When a child has cancer: The constructed experiences of mothers of children with cancer

by

ITUMELENG MONTSOKOLO MASISI

submitted in accordance with the requirements

for the degree of

MASTER OF ARTS

In the subject

PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: PROF MARIA PAPAIKONOMOU

DECEMBER 2017

Declaration

I declare that the study titled **WHEN A CHILD HAS CANCER: THE CONSTRUCTED EXPERIENCES OF MOTHERS OF CHILDREN WITH CANCER**, is my work and that the sources that I have used or quoted have been duly indicated and acknowledged by means of complete references.

2017/12/06

_____   _____

SIGNATURE (STUDENT)   Date

Abstract

When a child is diagnosed with cancer, the roles and responsibilities of family members change to accommodate the demands of the illness. The current study aimed to explore the experiences of mothers of children with cancer, focusing on their constructed roles within the family context and their social support. A case study design within the qualitative research approach was employed, underpinned by social constructionism as a theoretical framework. Three mothers were selected, using a combination of purposive and snowball sample techniques. Rich descriptive data were collected from three mothers through semi-structured interviews and reflective essays, and analysed using thematic analysis techniques. Results showed that although mothers of children with cancer experience some common themes, there are contextual differences influencing how they construct their stories. The following main themes were identified in the comparative analysis: events leading to the diagnosis, emotions, life changes, the effect of the illness and coping.

Keywords: childhood cancer, psycho-oncology, primary caregiver, social constructionism, qualitative research, case study, thematic analysis, mothers

Acknowledgments

I would like to acknowledge my Lord and saviour Jesus Christ, and I thank God for the wisdom and strength to achieve this degree.

To my wonderful mother (Ditshego Masisi), my elder brother (Bernard Masisi) and my younger sister (Ruthie Masisi), thank you for your support and encouragement through my journey. To my late father (Daniel Masisi), thank you for giving me opportunities that you did not have growing up and for making me believe that I can achieve whatever I set my mind on.

I would like to acknowledge the following key role players in the unfolding of my journey:

- My supervisor, Prof. Maria Papaikonomou, for taking me on as a student and guiding me through the proposal and completion of my dissertation. Thank you for the time and efforts towards the completion of this degree.

- The Masters in Research Consultation (MARC) class of 2015 and lecturers who provided constructive feedback on my work and helped me refine my research objectives.

- I would like to acknowledge all the MARC administrators, coordinators and course leaders from the Department of Psychology as well as the facilitators of every workshop and seminar in the MARC programme.

- Johanni du Toit for connecting me with the manager of Reach for a Dream Foundation, who then assisted me in finding participants.

- Daleen Botes, manager of Reach for a Dream Foundation in Pretoria, for assisting me in finding my participants.

A special thank you to the mothers who participated in my research study. You allowed me into you lives and related your stories with openness and emotion. Indeed, without you my research study would not have been possible. I am truly grateful.

Dedicated to the memory of little Ruan Wolhuter,

who gained his angle wings on 7 April 2017

"Let the little children come to Me, and do not hinder them, for the kingdom of God belongs to such as these" – Luke 18:16 (NIV)

Table of contents

List of figures

List of tables

Abbreviations and acronyms

ALL	acute lymphoblastic leukaemia
CANSA	Cancer Association of South Africa
CHOC	Childhood Cancer Foundation South Africa
CNS	central nervous system
GP	general practitioner
IARC	International Agency for Research on Cancer
PTSD	post-traumatic stress disorder
PTSS	post-traumatic stress syndrome
QOL	quality of life
TA	thematic analysis
UNISA	University of South Africa
WHO	World Health Organization

Chapter 1: Introduction

1.1. Background

It is widely believed that a cancer diagnosis is not only devastating for the patient, but for the family as a whole, leading to the description of cancer as a we-disease (Kayser, Watson, & Andrade, 2007). Children suffering from cancer and their parents, find themselves in a situation dominated by uncertainty and uncontrollability (Van Veldhuizen & Last, 1991). However, the illness also has an interpersonal effect on the family members of the patient.

The discovery of a life-threatening illness in a child can be a traumatic event for any parent. Life changes for the parents from the initial diagnosis, through to treatment, the post-treatment period and the terminal phase (if not cured). Caring for a child with cancer can be emotionally and financially draining and also time-demanding for parents. Parents experience a range of emotions, from anger or regret to blame.

As the primary caregivers, mothers undergo the most drastic change and have to walk through the cancer process with the child. In addition to caring for the ill child's needs, mothers also have the responsibilities of caring for other family members during the diagnosis and treatment periods. Therefore, mothers' experiences can be linked to the overall functioning of the family. Cancer disrupts family structures, and roles and responsibilities change for family members (Northouse, 2005) . Furthermore, Northouse (2005) indicates that distressed family caregivers hinder the adjustment of patients, and how well families cope could affect how well patients cope, i.e. each affects the other. The mother might neglect other roles and relationships in the family because of the demanding nature of her role as caregiver in the life of the ill child. For example, when a child is hospitalised, the mother has to be with the child, which might have an influence on her relationship with the other family members (spouse and/or other children). Therefore, mothers' experiences can be linked to the overall functioning of the family.

1.2. Problem statement

Information about childhood cancer in Africa is lacking due to few formal cancer registries across the continent (Stones, De Bruin, Esterhuizen, & Stefan, 2014) in addition to unreported cases of childhood cancer.

Cancer is still considered as a rare disease in South Africa; however, research has shown an increase in incidences of childhood cancer over the past years (CHOC, 2017b). Research on the psychosocial effect of cancer on the patient and general consequences for the family is still lacking. Such information

affects the implementation of interventions suitable to help families cope with their child's illness and thus improving their caregiving process.

