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**Applicability of the Integrative Framework of Stress and Coping
to the Experiences of Mothers of Children with Acute
Lymphoblastic Leukaemia in the Developing World**

by

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In memory of a dear friend,

Kariena van Niekerk

1987 – 2004.

(A brave cancer fighter)

Declaration by Language Editor

30 October 2017

To whom it may concern

I hereby declare that I have proofread and language edited (English) the article
APPLICABILITY OF THE INTEGRATIVE FRAMEWORK OF STRESS AND COPING
TO THE EXPERIENCES OF MOTHERS OF CHILDREN WITH ACUTE
LYMPHOBLASTIC LEUKAEMIA IN THE DEVELOPING WORLD by Lerie Nel to the
best of my ability.

However, it remains the client's responsibility to effect the suggested changes.

Yours sincerely

Lorene van Wyk

MA Language Practice (UFS)

Student Declaration

I declare that the dissertation (article format) hereby submitted by me for the Magister Artium (Clinical 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 further cede copyright of the dissertation in favour of the University of the Free State.



Lerie Rissa Nel

Date: 30/10/2017

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Abstract

The diagnosis of acute lymphoblastic leukaemia (ALL) in children is a distressing experience that has been associated with caregiver strain and decreased parental well-being. A large proportion of mothers caring for children receiving treatment for ALL live in low-and middle-income countries. The contextual challenges these individuals face, as well as the specific coping strategies they employ have received scant research attention. Similarly, no attempt appears to have been made to apply existing theoretical perspectives on stress and coping to the understanding of these women's experiences. Consequently, the current study aimed to explore the applicability of an Integrative Framework of Stress and Coping (IFSC) within the context of mothers caring for a child undergoing maintenance treatment for ALL in a developing country. A multiple case study design was employed, and six participants were recruited from the database of a paediatric oncology unit at a large academic hospital. Semi-structured interviews were conducted with the mothers and deductive thematic analysis was used to analyse the data. Results suggest that mothers in the current study experienced significant contextual (environmental) challenges in the form of cultural power imbalances and socioeconomic difficulties. Dispositional factors, together with participants' historical backgrounds, appeared to influence their appraisals of the diagnosis and disease trajectory which, in turn, impacted their ability to effectively cope as caregivers. Passive coping seemed a customary stress response for these women that did little in terms of promoting their well-being. In general, participants seemed to predominantly experience poor psychological health. Findings from this study suggest that the IFSC holds utility for the conceptualisation of both individual components and integrative processes influencing maternal coping with paediatric cancer in a developing world context.

Keywords: Acute lymphoblastic leukaemia (ALL); paediatric cancer; maternal coping; Integrative Framework of Stress and Coping; thematic analysis; developing world; psycho-oncology

Opsomming

Die diagnose van akute limfoblastiese leukemie (ALL) in kinders is 'n ontstellende ervaring wat verband hou met versorgerspanning en 'n afname in ouerlike welsyn. 'n Groot deel van moeders wat sorg vir kinders wat onderhoudsbehandeling ontvang vir ALL, woon in lae- en middelinkomste gebiede. Die kontekstuele uitdagings wat hierdie individue in die gesig staar, sowel as die spesifieke hanteringstrategieë waarvoor hulle beskik, is nog nie nagevors nie. Net so is daar tot dusver geen poging aangewend om bestaande teoretiese perspektiewe op stres en die hantering daarvan toe te pas op die begrip van hierdie vroue se ervarings nie. Gevolglik het die huidige studie daarop gemik om die toepaslikheid van 'n Integreerende Raamwerk van Stres en Hantering (IFSC) te ondersoek binne die konteks van moeders wat sorg vir 'n kind wat onderhoudsbehandeling vir ALL in 'n ontwikkelende gebied ondergaan. 'n Meervoudige gevallestudie-ontwerp is toegepas en ses deelnemers is gewerf uit die databasis van 'n pediatriese onkologie-eenheid by 'n groot akademiese hospitaal. Semi-gestruktureerde onderhoude is met die moeders gedoen en deduktiewe tematiese analise is gebruik om die data te analiseer. Resultate dui daarop dat moeders in die huidige studie aansienlike kontekstuele (omgewings) uitdagings ervaar het in die vorm van kulturele-magswanbalanse en sosio-ekonomiese probleme. Wisselvallige faktore, tesame met die historiese agtergrond van deelnemers, het hul evaluasies van die diagnose en siektetrajek beïnvloed wat op hul beurt hul vermoë om as versorgers effektief te hanteer, beïnvloed het. Passiewe hantering was 'n gewoontestresreaksie vir hierdie vroue wat min gedoen het ten opsigte van die bevordering van hul welsyn. Oor die algemeen blyk dit dat deelnemers swak sielkundige gesondheid ervaar. Bevindinge van hierdie studie stel voor dat die IFSC nuttig is vir die konseptualisering van beide die individuele komponente en integreerende prosesse wat die moederlike hantering van pediatriese kanker in 'n ontwikkelende wêreldkonteks beïnvloed.

Sleutelwoorde: Akute limfoblastiese leukemie (ALL); kinderkanker; moederlike hantering; Integreernde Raamwerk van Stres en Hantering; tematiese analise; ontwikkelende wêreld; psigo-onkologie

Introduction

Childhood cancer is a significant international health concern with approximately 215 000 new cases diagnosed annually (International Agency for Research on Cancer, 2016). More than 80% of childhood cancers are reported to occur in low- and middle-income countries (Rodriguez-Galindo et al., 2015). In South Africa – an upper middle-income country – between 1987 and 2007, the age-standardised average annual incidence for all malignancies in children younger than 15 years was 45 per million (Stefan et al., 2015). This amounts to a substantial number of paediatric oncology cases considering that the current child population in South Africa is roughly 17 million (Statistics South Africa, 2016; World Bank Group, 2016).

Leukaemia is the most common form of childhood cancer globally, as well as in South Africa (Kotecha, Kees, Cole, & Gottardo, 2015; Stefan, 2010). Acute lymphoblastic leukaemia (ALL) accounts for the majority of paediatric cancer diagnoses in the USA (Siegel, Miller, & Jemal, 2017). Similarly, at a prevalence of eight per million, ALL accounts for the majority of childhood cancers diagnosed in South Africa (Stefan et. al, 2015). Recent advances in diagnosis and treatment have significantly improved the prognoses of children diagnosed with ALL. Reported five-year survival rates in the developed world approach 90%. By comparison, five-year survival rates in many low- and middle-income countries, while historically much improved, remain below 60% (Allemani et al., 2015; Hunger et al., 2012). The South African five-year survival rate for paediatric leukaemia is estimated at 48.8% (Stones, De Bruin, Esterhuizen, & Stefan, 2014). Notwithstanding the disparity in survival rates between the developed world and the developing world, globally more children than ever are being diagnosed and effectively treated for childhood cancers like ALL (Armstrong et al., 2016).

Treatment of ALL typically involves three distinct phases that routinely span three to four years (Cooper & Brown, 2015; Inaba, Greaves, & Mullighan, 2013). The initial one-month remission-induction phase of treatment aims to destroy all cancer cells and restore normal haematopoiesis. This phase of treatment is associated with increased risk for complications and infections. Frequent doctor visits or hospitalizations for the entire induction phase are not uncommon (Cooper & Brown, 2015; Mitchell et al., 2016). In the second phase patients typically receive a combination of several chemotherapies until remission is achieved. This phase of treatment may last anywhere from one to nine months. Once in remission, the patient typically enters a two- to three-year maintenance phase during which low dosage oral or intravenous chemotherapy is administered (Hunger & Mullighan, 2015; Inaba et al., 2013). Usually a parent or primary caregiver oversees maintenance treatment at home. However, weekly or monthly hospital visits may be indicated, depending upon the patient's specific risk for relapse (Lau et al., 2014; Sung et al., 2011).

Adjusting to a paediatric cancer diagnosis is overwhelming for parents (Rosenberg et al., 2013; Shortman et al., 2013). Treatment must often be initiated immediately, leaving parents little time to adjust to the complex medical world of ALL and the role of caregiver to a child undergoing long term medical treatment (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010; Sposito et al., 2015). The maintenance treatment that children with ALL undergo means that parents have the additional responsibility of being actively involved in their treatment and management for an extended period of time (Hunger et al., 2012; Lau et al., 2014).

The dual role of parent and medical caregiver to a child undergoing extended cancer treatment presents significant challenges (Granek et al., 2014; Jones, 2012; Kohlsdorf & Costa Junior, 2012). Parents incur transport costs with regard to medical facility access, as well as accommodation while the child is hospitalized. Family incomes are often reduced by

one parent downscaling or giving up their employment in order to care for the sick child. Disruption of family life and a lack of social support are frequently reported by parents (Granek et al., 2014; Lau et al., 2014). Furthermore, considerable time and energy are required for parents to meet the medical, physical, and psychological needs of their ill child, while attempting to maintain normal family cohesion and routines (Barakat, Marmar, & Schwartz, 2010; Jones, 2012). Medically, parents view the administration of medication, maintenance of catheters, infection control, feeding difficulties, and unforeseen visits to the emergency room as stressors synonymous with childhood cancer (Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011; Kelly & Kelly, 2013). Specific psychosocial challenges include addressing issues their child experiences with regard to their mortality, changes in peer relationships, the impact of treatment on school functioning, and chemotherapy related mood lability (Bates & Kearney, 2015; Thompson et al., 2015; Williams & McCarthy, 2015).

Caring for a child undergoing cancer treatment negatively impacts upon parental psychological health. Anxiety, anger, depression, pervasive feelings of powerlessness, and self-blame are frequently reported (Naidoo et al., 2016; Rosenberg et al., 2013; Sultan, Leclair, Rondeau, Burns, & Abate, 2016). Parents typically associate these emotional states with a perceived inability to balance their ill child's needs with the emotional and physical demands of the rest of the family (Kelly & Kelly, 2013; Williams & McCarthy, 2015). Other significant stressors include domestic and occupational role strain, caregiver burnout, marital conflict, and sibling neglect (Demirtepe-Saygili & Bozo, 2011; Shortman et al., 2013; Silva-Rodrigues, Pan, Pacciullo Sposito, De Andrade Alvarenga, & Nascimento, 2016).

