with cancer do not differ from children in the general community (Eiser, Hill, & Vance, 2000; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). Similarly, a study conducted by Zebrack et al. (2007) reported that 2 778

adult survivors of solid tumours diagnosed in childhood and 2925 siblings in his study, completed a long-term follow up questionnaire to identify significant correlates of psychological distress. Symptoms of depression, somatisation and anxiety as well as demographic, health and medical information were assessed. Overall, a large majority of siblings and survivors reported few if any symptoms of psychological distress. Overall, however, cancer survivors reported significantly higher levels of global distress as well as higher levels of somatising and anxiety than did their siblings. However when compared to population norms, both survivors and siblings reported lower levels of global and dimensional distress. Female gender, lower educational and income attainment were associated with reporting psychological distress for both survivors and siblings.

Zebrack (2001) noted that there are many challenges that childhood cancer survivors face. These include symptoms of post-traumatic stress, diminished self-esteem and body image, employment discrimination, difficulties obtaining medical aid and limits on educational and employment opportunities due to treatment induced cognitive deficits. Some of the survivors experience continuing discrimination in terms of expensive health or life insurance. In addition, there are many who find themselves rejected for employment by virtue of their medical histories such as in the military services (Chesler & Barbarin, 1987). Each of these challenges has the potential to affect the cancer survivor emotionally.

Zebrack (2001) noted that, in spite of the challenges the cancer survivor faces, there are many studies that have indicated that life after cancer is not all negative, and that for the most part, childhood cancer survivors are psychologically well and in some cases more healthy in psychosocial terms than healthy controls without a cancer history. In the longer term, the prevalence of psychological problems experienced by children treated for cancer does not differ from those found in children in the general community (Sawyer et al., 1995). Existing studies have documented that overcoming cancer has resulted in positive changes, deep personal growth and an enhanced outlook on life (Linley & Joseph, 2004; Zebrack, 2001).

3.6 CONCLUSION

The experience and impact of childhood cancer is contextual. It occurs at a time when significant and concurrent developmental tasks are taking place. The impact between development and cancer is bi-directional. The specific developmental tasks of middle childhood and adolescence make these children vulnerable to the impact of the diagnosis and experience of cancer. These would include an increased understanding of information, an awareness of death and its implications, the increased need for peer acceptance and peer social interaction and an emphasis on appearance as well as the consequences of treatment and the disruption to their usual home and school routines. The literature suggests that the risk is somewhat higher for girls than for boys (Allen & Sheeber, 2009a). Since cancer impacts upon the child in the context of family, the health and well-being of the childhood cancer survivor is inextricably linked to the health and well-being of the family (Long & Marsland, 2011; McCubbin, M., & McCubbin, H., 1993). However, the literature notes that children with cancer are as psychologically normal as physically healthy children albeit some children with cancer are vulnerable to psychological and emotional pathology, as are healthy ones (Chesler & Barbarin, 1987; Zebrack et al., 2007).

As a result of advances in diagnostic and treatment technologies and the co-ordination of childhood cancer treatment protocols via clinical trials, three out of every four children diagnosed and treated for cancer will attain complete remission and cure (Zebrack, 2001) with improved long-term disease-free survival figures approaching almost 80% for some cancers (Patterson et al., 2004; Pogany et al., 2006; Shepard & Mahon, 2002). However, in an era in which good health is not just the absence of disease but also the presence of psychological and social well-being, Zebrack (2001) asks whether these advances have resulted in what van Eys (1991) calls the “truly cured child”. The words of van Eys (1991) require consideration. He describes what he considers the “truly cured child”. Biological cure indicates that the disease is not discernible from any objective measure, and that the individual dies in old age from unrelated causes. Psychological cure means that the child is at ease with having or having had cancer, and that past and current events are incorporated into the child’s total experienced reality. Social cure requires that the child is accepted in society as if the disease were a relatively irrelevant incident. Van Eys (1991) emphasised that the way we care for the child should determine the cure and that it should not determine the

care. Achieving the goal of the truly cured child require a multi-disciplinary approach to the development of interventions that successfully meet the bio-behavioural challenges of childhood cancer (van Eys, 1991). This view is supported by Poole (2003), who notes that the optimum practice of paediatric oncology requires more than just knowledge of cancer and its treatment and should cater for the psychological needs of both the child and its family (Poole, 2003). Zebrack (2001) emphasises the statement of the American Cancer Society Task Force on Children and Cancer released in 1998 - that the progress achieved in attaining an 80% survival among children adolescents and young adults can be justified only if their physical, emotional and social qualities of life are also protected.

In the following chapter, a general conceptual understanding of the constructs of coping and well-being, and the link between them is presented, as well as the variables that moderate them. Coping resources, both internal and external, as well as modes of coping are discussed. Moos' (2002) revised model, adapted for youth and applicable to adolescents with chronic disorders, is also presented.

CHAPTER 4

COPING AND WELL-BEING

4.1 INTRODUCTION

The purpose of this chapter is to provide a general conceptual understanding of coping and well-being and how they apply to the child with a diagnosis of cancer. The link between coping and well-being is emphasised and the variables that moderate coping and well-being discussed. Coping resources, both internal and external, as well as modes of coping are presented as is Moos' (2002) revised model, adapted for youth and applicable to adolescents with chronic disorders.

4.2 UNDERSTANDING THE LINK BETWEEN COPING AND WELL-BEING

As discussed in Chapter 2, numerous theoretical models have described adaptation and coping with major life transitions in general, and with the onset of chronic illness in particular (Samson & Siam, 2008). Two main paradigms are reflected in the literature. The first proposes the notion that individuals adapt by moving through a linear set of phases and the second revolves around the notion that adaptation to change is accomplished by a nonlinear series of adaptation tasks. Common to both paradigms, is an effort to cope with a specific aspect of life that has been affected by the onset of a stressor, or chronic illness in particular (Corr, C., Nabe, & Corr, D., 2003). Task-based models of coping and well-being are based on the empirical foundations that represent the process of coping of which the primary goal is survival and ultimately well-being.

The theoretical assumptions of the Integrated Stress and Coping model of Moos and Schaefer (1993) form the guiding framework for this study. In 2002, Moos adapted and revised his model specifically for youth and noted its application to adolescents with chronic disorders. The following is a diagrammatic representation of Moos' Model of the Interplay

between Context, Coping, and Adaptation Among Youth. While there is significant overlap between Moos' model (1993) and this one, the purpose of the inclusion of this specific model is that the literature calls for models of stress and coping that are specific to children. The relevance to this study is that this model is applicable to children and is relevant for those with chronic disorders. Additions relevant to children with chronic illnesses have been highlighted in colour.

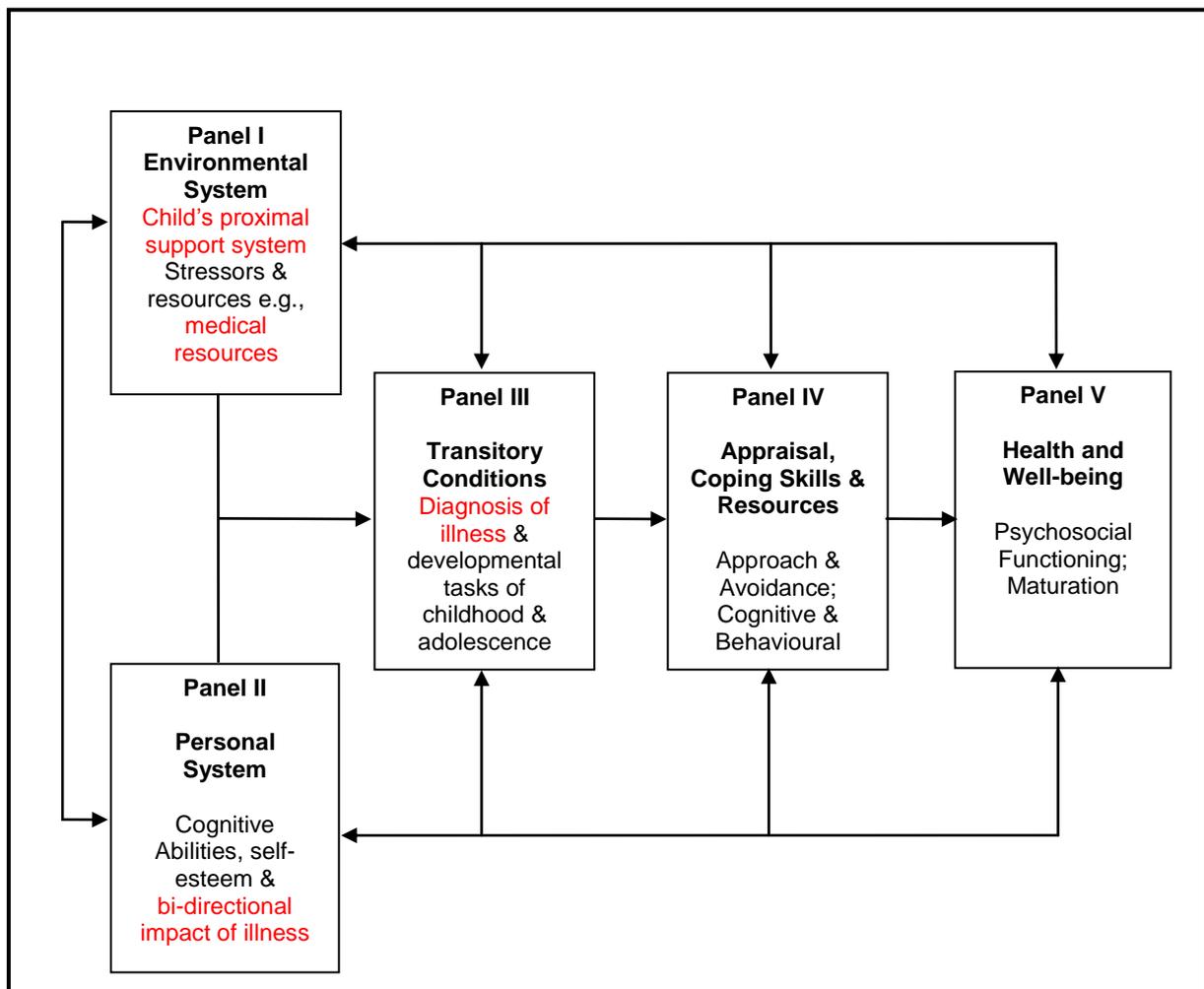


Figure 6. A Model of the Interplay between Context, Coping, and Adaptation Among Youth (Moos, 2002, p. 3).

The following outline provides an understanding of the model with specific reference to the child with a diagnosis of cancer.

Panel 1 emphasises the environmental system as an important factor in the stress and coping process and the resources which it has available. For the child with cancer, this includes proximal systems such as the family and the community. The quality of these social support networks, as well as financial and medical resources is important. The family, which is also part of a broader social context, is considered the single most important influence on the development of the child and its coping (Frydenberg, 2008).

Panel 2 recognises that the child brings to the illness situation personal factors such as the cognitive sense it makes of the diagnosis, sense of self and self-confidence. These influence adjustment and interpersonal relations such as seeking out social support. It also recognises the bi-directional impact that the illness has on factors such as self-esteem. It is the interplay of panels 1 and 2 that influences the process of adaptation (Moos & Tsu, 1977, Samson & Siam, 2008). Factors such as age, gender, socio-economic status, culture and ethnic origin, which may moderate the impact of the illness, choice of coping responses or the meaning of the illness are also included.

Panel 3 recognises the impact of the diagnosis of cancer as a life crisis at a time when concurrent developmental transitions (middle childhood and adolescence) are taking place, both of which require significant adjustment (Moos, 2002).

Panel 4 reflects thoughts, feelings and coping behaviours that the child utilises to deal with challenging situations (Frydenberg, 2008). The reaction to the diagnosis and the achievement of adaptation tasks hinges largely on the cognitive appraisal of the stressor (diagnosis). The diagnosis does not affect individuals in a uniform way because the experience itself is a function of appraisal. Primary appraisal results in different ways of conceptualising the impact of cancer on well-being. Secondary appraisal consists of evaluating coping resources and alternatives in order to deal with the difficulties, restrictions and demands that cancer imposes on life. It is secondary appraisal that allows the accomplishment of adaptation tasks (coping) (Samson & Siam, 2008).

Panel 5 reflects the health outcome of the child's coping. Panels 1, 2, and 3 are what the child brings to the diagnosis of cancer. A variety of coping strategies can be applied with different consequences for well-being (Panel 4). Risk factors, resources and the efficacy of coping strategies can impact on the child's level of vulnerability under stress (Kruger, 2010)

and determine the level of well-being (Compas, Conner-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Frydenberg, 2008; Lazarus & Folkman, 1984). Functional coping strategies (such as planning, active coping and finding social support) can enable resilience and can serve as a buffer against stress. They can also enhance psychological health (Lazarus & Folkman, 1984; Moos, 2002) and determine a positive or negative outcome. A positive outcome indicates a new state of equilibrium highlighted by a sense of normalcy and life satisfaction (Samson & Siam, 2008). This has the potential to mould the adolescent into an individual with adequate levels of self-esteem and a sense of mastery of developmental tasks (Kruger, 2010). A negative outcome would manifest in a degree of psychological deterioration and dissatisfaction. It is the interplay of all of the above factors that determines psychological well-being (Cohen & Lazarus, 1979; Moos & Tsu, 1977; Samson & Siam, 2008).

There are a number of recent models which endorse the theoretical assumptions and principles of Moos' model. An example is the Comprehensive Task Model developed by Samson and Siam (2008), which is specific to people with medical illnesses. It emphasises the adaptive tasks required following the stress of the diagnosis and recognises the individual's personal and social contexts. It also emphasises the role of cognitive appraisal in the interpretation of the illness situation, which determines the use of coping skills. The interaction of personal and environmental factors combined with developmental transitions and coping responses, determines whether the outcome (well-being) will be positive or negative (Samson & Siam, 2008).

Such models provide a conceptual framework for understanding the link between coping and well-being. Moos' (2002) revised model is specific to coping and well-being in children. He noted that his conceptual model is consistent with the idea that life crises such as cancer can be constructive confrontations that challenge a child (coping) and provide opportunities for learning new skills and growth. The process of managing transitions (development) shapes new experiences and coping skills and, if successful, contributes to a sense of mastery, self-confidence and ultimately well-being. Perceived growth in individuals who have overcome adversity tends to be reported in terms of changes in perception of self, changed relationships with others, for example, increased emotional closeness with at least some other person (Calhoun & Tedeschi, 1999), perceived freedom to express emotions, and an increase in reported sympathy and understanding of the suffering of others. Changes in

the philosophy of life, changes in life priorities, an increased experience of existential wisdom and a greater interest in openness to spiritual and religious matters are also reported (Calhoun, 1998; Updegraff & Marshall, 2005).

The following discussion provides a conceptual understanding of the constructs of coping and well-being.

4.3 THE CONSTRUCT OF COPING

The concept of coping is not a unified construct with a readily agreed-upon meaning. It more accurately represents a meta-construct (Lazarus & Folkman, 1984) which is multi-dimensional (Beutler & Moos, 2003; Beutler, Moos & Lane, 2003; Frydenberg, 2008; Kato & Pederson, 2004; Lazarus & Folkman, 1984). What distinguishes coping from other aspects of human behaviour is its relevance to adaptation in the face of stressful life experiences or conditions. The concept of resilience has been closely linked with that of coping and is defined as “the process or capacity for, or outcome of successful adaptation despite challenging or threatening circumstances” (Masten, Best, & Garmezy, 1990, p. 429). Resilience also implies “the possession of multiple skills, in varying degrees, that help individuals to cope” (Alvord & Grados, 2005, p. 238). Masten (2001) confirms the complexity of coping as a construct noting that resilience, and hence coping, need to be understood at multiple levels, from genes to understanding the link between adversity, brain development and the quality of adaptation. She notes recent studies that corroborate the importance of a small set of global factors associated with resilience including connections to competent and caring adults in the family and community, cognitive and self-regulation skills, positive views of self, and motivation to be effective in the environment.

As noted in Chapter 2 (p. 18), coping is defined by Lazarus and Folkman (1984) as the “constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as exceeding the resources of the person” (p. 141). The principles of this definition are supported by recent researchers (Basson, 2008; Frydenberg, 2008; Kruger, 2010), whose concepts of coping also support the idea that coping efforts change according to situations over time (Eckenrode, 1991) and that, although stress is an inevitable aspect of life (Lazarus & Folkman, 1984; Frydenberg, 2008; Kruger, 2010), coping

is essential for adaptation and is a central facet of human development (Compas et al., 2001). The choice of individual coping response or strategies is influenced by the nature of the stressor and availability of resources. Transactions with the environment, appraised as threatening, harmful or challenging, prompt the application of strategies to reduce the distress or manage the problem (Frydenberg, 2008; Kruger, 2010). Snyder and Dinoff (1999) define coping as “a response aimed at diminishing the physical, emotional and psychological burden that is linked to stressful life events and daily hassles” (p. 5). Effective coping should lessen the burden of challenges of both short-term immediate stress and should also contribute to longer-term stress relief (Compton, 2005).

According to Moos and Holahan (2003), one cannot adequately predict how individuals will cope with a specific stressful circumstance without considering the unique adaptive demands of the situation and the associated cognitive appraisals employed (van Lill, 2007). Successful adaptation to stress includes the ways in which individuals manage their emotions, think constructively, regulate and direct their behaviour, and act in their environments to modify or lessen sources of stress (Compas et al., 2001). More specifically, coping with illness does not occur in a vacuum and includes life context as well as illness perceptions (Karademas, Karamvakalis, & Zarogiannos, 2009).

A prerequisite for coping is the presence of an event or condition appraised as harmful or threatening to the individual (Lazarus & Folkman, 1984) and an important aspect of coping is the number of negative life events, as they have a cumulative effect (de Matos et al., 2008). Coping was hypothesised to become less effective in the presence of chronic stressors (Wetherington & Kessler, 1991), a notion challenged by other researchers who noted that resilience and the ability to cope is not uncommon albeit individual differences exist. Masten (2001) states “the great surprise of resilience research is that resilience appears to be a common phenomenon that results in most cases from the operation of basic human adaptational systems. Resilience does not come from rare and special qualities, but from the everyday magic of ordinary, normative human resources in the minds, brains and bodies of children, and in their families and relationships and in their communities” (p. 227). Supporting this is neurobiological research in humans and animals that identifies the presence of neural circuits controlling stress adaptation (Charney, 2004; Taliáz et al., 2011).

The definition of coping in children with chronic illness is a unique and challenging task because children have views that diverge from those of adults on the subject of etiology and treatment of illness, and have their own strategies to deal with them (Schmidt, Petersen & Bullinger, 2003). Some researchers have even argued that the traditional concept of coping is inappropriate for children as one can only assess perceived stress and behavioural reactions (Schwark, Schmidt, & Strauss, 2000). Historically, coping and development have been studied separately but, in children, they are inherently interconnected, with age-related factors playing a major role in shaping adaptational processes. Schmidt, Petersen and Bullinger (2003) note that “coping is a process that is shaped by developmental organisation and, likewise development is shaped by coping processes” (p. 3). They add that “coping is more than a simple strategy; it is a cumulative history of interactive processes that are embedded in developmental organization” (p. 12).

In sum, numerous researchers have consistently defined coping as the behavioural and cognitive efforts to manage the demands on the individual that have been appraised as threatening, and exceed the resources of the individual at any given time. Coping skills used are influenced by the available resources and the coping strategies that the individual uses.

The field of stress and coping is vast and the research into coping has resulted in an array of terminology which overlaps and is used interchangeably. The following concepts will be clarified: **coping resources**, **coping strategies**, **coping skills** and **coping styles**.

4.3.1 Coping resources

Resources are the primary unit of interest in the stress process as stress is predicted when circumstances represent a threat of resource loss. In addition, it is the extent to which the resources fit the demands of the situation that determines their role in adaptation (Hobfoll, 1998). Coping resources are characteristics of the person or environment that are available following the onset of stressors, and they influence coping processes. According to Alvord and Grados (2005), resilient children adapt to difficult circumstances by using both internal and external coping resources. These include their skills and abilities, social resources, physical resources (e.g., health), tangible resources (e.g., financial support) and psychological resources (e.g., beliefs, morale), as well as cultural and political resources (Eckenrode, 1991).

According to Hobfoll (1998), “having resources and the ability to use them effectively are related but are far from one and the same” (p. 119).

Research has demonstrated that accumulation of risks is strongly related to increased risk of poor outcomes in psychosocial competence, psychopathology, and health (Rutter, 1979; Masten, 2001). Most risk gradients can be inverted to create an asset/resource gradient showing that high levels of resources are associated with better outcomes (Masten, 2001). Factors that constrain the use of coping resources include internalised cultural values and beliefs and psychological vulnerabilities. For example, in South Africa, there are a number of children with cancer who present at advanced stages due to the use of indigenous and spiritual healers without using the available medical resources for diagnosis and treatment.

The literature describes a number of coping resources which may be broadly categorised as internal and external coping resources. Hobfoll (1998) defines internal resources as “those that are possessed by the self or are within the domain of the self” and external resources as “not possessed by the self, but are external to it” (p. 57). According to Hobfoll (1998) the value of this distinction is that it is organised around a central concept of “the self”. Some resources may however fall into both categories for example, religion provides both an internal and external resource which may be used by the individual. Social support can also be considered an external support but may be conceptualised as internal when it involves perceived social support (Tak & Mc Cubbin, 2002).

4.3.1.1 Internal coping resources

Internal resources play an important role in determining and maintaining well-being. In this section, Spiritual/religious or philosophical belief systems, Meaning/Purpose in Life and Hope as well as Self Esteem will be discussed as examples of internal resources, contributing to psychological well-being. Other examples of internal coping resources are an easy going disposition and dispositional optimism, sense of coherence, humour and perceived mastery. A lack of such resources may be classified as a stressor.

4.3.1.1.1 Spiritual/religious or philosophical belief systems and Meaning/Purpose in Life

Spirituality is a multi-dimensional, dynamic, subjective experience innate to humans. It includes a conscious choice by an individual to engage in one or all of the following: the pursuit of a connectedness to a divine being, the ability to relate to other human beings with compassion, and interaction with nature. Spirituality includes, but is not limited to, religious expression (Burnell, 2006). Gomez and Fisher (2003) define spiritual well-being as “a state of being, reflecting positive feelings, behaviours, and cognitions of relationships with oneself, others, the transcendent and nature, that in turn provide the individual with a sense of identity, wholeness, satisfaction, joy, contentment, beauty, love, respect, positive attitudes, inner peace and harmony, and purpose and direction in life” (p. 1976).

There is evidence in the literature of the relationship between spirituality and religion, and mental health. From a review of 20 research articles on the topic between 1998 and 2004, Wong, Rew and Slaikeu (2006) found that 90 % of the articles were associated with better mental health in adolescents. Adolescents with higher levels of spiritual well-being (some connection with religious/spiritual concepts and in particular, existential well-being), had fewer depressive symptoms and fewer risk-taking types of behaviours (Cotton, Larkin, Hoopes, Cromer, & Rosenthal, 2005). Other researchers confirmed the positive relationship between religiosity and adolescent mental health, but found it had the least effect on depressive symptomatology (Pikó & Kovács, 2009). Howsepian and Merluzzi (2009) noted that religious beliefs may not directly affect adjustment; however, (cancer) patients who have religious beliefs may experience an enhanced sense of social support from a community with shared beliefs.

Spirituality is thought to contribute to a positive cognitive appraisal of negative life events (Martin & Carlson, 1988; Maton, 1989), while a lack of spirituality has been associated with negative behavioural and psychological outcomes (Davis, Kerr, & Kurpius, 2003). Both religion and spirituality can provide an “overarching interpretive scheme” (Petersen & Roy, 1985, p. 51) that allows individuals to perceive their circumstances against a larger cohesive backdrop of order and normality. In contrast, a study which did not find a significant relationship between religious commitment and life satisfaction was conducted by Fife, Adegoke, McCoy and Brewer (2011). Their findings supported the view that, although

religion/religious commitment may serve as protective factors, life satisfaction (as a dimension of well-being) involves more than just spirituality and religious commitment.

The impact of a diagnosis of illness or other trauma can impact upon people's meaning-making process. According to Brown (2008), it tears them away from the comfort of their meaning-making systems, causes chaos and unpredictability in ways that cannot be denied or ignored and interferes with the practices that embody their systems of belief. Niemeyer and Anderson (2002) note that, once there has been a disruption to the assumptive world, a revision of meaning (which is culturally sensitive) is required for coping and adjustment to take place. According to Brown (2008), it is important to recover meaning and meaning-making systems, of which religion and spirituality are parts.

The role of religion/spirituality in children with illness has also been investigated and found to have a positive relationship with well-being. In a study of children with chronic illnesses (average age of 8.05 years - SD ± 1.81), they were found to use religion to gain control, make meaning, and find comfort (Cotton, Grosseohme, & McGrady, 2012). A further study of 60 children (aged 6-17) with cancer suggested that 78% did something to "feel close to God such as prayer". The most specific request in their prayers (59%) was for a "sense of normalcy" (Kamper, Van Cleve, & Savedra, 2010). In adolescents with chronic illnesses, not only were high levels of religious attendance, a belief in a higher being and high levels of spirituality found but also a high level of "spiritual struggle". The latter may be the adolescents' attempts to make sense of their world and understand the reason for their illnesses (Cotton et al., 2009; Pendleton, Cavalli, Pargament, & Nasr, 2002).

An important dimension of spiritual well-being is a sense of meaning or purpose in life (Frankl, 1969). Both have been associated with psychological well-being (Fourie, 1999; Davis et al., 2003; Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006; Wiley, 2006). In an early paper by Comaroff and Maguire (1981), they emphasise that the "experience of uncertainty and the search for meaning were *the* characteristic features" of the impact of childhood cancer on children and their families (p. 115). The ability to find meaning has been associated with a slower course of illnesses such as HIV (Taylor & Sherman, 2004). A South African study of older adolescents found a significant positive correlation between spiritual well-being and presence of meaning, of which the sources of meaning follow a developmental path (Burnell, 2006). Frankl (1984) recognised that the belief that one's life

fulfils a higher purpose and serves a higher power can be of significant psychogenic value. He stated that “there is nothing in the world, ... that would so effectively help one to survive even the worst conditions as the knowledge that there is a meaning in one's life” (p. 126). Frankl believed this held true not only for adults but also for adolescents (Dienelt, 1984).

Indigenous spirituality has also been investigated as a protective factor (Fleming & Ledogar, 2008) and this has applications for South Africa. It is described as a more complex phenomenon than the term “spirituality” alone, as it is closely bound up with culture, cultural identity and ways of living in indigenous communities which include participation in traditional and spiritual activities.

4.3.1.1.2 Hope

Lazarus (1999) explored the role of hope as an emotion and as a coping resource against despair. Hopeful adults believe that adversity can be overcome and that challenges can be coped with. They use positive internal dialogue and focus on successes rather than failures/obstacles in attaining their valued goals (Snyder, 2000). Snyder, Irving and Anderson (1991) conceptualised hope as an overall perception that one's goals can be met. Although goal-directed thinking has a long history, the importance of goals in guiding the lives of children has only gained attention in the last few decades (Snyder et al., 1997).

While hope is relevant to children in general, it has specific relevance to children who have chronic illnesses. Children's hope is conceptualised as a cognitive set involving the belief in one's capabilities to produce workable routes to goals (pathways) as well as the self-related beliefs about initiating and sustaining movement towards these goals (agency) (Snyder et al., 1997). Higher levels of hope reflect increasing levels of both pathway and agency thinking about goals (Snyder, Irving, & Anderson, 1991). Both components together provide an overall sense of the child's hope and underlie the related notions of perceived competence and control (Snyder et al., 1997). According to Snyder et al. (1997), the basic components of hope should be established by the age of three.

The theoretical relation between hope and coping is based on an assumption that the appraisal of stressors affects coping efforts (Lazarus & Folkman, 1984). The fundamental implications of this concept for children in general, and specifically children facing chronic

illnesses, is that how they think about their goals makes a difference in how they handle stressors, especially those related to illness. The diagnosis of an illness can offer impediments to the child's usual goal pursuits. For the short term, and often longer, children with health problems need to focus on new goals, find alternative ways to do things, and find the mental energy to begin and continue treatment regimens. Hopeful thinking makes it possible to envision differing means to achieve desired health outcomes (pathways thinking). It also enables them to initiate and sustain efforts at applying themselves to these means (agentic thinking). They can therefore embrace goals related to the successful treatment of their medical problems and this facilitates ongoing medical treatment (Snyder et al., 1997).

Hope is relevant when children are both healthy and when they are ill, as it has a moderating and mediatory role in stress. Children with high levels of hope perceive themselves as uniquely invulnerable to sources of harm in their environments (Snyder et al., 1997) provided such positive self-distortions are in the slight to moderate range (Taylor & Brown, 1998). How children learn to think about themselves in relation to barriers is an important contributor to hope (Snyder et al., 1997). In the context of the present hope theory, impediments to goal pursuits elicit negative emotions while the successful pursuits of goals, especially in spite of impediments, results in positive emotions (Snyder, 1994). It is Snyder's view that hopeful thoughts precede self-esteem as the degree to which children perceive that they can successfully attain their desired goals serves to guide their self-worth. Hope and self-esteem indices should thus be positively correlated. Hope correlates negatively with depression and is predictive of physical and mental health as well as health promoting behaviour. Hopeful people are therefore happier and healthier; they have more effective immune systems, cope better with stress and have better social support networks (Snyder, 2000). Hope thus contributes to well-being.

Snyder notes a developmental perspective to hope and offers an analogy of the immunisation process. By handling impediments to early childhood goals, children may be protected by their hopeful thinking patterns in subsequent difficulties that are encountered (Snyder et al., 1997). Over the lifespan, hope was found to be more prevalent in adolescents than in adults (Seligman, Steen, Park, & Peterson, 2005).

4.3.1.1.3 Self-Esteem

The development of self-concept and self-worth begins early in life (Deater-Deckard, Ivy, & Smith, 2005). Self-esteem is how we evaluate ourselves and determine our own self-worth (Basson, 2008). It is defined as the evaluative dimension of the self-concept, on a scale that ranges from positive to negative (Snyder & Lopez, 2002). After gaining an awareness of self, a comparison of self in relation to others, develops (Deater-Deckard et al., 2005).