1.3. Rationale

Upon the exploration of literature on this topic, the researcher identified the need for further empirical investigation of the experiences of mothers caring for a child with cancer. Dumont et al. (2006) suggest that healthcare professionals prioritise family caregivers' needs in order to help them adjust better to coping with cancer caregiving. Giving attention to the caregiver's experiences could help to ensure the provision of better care for children and their primary caregivers. Literature shows that less is known about practical knowledge and support caregivers need in order to provide physical care in the homes (Caress, Chalmers, & Luker, 2009). Mothers are usually the main caregivers of children and are largely in charge of their children's wellbeing. According to Wright and Maree (2008, p. 36), "a healthy life for a mother and a child is essentially dependent on the level of knowledge and education of the mother as the recipient of health care messages".

There is thus a need for research that will inform well-defined interventions on practical skills needed when a child is diagnosed with cancer. Understanding factors that contribute to the health and wellbeing of parents and how these relate to important caregiving variables is a necessary elementary step toward designing interventions to help parents adjust and cope when their child is diagnosed with cancer (Klassen et al., 2007).

Most of the research on paediatric caregiving has been conducted in psycho-oncology and paediatric oncology nursing, being referred to as caregiver burden (Northfield & Nebauer, 2010) or caregiver strain. 'Caregiver burden' may refer to stress that may be experienced by people who are caring for another person (usually a family member) with a certain illness (Tull, 2017). For example, the caregiver may experience financial strain, stress, the burden of bathing and feeding the ill person, etc.

These terms have a negative connotation and mothers would not necessarily describe their experience of caring for an ill child as a burden. Nijboer et al. (1998) also noted that some caregivers perceive the care as a burden, while others consider it a challenge, and argue that the term 'burden' reflects a negative approach towards experiences of caregiving. Mothers may language their experiences differently and may also have a rather positive experience of caring for their child. Therefore, the current study focused on how the participants constructed their reality.

1.4. The aims of the study

This study aimed to explore the experiences of mothers of children with cancer, focusing on their constructed roles within the family context and in the wellbeing of their child. Mothers may experience

automatic role changes after the diagnosis of their child. The study also aimed to explore the formal support system and the social support available to mothers of children with cancer. Support systems could include contacts from both personal and professional contacts available to a person for practical or emotional support. Support systems could help mothers to cope with their child's illness and the day-to-day demands they face, and will have an influence on how mothers experience their child's illness.

1.5. Research questions

The general research question to be answered by the study was: How do mothers of children with cancer experience their child's illness?

The following sub-questions assisted in answering the general research question and in fulfilling the aims of the study:

- How have their roles changed in the family?
- Which kind of support did participating mothers have?
- Which kind of support was needed by participating mothers?

1.6. Research design and methods

A majority of the studies conducted on the experiences of parents of children with cancer were within the positivistic empirical approach. Much of the research focused on parenting stress and quality of life (Eiser, Eiser, & Stride, 2005; Kazak & Barakat, 1997), psychological distress (Norberg & Boman, 2008; Pai et al., 2007; Sloper, 2000b), and how parents cope with and adjust to their child's illness (Van Dongen-Melman, Van Zuuren, & Verhulst, 1998).

In this research study, case study design was used within the qualitative research approach. The aim was to gain a greater understanding of the dynamics of a specific situation and to provide a description of the case, in this case, the experiences of mothers of children with childhood cancer. The case study approach was suitable for investigating all possible aspects of the experiences of mothers caring for a child with cancer and in providing richer descriptions of their experiences. The case studies were viewed through the lenses of social constructionism.

Participants who could provide reach descriptions of their experiences of caring for a child who had been diagnosed with cancer were selected according to the criteria specified in Chapter 4 (see 4.6). A combination of purposive sampling and snowballing (or chain sampling) was used in this study. In qualitative research, there are no rules concerning the most appropriate sample sizes (Wagner, Kawulich, & Garner, 2012); however, qualitative samples are usually small in size. Three cases were selected for the purpose of this study.

The data was collected using semi-structured interviews and a reflective essay. Open-ended, probing questions were asked using an interview guide; however, the interview was not limited to the scope of the questions. The interviews were tape recorded and then transcribed for analysis. The reflective essay allowed the researcher to capture data that might have been too sensitive for the participants to discuss during the interviews or to relate experiences otherwise not touched upon during the interview.

The interviews were transcribed and analysed thematically. This was done in order to identify themes that characterised each participant's experience of her child's illness. The data was analysed following the steps outlined by Braun and Clarke (2006) as specified in Chapter 4. The three cases were then cross-analysed for similarities or differences and this is discussed in the comparative analysis chapter (see chapter 8). Cross-analysing the different cases showed how mothers constructed their experiences and our understanding of their experiences.

1.7. Ethical considerations

Ethical approval was obtained from the Department of Psychology at the University of South Africa. An additional set of ethical principles were adhered to during the study. Firstly, participants were treated with respect and dignity, allowing them the space to tell their stories. Secondly, informed consent was sought from the participants and participation was voluntary. Thirdly, confidentiality was ensured by the omission of any personal identifying information in the report, assuring the anonymity of the participants. Lastly, the study did not intend to harm the participants, and measures were put in place to mitigate the possible emotional discomfort that could be evoked during the interviews.