The extensive literature on parental adjustment in paediatric cancer appears to focus primarily on the nuclear family within first world contexts (Sultan et al., 2016). However, Naidoo and colleagues (2016), point out that in the developing world the caregiver burden in paediatric cancer falls primarily on mothers. Moreover, caregivers from low- and middle-

income countries tend to face challenges very different from those experienced by mothers in the developed world (Edwards & Greeff, 2017; Hopkins, Burns, & Eden, 2013; Sitaresmi, Mostert, Schook, Sutaryo, & Veerman, 2010). The experiences of mothers of children being treated for cancer in the developing world thus appear to have been less extensively researched. In addition, the exploration of maternal adjustment to paediatric cancer in developing world contexts from within a systematic theoretical framework of stress and coping appears to have been largely ignored (Klassen et al., 2011; Lin, Yeh, & Mishel, 2010).

Moos and Holahan (2003) have proposed a conceptually integrated framework of stress and coping. This framework combines dispositional and contextual perspectives on coping in order to better understand how the relationship between significant life stressors and health outcomes might be mediated. The model shown in Figure 1 depicts the Integrative Framework of Stress and Coping (IFSC) hypothesised by Moos and Holahan (2003) and highlights four components central to the understanding of how individuals adjust to the challenges they face: (a) the environmental system, (b) the personal system, (c) transitory conditions, and (d) cognitive appraisals and coping responses.

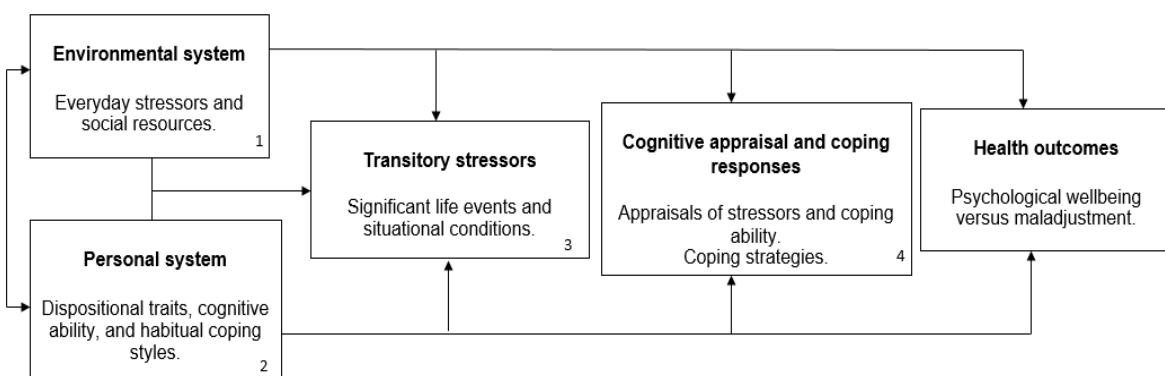


Figure 1. A model of the IFSC depicting the interplay among key components. Adapted from “Dispositional and Contextual Perspectives on Coping: Toward an Integrative Framework”, by R. H. Moos and C. J. Holahan, 2003, *Journal of Clinical Psychology*, 59(12), p. 1393. Copyright 2003 by Wiley Periodicals, Inc.

Moos and Holahan (2003) view the environmental (contextual) system as relatively stable and comprising ongoing life stressors, as well as the social resources at the individual's disposal. The personal system consists of dispositional factors such as personality traits, cognitive abilities and preferred coping responses. These two systems form the broader environmental and individual contexts within which transitory conditions such as situational stressors are experienced. They also form the context within which the cognitive appraisal of these transitory conditions, as well as the selection and implementation of associated coping responses, occur. Viewed directly, the use of specific coping responses exerts an influence on the health and well-being of the individual. However, this linear perspective is limited. Moos and Holahan (2003) emphasize the interactional nature of the model in that each component of the IFSC is influenced by and in turn, influences all other components via a series of bidirectional feedback loops.

The IFSC has previously been applied to the study of adults with cancer (Bauer et al., 2016; Ptacek, Pierce, & Ptacek, 2007). A review of the literature on caregiving in paediatric cancer suggests that the IFSC might also prove useful in understanding stress, appraisal and coping in this population. At the level of stable contextual factors, Shortman and colleagues (2013) found that assistance caring for the sick child, sufficient financial resources, adequate access to transport, and information from healthcare providers were positively associated with maternal coping and psychological well-being. Emotional support, particularly from other parents of children with cancer, has been linked to lower levels of perceived isolation and improved mental health outcomes more generally (Gage, 2013; Naidoo et al., 2016). Conversely, low socioeconomic status and limited social resources have been associated with poor mental health outcomes (Bemis et al., 2015; Stoppelbein, Greening, & Wells, 2013).

According to Moos and Holahan (2003), the personal system contains dispositional factors that influence individuals' ability to adjust successfully to a stressor. Self-efficacy,

optimism and humour have all been associated with more positive parental adjustment to paediatric cancer (Gardner et al., 2017; Harper et al., 2013; Shortman et al., 2013). By contrast, elevated trait anxiety and pervasive feelings of powerlessness have been related to parental distress and maladjustment (Calderón et al., 2011; Edwards & Greeff, 2017). Hullmann, Fedele, Molzon, Mayes, and Mullins (2014) have linked dispositional hope to seeking social support, as well as to the improved parental adjustment to treatment in paediatric cancer. Religious coping has been shown to buffer against the strains of maternal caregiving for a child with cancer (Elkin et al., 2007). Furthermore, social support seeking (Fletcher, Schneider, & Harry, 2010) and coping that emphasises family integration (Han, Cho, Kim, & Kim, 2009) have been found to result in reduced family dysfunction and to improve maternal well-being. Dispositional coping strategies that do not facilitate emotional regulation have been associated with increased risk for maternal depression (Gardner et al., 2017; Rodriguez et al., 2016).

Moos and Holahan (2003) view transitory conditions as the primary catalyst in the stress and coping relationship. These conditions usually force the individual to reappraise the efficacy of their dispositional coping strategies. In addition to the initial diagnosis, high-risk or intensive treatment phases represent significant transitory stressors in the lives of parents of children with cancer (Granek et al., 2014; Palmer et al., 2011; Salvador, Crespo, Martins, Santos, & Canavaro, 2015). Moreover, the behaviour and attitudes of individuals who are intimately involved with the child, such as teachers and healthcare workers, are also frequently reported transitory sources of stress (Palmer et al., 2011; Thompson et al., 2015).

The manner in which individuals appraise transitory conditions is hypothesised to determine the extent to which these conditions are interpreted as stressors (Lazarus & Folkman, 1984; Moos & Holahan, 2003). In a systematic review by Vrijmoet-Wiersma, Egeler, Koopman, Lindahl Norberg, and Grootenhuis (2009), appraisal of the cancer

diagnosis primarily as a threat to the child's survival was positively associated with maternal distress. Similarly, increased perceptions of caregiver burden have been associated with appraisals of cancer as a severe illness (Salvador et al., 2015). Appraisals are thought to largely determine the specific manner in which individuals attempt to cope with a stressor (Lazarus & Folkman, 1984; Skoluda et al., 2015). Greeff, Vansteenwegen, and Geldhof (2014) found that parents who adjusted functionally to their children's cancer diagnoses were more inclined to normalize the illness, communicate a sense of having control over life events, and to construct meaning from adversity. It would thus appear that less catastrophic appraisals of the initial diagnosis in paediatric cancer may result in the selection of more adaptive coping responses or strategies.

Stoppelbein, Greening, and Wells (2013) found that both active and avoidant forms of coping were related to elevated distress among mothers of children with cancer. Emotion-focussed coping has been associated with increased levels of parental depression in paediatric cancer (Demirtepe-Saygili & Bozo, 2011). In addition, it has been claimed that the specific coping responses employed by parents may influence the manner in which they appraise the transitory stressors of cancer diagnosis and providing care for their sick child. Salvador Crespo, Martins, Santos, and Canavarro (2015) for example, reported that more adaptive parental coping resulted in cancer being appraised as interfering less with the child's functioning. However, research does not support a consistent link between coping strategies that are problem-focused and positive outcomes, nor between avoidance coping and negative parental outcomes (Compas et al., 2015; Kvåle, 2007; Vrijmoet-Wiersma et al., 2008).

Parents of children with ALL are required to adapt to a very specific and unique set of stressors. Furthermore, a large proportion of these individuals live in low- and middle-income countries (Rodriguez-Galindo et al., 2015). To date, much of the research on coping among parents of children being treated for cancer in general, and ALL more specifically, has

been conducted in developed countries (Compas et al., 2015; Stoppelbein et al., 2013). The challenges that parents, particularly mothers, in the developing world face, as well as the coping strategies they employ appear to have remained largely unexplored. Moreover, even though aspects of the IFSC (Moos & Holahan, 2003) have been used to facilitate understanding of the adjustment of adult cancer patients (Bauer et al., 2016; Ptacek et al., 2007), little is known about its applicability to the context of maternal coping in paediatric cancer. Consequently, this study aims to explore the utility of the IFSC within the context of mothers caring for a child undergoing maintenance treatment for ALL in a developing country, namely South Africa.

Methodology

Design

A qualitative approach was adopted in order to access rich and descriptive accounts of maternal stressors, appraisal, and coping in paediatric ALL. A multiple case study design was employed. This design is well suited to exploratory work in under-researched or novel contexts within health psychology (Green & Thorogood, 2014; Yin, 2014). A multiple case study design allows for the analysis of differences and similarities between contextually comparable cases (Mertens, 2015; Neuman, 2014), while facilitating an in-depth understanding of intricate issues as they occur in the real-life context (Crowe et al., 2011; Yin, 2014).