High levels of self-esteem are negatively perceived in the literature when they involve relentless pursuits of self-enhancement or inflated self-evaluations (Crocker & Park, 2004; Neff, 2011; Sedikides & Gregg, 2008), however positive self-esteem is generally viewed as a central factor in good social-emotional adjustment and adaptive outcomes (Basson, 2008; Pyszczynski, Greenberg, Solomon, Arndt, & Schimel, 2004). A high level of self-esteem is therefore a strong predictor of well-being (Diener, 1984; Pyszczynski et al., 2004; Snyder & Lopez, 2002). High levels of self-esteem are frequently associated with good personal judgments, positive affectivity, personal independence, internal locus of control, greater self-knowledge and goal setting, coping well with criticism and managing stressors well (Diener, 1984; Snyder & Lopez, 2002).

The experience of having cancer has the potential to impact negatively on self-esteem. For example, for some children, losing their hair affects how they are seen by themselves and by peers. Positive self-esteem has however been found to provide an important internal resource in the coping process. Self-esteem was found to correlate positively with quality of life perceptions (Jonovska et al., 2009) and to correlate negatively with depression (Bragado, Hernández-Lloreda, Sánchez-Bernardos, & Urbano, 2008; Jonovska et al., 2009) and anxiety in children with illness or injury (Jonovska et al., 2009). This has been supported by other authors who noted that self-esteem provides a buffer against the potential for anxiety generally (Crocker & Park, 2004; Pyszczynski et al., 2004), and also specifically for anxiety engendered by the human awareness of mortality (Pyszczynski et al., 2004). Gender differences were found in self-esteem measures in adolescence, with boys scoring higher (Birndorf, Ryan, Auinger, & Aten, 2005).

In sum, spiritual or philosophical belief systems, sense of meaning and purpose in life, hope and self-esteem are important internal coping resources that can be drawn upon in situations appraised as stressful. They also play an important role in determining and maintaining psychological well-being. Each of these has shown a positive relationship with mental health, contributes to the positive appraisal of negative life events and would influence coping efforts. In particular, these internal coping resources have been found to be relevant to children with cancer.

The following is a discussion of external coping resources.

4.3.1.2 External coping resources

External coping resources also play an important role in determining and maintaining well-being. In this section, **Social Support, Information and Basic Conditions and Services** will be discussed as examples of external resources, contributing to psychological well-being. Other examples of external coping resources are education and financial resources (Antonovsky, 1979; Eckenrode, 1991) and a lack of these resources may be experienced as a stressor.

4.3.1.2.1 Social Support

Early work on social support in the 1970s provided evidence of a beneficial link between social support, health and adjustment (Pierce, B. Sarason, I. Sarason, Joseph, & Henderson, 1996), especially to those in the process of development (Ahern, 2006; Kiritz & Moos, 1974; A. Louw & D. Louw, 2007). Antonovsky (1979) emphasised that the extent to which one is embedded in social networks serves as a crucial resource (GRR).

Social support is a complex construct which encompasses at least three components that are mutually exclusive but influence each other (I. Sarason, B. Sarason, & Pierce, 1990). The first is support schemata. These are knowledge structures which include information regarding the individual's perception of the availability of others to give support. Perceived social support has been found to be one of the most consistent and strongest predictors of personal adjustment and life satisfaction (I. Sarason, B. Sarason, & Pierce, 1990; Fife, Adegoke, McCoy, & Brewer, 2011). Individuals with high levels of perceived social support

are also more effective in developing supportive relationships in new social environments (Lakey & Dickinson, 1994). In his study of female survivors of childhood maltreatment and trauma, Wells (2010) found evidence that social support schemata are stress buffers that reduce negatively-valenced emotional reactivity and facilitate coping when children have adequate psychological and social resources. The second component is supportive relationships. While individuals have supportive schemata that incorporate expectations about how others will respond to them, they also have expectations as to how specific supportive others will respond to them, in times of need (Sarason et al., 1990). There is general agreement that access to supportive social relationships and/or perceptions of feeling supported are important buffers to the negative psychological consequences of stressful experiences (Eckenrode, 1991; Lakey & Dickinson, 1994). The third component is supportive transactions. Research on social support has traditionally focused on the supportive relationship as having a provider and recipient of support. Sarason et al. (1990) believe this neglects to see that the individual can be both a source and recipient of support and emphasises the interconnectedness of these two roles. Supportive transactions consist of supportive behaviours, support seeking, support provision and support receipt. Low levels of support seeking are associated with lower levels of support receipt (Pierce, B. Sarason, I. Sarason, Joseph, & Henderson, 1996). Socially supportive behaviours are generally categorised into two forms of support: emotional support and instrumental support (task based). Examples of instrumental support that families with children with cancer have found useful include transportation, assistance with siblings, providing meals or doing errands (Shephard & Mahon, 2002). These overlap in function and therefore correlations between them is not uncommon.

An important protective benefit of social support is that there is evidence to suggest that social support is positively related to self-appraisals (Sarason et al., 1990). This may assist the person to appraise the stressful events differently (Moos & Holahan, 2003). In particular, individuals in supportive families engage in more active problem-focused and less avoidant coping (Holahan, Moos, Holahan, & Brennan, 1997). Social support may also facilitate the ventilation of feelings which contributes to coping and self-esteem (Birndorf et al., 2005; Eckenrode, 1991; Moos & Schaeffer, 1986). Specifically, children whose interactions with parents are supportive and well matched to their needs, develop positive expectations about the potential of others to provide support (Lakey & Cassidy, 1990). These children also have an opportunity to acquire coping skills that enable them to meet the

challenges posed by stressful situations by increasing their coping resources (Moos & Schaeffer, 1986; Pierce et al., 1996).

In a comparative study of British and South African adolescents from the Northern Cape region, Kruger (2010) found that good relationships with family and friends are pivotal support systems that promote the establishment of safe and psychologically supportive environments. They serve as resources which facilitate the adolescent's sense of security and hope (Kruger, 2010). In view of the challenges facing the child with cancer, social support is specifically beneficial. Supportive relationships from family members were found to be the primary resource (Engel & Melamed, 2002; Shephard & Mahon, 2002; A. Louw & D. Louw, 2007) for children with chronic illnesses and their families (Engel & Melamed, 2002; Shephard & Mahon, 2002) and have been associated with better adaptation in adolescents with medical disorders (Moos, 2002). Fewer behavioural and emotional problems and better functional status in daily activities such as school and social functioning were also found. In particular, Moos (2002) found family relationship dimensions of cohesion and expressiveness as the most consistent predictor of psychological and social adjustment of children with newly-diagnosed cancer at 1 month, 6 months and 9 months post diagnosis. They were also associated with less reported pain and better adherence to treatment regimes.

Social support groups have been recognised as low cost vehicles for supplementing social support (Taylor & Sherman, 2004). Such groups are vital resources for managing stressors and provide a forum for discussions of mutual concern and disease specific information. They also provide opportunities for participants to share their emotional responses with others going through the same situation. With the advances in technology, these groups have now extended to the Internet. Apart from the benefit of being easy to access logistically, and being inexpensive, it is a means of reducing social isolation. It is particularly beneficial for those who are isolated geographically or because of their medical conditions. Internet support has proven to be a valuable support for both children and their families (Hazzard, Celano, Collins, & Markov, 2002; Taylor & Sherman, 2004). A search conducted by the researcher (April, 2012) using search terms (internet, support groups, child* and cancer) yielded in excess of 53 000 results, reflecting the extent of available Internet resources for support.

4.3.1.2.2 Information

Information is conceptualised as a form of cognitive control and it has both an informational and supportive element (Van Der Molen, 1999). Information to be communicated in paediatric cancer care is complex and can be uncertain and emotionally charged, which can set the stage for mis-communication (Sobo, 2004). Due to the fragmentary nature of cancer care, there are often a number of healthcare professionals consulted (Van Der Molen, 1999). There is strong evidence that information about diagnosis and treatment can reduce uncertainty and thus be experienced, by the child with cancer and the family, as a resource. Further, there is evidence that psychosocial adjustment is related to a child's early knowledge of the diagnosis (Clarke, Davies, Jenney, Glaser, & Eiser, 2005). Parents are most often a primary source of information and gatekeepers of information between health care professionals and their children (Scott, Harmsen, Pricor, Sowden, & Watt, 2003) and their understanding influences the child's thinking about the illness (Chesler & Barbarin, 1987; Clarke et al., 2005; Jithoo, 2010). Research by Mack and Grier (2004), on the communication of bad news, suggests that the shock of the news results in the majority of parents understanding less than half of what doctors say at the initial consultation thus preventing retention of the information. Factors which influence this include the extent to which the parent is overwhelmed by the volume of information, while simultaneously confronting fears and anxieties about the nature of the illness, responding to treatment related decisions, religious beliefs and the extent to which the parent has support (Chesler & Barbarin, 1987; Clarke et al., 2005; Jithoo, 2010).

Historically, communication about illness was the sole domain of the physician who decided whether and to whom to reveal the diagnosis (Jithoo, 2010). Early literature reflected divergent views regarding disclosure of the diagnosis, treatment and prognosis by doctors to their patients (van Dongen-Melman & Sanders-Woudstra, 1986). The protective approach was premised on the pretence that nothing was wrong, in the belief that this would protect children from the situation, so that it did not add to their distress (Clarke et al., 2005). Over the past two to three decades, there has been a shift to the open approach which entrenches the rights of patients to information and an acknowledgement that it is virtually impossible to protect the child from an awareness of the illness and its seriousness. This conceptual shift has facilitated a relationship-centered approach characterised by open communication and active participation and information exchange between physician, child

and family (Jithoo, 2010). However, as noted previously, communication is a complex process and is more than just the exchange of information. It involves interpersonal relationship-building, shared decision-making and information exchange (Sobo, 2004). In addition, cancer information needs vary as illness by its nature is a subjective experience, influenced by a biological state as well as cultural, social factors and other situational variables (Jithoo, 2010).

Jithoo (2010), in her study of South African children with cancer and the information-seeking behaviour and communication of parents ($n=100$) found that only 10% of parents provided the full spectrum of information to their children (about diagnosis, treatment and the life threatening nature of cancer). Irrespective of race or educational levels, most parents regurgitated information given to them and thus children were often well versed on technical, physical and medical aspects and had information such as medication names and procedures, thus the conversation between parent and child was restricted to factual information. Eighty nine percent of parents were unwilling to discuss the possibility of death with their children as they reported it was something that they had blocked out and had rationalised that the topic would distress the children. A greater majority (92%) of parents reported that they had not prepared their children emotionally but did not have the emotional resources themselves to address this. According to Clarke et al. (2005), this behaviour of parents gives the child overt and covert messages not to talk about such matters. In response, the children try to conceal their knowledge and avoid conversation to protect the adults. Chesler and Barbarin (1987) noted that the children become caught in a charade where they learn to accommodate the adults and conceal their need for openness and candour. For the 11% of parents who did not divulge any information to the children, there was evidence that the children were not ignorant about their illness, confirming that they had obtained information from other sources and environmental cues. These findings are supported by earlier studies (e.g., Clafflin & Barbarin, 1991). Other parents preferred to give their children incremental information, in response to questions from the child or necessary treatments or procedures. Jithoo's findings confirmed those of Clarke et al. (2005) that children who are not given information are not protected from fear and worry. Further, parents experience increased stress when not disclosing information (Clarke et al., 2005). Refusal and non-compliance with treatment in children and adolescents are correlated with lack of understanding and poor communication regarding diagnosis and treatment. Conversely, children with appropriate information about

their condition are more compliant with treatment and more open about discussing their concerns (Clarke et al., 2005).

While parents are the primary source of information for their children, Jithoo (2010) found that 59% of parents did not actively seek out information (but did not avoid it) and 62% resorted to information avoidance. Fear of increasing personal distress was cited by parents as a reason for this (Van Der Molen, 1999; Jithoo, 2010). Leydon et al. (2000) note that factors influencing this are complex and orientation towards factors such as hope may mean that at points of the illness they prefer not to have information. Cultural factors may influence information-seeking (Jithoo, 2010; Sobo, 2004). In Jithoo's study, of the 36% of parents who actively sought out information the majority were White. She notes that there is a strong acceptance, by Black parents, of the maxim that the doctor knows best which renders the wish for additional information obsolete. Sobo (2004) notes that communication preferences are "ever evolving systems for making meaning" (p. 151) and are culturally influenced. In Sobo's study with English and Spanish speaking parents, two thirds of nurses misjudged parents' communication preferences and 50% of nurses underestimated parents' information desires (Sobo, 2004).

According to Mack and Grier (2004), for information to become a resource it is important to ensure that the exchange of information among the patient, family, and physician will continue as the shock of the initial diagnosis fades. Information about diagnosis, treatment and treatment goals (active treatment or palliation) and causation are necessary. The latter is considered especially important by these authors as many families try and seek meaning for such a devastating event, and they may irrationally blame themselves for something over which they had no control. For physicians to be a resource in imparting information they need to be guided by the emotional response of the child and family, and to their need for information (Mack & Grier, 2004).

4.3.1.2.3 Basic living conditions and services

Financial prosperity, adequate living conditions, healthcare services, education and political stability can promote the development of the individual (Kruger, 2010) and are important resources when facing life stresses. However, in South Africa there are many

challenges in the provision of basic living conditions and services, and this is particularly relevant when trying to meet the medical and psychosocial needs of a child with cancer.

In the 2010/2011 edition of the South African Child Gauge, it is noted that there has been a significant decline in child poverty in recent years largely due to the expansion and extended availability of social grants. However, the reality remains that 61% (Statistics South Africa, 2010a) of South African children live in households below the income poverty line with a monthly per capita income of below R552 in 2009 (Bray, 2011). This lack of adult income in the home compromises many children's access to basic services, adequate food, water, sanitation and housing. Nearly one in four economically active adults is unemployed and more than a third of children (36%) live in households without an employed adult (Statistics South Africa, 2010a). Only 63% of children live in households with basic sanitation (Statistics South Africa, 2010b), which includes flushing toilets and ventilated pit latrines that dispose of waste safely and are within or near a house.

In a study conducted by Kruger (2010), of the relationship between risk factors, resources and suicidal ideation in South African and British adolescents, he found that, for the Northern Cape group, the most prominent stressors were those of home, money and negative life experiences. It was hypothesised that this may be reflective of the Northern Cape's lower levels of socio-economic prosperity and adverse environmental and political circumstances as well as a higher frequency of life-crises which, according to the literature, is often the case with people from lower socio-economic groups.

Poverty, distance from the health-care facilities, poor knowledge about the seriousness of the child's condition and the use of traditional healers and medicines are factors which influence and contribute to the low health-care seeking practices of mothers for their children in rural communities in Africa, and specifically South Africa. These practices contribute to the late diagnoses of cancer and other diseases and presenting to medical facilities in the advanced stages of disease or deterioration of condition (Hill, Kendall, Arthur, Kirkwood, & Adjei, 2003; Mbagaya, Odhiambo, & Oniang'o, 2005; Tsion, Tefera, Ayalew, & Amarew, 2008). More specifically related to childhood cancer in South Africa, a low level of formal education was associated with lack of confidence and conceptual ability to deal with the complexities of cancer (Jithoo, 2010). However this is not restricted to Africa. Internationally, those who have low health literacy and low levels of income face

worse health outcomes (including higher mortality rates) than their more affluent peers because of lack of cancer screening, late-stage diagnoses, and difficulty with maintaining treatment regimens (San Francisco General Hospital Foundation, 2012).

Due to understaffing and shortage of trained health-care professionals, there is limited access to trained paediatric nursing care for children in South Africa. Statistics for 2006 (Kruger & Coetzee, 2011), indicate that there are only 1691 registered paediatric nurses for a population of 18 million children. Societal and cultural norms and values pose a further challenge since these are inherent in how health professionals and families treat children who are ill. While nurses recognise that appropriate nursing care requires empathetic care of the whole child, their daily schedules and distress in coping with many sick and dying children stretches them beyond limits. Interacting with their young patients in an impersonal way helps nurses to cope (Kruger & Coetzee, 2011).

In sum, social support, information and access to basic services and conditions of living are all powerful external resources for individuals facing stressful life experiences. Social support has been found to be a crucial resource in buffering the negative consequences of such experiences. As one of the most consistent and powerful predictors of personal adjustment and life satisfaction, it is positively related to self-appraisal, self-esteem and more active coping. Information has been shown to be a potent external resource as it has a cognitive component and one of support. In the case of children with cancer, age appropriate, accurate information, is an important way of assisting them to feel in control and provides an important resource. Information which is age-inappropriate, too much or too little information can result in feelings of loss of control, misperceptions or anxieties and may therefore be experienced as a stressor. Access to basic living conditions and services promotes the development of individuals and provides resources in times of life stresses. For children with cancer, South Africa has access to developed world medicines and international paediatric treatment protocols. In addition, there are a number of specialised paediatric oncology treatment centres in major cities around South Africa that are significant resources to all children of this country. However, there remain major challenges to achieving the international survival rates or meeting the psychosocial needs of many of these children. In the personal experience of the researcher, a number may remain in hospital for extended periods, often without the support of family and despite the psychosocial consequences, for the purposes of survival, even though the child's medical status warrants discharge. In view

of the nature of childhood cancer with the high need for specialised medical care, good living conditions, adequate nutrition and access to basic services such as sanitation, for a number of children in the lower income groups, returning to these conditions may compromise their health status. The provision of basic living conditions and services as an external coping resource remains the greatest challenge in South Africa.

The preceding discussion has provided an overview of coping resources. The availability of these resources will influence the individual's mode of coping, of which discussion follows.

4.3.2 Modes of coping

Modes of coping include the various coping strategies and coping skills which individuals use. These include approach and avoidance coping on both cognitive and behavioural levels. The dimensions of coping include problem- and emotion-focused coping as well as relational coping. The following discussion provides an overview of these concepts.

4.3.2.1 Coping Strategies

There has been little consensus on the issue of coping strategies in children. Early researchers such as Kavsek and Seiffge-Krenke (1996), postulate that coping strategies take on several dimensions in adolescence. Later researchers suggested that children use a number of single strategies that later transform into general coping traits (Schmidt et al., 2003). Other researchers have however demonstrated that coping in chronically ill children and adolescents is stable over time but varies across situations (Spirito, Stark, Gil, & Tyc, 1995). Most researchers have however concluded that coping in children is more concrete, consisting of various single behavioural strategies which change qualitatively as the child gets older, leading to an emergence of coping strategies that can be used in a flexible manner (Schmidt et al., 2003).

Children and adolescents use diverse coping strategies in different domains for example, school and family life. These differ in stress situation evaluation and in coping strategy assessment depending on personal characteristics and abilities (Wenger, Sharrer, &

Lynd, 2000) as well as on family support, school support and links between these. Maladaptive coping strategies under stressful situations are associated with emotional problems and impact on the psychosocial adjustment of the child (de Matos, 2008).

From a developmental perspective, it is argued that behavioural coping strategies develop earlier and remain fairly consistent across ages, whereas cognitive and emotional coping strategies increase with age (Compas, Worsham, & Eys, 1992). It is suggested that in the transition from the concrete to formal operational stages, adolescents develop the ability to use subtle forms of appraisal and consequently may be more flexible and differentiated in the coping strategies they use (Hoffman, Levy-Shiff, & Sohlberg, 1992). Some controversies remain as to whether the nature of coping is consistent within each of the developmental stages or whether it is intra and inter-individually flexible and open to change (Schmidt et al., 2003).

4.3.2.2 Coping Skills

Coping skills have been identified in the literature as a multi-dimensional set of cognitions and types of behaviour called upon to help a person manage or tolerate the demands imposed by acute or chronic stressors (Eckenrode, 1991). Coping *skills*, unlike coping *styles*, refer to both a cognitive and an affective component (Beutler, Moos, & Lane, 2003). Moos and Schaefer (1986) note that the use of the word “skill” in coping skill emphasises the positive aspects of coping and depicts it as an ability that can be taught and used flexibly as the situation requires.

In general, researchers have used two main conceptual approaches to classify coping skills individuals use in specific situations. In the first, the focus is on the individual’s orientation to the problem. Dimensions of coping include approach coping, in which active efforts to resolve the problem are made, whereas in avoidance coping individuals may choose to avoid the problem or focus on managing the emotions associated with it (Beutler, Moos, & Lane, 2003; Moos & Holahan, 2003). In the second approach, the specific coping methods employed by individuals in their attempts to deal effectively with stressors, that is, whether a response entails primarily cognitive or behavioural coping (Beutler, Moos, & Lane, 2003; Moos & Holahan, 2003). By combining these two approaches, Moos and Holahan (2003)

were able to define four basic types of coping responses: cognitive approach coping, behavioural approach coping, cognitive avoidance coping and behavioural avoidance coping.

4.3.2.2.1 Approach coping

Cognitive approach coping includes logical analysis and positive reappraisal (Moos & Holahan, 2003), the purpose of which involves paying attention to one aspect of the crisis by breaking an overwhelming situation into smaller, potentially manageable parts, by drawing on past experiences and mentally rehearsing alternative actions and probable consequences (Moos & Schaefer, 1986). Finding a general purpose or pattern of meaning in the course of events can make an uncontrollable situation feel more manageable. Belief in a divine purpose or putting the experience into a long-term perspective also makes the individual events seem more tolerable. Cognitive redefinition involves a restructuring of the situation with an acceptance of the basic reality of the situation, for example, “it could have been worse” (Holahan & Moos, 1987a).

Behavioural approach coping includes seeking guidance and social support and problem-solving (Calhoun, 1998; Holahan & Moos, 1985; 1987a; Moos & Holahan, 2003). In their study of 84 chronically ill adolescents, Meijer, Sinnema, Bijstra, Mellenbergh and Wolters (2002) found that the most frequent coping style was making use of social support. In cancer care, behavioural coping strategies have been found to be important for managing chemotherapy-induced nausea and vomiting (Moore, 2002).

Consistent with the findings of Billings and Moos (1981), Wetherington and Kessler (1991) found cognitive approach coping to be associated with poor emotional adjustment and behavioural approach coping with good adjustment. Their rationale is that thinking about ways to make a situation better without acting on it can be harmful to the situation and can cause increased stress. Such thinking is however challenged by researchers such as Hobfoll (1988).

4.3.2.2.2 Avoidance coping

Avoidance coping is a response to threatening situations when personal and contextual resources are scarce (Holahan & Moos, 1987a). Cognitive avoidance or denial

encompasses an array of skills aimed at denying or minimising the seriousness of the crisis and is aimed at refusing to confront difficulties presented by life. It is an attempt to reject the importance of the stressor or its impact. These are “self-protective” mechanisms in response to the stress (Lazarus & Folkman, 1984). Behavioural avoidance coping includes seeking alternative rewards and emotion discharge (Calhoun, 1998; Holahan & Moos, 1985; 1987a; Moos & Holahan, 2003) and avoidance coping includes cognitive avoidance and acceptance/resignation (Moos, 2003).

As the child functions within a family system, breakdowns in family adaptation have been associated with the severity of the child's condition, parental functioning and use of avoidance rather than approach coping skills (Holahan & Moos, 1985; 1987a). These researchers were consistent in their finding that children who used approach coping skills resolved focal stressors more quickly, experienced increased self-confidence and less distress, whereas avoidant copers were associated with increased outbursts, adjustment difficulties, and stress symptoms (Holahan & Moos 1985; 2002).

Much has been written about the various modes of coping. Over the years, it has evolved into two broad dimensions of coping: problem-focused and emotion-focused. The following is a discussion of each of these and includes a brief description of relational coping which is emerging as a third dimension.

4.3.2.3 Dimensions of coping

The most widely used dimensions of coping are problem- versus emotion-focused coping (Compas et al., 2001; Frydenberg, 2008). Both forms occur in nearly all stressful encounters with problem-focused coping presumably reducing stress and resulting in greater well-being in situations that are amenable to change, whereas emotion-focused strategies presumably give a more positive result in situations considered unchangeable (Eckenrode, 1991; Lazarus, 1999). More recently relational coping has been included in the dimensions of coping (Frydenberg, 2008). Social support for example, may be an example of all three dimensions of coping. Cognitive appraisal is central in mediating thought, feelings and actions and is a potent predictor of whether coping is oriented toward emotion regulation (emotion-focused coping) or doing something to relieve the problem (problem-focused coping) (Lazarus & Folkman, 1984). The following is a discussion of the dimensions of

coping, which include problem-focused coping, emotion-focused coping and relational coping.

4.3.2.3.1 Problem-Focused Coping

Problem-focused coping is described as a coping style which is used in an attempt to change the situation causing the stress through the use of realistic strategies (Lazarus & Folkman, 1984). Most problem-focused coping is considered healthy, as it helps achieve goals (Hobfoll, 1998). Examples of problem-focused coping include active coping, planning, information, social support seeking and restraint coping, where the individual considers the timing of the response. The purpose of these is to restore a sense of control about the demands, and mentally prepare for the steps involved. Information-seeking is often used in conjunction with logical analysis. Problem-focused coping involves taking concrete action to deal directly with the crisis or its aftermath, such as putting in place structures to deal with day-to-day tasks.

Hope is considered a significant and unique predictor of problem-focused coping when controlling for negative affectivity and optimism. People with high levels of hope focus on success rather than failure when pursuing goals and are more likely to use adaptive coping strategies (Snyder et al., 1991), such as increased problem-solving (Snyder & Dinoff, 1999).

According to Frydenberg (2008), cognitive coping and problem-focused coping are largely used by adolescents with chronic illnesses but she noted research that also referred to the use of defence mechanisms such as denial or rationalisation. The coping of adolescents was however thought to be stable across time.

4.3.2.3.2 Emotion-focused Coping

Emotion-focused coping involves affective regulation (Gross, 2002; Moos & Schaefer, 1986) and is an individual's attempts to change negative emotions. It is aimed at normalising the emotional response to a stressor (Lazarus & Folkman, 1984) and involves the skills required to maintain hope and control emotions despite the situation (Moos & Schaefer,

1986). The goal is to “release the tension, forget the anxiety, and eliminate the worry or just release the anger” (Compton, 2005, p. 118).

Examples of emotion-focused coping include withholding immediate action and “keeping strong”, or gradual exposure to aspects of the stressor. It may also involve seeking social support, turning to religion, venting of emotions such as crying or screaming, or using humour to relieve the tension of the situation (Moos & Schaefer, 1986). Strategies such as seeking support and turning to religion are associated with the successful management of situations and higher levels of optimism and resilience (Frydenberg, 2008). Social support-seeking as a form of emotional coping was used more frequently by adolescent girls and was reported to reduce feelings of hopelessness and helplessness, and create a feeling of belonging (Meehan, Peirson, & Fridjhon, 2007; Wissing, Claassens, & Du Toit, 1998). Other helpful emotion-focused coping strategies can include acceptance and positive reinterpretation (Hobfoll, 1998). Of relevance to cancer patients, the most frequently used emotion-focused coping strategies for the management of nausea include wishful thinking, emotional regulation, distraction and seeking social support (Moore, 2002).

4.3.2.3.3 Relational Coping

Apart from the problem- and emotion-focused modes of coping, the literature also identifies relational coping (Frydenberg, 2008). Models of stress and coping have traditionally focused almost entirely on the coping efforts used by individuals. A relational perspective needs to be incorporated as major life stressors affect not only individuals but the lives of significant others in their social networks (Kayser, Watson, & Andrade, 2007). In order to fully understand the relationship between stress and mental health, Kayser, Watson and Andrade (2007) believe that coping, as it occurs within the context of significant relationships, should be considered. Relational coping may be defined as “stress adjustment activities involving a significant other” for example seeking advice from a best friend (Hardie, 2005, p. 27).

Relational coping is seen as an extension of social support. Lakey and Orehek (2011) hypothesise that the main effect between mental health and perceived social support is relational in that people “regulate their affect, thought, and action through ordinary yet affectively consequential conversations and shared activities” (p. 482).

In sum, coping strategies and coping skills are determined and differentiated according to the individual's appraisal of the stressful situation and are called upon to manage the demands imposed by the stressor (Eckenrode, 1991). Although consensus has not yet been reached on the exact nature of the development of coping strategies in children, there is general consensus that these change qualitatively as the child gets older, leading to an emergence of coping strategies that can be used in a flexible manner (Schmidt et al., 2003). Coping skills are defined according to their orientation to the problem and attempts to deal with the stressors and include active or avoidant coping on both behavioural and cognitive levels. The most common dimensions of coping include problem- and emotion-focused coping, both of which are thought to occur in most stressful situations. Problem-focused coping is generally associated with active attempts to deal with the stressful situation, while emotion-focused coping is associated with emotional regulation. Relational coping is an effective dimension of coping as coping most often occurs within the context of significant relationships.

4.3.3 Factors moderating coping

There are numerous constructs that have the potential to moderate coping. Age, gender, culture and socio-economic factors have been selected for discussion as they are most commonly cited in the literature and are specifically relevant to this study, and as the focus is developmental. Age and gender are frequently cited in the literature and by their nature are culturally embedded and influence the way children cope with stress (Fields & Prinz, 1997; Frydenberg, 2008). In studies of child resilience, resources and risk factors have been operationally defined in diverse ways and most frequently include socio-economic factors (Masten, 2001) the relevance of which is that they may also influence coping. Factors such as poverty and lack of adequate resources may result in adolescents resorting to functional or dysfunctional coping strategies in dealing with stressors (Schlebusch, 2005). The following is a discussion of these moderating variables.

4.3.3.1 Age

Skinner and Zimmer-Gembeck (2007) emphasise the importance of the application of a developmental framework to coping noting that in infancy, coping is akin to emotional regulation. Over time, coping develops from simple reactions to stress responses to highly

co-ordinated and specialised cognitive efforts to regulate and control the effects of the stressor. Research findings indicate that there are important differences in coping across the lifespan and thus age is relevant (Frydenberg & Lewis, 2000; Skinner & Zimmer-Gembeck, 2007). Researchers such as Frydenberg and Lewis (2000) note that functional coping decreases with age, whereas emotional coping increases.

Three independent studies conducted on children (Australian, 11-19 years, $N=829$: Frydenberg & Lewis, 1999); (German, 8-14 years $N=1123$: Hampel & Petermann, 2005); (Australian longitudinal study, 12-17 years, $N=168$: Frydenberg & Lewis, 2000) demonstrated age differences in general coping, for example, with regards to choice of coping strategies. However, it was noted that the age differences were made more complex by gender differences and other changes co-occurring within the individuals and their social environments during the adolescent period (Frydenberg, 2008). In their study, Hampel and Petermann (2005) noted that situation-specific coping did not differ with age and gender.