1.8. Chapter outline

This thesis comprises a literature survey, the theoretical framework which underpinned the study, as well as a practical component. The thesis is presented by means of the following chapters:

```
                    ┌─────────────────────────────────┐
                    │    Chapter 1: Introduction      │
                    └─────────────────────────────────┘
                                    │
                                    ▼
                    ┌─────────────────────────────────┐
                    │   Chapter 2: Literature review  │
                    └─────────────────────────────────┘
                                    │
                                    ▼
                    ┌─────────────────────────────────┐
                    │ Chapter 3: Theoretical framework│
                    └─────────────────────────────────┘
                                    │
                                    ▼
                    ┌─────────────────────────────────┐
                    │ Chapter 4: Research methodology │
                    └─────────────────────────────────┘
                                    │
                                    ▼
┌──────────────────┐      ┌──────────────────┐      ┌──────────────────┐
│ Chapter 5: Case 1│◄─────│ Chapter 6: Case 2│─────►│ Chapter 7: Case 3│
└──────────────────┘      └──────────────────┘      └──────────────────┘
                                    │
                                    ▼
                    ┌─────────────────────────────────┐
                    │   Chapter 8: Discussion         │
                    └─────────────────────────────────┘
                                    │
                                    ▼
                    ┌─────────────────────────────────┐
                    │ Chapter 9: Conclusions,         │
                    │ limitations and recommendations │
                    └─────────────────────────────────┘
```
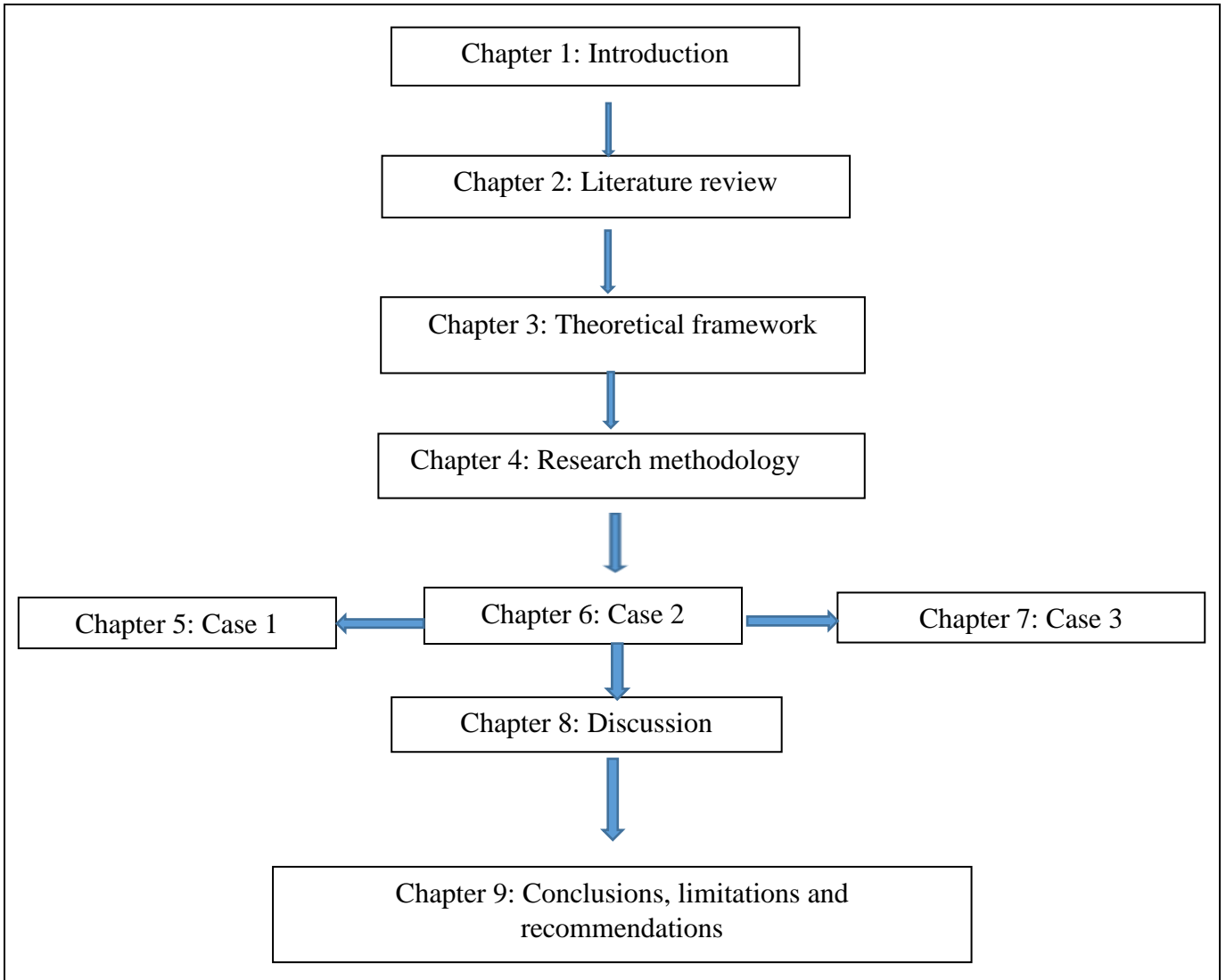
Figure 1: Chapter outline

1.9. Summary

This chapter provided the outline of the thesis, including the background to the research problem, the rationale for the study, the aims of the exploration, the research questions to be answered, the research design and methods, ethical considerations, and the outline of the chapters.

Chapter 2: Literature review

2.1. Introduction

Cancer is the second leading cause of death globally, and was responsible for 8.8 million deaths in 2015 (World Health Organization [WHO], 2017). Cancer is also the leading cause of death by disease in children younger than 15 years (Brown, 2006). The status of paediatric oncology is directly related to the developmental level of a country (Yaris, Mandiracioglu, & Büyükpamukcu, 2004). Much research has been conducted on childhood cancer from a biomedical perspective as well as from a biopsychosocial perspective, especially within the field of psycho-oncology. However, information about childhood cancer in Africa is lacking, due to few formal cancer registries across the continent (Stones et al., 2014). This chapter begins with an understanding of cancer from the biopsychosocial perspective as well as an overview of childhood cancer.

This study focused on the experiences of mothers (as the main caregivers) of children who had been diagnosed with cancer. The assumption was that the whole family experiences unexpected change when a child is diagnosed with cancer. Therefore, an exploration of literature on the effects of childhood cancer, on the patient and on the different members of the family, is provided in this chapter. The focus then moves to mothers and mothering in the context of a childhood cancer.

2.2. Biopsychosocial model

It is inevitable that the cultural and professional models of illness adapted in healthcare will influence decisions on individual patients and the delivery of healthcare (Wade & Halligan, 2004). How medical, nursing and other healthcare professionals approach patients and their families is influenced largely by the conceptual models around which their knowledge and experiences are structured.