Participants

Purposive sampling was utilised to recruit mothers caring for a child with ALL in maintenance phase treatment (Creswell & Plano Clark, 2011; Patton, 2015). Participants were identified from the database of a paediatric oncology unit at a large academic hospital located in an urban centre. The unit serves children with cancer and their families across

Central and North-Western South Africa. Only biological mothers of children undergoing maintenance treatment for ALL were eligible for inclusion in the study. The rationale for including mothers of children receiving maintenance therapy was to gain a more normative and retrospective impression of their coping. Mothers of children in earlier phases of treatment might not yet have adjusted to the initial diagnosis or be able to provide much information regarding their experience of treatment.

Childhood cancer is typically defined as occurring in individuals aged 14 years and younger (Stefan et al., 2015). However, in order to maintain some degree of homogeneity among the participants, it was decided to exclude mothers caring for children below five years of age. These individuals likely face specific challenges that are not necessarily shared by mothers of older children with cancer. Consequently, only mothers of children aged between five and 14 years were eligible for inclusion. Proficiency in either English or Afrikaans served as an additional inclusion criterion.

Eligible participants were interviewed until data saturation was achieved (Rubin & Rubin, 2012). Data saturation was achieved after six participants had been interviewed. The size of the final sample meets the minimum criterion recommended by Baker and Edwards (2012). The sociodemographic data for these women, as well as for their child receiving maintenance treatment for ALL are reported in Table 1:

Table 1

Sociodemographic data for the sample of mothers of children with ALL (n=6)

Mother					Child with ALL			
Age	Race	Language	Occupation	Relationship status	Age	Grade level	Sex	Time since initial diagnosis
34	Caucasian	Afrikaans	Unemployed	Married	9	Grade 4	M	13 Months
26	Mixed heritage	Afrikaans	Admin clerk	Single	8	Grade 2	F	29 Months
35	Black	Sesotho	Admin clerk	Married	5	Pre-school	M	25 Months
22	Black	Sesotho	Unemployed	Co-habiting	9	Grade 2	M	28 Months
29	Black	Sesotho	Operator at mine	Married	7	Grade 1	F	26 Months
44	Black	Sesotho	Unemployed	Married	6	Grade 1	M	23 Months

According to Table 1, the sample consisted of four Black mothers, one Caucasian, and one mother of mixed heritage. The average age of the participants was 31.7 years (range: 22–44). At the time of their respective interviews, four of the mothers were married, one was cohabiting with a partner, and one was single. Only half of the participants were employed. All of the mothers reported that their children with ALL were attending school. The average age of these children was 7.3 years (range: 5–9). An average of 24 months had elapsed since all, but one of the participants' children had initially been diagnosed with ALL. Two-thirds of the children were male.

Procedure

Ethical clearance was granted by the Research Ethics Committee of the Faculty of Health Sciences at the University of the Free State (ECUFS NR 220/2015) prior to recruitment of participants. A paediatric oncologist at the targeted academic hospital informed mothers who met the inclusion criteria as to the purpose of the study and inquired whether they would be interested in participating. Mothers willing to take part in the study gave permission for the oncologist to pass on their contact details to the researcher, a graduate student in psychology with specific interest in health psychology. The researcher then proceeded to contact each of the mothers telephonically to arrange interviews. Each participant provided written informed consent prior to being interviewed (see Appendix A). Given the nature and focus of the study, semi-structured interviews appeared to be the most suitable method of data collection. In addition to being an appropriate and accepted methodology within health research (DiCicco-Bloom & Crabtree, 2006; Galletta, 2013), semi-structured interviews are also suited to theory-driven qualitative research (Galletta, 2013). The interview schedule (see Appendix B) used in this study was based on the components of the IFSC.

None of the participants lived in the city where the paediatric oncology unit is situated. Consequently, participants were interviewed during one of their children's follow-up appointments at the unit. All interviews were electronically recorded and conducted in a private room so as to ensure the participants' privacy and dignity. The interviews were transcribed verbatim by the researcher who is fluent in both English and Afrikaans. Two of the participants were Afrikaans first-language speakers and were interviewed in Afrikaans. The remaining participants were Sesotho-speaking, but were proficient in English and were thus interviewed in English.

Analysis

Thematic analysis was conducted in accordance with the six guidelines proposed by Braun and Clarke (2006). First, familiarisation with the data was accomplished through several readings of the transcripts and actively noting points of interest. Second, the data was systematically coded by extracting salient statements from each transcript that could help understand mothers' coping with paediatric ALL. Third, selected codes were consolidated and given a descriptive label in order to reflect a specific subtheme. Fourth, subthemes were reviewed and refined to eliminate coding redundancies and to ensure that the data was accurately portrayed. Fifth, subthemes reflecting a similar idea were merged into global themes. Given that this study aims to explore the applicability of a specific framework of stress and coping to the experience of the participants, the previous two phases of the thematic analysis were carried out deductively (Fereday & Muir-Cochrane, 2006; Gale, Heath, Cameron, Rashid, & Redwood, 2013). Lastly, the research project was written up in such a manner as to convey the trustworthiness and rigour of the results, coherently relate participants' experiences, and link the results to current literature (Braun & Clarke, 2006).

The prevailing opinion in qualitative cross-lingual research seems to be that, where possible, transcripts should be analysed in the language the participants were interviewed in (Chen & Boore, 2010; Lopez, Figueroa, Connor, & Maliski, 2008; Temple & Young, 2004). This process is considered to provide the most authentic analysis of the content, nuance, and meaning of the interviews (Regmi, Naidoo, & Pilkington, 2010; Wong & Poon, 2010). Consequently, two transcripts were thematically analysed in Afrikaans by the researcher and her supervisors (all of whom are fluent in both Afrikaans and English). Once the analysis had been completed, relevant excerpts were translated into English for the purpose of reporting the results. This was done via the back-translation method (Chen & Boore, 2010). The original Afrikaans excerpts are provided in Appendix C.

The analysis was conducted in a manner that would enhance the trustworthiness and rigour of the study. Credibility of the research findings was strengthened by employing three types of triangulation (Patton, 2015). Triangulation of sources was employed whereby the six interviews were compared for consistency. Attention was given to theoretical triangulation by viewing the findings in relation to existing literature on parental coping within the context of paediatric cancer. Analyst triangulation occurred via the review process of the findings by the research supervisors (Denzin, 1978; Patton, 2015). The research supervisors also evaluated each step of the research process to improve dependability of the study in general (Amankwaa, 2016; Cope, 2014). Moreover, thick descriptions of the participants' experiences were given to enhance transferability of the findings whereby individuals external to the context of paediatric cancer may also find the study meaningful (Creswell & Miller, 2000). Taking care to meet standards of credibility, transferability, and dependability were considered vital in improving the confirmability of the research method and findings (Lincoln & Guba, 1985; Ryan, Coughlan, & Cronin, 2007).

Results

Deductive thematic analysis was used to explore the applicability of the IFSC to the experience of six mothers caring for children in the maintenance phase of treatment for ALL (Fereday & Muir-Cochrane, 2006; Gale et al., 2013). This theory-guided thematic analysis was structured around the components of the IFSC proposed by Moos and Holahan (2003). The six global themes and subthemes identified from the analysis are illustrated in Table 2:

Table 2*Global themes with corresponding subthemes*

Global themes	Subthemes
Environmental Stressors and Resources	Logistics; finances and employment; ethnic, cultural and language disparities; sources of social support.
Maternal Personal System	Maternal role; use of interpersonal relationships; surrendering control.
Transitory Stressors	Uncertainty and awaiting diagnosis; caregiver strain; permeating effect of caregiver strain into other areas of life; cancer stigma.
Maternal Appraisals	Initial appraisals of child's mortality; mothers' appraisals of their coping ability.
Maternal Coping	Social support seeking; prayer; personal meaning making; positive reappraisal; denial of children's illness and wishful thinking; accepting that they had no control over their children's fate; emotional discharge.
Psychological Health Outcomes	Poor maternal psychological health.

Environmental Stressors and Resources

All the participants in this study viewed caring for a child with ALL as significantly challenging. The mothers considered transporting their children long distances to receive treatment and the expense associated with travel and subsistence during this time as particularly distressing. Long absences from their family responsibilities and employment adversely impacted their well-being, while cultural and ethnic disparities in hospital were noted as additional stressors. These challenges were mitigated to some degree by the social support the participants received. The most significant sources of support in the women's lives appear to have been their partners, extended families, and church, as well as the other mothers and medical staff at the paediatric oncology unit. However, the general perception

among the participants was that the support they received was outweighed by the demands they faced.

Logistics.

The limited number and geographical distribution of specialist paediatric cancer treatment facilities meant that most of the participants had to travel great distances to bring their children for treatment. The majority of the mothers reported living in small rural towns and most of them did not own a motor vehicle. Some participants made use of transit-ambulances provided by their local health clinics. However, this system presented its own challenges with regard to organization and reliability, as well as demand for the service outstripping supply. One mother expressed her experience thus: “The ambulance is small, but the people are many. So, we have to stand there so they resolve that issue of why the people, the number is so high, but they are not fitting in the seats.”

Generally, participants turned to family, friends and, in one instance, their employer for assistance with transport. Some of the mothers had no choice but to hitchhike. One of the mothers reflected on her experience of hitchhiking on a long-haul truck:

I did not have a car at that time... I climbed a truck. A woman climbing a truck...it was very challenging for me because I have never climbed a truck before at night and arriving at night. When I arrived at the hospital, [my daughter] was admitted...so, I have to go and ask at [NGO providing accommodation for parents and their children with cancer] to give me some place to sleep... It was very difficult, it was a very sad time for me.

The participant who did own a motor vehicle, while arguably not facing the same difficulties the other women did, still experienced travelling long distances as very difficult:

I have to drive back to [our home town] which is 400km. In the car she is vomiting.

She is diarrhoea [*sic*], she is having diarrhoea. She is having a lot of things. So, I

have to stop and take care of [my daughter] and drive again. So, it is not good.