In a comparative study of the coping strategies utilised by South African (Northern Cape region) and British youths (Kruger, 2010), the results indicated that South African youths made more frequent use of problem- and emotion-focused coping strategies but also used denial as a dysfunctional coping strategy. Age as a moderating variable was considered one explanation for the greater repertoire of coping strategies used by South African participants. According to the literature on the subject, as adolescents mature cognitively and emotionally they become more competent in their application of a wider range of coping strategies (Frydenberg, 2008).

In a study of Taiwanese children with cancer, aged 4 to 17 years, age was found to be a significant factor determining adaptation to cancer in five different areas: physical and psychological (functional integrity and feelings about the illness), cognitive (perceptions of the illness), social (interpersonal relationships) and future orientation (feelings about the future) (Yeh, 2001).

While the above studies support age as a significant moderating factor for children with and without cancer, Engel and Melamed (2002) note that each person's resources must be understood over time because age is deceptive if used without the knowledge of the

child's conceptual level of reasoning and physical maturation, or in the case of a child with cancer, limitations imposed by illness.

4.3.3.2 Gender

The most frequently reported discriminator of coping is gender, which is often societally influenced (Frydenberg, 2008). In reviewing the literature, it is evident that a number of authors depict differences in the coping behaviour of males and females. A traditional perspective has been to associate males with problem-focused coping strategies, emotion-focused coping strategies (such as aggression) and dysfunctional strategies such as denial as well as alcohol and drug disengagement. By contrast, females are perceived as engaging in emotion-focused coping strategies, such as seeking social support for emotional reasons and venting emotions (Frydenberg & Lewis, 1999; Frydenberg & Lewis, 2000; Hampel & Petermann, 2005; Lazarus & Folkman, 1984; Wissing et al., 1998).

Turning to religion is seen as an emotional coping strategy used more frequently by females. Burnell (2006), in her study of the relationship between spiritual well-being and sense of meaning in South African late adolescents, found gender differences in spiritual well-being. Research consistently reports the greater tendency for boys to turn to sport and other diversions while girls turn to others for support. Frydenberg (2008) noted that girls are more likely to turn to emotion-focused coping and are more inclined to admit that they require help whereas boys ignore the problem or keep it to themselves.

The above findings are challenged by a South African study by Meehan et al. (2007) who caution against stereotypical perceptions having found that both genders of adolescents utilise similar problem-focused coping strategies. Although both genders demonstrated that they use functional coping strategies, there were some inter-gender differences which showed that adolescent girls tend to use social support and approval (relational coping) more frequently. Supporting the findings of Meehan et al. (2007) in a previously cited study, Kruger (2010) found few gender differences in the South African group, which consistently reported more frequent use of problem-focused coping in terms of active coping, planning, restraint coping and seeking social support for instrumental reasons. This indicated that they favoured active efforts to eliminate stressors and to seek advice and guidance when faced with stressful situations. As in the study of Meehan et al. (2007), gender differences were

found in the South African group for seeking social support. The above-mentioned studies support the findings of Frydenberg (2008) that indicate that girls tend to rely on relational coping as an effective means of dealing with a stressful situation.

Despite the above differences in findings, a gap between the coping behaviours of male and female adolescents are thought to increase with age, with a greater shift in coping occurring between the ages of 14 and 16 years. In addition, older adolescents are more likely to blame themselves for their stressors and resort to tension-reducing (dysfunctional) strategies such as the use of alcohol and drugs (Frydenberg, 2008; Meehan et al., 2007). The emergence of more maladaptive coping patterns was noted in girls during the adolescent years (Frydenberg, 2008).

4.3.3.3 Culture

There is evidence to suggest that culture influences preferred coping strategies and the use of available resources, and thus culture plays a significant role in moderating coping (Han, Cho, D. Kim, & J. Kim, 2009). There is evidence that, despite many similarities, adolescents from different cultural backgrounds draw on different coping strategies, however, contextual factors and social and cultural norms are also important determinants (Frydenberg, 2008). According to Antonovsky (1979), culture provides the individual with a place in the world and a wide range of answers to demands. From the psychological point of view, these answers are internalized, while from the sociological point of view they are institutionalised.

The literature suggests that social support is culturally influenced as culture provides a shared belief system providing direction and guidance as to how social support is given and received (Dilworth-Anderson & Marshall, 1996). In a comparative studies of Black and White families with children who have cancer, White families identified emotional support (e.g., support conveying empathy and understanding) as their primary type of support whereas Black families identified instrumental assistance (e.g., help with other children and with transportation) as the primary means of support (Engel & Melamed, 2002; Pierce et al., 1996). Asian cultures generally have family-centered support systems in which emotional, financial and instrumental support is given. This support system is maintained through a cultural sense of family loyalty and the predominance of the group is maintained over the individual (Gellis, 2003). Rules regulating respect for older adults, especially parents, and

strict gender hierarchies are instilled. Two other characteristics define relationships among Asian families: shame and harmony. The social support system in these families incorporates both shame and harmony in giving and receiving help (Dilworth-Anderson & Marshall, 1996). In a study of the coping strategies of Korean mothers of children with cancer, Han, Cho, D. Kim, and J. Kim (2009) found that less use was made of seeking social support than Western norms as these needs were met within the family.

Information has been discussed as a coping resource, and information-seeking as a mode of coping. Sobo (2004) is of the view that all cancer care communication, between doctor and child or its parents, is influenced by cultural differences. In Asian and Hispanic cultures, cultural expectations, such as the right of the family to protect the patient are prevalent, implying that the family member and not the patient should be informed. In these communities, disclosure can be seen as taking away hope (Gotay, 1996). In terms of medical communication, Western patients and their families present a well-documented contrast to other cultural groups. Value is placed on openness and full disclosure of information about diagnosis, with active participation in treatment decisions. The “right to know” receives primary emphasis (Gotay, 1996).

Insight into the world view of a cultural group is important when considering their use of resources and modes of coping. In the Western world, science is relied upon to explain etiologies whereas in the traditional African worldview it is mainly magico-religious and consultation of divination systems is widespread. Such consultation is used to determine events such as disease causation, prevention and treatment (Munthali, 2002). These cultural belief systems determine the coping strategies and health-care seeking practices individuals would use. What disease means in biomedicine is different from what it means in traditional African health care, where the term is more ambiguous. In the Zulu culture (which is unique to those who live in the KwaZulu-Natal region and from which the majority of the participants of this study came), disease is referred to as “*isifo*” and refers not only to somatic symptoms but also to “states of vulnerability to misfortune and disease (Munthali, 2002, p. 80). In such cultures an understanding of taboo is relevant. A taboo (that which is forbidden) is a cultural construct which provides behavioural codes that regulate and guide people how to behave in certain circumstances. A violation of a taboo is thought to result in a person having misfortune or illness. It may not be the one who has committed the breach that suffers but it could be the spouse or children (Munthali, 2002). There is also a general internalised

belief in African societies that ancestors influence their destinies and thus regulate their behaviour. The extent to which these beliefs are internalised, may result in a fear of punishment from the ancestors. There is a belief that the ancestors need to eat therefore there is an obligation to have rituals in which animal sacrifices are made to avoid misfortune or disease. While the methods employed above may seem irrational from a biomedical point of view, it is an important part of the African heritage (Munthali, 2002). Belief systems outlined above would influence the understanding of disease causation and thus influence appraisal of illness and selection of modes of coping.

Motherhood and parenting in African American and African cultures have a strong cultural meaning. On the basis of traditional cultural beliefs, mothering occurs as part of the extended family as opposed to the nuclear family and is not reserved exclusively for the biological mother. Parenting and mothering roles are assumed by others both within and out of the family, thus the assumption of parenting roles by several responsible adults is commonplace (Dilworth-Anderson & Marshall, 1996). Such practices may influence the extent to which the biological mother is involved in the primary care of the ill child and has implications for how this is perceived by Western medical personnel and Western medical facilities. The attitudes towards such practices have the potential to influence the extent to which these facilities are experienced as resources.

4.3.3.4 Socio-economic factors

According to Lantz and Pritchard (2010), socio-economic indicators include factors such as:

- 1) Income: this includes average household income and per capita income.
- 2) Poverty rate, percentage of households receiving public assistance and percentage of children receiving free or discounted lunch.
- 3) The unemployment rate and the percentage employed in professional or managerial occupations.
- 4) Affordability of housing and homelessness rate.
- 5) Percentage of the population aged 18 to 24 years with less than high school education, school dropout rate and graduation rates, percentage of third and

tenth-grade students at grade level in reading, and percentage of tenth-grade students at grade level in Mathematics.

According to these indicators, as discussed above, the number and proportion of children in South Africa living below the income poverty line is 61% (Statistics South Africa, 2010a). Nearly one in four economically active adults are unemployed and more than a third of children (36%) live in households without an employed adult (Statistics South Africa, 2010a). In 2008, 71% of South African children lived in formal housing, while almost 2.3 million children lived in backyard dwellings or shacks in informal settlements. Nearly a third of children (30%) lived in over-crowded households. A fifth of children (21%) lived far from their nearest primary school and this increases to a third of children (33%) in the high school phase. Eighteen percent of children (2005) between 1 and 9 years were found to be chronically malnourished (Hall & Lake, 2011). Based on these indicators, a significant number of children living in South Africa would be classified as living in poverty.

Poverty is a multi-dimensional phenomenon, encompassing an inability to satisfy basic needs, lack of control over resources, lack of education and poor health. People in lower socio-economic classes, by virtue of their life circumstances, are exposed to and have greater vulnerability to stressors and have fewer resources to manage them. People who live in poverty are not part of mainstream society and are often isolated from information and support (Lake & Reynolds, 2011; Murali & Oyebode, 2004) yet researchers such as Hossain, (2005) note that poverty is not defined solely in terms of low income and a lack of assets, but also by the lack of choice with respect to alternative coping strategies. In his study of people living in extreme poverty in Bangladesh ($N=500$), use was made of active coping solutions such as withdrawing children from school and sending them to work.

In sum, there is evidence that age, gender, culture and socio-economic factors have the capacity to moderate coping and in many instances are linked to one another. They have relevance to the coping process in general, and to the child in the process of development in particular. They influence the use of available resources and the selection of coping strategies and modes of coping.

The preceding section has examined the link between coping and well-being and has presented a comprehensive theoretical overview of the construct of coping and its various

dimensions. The following discussion provides a conceptual understanding of well-being which is the outcome in stress and coping models.

4.4 WELL-BEING AS A CONSTRUCT

Well-being as a construct has been extensively studied (e.g., Diener, 1984, 2000; Diener et al., 1999; Ryan & Deci, 2001; Ryff, 1989). While there are a number of interpretations, the general consensus is that well-being refers to optimal psychological functioning and experience (Springer & Hauser, 2006). According to the World Health Organisation, health is not only the absence of disease and infirmity but a state of complete well-being in a physical, mental and social meaning (United Nations, 1948). Well-being is thus viewed as a synonym for wellness and health (Wissing & van der Lingen, 2003). Historically, two broad philosophical perspectives have been used to explore well-being: the hedonic tradition and the eudaimonic tradition (Ryan & Deci, 2001; Ryff & Singer, 2008; Waterman, 2008). According to Keyes (2009), there is more research on children and adolescents from a hedonic well-being perspective than there is from a eudaimonic perspective.

4.4.1 The hedonic perspective on well-being

In the hedonic approach, subjective well-being, often used interchangeably with happiness (Deci & Ryan, 2008; Snyder & Lopez, 2007) explains well-being. It is frequently operationalised as the balance between positive and negative affect (Ryan & Deci, 2001; Ryff, 1989). Subjective well-being has been broadly constructed to include the individual's cognitive and affective judgments about good and bad elements of life and what makes it pleasant or unpleasant (Diener, 1984, 2000; Diener, Oishi, & Lucas, 2003; Ng, Ho, Wong, & Smith, 2003; Tov & Diener, 2007). More specifically, well-being involves the individual's experience of pleasure and appreciation of life's rewards. Diener (2006) indicates that subjective well-being and ill-being can be observed objectively in verbal and nonverbal behaviour, actions, biology, attention and memory. Initially, Diener (1984) described subjective well-being as having three components: frequent positive affect, infrequent negative affect and elevated life satisfaction as a global judgment. Positive affect denotes pleasant moods and emotions, and positive reactions to events. Negative affect includes moods and emotions that are unpleasant and represent negative responses to life events, if

they are frequent or extended (Diener, 2006). Life satisfaction is considered related to, but partially independent of, the affective aspects of subjective well-being (Lucas, Diener, & Suh, 1996). Diener (2000, 2006) added a fourth component which included satisfaction in important domains of life such as health and relationships. This is supported by Kitayama and Markus (2000), who suggest that life satisfaction is more than just personal happiness and includes relationships with others.

From a hedonic perspective, subjective well-being is often measured through questionnaires where both the cognitive construct (life satisfaction) and affective states (positive and negative affect) are measured (Diener, 1984; 2000). People who are considered high in subjective well-being are usually considered high in positive affect and low in negative affect as they frequently appraise their lives in a positive manner (Ng et al., 2003). An additional component of subjective well-being is low neuroticism because there is an inverse relationship with negative emotions and neuroticism. The less neurotic the individual, the higher the level of subjective well-being (Compton, 2005). Subjective well-being is thus considered a measure of the individual's quality of life (Diener et al., 2003; Tov & Diener, 2007). According to Huebner and Diener (2008), there is limited knowledge regarding subjective well-being in youth. As life satisfaction is the criterion variable of this study, this component of subjective well-being will be discussed.

4.4.1.1 Life Satisfaction

Life Satisfaction is the cognitive component of subjective well-being. It refers to a personal judgment about the acceptability of the individual's life (Diener et al., 1985; Diener, 2000; Tov & Diener, 2007) and is considered an indicator of general psychological well-being (Wissing & van Eeden, 2002). Life satisfaction was thought to be stable in spite of negative life events (Pavot & Diener, 2008), however there is research which suggests that certain external influences such as illness and disability can result in moderate to major decreases in life satisfaction (Lucas, 2007). It must be thus considered that life satisfaction may be malleable under certain conditions (Bach, 2011).

There is evidence that higher levels of life satisfaction are correlated with various indices of positive functioning in adolescents (Bach, 2011). Elevated life satisfaction has been associated with positive self-esteem and adaptive functioning, particularly in

interpersonal relationships (Compton, 2005; Ryan & Deci, 2000), and with emotional regulation (Suldo & Shaffer, 2007). In addition, coping resources and the efficacy of coping strategies have been associated with increased levels of well-being (Compas, Conner-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Frydenberg, 2008; Lazarus & Folkman, 1984). In particular, functional coping strategies (such as planning, active coping and finding social support) are associated with increased well-being (Lazarus & Folkman, 1984; Moos, 2002) and specifically life satisfaction (Samson & Siam, 2008).

The core variables that predict life satisfaction include positive self-esteem, extroversion and optimism, perceived control, positive social relationships and sense of meaning and purpose in life (Compton, 2005; Ryan & Deci, 2000). Positive self-esteem, considered a powerful predictor of life satisfaction, is frequently associated with a heightened capacity for creative and productive work, except in collectivistic countries where autonomy and self-assertion are less important than family and social cohesiveness (Diener & Suh, 2000; Ng et al., 2003). Perceived control or a sense of having personal control over events in life extends to factors such as intrinsic motivation and empowerment. It is seen as a person-environmental transactional process, in a complex pattern of mutual influence (Compton, 2005) and is it is relevant to subjective well-being across cultures (Diener, Oishi, Lucas & Smith, 2003). Ng et al. (2003) challenge this latter statement suggesting that it is more relevant to individualistic cultures. Extroversion describes an interest in physical and social environments external to self (Compton, 2005) and is one of most significant predictors of subjective well-being (Diener, Suh, Lucas, & Smith, 1999). Early studies have shown this to be consistent, even up to 30 years after initial testing (Costa & Mc Crae, 1986). While research does not imply that introversion is a factor associated with low levels of subjective well-being there is evidence of a predisposition in extroverts for the experience of positive emotions (Lucas, Diener, Grob, Suh, & Shao, 2000), which in turn leads to a greater likelihood that such events are encoded in memory as positive (Compton, 2005). There is evidence that this applies cross culturally (Lucas et al., 2000). Optimism is generally associated with increased feelings of happiness and satisfaction with life (Diener et al., 1999) and is linked to other predictors of well-being such as perceived control and positive social relationships. In addition, it is associated with better coping strategies and perceived health status (Compton, 2005). Positive social relationships with family and friends are considered strong predictors of subjective well-being (Compton, 2005; Diener, 2000; Diener et al., 1999) across cultures (Diener, Oishi, & Lucas, 2003) as these have two primary aspects: emotional

intimacy and social support. In particular, high quality relationships with spouses, family members or friendships are considered the strongest predictors of life satisfaction. The association between subjective well-being and positive social relationships is reciprocal. Sense of meaning and purpose to life is an important predictor of life satisfaction and is commonly associated with religious belief systems because of the additional benefits of social support and self-verification through shared values (Compton, 2005). However, there is evidence that in addition to religion, the pursuit of any goal that is meaningful enhances subjective well-being (Oishi, Diener, Suh, & Lucas, 1999).

4.4.2 The eudaimonic perspective on well-being

In the eudaimonic tradition, well-being goes beyond hedonistic conceptions (Deci & Ryan, 2008; Waterman, 2008) and includes self-realisation, fulfilment of inner potential and living according to the individuals 'true self' (Waterman, 1993, 2008). In a review by Waterman (1993), it was noted that philosophers such as Aristotle associated eudemonia with human flourishing and living a life of virtue and happiness based on a lifelong pursuit of meaningful goals. The eudaimonic perspective is considered more complex than the hedonistic perspective (Diener et al., 2003; Ryff, 1989; Strümpfer, 2006), and as a result the latter is thought to have limited scope to account for optimal functioning as it operationalises psychological well-being as subjective well-being, referring only to the individual's personal evaluation of his own life (Diener et al., 2003; Ryff, 1989).

A multi-dimensional construct was thus proposed incorporating both hedonic and eudaimonic well-being (Ryan & Deci, 2001). Ryff (1989) proposed a model incorporating six dimensions of well-being. More recently, Ryff and Singer (2008) linked this well-being model to the eudaimonic conception of well-being. The components of this model include the following and are seen as the building blocks of well-being (Ryff, 1989; Ryff & Keyes, 1995):

- 1) Self-acceptance includes a positive attitude towards self as well as acknowledgement and acceptance of the various aspects of self.
- 2) Positive relations with others include the ability to maintain trusting relationships with others and the capacity for empathy and concern for the welfare of others.

- 3) Autonomy includes regulation of behaviour, independence and the ability to resist social pressures.
- 4) Environmental mastery includes sense of mastery and competence in managing the external environment.
- 5) Purpose in life includes goals, meaning in life, and beliefs that provide purpose in life.
- 6) Personal growth includes a perception of self as in the process of growth and an openness to new experiences.

In particular, and of relevance to the nature of this research, Ryff and Keyes (1995) note that eudaimonic living, operationalised as psychological well-being, can influence physiological systems related to immunological functioning and health promotion. Well-being according to the eudaimonic perspective may thus be defined as multi-dimensional construct with many different interacting factors. These factors include personal and environmental stressors and resources, coping styles as well as demographic variables such as race, gender and socio-economic class.

Hedonistic and eudaimonic perspectives each have unique features. From the hedonistic perspective the focus is on the individual's life satisfaction judgments based on temporarily accessible information from the immediate or very recent context, while the eudaimonic perspective represents a careful evaluation of life as whole (Schwarz & Strack, 1999), associated with lasting experiences of well-being related to values and meaning. It is acknowledged that there are elements in each of these perspectives that overlap, and are common to both, as by engaging in eudaimonic pursuits, subjective well-being will occur as a result (Baxter 2010).

4.4.3 Factors moderating well-being

As with the factors that moderate coping (see section 4.3.4), there are numerous constructs which have the potential to moderate well-being. Age, gender, culture and socio-economic factors have been selected for discussion. Age and gender have specifically been selected due the developmental focus of this study as well as the fact that these are commonly cited in the literature. Culture and socio-economic factors have been included as they are associated with risks, resources and coping in children, which determine well-being (Fields &

Prinz, 1997; Frydenberg, 2008; Masten, 2001). As many of these variables are interrelated they may be applicable to more than one heading. The following is a discussion of these moderating variables:

4.4.3.1 Age and gender

In children, age also implies various developmental stages and developmental tasks and thus these will be used interchangeably. As these developmental tasks are the same for children of both genders, age and gender will be presented under one heading.

In a collaborative study between the Children's Society (UK) and the University of York (UK), of 30 000 children aged 8 to 16, investigating what affects their well-being, it was found that 9% of children have low well-being (*The Good Childhood Report, 2012*). Their findings also provided evidence that well-being declines with age in this age range, with 4% of children aged eight with low well-being and 14% of those aged 15. Gender differences were found in this study but were not explained. Family was found to be the most significant factor for well-being in children but the quality and stability of the relationship rather than the structure was found to be important as well as the level of harmony or conflict. In children, peer friendships and social identity are important especially in adolescence with 6 % of the children feeling that they did not have enough friends, a factor linked to lower than average well-being. Children who had experienced bullying were six times as likely to have low well-being than their peers (*The Good Child Report, 2012*).

In a UK based study of children aged 7.5 to 13.8 years who have a number of risks to well-being in their lives, the goal was to identify those factors which may help protect it. Small but significant gender differences were found. Girls were found to be more likely to experience slightly lower levels of, and greater declines in, their emotional well-being while boys showed lower behavioural, school and social well-being than girls, although the gender gap in social well-being narrows from mid childhood to early adolescence. Some risk factors to well-being were also found. Boys experienced greater declines in well-being in the presence of maternal alcoholism (paternal alcoholism was not included) and stressful life events, whereas girls did not. Parental feelings about their child seem to protect against declining well-being for girls with multiple risks in their lives, but did not seem to have the

same protective power for boys at high risk (Gutman, Brown, Akerman, & Obolenskaya, 2010).

Physical appearance was a factor that varies significantly with age and gender. By age 10, a quarter of children were found to be concerned with appearance, with no gender differences. By age 15, gender differences were evident with 32% of boys being concerned about appearance compared to 56% of girls. The need for autonomy and choice increases with age. Factors such as low material well-being and changes in family structure were linked to life satisfaction levels of children and the amount of choice they had in life. Sense of security is also an important factor in the developing child. Children who did not feel safe in the home or at school or with their peers had lower levels of well-being.

4.4.3.2 Culture

According to Tov and Diener (2007), correlates of well-being may differ culturally. Self-esteem, for example, has been demonstrated in the literature to be a strong predictor of life satisfaction (Compton, 2005; Ryan & Deci, 2000) yet in collectivistic cultures such as in Asia and India, little emphasis is placed on self-esteem development or self-enhancement (Brown & Kobayashi, 2002, 2003; Miller, Wang, Sandel, & Cho, 2002). In rural Taiwan for example, high self-esteem is culturally frowned upon and it is feared that this will impair the child's ability to take criticism (Miller, et al., 2002). Similarly, in Japan, where interdependence is emphasised, self-criticism is valued (Tov & Diener, 2007). In these cultures, self-esteem is de-emphasised and even considered undesirable for achieving cultural goals (Tov & Diener, 2007). It is therefore not unexpected to find that self-esteem was a stronger predictor of life satisfaction in individualistic cultures (E. Diener & M. Diener, 1995a; Tov & Diener, 2007). The strength of the association is thus predicted by the individualism (Tov & Diener, 2007) of the ethnic group or culture.

Extraversion and neuroticism were also found to be more predictive of life satisfaction in individualistic cultures such as Germany and the USA than in collectivistic cultures such as Ghana, Japan and Mexico as it may be dependent on the cultural value of the emotional experience (Tov & Diener, 2007). Similarly, autonomy is associated with higher levels of life satisfaction (Ryan & Deci, 2000). However, Oishi (2000) found that the association between life satisfaction and autonomy was stronger in individualistic countries

such as Australia and Denmark than it was in collectivistic countries such as China and Korea. Challenging this view, Ryan and Deci (2000) note that it is possible to be dependent on others and still experience autonomy if value is found in dependence. It is argued that it is the internalisation of values and the pursuit of personal goals that moderate well-being (Oishi, 2000), which may be culturally determined (Oishi & Diener, 2001).

Social relationships with others have been found to correlate strongly with well-being (Compton, 2005; Diener, 2000; Diener et al., 1999) and there is evidence that it is the experience of social relationships is culturally influenced. Oishi, Diener, Scollon and Biswas-Diener (2003) reported that Japanese participants reported less pleasant affect when alone than did Americans. While both groups reported more pleasant affect when with friends than when alone, the effect was greater for the Japanese, and this was similar for Hispanic Americans. The relative importance of relationships across cultures was found to be associated with life satisfaction and the impact of a breakdown of relationships such as divorce was also culturally influenced, as the social support in collectivistic cultures was greater sustaining well-being (Tov & Diener, 2007).

4.4.3.3 Socio-economic factors

An examination of the link between income and well-being suggested that, once household income was above the poverty line, additional increases in income were not necessarily associated with increased well-being (Snyder & Lopez, 2007; Tov & Diener, 2007). However, people in wealthy nations generally reported higher levels of subjective well-being but it is possible that the higher levels of income facilitate the pursuit of other goals (Tov & Diener, 2007). Life satisfaction was found to be more highly correlated with financial status in poor nations (E. Diener & M. Diener, 1995a; E. Diener, M. Diener & C. Diener, 1995b) based on the levels of satisfaction with life of college students from 31 nations. These studies were supported by the results of *The Good Child Report (2012)* in which children living in the poorest 20% of households had much lower life satisfaction than average but above that level there was little difference. Of interest from this study, more important for life satisfaction than the actual level of household income is the child's experience of poverty.

In a comparative study conducted by Biswas-Diener and Diener (2006), using American and Indian samples of homeless people, the majority of American respondents reported below neutral levels of life satisfaction and all reported high negative affect, while the homeless group in India reported higher levels of life satisfaction. In addition, these life satisfaction levels were in the positive range. Possible explanations provided by these authors are the attitude of the community to the poor in India as opposed to America, as well as the stronger community and social relationships.

There is evidence from cross-national comparisons of a link between children's subjective well-being and various economic indicators including GDP, income inequality and deprivation (Bradshaw, Keung, Rees, & Goswami, 2011; Bradshaw & Richardson, 2009). A comparative study of child well-being was conducted in 27 countries of the European Union and Norway and Iceland. Seven domains were included: health, subjective well-being, personal relationships, material resources, education, behaviour and risks, housing and the environment. Overall, child well-being was highest in the Netherlands and in the former Eastern bloc countries, with the exception of Slovenia. Lithuania performed in the bottom third on all domains. The United Kingdom (UK) levels were low, given its level of national wealth. The results demonstrated that well-being was associated with the material and housing circumstances but not family relationships or family structure (Bradshaw & Richardson, 2009; Bradshaw et al., 2011)

There were contradictory findings in two British studies. The first was based on an analysis of a household panel survey (Knies, 2011) conclusions of which were that family economic factors were not significantly associated with children's happiness once other factors such as family structure, number of siblings and country of residence were considered. The second found that economic factors do have a significant link with children's well-being (Rees, Pople, & Goswami, 2011). In particular, lower levels of household income, recent decreases in income and greater adult economic concerns about the future were associated with children having lower average levels of subjective well-being, even when other factors such as age, household composition and country of residence were taken into account. In considering the discrepancies in results, apart from methodological differences, Rees et al. (2011) noted that there may be other factors operating in conjunction with low levels of income, such as parental separation or parental death.

In sum, there are a number of correlates of well-being that are different across cultures but some exist universally, such as the internalisation of cultural values. Variations in the cognitive and affective experiences of well-being correspond with cultural differences in self-definition and the importance of social relationships (Tov & Diener, 2007). Tov and Diener (2007) warn against making “cultural generalizations at the sacrifice of specificity” (p. 38) and suggest that different groups within a nation may differ in their attitudes and experiences of well-being. Socio-economic factors also contribute to well-being with the relationship being stronger for impoverished communities.

4.5 CONCLUSION

The link between coping and well-being is clearly described and is theoretically and conceptually guided by interactional models of stress and coping, of which well-being is the outcome (Antonovsky, 1979; Lazarus & Folkman, 1984; Moos, 2002; Moos & Schaeffer, 1993). The construct of coping is multi-dimensional (Beutler & Moos, 2003; Beutler, Moos & Lane, 2003; Frydenberg, 2008; Kato & Pederson, 2004; Lazarus & Folkman, 1984) and is conceptualised as cognitive and behavioural efforts to manage external or internal demands appraised as exceeding the resources of the person (Lazarus & Folkman, 1984). The extent to which coping is successful is determined by the interaction of a number of factors, which include individual appraisal, available internal and external coping resources and coping strategies employed. Important for well-being is the fit between each of these factors in relation to the stressor (Hobfoll, 1998). For the child with cancer, there are numerous internal and external demands which exceed their resources, at a time when concurrent developmental processes are taking place. Apart from the impact of the diagnosis the child has to cope with the treatment and its side effects (Chesler & Barbarin, 1987), as well as the effect on its family and other systems, for example, peers (Long & Marsland, 2011). The availability of internal coping resources such as self-esteem (Basson, 2008; Pyszczynski et al., 2004), spirituality (Burnell, 2006; Wong et al., 2006), finding meaning (Fourie, 1999; Davis et al., 2003; Thuné-Boyle et al., 2006) and hope (Lazarus & Folkman, 1984; Snyder et al., 2007), as well as external coping resources such as social support (I. Sarason et al., 1990; Fife et al., 2011), information (Clarke et al. 2005; Mack & Grier, 2004) and access to material resources and facilities (Kruger, 2010), have been shown to be beneficial as protective factors, moderators of stressors and influential in the selection of coping strategies. Most commonly

used coping strategies used by children with chronic illnesses include cognitive and problem-focused coping such as cognitive reformulation as well as forms of emotion-focused coping such as acceptance, social support seeking and emotional regulation (Frydenberg, 2008).

Well-being is synonymous with wellness and health (Wissing & van der Lingen, 2003) and is not only the absence of disease, but refers to a state of complete well-being in physical, mental and social spheres (United Nations, 1948). The hedonic perspective of well-being makes reference to the individual's evaluations of subjective well-being, of which satisfaction with life, a balance between positive and negative affect (Ryan & Deci, 2008; Ryff, 1989) are components, based on immediate or recent life contexts (Schwartz & Strack, 1999). Subjective well-being also includes low levels of neuroticism (Compton, 2005). The eudaimonic perspective is considered more complex than the hedonistic perspective (Diener et al., 2003; Ryff, 1989; Strümpfer, 2006) and is associated with well-being based on longer lasting evaluations and experiences, meaning in life, self-realisation and fulfillment of inner potential, and living which is congruent with individual values (Waterman, 1993, 2008). The incorporation of both perspectives has led to the theoretical conceptualisation of well-being as a multi-dimensional construct (Ryan & Deci, 2001; Ryff, 1989; Ryff & Singer, 2008). Well-being as a construct is important for the field of psycho-oncology as the literature clearly demonstrates that children with cancer have the potential to be as well-adjusted as physically healthy children (Chesler & Barbarin, 1987; Zebrack et al., 2007) and attain well-being regardless of the improvement or deterioration of the disease.