In the past, the **biomedical model** of illness dominated healthcare, and it has been used to define and explain the causes of illness and diseases (Wade & Halligan, 2004). This model excludes psychological and social factors, and includes only biologic factors in its attempt to understand and treat medical illnesses or disorders. The biomedical model is a conceptual model of illness that considers disease primarily as a failure within the body, resulting from injury, infection, inheritance and the like (Alonso, 2004). Furthermore, the biomedical model embraces both reductionism (the philosophic view that complex phenomena are ultimately derived from a single primary principle) and mind–body dualism (the doctrine which separates the mental from the somatic). However, evidence shows that an individual's emotional state always affects his or her functioning and the presentation of physical symptoms (Wade & Halligan, 2004). Moreover, how one constructs one's reality is also influenced by history and culture, which are contextual factors in the individual's social environment.

From a biomedical stance, it can be argued that what is really affected by disease is organ systems (Patterson & Garwick, 1994). This means that only the affected organ will be treated; disregarding the effect of the disease on other systems, such as the social system. However, the consequences of diseases reach much further into the ecological context (Patterson & Garwick, 1994). For example, those who are in close relationships with the cancer patient cannot escape the effect (emotional, cognitive, and behavioural) of cancer on themselves. Thus, the argument in the current study was that the biomedical model cannot fully explain or be used to understand the effect of cancer. This is due to what Engel (1977, p. 129) calls "medicine's crisis", which derived from the logical inference that since disease is defined and understood in terms of somatic factors, doctors do not need to be concerned with psychosocial issues which lie outside of medicine's responsibility and authority. A crucial weakness of this model is its exclusion of the patient and his or her attributes as a person, in its conceptualisation of illness (Engel, 1981).

Within the biomedical model, childhood cancer is thought to be caused by developmental issues in the child's immune system (Brown, 2006). However, this logic is not sufficient and cannot solely explain the causes of cancer or the effect thereof. Recent research (see Herbst, 2016) identified other behavioural factors (healthy eating), social factors (lifestyle) and environmental factors (exposure to radiation) that may cause or aggravate cancer. These factors suggest an aetiology that goes beyond the biomedical perspective. The major identification of all disease in society has been behavioural, psychological and social in nature (Engel, 1977), which called for a more integrative perspective of illness and health.

In light of the limitations of the biomedical model, the current study argued that childhood cancer cannot be understood only from a medical point. The researcher chose to view both the child with cancer and the mothers from the **biopsychosocial** perspective. The biopsychosocial model is an alternative model constructed by psychiatrist George Engel who was frustrated with the dominance of the biomedical model in medicine and psychiatry (McCutcheon, 2006). Engel argued that particular disease states are multi-determined and may result from biological, psychological or social processes in variable forms of interaction (1977, as cited in Pilgrim, 2015). Hence, the biopsychosocial model considers not only the biological criteria, but also the social, cultural and psychological variables of disease causation (Hewa & Hetherington, 1995). In the current study, this model was taken further in understanding the outcomes of cancer on the lives of mothers of children with cancer, although the mothers were not sick themselves. Mothers are integral to the psychosocial aspects of the child's (patient) wellbeing.

Engel (1977, as cited in McCutcheon, 2006) defines six ways in which the biomedical model failed to explain the geneses and treatment of illness and disease:

- Biochemical deviation from the norm is not in itself sufficient to explain the development of disease. Individuals may possess abnormalities that are never manifested as disease.

- In order to understand and correctly interpret patient reports of symptoms, physicians must understand how psychological, social and cultural factors influence patients' communication about their symptoms, rather than relying solely on laboratory tests and measurements.

- Susceptibility to disease is influenced by the environmental and social conditions in which people live.

- Individual psychological and social factors influence when a person seeks treatment for symptoms.

- Treatment and correction of a biochemical abnormality do not always restore the patient to health; treatment outcomes also depend on psychological and social variables.

- The patient–physician relationship is itself influential in the treatment of illness or disease.

As determined above, unlike the biopsychosocial model, the biomedical model does not make provision for the person as a whole or for data of a psychological or social nature (Engel, 1981) or behavioural aspects. On the contrary, the biopsychosocial model is based on a systems approach, which acknowledges that no system can be viewed in isolation. "While each system operates independently, they interact with one another when they act as a whole" (Hewa & Hetherington, 1995, p. 136). Hence, a patient cannot be viewed in isolation from his or her family, society or community. Each system influences and is influenced by the other.

In the current study, although mothers of children with cancer were not ill (biomedical perspective), their child's illness affected their physical health and wellbeing, in turn the mother's wellbeing affected the wellbeing of the ill child. Engel's (1977) model considers the individual, the social context of the individual, the social context of the healthcare system, and the physician–patient relationship (McCutcheon, 2006). Thus, mothers of children with cancer fit into the social context of the patient, being the child.

In a call for a 'new medical cosmology', Greaves (2002) identified between a biopsychosocial paradigm A and B. The **biopsychosocial paradigm A** is "a modification of biomedicine's paradigm, and aims to retain its scientific assumptions whilst enlarging its scope to include psychological and social elements"(Greaves, 2002, p. 82). The main concern with this paradigm is that it reduces qualitative accounts to quantitative data, which then results in insights into meaning being converted

into causal descriptions (Greaves, 2002). Here the psychosocial elements of disease are dealt with in a similar way to the biological aspects.

The **biopsychosocial paradigm B**, on the other hand, is an amendment of the paradigm of biomedicine through the addition of a humanistic element (Greaves, 2002). This paradigm provides a separation between issues applicably considered quantitative on the one hand and qualitative on the other. The psychosocial dimension is added to the biological dimension to keep the presuppositions of the biological dimension intact. The current study was aligned to biopsychosocial paradigm B, although the focus was on the qualitative aspects of the effects of childhood cancer on the mother as the primary caregiver. (Greaves (2002) contends that although the biopsychosocial model addresses both the scientific and humanistic aspects of health, this model still fails to harmonise these biological, psychological and social factors and thus cannot deal sufficiently with the challenges that medicine faces. He argues for a more 'integrated' alternative approach, which extends the biopsychosocial model to include the arts as well as psychosocial dimensions.