Visits to the hospital also meant that the participants had to prepare their families and homes for their absences. They described arranging with female family members or partners to take over domestic responsibilities and the care of their other children. However, it was difficult for participants to relinquish control of their households. One mother described feeling guilty for leaving her family: “Because I know as the mother, I am the one who is supposed to take care of everything at home, so I was worried of [*sic*] those who are left behind.”

Finances and employment.

Significant financial stress was experienced by each of the participants in this study. The mothers all noted interaction between their child’s condition, treatment needs, and their financial resources. One mother expressed how travel and subsistence expenses associated with hospital visits were depleting her family’s monetary resources:

We are having difficulty, we are having financial difficulties because we are coming from [our home town] which is far. And we have to...petrol, food. Like now they don’t give us a place to stay at [NGO]. So, we have to book us now and right now we have to go and buy some food to eat. Tomorrow we are going back home. So, we use a lot of money on travelling. We use a lot of money.

Participants were faced with having to pay for travel costs, provide for their own needs during the child’s hospitalization, and cover expenses related to unexpected events such as additional or extended hospitalizations. Some of the mothers were able to rely on their partner to provide the necessary finances. However, other participants had to continue working in order to meet their financial obligations. These women had to leave their children

in hospital in order to return to their jobs. One participant expressed the distress she experienced at having to leave her sick child in someone else's care:

...really not being there as a mother. It was difficult. My sister just call me that [my daughter] is being admitted to ICU, and right now I was at work. So, I panicked, you know that emotional thing, I became sad.

Ethnic, cultural and language disparities.

Some of the participants were not from the same ethnic or cultural group as the majority of the mothers of children receiving treatment. Their lack of familiarity with the dominant culture, as well as their inability to speak the dominant language was experienced by some participants as socially isolating. One participant expressed her experiences in this regard as follows:

...race played a big part, because the first time we got there [at the hospital], we were the only Coloureds [individuals of mixed heritage]...we [mother and daughter] felt very different, because most people there were from [*sic*] Sesotho [referring to individuals who speak Sesotho]...and the other thing is, they could not speak my language, and I could not speak their language...this made it look like I thought I was better than them or that I did not want to speak to the people, but that was not the thing. It was just not our language. I felt very left out.¹

Historical social inequality in South Africa has resulted in an overrepresentation of Caucasian English- and/or Afrikaans-speaking professionals in the healthcare system. Consequently, the predominantly Black Sesotho-speaking sample experienced frustration regarding communication with medical staff. Participants expressed frustration at the paediatric

¹ See Appendix C for original Afrikaans excerpt

oncologist's use of English to explain their children's diagnosis and treatment procedures.

One participant expressed a need for:

...someone who can speak in our own language so that we can understand what is cancer, how does it affect our kids...the treatment, the radiation, because I know nothing about radiation. The doctors explained it, but I could not understand.

Language barriers also made requesting information from doctors difficult. Consequently, some of the participants resorted to asking mothers of other children receiving treatment for ALL for advice and information.

Sources of social support.

The participants described varied sources of social support, including employers allowing them time off from work, church clerics accompanying them to hospital to pray, and sharing their experience with other mothers in the paediatric oncology unit. When possible, family members took over their parental duties in their absence, escorted their children to hospital if they were unable to do so themselves, and/or provided financial assistance.

Mothers who were in relationships all identified their partners as important sources of support. These women viewed their partners as offering primarily instrumental support with regard to household tasks and child care, as well as being the family's main source of income. Despite this support from partners, the mothers felt frustrated at the extent to which they were still expected to care for their families in addition to caring for their child with ALL. One mother expressed her frustration in this regard:

I am a mother, I have to, you know, sometimes my husband is like a child. You have to cook – to do all those things. Sometimes I am shouting at them “you have to help me, I can't do this by myself!”

Medical staff played a central role in providing support to the participants. Participants reported that the doctors and nurses helped them to cope with the diagnosis by assisting with

the medical care of their children, while also supporting them emotionally. The paediatric oncologist was singled out as a particular valued source of support. As one mother explained: "...the support. Firstly, from Prof [paediatric oncologist] as a doctor. I have to trust Prof with my child's life. So, Prof, he is doing a lot."

Maternal Personal System

Given that the interviews were conducted following the participants' experiences with their children's ALL diagnoses and treatment, direct interpretations of their dispositional coping strategies prior to these events cannot be drawn. However, particular themes running through the interviews suggest that they were inclined to hold certain perspectives and engage in specific coping strategies in wider contexts too. The mothers in this study seemed largely defined by their maternal identity. Furthermore, they appeared dispositionally inclined to view themselves as incapable of exerting noteworthy influence on significant life stressors they were confronted with. They tended to favour social support seeking and surrendering control of stressors as their primary means of coping with challenging situations.

Maternal role.

Participants strongly identified with their roles as mothers. They demonstrated a strong commitment to the care and welfare of, not only their children receiving treatment for ALL, but also to their families in general and children in particular. One mother stated:

The most difficult thing was to divide my attention to some of my children. I was giving him [my child with ALL] more attention than them... So that was difficult, because the other one is two years older than him, so it was like I did not give much care to her.

Given their perceived lack of ability to directly influence the treatment of their ill children, these mothers focussed their efforts on providing for their basic needs. This included providing nutritious meals, monitoring for symptoms that may suggest relapse or worsening of health and general management of their children's daily lives. As one mother noted: "I cannot relax if he is not by my side. I know my mom can take care of him, but that feeling, I want me to take care of him."

Use of interpersonal relationships.

In crisis situations, the participants were inclined to seek emotional support through their interpersonal relationships. They described enlisting family and friends as emotional soundboards, as well as turning to these individuals for comfort and reassurance. One mother reflected that her sister had always been a source of support, even before her child's diagnosis of ALL: "She supported me a lot, look, actually emotionally. She was there for me and she always made me understand we would get through this. We have already been through so much, this is just another challenge."² The mothers also tended to believe emotional support from significant others necessary for their well-being:

From his [my son's] father's side I did not get any support. So, I had...I felt that I am...over loading my family on my side... At the time I hated them [my husband's family] because I thought I needed their support. I needed them to be there for me and my child.

Surrendering control.

Participants were inclined to believe themselves incapable of influencing significant life stressors. This belief resulted in the majority of mothers surrendering control of stressors to a higher power, including the eventual outcome of their children's ALL. One mother

² See Appendix C for original Afrikaans excerpt

expressed her general disposition to surrendering control as follows: "...only God knows what will happen to us. Today I can be here, and then other day I can be somewhere else."

Another mother described praying for God to assume control as customary for both herself and her child:

She [my daughter] can pray for herself. I taught her to pray for herself. Even when her leg is painful, I tell her "You must pray for your legs"... I taught her that after praying you know everything is going to be fine.

The tendency to surrender control of stressors was also apparent in the manner in which the mothers dealt with their children's treatment process, allowing the medical staff to assume complete responsibility:

All you must do is tell yourself that I come here [to the hospital] with my son, me and my son alone. I am not going to listen to other mammas. I am only going to talk to the doctors and the doctors are doing what they are believing is going to happen.

Transitory Stressors

Delays in diagnosis were experienced as significant stressors by participants. Having to witness and/or administer painful treatment procedures on their children, treatment side-effects, uncomfortable questions from their children regarding cancer, and lack of conveniences in hospital placed additional stress on the mothers. Participants living in rural towns experienced cancer stigma when they returned home after taking their children for treatment in the city. Mothers also felt distressed by the responsibility and strain of continuing with their child's medical care at home. They reflected that caregiving impacted negatively on family relationships, employment and personal goals.

Uncertainty and awaiting diagnosis.

The period before diagnosis was significantly distressing for participants. They described becoming concerned when symptoms such as fever, swollen glands, and fatigue worsened and persisted. At both primary and secondary levels of healthcare, mothers reported disagreements with medical staff about the severity of their children's symptoms and the need for further examination. Participants described awaiting clarification of their child's diagnosis as disconcerting:

Her glands started to swell...we took her to the doctor and the doctor said "No man, it is some form of infection in the body, or bacteria...", we went with what the doctor said and gave the child antibiotics... The glands did not get smaller...then the doctors suspected it was TB...and we did the tests and the tests came back alright...and he [the doctor] arranged for us an appointment with the doctor for blood tests and all those things...it took long... And so we waited and waited and the glands just got bigger.³

Caregiver strain.

Participants described feeling distressed in seeing lumbar punctures, blood being drawn, and intravenous starts performed on their children. The severity of treatment side-effects also elicited questions from their children regarding their illness and mortality. Participants expressed feeling overwhelmed by these emotional demands and in one case, a mother described it easier to withhold information from her child:

It was only the time when the hair was...have to go out [*sic*] and she wanted to know "Mamma, why is my hair getting off [*sic*], what did you do to my hair?" So, I have to, first I have to take her to salon around the shop there and tell her that, "You See

³ See Appendix C for original Afrikaans excerpt

Mamma had to bring a hairdryer, so your hair is dirty, I have to cut it, then I will buy some other hair to fix it". So yes, it was very difficult.

In hospital, participants described sleeping on plastic chairs while keeping vigil at their children's bedsides, walking to nearby shops to buy food since only patients received meals, and feeling confined and isolated. Home-based care, in turn, involved management of intravenous catheters described as painful to the child, remembering to give medication, preventing infections, and handling treatment-related mood lability. In general, mothers described the caregiving experience as all-consuming and anxiety provoking:

I have to prepare her, feed her, give her the medication, running the house and also preparing myself...when I arrive at work I feel so tired because I have to wake up at around half past four... Sometimes I panic. Even when I am at work I have to think did I give [my daughter] the medication.

Permeating effect of caregiver strain into other areas of life.