Coping and well-being are inextricably linked and there are a number of factors that moderate each of these processes including age, gender, culture and socio-economic factors, which are interrelated. Age and gender in children have developmental associations. Self-esteem, which is considered central to well-being, showed gender differences with boys scoring higher (Birndorf, Ryan, Auinger, & Aten, 2005). Social support-seeking as a form of emotional coping was used more frequently by female adolescents (Meehan, Peirson, & Fridjhon, 2007; Wissing, Claassens, & Du Toit, 1998). Culture was found to be an important moderating variable in coping and well-being and differences in coping and well-being correlates were found between individualistic and collectivistic cultures (Tov & Diner, 2007). Common to all cultures was the internalisation of values and the pursuit of goals that moderate well-being (Oishi, 2000). Socio-economic factors moderated coping and well-being in terms of access to, and the use of, coping resources and selection of coping

strategies. Socio-economic factors had greatest impact in impoverished communities. Of specific concern and of relevance to South Africa is the statistic that 61% of children are living below the income poverty line (Statistics South Africa, 2010a). Poverty is known to be associated with lack of control over resources such as information and access to health facilities (Lake, & Reynolds, 2011; Murali, & Oyebode, 2004). In South Africa, this is also associated with limited access to sanitation, inadequate living conditions, running water and adequate nutrition (Hall, 2011). Access to adequate basic resources is essential for the care of children with cancer who require adequate facilities and nutrition in view of the nature of their illness.

An understanding of the link between coping and well-being and the knowledge that it is possible for a child with cancer to attain psychological well-being is important not only for facilitating well-being but also to identify those children who may be at risk.

In the next chapter, the research design and methodology of the study are described, with details of the participants, data gathering process, measuring instruments and data analysis procedure. Measures taken to ensure adherence with the ethical issues involved as well as the process of obtaining ethical approval are discussed.

CHAPTER 5

RESEARCH DESIGN AND METHODOLOGY

5.1 INTRODUCTION

In this chapter, the research design and methodology of this mixed method study are described, with details of the participants, data gathering process, measuring instruments and data analysis procedure. Measures taken to ensure adherence with the ethical issues involved in the research study, including the process of obtaining ethical approval and dealing with the data gathering in a responsible manner are recorded.

5.2 RESEARCH DESIGN

A mixed method sequential explanatory design was used in this study (Cresswell & Plano Clarke, 2011), consisting of two distinct phases: quantitative and qualitative. The quantitative data was gathered and analysed, using the levels of satisfaction with life and the predictors of the life satisfaction experienced by a group of participants with chronic, life threatening illnesses. This was followed by the qualitative data gathering process, involving six participants with high levels of life satisfaction.

The qualitative data was used to elaborate on and add insight into the findings of the quantitative study, with regard to the participants' experience of and factors contributing to their life satisfaction. The final phase of the study involved an integration of the qualitative and quantitative findings to enunciate how the former explains the latter. The advantage of a sequential explanatory design is that the qualitative component contributes to an in-depth understanding of the life satisfaction construct (Cresswell & Plano Clarke, 2011), but the main disadvantage is that it is time-consuming.

5.3 THE OVERARCHING AIM OF THE STUDY

The overarching aim of the study was to develop a better understanding of the construct of life satisfaction, as experienced by a group of children with chronic life threatening illnesses. The quantitative strand of the study aimed to investigate the factors that enable these children to attain a state of psychological well-being in the presence of a chronic life threatening illness and to determine the extent to which those with high and low levels of life satisfaction differ from one another. The qualitative study aimed to explore the personal experiences of a small group of these children with high levels of life satisfaction, with regard to their experiences of the illness, the resources that promote coping and the strategies they use in the coping process.

5.4 QUANTITATIVE STUDY

The quantitative study made use of a non-experimental, cross-sectional research design. More specifically, a correlational design was used to investigate the relationship between life satisfaction as criterion variable, and coping resources, hope and fortitude as predictor variables. Although the correlational design enabled the researcher to test hypotheses about the relationship between variables, it can neither make cause-effect statements nor explain the reasons why variables are related (Mitchell & Jolley, 2010). The following objectives and research hypotheses formulated for the quantitative study will be discussed.

5.4.1 Research questions, objectives and hypotheses

The research questions of the quantitative phase of the study were as follows:

- What are the levels of life satisfaction and coping resources that children with chronic, life threatening illnesses experience?
- To what extent do hope, fortitude and coping resources explain the level of life satisfaction experienced by the participants?
- How do children with low and high levels of life satisfaction differ from one another with regard to hope, fortitude and coping resources they report?

The following research objectives were formulated for the quantitative study:

- To determine the level of life satisfaction and extent of the coping resources reported by the participants.
- To describe the relationship between the predictor variables (hope, coping resources and fortitude) and life satisfaction.
- To investigate the contribution of the predictor variables (hope, coping resources and fortitude) to the variance in the life satisfaction of the participants.
- To compare a group of participants with low and high levels of life satisfaction with regard to hope, fortitude and coping resources.

The following research hypotheses were tested in the quantitative study:

- 1 H₀ The levels of fortitude, coping resources and hope of children with chronic, life threatening illnesses are not significantly related to their life satisfaction.
- 1 H₁ The levels of fortitude, coping resources and hope of children with chronic, life threatening illnesses are significantly related to their life satisfaction.
- 2 H₀ Significant differences in the average fortitude, coping resources and hope scores do not exist between children with high and low levels of life satisfaction respectively.
- 2 H₁ Significant differences in the average fortitude, coping resources and hope scores exist between children with high and low levels of life satisfaction respectively.

5.4.2 Research participants

The population of the study comprised patients between 10 and 18 years old who had been diagnosed with a long term life threatening illness. Inclusion criteria used in the selection of patients were that they had been diagnosed with cancer, leukaemia or a haematological disorder within the last two years, or were on active treatment or required current medical follow up for this diagnosed condition. They must also have been treated at private or state Haematology or Oncology centres in Bloemfontein or Durban, South Africa, been medically well enough to participate and have the consent of a parent or guardian, as well as giving their own. Exclusion criteria were patients diagnosed in the previous month, those considered medically unfit to participate in the study by their medical doctor or nurse,

those in the end stage of their illness, those with significant cognitive impairment, or those where informed parental/guardian consent, or assent in the case of children eight years and older, had not been obtained.

Due to geographical constraints, the researcher, resident in Durban, recruited patients only from Durban and Bloemfontein, namely the departments of Haematology and Oncology at the Universitas Hospital, Bloemfontein, Free State; the departments of Haematology and Oncology at the Inkosi Albert Luthuli Central Hospital, Durban, KwaZulu-Natal (KZN); and private Haematologists/Oncologists in Durban, KZN.

A total of 47 participants were recruited. In view of the relatively small population of children with chronic, life threatening illnesses, it was evident that patient availability was likely to be a major challenge in the execution of the study. Three participants were excluded. The first did not complete the questionnaire due to fatigue and was then discharged from hospital. The second was excluded as a result of an accident related brain injury following the diagnosis of cancer. The third interview was discontinued due to the participant's medical status. A total of 44 participants were thus included in the data analysis phase of the quantitative study.

5.4.2.1 Demographic characteristics of participants

5.4.2.1.1 Age

The age range of the participants was from 10 to 18 years, with a mean of 13. Figure 7 summarises the age distribution of the participants.

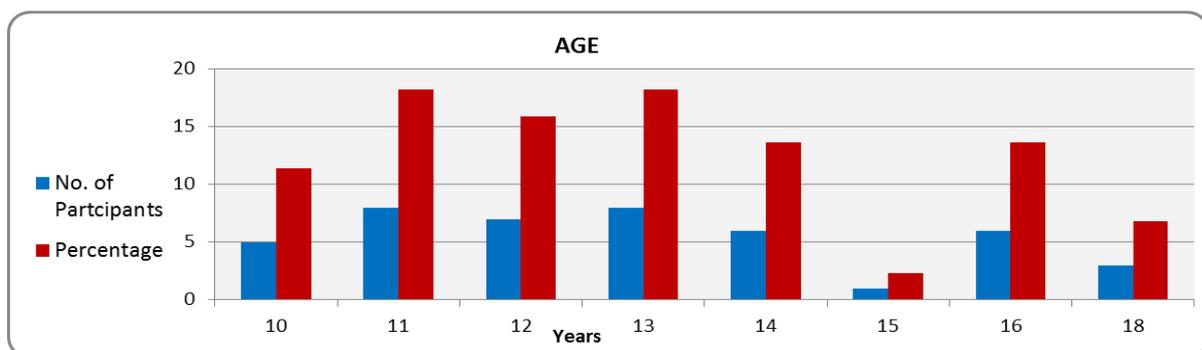


Figure 7. Age distribution of participants ($N=44$)

5.4.2.1.2 Gender

There were significantly more males (65.9%: $n=29$) than females (34.2%: $n=15$), as represented graphically in Figure 8 below.

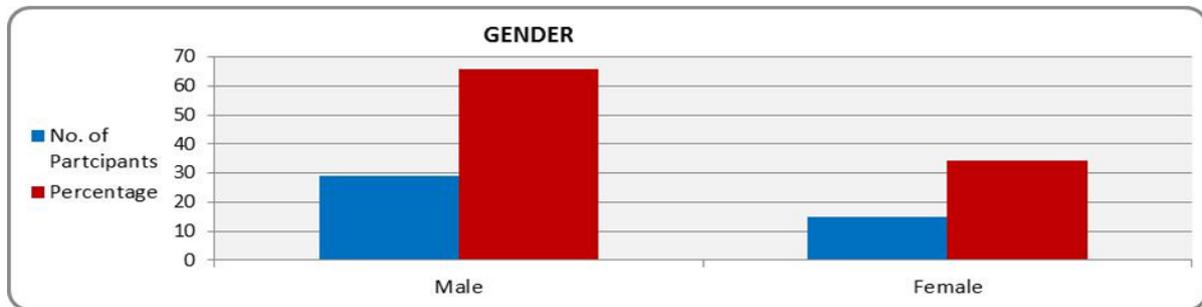


Figure 8. Gender distribution of participants

5.4.2.1.3 Racial Distribution of Participants

The majority of the participants (73%) were Black, which reflects the demographics of South Africa. The White (11%) and Indian (14%) representations were similar, with the Coloured (mixed race) group at 2%. Figure 9 represents the racial distribution of the participants:

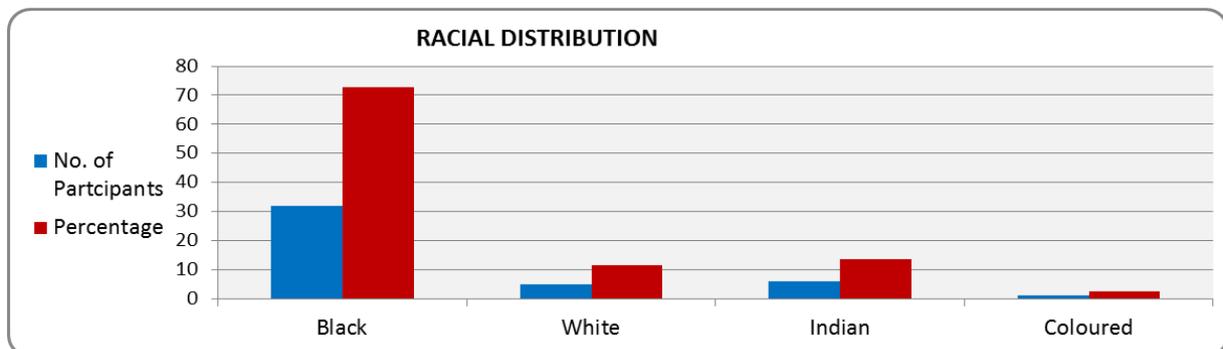


Figure 9. Racial distribution of participants

5.4.2.1.4 Educational Levels of Participants

The participants' educational levels ranged from Grades 1-3 (category 1) to Grades 11-12 (category 4) despite the age range being 10 at the lower end of the age spectrum. The primary reason that some of the children were old for their grade was disrupted schooling,

secondary to the illness and the required treatment. Figure 10 summarises the grade distribution of the participants.

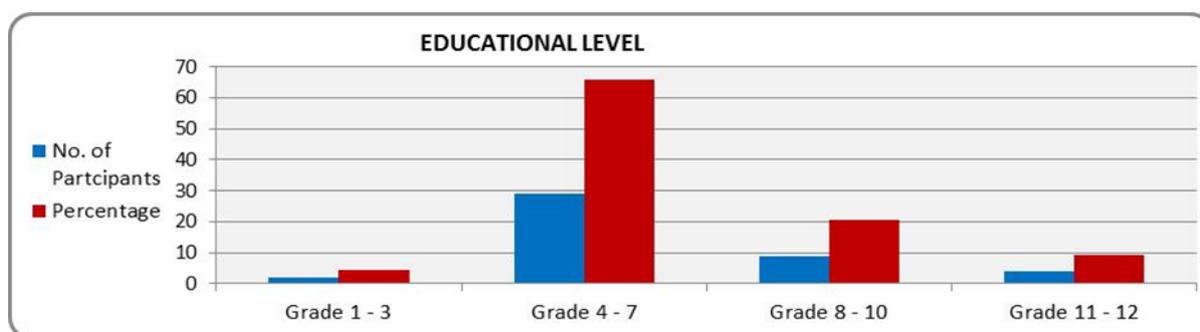


Figure 10. Educational levels of participants

5.4.2.1.5 Medical Diagnoses

The category for ‘cancer’ included all solid tumours, while the category for ‘leukaemia’ included all types of leukaemia. The category ‘blood disorders’ only included haemophilia, while the category ‘unknown’ included all children and/or parents/guardians who were unaware of the diagnosis or this information was not available due to restrictions by the hospital for accessing patient records. These participants were however being treated in a Haematology and Oncology unit for children and adolescents, and were thus included in the study. The incidence (30%) of children or guardians who did not know the diagnoses may reflect the extent to which information was provided. Figure 11 presents the distribution of participants’ diagnoses.

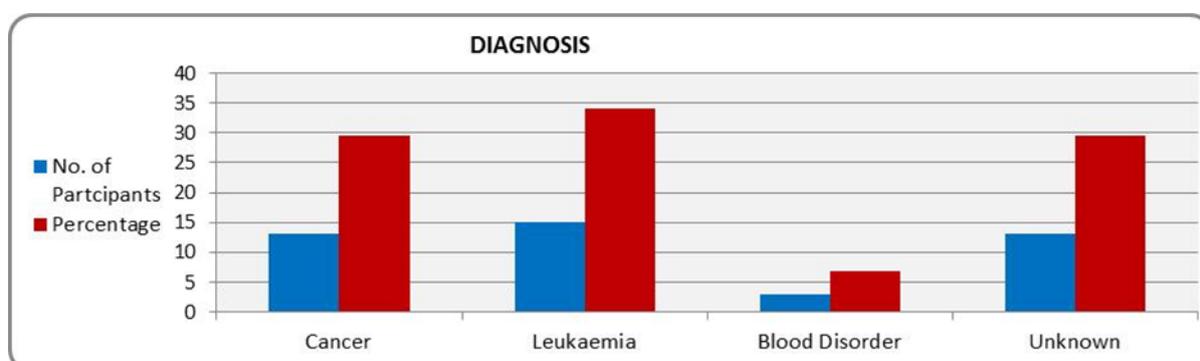


Figure 11. Medical diagnoses of participants

5.4.2.1.6 Time lapse since diagnosis

The following data provides information of the lapse in time since the initial diagnosis of the patients. For some, who had diagnoses of cancer and leukaemia, relapses explain the length of time they have been on treatment and follow up. For patients with haemophilia ($n=3$), it is a lifelong, life threatening condition and thus explains the length of time since the initial diagnosis.

The purpose of this information is to quantify the time these participants have had to live with their illnesses. The majority of the participants (61.2%) were in the first year of treatment since diagnosis. Figure 12 presents the lapse in time since initial diagnosis.

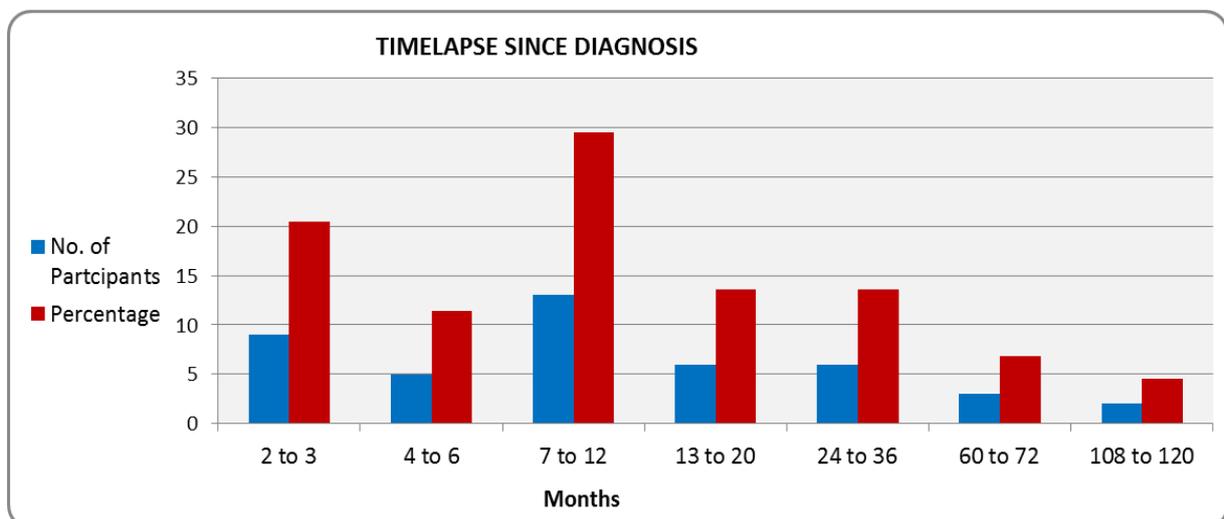


Figure 12. Lapse in time since initial diagnosis

5.4.2.1.7 Treatment Centres

The number of participants recruited from the various treatment centres is outlined, with 50% being treated at a state facility (Nkosi Albert Luthuli Central Hospital) and 31.8% at a private hospital in Durban. Therefore, 81.8% of the participants were from Durban, KZN. The remaining 18.2% were treated at a state hospital (Universitas Hospital in Bloemfontein, Free State), which has a public/private partnership and thus treats both categories of patient. Figure 13 summarises the number of participants recruited from each of the treatment centres.

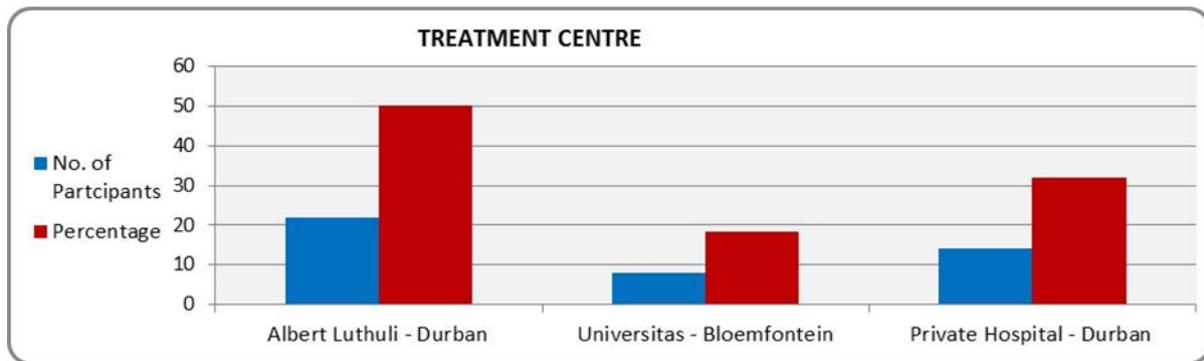


Figure 13. Recruitment of participants from state and private treatment centres

5.4.2.1.8 Parental Employment Status: Father

Data regarding the fathers' employment status suggests that 59.1% of the participants' fathers were in some form of employment, ranging from temporary and informal employment to permanent forms of employment. Of relevance and interest is the 40.9 % of missing data regarding the father's occupation. For many, the fathers were not living at home but were working away, and so saw the children infrequently or not at all. Figure 14 summarises the data regarding the fathers' employment status.

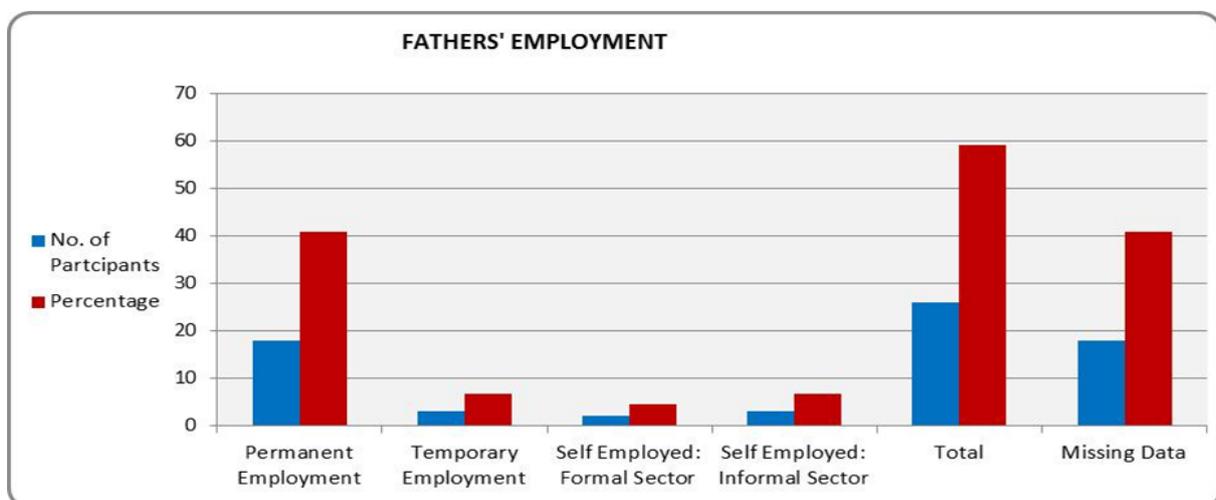


Figure 14. Parental Employment Status: Father

5.4.2.1.9 Parental Employment Status Mother

Data regarding the mothers' employment status reflects a percentage of 29.5% in permanent employment, with a further 2.3% self-employed in the formal sector. A

significantly higher percentage (56.8%) was self-employed in the informal sector (e.g., street hawking). In contrast to the percentage of missing data for the fathers, that for the mothers' employment was 6.8%. Figure 15 summarises the information for mothers' employment status.

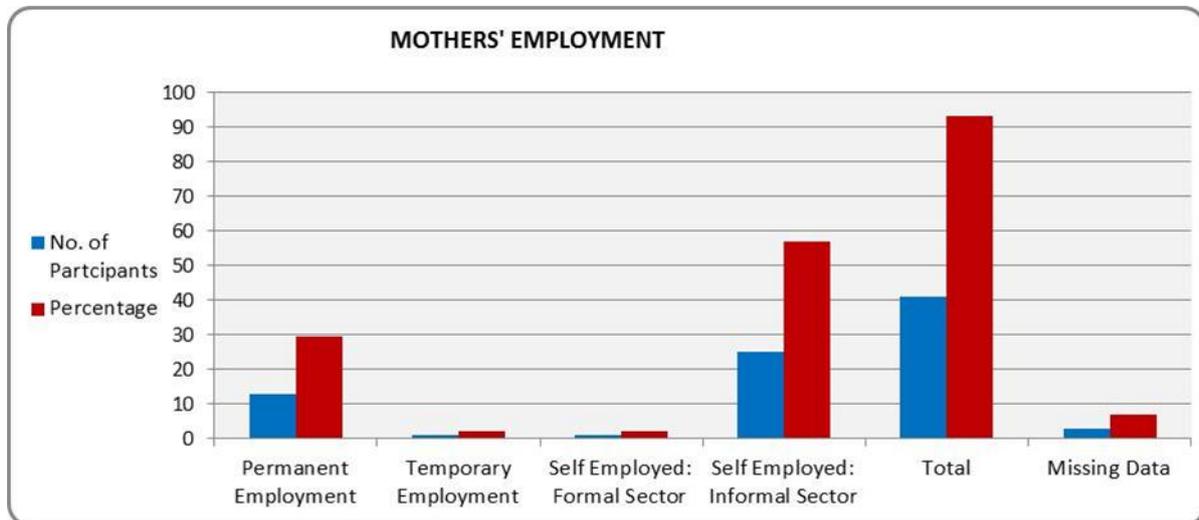


Figure 15. Parental Employment Status: Mother

The biographical questionnaire included a category 'parental marital status', however during the administration of the questionnaire it became evident that there were a number of cultural factors which determined this status and that any implications to be drawn from the category would be invalid in terms of the broader context of a family. They were thus excluded from the demographic characteristics of the study.

5.4.3 The quantitative data gathering process

A booklet of questionnaires was used to gather data on the life satisfaction, coping resources, hope and fortitude of the participants. All questionnaires were translated from English into Sotho by accredited language practitioners, into Zulu by doctoral research graduates, and into Afrikaans by an accredited language practitioner. Back translations were also made for each of the languages by a second translator.

The interviews took approximately an hour to administer and where possible were completed in one session. However, if there was evidence of fatigue the interviewers were instructed to allow the participants to complete them in two sessions. Although the

questionnaires were in the form of a booklet and it was possible for the participants to complete them independently, interviewers read the questions and recorded all answers. This decision was made in view of the varying literacy levels of the participants and to ensure standardisation of administration. The following is an outline of the data gathering process at the various treatment centres.

5.4.3.1 Universitas Hospital, Bloemfontein

As the researcher lives in the KZN area, two research assistants (Sotho and Afrikaans speaking) were recruited. They were orientated to the research and trained in the administration of the standardised questionnaires. Both were registered mental health counsellors and postgraduate students. They visited the Oncology and Haematology wards on a weekly basis, during the university terms. When patients were identified, patient assent and parent or guardian consent was obtained, and an information sheet on the study provided. When a parent or guardian was unavailable, telephonic consent was obtained and the content of the information sheet read to them. The biographical questionnaires were administered by the research assistants and returned to the researcher. All interviews took place in the hospital wards.

5.4.3.2 Inkosi Albert Luthuli Central Hospital, Durban

In order to identify potential research participants, the researcher attended a Paediatric surgery and Oncology ward round as well as the weekly Oncology follow-up clinic with the treating doctors. In addition, on a weekly basis, the researcher returned to the hospital and visited the Oncology and Haematology wards with a translator, in order to obtain participant assent, parent or guardian consent or contact details. An information sheet was provided. When a parent or guardian was unavailable, telephonic consent was obtained and the information sheet read to them. Once consent or assent had been obtained, the standardised questionnaires were administered and biographical data obtained. All of the interviews took place in the hospital wards and were conducted by the researcher.

Participants were also recruited from the CHOC (Childhood Cancer Foundation) Lodge, a step down facility for patients on treatment and well enough to be at home, but who could not be for reasons such as transport or financial difficulties. This facility was on the

hospital premises. The same procedure as for the Universitas Hospital was used to obtain assent and consent and administer questionnaires. The interviews were conducted at the CHOC Lodge by the researcher.

5.4.3.3 Private patients, Durban

Private patients in Durban were identified by their treating Haematologists or Oncologists. Once their details were obtained, contact was made with their parents or guardians and they were informed of the study. An arrangement was made to meet them at their homes or at the researcher's private practice. Assent and consent forms were completed and an information sheet provided. Biographical data was obtained and questionnaires were administered by the researcher.

The researcher is employed as a sessional psychologist for CHOC at a private hospital in Durban. During the consultations in the Oncology ward, patients were identified. The researcher returned to the ward in order to discuss the research, obtain permission and gain consent or assent, administer the questionnaires and obtain biographical data. These interviews were conducted in the wards of the private hospital. Some of the patients were interviewed in their own homes, following discharge.

5.4.4 Practical problems associated with data gathering

There were a number of practical problems encountered with data gathering. In all treatment centres, with the exception of the private hospital where the researcher was employed, there were difficulties with access. With the changeover of staff in various rotations, from security staff to matrons and nursing staff, there were challenges. Often lengthy time delays occurred, for example, security attempting to verify the identity of the researcher and translator. There were many occasions on which permission was denied as the person who could provide confirmation was not on the premises at the time.

In addition, there was little predictability in terms of being able to recruit participants or administer the questionnaires at the hospital. As administration could only take place once consent had been obtained and the majority of the children were in the state hospital without a parent or guardian, telephonic consent had to be obtained in the majority of cases. There

were frequent delays in locating a parent or guardian and, in some instances, before this could be done the patient had been discharged. There were occasions when an arrangement had been made to see these patients at the next chemotherapy cycle but they did not arrive at the hospital due to problems with transport or finance. It was also uncertain during the routine weekly visits to the hospital whether patients who were inpatients would be well enough to be interviewed.

With the patients recruited from the outpatient clinic there were a number who had travelled long distances to be at the appointment. While they were willing to be part of such research they were unable to stay for the interview as they were scheduled to be transported back by public transport and had waited for most of the day to be seen by the doctor. They were unable to schedule a follow-up appointment with the researcher for geographical reasons.

5.4.5 Measuring instruments

Self-report instruments were used to measure life satisfaction, coping resources, fortitude and hope of patients. The following self-report instruments were used:

- Satisfaction with Life Scale (Diener, Emmons, Larsen & Griffin, 1985) - (5 items).
- The Coping Resources Inventory (Hammer & Marting, 1988) - (60 items).
- The Children's Hope Scale (Snyder et al., 1991) - (6 items).
- The Fortitude Questionnaire (Pretorius, 1998) - (20 items).
- A Biographical questionnaire compiled by the researcher (14 items).

Literature suggests that an advantage to using self-report instruments is that children can provide a more accurate account of their internal feelings than parents or teachers (Barrett, Berney, & Bhate et al., 1991; Birmaher, Ryan, & Williamson, 1996; Noll, Gerhardt, & Vannata, 2003). The following is a description of the research instruments used in this study.