Such integrations of social and biological research will contribute to a better understanding of the aetiology (i.e. the cause) of disease/illness (and other health concerns) and to improved prevention and treatment. Previous research in childhood cancer has also focused on an understanding of the biological, psychological and social stressors and effects imposed by a cancer diagnosis on the psychological functioning and wellbeing of the child and the family (Brown, 2006). More so, research conducted in psycho-oncology (Girgis et al., 2013), oncology nursing (Bemis et al., 2015) and clinical nursing (Arabiat & Altamimi, 2012) has focused attention on the psychosocial aspects of childhood cancer. Paediatric oncology is concerned with an understanding of these biopsychological stress effect (Noeker & Petermann, 2015).

2.3. Childhood cancer

The types of cancer that appear in children are very different from those seen in adults. Childhood cancers tend to occur in different parts of the body, most often occurring in the developing cells like bone marrow, blood, kidneys and nervous system tissues (CHOC, 2017a) and commonly have the microscopic features of embryonal tissue (Dixon-Woods, Young, & Heney, 2005). According to the International Agency for Research on Cancer (IARC), the incidence of cancer in children aged 0–14 years was 140,6 per million person-years, and in those aged 0–19 years, it was 155,8 per million person-years between 2001 and 2010 (Steliarova-Foucher et al., 2017).

Childhood cancers are the second most common causes of death in children 5 to 14 in Western countries, although it is relatively rare. However, in Africa, childhood cancer is not counted in the top 10 common causes of death in children.

In South Africa, accurate figures have not yet been published, although it was previously estimated that between 500 to 600 children are diagnosed with cancer annually (Low & Rankin, 2010). Most child cancers are not reported, making it difficult to register its occurrence, in addition to the challenges facing the National Cancer Registry, such as not being able to capture data on children treated by private oncologists (see CHOC, 2017b). Moreover, childhood cancer sometimes goes undiagnosed and untreated due to limited access to specialised medical services needed , especially in rural areas and poor communities (Low & Rankin, 2010).

The most common childhood cancers both worldwide and in South Africa are leukaemia (cancer affecting the blood), followed by brain tumours and lymphomas (tumours that start in the lymph), then embryonal tumours and sarcomas (tumours that begin in the connective tissue). Rather than the primarily organ-based system of classification used in adults, the classification of malignancies in children is usually accomplished mainly on the basis of the cell types involved (Dixon-Woods et al., 2005).There are many different theories and ongoing research into the possible causes of childhood cancer; however, the causes remain unknown to a large extent (Low & Rankin, 2010). The causes of cancer are diverse, complex and only partially understood (Herbst, 2015).

Cancer is a malignant growth or tumour caused by abnormal and uncontrolled cell division. However, cancer in adults is associated with epithelial cells, which are cells that line the body cavities or cover body surfaces, and is promoted by some interaction with the environment (Eiser, 2004b). In comparison to adult cancers that are frequently the result of one's lifestyle (e.g. lung cancer caused by smoking) and environmental causes (e.g. asbestos, radiation), there is much less evidence of any environmental or behavioural explanations for cancer that occur in children (Brown, 2006). However, childhood cancer (like adult cancers) cannot be viewed solely from a biomedical perspective due to the other social and environmental factors that may play a role in the causes of the illness. The study of environmental factors in the causation of childhood cancers has been ongoing for a number of years (Mcbride, 1998) and due to improvements in research and technological advancements, more information is available on the potential factors affecting the risk of childhood cancer.

Children are especially vulnerable to toxins in the environment because their organs and immune systems are still developing (Yaris et al., 2004). Therefore, different types of childhood cancers are linked to different environmental factors acting as carcinogens. A carcinogen is a substance that is capable of causing cancer in humans or animals (Herbst, 2016). This also includes substances known to promote or aggravate cancer, but not necessarily cause cancer. Although there are different substances and things that are believed to contribute to the cause of cancer, a substance is only considered carcinogenic if there is significant evidence of its carcinogenicity, that is its ability to cause

cancer (Herbst, 2016). These include environmental factors such as air pollution, man-made chemicals, tobacco smoke, the sun, natural and man-made radiation, asbestos, and exposure to infectious agents. It is evident that childhood cancers are different from cancer in adults; therefore, the diagnosis, treatment and effects of the illness are distinct.

2.4. Diagnosis, treatment and effects

Treatment of cancer depends on the type of malignancy, the stage of the illness, age and gender of the child. Childhood cancers require specialised treatment provided by a paediatric oncologist, comprising chemotherapy, surgery, radiation or a combination of some treatments(CHOC, 2017a). In some cases, bone marrow or stem cell transplantation is necessary (CHOC, 2017a). Treatment usually begins with a series of tests and examinations in order to get a definitive diagnosis. Treatment varies especially according to the type of cancer that occurred and how far it had spread (which determines the 'stage' of cancer), among other factors. It may occur over a 2- to 3-year period, with initial intense phases of chemotherapy followed by less severe treatment periods (Earle, Clarke, Eiser, & Sheppard, 2006). Medication is administered into the cerebrospinal fluid concurrently in order to prevent the spread of the disease to the central nervous system. This aspect of treatment is most directly associated with neural toxicity that may have effects on the child's body, and necessitates hospitalisation.

Radiation therapy has also been an essential element of the treatment of childhood cancer, which resulted in improvements in survival for some of the most common malignancies; however, the increase in radiation use has also resulted in long-term adverse outcomes for patients (Armstrong, Stovall, & Robison, 2010). Armstrong and colleagues argue that radiation therapy has been previously associated with increased risk of late mortality, development of second neoplasms, obesity, and pulmonary, cardiac and thyroid dysfunction as well as an increased overall risk for chronic health conditions.

In South Africa, most of the child's treatment takes place at the hospital, and hospital stays can vary from several days to several weeks at a time (Low & Rankin, 2010). During the phase of less intense treatments, children are usually taken care of at home and have shorter hospital visits. Once treatment has been completed, children may remain under surveillance to detect any evidence of disease recurrence. During the child's treatment, some mothers stay in facilities like the Cancer Association of South Africa (CANSA) care homes and care facilities in order to be close to their ill child (CANSA, 2016).