Caregiver strain was reported by participants as adversely affecting various domains of their lives, especially work and family. The mothers expressed feeling tired at work and finding it difficult to focus on anything aside from their child's ALL. They also perceived frequent absences from their jobs in order to accompany their children to hospital as jeopardising their employment. Most participants experienced a sense of ambivalence in that they were determined to be with their ill child, but were also consumed by worries about leaving their families. Mothers described feeling guilty for neglecting the needs of their other children while devoting most of their time, energy, and attention to their child with ALL:

She even told me that I love this one [my son with ALL] more than I love her. And I told her that this one [my son] needs special attention and that you are okay, you do not have any sickness, you are healthy, you have everything.

For some participants, the demands of caregiving necessitated giving up or temporarily side-lining their own personal goals and ambitions. One mother described discontinuing her tertiary education in order to provide consistent care without distractions: “...through his illness I dropped out of school, I was studying. So, I had to drop [*sic*], look after him.”

Cancer stigma.

When their children returned to school after several weeks in hospital, the mothers expressed often being confronted with unsupportive school teachers, insensitive questions from parents, and school bullies mocking their child’s swollen appearance and hair loss. One mother shared her experience: “They [children at the school] have thrown him [my son] with stones. They have teased him because he has no hair...”⁴

Some participants explained that cancer is viewed as an infectious disease in the rural communities they come from. Consequently, they often felt that it was in their child’s best interest to keep their diagnosis secret:

...we have this tragedy that if this child is sick, and you start telling maybe the friends and the friends are going to tell the mammas, the mammas are going to say, “You must stop playing with that child, because he is sick. He is having what and what ...”
And then the children start to...separating themselves to your child.

Maternal Appraisals

The participants appeared to engage in two appraisal processes. First, initial reaction to diagnosis and prognosis. Second, their reaction to their own evaluation of their ability to cope with their child’s possible mortality. The mothers considered ALL akin to a death sentence. They reported a significant decrease in their sense of agency following the ALL

⁴ See Appendix C for original Afrikaans excerpt

diagnosis and, for the most part, perceived themselves as unable to cope with the possibility of losing their children. They reflected that their children's deteriorating health, doubts regarding treatment success, and lack of support all influenced their self-appraised coping ability.

Initial appraisals of child's mortality.

Participants reflected experiencing the diagnosis as a significant threat to their child's life, as well as to their own emotional well-being. Most mothers described experiencing an overwhelming fear of losing their children upon receiving the diagnosis. One mother indicated that she stopped listening to the paediatric oncologist when he said "leukaemia" and only thought of her child dying:

You hear what they are saying, but it is as if you are not taking in everything, you cannot see beyond this wall, this naked wall. It is, I almost want to say that when you see it, hear leukaemia, then you hear death sentence.⁵

Some of the mothers referred to cancer as the "killing disease". These women stated believing all cancer sufferers die despite receiving treatment. These perceptions and beliefs, along with fears about their children's death, were exacerbated upon hearing of the deaths of other children receiving treatment for ALL. As one mother stated: "...and the other thing is...they [the children with cancer] had just completed their treatment and then something happens, or they get a relapse or something, and then it's the end..."⁶

Mothers' appraisals of their coping ability.

The participants expressed a significant decrease in their sense of agency following their child's ALL diagnosis. They perceived themselves as powerless bystanders to painful medical procedures they understood poorly. One mother stated: "I don't want anyone

⁵ See Appendix C for original Afrikaans excerpt

⁶ See Appendix C for original Afrikaans excerpt

coming and telling me my son is being injected with something and something. No, I just want to see it with my own eyes...” Although treatment was evidently causing their children to suffer, the mothers indicated having no alternative but to submit their children to this treatment. Non-adherence meant denying their children their only chance of survival:

When I have to come to the hospital, I don't sleep at night because I am going there.

She is going to be injected. She is going to have this and this and this. But there is nothing that I can do. I have to come.

Participants perceived themselves as ill-equipped to cope with their children's prolonged and invasive treatment. When reflecting on her child's diagnosis, one mother stated: “I was asking myself if I would have the strength to handle this.” Most mothers evaluated themselves unable to cope effectively with their children's deteriorating health:

He [my son] really wants to play rugby...most days it feels like I can sit on a heap and cry, because I was very active at school and he really wants to play rugby and he wants to play cricket, but...we [my husband and I] are too scared, because if he gets hurt...⁷

Some participants appraised themselves as almost completely unable to cope when treatment appeared to be failing and they were confronted with the reality of their child's mortality. The majority of participants appeared to rely heavily on social support to see them through these difficult times. As one mother explained: “If you are having someone supporting you then you feel comfortable and you know what to do, because it couldn't be easy if I was alone with a child with cancer.”

⁷ See Appendix C for original Afrikaans excerpt

Maternal Coping

Participants attempted to cope with paediatric ALL in various ways. The coping strategies most commonly employed by the participants were social support seeking and prayer. In addition, they created meaning from their caregiving experience, made use of positive reappraisal, at times denied that their children were ill, engaged in wishful thinking, and accepted that they had no control over their children's fate. When overwhelmed by their experience, most mothers engaged in emotional discharge.

Social support seeking.

In dealing with logistical challenges, participants solicited help and advice from various individuals. Family, friends, and even employers were approached to help with transport, domestic tasks, and childcare. NGO's catering for cancer patients and their families were a significant source of logistical support for the majority of mothers.

Participants sought emotional support and comfort from their partners, families, and at times from clerics and church members. They also turned to other mothers at the oncology unit for support. The participants reflected that being able to share their experiences and talk to mothers in a similar position to them helped to significantly alleviate their distress.

According to one participant:

It is very painful and stressful, but if you have someone to talk to it becomes much easier for you to handle. But if you keep quiet, it is only going to stress you more and more and more... But if you can find someone to talk to, then you will be stress free.

Participants reported to read up on ALL on the internet or from pamphlets. However, they most frequently sought information and advice from the medical staff. This information appeared to primarily be used as a source of reassurance and encouragement, rather than informing treatment decisions or childcare. This is particularly evident in that the mothers

almost always sought, and acted on medical advice rather than relying on their own caregiving abilities. One mother put it this way:

So, I panicked a lot, calling Prof [paediatric oncologist]. I still remember I called Prof when he was at the airport asking about...“Prof, the wound is doing this and this what must I apply...?”

Prayer.

All participants reported praying for direct intercession from God. They described praying for a miracle and for God to cure their children. Some participants expressed the belief that cancer was caused by evil or demonic spirits which needed to be exorcized from their children through prayer. Although all mothers described themselves as being religious prior to their child’s illness, they reported praying significantly more following the ALL diagnosis:

I used to pray, just pray, but not feeling that I was praying. But now, after he [my son] got this sickness, is then [sic] I was looking for God more than ever. Now I know that I have to pray hard.

Personal meaning making.

The majority of participants sought meaning in their children’s illness and suffering. Some mothers described developing a greater appreciation for their loved ones and families. Others considered themselves to have become more resilient and mature in dealing with adversities. However, ascribing religious meaning to their experiences appears to have been the most common way in which the participants made sense of the challenges associated with their children’s ALL diagnosis and treatment. In one mother’s words:

At first it was difficult. But now, what I am telling myself is that it was God's purpose and it made me a strong person because now I can tell somebody that... "One goes through a situation with a reason". So, it was like to me a test of my faith.

Positive reappraisal.

Some participants indicated coping by comparing themselves with mothers in the unit whose children were worse off than their own. One participant described how drawing such comparisons helped her develop a new perspective on her experience: "Every mother will tell you about her problem. Mine was like this, mine was like that. And sometimes you see that yours were better than that mom." However, the majority of participants tended to rely on others to provide positive reappraisal of their situation. Mothers primarily made use of survival statistics provided by medical staff and/or assurances from family and friends to positively reframe their appraisals. One mother indicated how the perspective provided by the oncologist helped her to see things more hopefully:

It is hard, but sometimes when you are here the doctor will show you that: "You see this girl or boy, he started taking his treatment for leukaemia when he was two years, but when you see him or her, he is 18 or 21 years". So, there is a lot of hope.

Denial of children's illness and wishful thinking.

Participants indicated feeling shocked upon hearing their child's diagnosis. In the majority of cases, this initial reaction was followed by a period of denial. Other participants indicated making efforts to avoid thinking about their child's diagnosis and treatment. One mother considered the calming effect she perceived her avoidance to have on herself as positively influencing her child's well-being: "The more you worry or think about this disease...the more he is going to get sick. But if you think that I know my son has this disease, but not to always think about it, just accept it."

Wishful thinking was evident in many cases. Mothers most frequently expressed wishing that they could switch places with their ill child or that the cancer would miraculously disappear. As one mother stated: "Taking the cancer away, or maybe this illness comes to me."

Accepting that they had no control over their children's fate.

Despite engaging in the positive reappraisal and cognitive avoidance mentioned above, the majority of mothers expressed the realisation that they had no control over the situation. Consequently, most of them reached a point of despondent resignation:

...it feels like you are feeling sorry for yourself and your child. Maybe I could have done something so that my child cannot be involved in this cancer thing. So, it is not about [*sic*] us to say, or it is not your choice that your child is having cancer. It just happened that your child is having cancer.

If anything happens, I will be fine. I will be... I will know that the doctors tried their best and I tried my best being a good mother to him, because I do not want anything to happen to my son. I love him with all my heart. And I will know that it was God's will.

Emotional discharge.

Crying was reported by participants as a way of dealing with pent-up emotions related to their child's uncertain future. As one mother described: "Sometimes I feel like crying. If I cry the pain will go away." The mothers also vented their frustrations on significant others. They described misdirecting the anger and sadness they felt regarding their child's diagnosis and suffering towards their partners and other children. One mother said: "I would take it out on everyone around me." Another mother recalls: "Every time I see something is not

according to the way I thought it would be I would shout at my husband, at my children. So, they...we went through that.”