5.4.5.1 Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985)

The Satisfaction with Life Scale (SWL) assesses an individual's global judgment of general quality of life in order to measure the construct of life satisfaction. It is used to measure the cognitive component of subjective well-being, for all age groups (Pavot, Diener, Colvin, & Sandvik, 1991). It is a five-item scale completed on a seven-point Likert scale with a response range consisting of *1-strongly disagrees* to *7-strongly agrees*. The scores on the SWL range from 5 to 35, with scores of 20-24 considered to reflect average to high average levels of life satisfaction. Scores of 25 to 29 indicate high levels of life satisfaction with scores of 30 and above as indicating very high life satisfaction (Diener, 2006). Based on these guidelines provided by Diener (2006), a score of 25 or higher was used to select the group of children with high satisfaction with life and a score of 19 or lower with low satisfaction for life.

This measure has been found to have favourable psychometric properties. Numerous research studies have found acceptable validity and content and criterion related validity. There is evidence of convergent validity of the SWL scale with other self-reported measures of life satisfaction. In addition, there is evidence of test re-test reliability over fortnightly intervals with scores ranging between 0.54 and 0.84 (Pavot et al., 1991). Confirmation that the scale measures a single construct has been statistically determined (Lewis, Shevlin, Bunting & Joseph, 1995; Pavot et al., 1991). Pavot and Diener (1993) noted good internal consistency of the scale with alpha coefficients of 0.8 and more. This was confirmed by a study of Fife et al. (2011), which examined the relationship between life satisfaction, religious commitment and social support among American college students. They found the alpha coefficient to be 0.81. In a study of South African adolescents, Basson (2008) found an alpha coefficient of 0.71 in an ethnically diverse group of adolescents. Alpha coefficient for this study was 0.69.

This questionnaire was selected for inclusion as it measures the cognitive component of subjective well-being, it has high reliability in many language and ethnic groups and its internal consistency with both international and local participants has been demonstrated. In addition, as it has only five items and administration time is short it is suitable for children.

5.4.5.2 Coping Resources Inventory (Hammer & Marting, 1988)

The Coping Resources Inventory (CRI) was developed in response to stress research that had been directed towards the identification of variables believed to mediate between stressors and psychological and physical outcomes. The questionnaire was developed on high school and college students, and adults. According to Hammer and Marting (1988), the questionnaire was administered on subjects aged 14 to 83 years and may be used on younger subjects, although they noted the spiritual/philosophical items may be challenging. In this study this was overcome as all items were read and explained to all participants. The purpose of the CRI is to provide a measure of coping resources that are available to the individual that may prove important in mediating the stress response (Hammer & Marting, 1988). In this study the alpha coefficient of the social, cognitive, emotional and spiritual/philosophical subscales were 0.80, 0.62, 0.87 and 0.79 respectively.

The CRI is a 60-item instrument measuring resources in five domains: cognitive, social, emotional, physical and spiritual/philosophical. The following is a description of each of the subscales (Hammer & Marting, 1988):

- Cognitive: the extent to which individuals maintain a positive sense of self-worth, a positive outlook towards others and optimism about life in general.
- Social: the degree to which individuals are embedded in social networks able to provide support in times of stress.
- Emotional: the degree to which individuals are able to accept and express a range of affect.
- Physical: the degree to which individuals enact health-promoting behaviour.
- Spiritual/philosophical: the degree to which actions of individuals are guided by stable and consistent values derived from religious, familial or cultural tradition or from personal philosophy. The content domain for this scale is broader than traditional Western religious definitions of spirituality.

For each item, a four-point scale (i.e., never, sometimes, often, always) is used for participants to indicate how often they have engaged in a particular type of behaviour over the past six months, for example, "I express my feelings to close friends". Six items with

negative wording are reverse scored, before adding their points to the total score for that scale. A total resource score is calculated by adding the five individual scale scores together. The higher the scale score, the higher the resource. As the scales have a different number of items, direct comparisons among them based on raw scores is not possible, thus the raw scores are converted to standard scores. The mean for standard scores is 50 with a standard deviation of 10. Approximately 95% of individuals will have standard scores between 30 and 70. Based on these scores, high and low resources may be identified (Hammer & Marting, 1988). The questionnaire takes approximately ten minutes to administer.

The CRI has favourable psychometric properties. Alpha coefficients for the five individual domains ranged from 0.71 to 0.84. For the Total score, the alpha coefficient was 0.91, suggesting good internal consistency. The CRI was also found to show evidence of predictive, convergent, divergent, discriminant and concurrent validity (Hammer & Marting, 1988). In this study, alpha coefficients for four domains: Social, Cognitive, Emotional and Spiritual/Philosophical ranged from 0.61 for the Cognitive Scale, with the others ranging from 0.79 to 0.87.

This instrument was included in this study as coping resources are central to the stress and coping process as defined by Moos and Schaefer (1993). In addition, the psychometric properties are favourable.

5.4.5.3 Children's Hope Scale (Snyder et al., 1991)

The Children's Hope Scale is based on the premise that children are goal-directed and that their goal thoughts can be understood, according to two interrelated components:

- Agency (agency thoughts reflect the perception that children can initiate and sustain action towards a desire goal).
- Pathways (thoughts reflect the children's perceived capability to produce routes to these goals).

Hope thus reflects the combination of agentic and pathways thinking towards goals. The first general purpose of this scale was to select items tapping agency (odd numbered

items) and pathways thoughts (even numbered items) towards goals Items were selected that reflected each type of thinking.

The Children's Hope Scale was adapted from The Hope Scale (Snyder et al., 1991), which is the adult version comprising 12 items measuring the two interrelated aspects of hope. In the development of the Children's Hope Scale, seven sample groups were selected from American children aged 8 to 17 years. Two of the sample groups were children with cancer from hospitals in Kansas City and Texas. These samples were selected on the basis of the belief that illness provides a stressor that is analogous to other stressors faced by children and that hope is important in dealing with the illness (Snyder et al., 1997).

The Children's Hope Scale is a 6 item dispositional self-report index validated for use with children 8 to 16 years of age. The scale evidenced internal consistency (Cronbach alpha range 0.72 to 0.86, with a median alpha of 0.77) and was relatively stable over retesting ($r(359) = 0.71, p < 0.001$) over a one month period. In addition, the scale exhibited predictive validity ($r(100) = 0.50, p < 0.001$), discriminant validity $r(303) = 0.21, p < 0.001$; $r(66) = 0.27, p < 0.03$) and incremental validity (0.22, $p < 0.001$). No gender differences emerged in the samples. There were no racial differences found in two samples (Snyder et al., 1997). The alpha coefficient for this study for the total hope scale (agency and pathway) was 0.71.

To administer the questionnaire, it is presented to the testee who has to respond to six items. The total score is achieved by adding the response to the six items on a six point Likert scale from 1 (none of the time) to 6 (all of the time). Scores can thus range from a low score of 6 to a high score of 36 for the entire scale. The higher the score, the higher the level of hope.

This scale was selected for inclusion as hope as a construct has been associated with well-being and was thus important given the nature of this study and in particular the target population. The administration time of the scale is short and thus advantageous in terms of the age range of children.

5.4.5.4 Fortitude Scale (Pretorius, 1998)

The Fortitude Scale measures psychofortigenic factors or the construct of fortitude of a person. It measures the extent to which a person has the ability to deal with stress and manage challenging situations. Fortitude is described by Pretorius (1998) as the strength to manage stress and stay well. He proposes that this is derived from an appraisal of the self, family environment and general social support. Pretorius (2004) proposed that fortitude is the sum of the following three domains:

- Self-Appraisals: including both the global appraisal of the self as well as more specific appraisals such as mastery or competence and problem solving efficacy.
- Support Appraisals: an evaluative awareness of support from others. This includes both qualitative dimensions of support (e.g., perceived support) as well as quantitative levels of support (e.g., perceived levels of support). It also includes beliefs about the efficacy of using such support resources.
- Family Appraisals: an evaluative awareness of the family environment which includes support from the family, level of conflict and cohesiveness in the family and family values.

The 20 items of the scale are divided into three subscales (Pretorius, 2004), and can be administered individually or in groups and take less than ten minutes to complete. Questions are answered on a four-point Likert scale ranging from 1 (*does not apply*) to 4 (*applies very strongly*). One of the items is worded negatively and must be reversed before scoring. The median scores for the respective subscales are 21.33 for Self-Appraisals, 19.91 for Family-Appraisals and 16.61 for Support-Appraisals. Higher scores on the subscales reflect higher levels of stress resistance related to that specific dimension. Intercorrelations between subscales are reasonably low and therefore support the use of the three independent subscales (Pretorius, 1998, p. 217).

The scale was standardised on a group of culturally diverse South African students and has also been used in South African studies involving children and adolescents (Campbell & Pretorius, 2004; De Villiers & Van den Berg, 2012). Pretorius and Heyns (2005) reported an alpha coefficient of 0.85 for the total fortitude scale and alpha coefficients

from 0.74 to 0.82 for the respective subscales of a group of students. This testifies to a high level of internal consistency of the measure. Pretorius (1997) also reported positive findings regarding the validity of the scale. Predictive validity was established with correlations ranging between -0.27 and 0.52, indicating strong and consistent relationships between Fortitude and measures of psychological well-being and distress. Concurrent validity of the three domains of Fortitude and other measures of self, family and support was established (Pretorius & Heyns, 2005).

The reason for the use of this measure in the current study is that it provides important information on the personal resources that the children use to manage the stressful situations they experience. In addition, the measure was developed for use with diverse South African populations and that the construct of Fortitude represents the interplay of various resources, and is strongly associated with the ability to manage stressful situations. These were important considerations in the inclusion of the scale.

5.4.5.5 Biographical Questionnaire

The biographical questionnaire, consisting of 14 items, was compiled by the researcher (see Appendix D). It was based on literature about the demographic factors relevant to children with chronic, life threatening illness. It consisted of information that included items to gather information on:

- Age
- Mother tongue of participant
- Participant's gender
- Participant's level of education
- Participant's medical diagnosis
- Period of time since initial diagnosis
- Centre of treatment
- Parents' educational levels (mother and father)
- Parents' employment status (mother and father)
- Frequency of contact with significant others while in hospital and/or receiving treatment.

5.4.6 Statistical data analysis

In order to investigate the research questions and to test the research hypotheses, a number of statistical procedures were used. The SPSS computer software programme-version 17 (SPSS, 2009) was used to analyse data.

The descriptive statistics (means, standard deviations) were calculated for all the scales and subscales, followed by the calculation of Pearson Product Moment Correlations to establish the intercorrelations between the variables. In order to investigate hypothesis 1, hierarchical regression analysis was used. In order to investigate hypothesis 2, the Mann-Whitney U Test was used, comparing the two independent groups (high and low satisfaction with life) in terms of coping, fortitude and hope variables. As this involved a small number of participants, this non-parametric test was selected.

The criteria for the significance of results were at the 5% and 1% level of confidence. The practical significance of findings was also investigated by calculating the effect size of statistically significant results (Steyn, 1999). According to Cohen (Steyn, 1999), the following guideline values can be used to determine the significance of the effect size for regression analysis (f^2): 0.1 - small effect, 0.25 - medium effect and 0.4 - large effect. The following guideline values (r) were used in the Mann Whitney U test to determine effect size: 0.1 - small effect, 0.3 - medium effect and 0.5 - large effect. Effect sizes were only shown for statistically significant results.

5.5 QUALITATIVE STUDY

The qualitative phase of the study was executed after the analyses of the quantitative data. The qualitative study involved an exploration of the personal experiences of six children with life threatening illnesses. Each was identified as reporting high scores on the Satisfaction with Life Scale, which was used as the criterion variable reflecting psychological well-being in the current study. The aims and objectives of the qualitative study, the characteristics of the six participants as well as the interviewing process are discussed in this section. The section on the qualitative component of the study is concluded with a discussion of the procedures followed in the qualitative data analysis.

5.5.1 Aims and goals of the study

The primary aims of the qualitative interviews were:

- To understand how the participant experienced living with a long term life threatening illness
- To explore the impact of the illness on the individual child in terms of daily living
- To investigate the impact of the illness on systems such as family (immediate and extended) peers, community and education
- To identify the coping strategies used and coping resources available to the individual participants, to enable coping.

5.5.2 Research design

The qualitative component of this mixed method study made use of an interpretive, phenomenological approach to describe the lived experiences of the group of participants. Phenomenology contributes to a deeper understanding of the phenomenon (Starks & Trinidad, 2007).

5.5.3 Research participants

The qualitative interviews were conducted with six participants who were identified as falling within the category of high satisfaction with life (a score of 25 and above) on the Satisfaction with Life Scale (SWL). Participants included four males and two females ranging in age from 12 to 17, with a mean age of 14. Race distribution of the participants included one White, one Asian, and four Black children, which is consistent with the racial distribution of the total group in the country. Four of the participants were treated at a private hospital and two at a state hospital. Table 1 summarises participant information and includes their Satisfaction with Life scores.

Table 1

Summary of Participant's Information – Qualitative Interviews

	Gender	Age	State/ Private hospital	Race	Satisfaction with life scores
P1	Female	12	Private	White	33
P2	Male	16	Private	Asian	25
P3	Male	12	Private	Black	27
P4	Female	12	State	Black	28
P5	Male	15	Private	Black	25
P6	Male	17	State	Black	25

5.5.4 Data gathering process

Potential participants for the qualitative interviews were identified by their scores on the Satisfaction with Life Scale during the quantitative component of the study. Contact was made with these participants and their parents or guardians and they were informed of the purpose and nature of the qualitative interviews. Once permission was obtained to conduct the interviews from both parents or guardians, as well as the participants, a time was arranged for the interview. Five out of six interviews took place in the hospital wards as this was convenient for the families and two of the participants lived far from the treatment centre. One of the participants was interviewed at the researcher's practice, which was also hospital-based.

5.5.5 Interview process: semi-structured interview process

The interviews took place with the researcher and translator present, with the exception of participants 1 and 2 who were English first language speakers. The interviews were completed in sixty to ninety minutes. The initial phase of the interview involved rapport-building, which Neuman (2003) notes is important for facilitating communication and trust. A few questions of general interest were asked to stimulate discussion for this

purpose, and then the researcher oriented the interview towards the research and its purpose, as well as the interview format. Neuman (2003) emphasises that social research must be normalised by helping participants to feel that the process is not threatening but predictable and normal. Permission was requested for the interviews to be recorded.

A semi-structured questionnaire was used, compiled by the researcher (Appendix E). According to Santiago (2009), semi-structured interviews provide an opportunity to explore participant responses by asking for clarification or additional information, especially when investigating a topic that is very personal. Benefits of a semi-structured interview include the ability to gain rapport and participants' trust, as well as a deeper understanding of responses. A disadvantage of using this style is that data sets obtained are larger than those with structured interviews.

The themes around which the interview was structured included the child's experience of the **impact** of cancer and treatment, the **resources** that were available and the **coping strategies** used to deal with the illness.

5.5.6 Methods of data analysis

Interviews were analysed using thematic content analysis, a method that facilitated systematic collation of explicit themes (Neuman, 2003). This involved transcribing the interviews verbatim and incorporating notes made during the interviews. The transcripts were then studied to familiarise the researcher with the content of the information. They were printed, read and re-read line by line. A sifting process then took place and broad categories were employed to establish the elements of the meaning-generating themes using exact words from all participants. After careful examination of the data and exhausting the capacities of all of the categories, recurrent themes were grouped into categories and simplified. The employment of this method was advantageous as it generated categories based on the current research instead of allocating data into predetermined categories (Jithoo, 2010), with the exception of broad categories of stressors, resources and coping strategies as outlined by Moos' model (Moos & Schaefer, 1993), which is the guiding framework for this study.

The trustworthiness of the common themes extracted and described was improved with a review and discussion of the responses with an independent reviewer (the research supervisor) who worked through the same responses. This allowed for the correction of any misrepresentations of the information.

5.6 ETHICAL CONSIDERATIONS

The sensitive nature of the diagnosis and illness of the children, as well as the potentially invasive nature of the questions asked in the qualitative strand of the study, required ethical approval from the Medical Ethics Committee of the Faculty of Health Sciences, University of the Free State. The process of obtaining ethical approval is discussed first, followed by a discussion of the ethical guidelines adhered to in the execution of the study.

A letter of request was sent to the Head: Department of Paediatrics and representation was made to the Heads of the Departments of Haematology and Oncology (Universitas Hospital - Bloemfontein, Free State). A letter granting permission was received (February 2007) on condition that permission was obtained from the Clinical Head of the Free State Department of Health. An application was made to the Clinical Head: Department of Health, Free State Province (April 2007) to conduct research at the Universitas Hospital. Permission was granted on condition that approval was obtained from the Ethics Committee. Application was made to the Ethics Committee: Faculty of Health Sciences- University of Free State to conduct the research at the Universitas Hospital. Approval was granted (May 2007).

In order to collect data from the Inkosi Albert Luthuli Central Hospital in Durban, permission was required from the Department of Health, KZN, in addition to the ethical approval from the Department of Ethics, Faculty of Health Sciences, and University of Free State. Approval was granted 8 July 2009. A letter was circulated to Oncologists/Haematologists in the private sector in Durban informing them of the study and requesting permission to identify their patients who would meet the inclusion criteria. With patient assent and guardian consent, contact was made with these patients. Furthermore, permission was obtained from Oncologists/Haematologists (Heads of Departments) at the

Albert Luthuli hospital in Durban, (with proof of Ethical approval and Department of Health approval), informing them of the study and requesting permission to interview patients on their wards.

All ethical criteria as outlined by the Medical Ethics Committee at University of Free State were met and permission was obtained from all relevant authorities, including the Department of Health, individual hospitals and relevant departmental heads. Consent was obtained from the parents and legal guardians of the participants, and when unavailable due to geographic distance, telephonic permission was obtained following a full explanation of the study and participants' rights. Assent was obtained from all research participants. All questionnaires were translated into their mother tongue and a translator was used when necessary, as the researcher was English speaking. A hand-out was given to all participants and their parents or guardians, informing them of the purpose of the study and that participation was voluntary. Where not available, this was read to them telephonically.

Counselling was offered, free of charge, to research participants and/or their parents or guardians should they be in need of such services or should they request therapeutic support, in return for their participation in the study. For participants living in the Free State, counselling was offered at the Department of Psychology, University of Free State and was provided by Psychology Masters' students. All students were under the supervision of a registered psychologist who specialises in child psychology. For participants living in KZN, counselling was offered by the researcher, who is a full time practising Educational Psychologist in the Durban area. Finally, all research data was stored according to the relevant ethical guidelines.

5.7 CONCLUSION

In this chapter the research design and methodology of this mixed method study were detailed, as well as the overarching aims and objectives. The research questions were outlined as well as the data gathering processes for both quantitative and qualitative strands of the study. Ethical considerations were described. In the next chapter the results and findings of the quantitative and qualitative components of this study will be presented and discussed.

CHAPTER 6

RESULTS AND DISCUSSION

6.1 INTRODUCTION

In this chapter the research findings of the quantitative study are reported first, followed by a presentation of the qualitative research findings. The chapter is concluded by an integration (triangulation) of the quantitative and qualitative findings.

6.2 QUANTITATIVE RESULTS

The presentation of the quantitative results includes the reliability coefficients, descriptive statistics, intercorrelations between the level of satisfaction with life and the coping resource variables, and a hierarchical regression analysis. This section of the quantitative results is concluded with the results of the significance of differences in coping resources between children with high and low levels of life satisfaction.

6.2.1 Reliability Coefficients and Descriptive statistics

The alpha coefficients will be discussed followed by a discussion of the means and standard deviations for the investigated group. The internal consistency of the items for each scale/subscale was computed using Chronbach alpha reliability indices. The results are presented in Table 2.

Table 2

Alpha-coefficients for subscales of measuring instruments

Subscales of measuring instruments	α coefficient
Satisfaction with Life scale	0.69
Coping Resources Inventory:	
Social	0.80
Cognitive	0.62
Emotional	0.87
Spiritual/Philosophical	0.79
Physical	0.37
Fortitude Scale:	
Family Appraisals	0.81
Self Appraisals	0.47
Support Appraisals	0.78
Hope Scale:	
Agency	0.53
Pathway	0.47
Total (Agency and Pathway)	0.71

According to Nunnally and Bernstein (1994) coefficients of 0.70 and above are considered acceptable for non-cognitive constructs. From Table 2, it is evident that the two subscales of the Hope Scale did not deliver reliable coefficients nor did the Physical subscale of the Coping Resources Inventory and the Self Appraisals subscale of the Fortitude Scale show acceptable internal consistency. As a result, measures with these subscales were excluded from further analyses. After the exclusion of these subscales, the remaining two subscales of the Fortitude Scale (Family Appraisals and Support Appraisals), the four remaining subscales of the Coping Resources Inventory (Social, Cognitive, Emotional and Spiritual/Philosophical) as well as the total score of the Hope Scale were used as predictor variables, with Satisfaction with Life as the criterion variable.

Prior to testing the formulated research hypotheses (see Chapter 5, section 5.4.1), the descriptive statistics (averages, standard deviations and intercorrelations) were calculated for all variables. The results for the total group ($N=44$) are presented in Table 3.

Table 3

Averages and standard deviations for the total investigated group

Variables	\bar{X}	SD
Satisfaction with Life scale	23.18	6.62
Coping Resources Inventory		
Social	38.75	6.78
Cognitive	28.70	4.03
Emotional	46.80	9.27
Spiritual/ Philosophical	33.59	5.63
Fortitude Scale		
Family Appraisals	22.14	3.91
Support Appraisals	18.75	3.47
Hope Scale – Total	24.52	5.86

The mean score on the Satisfaction with Life Scale was 23.18 with a standard deviation (SD) of 6.62 for the current study. According to Pavot and Diener (1993), a score of 20 is the neutral point on the scale (suggesting that the participant is neither satisfied nor dissatisfied). The mean life satisfaction scores across their samples ranged from 23 to 28, representing slightly satisfied to satisfied levels of life satisfaction. The current results for the Satisfaction with Life Scale correlated well with adolescent studies from England (Bach, 2011) and South Africa (Basson, 2008). The mean was 23.67 with a standard deviation of 6.26 in Bach's (2011) study. Basson (2008) found the mean score to be 24.84 with a standard deviation of 6.07. Consistent with these studies, the results in this study suggest slightly above average levels of life satisfaction.

The mean scores and standard deviations for the four subscales of the Coping Resources Inventory correlated well with the original scores provided by Hammer and Marting (1988) on American participants. As the four subscales have different numbers of items attributed to them, direct comparisons among scales based on raw scores was not possible and therefore these scores were converted into standard scores, with a mean of 50 and a standard deviation of 10. According to Hammer and Marting (1988), approximately 95% of individuals will have standard scores that fall between 30 and 70. Scores below 30 are therefore assumed to be below average while scores above 70 are considered above average.

Table 4 provides a comparison of the means and standard deviations for the current investigated group, with groups of students from Hammer and Marting's study (1988): one group of high school students and two groups of students with perceived stress (ill and healthy).

Table 4

Comparison of means and standard deviations of healthy and ill students and investigated group-Coping Resources Inventory

Coping Resources Inventory	A		B		C		D	
	\bar{X}	<i>SD</i>	\bar{X}	<i>SD</i>	\bar{X}	<i>SD</i>	\bar{X}	<i>SD</i>
Social	38.75	6.78	37.20	5.93	42.69	5.9	40.78	5.0
Cognitive	28.70	4.03	25.56	4.44	28.77	4.3	26.51	4.3
Emotional	46.80	9.27	44.10	7.53	46.83	6.3	44.26	6.6
Spiritual/Philosophical	33.59	5.63	29.31	5.39	32.95	5.7	29.96	5.2

- A Current investigated group
- B High school students
- C Students with perceived stress (healthy group)
- D Students with perceived stress (ill group)

The above results compare well with the results of Hammer and Marting (1988). It is noteworthy that the participants' scores from this study correlated best with the healthy group with perceived stress on three of the subscales (Cognitive, Emotional and Spiritual/Philosophical) followed by the correlation with the ill group with perceived stress rather than high school students. The exception to this was the correlation for the Social resource subscale which correlated best with high school students. This is likely to reflect a developmental factor where social needs remain high at this stage of development.

A search was conducted (06/06/12) using the EBSCOhost database (Academic Search Complete, Africa-Wide Information, PsycARTICLES and PsychINFO) to identify South African studies using the Coping Resources Inventory. Of the 23 studies identified, all were adult studies. Only one study was conducted with cancer patients (Cairns, 2001). The means and standard deviations of this group of adult cancer patients on the four subscales for this study were as follows: Social resource subscale (mean 55.88, SD: 10.68); Cognitive resource subscale (mean 54.21, SD: 9.73); Emotional resource subscale (mean 54.71, SD: 9.08) and Spiritual/Philosophical resource subscale (mean 57.79, SD: 7.56). Possible reasons for the differences in mean scores between this study and Cairns' study (2001) for the resource subscales may be that Cairns' group ($N=34$) was largely a mature group (40-69 years), predominantly female, 76% of the group were married and 68 % had education ranging from Grade 12 to tertiary education. Cairns (2001) notes the positive benefits and protective factors of females having stronger support networks, being in a relationship, and education as a cognitive resource and its impact on health behaviours. In addition to these, a primary reason for these differences in scores may be developmental, particularly in terms of cognitive, social and emotional development.

The mean scores and standard deviations for the two subscales of the Fortitude Scale of the current group of participants were 22.14 (SD: 3.91) for the Family Appraisals subscale and 18.75 (SD: 3.47) for the Support Appraisals subscale. In a South African study of undergraduate students (Pretorius & Heyns, 2005), the means and standard deviations were 19.91 (SD: 4.81) for the Family Appraisals and 16.61 (SD: 3.94) for Support Appraisals. In a study specific to 12 year old ($N=161$) South African children (de Villiers & van den Berg, 2012), who were exposed to a resiliency programme, the means and standard deviations (pre implementation) were 22.9 (SD: 3.8) for the Family Appraisals subscale and 19.4 (SD: 3.5)

for the Support Appraisals subscale. These suggest good correlations between the results, specifically with regards to the child study.

The total score for the Hope Scale was used to calculate the mean and standard deviation. According to Snyder et al. (1997), both components (Agency and Pathways) must be assessed together to obtain an overall sense of a child's hope. The mean and standard deviation of the current participants using the Total score were 24.52 with a standard deviation of 5.86. In the original data of Snyder et al. (1997), using 91 American children of both genders (aged 9-17) with arthritis, sickle cell anaemia and cancer, the mean and standard deviation were 25.93 (SD:5.23). Snyder et al. (1997) also used children of both genders with cancer (aged 8-16). The mean was 25.84 and standard deviation 5.01. In a South African study (Pretorius, 2003) investigating the relationship between Hope, Self Esteem and Coping behaviours of 10-12 year old children of both genders ($N=461$), the mean and standard deviation for the Total Hope score were 25.95 (SD: 4.80). The current study correlated well with the original data of Snyder, as well as with the South African study.

In sum, based on the above results, the means and standard deviations for the selected measuring instruments showed good correlations with other studies both locally and internationally, with the exception of a single South African adult cancer study using the Coping Resources Inventory. It was however concluded that the discrepancy in scores was likely to be secondary to developmental factors.

6.2.2 Intercorrelations

The relationship between the predictor variables (coping resources and strategies) and the criterion variable (satisfaction with life), as well as between the different predictor variables, was investigated using the Pearson Product Moment Correlation Coefficient.

Due to the small sample size, the 1% ($p \leq 0.01$) and 5% ($p \leq 0.05$) levels of significance were used. In addition, the practical significance of statistically significant findings was also considered by using effect sizes (Steyn, 1999). A cut off point of 0.5 (large effect) was set for the practical significance of correlation coefficients (Cohen, 1988). Intercorrelations with a practical significance of $r > 0.3$ indicate a medium effect size and $r > 0.5$ indicates a large effect size (Steyn, 1999). All of the statistically significant

intercorrelations were also practically significant, with at least medium effect size. The results are presented in Table 5.

Table 5

Intercorrelations between predictor variables and the criterion variable (N = 44)

Variables	CS	CC	CE	CP	FF	FS	HP
Satisfaction with Life Scale	0.29	0.35*	0.28	0.23	0.27	0.49**	0.47**
Coping Resources Inventory							
Coping: Social (CS)	-	0.52**	0.69**	0.41**	0.29	0.47**	0.40**
Coping: Cognitive (CC)		-	0.51**	0.53**	0.36*	0.33*	0.29
Coping: Emotional (CE)			-	0.59**	0.24	0.29	0.41**
Coping: Spiritual/Philosophical (CP)				-	0.34*	0.17	0.34*
Fortitude Scale							
Fortitude: Family Appraisals (FF)					-	0.47**	0.12
Fortitude: Support Appraisals (FS)						-	0.29
Hope Scale (HP)							-

** $p \leq 0, 01$

Medium effect size > 0.3

* $p \leq 0, 05$

Large effect size > 0.5

From Table 5, it can be inferred that the following three variables correlate significantly with satisfaction with life: hope ($p \leq 0.01$), social support ($p \leq 0.01$) and cognitive coping ($p \leq 0.05$). Each of these significant correlations is a positive correlation indicating that higher levels of social support, cognitive coping and hope are associated with higher levels of satisfaction with life. All of the intercorrelations between the coping resource subscales are statistically significant at the 1% level of significance with a large effect size, with the exception of the intercorrelation between Coping resource (Social) and Coping resource (Spiritual/Philosophical), which had a medium effect size. This indicates that there is a strong interdependence between the different coping resources.