Fortunately, due to advances in treatment, a cancer diagnosis no longer represents a death sentence for a child (Bishop, Stedmon, & Dallos, 2014). Major advances in diagnosis and treatment of many childhood cancers have resulted in significant and striking survival rates. In the present day, the

majority of childhood cancers can be treated very effectively, and if detected early, the child can be completely cured. Progress made in the treatment of childhood cancer has led to 70% cure rates (Low & Rankin, 2010). However, Stones et al. (2014) recently demonstrated that overall survival in childhood cancer remains low (52.1%) in South Africa when compared with international data. In addition, they found black children to have worse survival rates than other ethnic groups. The possible reasons mentioned for these differences include late presentation, poor nutritional status, socioeconomic status, genetic factors and associated comorbidities, such as HIV infection and tuberculosis (Stones et al., 2014)

Engel (2000) argues that these drastic improvements in the prognosis of cancer brought along a shift in the focus of the psychological literature from issues of family bereavement associated with a child's death to quality of life. The focus of healthcare professionals is now on helping families cope and adjust to the child's illness through treatment and post-treatment care. Furthermore, healthcare professionals have been compelled to include concerns about treatment effects and late effects in the total care plan for children with cancer.

Despite the advances in the treatment of childhood cancers and the improved survival rates, the aftermath of the diagnosis and maintaining the treatment remain a stressful and traumatic time for both the child and the family (Earle et al., 2006; Mitchell, Clarke, & Sloper, 2006). The care of a sick child in the home has an effect on the entire family: the sick child, the siblings, and the parents. Monitoring how the child responds to treatment may involve multiple medical procedures, from repeated blood draws to bone marrow aspirations and lumbar punctures (Long & Marsland, 2011). The symptoms and effects of cancer on the child vary according to the type of cancer, the stage of the illness and treatment required. For example, chemotherapy is associated with a number of adverse side-effects, which include nausea, vomiting, hair loss, diminished appetite, mouth sores, general malaise and low blood counts that make the child susceptible to infection (Brown, 2006). Nevertheless, some of these side-effects are short term and can be alleviated by medication whereas some are longer term, depending on the type of treatment. Many of the side-effects temporarily make the child feel sicker than the cancer itself.

Different types of childhood cancer will yield different effects in relation to the treatment required for that specific type. For example, children diagnosed with brain tumours may experience cognitive problems requiring special education to assist with coordination, balance and motor skills, and they may experience general tiredness. Children are often extremely ill, spending much time in hospital. In addition, they are reliant on professional nursing care with input from different specialised

staff and a team of medical sub-specialists (Dixon-Woods et al., 2005). The care team may include physiotherapists, pharmacists, dieticians, play therapists and psychologists.

The duration of hospital stays could influence the children's quality of life negatively (Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011). Most childhood cancer patients miss an extensive amount of school because of their treatment regimen or treatment-related side-effects (Brown, 2006). Similarly, keeping up with schoolwork and maintaining friendships are particularly challenging tasks for children treated for cancer. Treating cancer is therefore an extremely difficult and gruelling process, both for the patient and the parents.

2.5. The child with cancer

Much more than healthy children, children with cancer are dependent on significant others in their environment, most notably mothers as the primary caregivers. Previous research has shown that cancer has a physical, emotional and psychosocial implications for the ill child (Brown, 2006; Kreitler & Weyl Ben Arush, 2004; H. C. W Li, Chung, & Chiu, 2010).

Cancer is characterised by pain, especially during the treatment phases of the illness. Children endure demanding healthcare regimens (Pai et al., 2007), painful medical procedures (Hampel, Rudolph, Stachow, Laß-lentzsch, & Petermann, 2005), unpleasant treatment side-effects (Brown, 2006; Low & Rankin, 2010), anxiety and the threat of death (Pai et al., 2007). The child with cancer is expected to adhere to and co-operate with required treatments and to adapt to possible changes in his or her routine (Knafl et al., 2013). Furthermore, the social development of children with cancer is hampered as they are deprived of constant interaction with friends and family.

In a study conducted in China, Li, Chung, and Chiu (2010) examined the effect of cancer on the psychical, emotional and psychosocial wellbeing of children (aged 7 to 15 years). Their findings indicated that children scored highly on anxiety upon admission for treatment and depressive symptoms during their hospital stay. In addition, participants expressed different degrees of sadness, unhappiness and worry. The physical effect included pain resulting from diagnostic procedures and treatment while the psychosocial effects included confinement, feelings of estrangement and a change in appearance. Although the change in appearance was a physical effect of cancer and its treatment, it had a psychosocial effect on the child.

Schoolchildren face challenges due to absenteeism, especially during treatment phases, and other concerns, especially when returning to school. Vance and Eiser (2002) reviewed literature with the aim of investigating school absence, behaviour problems and social relationships of children with cancer on return to school. Their review revealed a high level of school absence among children with cancer compared to their healthy counterparts and those with other chronic conditions. There also

appeared to be mixed findings about whether children showed behavioural problems or not. However, it was found that studies involving social relationships generally concluded that children with cancer are sensitive and isolated than their peers, according to both peer and teacher report (Vance & Eiser, 2002). Older children themselves also reported anxiety and concerns about their academic performance resulting from school absenteeism (Li et al., 2010).

The ill child's quality of life is potentially compromised through pain, fatigue and possible disability, with implications for limited participation in everyday life, school and other social activities (Eiser et al., 2005). In addition, the child has limited opportunities to partake in normal, age-appropriate social activities and other physical activities (Eiser, Greco, Vance, Horne, & Glaser, 2004).

2.6. Survivorship and long-term effects of cancer

Because of the advances in cancer diagnosis and treatment, which results in children surviving cancer, substantial previous research focused on survivors of childhood cancer and their quality of life (Armstrong et al., 2010; Eiser, 2004a; Kim & Given, 2008; Parry, 2003; Svavarsdottir, 2005; Zebrack & Chelser, 2002). The classification of a child as a survivor is dependent on various aspects ranging from the time the child was diagnosed to the period after treatment (Robison & Hudson, 2014). For the purpose of this study, a 'cancer survivor' referred to a patient who went through treatment and who was in remission at the time of the study.