Psychological Health Outcomes

The participants all viewed the experience of caring for a child with ALL and associated stressors as significantly compromising their well-being. They expressed devastation at having to witness their child’s prolonged treatment and suffering and described often experiencing bouts of tearfulness. Furthermore, constant feelings of trepidation were noted with regard to the uncertainty about their children’s survival. They also reflected feeling angry and frustrated at the perceived injustice of their children having cancer – often aggressively venting their frustrations at other people. Increased social isolation, insomnia, stomach ulcers, tension headaches, and physical exhaustion were reported by the majority of participants. Symptoms of burnout, mental exhaustion, and depressed mood were common place in the participants’ accounts. One mother summed-up her current emotional state as follows:

It drains a person. Most days I feel like I can just go and sit in the corner and cry...it exhausts you. Like I told you, it is not only physical, but deep within me, in my soul, I am tired.⁸

Discussion

This study sought to explore the applicability of Moos and Holahan’s IFSC within the context of maternal coping in paediatric oncology in a developing country. However, the data also provide insight into the challenges these women face, the resources they are able to access, the manner in which they attempt to cope and their resulting state of well-being. This broad picture will be sketched before dealing with the primary aim of this study.

⁸ See Appendix C for original Afrikaans excerpt

Mothers in this study highlighted logistical difficulties, financial concerns and poor public healthcare delivery as significantly complicating their efforts to care for their child with ALL. Cancer stigma within their communities was also a significant stressor. These stressors appear to be shared by individuals caring for children with cancer in other developing world contexts (Edwards & Greeff, 2017; Hopkins et al., 2013; Sitaresmi et al., 2010). Conversely, difficulties with transport, finances and basic healthcare delivery are less frequently reported in studies conducted in the developed world (Granek et al., 2014; Jones, 2012; Kohlsdorf & Costa Junior, 2012). Language and cultural barriers, as well as pronounced discrepancies in the education level and social status of caregivers and healthcare staff were noted as additional stressors in the current sample. These hindrances were viewed as creating a sense of isolation and helplessness. Communication of important information related to the children with ALL's care was also negatively impacted. These experiences appear to be shared by many recipients of public healthcare in the developing world, but are much less prevalent in higher income countries (Meuter, Gallois, Segalowitz, Ryder, & Hocking, 2015; Paternotte, Van Dulmen, Van Der Lee, Scherpbier, & Scheele, 2015). Witnessing their child suffering through invasive procedures and treatment side-effects seem to be stressors commonly experienced by mothers across the socioeconomic divide. Similarly, reports of caregiver strain related to managing and administering treatment on their own are as prevalent in studies conducted in the developed world as they are in the current study (Flury et al., 2011; Kelly & Kelly, 2013; Lau et al., 2014; Sultan et al., 2016).

Social relationships were the primary source of support accessed by the participants in the current study. This seems to be a common trend in the global literature on caregiver coping in paediatric cancer (Fletcher et al., 2010; Naidoo et al., 2016). Nevertheless, the applicability of social support is viewed differently across socioeconomic contexts. While parents from the developed world seem to place greater importance on emotional

reinforcement from social support networks (Gage, 2013), the mothers in this study used these resources more instrumentally. They were more inclined to rely on their broader social support system for financial assistance and information. This emphasis on the practical and instrumental support their social environment provides seems particular to the developing world context (Hopkins et al., 2013; Nur Sadaah, Siti Hajar, & Rezaul, 2014).

The mothers who participated in this study primarily employed social support seeking and religious coping as means of dealing with the ongoing challenges they faced. More avoidant coping responses such as emotional discharge, denial and wishful thinking were evident at the time of diagnosis. These seemed to be employed less frequently as treatment progressed. The aforementioned coping strategies appear to be universally employed by mothers of children undergoing oncology treatment (Greeff, Vansteenwegen, & Geldhof, 2014; Stoppelbein et al., 2013). In contrast to the literature on mothers in the developed world, participants in the current study were less likely to employ problem-solving as a coping strategy (Shortman et al., 2013; Vrijmoet-Wiersma et al., 2008). Furthermore, instances of positive reappraisal seemed to be more a case of repeating the reappraisals of others – primarily healthcare professionals – rather than being spontaneously generated. This might be partially a consequence of the sample's level of education and socioeconomic status, as well as race-related power imbalances inherent in broader South African society (Jackson et al., 2010).

Participants reported that their emotional well-being was significantly compromised by the process of coping with their child's diagnosis and treatment. Emotional distress, behavioural symptoms and physical ailments related to caregiver strain were reported. Although literature from both the developed and developing world emphasises poor parental well-being and maladjustment within the context of paediatric cancer (McCarthy, Ashley, Lee, & Anderson, 2012; Naidoo et al., 2016; Sultan et al., 2016), posttraumatic growth and

benefit finding seem to be more evident among parents living in high income countries (Gardner et al., 2017; Hullmann, Fedele, Molzon, Mayes, & Mullins, 2014).

The primary aim of this study was to explore, from within the IFSC (Moos & Holahan, 2003), the coping narratives of maternal caregivers to children receiving maintenance treatment for ALL. Moos and Holahan (2003) emphasize the foundational nature of the environmental system in understanding the interplay between stress and coping. Participants identified limited financial and personal resources, as well as logistical constraints as their primary environmental stressors. Inadequate communication and cultural isolation were identified as stressors specific to the broader oncology care environment. Moos and Holahan (2003) note that the environmental system, despite containing stressors, is also a primary source of support. In keeping with the broader research on caregiving in cancer (Gage, 2013; Shortman et al., 2013), participants in this study primarily relied on the resources inherent in their social support networks to help them cope. However, they appeared to experience difficulty effectively accessing their social support networks. Gage (2013) has noted that parents of children with cancer find negotiating social support difficult. The environmental resources that the participants were able to muster appeared to have been overwhelmed by the number and magnitude of the challenges inherent in their environmental systems.

The contextual basis of the IFSC is complemented by a focus on dispositional characteristics. Any dispositional characteristics that may modulate the experience of stress or influence coping are included in the personal system (Moos & Holahan, 2003). The methodology employed in the current study did not allow for the identification and quantification of participants' dispositional traits. However, the data did provide some insights in this regard. The participants strongly aligned with their identities as mothers and tended to measure their worth in terms of the well-being of their families. These

dispositional tendencies were expressed through an emphasis on maternal devotion that left these women torn between caring for their ill child and meeting the needs of the rest of their families. Fouquier (2011) has stated that motherhood is often a source of meaning and empowerment, particularly for women facing significant social and economic hardship. However, the mothers in the current study also seemed to experience their strong maternal dispositions as potential sources of uncertainty and stress. The majority seemed to experience a poor sense of agency, which tended to find expression in their characteristic use of coping strategies that averted direct confrontation of stressors. Social support seeking and attributing stressors to factors beyond their control appeared to be a common coping response for most participants. This would seem to be in keeping with literature suggesting that collectivist cultures are more inclined to present with an external locus of control (Norenzayan & Lee, 2010). Similarly, self-efficacy has been linked to social status, income, and level of education (Phillips & Klein, 2010). The personal system, as outlined by Moos and Holahan (2003), does seem to exhibit some utility with regard to understanding how dispositional factors may impact upon the stress experience and coping responses of mothers of children receiving treatment for ALL in a developing country.

The environmental and personal systems are held by Moos and Holahan (2003) to form the broader context within which transitory stressors are experienced. The diagnosis of their children with ALL and the associated consequences was experienced as a series of significant transitory stressors in the lives of all the participants. Awaiting diagnosis while coping with the uncertainty surrounding their child's deteriorating health was a salient transitory stressor for the mothers. While disease-related uncertainty is a widely recognised source of stress among parents of children with cancer (Lin et al., 2010), slow referral systems and insensitive healthcare staff exacerbated the participants' stress during the early stages of the disease. Participants' narratives were characterised by reference to a series of

transient stressors that punctuated the progression and treatment of their children's illness. Perhaps most salient amongst these were the stigma their children suffered in the local community, as well as the physical and psychological impact of caregiving. Butow et al. (2012) highlight a lack of research regarding caregiver tasks and burden in more informal contexts. Data from the current study suggests that transitory stressors are an obvious and highly impactful aspect of maternal caregiving in paediatric cancer in developing world contexts.

It is hypothesised that the manner in which individuals appraise transitory events largely determines the extent to which they are experienced as stressors (Lazarus & Folkman, 1984; Skoluda et al., 2015). Lazarus and Folkman (1984) contend that events are appraised as stressors only when they are perceived as a threat to the individual and as exceeding the individual's coping ability. The mothers in the current study all report having viewed their child's ALL diagnosis as life-threatening. Moreover, their appraisals of the treatment process were characterised by an enduring sense that their children's lives, or at least, health and well-being were under threat. Knowledge of cancer diagnosis and treatment was limited among the mothers in this study. This is often characteristic of caregivers in lower socioeconomic settings and seems to have amplified their perceptions of threat (Edwards & Greeff, 2017; Hopkins et al., 2013). These women reported feeling powerless and overwhelmed by the challenges they faced. Harper and colleagues (2013) have noted that caregivers' sense of self-efficacy is associated with perceptions of paediatric cancer as a challenge rather than a threat. The women in the current study appraised themselves as unable to cope, which lead them to view their child's illness predominantly as a threat. The IFSC does appear useful for understanding the appraisal process that mothers of children with cancer in the developing world may engage in. More specifically, this approach seems to

highlight the extent to which knowledge (environmental and personal system) and self-efficacy (personal system) impact on this appraisal process.

Moos and Holahan (2003) built on the work of Lazarus and Folkman (1984) by proposing that appraisal processes largely determine the way transitory stressors are viewed. These perceptions are, in turn, proposed to impact upon the coping strategies that individuals implement. The participants in this study generally perceived their children's diagnosis and treatment as significantly life threatening and life limiting. Furthermore, they considered their ability to meet the challenges they faced as inadequate. Theoretically, these women would be expected to have employed primarily avoidant and emotion-focused coping strategies. This does appear to have been the case. The participants primarily employed coping strategies aimed at minimising the negative emotions they experienced. These generally took the form of sharing their experiences with mothers in similar situations and seeking reassurance from healthcare staff. Religious-meaning making was evident in the way that many participants viewed their child's diagnosis as serving a higher purpose. Furthermore, denial and wishful thinking appeared to have the effect of creating distance between participants and the reality of the diagnosis. Ultimately, however, these women all reported resigning themselves to the uncertainty of their children's future and modulating their stress via emotion-focussed coping such as crying, venting, or shouting at family members. In this regard, their reactions appear to be largely in line with previous research on parents of children with cancer (Miedema, Hamilton, Fortin, Easley, & Matthews, 2010; Palmer et al., 2011). The IFSC appears to provide a useful lens through which to view coping strategies employed by the participants. Moreover, this model facilitates consideration of the impact that limited physical and emotional resources, as well as limited disease-specific knowledge and a generally poor sense of self-efficacy had on the coping strategies these women ended up employing.