In terms of the two Fortitude subscales, the intercorrelation between Family Appraisals (FS) and Support Appraisals (FF) also displayed a strong relationship at the 1% level of statistical significance, with a medium effect size. The Hope Scale correlated significantly with the Social (CS) and Emotional (CE) coping resources at the 1% level of significance, with medium effect size, as well as with the Spiritual/Philosophical (CP) resources at the 5% level of significance and medium effect size. This supports the literature that reflects the interconnectedness of resources. For example, social support (particularly family) serves as a resource which facilitates the child's sense of security and hope (Kruger, 2010). Conversely, people with higher levels of hope are found to have stronger social networks and thus cope better with stress (Snyder, 2000). Hope has been shown to be particularly relevant for children with chronic illnesses (Engel & Melamed, 2002; Moos, 2002; Shephard & Mahon, 2002). Fortitude is also linked to appraisals of family support and general social support (Pretorius 2004, Pretorius & Heyns, 2005). Hope is also considered a significant and unique predictor of cognitive coping (Snyder et al., 1991) such as increased problem solving (Snyder & Dinoff, 1999). The link between social support, coping and higher levels of hope are established (Frydenberg, 2008; Moos & Schaefer, 1986). In particular, seeking social support, especially among female adolescents, was reported to reduce feelings of hopelessness (Meehan, Peirson, & Fridjhon, 2007; Wissing, Claassens, & Du Toit, 1998). This follows that the higher the level of hope, the more frequent use of cognitive coping and the higher level of social support, the higher the satisfaction with life. This is consistent with research findings that hope and social support play an important role in explaining the variance in satisfaction with life in children with chronic life threatening illnesses and that the use of cognitive coping strategies promotes satisfaction with life. These results are consistent with a South African study (Basson, 2008) who also found a significant

positive correlation at the 1% level of significance between the criterion (Satisfaction with life) and hope. In addition, she found statistically significant correlations at the 1% level between Satisfaction with Life and problem- and emotion-focused coping.

In sum, the intercorrelations were statistically significant with at least medium effect size and suggest that higher levels of social support, cognitive coping and hope are associated with higher levels of satisfaction with life. A strong interdependence between the different coping resources was also suggested. It is however noted that the intercorrelations only reflect the relationship between variables and are not suggesting a causal relationship. It is further noted that the variables have a bi-directional relationship. Just as each variable can contribute to satisfaction with life, a higher level of satisfaction with life can contribute to higher levels of hope, cognitive coping and factors surrounding social support.

6.2.3 Hierarchical Regression Analysis

In order to investigate the first hypothesis which follows, a hierarchical regression analysis was conducted.

Hypothesis 1: H_0 . The levels of fortitude, coping and hope of children with chronic, life threatening illness are not significantly related to their life satisfaction

Hypothesis 1: H_1 . The levels of fortitude, coping and hope of children with chronic, life threatening illness are significantly related to their life satisfaction.

The results of the hierarchical regression analysis are presented in Table 6.

Table 6

The contribution of the different variables to R²

Variables analysed	R²	Contribution to R²: full minus reduced model	F	f²
1. [Hope]+[Fortitude]+[Cope]	0.389	1-6=0.028	0.412	-
2. [Hope]+[Fortitude]+social	0.364	2-6=0.003	0.184	-
3. [Hope]+[Fortitude]+cognitive	0.375	3-6=0.014	0.874	-
4. [Hope]+[Fortitude]+emotional	0.361	4-6=0.000	-	-
5. [Hope]+[Fortitude]+spiritual	0.362	5-6=0.001	0.061	-
6. [Hope]+[Fortitude]	0.361			
7. [Hope]+[Cope]+[Fortitude]	0.389	7-10=0.116	3.417*	0.19
8. [Hope]+[Cope]+Family support	0.299	8-10=0.026	1.372	-
9. [Hope]+[Cope]+Social support	0.388	9-10=0.115	6.953*	0.19
10. [Hope]+[Cope]	0.273			
11. [Cope]+[Fortitude]+[Hope]	0.389	11-12=0.099	5.833*	0.16
12. [Cope]+[Fortitude]	0.290			

[] = indicates set variables

** $p \leq 0.01$

* $p \leq 0.05$

f² = effect size

Small effect size > 0.1

Medium effect size > 0.25

Large effect size > 0.4

The results in Table 6 show that together the predictor variables explained 38.9% (R²=0.389) of the variance in life satisfaction in children with life threatening illnesses. This calculated R² value is significant at the 1% level of significance [$F_{7, 36}=3.268$; $p < 0.009$].

The four subscales of the Coping Resources Inventory (combined) explained 2.8 % of the variance in life satisfaction in the same group of participants. From Table 6, it is evident that the subscales individually or combined did not make a contribution to the variance in life satisfaction.

The two Fortitude subscales together (Family Appraisals and Support Appraisals) explained 11.6% of the variance in life satisfaction. This finding is significant at the 5% level of significance [$F_{(3; 36)}=3.417$]. The corresponding f^2 -value (0.19) is indicative of a result with a moderate practical value. When the subscales of the Fortitude Scale were analysed separately, the Support Appraisals subscale explained 11.5% of the variance in satisfaction with life which was significant at the 5% level of significance. The corresponding effect size was moderate. Table 5 has already demonstrated that the direction of the correlation between social support and satisfaction with life is positive.

The Hope Scale made a unique contribution of 9.9% of the variance in satisfaction with life of the participants at the 5% level of significance [$F_{(1; 36)}=5.833$]. The corresponding f^2 -value (0.16) was indicative of moderate practical significance. In Table 4, a positive correlation between hope and life satisfaction had been demonstrated. In view of the above findings and discussion, the alternative hypothesis (H1) is partially accepted. The link between hope and life satisfaction is supported in the literature (Basson, 2008, Snyder, 2000) as hope correlates negatively with depression, is predictive of physical and mental health as well as health promoting behaviours. Hopeful people are happier and healthier; they cope better with stress and have better social support networks (Snyder, 2000).

6.2.4 Significance of differences between groups with high and low life satisfaction

In order to investigate hypothesis 2, the Mann Whitney U test (Howell, 2007) was used.

- Hypothesis 2: H_0 Significant differences in the average fortitude, coping and hope scores do not exist between children with high and low levels of well-being respectively.
- Hypothesis 2: H_1 Significant differences in the average fortitude, coping and hope scores exist between children with high and low levels of well-being respectively.

In order to test this hypothesis, the significance of differences in children with high and low satisfaction with life, was determined. In view of the small number of participants who complied with the selection criteria, a non parametric test was used (Mann Whitney U test) to compare the two independent groups with regard to coping, fortitude and hope variables. See Table 7 for results.

Table 7

Mann-Whitney U results on the scales for the two groups

Criterion variable	Satisfaction with Life				U-value +	p	r
	Low (n=13)		High (n=18)				
	\bar{X}	s	\bar{X}	S			
Coping Resources Inventory							
Coping: Social	37.77	7.10	39.72	5.97	96.50	0.41	-
Coping: Cognitive	27.69	5.17	29.39	3.55	101.50	0.53	-
Coping: Emotional	44.92	9.12	49.33	7.83	81.00	0.15	-
Coping: Spiritual	33.38	5.71	34.44	5.76	107.00	0.69	-
Fortitude Scale							
Fortitude:Family Appraisals	21.23	5.45	23.50	3.13	89.00	0.26	-
Fortitude:Support Appraisals	16.69	4.13	20.56	2.46	43.50	0.00	0.53
Hope Scale							
Hope – total score	22.00	4.49	27.11	5.55	56.50	0.01	0.44

+ Corrected for equal rank orders

* Critical value for two- sided U-test at 5% level of significance = 67. 00

* Critical value for two-sided U- test at 1% level of significance = 53. 00

f^2 = effect size

Small effect size > 0.1

Medium effect size > 0.3

Large effect size > 0.5

It is apparent that the average scores for the Support Appraisals subscale of the Fortitude Scale, as well as the total score of the Hope Scale, differed significantly at the 1% and 5% levels of significance, respectively. Each of these results showed large effect sizes that indicated strong practical significance.

The information in Table 7 shows that the participants with low satisfaction with life scores differed significantly from those with high satisfaction with life, with regard to their sense of hope and their appraisal of social support. Findings in the literature support the link between social support and hope (Snyder, 2000; Wells, 2010) especially in cancer patients (Moore, 2002).

Based on the above findings, the alternative hypothesis (H 2) was partially accepted because the children did not differ significantly with regard to their scores on the Coping Resources Inventory.

The qualitative results will be discussed next. This discussion will be followed by an integration of the quantitative and qualitative results.

6.3 QUALITATIVE RESULTS

Thematic content analysis was carried out of the participants' narratives in order to explore relevant themes related to their illness experiences. As Moos' model (Moos & Schaefer, 1993, 2002) is the guiding framework for this study, the themes were selected in terms of a stressor which represents the impact of cancer and the cancer experience, moderating factors such as coping resources and modes of coping (coping strategies), and the outcome which is psychological well-being. As many of these themes interrelate, at times these will be discussed under one or more of the headings.

The following themes were identified:

6.3.1 Theme 1: Cancer as a stressor: Impact of diagnosis and treatment

In this section, the main subthemes that emerged from the participants' responses included: the emotional impact of cancer, the disruption to the daily lives of the participants, the impact on significant relationships and the impact on education and intellectual stimulation.

6.3.1.1 The emotional impact of cancer

a) Sense of confusion, powerlessness and uncertainty

A sense of confusion, powerlessness and uncertainty is commonly described by patients and families from the time a diagnosis is made. The period of being unwell, even prior to the diagnosis, was a time of uncertainty for many of the participants.

Participant 1 (P1) described her experience before she was diagnosed:

I didn't know what to think. I'd been sick and the worst thing about it was not knowing what was wrong ... At the end of Grade 3, I kept on getting sick. One of the doctors said I am acting, (that) there is nothing wrong with me and that my mother is neurotic". (P1)

At a time of uncertainty, the response of the medical professional in this case, rather than being a resource, was experienced as a stressor. Her response confirms this. She described a different experience once referred to another professional who became a resource to her and her family:

“Then he (our paediatrician) referred me to Dr X. She looked at me for five minutes, sent me outside. The next day we went for a bone marrow biopsy and I was 95% leukaemia”. She described what it was like to finally receive a diagnosis: “a big relief”.

The diagnosis in this case was a validation of her illness experience whilst the dismissal of her symptoms negated her illness experience. The patient-doctor relationship and the perceived power distance between patient and professional played a significant role in this experience.

The emotional responses of the participants to the diagnosis of cancer reflected the range of emotions they experienced. Confusion (P2), anger (P3; P4), sadness (P5) and fear (P3) were the most common. The following selection of responses reflects these.

“Mostly confusion. (asking) why does this happen to you? Mostly questions”. (P2)

“I feel angry ... I thought I was going to die (when told about the diagnosis)”. In further discussion, he acknowledged being scared (P3).

“I was just sad because I didn’t realise that I had that (cancer)”. (P5)

b) The emotional impact of hospitalisation

The impact of hospitalisation on the participants was significant. There are limited dedicated paediatric hospitals in South Africa. More specifically, specialist Paediatric and Adolescent Haematology and Oncology units are limited. Placement in a medical facility which caters for the developmental needs of the patient is important. Adolescents are often treated in adult oncology wards and in some facilities children are placed in the adult oncology wards due to the risk of infection in general paediatric wards. The nurses may not be paediatrically trained thus the medical system also plays a role in terms of whether this is

experienced by the child as a stressor or resource. The response of P1 who was treated and/or hospitalised in adult Oncology wards reflects her own experience and that of other participants. A contrasting response is provided regarding her experience in the paediatric ward.

“It was really scary because at the beginning at the oncology ward (adult) – it is horrible there, the nurses are all used to people dying and I am not dying, ... It is not nice at all because older people are there, most of them are dying”. (P1)

“The nurses (in the adult oncology ward) are just so hard, they don’t think that we are just children still and they are so mean”... “They don’t socialise with any of the children, they don’t socialise with anyone in the ward”. (P1)

“Because the nurses (in the paediatric ward) make friends with you and lots of my friends are in the paediatric ward, because to them we are still just children”. (P1)

The extended and frequent stays in hospital were described by the participants as the most impactful and were experienced by them as living in two worlds. The responses of P5 provide some insight into their experiences.

“It is like you are just locked up in a cage with no one there, just you and people that have to do their job to come inside (the ward) to tell you to do this and that. I am not really used to that, I am used to being with people, sharing my things with them, talking about life. It is just hard for me being here (in the hospital), not something I am used to”. (P5)

“Inside here (hospital) you eat three times a day, when I am outside (at home) I eat normally five times a day (because I train) and inside here I don’t really play with friends, I have to keep inside with a lot of people and I can’t go to soccer training, I can’t go to school and outside you can do all these things. It has been very hard for me because I am not used to being like in a place where there are times you do things”. (P5)

“They (the family) don’t really speak to me about things that happen outside because (I have told them) I get worried, I feel like I am left out”. (P5)

c) The impact of treatment

The impact of treatment is a significant source of stress for children with cancer. The invasive nature of the treatment, as well as its side effects, were often experienced as the most stressful. The feedback from the participants provides insight into how they experienced the treatments as invasive and how they experienced the physical/physiological aspects and side effects of the treatment.

The most difficult aspect of treatment to cope with was *“the pain I felt, the needles”*. (P3)

The hardest physical thing about the treatment (chemotherapy) was *“I got nauseous a lot, could not keep my food down”* (P2); *“I couldn’t eat, I didn’t feel like it”* (P3). *“It really made me sick. The first chemo I was struggling to walk, I felt a bit dizzy, I just felt like I just had to sleep every time”* (P5); *“Always sick and tired”*. *“Always not feeling well”*. *“Feels like vomiting”*. *“Don’t take food”* (P6).

On medication it feels like *“going on a roller coaster, ‘cause they move the bed before they give me the lumbar puncture and adjust the bed the height the doctor needs it to be. It feels like I am going on a roller coaster, up down, all around”*. *“I don’t like the Dormicum because it makes me forget... my hearing is gone a bit when I am under Gentamine, so I shout”*. (P1)

d) Impact on sense of self

The side effect of the chemotherapy of hair loss was distressing for most of the participants. Pre-adolescence and adolescence is a developmental phase in which sense of self and identity is primary. Physical appearance and peer identification and approval are important factors. The impact on sense of self was significant. There was evidence that self-esteem, social stigmatisation and sense of isolation were affected. The need for understanding and dialogue was revealed. The responses from the participants provide evidence of this:

“The most difficult thing was that I’d lost my hair and often people would tease me and just stare. They just stare and stare at you”. (P1)

“I wasn’t ok with it (losing my hair). When I went out I had a cap on or a jacket with a hoody; I did not want them to see that I did not have any hair” (P2).

P3 stated that he was angriest about his cancer because of losing his hair. He describes his experience as *“Not nice because I had a lot of chemo and lost my hair. They (friends) were rude. Like teasing me and say I have a bald head now” (P3).*

“I got upset but I didn’t wear bandanas or anything; I wanted people to see that I had no hair. I wanted them to ask and understand” (P1). When she was asked whether people asked, she responded: *“No, no one asked”. “I often like telling them, then they will understand and the next time they see someone with no hair, they won’t just stare and point fingers, they will ask and will be inquisitive and won’t just stare. That is the most uncomfortable thing” (P1).*

“They (peers) just didn’t understand” (P3).

6.3.1.2 Impact on physical abilities

Four of the six participants described the impact of the illness on their physical abilities. Three of the four respondents were male, suggesting possible gender bias in terms of the importance of physical abilities. The following are some of the participants’ responses when asked “has the illness changed the way your body works?”

“Before I was very active; I used to play volleyball and cricket, but now since the illness I get tired quickly” (P2). *“I have to walk on crutches (now) - my legs were okay before” (P4).* *“I don’t feel like I can walk or am speaking well” (P6).*

P5 expressed his worry that he is unable to go to school and do sport. Prior to his diagnosis of cancer he played sport regularly and worked out in a gymnasium. He described how physically restricted he felt by being in the hospital environment.

“I am doing some exercises with the physio’ but just stretching my arm and running (in the ward) but those are the light things for me, I don’t like doing those types of things, they are too small for me ... I am a person that likes lifting weights, using the machine to gym. I don’t

really like exercising like how she (physiotherapist) does it ... maybe she can order for me like more weights to lift or they can hire me a bicycle (to ride in the ward passages) ... just down there is a place (to ride) or maybe they can bring me a soccer ball, I can kick it in the ward. It comes back to me in different directions, so that give me a chance to move“ ... “(but) maybe I have forgotten how to kick a ball” (P5).

6.3.1.3 Disruption of daily lives

The disruption on their daily lives and the impact of removal from familiar home environments was significant for all participants. These responses from the participants reflect the extent to which treatment and hospitalisation impacts on their daily lives.

“In the beginning I was in hospital every week. Sometimes I’d stay in there for months” (P1).

Participant 3, who had spent a total of 11 months in and out of hospital described: *“It started like three weeks and then from two weeks and then till one week and then three days (at a time)”*.

For participant 4, she had been in hospital for six months. When asked whether she had been home during that period she responded: *“No, I have been in hospital all the time” (P4).*

A contrasting response is presented from a participant where the flexibility of the medical team (when medical conditions allow) became a resource for one of the families. The patient was allowed to have treatment closer to home and this provided some relief from the disruption to their family life:

“I went in for a lumbar puncture (then) my doctor would just give my mom the medicine so she could give it to our local paediatrician, so he could give it to me. He would administer it there so I could be closer to home” (P1).

6.3.1.4 The impact on significant relationships

The impact of the illness extends to the family system. The patients have little control over the treatment, procedures and side effects. Medical procedures are often invasive. Significant others are not in a position to protect them from this and are often required to leave the room or they are performed in their presence. Either way, there are consequences. Well-meaning parents in their efforts to protect the child will frequently inform the child “it will not hurt” impacting upon trust issues between parent and child. In some cases parents who are unable to cope with the treatment process will avoid the hospital. Due to the demands placed on the parents, siblings often need to spend time with other caretakers. The following responses illustrate the disruption to the family:

“... it has been tough on my parents because my brothers they got to move from my aunt and uncle to granny, they have to move around (in order to be cared for)” (P2).

“... it wasn't very nice because my lifestyle has changed and I didn't want my family to change too much... It was really hard for me” (P1).

“My dad was the one who reacted to the leukaemia because he got very stressed. He is a very brave man, he is in the police force. He was very sad (because he couldn't stand me being hurt) but he didn't want to show it to anybody, he didn't want to show that he is weak. He wouldn't come to chemo, he never visited me (in hospital) when I was on intensive chemo” (P1).

Participant 1 noted that her father had not been with her during her treatments over a three year period. She described the first time he went with her to her lumbar puncture and then chemotherapy:

“When he (dad) came (to chemo) last month, he went out for two smoke breaks, one was fifteen minutes, the next smoke break was 1 and a half hours ... he went for a walk. When he gets stressed he wants to go smoke. Every five minutes he wanted to go smoke. He doesn't like me to get hurt” (P1).

The impact of hospitalisation on the sibling interaction is also significant. As the hospital policy generally prohibits children under the age of 12 from visiting (due to the risk of cross infection), participants with younger siblings are further restricted in their sibling interaction. In addition, if siblings are not informed at an age appropriate level about cancer, they may be fearful that they will become sick too. It is not uncommon for the well sibling to have ambivalent feelings towards their sick sibling in terms of the time and attention given to them, especially by the parents, but at the same time to feel guilty about their feelings. The responses from the participants provide evidence of this.

“They are able to (visit) but they can only come for a few minutes because of their age. My brother will be twelve this year and my sister will be eight” (P2).

“My brother was quite scared that he would catch it (leukaemia) and he was very very scared. One day I had a bottle of juice, he said he was very thirsty and I said he can have some and he said no, I will get the leukaemia” (P1).

“I hated it when he (my brother) came in, there was a Disney channel on TV and every time he came in, he didn’t want to speak to me, he just said ‘can I turn on the TV’. I hated it. I hated it that he wanted to watch TV more than he wanted to see me” (P1).

“He (my brother) often got very frustrated that mom was looking after me instead of looking after him, because he was the baby in the family and was used to getting all the attention and he used to like get really, really mad. He would often be mad with me and try to hit me, but now he understands it. Sometimes he does still get a bit jealous, but he is fine” (P1).

She further described the impact on their relationship on her return from hospital:

“He would try and hit me but he would not talk to me, we used to have fun because we stayed in the same room and we used to swop beds and play tricks on mom but he wouldn’t play with me anymore. He changed completely” (P1).

The impact on of the illness, treatment and hospitalisation impacts upon peer relationships at a developmental time when the peer group forms an important part of the developmental tasks the pre-adolescent and adolescent have to negotiate. The experience of

participants in terms of the peer group ranged from support to isolation and in some cases, both. The responses of the participants reflect the range of peer support they received.

“They (my class) were big supporters, also things they made me. I am wearing one of the bandanas now. The whole class of Grade 4, they signed all these once (she showed these). There is quite a cool message on that says ‘Drink your tea, think of me, drink it hot, forget me not’. I have a whole box full of all the cards and a whole lot of teddy bears” (P1).

“I talk to my friends (when they visit me in hospital). Like what is happening in hospital and the life in hospital” (P3).

However, the sense of peer isolation due to lack of contact for many of the participants was a common experience. In part, hospital rules about younger visitors (under 12) not being allowed in the ward and to reduce the risk of cross infection, played a role. The treatment protocols resulting in immune compromise were also factors.

“The only time I saw them (my school friends) in the 6 months was on my 10th birthday” (P1).

*“Not so much. Not at all. I barely get to see them (my friends). I am mostly in the hospital”.
“I have a best friend and a whole bunch of friends. We normally send SMS’. That is about it” (P2).*

“They (peers) come and visit me, they tell me about what is happening at school. Thing I don’t like is when they tell me about school. I can’t say they help me in any way but I can say some have been supporting me, they come to visit me but sometimes they come to talk mostly about what is happening in school and I don’t really like to be reminded about what is happening in school because I like to be in school around other people” (P5).

An issue for participants who live geographically far from the treatment centres is that peer support is generally not possible. In addition, the consequence of the treatment results in immune suppression and thus requires medical isolation from peers. Resignation regarding these issues and their impact on peer support and interaction was reflected by the response of these participants:

“I think that the friends should come to visit me but they are not coming to visit. It makes me feel bad but there is nothing to do about it” (P6). “They (friends) can’t come visit you, you have low bloods” (P2).

6.3.1.5 Impact on education and mental/intellectual stimulation

Most participants described a sense of disconnection from academics and school peers and social groups. The disruption to school life and missing school was a source of stress, both during the treatment and on their return to school, in view of the work that had been missed. In some cases, an academic year had to be repeated. For some of the learners, in view of the amount of schooling they had missed, they were older than their peer group for the grade. The responses of the participants illustrate their experiences

“I didn’t go to school at all in the first six months of chemo sessions ... the thing I missed most was interacting with the other children” (P1).

“March I was diagnosed and I have not been back (for the last three terms of Grade 8) ... the worst part about missing out on school (is) your friends” (P2).

“I have missed out on school and a lot of work... the first term of this year... the 3rd and the 4th term (of last year)... I had to repeat ... It (being in hospital) wasn’t nice and I miss my friends and school” (P3).

“Yes, (I missed) a lot, the tests, the class work and I worry about the work I am missing”. She also noted that in the time she had been in hospital she had not seen any of her school friends.

P6 is old for Grade due to work he has missed as a result of his illness (17 in Grade 8). When asked whether he was being helped to catch up on the work he is missing he stated that he was not.

“I can’t go to school because I am supposed to come here (hospital) ... so I don’t get time to go to school ... it affects me a lot, because I am being left behind” (P6).

The school is a potential resource for children during their time of illness however most of the participants described very little contact from the school or school peers while they were on treatment either in terms of assisting with work missed or social contact. The following responses from the participants provide insight into their experiences of their schools:

“... no support (from the school) but they understand” (P2) “No they haven’t brought anything (school work) as yet but my reading I think is quite good but I think my spelling will not be good because I normally sit here (in hospital), the only thing I do is playing games, I walk around. There is no one to teach me how to spell, I think I forgot how to spell” (P5).

“Since I broke up from school (because of his illness), I don’t feel like I can see them (school friends) because I don’t feel positive anymore (about my school friends) ... because I break up from school because I am sick ... I don’t go to school anymore (because of my illness)” (P6).

The nature of the illness and treatment often includes extended periods of hospitalisation. The lack of intellectual, mental and social stimulation was noted by many of the participants to be a problem for them. Boredom and keeping their minds busy was described by many of participants as challenging.

“We do bring stuff (to play with) but sometime there is no one to play with ... it is lonely” (P5). “My chemo goes on for four hours a day, the rest of the day I am doing nothing. I have to keep myself occupied ... nothing to do here (in hospital)” (P2).

6.3.1.6 Overview of the impact of diagnosis and treatment

In terms of the emotional impact of cancer, the responses of the participants provided evidence that a sense of powerlessness and uncertainty was a significant theme. The responses of the participants were consistent with findings in the literature regarding the strong sense of uncertainty related to the diagnosis, treatment and even prognosis (Chesler & Barbarin, 1987; Comaroff & Maguire, 1981; Heath et al., 2006; Matteo & Pierluigi, 2008). In a qualitative study of families living with childhood cancer, the central theme for these families was that “the only certainty becomes the diagnosis” (Papaikonomou & Niewoudt,

2004, p. 9). The impact of treatment and hospitalisation on many aspects of the participants' lives emerged as another significant theme and caused significant disruptions to their daily lives, supporting current literature (Chesler & Barbarin, 1987; Engel & Melamed, 2002; Li et al., 2010). These included the invasive nature of the treatments and their side effects of which hair loss was the most significant for the participants given their development stage when appearance is important, thus impacting upon sense of self. The restrictions that treatment placed on their physical abilities were also significant and more so for the boys than girls. The impact of treatment and hospitalisation on significant relationships was consistent with the literature (Chesler & Barbarin, 1987; Houtzager, 2001; Long & Marsland, 2011). This was particularly evident for siblings and peers and for those who lived geographically far from the treatment centres the impact on their relationships with family members was significantly affected. Hospital policies, designed for the medical protection of the children often impact upon contact with siblings and peers. Disruption to education and the social networks it provides to the child was a significant source of stress, and coping with the lack of intellectual stimulation and boredom was a significant challenge.

6.3.2 Theme 2: Coping resources and coping strategies

The preceding discussion has highlighted the significant impact of cancer on the child, yet the literature notes that that in spite of this, it is possible to attain a state of psychological well-being and be psychologically well-adjusted and physically healthy children (Chesler & Barbarin, 1987; Horsburgh, 2000; Zebrack et al., 2007). The guiding theoretical framework for this study (Moos, 1993, 2002) notes that the availability of resources and the modes of coping that children use influence their ability to deal with a stressor such as the diagnosis such as cancer, and determine their well-being. The following is a presentation of the responses of the participants which provides insight into the most commonly used resources and modes of coping.

6.3.2.1 Coping resources

Based on the participants' responses, the following themes emerged as the most common coping resources used by the participants: Information and Social support. Coping resources can become stressors when absent or when used in a way that is not appropriate for developmental level or when not meeting the needs of the child. The responses of the children will be presented which provide evidence of both.

6.3.2.1.1 Information as a resource

Information about cancer was described by the participants as one of the most significant resources, regardless of their cultural backgrounds. At the time of diagnosis this is the way in which they find out about cancer. The need for information by the participants is evident. The importance of age appropriate information from the primary sources of information, which are usually parents and the doctor, cannot be overemphasised. The perception that information is not being withheld was important for the participants.

The following responses provide evidence of the relief experienced by the child at the time of diagnosis:

"I can't explain it. I was shocked at first (to have a diagnosis of cancer) because I didn't know what it was". He described his relief once he had been given information on his diagnosis. *"Yes I thought it was something severe, I didn't know it was something mild ... that it wasn't the most severe leukaemia"* (P2).

P3 stated that when he heard about his diagnosis, he thought he was going to die. He said that he no longer thinks that. When asked what changed his thinking, he responded: *"The doctor and my mother... they explained what is going to be happening and all of those things"*.

The participants indicated that they felt positive about having information. The following response illustrates this:

“I like more information, I know what is going on in my body and it is actually helped me. I go to hospital once every three months now, then when I go once every three months, the day before I think of all these questions to ask my doctor” (P1).

The perception by the participants that information is not being withheld from them by their parents and doctor was important to them. The following responses demonstrate this:

“My mom told me I have leukaemia, ‘cause often parents don’t tell their children. The doctor explained that it was a type of cancer because Dr. X explains everything to us” (P1).

“My parents have a lot of questions, they will ask in front of me and doctor will explain if I don’t understand ... it (information) has been helpful but every now and again you get scared“. Later he stated “There is no fear because I know what is going on. Whatever new symptoms doctor finds, she tells me. She does not hide anything from me“ (P2).

“Maybe I am wondering about some information, maybe there is more information that they need to give me. It was all that they (doctor and father) told me...I wanted to know if I was positive or negative...maybe like Aids...she (doctor) just told me it (blood results) is okay but I don’t feel the answer that she gave me is enough (to make me not worry)” (P5).

With reference to the above statement, P5 was concerned that his doctor may not have given him all of the information and he was fearful that he may have HIV Aids, in addition to leukaemia as many people in his community were known to have HIV Aids. He did not however express his fear with his doctor as culturally he did not feel it appropriate to question the doctor directly. Despite these cultural inhibitions, his desire for the information remained and he gave permission for the researcher to discuss his fears with the doctor. He was relieved once he received information that confirmed that he did not have HIV Aids.

Accurate information about treatment and side effects can provide significant benefits to the child in terms of allaying fears and reassuring them. In addition, the relationship which involves trust between doctor and patient can be a significant resource.

P2 described that the single thing that made him the angriest about having leukaemia was losing his hair. He found the information he got from his doctor the most helpful in

helping him to deal with this. He also had to go on a new treatment protocol. The following responses reflect how information from a trusted source can be a significant resource:

“(I felt better) when the doctor told me it (my hair) will grow back ... and then I saw some children in the hospital that have had leukaemia and their hair grows back. I have been to ICU for chemo. These last two blocks that I have done is new treatment, only eleven people in the world have used it and in South Africa I am the first kid ...first you are scared – you don’t know what is going to happen but the doctor has done research and she tells you and (she) has spoken to people that have been on it, (she has) spoken to professors (P2).

Not enough or too much information, inaccurate information, over-discussion by adults in the presence of the child or with the child or conflicting information can become a stressor rather than a resource. These responses provide examples of this and clearly reflect how these could result in information being a stressor rather than a resource.

“I didn’t like it (leukaemia), I hated it, because at first I thought, because sometimes it can be genetic – the leukaemia, but there was no history of cancer in my family and I thought that if I had had it, if I was able to have a child, she would also have leukaemia” (P1).

“We don’t often go for take-aways (now), maybe that’s what caused it (leukaemia), not too sure ... maybe the pollution, not sure ... I went for a month on just eating vegetables (after the diagnosis)” (P2).

“It is different what I got here (current hospital) because here they told me that I have cancer whereas at the G (previous hospital) they told me that that it was TB. I would like to know ... I want to know more about what I can do about it. I would like you (researcher) to tell me about the treatment and what it does and if it can be cured. They (people) only told me I must not drink beer or something because then it (my sickness) won’t be cured” (P6).