Cancer is now considered a life-threatening disease that may have long-term effects rather than a fatal illness leading to death, as was previously seen (Svavarsdottir, 2005). Nevertheless, its treatment places survivors at risk of compromised physical and psychological functioning. Childhood cancer survivors have previously reported a generally positive quality of life (Zebrack & Chelser, 2002). However, due to the long-term effects of cancer and its treatment, survivors experience certain concerns. Figure 2.1 below summarises some of the issues that are faced by survivors of childhood and adolescent cancers.
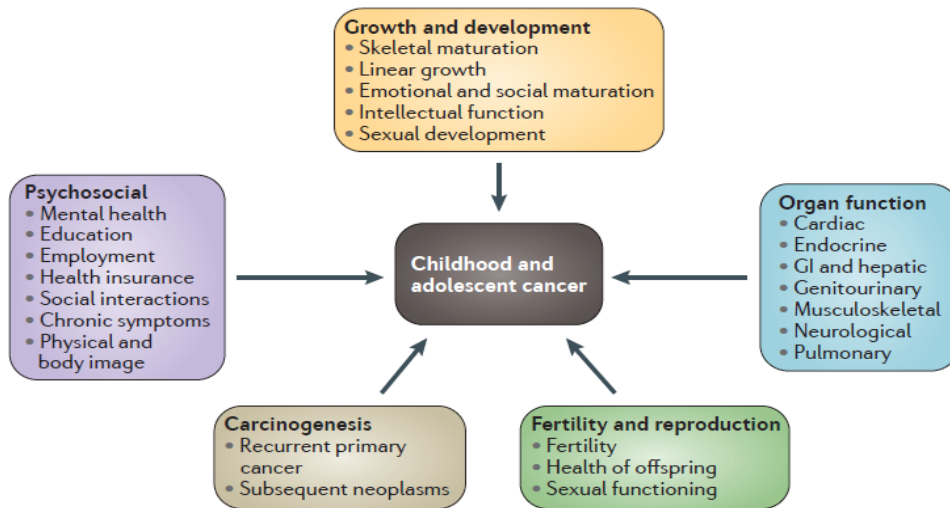
Figure 2.1: Range of health-related and quality-of-life outcomes among long-term survivors of childhood and adolescent cancer

(Robison & Hudson, 2014)

Other medical, psychosocial and late effects of concern for survivors include neuro-psychosocial problems, visible physical impairment and disability (Zebrack & Landier, 2011), late mortality, second neoplasms, organ dysfunction, impaired growth and development, impaired cognitive functioning, and overall reduction in quality of life (Armstrong et al., 2010). A study by Li, Chung, Chiu, Ho, and Lopez (2014) explored the effect of cancer and its treatment on physical activity level and behaviour in childhood cancer survivors. They found that survivors' physical activity levels were very low after remission. Survivors could no longer participate in some physical activities as they had done before due to tiredness and decreased physical strength and endurance after remission. The low physical activity levels may have been a result of the advice from health professionals or parents that children should rest in order to avoid fatigue. The cultural context of China was taken into consideration in the understanding of the results. This highlighted the contextual differences in how children adjust to cancer and how their lives will be affected. Placed in their context, children were understood better in terms of the findings of the research.

In one study, Eiser et al. (2004) identified some discrepancies in the quality of life (QOL) of survivors of childhood cancer. One of the aims of the study was to elicit survivors' views about their QOL through an interview focused on the following themes: social and family relationships, body image, physical functioning, school progress and their attitudes towards the illness. Survivors of tumours of the central nervous system (CNS) reported worse QOL and more discrepancies than survivors of acute lymphoblastic leukaemia (ALL), which showed the relativity of how cancer is experienced and how quality of life will be affected. Discrepancies were found between what survivors could do and what they would like to do, which feeds into the concept of QOL. Correspondingly,

Vance, Eiser, and Horne (2004) also found discrepancies in that survivors were not achieving at a level that they personally expected, or as family and friends expected. For example, a child would desire to participate in sport activities, while not being able to do so due to fatigue. However, parents actively attempted to provide replacements or alternatives for the discrepancies in their child's life. These discrepancies provided an understanding of the effect of cancer on the QOL of a childhood cancer survivor.

According to Zebrack and Chelser (2002), although symptoms associated with treatment decline over time, other long-term effects, such as fatigue, aches and pain continue to have a negative effect on the QOL in survivors. On the other hand, survivors also rated themselves high on happiness, feeling useful, life satisfaction and their ability to cope despite having had cancer, although their hopefulness remained tempered by uncertainty and the fear of cancer re-occurring. The uncertainty of the day-to-day course of the illness as well as uncertainty about the long-term prognosis makes it difficult to predict or plan future events concerning the child (Clarke-Steffen, 1997). Therefore, parents' aspirations and goals for the child may change or be altered due to the uncertainty and long-term effects of the disease.

Uncertainty has been noted as a central theme in literature on cancer survivorship and coping literature (Parry, 2003). Parry (2003, p. 229) argues:

> [T]he primary approach to constructing and contextualizing uncertainty in the cancer survivorship literature is rooted in the stress and coping paradigm and involves the description of uncertainty as a phenomenon that can adversely affect the quality of life of cancer survivors.

Parry (2003) further argues that, although uncertainty has the potential to affect cancer survivor's QOL adversely, the single construction connoted with negativity might conceal the complexity of the term 'Quality of life' and the richness of its meaning. Findings from Parry's study showed that uncertainty can also be positive. In positive light, as argued by Parry (2003), uncertainty could be a catalyst for growth, could provide an appreciation for life, and could provide a greater awareness of the purpose of life, development of confidence and resilience, and optimism in the survivor and their families.