According to Moos and Holahan (2003), the various components of the IFSC interact to determine health outcomes. In this particular study the emphasis was on determining the utility of the IFSC to the understanding of maternal coping in paediatric cancer within a developing world context. Consequently, a detailed exploration of the participants' health outcomes was beyond the scope of the study. However, it was obvious that the participants almost exclusively reported emotional distress, burnout and various physical manifestations of stress in relation to their children's diagnoses and treatment. They associated their children's ALL diagnosis with significant sadness, frustration, and anxiety. Moreover, there did not appear to be an improvement in the general emotional and physical health of participants as the treatment of their children progressed and the spectre of death receded. These findings appear to contrast those reported by Sodi and Kgopa (2016). These researchers reported that mothers caring for chronically ill children in a rural South African setting showed a high degree of hope and resilience which resulted in an improvement to these women's overall experience of caregiving. However, their sample was not cancer specific, which may at least partially account for these differences. Much of the distress reported by mothers in the current study revolved around a discrepancy between their need for social support and their perceptions of its availability. Participants' primary focus on aversive future eventualities conceivably left little energy for more proactive or hope promoting coping strategies.

The IFSC stresses the reciprocal interaction of each of its components in determining health outcomes (Moos & Holahan, 2003). The environmental (contextual) system was viewed as the primary predisposing factor for the poor psychological health and adjustment difficulties experienced by mothers in the current study. These women's circumstances were such that they had extremely limited means by which to solve problems or exert an influence on events that confronted them. Consequently, it would seem that their dispositional coping

(personal system) was largely determined by their historical environment and confined to trying to manage the emotional impact of life events, most of which seem to have been perceived as being beyond their control. A possible exception appears to have been their strong identification with their maternal roles. This potentially provided the perception of being able to directly impact the welfare of their children and families. However, the general interaction between the environmental and personal systems appeared not to result in contextual or dispositional attributes well suited to meeting the challenges of major life stressors such as paediatric ALL. Consequently, participants seemed overawed by their children's illness and possible mortality. Furthermore, they generally appraised themselves as unlikely to be able to deal successfully with the challenges they faced. These appraisals, in turn, appear to have largely led to the passive and avoidant coping strategies the participants predominately reported employing. It is, however, important to bear in mind that contextual limitations also seemed to significantly influence these appraisals. Moreover, some coping strategies employed by these women were not unique to their children's illness, but appear to have been implemented in numerous other settings too. The ineffectiveness of some of these coping strategies appeared to reinforce participants' sense of being overwhelmed by their environmental circumstances. This seems to have strengthened their appraisals of threat and resulted in further implementation of passive coping strategies. Based on the preceding discussion, it would appear that the IFSC holds promise as a means of conceptualising both individual components and integrative processes influencing maternal coping with childhood cancer in a developing world context.

Limitations and Directions for Future Research

The current study has several limitations that require mentioning. First, the sample only consisted of six mothers of children receiving maintenance treatment for ALL at a paediatric oncology unit at an academic hospital located in a specific geographical location.

The sample can, therefore, not be considered to be representative of maternal caregivers in paediatric cancer, even at a local level. Consequently, the findings cannot be generalized beyond the context of this study. Future research should focus on conducting similar explorative studies using larger and more diverse samples. This might provide perspectives more applicable to a variety of contexts and experiences. Second, while the study explored maternal coping across all the treatment phases of paediatric ALL, data was collected at a specific point in time. Collecting data on more than one occasion or following a longitudinal methodology would, in all probability, have produced different data and might have resulted in different conclusions. At the very least, it may have produced richer narratives and accessed more reflective accounts from the participants. Particular care should be exercised when comparing the findings from the current study to those from research that adopts a longitudinal perspective to studying parental coping with childhood cancer.

Third, the current study exclusively employed a qualitative methodology to explore the utility of the IFSC in facilitating understanding of mothers coping with a child receiving maintenance treatment for ALL in a developing country. This approach provided depth through rich descriptions of mothers' experiences as they pertained to the particular theoretical framework. However, this approach could be criticized for failing to provide a structural or quantifiable test of the applicability of the model. Future research should employ more quantitative methodologies to statistically test the fit of the IFSC to data generated within the context of maternal coping with paediatric ALL in developing countries. Furthermore, a need exists for both qualitative and quantitative studies comparing the utility of the IFSC to that of other models of coping in caregiving within the context of paediatric cancer.

Finally, four of the six participants were not interviewed in their home language. They were all sufficiently proficient in English to provide coherent accounts of their

experiences. However, there is a very real risk that these participants were not able to express themselves as fully as they would have in their home language. Consequently, some depth and nuance might well have been lost in their accounts. However, according to Brinkmann and Kvale (2015), interviewing in a non-mother tongue is deemed acceptable in cross-lingual research when the language is proficiently spoken by both the interviewer and interviewee. Cross-lingual interviewing is also increasingly becoming a reality in social research in a globalised world (Filep, 2009). Given the risk for misinterpretation inherent in cross-lingual research (Choi, Kushner, Mill, & Lai, 2012), emphasis was placed on ensuring that the participants fully understood the questions the researcher was asking. The researcher also frequently clarified and verified her understanding of statements made by the participants. Although a translator could have been used, this was decided against due to the risk of losing the original meaning of responses in the process of translation, as well as the effect that having a third party in the interview might have on the participants' privacy and comfort (Fung, Lagha, Henderson, & Gomez, 2010; Lopez et al., 2008; Regmi et al., 2010). In light of concerns regarding cross-lingual research, future studies should attempt, to the extent possible, to conduct interviews in the preferred language of their participants. This also highlights an avenue for comparative research to examine the trustworthiness and rigour of the findings presented in this study.

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Appendix A

Informed Consent: English and Afrikaans

Dear Participant

Your willingness to participate in this study is greatly appreciated. This research study aims to investigate coping among mothers of children receiving maintenance treatment for Acute Lymphoblastic Leukaemia (ALL). I am interested in what challenges you face as the primary caregiver of your child, how you view these challenges, and how you go about coping with them.

Your decision to participate in the study is completely voluntary. You are not obligated to partake in any way. You will not gain from your participation, nor will your child's treatment be affected by your participation. You also retain the right to withdraw from the research throughout the study. Your contribution to this study will consist of a single interview with me which will be recorded electronically. The interview will take about 45 to 90 minutes to complete and will be conducted at the Universitas Hospital Academic Complex. The recording will be transcribed by a second party who has signed a confidentiality agreement. Only the second party, my research supervisor and I will have access to your electronic and transcribed interview. I will analyse the transcriptions and upon completion of the study will destroy/erase all interviews.

I am conducting this research as part of the requirements for my Master's degree in clinical psychology. The findings from this research may also be published in articles in scientific journals or presented at conferences. However, the identity of all participants and their children (as well as every other individual's named during the interview) will be protected. Anonymity of identity will be facilitated by using participant codes or pseudonyms in any transcripts and publications of the research.

Given the sensitive nature of this study, you are encouraged to contact me at **060 725 1649** if you feel emotionally distressed or overwhelmed by what was discussed during your interview. You are also welcome to raise any concerns you have in this regard with Prof Stones during your child's next consultation. In such an event that you are distressed as a result of your participation in this research, a referral to a psychologist will be facilitated for you, if you so wish. A copy of the final research report will also be made available to you on your request.

This research has been approved by the Research Ethics Committee of the Faculty of Health Sciences at the University of the Free State (ECUFS NR 220/2015). You are welcome to contact me (Lerie Nel: 060 725 1649), my supervisor (Prof Stephen Walker: 051 401 2775) or the secretary of the Research Ethics Committee of the Faculty of Health Sciences at the University of the Free State (Ms Marais: [051] 4017795) with any concerns or complaints you might have regarding this research or the manner in which it has been conducted.

Kind regards,

Lerie Nel

Researcher

Date

Prof Stephen Walker

Research Supervisor

Date

I, _____ (name of participant)

have been informed of the nature of this study by the researcher and fully understand the

conditions thereof. I also understand that my participation will be entirely voluntary. I

hereby **consent/do not consent** (please circle the applicable option) to take part in this study.

Furthermore, I **request/ do not request** a copy of the final research report.

Signature of Participant

Date

Geagte Deelnemer

U bereidwilligheid om deel te neem aan hierdie studie word baie waardeer. Hierdie navorsingsstudie beoog om die hantering onder moeders van kinders wat onderhoudsbehandeling ontvang vir Akute Limfoblastiese Leukemie (ALL) te ondersoek. Ek stel belang in watter uitdagings u ervaar as die primêre versorger van u kind, hoe u hierdie uitdagings sien, en hoe u te werk gaan om dit te hanteer.

U besluit om aan die stude deel te neem is heeltemal vrywillig. U is nie verplig om deel te neem nie. U sal nie vergoeding kry vir u deelname nie, en u kind se behandeling sal ook nie geaffekteer word deur u deelname nie. U behou die reg om ter enige tyd van die navorsing te onttrek. U bydrae tot die studie behels 'n enkele onderhoud met my wat elektronies opgeneem sal word. Die onderhoud sal ongeveer 45 tot 90 minute duur en sal plaasvind by die Universitas Akademiese Hospitaal. Die opname sal getranskribeer word deur 'n tweede party wat 'n vertroulikheidsooreenkoms onderteken het. Alleenlik die tweede party, my studieleier, en ek sal toegang tot die elektroniese en getranskribeerde onderhoude hê. Ek sal die transkripsies ontleed en na voltooiing van die studie alle onderhoude vernietig/uitvee.