“I was told by my mother ... that I had blood cancer ... they (the doctors) have told me nothing ... I would like to know what it is all about and how dangerous it is” (P4).

P4 and P6 indicated that they would like information but there had been no one to tell them as they both lived far away from the hospital and for cultural reasons would not ask the

doctor. While it is evident that the participants, regardless of their cultural backgrounds or socio economic backgrounds, had a high need for information and to talk about their illness, they were often reliant on parents/significant others as a source of information. Both participants 4 and 6 who had not received any information about their diagnoses came from similar cultural backgrounds (Zulu), both were in state hospitals, both came from disadvantaged backgrounds and both had families who lived significant geographic distances away, and both were in hospital for extended periods with little contact from family members. In these specific cases, the provision of information for the children was not provided by medical staff or health care professionals. Discussion by the researcher with medical professionals indicated that language barriers, inadequate resources in terms of staff shortages and time constraints were factors which contributed to this.

The absence of having significant others to communicate with about the illness, and express their feelings to, can result in a sense of isolation. Without exception, each of the participants expressed the need for information and the need to communicate about cancer, however three indicated that they had no one to talk to about the illness. A common characteristic of these participants is that they were all Black patients, two were from state hospitals and the other was from a private hospital. The following statements illustrate this:

“If there is somebody to counsel me about the cancer, I would like that”. P6 shared that there was no one in the family that he can talk to about the cancer.

“I would like them (family members) to talk to me so I could share about my illness ... there is no one to talk to about it ... I tried to talk to my uncle but he didn't speak about it “(P4).

“Maybe there are some (people in my family I could ask). They wouldn't quite give me the answer what I am looking for” (P5).

Books which provide information on cancer or where others have shared their experiences can provide children and their families with a good source of information and allow for a shared experience. This allows for a normalisation of some of the difficulties or addresses some of the issues they are working through. The responses of some of the participants reflect this:

“I should have brought that book of Leandrew (which I found useful). One of his aunts wrote a book for him to explain to the children in his class about leukaemia because he is only in Grade 1” (P1).

“I was reading books (about cancer) and I found that it was not anybody’s fault or it is not my fault that I got leukaemia” (P3).

Media such as movies and documentaries of people with cancer also allows the patient and/or the family members to identify with various characters and to connect with the narratives of the various characters.

“We watched (the movie) ‘My Sister’s Keeper’, cause she also had leukaemia. So I said you know she has just shaved because you can see the little stubs of hair, she hasn’t lost her eyebrows or her eye lashes or anything. I lost my eyebrows, my eyelashes, and all hair over my body” (P1).

Access the Internet and a social network such as Facebook can be a resource to the child and the family. They are able to meet and communicate with other cancer sufferers with no geographic restrictions and also source sites which provide information on cancer. Such resources have the capacity for both information and social support. The response of one of the participants reflects the benefits of this. He and his family were able to source information which was useful and which normalised his experience of cancer:

“It (getting information from Facebook and the Internet) is very useful, ‘cause I thought it was something new, cause I didn’t know other people also had it (cancer). My father used Facebook and Internet and we had some people that experienced the infection. So they told us about the infection, so I knew about it so I didn’t get a big shock ... (I found out) about the side effects that I had before I knew that I had it. It is the things that people experienced, who had the same thing, like headaches. They slept long, they had vomiting and sometimes they feel dizzy. They just couldn’t do anything, they felt tired” (P5).

6.3.2.1.1.1 Overview of information as a resource

The participant's responses confirmed the literature that appropriate information from a trusted source was a significant resource in terms of reducing their anxiety in a context of great uncertainty (Clarke et al., 2005). It was important to them that they could trust that information was not being withheld from them as, at this developmental stage, they are able to judge the seriousness of the situation by context and are well able to read the nonverbal cues of those around them (Claffin & Barbarin, 1991; Clarke et al., 2005; Louw, D., & Louw, A., 2007). Misinformation, the absence of information or too much information can be a burden for them and become a stressor.

While the literature notes that there is a cultural preference in terms of information needs, the findings of this study suggest that regardless of culture, the children have the need for information but that cultural factors may prevent them from asking and may influence their information-seeking behaviours. Jithoo (2010), reports that Black parents have greater difficulty communicating about all facets of the illness in comparison to their White counterparts. At a cultural level such matters are not generally discussed with children but instead amongst elders of the family which they believed were in the best interest of the child. There was also a belief that disease related information was in the territory of the medical staff whose authority and status should not be questioned.

Both in the initial stages and during the treatment, the literature suggests that when information is given by parents it is often limited to factual information and that they do not prepare their children emotionally because they do not have the emotional resources themselves to address this (Jithoo, 2010). In Jithoo's (2010) study, 89% of parents reported that they were unwilling to discuss the topic of death as it was something that they had blocked out and they were afraid that it would distress the children. According to Clarke et al. (2005), this behaviour of parents gives the child overt and covert messages not to talk about these matters. In response, the children try to conceal their knowledge and avoid conversation to protect the adults. Chesler and Barbarin (1987) note that the children get caught in a charade in which they learn to accommodate the adults and conceal their need for openness and candour. Yet, in spite of parental attempts to avoid discussion with their children, Jithoo (2010) reported that children discussed these issues with fellow patients, volunteers and nurses, confirming their high need for communication. In this study, there

was evidence from the participants' responses that the sense of isolation was more pronounced for Black participants. Possible contributory factors were the geographic distances from the treatments centres as well as cultural factors in terms of information seeking as well as spiritual/religious limitations in terms of practicing traditional religion in the hospital setting.

The primary sources of information for the child include the parent (Clarke et al., 2005; Jithoo, 2010), and in many instances, the doctor. However, the parents are also in the process of dealing with the diagnosis of cancer and in many instances the doctors have demanding work schedules. The need for psychosocial services which can address both the information needs and emotional adjustment of the children and their families would be an important resource. Cultural sensitivity in terms of information provision and knowledge of information seeking behaviours of the child and its family are important.

Participants' responses indicated that literature, the Internet and social networks were useful additional resources of information as they overcome geographic boundaries and are immediate and can be an additional resource for social support. However, South Africa lags behind international statistics of Internet usage as an information resource for families with cancer, as Internet technology in South Africa "remains the reserve of a select few" (Jithoo, 2010, p. 354). Compared with 30% of European families ($N=82$, Matteo & Pierluigi, 2008), only 3% of South African families use the Internet ($N=100$, Jithoo, 2010). Information can be overwhelming for parents and their children and it is important that they are guided by medical and health care professionals. Matteo and Pierluigi (2008) emphasise the importance of the role of a medical "advocate" who can guide the parents in terms of useful and up to date resources to eliminate misleading and unreliable information.

6.3.2.1.2 Social support as a resource

Based on the participants' responses, the primary source of social support was from the family. To a lesser extent, and strong potential social support resources, were the school, fellow cancer sufferers and members of the community and support organisations. The following is a discussion of each of these. Social support as a resource overlaps with social support seeking behaviour as a coping strategy. As these overlap they may be included in both sections.

a) Family

The family is the primary means of social support for the child. The role of the extended family was a resource to the patient and the parents. The following responses from the participants illustrate the nature of the support they have received from their family members, both primary and extended:

“Firstly I didn’t want it (hair) to fall out but then also all the men in my family, my dad, my uncle and my cousins they cut their hair really short. My dad shaved his hair off. They (family) have been here through everything. They have been here when I was sick. When I am well, they have been here” (P2).

“My father, my step mom, my step mom’s uncle, my aunty, my other aunty, my father’s brothers ... they come here (to the hospital), they speak to me,” (P5).

“I have an aunt and uncle (who live) in Park Rynie. Grandpa and granny, they live in Montclair, they normally take care of my brother and sister” (P2).

Families who live long distances away from the treatment centres are restricted in terms of hospital visits, and may be limited as to the nature of the support provided. There is evidence however that when contact is possible, it is valued by the child.

“My mom and dad ... they take me to hospital to get my medicine. Yes (it’s good), my mother and father... (they visit me in hospital) once a week”. (P4).

b) School and educators

The role of the school and educators can provide a buffer to the educational disruption and can be a resource to lessen the stress of absences from school and the work that is missed. In addition to providing academic support, they can provide social support. The responses from the following participants illustrate the important role that the school and its educators can play:

“They (school) sent all the schoolwork back with my brother ... I passed Grade 4 with flying colours, I was able to go (to school) the last six months” (P1).

“They (school) have been understanding. I do some projects and I get some marks” (P2).

However, this was not the experience of all participants. The absence of such a resource may be experienced by children with cancer as a stressor. Many of the participants provided information regarding lack of support from the school:

“No support but they (school) understand” (P2). “No I didn’t get any schoolwork (from the school) and no support” (P3).

c) Fellow cancer sufferers and parents of patients

Connecting with same age patients, fellow sufferers or parents of patients provided a sense of belonging and hope and can be a significant source of social support. In addition to support receipt, there is evidence that providing support can be equally beneficial. There are however restrictions in terms of meeting fellow sufferers in hospital due to immunosuppression. The following responses from the participants reflect the value and some of the challenges of meeting same aged peers or those with a similar diagnosis:

“I did make some friends (during a stay in hospital) that I still keep now. There was one boy, he was diagnosed on the exact day as me and we still keep in touch now, although he has moved up to Mozambique again” (P1).

“Firstly I met people with my symptoms, made friends with them, we kept contact with them”. When asked whether their friendship extended beyond the medical environment, P2 elaborated *“No, we see each other in doctor rooms but not at their house” (P2).*

“I remember one child, he was on maintenance already. His hair had grown back. I thought, one day when I’ve finished my treatment I am also going to be like him with my hair growing back” (P3).

The following response provides evidence of how social support and/or social receipt can be beneficial:

“We both help each other, because since I just entered my maintenance phase, my gran got breast cancer. We helped each other through. “Because she understood... we (would) talk about things like losing our hair. I could support her (gran), cause if I hadn’t got it before her, I think she would have gotten way too depressed. ... My (school) principal got colon cancer and when he came back to school, I just gave him a big hug because I have gone through it“ (P1).

“We spoke to (someone) that came to our house before I came back to the hospital and that was J’s mother. She spoke to us. She told us there are things that really helped. So I was really happy about her giving us the support and information” (P5).

“Anyone who needs my advice, I will gladly step up” (P2).

P 3 explained why it is difficult to meet fellow patients in the hospital when many of them are in medical isolation for extended periods: *“Because they might carry germs and infections and they could easily pass it on to me”.*

While connecting with fellow patients can be a source of support in terms of a sense of belonging and emotional support, it can also be a source of stress in terms of accepting responsibility for the other patient. The death of a fellow sufferer can be a confrontation of one’s own mortality and can impact upon future orientation and sense of hope. The following responses reflect these:

“Yes (I felt responsible for gran), because she used to be quite sociable but now she is not really social anymore because she had to have the one whole breast removed, but luckily they caught it in an early stage” (P1).

“It is sometimes a bit scary because one of my friends, I was in my last session of chemotherapy, and we met him and then he was diagnosed with a brain tumour. His name was J and one morning I just woke up and said to mom, call J’s mom and she said okay, and that morning he died” (P1).

“I don’t have the hope that I will get better when I see some other people (fellow patients who have relapsed), they have three years, five years being sick ... and then I lose the hope that I will be healed” (P6).

d) Community and Support Organisations

The role of the community, in terms of church or religious affiliation and support organisations can also be a resource to patients and their families. The following responses from the participants reflected their perceptions of contact from these groups that were useful to them. For some the support was instrumental in terms of sourcing medical assistance, for others it was helpful to pass the time and to have someone to talk to, while for others it was in terms of gifts and activities. The following responses provide insight into this:

“We had our pastor coming in (to the hospital) to pray for a while ... nurses from other wards that pop in now and then, that nursed me before to see how I am doing”. When asked whether this was contact he enjoyed, he indicated that it was (P2).

“CHOC (Childhood Cancer Foundation) and Reach for a Dream ... they bring me things and they chat to me. Reach for a Dream is like – they make your dreams come true ... I wanted to go see Kaiser Chief’s soccer players ... my favourite player from there is Josh Dladla and he gave me a gift ... soccer boots, Kaiser Chief’s jersey, a sweater and socks ... Yes it is nice to have them there (CHOC and Reach for a Dream) and it has helped me to pass the time” (P3).

“Sometimes they (people in the community) come to see me or call the ambulance if I am getting worse” (P4).

“Some of them (from the local community) are teachers; some of them are my neighbours where I live” (P5).

e) Overview of social support as a coping resource

Social support was a significant resource to the participants and served many functions. Receiving social support as well as providing it appeared to be important to the participants and provided them with a sense of support and connectedness. This is consistent

with the literature that identifies the value of both support receipt and provision (Engel & Melamed, 2002; Sarason et al., 1990; Shephard & Mahon, 2002; Moos, 2002). In addition to the social support component, support from schools also provided a buffer from the disconnection from academics and the school peer group for some of the participants as noted in the literature (Chesler & Barbarin, 1987; Engel & Melamed, 2002). Connections with fellow cancer sufferers provided a sense of hope and belonging for many of the participants. Relapse and the death of their fellow patients however served as a reminder of uncertainty which is a characteristic of the illness, as well as it allows them to appreciate the seriousness of their condition and confront their own mortality (Chesler & Barbarin, 1987; Jithoo, 2010). Support and information from parents of other diagnosed children was a useful resource to one of the families for their support and information needs. This type of interaction allows for shared experiences and strong identification with each other's emotional needs. In the absence of formal support groups, parents can form informal support systems for advice and support, and this provides a forum to voice difficulties (Jithoo, 2010). Support from the members of the community and from religious groups was found to be a support to both the child and its family. This is supported by the literature regarding the provision of social support in terms of similar shared beliefs but also the facilitation of spiritual coping (Cotton et al., 2012; Burnell, 2006; Frydenberg, 2008). Support organisations appeared to fulfil a number of functions ranging from social support to information to providing some relief to the participants in terms of positive distractions in terms of passing time, gifts and the realisation of some of their wishes such as outings.

Each of the above means of social support provided different components of support and met the needs of the children and their families in various ways. The mobilisation of each of these would be beneficial as potential resources.

6.3.2.2 Modes of coping

Based on the participants' responses, the most commonly used modes of coping included cognitive coping, emotional coping and avoidant coping, relational coping and active behavioural coping. The following responses from the participants provide evidence of this.

a) Cognitive coping

Cognitive coping was the mode of coping most frequently used by the participants. Cognitive reformulation, positive internal dialogue, finding meaning and humour were used by the participants. The following responses provide examples of cognitive redefinition or reformulation used to focus on a particular aspect of the problem which minimises other aspects:

“No (I don’t get upset by the leukaemia) ... not really because I always think there is something worse, I could be dead. There is always something worse than what you have got ... (I am) 5% leukaemic. It means that the chemotherapy has worked and it went from 95% to 5% in six months” (P1).

“I have gotten over it (death of a friend with a brain tumour). I’m in remission. Remission means that the cancer has gone below 10% and it has gone down ... there is always something worse that could happen, like with me getting leukaemia, I could have been dead” (P1).

Positive internal dialogue was used by the following participants:

“God, the medicine, support from my family and a positive mind. I just keep on saying to myself I am better already ... I just think it is a sickness (leukaemia) that is going to pass by” (P3).

“At the moment I am here (hospital) because I am fighting for my life ... (with) my body and my mind ... in my mind I fight it like I say (in my mind) to those (nurses and doctor) who poke me a lot, put in drips, I had to forget that there was something in my body, so I just had to forget about everything and get along with it... with the pain that I had, I said (to myself) today I am ok because of all that I was fighting and be strong” (P5).

Finding meaning or a purpose is a form of cognitive coping used by many of the participants, as constructing meaning is a way to manage the uncertainty of the illness and treatment. The responses of the participants reflect the meaning that they have constructed:

“To me it has been a test ... A test from God, I have got closer to Him, I have got baptized, I have accepted him. Test for me is that the whole family got closer to God” (P2).

“I thought about questions like why me and why did I get it (leukaemia) ... (it was) to trust in God” (P3).

“I think everything happens for a purpose and the purpose of me getting leukaemia was to teach other people no matter what happens ... I can explain it to other children that have illnesses ... to explain what happens” (P1).

P1 has informed the researcher that she also sees her diagnosis as having a purpose so that she could assist her grandmother with her cancer. *“She (gran) would be really really depressed and then I just come and talk to her and tell her that we can get through this and we can manage”.*

Humour is also an effective cognitive coping strategy which allows ‘distance’ from the problem. The following response reflects this:

“Yes, it is funny because I used to wear a wig. It was just so funny seeing the people looking at me thinking ‘one day she has short hair, the next day she has nice long hair’, now they ask me ‘is that your real hair’ and I have to say yes (laughing) and I pull it like this (pulling her hair)” (P1).

b) Emotional coping

Being able to communicate about cancer was important to many of the participants. Having communication channels which are open facilitates the expression of emotions. When asked whether they liked to or had a need to talk about their illness, they responded:

“I often like telling them (people in general), then they will understand the next time they see someone with no hair” (P1). “I like to talk about it”. When asked who he does talk to he responded, “I have got my aunt, she is a nurse; I have got my parents, my grandparents ... my grandma is also a nurse” (P2).

P3 responded that it makes him feel better when he has a chance to speak about his illness. *“I like to talk about it”*.

P5 said, *“I think there would be a need for me to share my experience about the illness. I prefer talking about it because so it doesn’t stay in my heart”*. He explained who he would like to talk to, *“someone that will be interested and asking some questions about the illnesses ... who will ask me about the treatment, how I manage to fight it because it is something new in my blood”*.

P6 comes from a rural traditional setting in which his grandmother heads discussions. He noted that his grandmother was a very important person in the family and he was close to her. His extended stays in hospital have resulted in no contact with the grandmother who was geographically far away. He describes how communication works in his family:

“I normally tell my grandmother and she will combine the family and they will talk about the problem, try to resolve it. Only my grandmother can lead the conversation ... I prefer to tell my grandmother than to tell everyone”.

Avoidant coping, suppression of feelings, withdrawal and disengagement were also used by some of the participants as forms of emotional coping. Avoidant coping assists with denying or minimising the seriousness of the problem and can be a “self-protective” mechanism in response to stress. The responses of the participant’s provide evidence of these:

“I just kept quiet... I just walked away” when he was teased that he had no hair (P3).

“I just sleep ... (but) the anger doesn’t go away (about having cancer)” (P4).

“When I feel sad about something, it is for my own good, I just keep it to myself ... I don’t feel (like) sharing these things ... I just listen to music, like (to) listen to Michael Jackson and Lucky Dube ... I like the old music, not the new music ... sometimes old music with messages” (P5).

“I don’t hate it, I like staying alone most of the times ... because I am sick now. I was never like that before” (P6).

c) Relational Coping

Relational coping, which is an extension of social support, was used by the participants as the experience of cancer occurs in a relational context as it affects the child and its family members. When asked if there were any significant people in their lives that facilitated their coping, the participants responded:

“Prayers from all my family members” (P1). “My mother and grandmother” (P6).

“My dad or my granddad ... they have been here through everything. They have been here when I was sick, when I am well they have been here. They have taught me the way of God, to pray and praise him. We do it (pray) loud, my dad, my mom, we will all sit and pray at the same time ... we take turns, my dad will take a turn and then my mom.” (P2).

“The doctor and my mother. By giving me medicine and knowing what type of medicine I should get and all that and my mother stayed with me in hospital ... taking care of me, making sure I try to eat” (P3).

“It would be my father and my sister ... they say keep strong, don’t rush, you must not look at the calendar” (P5).

When asked what it is she believes in when things are difficult for her, P4 responded: *“I believe that coming to hospital will help me ... the doctors will help me. God will help the doctors to help me and the medicine”.*

None of the participants had seen a psychologist for therapy to assist them through the diagnosis and/or treatment process. The focus for the children appeared to be on the medical aspect of treatment. One of the participants noted that her younger sibling, who was acting out behaviourally following the mother’s extended stay in hospital with her, was seen by a psychologist to deal with his feelings. The response of this participant was as follows:

“They (mom and brother) went to the psychologist and mom explained to him that she still loved him (even though she wasn’t at home with him)”.

d) Behavioural coping

Behavioural coping involves active behaviours which alleviate the stress of the situation, allow distraction or allow feelings of a sense of control. Self-nurturing behaviour was practiced by one of the participants: *“To relax, I often just light some scented candles, put them in my room and have a nice hot bath and then go into my room, just relaxing”* (P1).

For another participant, a restricted eating programme, which had religious significance was helpful and was another example of behavioural coping which, apart from allowing a sense of control, has an additional component of religious coping. *“My granddad use to say that vegetables are from the earth and I went for a month on just eating vegetables”* (P2).

Other forms of behavioural coping used by participants included the use of games, watching TV, reading, walking and other forms of exercise which allow distraction and relief from the reality of the situation. Exercise and following a diet programme are also health seeking behaviours and reflect a future orientation and sense of hope. The following responses reflect this:

“(I avoid) the things I have to be careful of and (I watch) the food I eat ... I eat a lot of food and drink a lot of water (to keep my body healthy) ... I read, watch TV, I play Playstation” (P3).

“Playing games, watching TV, walking outside, listening to the birds and swimming ... It (video games) makes me feel I am with someone, sharing my feelings with someone ... By looking at different movements of actions that happened in the games when they play ... it makes me feel like I am moving, makes the feeling (sad feeling) go away. Exercising sometimes helps me with my brain to forget about a lot of things because normally when I exercise I feel more stronger and everything that is in my mind like comes out” (P5).

Active behavioural coping which took the form of rebellion was described by one of the participants. She described what she did when people stared at her when she lost her hair: *“I (would) just stare back at them and then they (would) look away (because) they get such a fright!”* (P1).

e) Religious coping

Turning to religion was commonly used by the participants. In addition to it providing an internal means of coping, as religious and spiritual belief systems often involve others who share these beliefs, religious symbols and rituals, social support is an additional component. The following responses from the participants provide evidence of this:

“I prayed with my mom and then my gran asked her friends. I have a prayer cloth, from England. My gran asked one of her friends to get one. It is just a cloth that they all prayed on. I keep it by my bedside. Whenever I am sad, I just hold it close because it makes me feel God is near. (When I am sad) I like to think about God and that I am still alive, (and that) I was diagnosed just in the nick of time” (P1).

“They (family) have taught me the way of God, to pray and praise Him, to ask Him for this (to get better), asking (in prayer) if you are not feeling well and ask him and He will grant it to you. I have learned that if you want something you have to ask for it (pray). I asked for it and I got it, when I was feeling nauseous I ask it to stop and it stopped ... whatever is wrong at the moment I ask and He gives it to me” (P2).

“When I am sad I believe in God ... that is because when I came here (hospital) I was not really well but when I started praying and reading the Bible and what God has done for the people. Fighting for His life has helped me a lot because today I am sitting on the couch because of him. He has helped me with my illness and the pain that I had in my body is healed up so I think He is helping me a lot ... my parents come and they pray before they go home and I usually sleep with the Bible under my pillow” (P5).

P2 also ate fruit and vegetables for a month. He explained that his thinking was based on the fact that Daniel in the Bible went on a fast and ate only fruit and vegetables.

“He (Daniel) was more stronger than those who had meat, so that is what we (he and his grandfather) were trying to do. We follow the Bible. Mostly vegetables and no more take aways ... I went for a month on just eating vegetables” (P2).

For P4 and P6, they were not able to use religious coping as the hospital environment was not conducive to this. These participants outlined their belief systems. When asked whether he was able to feel supported by his ancestors when he was in hospital P6 responded that he did not. He indicated that he could not do this in the hospital; he was only able to do this back home and he had been in hospital for months. The following responses reflect the belief systems and rituals of participants

“I believe in the tradition ... what I can do when I am sick ... we can slaughter a goat and then ask from the ancestors to clean me and when I am healed we can slaughter another goat or a cow and thank them. If there is something we want from the ancestors we burn the grass and then go to a certain room and talk to the ancestors and then pray to them for what we asked for. We burn the grass and kneel down and talk to them directly as if we see them” (P6).

“I don’t know how to pray. My uncle prays... we go (to traditional church) once a week when I am not in hospital. My uncle also asks our ancestors to make me better... They go into a room and burn a special grass and they ask the ancestors to help me. I don’t believe that will help me to get better”. When asked what she thought would help her to get better she stated “the hospital and the medicine” (P4).

f) Overview of modes of coping

Lazarus and Folkman (1984) suggest that coping is defined by “constantly changing cognitive and behavioural efforts to manage the specific external and internal demands” (p. 141). There is evidence that the participants used a range of coping behaviours which allowed them to cope with the internal and external demands placed on them by the diagnosis and treatment of cancer. The literature suggests that children use single behavioural strategies which change qualitatively with development and that coping in children with chronic illness is generally stable over time but varies across situations (Schmidt et al., 2003; Spirito et al., 1995; Ryan-Wenger et al., 2000). While it is not possible, because of the scope

of this study, to draw any conclusions regarding the qualitative changes over time, there was evidence that this group of children used a variety of coping strategies which appeared well suited to the demands of the situation combined with their capacity to draw on their available resources.

The responses of the participants provided evidence of a range of coping behaviours which included cognitive and emotional coping, relational coping, religious/spiritual coping, avoidant emotional coping and active behavioural coping. The most frequently used mode of coping was cognitive coping in the form of cognitive reformulation, positive internal dialogue, constructing purpose and meaning (which closely overlaps with religious/spiritual coping and relational coping) and humour. Cognitive reformulation allows for a mental restructuring of the situation and according to Holahan and Moos (1987a), facilitates a basic acceptance of the reality of the situation. Positive internal dialogue is closely associated with hope. Hopeful people are found to use more positive than negative internal dialogue (Snyder, 2000). It is thus reasonable to consider that those with positive internal dialogue would cognitively reformulate more positively, as according to Lazarus and Folkman (1984) the relationship between hope and coping is in the appraisal of the stressor. Finding purpose and meaning by the participants included spirituality but was not restricted to it. Finding an altruistic purpose was also evident. Search for purpose and meaning has been cited as the feature most characteristic of children with cancer and their families (Comaroff & Maguire, 1981; Cotton et al., 2009; Pendleton et al., 2002). Humour was also used, to a lesser extent, by a participant. According to Frankl (1967), humour allows detachment from pain and suffering as it provides a sense of choice and control.

Relational coping was an important coping strategy and frequently overlapped with spiritual/religious coping as both have a social support component. Participants from disadvantaged backgrounds who lived distances from treatment centres showed the need for such forms of coping but were restricted in their access to them.

The participants provided less evidence of emotional coping in terms of emotional expression and venting of feelings but did provide evidence of a desire to communicate about cancer. There was more evidence of avoidance emotional coping in terms of suppression of feelings, withdrawal and disengagement. The use of avoidant coping in this group may be seen as an adaptive coping behaviour as overall they were identified as high scorers on the

life satisfaction measure. There was little evidence of the availability of mental health facilities to facilitate the communication of cancer and emotional coping. Psychological practitioners usually become involved in the care of patients coping with illness at points of crisis, rather than through the complete history of the disease (Jithoo, 2010).

Behavioural coping was used by many of the participants which is congruent with their developmental phase and interest such as watching movies, playing TV games or exercising (within medical limits). These also have the benefits of disengagement and distraction.

6.4 SUMMARY AND INTEGRATION OF QUANTITATIVE AND QUALITATIVE RESULTS

The findings of the quantitative study suggested slightly satisfied to satisfied levels of life satisfaction, as measured on the Satisfaction with Life Scale, for the entire group of children with cancer. This suggests adequate levels of life satisfaction even when compared with children without illness. The findings compared well with the results of international studies of Pavot and Diener (1993) and Bach (2011) as well as a South African study (Basson, 2008). This was further confirmed by the mean scores and standard deviations of the Coping Resources Inventory which compared well with the data obtained by Hammer and Marting (1988) for both healthy and ill high school students with perceived stress. The current group's scores were more comparable with healthy participants (with perceived stress) on the following subscales: Cognitive, Emotional and Spiritual/Philosophical and with healthy high school students for the Social Scale. This finding would suggest that children with cancer use the same coping resources as healthy children to mediate the stress response and that the use of available coping resources is not determined by the illness profile. The quantitative findings highlighted the fact that the most significant resources for the children were social support and information, the latter being a form of cognitive coping which both appear to be associated with higher levels of hope. These results supported the literature that it is possible to attain life satisfaction in spite of a life threatening chronic illness, regardless of the improvement or deterioration of the illness (Horsburgh, 2000). It also supports the literature that indicates that most children with cancer are as psychologically normal as physically healthy children (Chesler & Barbarin, 1987; Zebrack et al., 2007).

The qualitative component of the study provides important information which shows the significant impact of cancer on the child in all aspects of life. Yet it also clearly reflects that, in spite of the impact of illness, satisfaction with life is possible by drawing on available resources and the use of coping strategies. The fact that the selected participants for the qualitative study were all high scorers on the life satisfaction measure confirms this. These results also challenge the medical model paradigm that a person who has a chronic life threatening illness cannot attain a state of well-being in the presence of disease (Lyon, 2000). This is an important finding and supports the urgent need for attention to be paid to the psychological well-being of the child as an important health outcome, in addition to the medical treatment of the disease.

The intercorrelations suggested a strong interdependence between the coping resources supporting literature that shows the interrelatedness of resources. The literature and the qualitative findings support this. Spiritual/philosophical resources, for example, frequently result in social support because of shared beliefs which in turn provide a potential emotional resource (Howsepian & Merluzzi, 2009) and may also facilitate the ventilation of feelings (Birndorf et al., 2005; Eckenrode, 1991; Moos & Schaeffer, 1986). Many of the participants found religious expression with members of their family or extended family a significant form of social and emotional support.

As can be further inferred from the intercorrelations, satisfaction with life was found to correlate significantly with hope and social support (1% level of significance) and cognitive coping at the 5% level of significance. These results indicate that higher levels of hope, social support and cognitive coping are associated with higher levels of satisfaction with life. The literature suggests that hope is considered a significant and unique predictor (Snyder et al., 1991) of adaptive coping modes and is associated with life satisfaction (Snyder, 1997). The importance of hope and social support was further supported by the results of the hierarchical regression analysis. The predictor variables together accounted for 38.9% of the variance of life satisfaction at the 1% level of significance. The two most important contributors to life satisfaction were found to be hope and appraisal of social support.

Further, hierarchical regression analysis found that the four subscales of the Coping Resources Inventory individually or combined only accounted for a small percentage of the

variance in life satisfaction. This is not consistent with existing literature and may be a reflection of this measure for this population of children.