Die uitvoer van hierdie navorsing vorm deel van die vereistes van my Meestersgraad in kliniese sielkunde. Die bevindings van die navorsing mag ook gepubliseer word in artikels in wetenskaplike joernale of aangebied word by konferensies. Die identiteit van alle deelnemers en hulle kinders (asook enige ander individu genoem gedurende die onderhoud) sal egter beskerm word. Anonimiteit van identiteit sal gefasiliteer word deur die gebruik van deelnemerkodes of skuilname in enige transkripsies en publikasies van die navorsing.

Gegewe die sensitiewe aard van die studie, word u aangemoedig om my te kontak by (persoonlike telefoon nommer) as u emosioneel ontsteld of oorweldig voel oor wat gedurende u onderhoud bespreek is. U is ook welkom om enige kommernisse in hierdie verband met

Prof Stones op te neem met u kind se volgende konsultasie. Indien u emosioneel ontsteld of oorweldig sou voel as gevolg van u deelname in hierdie navorsing, sal daar met u goedkeuring 'n verwysing na 'n sielkundige vir u gemaak word. 'n Kopie van die finale navorsingsverslag sal ook op u versoek aan u beskikbaar gemaak word.

Hierdie navorsing is goedgekeur deur die Navorsingsetiekkomitee van die Fakulteit van Gesondheidswetenskappe aan die Universiteit van die Vrystaat (ECUFS NR 220/2015). U is welkom om my te kontak (Lerie Nel: 060 725 1649), my studieleier (Prof Stephen Walker: 051 401 2775), of die sekretaris van die Navorsingsetiekkomitee van die Fakulteit Gesondheidswetenskappe aan die Universiteit van die Vrystaat (Me Marais: [051] 4017795) met enige kommernisse of klagtes wat u mag hê aangaande die navorsing of die manier waarop dit uitgevoer is.

Vriendelike groete,

Lerie Nel

Navorser

Datum

Prof Stephen Walker

Navorsingsopsiener

Datum

Ek, _____ (naam van deelnemer) is ten volle ingelig deur die navorser aangaande die aard van die studie en verstaan die voorwaardes daarvan volkome. Ek verstaan ook dat my deelname heeltemal vrywillig is. Hiermee gee ek **toestemming/nie toestemming** (asseblief omkring die toepaslike opsie) om aan die studie deel te neem. Verder, **wil ek graag/wil ek nie** 'n kopie hê van die finale navorsingsverslag.

Handtekening van deelnemer

Datum

Appendix B

Interview Schedule: English and Afrikaans

Interview Schedule

- How would you describe being a mother of a child with cancer?
- Can you tell me about how caring for your child influences you?
- In these special circumstances, what are your needs as a mother?
- As a mother, what does it feel like coming to the hospital for your child's treatment?
- How does parenting a child with cancer affect your quality of life?
- Can you tell me a bit more about how you have experienced your child's treatment process thus far?
- Can you describe the special requirements of a child with cancer?
- Can you tell me about a time in your child's treatment process that was especially difficult for you?
- What are the challenges you experience in caring for a child with cancer?
- Is there anything that is especially hard for you to deal with?
- Can you tell me more about any setbacks you have experienced?
- What challenges do you still foresee?
- Can you describe to me how you have dealt with the challenges you faced?
- What helps you to cope with difficulties/challenges/setbacks?
- How do you stay motivated to continue with your child's treatment process?
- Where do you find support during very difficult times?
- Looking back, what would you say has helped you the most to deal with difficulties and challenges?
- Is there anything that you would have done differently?
- What advice would you give to other mothers also caring for a child with cancer?

Onderhoudskedule

- Hoe sou u beskryf is dit om 'n ma te wees van 'n kind met kanker?
- Kan u vir my vertel hoe dit u beïnvloed om na u kind om te sien (te versorg)?
- In hierdie spesiale omstandighede, wat is u behoeftes as 'n moeder?
- As 'n moeder, hoe voel dit om na die hospitaal te kom vir u kind se behandeling?
- Hoe beïnvloed die versorging van 'n kind met kanker u lewenskwaliteit?
- Kan u vir my 'n bietjie meer vertel oor hoe u die behandelingsproses van u kind tot dusver ervaar het?
- Kan u die spesiale behoeftes van 'n kind met kanker beskryf?
- Kan u vir my van 'n tydperk in u kind se behandelingsproses vertel wat besonders moeilik was vir u?
- Wat is die uitdagings wat u ervaar om na 'n kind met kanker om te sien (te versorg)?
- Is daar enige iets wat besonders moeilik is vir u om te hanteer?
- Kan u vir my meer vertel oor enige terugslae wat u ervaar het?
- Watter uitdagings voorsien u nog?
- Kan u vir my beskryf hoe u die uitdagings waarmee u reeds gekonfronteer is hanteer het?
- Wat help u om die probleme/uitdagings/terugslae te hanteer?
- Hoe bly u gemotiveerd om met u kind se behandelingsproses voort te gaan?
- Waarvandaan vind u ondersteuning in baie moeilike tye?
- As u terug kyk, wat sou u sê het u die meeste gehelp om probleme en uitdagings te hanteer?
- Is daar enige iets wat u anders sou doen?
- Watter advies sou u vir ander moeders gee wat ook na kanker kinders omsien (versorg)?

Appendix C

Original Afrikaans Excerpts and English Translations

Original Afrikaans excerpts	English translations
<p>¹...ras ook 'n groot rol gespeel, want die eerste keer toe ons daar [by die hospitaal] kom, was ons die enigste Kleurlinge...ons [ma en dogter] het baie vreemd gevoel, want die meeste is mos maar die mense van [sic] Sesotho [met verwyssing na mense wat Sesotho praat]...en die ander ding is, hulle kon nie my taal praat nie, ek kon nie hulle taal praat nie...dan het dit altyd weer gelyk of ek kom beter voor of ek wil nie met die mense gesels nie, maar dit was nie die ding nie...dit was nie ons taal nie. Ek het baie uitgevoel.</p>	<p>...race played a big part, because the first time we got there [at the hospital], we were the only Coloureds...we [mother and daughter] felt very different, because most people there were from [sic] Sesotho [referring to individuals who speak Sesotho]...and the other thing is, they could not speak my language, and I could not speak their language...this made it look like I thought I was better than them or that I did not want to speak to the people, but that was not the thing. It was just not our language. I felt very left out.¹</p>
<p>²Sy het my baie bygestaan met, kyk, eintlik emosioneel. Sy was daar vir my gewees en my altyd laat verstaan ons sal hier deurkom. Ons is alreeds deur so veel, die is net nog 'n uitdaging.</p>	<p>She supported me a lot, look, actually emotionally. She was there for me and she always made me understand we would get through this. We have already been through so much, this is just another challenge.²</p>
<p>³Haar kliere het begin...ons het haar dokter toe gevat en die dokter het gesê "Nee man, dis een of ander infeksie in die lyf, of bakterië...", ons het gegaan met dit wat die dokter gesê het en die kind antibiotika gegee... Die kliere het nie kleiner geraak nie...toe vermoed die dokters dis TB...en hy [dokter] reël toe vir ons 'n afspraak met die dokter vir die bloed trekkery en al die goed...en dit het lank gevat... En so het ons nou maar gewag en gewag en die kliere het net al groter geraak.</p>	<p>Her glands started to swell...we took her to the doctor and the doctor said "No man, it is some form of infection in the body, or bacteria...", we went with what the doctor said and gave the child antibiotics... The glands did not get smaller...then the doctors suspected it was TB...and we did the tests and the tests came back alright...and he [the doctor] arranged for us an appointment with the doctor for blood tests and all those things...it took long... And so we waited and waited and the glands just got bigger.³</p>
<p>⁴Hulle [kinders by die skool] het hom [my seun] al met klippe gegooi. Hulle het hom gespot omdat hy nie hare het nie...</p>	<p>They [children at the school] have thrown him [my son] with stones. They have teased him because he has no hair...⁴</p>
<p>⁵Jy hoor wat hulle sê, maar dit is asof jy nie alles inneem nie. Jy kyk teen hierdie muur vas, hierdie kaal muur, dis, ek wil amper sê as jy dit sien, hoor leukemia, dan hoor jy doodstraf.</p>	<p>You hear what they are saying, but it is as if you are not taking in everything, you cannot see beyond this wall, this naked wall. It is, I almost want to say that when you see it, hear leukaemia, than you hear death sentence.⁵</p>
<p>⁶...en die ander ding is...hulle [die kiners met kanker] maak net klaar met hulle behandeling en dan gebeur iets, of hulle kry 'n relapse of 'n ding, en dan is dit die einde...</p>	<p>...and the other thing is...they [the children with cancer] had just completed their treatment and then something happens, or they get a relapse or something, and then it is the end...⁶</p>
<p>⁷Hy [my seun] wil baie graag rugby speel... baie dae voel dit vir my ek kan in 'n houpie gaan sit en huil, want ek was baie aktief op skool en hy wil so graag rugby speel en hy wil krieket speel, maar...ons [ek en my man] is te bang want kry hy seer...</p>	<p>He [my son] really wants to play rugby...most days it feels like I can sit on a heap and cry, because I was very active at school and he really wants to play rugby and he wants to play cricket, but...we [my husband and I] are too scared, because if he gets hurt...⁷</p>

Original Afrikaans excerpts	English translations
⁸Dit “drain” ‘n mens. Baie dae voel dit ek kan in ‘n hoekie gaan sit en huil...dit put mens uit. Soos ek vir jou gesê het, nie net liggaamlik nie, maar hier diep binne in my, in my siel, ek is moeg.	It drains a person. Most days I feel like I can just go and sit in the corner and cry...it exhausts you. Like I told you, it is not only physical, but deep within me, in my soul, I am tired. ⁸