The quantitative findings support the literature which has found social support to be one of the most consistent and strongest predictors of personal adjustment and life satisfaction (Fife, Adegoke, McCoy, & Brewer, 2011; I. Sarason, B. Sarason, & Pierce, 1990). The correlation between hope and satisfaction with life supports the view of Snyder et al. (1997) that hope contributes to well-being. Hope is strongly associated with spiritual/religious coping which in turn is associated with well-being (Burnell, 2006; Frankl, 1969; Gomez & Fisher, 2003; Updegraff & Marshall, 2005). The participants from the qualitative study provided evidence that social support was an important mediator of stress and a powerful resource. There was evidence that participants benefitted from being recipients of social support as well as providing it. In particular, support from the family played an important role in term of emotional and practical support as well as in terms of information provision. The relationship with the doctors was perceived by the children as an important source of support information, provided that the power distance was balanced. The peer group from school and those who were fellow cancer sufferers were shown to be important sources of social support. However, the experiences of the children revealed that these connections were frequently frustrated by the restrictions placed on contact because of immunosuppression, hospital policy and long absences from school. This was exacerbated for those children who lived geographically far from treatment centres. Social support from the community, support organisations and, especially from those with shared religious beliefs, were found to be additional support resources.

A further important finding was with regard to the contribution of the two subscales of the Fortitude Scale, using hierarchical regression analysis. This suggested that the subscales of Family Appraisals and Support Appraisals together only accounted for 11.6 % of the variance in life satisfaction, of which the Support Appraisals accounted for 11.5 % and Family Support Appraisals only 0.1%. This is not consistent with the general trend in the literature where family support is considered the primary source.

An important quantitative finding showed that the difference between children with life threatening illnesses that are rated high and low in life satisfaction is in their sense of hope and appraisal of social support. This is consistent with the literature which notes social

support and hope to be powerful predictors of life satisfaction and thus psychological well-being (Fife, Adegoke, McCoy, & Brewer, 2011; I. Sarason, B. Sarason, & Pierce, 1990; Snyder et al., 1997). The qualitative findings supported the quantitative findings and the literature that hope is associated with life satisfaction and provided insight that in spite of the significant impact of cancer these participants remained hopeful. There was evidence of this in terms of their positive cognitive reformulation of information, health promoting behaviours such as wanting to exercise, fasting and restricted eating programmes, doing schoolwork while ill with a view to returning to school and achieving, and offering support and assistance to fellow cancer sufferers. The quantitative and qualitative findings also supported the literature with regard to the use of cognitive and problem-focused coping by adolescents with chronic illnesses (Frydenberg, 2008). Insight from the qualitative findings reflected the use of a number of variants of cognitive coping of which the most frequent were cognitive reformulation, positive internal dialogue and finding a meaning or purpose for the diagnosis of cancer. To a lesser extent humour was used, which is likely to reflect a developmental perspective.

6.5 CONCLUSION

In this chapter, the quantitative and qualitative results were presented and discussed. The quantitative study used fortigenic measures only, while the qualitative findings clearly reflected the significant impact of cancer on the child and its family, as well as the coping resources and modes of coping that enabled well-being. Combined, the quantitative and qualitative components of this study provided evidence that a state of psychological well-being is possible despite a significant stressor such as cancer. The quantitative component demonstrated a statistically significant correlation between life satisfaction and hope, social support and cognitive coping, as well as the interrelatedness of these coping resources. These variables accounted for 39% of the variance in life satisfaction. The qualitative findings supported the quantitative results regarding hope, social support and cognitive coping as important moderators of stress but provided evidence that other forms of coping are also used by these children such as emotional, relational and religious coping. Both components of this study provided evidence that children with cancer use the same coping resources as healthy children to mediate the stress response and that the use of available coping resources is not determined by their illness profile. The quantitative results also showed that the difference

between children with cancer, rated high and low in life satisfaction, is in their sense of hope and appraisal of social support.

In the next chapter, summaries and conclusions of the literature review and of the quantitative and qualitative components of the study will be presented. Finally, limitations and contributions of this study, recommendations for future research, as well as personal reflections will be outlined.

CHAPTER 7

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

The focus of this study is on the well-being of children with chronic, life threatening illnesses. This study is placed in a positive psychology framework, and has a salutogenic focus, which reflects the paradigm shift in psychology from pathogenesis to salutogenesis. An important implication of this shift is that psychological well-being becomes an additional health outcome to the medical treatment of childhood cancer.

A review of the international literature has indicated that the focus of childhood cancer studies reflect a pathogenic perspective, investigating the impact of cancer and that there are limited studies from a salutogenic perspective focusing on factors that predict well-being in children with cancer, with no identified studies of this nature in South Africa. This study addresses the need for such information.

This chapter will provide a summary and conclusion of the literature review and of the quantitative and qualitative study. Finally, limitations, recommendations, contributions, personal reflections and concluding remarks will be presented.

7.2 SUMMARY AND CONCLUSIONS OF THE LITERATURE REVIEW

The literature reflects a number of important paradigm shifts in psychology providing a theoretical foundation that has shifted the focus from pathogenesis to salutogenesis, resulting in an emphasis on health and well-being rather than disease and pathology (Antonovsky, 1979, 1987). A salutogenic framework is reflected in current stress and coping models where the outcome is psychological well-being. Theorists such as Lazarus (Lazarus

& Folkman, 1984) have made a significant contribution to coping literature, with the inclusion of appraisal as an evaluative process. This has provided a subjective component to the coping process and is central to many of the theoretical models which followed, including concepts such as subjective well-being. Using this as a foundation, Antonovsky (1979, 1987) extended this concept and included additional components such as resistance resources and incorporated a positive outcome into his model, following stress. Moos' model (2002) for youth is the guiding theoretical framework for this study. Based on the principles of his earlier model (1993), it is adapted for children and has application for those with chronic illnesses. It recognises the interplay between personal and contextual variables, the life crisis for example, cancer, and the developmental processes for example, developmental tasks of middle childhood and adolescence, taking place. Contextual factors include aspects of the child's environment which provide access to external resources such as social support networks embedded in the family and community. Personal factors that are unique to the child provide internal resources, including a positive self-esteem, optimism and sense of purpose. Demographic variables which may moderate the child's coping, such as culture and gender, are included. The model incorporates the use of coping behaviours secondary to appraisal. These factors in combination, which have a bi-directional relationship, determine whether the outcome of their interplay results in psychological well-being.

Common to all of these models is a salutogenic orientation, the recognition of individual differences in coping (Lyon, 2000), the notion that stress is a transaction between the person and the environment and that the individual's coping skills and resources have the potential to mediate life stressors (Antonovsky, 1979; Hobfoll, 1989; Lazarus & Folkman, 1984; Moos, 1993, 2002). As a result of these paradigm shifts in stress, there is the recognition that psychological well-being of children with life threatening illnesses is attainable (Lyon, 2000) and that they have the potential to be as psychologically well-adjusted as healthy children (Zebrack, 2007). The literature emphasises that psychological well-being should be an important health outcome, complimenting the medical model that focuses on the treatment of the illness. This is especially important for children with life threatening illnesses such as cancer, as progress in research efforts directed towards causes and risk factors, as well as advances in detection, diagnosis, treatment and supportive care, have resulted in a decrease in cancer mortality (Benaim & Sorrentino, 1996; Long & Marsland, 2011; Ostroff & Steinglass, 1996; Poole, 2003). As a result, there is evidence that there are more children living with cancer than dying from it and thus the literature notes that

quality of life issues require more attention. It is emphasised in the literature that the dramatic improvement in survival is only worthwhile if life quality justifies increased prolongation of that life (Chesler & Barbarin, 1987; Insel & Moos, 1974).

The literature on childhood cancer provides evidence of the significant physical, emotional and social impact of diagnosis and treatment on the child, including the systems to which it belongs, of which the family is primary (Chesler & Barbarin, 1987; Engel & Melamed, 2002; Long & Marsland, 2011). The developmental literature on middle childhood and adolescence also provides evidence of the extensive and rapid physical cognitive, emotional, moral and social developmental tasks and challenges taking place. While debate in the literature exists as to whether the pre-adolescent and adolescent periods of development are times of stress or involve normative transitions, the general consensus is that these developmental periods require significant adjustment (Frydenberg, 2008). The convergence of challenging developmental demands and the significant impact of cancer on the developing child, for example, hair loss from chemotherapy at a time when identity development, self-esteem and peer acceptance are primary developmental tasks, might increase the child's risk for potentially negative outcomes (Chesler & Barbarin, 1987; Orr, Weller, Satterwhite, & Pless, 1984). Isolation from peers because of disrupted schooling, hospital policy or immunosuppression, at a time when there is a stronger reliance on the peer group for social identity (Chesler & Barbarin, 1987; Engel & Melamed, 2002), is another example.

However, in spite of the significant stressors the child with cancer faces, the literature provides evidence that coping resources and coping strategies have the potential to moderate stress and result in well-being. Commonly used internal coping resources by children with illnesses include spirituality (Cotton et al., 2009; Pendleton, Kamper, Van Cleve, & Savedra, 2010), hope (Snyder et al., 1997) and self-esteem (Jonovska et al., 2009). External coping resources that they draw upon include social support (Engel & Melamed, 2002; Shephard & Mahon, 2002), age appropriate information about the illness and prognosis (Chesler & Barbarin, 1987; Clarke et al., 2005; Jithoo, 2010) and access to basic medical and mental health support and services (Kruger & Coetzee, 2011). There is evidence that diverse coping strategies are used by children depending on their appraisal of the stress situation and their personal characteristics and abilities (Wenger, Sharrer, & Lynd, 2000). Cognitive coping and problem-focused coping was found to be commonly used by adolescents with chronic

illnesses (Frydenberg, 2008). Behavioural coping strategies were found to be important for managing chemotherapy-induced nausea and vomiting (Moore, 2002). The most frequently used emotion-focused coping strategies for the management of nausea in children included wishful thinking, emotional regulation, distraction and seeking social support (Moore, 2002).

Globally, there seems to be a dearth of information on the positive adjustment of children with life threatening illness. In South Africa very little information is available on the psychological adjustment of these children, mainly because of the limited focus on the mental health care and support of cancer patients. The aim of the current study was therefore a focus on the psychological adjustment of the children and specifically on potential positive mental health outcomes, such as life satisfaction and effective coping.

7.3 SUMMARY AND CONCLUSIONS OF QUANTITATIVE AND QUALITATIVE RESEARCH FINDINGS

The goal of this study was to develop an understanding of the construct of life satisfaction as experienced by a group of children with cancer, as representative of children with chronic, life threatening illnesses.

The research objectives of the quantitative component of the study were to determine the level of well-being and extent of the coping resources reported by the participants, to describe the relationship between the predictor variables (hope, coping resources and fortitude) and well-being (life satisfaction), to investigate the contribution of the predictor variables to the variance in the life satisfaction of the participants, and finally, to compare the groups of participants with low and high levels of life satisfaction with regard to hope, fortitude and coping resources.

There were two research hypotheses: the first is that the levels of fortitude, coping resources and hope of children with chronic, life threatening illnesses are significantly related to their life satisfaction and secondly that significant differences in the average fortitude, coping resources and hope scores exist between children with high and low levels of life satisfaction respectively.

The research findings demonstrated that the levels of life satisfaction of the participants were in the slightly satisfied to satisfied levels of life range on the Satisfaction with Life Scale. These scores compared favourably with overseas groups (Pavot & Diener, 1993; Bach, 2011) as well as a South African group (Basson, 2008) of healthy children. The group from which the qualitative participants were recruited reflected high levels of life satisfaction. Comparisons of the mean and standard deviations of this study and those obtained by Hammer and Marting (1988) on the Coping Resources Inventory suggested that the scores of this group were more comparable with healthy children (with perceived stress) than with ill children. The qualitative information provided evidence of the children's life satisfaction as they were looking forward to getting back to school and seeing their peers, showed an interest in exercise and in life in general. These are important findings for the field of psychology and psycho-oncology as it reflects the potential for children with such illnesses to attain psychological well-being. It is also consistent with the literature that suggests that a state of psychological well-being is attainable in the presence of disease (Horsburgh, 2000) and that children with cancer can be as psychologically well-adjusted as their healthy peers (Chesler & Barbarin, 1987; Zebrack, 2007).

The relationship between the predictor variables (hope, coping and fortitude) and life satisfaction was established as well as between the predictor variables. These results demonstrated that life satisfaction correlated with hope and social support at the 1% level of significance and with cognitive coping at the 5 % level of significance. All statistically significant intercorrelations had at least medium effect size. These results suggest that higher levels of social support, hope and cognitive coping are associated with satisfaction with life. The importance of hope and social support was further supported by the results of the hierarchical regression analysis. The predictor variables together accounted for 38.9% of the variance of life satisfaction at the 1% level of significance. The two most important contributors to life satisfaction were found to be hope and appraisal of social support. This is consistent with the literature which suggests that life satisfaction is associated with hope (Snyder et al., 1997), social support (I. Sarason, B. Sarason, & Pierce, 1990; Fife, Adegoke, McCoy, & Brewer, 2011) and cognitive coping (Hobfoll, 1988; Holahan & Moos, 1987a). There was evidence from the qualitative interviews that the children demonstrated indicators of hope. These included a future orientation in terms of looking forward to returning to school, wanting to exercise and engaging in healthy eating programmes. In addition, social support from the family and other sources was important. Doctors, peers and fellow cancer

sufferers were important sources of support, provided that the quality of the relationship was good. The use of cognitive coping strategies was evident, particularly cognitive reformulation, finding meaning, and internal positive dialogue.

The results of the hierarchical regression analysis indicated that the four subscales of the Coping Resources Inventory individually or combined only accounted for a small percentage of the variance in life satisfaction. This finding is not consistent with literature (Alvord & Grados, 2005; Hobfoll, 1998; Masten, 2001) that emphasises the role of coping resources in the enhancement of well-being. While it is possible that the instrument may have had limitations for use with a South African group of children, consideration has been given to the possibility that the nature of social support and other resources for many of this group of children may be different to Eurocentric groups. Alternatively this result may be explained by the strong intercorrelations between the coping resource subscales and the subscales of hope and social support, which may have masked the contribution of the coping resource subscales to the variance in life satisfaction.

The intercorrelations also suggested a strong interdependence between the coping resources, supporting literature that shows the interrelatedness of resources (Birndorf et al., 2005; Eckenrode, 1991; Howsepian & Merluzzi, 2009; Moos & Schaeffer, 1986). The literature and the qualitative findings support this. Many of the children provided evidence in the qualitative interviews that social support provides emotional support or that religious coping is often associated with social and emotional support. The benefit of this knowledge is that the facilitation of social support, for example, by those who work with children with cancer, may also improve access to other resources such as information.

A relevant finding of this study was that support appraisals from the Fortitude Scale accounted for 11.6% of the variance of life satisfaction. However, the Family Appraisals subscale accounted for 0.1% while the Support Appraisals subscale was 11.5%. It was noted that this is not consistent with the general trend in the literature as the family is usually considered the primary source of social support. It is possible that these results may reflect a cultural component in terms of a broader definition of family and that support is being drawn from a wider net than the nuclear family. The qualitative findings supported this possibility as especially in rural Black families, the nuclear family was not always the primary source of support but included relatives and known members of the community. This is explained by

Mwizenge (1988) who notes the system of kinship, which seems common to virtually all the peoples of Central and Southern Africa including the Zulu of South Africa (of which the majority of the participants are), is that all brothers of the father are called "father", all sisters of the mother are called "mother", all their children "brother" and "sister". He stated that the basic family unit is not the nuclear family. Knowledge of this nature is relevant to the health care team and would lead to a greater understanding of the possible involvement of others in the care of the child.

A central finding of this study is that the difference between children with high and low levels of life satisfaction lies in their appraisal of social support and in their sense of hope. This information is valuable as children who are diagnosed and who have the services of mental health professionals available to them can be evaluated in terms of their life satisfaction. Children who fall in the low category can be identified for intervention which should include the consideration of the child's resources and coping skills.

Based on the above findings the objectives of the study were met. Both hypotheses 1 and 2 were partially accepted.

While the quantitative findings focused on salutogenic measures, the results of the qualitative component of the study reflected the profound impact of the diagnosis and treatment of cancer and the significant disruption to the child's world, at a time when extensive developmental tasks are being accomplished. The qualitative and quantitative components of the study complimented one another, with the qualitative component providing rich information which allowed insight into the personal experiences of the children.

7.4 LIMITATIONS OF THIS STUDY

A number of limitations are acknowledged. Due to the small data pool and practical obstacles in recruiting participants, the sample size was small. Generalisability of the results may have been affected, although it is noted that results of this study are consistent with the general trends in the literature. While extending the study to other treatment centres in South Africa may have yielded a larger representative sample, a decision was made to restrict it to

the two selected geographic regions, as the researcher lives a significant distance away from the other major centres and this would have made control and gathering of data difficult.

The developmental distinction between children in the middle childhood and adolescent phases of development is noted. However, in view of the challenges of participant recruitment, these groups were combined. Noting the social and cognitive realities of children in different stages of development, future research which separates these groups may provide information which is more developmentally specific.

For the majority of the participants, it was necessary to use translated versions of the quantitative measures and a translator was required for the administration of the questionnaires as well as many of the qualitative interviews. While steps were taken to ensure that the translators were trained in the administration of the questionnaires and that the administration was conducted in a respectful and ethical manner, that they were aware of the focus of the study and that it was important for them to convey only the information presented by the participant, it is acknowledged that complete control over the interaction and translation process is not possible. As the researcher was aware of these limitations, she was present at all of the interviews (81.8%) conducted in Durban.

It is noted that, with the exception of the Fortitude Scale which was developed in South Africa, the measuring instruments used in this study were developed in America, reflecting Western and individualistic conceptions of certain constructs such as self-esteem. However, three out of four of these measures had been used in studies on children in South Africa and one (Coping Resources Inventory) had been used in an adult cancer study. As 73% of the research participants are Black, it is acknowledged that some of the test items may not be as relevant to them and culturally sensitive. The use of measures specific to South African children, when they become available, would be an added advantage.

This study only used indices of well-being in the quantitative component of this study. The inclusion of pathogenic measures assessing potential negative outcomes such as depression and anxiety might have strengthened the quantitative results of the study. The qualitative component of the study highlighted the fact that an understanding of the impact of cancer, as well as coping and well-being, is important.

The cross section of participants in state and private hospitals was notably different. A measure of socio-economic status, and consideration of this as a correlate of well-being, would have provided an added dimension to this study. Difficulties obtaining access to the target population served as an important constraint to include larger numbers of participants, which limited use of various moderating variables such as socio-economic status and ethnicity in the quantitative study.

7.5 RECOMMENDATIONS

7.5.1 Recommendations for future research

- A longitudinal study of children with cancer is recommended. In addition to in-depth knowledge of the impact of cancer, coping resources and coping strategies used over time, developmental changes could be tracked. In addition, the inclusion of a larger sample is suggested where more sophisticated statistical methods could be employed. As the positive psychology discipline is growing, it is recommended that funding is made available for research and that academic/research institutions prioritise the development of well-being measures that are relevant for South African children
- A replication of this study is recommended using South African measuring instruments, when they become available. This would allow comparisons to be made regarding the use of coping resources, coping strategies and levels of well-being using culturally sensitive instruments.

7.5.2 Recommendations for practice

- Children with cancer should be treated in dedicated paediatric oncology facilities. This includes adolescents who are usually treated in adult wards, in view of age criteria. Ideally, nursing staff should be paediatrically trained and have experience in oncology.
- The findings of the study are important to assist medical professionals, health care workers and family members to understand that, although cancer is a

serious life threatening condition, it is possible to attain a state of psychological well-being. The need for the inclusion of relevant literature, such as contained in this study, is important for training modules for doctors and allied professionals such as nurses. It is recommended that such information is incorporated into the curriculum. In addition, dissemination of this information to parents, volunteers, support groups and support organisations is recommended.

- Due to the limited resources available, especially in State hospitals, the training of volunteers is recommended who can assist with visiting the children, providing age appropriate stimulation and offer support to the children.
- As the literature highlights the fact that the majority of children with cancer will be survivors, and the emphasis is on quality of life, in view of the disruption to schooling and academic gaps, it is strongly recommended that treatment centres have facilities which address this issue. Ideally, a hospital school should be considered. If funds are restrictive, an educational programme supported by educational volunteers is recommended.
- Programmes which incorporate the facilitation of coping skills in children is recommended.
- The literature has highlighted the fact that a significant number of parents seldom communicate with their children about the illness beyond factual information. The need for mental health services is important if the well-being of the child is prioritised as a health outcome. It is strongly recommended that, from diagnosis, psychosocial services are available and are not used only when adjustment difficulties are encountered. Ideally at each centre, a mental health professional should be part of the treatment team.

7.6 CONTRIBUTIONS OF THIS STUDY

This is the first study in South Africa to research predictors of well-being in children with cancer. This study has made an academic contribution to the field of psychology and psycho-oncology but the contribution extends to a human level, as the knowledge will assist in the promotion of quality of life. Raising the level of awareness that psychological well-

being is an essential health outcome is important, as in South Africa, there are few resources for psychosocial interventions and the medical treatment is the focus. From diagnosis, two health outcomes should be considered: the treatment of the disease and the child's psychological well-being. As the findings of this study have application to children with life threatening illnesses in general, in view of the significant number of children in South Africa with life threatening illnesses including HIV Aids, the incorporation of this information into health care policies and intervention programmes will make a further contribution. The abovementioned knowledge is relevant for clinical practice. The information regarding these predictors can be incorporated in intervention programmes. Measures of these variables can be used to identify at risk children.

In addition to the contribution that this study will make to the body of knowledge in South Africa, it will address the gaps of limited international research into the predictors of psychological well-being in children with illnesses, and specifically cancer.

7.7 PERSONAL REFLECTIONS

There were personal challenges in dealing with a population of children with cancer especially when, in addition to the cancer, their circumstances reflected extreme poverty, evidence of poor nutrition or there was information about a child-headed household. For many of the children in state hospitals, due to their circumstances, they were in hospital without a significant other for extended periods and had limited knowledge of when visitations or contact would occur. As I had a personal investment in this study, dealing with the death of some of the participants was challenging, especially one of the participants who had been part of the qualitative study.

In my professional dealings in paediatric oncology, the time spent with the children, especially in the qualitative interviews and for those that requested counselling, was valuable. I gained insight which will enrich my professional contact with both the children and their families. The knowledge that I gained from the literature, supported by the qualitative interviews regarding the disclosure of information, was particularly relevant. When working cross-culturally, rather than working with the Western assumption that full disclosure is essential for adjustment, working within the child's cultural framework and establishing what

it is the child wants to know and requesting permission to be able to provide it, will be implemented. This is knowledge that will be discussed with medical professionals I am in contact with, especially those that work in cross-cultural contexts.

As the study was largely from a developmental perspective, reading the literature and dealing with a homogenous group of children with cancer crystallised the needs of the children for me. As I am based in a paediatric oncology unit on a weekly basis and I have had a long-term involvement with CHOC (Childhood Cancer Foundation), raising awareness to management, doctors, nurses and organisations which fund and support children with cancer, of the needs of the children and providing them with a developmental perspective, will be a priority.

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APPENDIX A

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



Direkteur: Fakulteitsadministrasie / Director: Faculty Administration
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Ms H Strauss

2007-05-25

MS B TALBOT
14 DARTMOUTH ROAD
GLENWOOD
4001

Dear Ms Talbot

ETOVS NR 80/07
RESEARCHER: MS B TALBOT
PROJECT TITLE: THE PREDICTION OF PSYCHOLOGICAL WELL-BEING
CHILDREN AND ADOLESCENTS WITH CHRONIC, LIFE-THREATENING ILLNESS.

- You are hereby informed that the above-mentioned study was approved by the Ethics Committee on 22 May 2007 on condition that the information Leaflet and Informed Consent have to be available in the language of choice.
- The following documents are used by the Ethics Committee as guidance documents: Declaration of Helsinki, ICH, GCP and MRC guidelines on bio medical research, Clinical trial guidelines 2000 Department of Health RSA; Ethics in Health Research: Principles structure and processes Department of Health RSA 2004, the Constitution of the Ethics Committee of the Faculty of Health Sciences and the guidelines of the S.A. Medicines Control Council as well as laws and regulations with regard to the Control of Medicines.
- Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
- The Committee must be informed of any serious adverse event and/or termination of the study.
- A progress report should be submitted within one year of approval of longterm studies and a final report at completion of both short term and long term studies.
- Please refer to the ETOVS reference number in correspondence to the Ethics Committee secretariat.

Yours faithfully

for 
PROF BB HOEK
CHAIR: ETHICS COMMITTEE



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

Fakulteit Geesteswetenskappe / Faculty of the Humanities
Departement Sielkunde / Department of Psychology



CONSENT TO PARTICIPATE IN RESEARCH

Your child has been asked to be part of a research study.

You have been informed about this study by _____.

You can contact Brenda Talbot at 031 261 1461 at any time if you have questions or concerns about the research. A person who speaks your language will be available to address your concerns.

You may contact the Secretary of the Ethics Committee of the Faculty of Health Sciences, University of the Free State at telephone number 051 405 2812 if you have questions about your child's rights as a research subject.

Your child's participation in this research is voluntary and you can stop his / her participation in this research at any time.

If you agree to allow your child to participate you will be given a signed copy of this document and an information sheet, which is a written summary of the research.

This is to confirm that the research study and the above information have been explained to me verbally. I understand what my child's involvement in the study means and I give permission for him / her to participate.

Parent/Guardian's Name

Signature

Date

Witness' Name

Signature

Date

Translator's Name

Signature

Date

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



Fakulteit Geesteswetenskappe / Faculty of the Humanities
Departement Sielkunde / Department of Psychology

PERMISSION TO PARTICIPATE IN RESEARCH

You have been asked to be part of a research study.

You have been informed about this study by _____

You can contact Brenda Talbot at (031) 26 11461 at any time if you have questions or concerns about the research. A person who speaks your language will be available to address your concerns.

You may contact the Secretary of the Ethics Committee of the Faculty of Health Sciences, University of the Free State at telephone number (051) 405 2812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary and you can stop your participation in this research at any time.

If you agree to participate you will be given a signed copy of this document and an information sheet which is a written summary of the research.

This is to confirm that the research study and the above information have been explained to me verbally. I understand what my involvement in the study means and I give my permission to participate.

PARTICIPANT'S NAME

SIGNATURE

DATE

WITNESS' NAME

SIGNATURE

DATE

TRANSLATOR'S NAME

SIGNATURE

DATE

RESEARCH STUDY BIOGRAPHICAL DATA

Researcher
BRENDA TALBOT

Section 1: BIOGRAPHICAL INFORMATION To be completed by the parent / guardian

RECORD NUMBER

1. HOSPITAL

Albert Luthuli – Durban	1
Universitas - Bloemfontein	2
Private Hospital - Durban	3

2. CHILD'S GENDER

Male	1
Female	2

3. CHILD'S AGE IN YEARS

4. CHILD'S ILLNESS / DIAGNOSIS

5. HOW MANY MONTHS SINCE DIAGNOSIS

6. CHILD'S HOME LANGUAGE

English	1
Afrikaans	2
Xhosa	3
Zulu	4
Sesotho	5
Other (specify)	6

7. CHILDS EDUCATION

(What was the last grade passed?):

Grade 1 - 3	1
Grade 4 - 7	2
Grade 8 - 10	3
Grade 11 - 12	4

OFFICE USE

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1 - 3

4

--	--

5 - 6

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7 - 8

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9 - 11

12

13

8. PARENT INFORMATION

Both parents alive	1	14
One parent alive	2	
Neither parent alive	3	

9. PARENTS' EDUCATION (Highest educational level):

(a) Mother	No Formal Education	1	15
	Primary School	2	
	High School	3	
	Post Matric	4	

(b) Father	No Formal Education	1	16
	Primary School	2	
	High School	3	
	Post Matric	4	

10. MARITAL STATUS OF PARENTS:

Married	1	17
Divorced	2	
Single Parent	3	
Separated	4	
Widowed	5	
Customary Marriage	6	
Common Law Marriage	7	

11. EMPLOYMENT STATUS OF PARENTS:

(a) Mother	Permanent Employment	1	18
	Temporary Employment	2	
	Self Employed: formal sector	3	
	Self Employed: informal sector	4	
	Unemployed	5	

(b) Father	Permanent Employment	1	19
	Temporary Employment	2	
	Self Employed: formal sector	3	
	Self Employed: informal sector	4	
	Unemployed	5	

12. DOES THE CHILD ATTEND A PLACE OF WORSHIP **20**

Yes	1
No	2

13. IF APPLICABLE, HOW OFTEN DOES HE / SHE ATTEND RELIGIOUS CEREMONIES?

21

Weekly or more	1
Monthly	2
Occasionally	3
Not at all	4

14. DURING HIS / HER STAY IN HOSPITAL HOW OFTEN DO YOU HAVE CONTACT WITH HIM / HER?

22

Daily	1
Weekly	2
Monthly	3
Less than once a month	4

APPENDIX E

Semi Structured Interview

- Rapport Building
- Orientation towards study
- Interview format
- Permission to record

Can you tell me how long it has been since you found out that you were sick? What do you remember most about that time? What were you told at that time? Who was it that told you about this?

Did they tell you too much, too little, or did they tell you enough for you to understand? Has anyone told you about your treatment? If not what is it that you would like to know? Can you help me to understand a little more about your treatment?

Do you like having people that you can talk to about being ill? Who is it that you talk to? Does it help you after you have spoken to someone? How does it help?

Do you have feelings about being sick (feelings like cross, sad, worried)? What is that you do when you have these feelings?

Can you think of one or two people that help you with your illness. Can you tell me who they are? What is it that they do that helps you?

Do people in your family help you? Who helps you the most? If so, what is it that they do that helps you the most? If not, what is it that you would like them to do?

Do your friends help you in any way? If so, what is it that they do that helps you? If not, what would you like them to do?

Do people from your school help you in any way? If so, how do they do that? If not, how could people from your school help you?

Do people in the area where you live help you in any way? If so, what is it that they do that helps you? If not, what is it that they could do that would help you?

Is there any group (like a church or CHOC) that visits you while you are in hospital or at home when you are ill? If so, which one and what do they do that you like and how does it help you? If not, would you like these kinds of visits?

Is there anybody or anything that you believe in that helps you when things are difficult for you? (explain). What is it that you believe in? How does ... help you?

Is there anything that you can think of that will help me to understand a little more about what it has been like for you? If there was one thing that you remember the most what would that be?