In another literature review, Havermans and Eiser (1994) studied literature restricted to the implications of cancer and its treatment for long-term social and emotional development. They employed outcome measures which where categorised into the following: life goals and achievements; self-ratings of personality (for example depression, self-esteem, locus of control); and more general indices of 'adjustment', usually made by parents. Life goals were defined in terms of employment status, marriage or the ability to form a close relationship, birth of healthy children, and the attainment of life insurance cover. The review further revealed that survivors had good adjustment, they generally

achieved life goals, and had a level of education comparable with (or slightly above) the general population. The data also showed some residual social and emotional problems, which were reflected in a lower incidence of marriage and close relationships. This may however be different for very young children who survive cancer.

The literature review done during the current study showed that survivors of cancer are confronted with long-term effects that may have an effect on their quality of life. Many survivors continue to endure symptoms and long-term effects of cancer treatment. However, cancer is not only associated with negative effects; there are also positive aspects gained from their journey. The effects of cancer may be positive or negative, depending much on the way the child has lived through the cancer ordeal and his or her context. It is worth noting that the treatment of cancer itself is a significant contributor to the above effects rather than the actual disease.

2.7. Families of children with cancer

It is inevitable that families should be the main sources of support and more so when a member of the family becomes ill. A cancer diagnosis is not only devastating for the patient, but for the family as a whole, leading to the description of cancer as a 'we-disease' (Kayser et al., 2007). The diagnosis is "a contradiction to the natural order and organization of the family life, throwing assumed sequences and relationships out of order" (Cohen, 1993, pp. 82–83). Research has highlighted the effects of illness on family interaction, the interaction between the family system and its external community, and the way the family copes collectively (Ell, 1996).

The effect of cancer on families of cancer patients has been well documented (Björk, Wiebe, & Hallström, 2005; Eiser & Upton, 2006), especially with research from the family systems perspective. Long and Marsland (2011) argue that the cancer itself may not directly influence the child's adjustment, but rather the interaction of disease factors unfolding within the family system, which interacts with the child and affects his or her development. Disease factors include the treatment and prognosis, while the factors within the family system include parental distress, family functioning, and parenting. This is in agreement with Quinn and Herndon (1986), who suggest that the family system and the culture where that family functions are contexts within which the illness operates.

One assumption of the family systems theory is that "a change in one part of the system leads to a change in other parts of the system as well" (Patterson & Garwick, 1994, p. 131). Thus how the child and the family unit adjust to illness are seen as both influencing and resulting from the adjustment of individual members within the family system (Noojin, Causey, Gros, Bertolone, & Carter, 2000). Patterson and Garwick (1994) define a family system as a group of individuals and the pattern of

relationships between them. Figure 2.2. provides a representation of Patterson and Garwick's (1994) illustration of the ecosystem of a person with chronic illness.
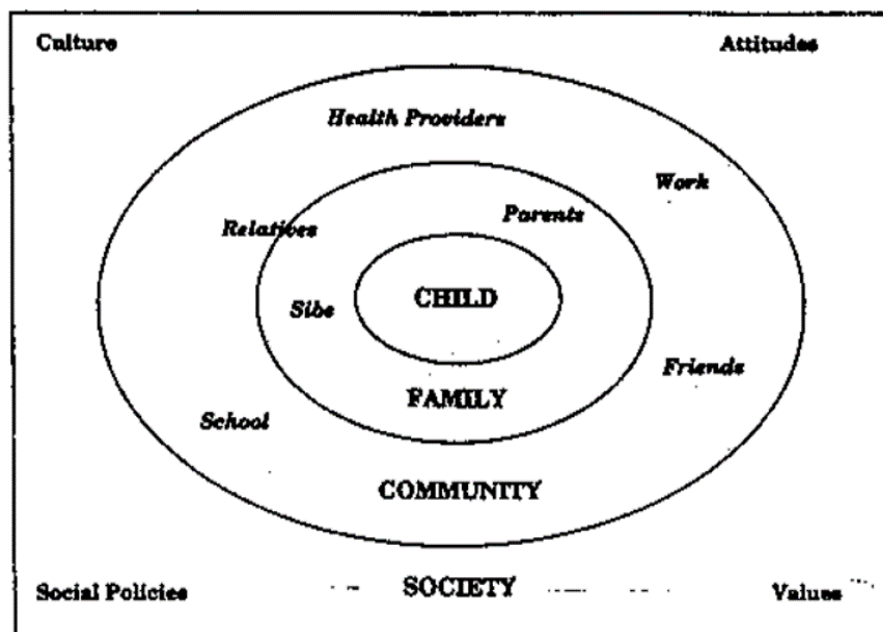
Figure 2.2: The ecosystem of a child with chronic illness

Source: (Patterson & Garwick, 1994, p. 132)

According to the ecosystemic perspective, how the family responds to childhood cancer affects the health care the child will receive, the child's response to the illness, and the child's psychosocial environment (Clarke-Steffen, 1993). Therefore, it is of paramount importance to consider the adjustment of the whole family when examining the adjustment of children affected by cancer.

In light of the child's illness, families have to make significant life changes and sacrifices to care for the child with cancer (Brown, 2006) and family relationships could also change. Family routine needs to be adapted to the demands of the illness (Flury et al., 2011) and as a result, families may be at risk of increased family conflict (Pai et al., 2007). In addition, families are usually isolated in their efforts to comply with the demands of the ill child's treatment regime and forging a new life. In the study by Björk, Wiebe, and Hallström (2005), family members experienced that the life world of the family fell apart. Life as the family had known it no longer existed (Fletcher, 2010). Families may feel that they have lost their lives as was previously known, or that their identity had been lost.

One of the emotional consequences of illness for families facing childhood cancer is the feeling of loss (Nikfarid, Rassouli, Borimnejad, & Alavimajd, 2015). In addition, uncertainty is a constant (Cohen, 1995) and is mostly associated with the continued fear of the possible recurrence of cancer. This often results in difficulties in psychosocial functioning, particularly in relationships with others. Moreover, parents of children with chronic illnesses experience uncertainty relating to the illness event,

the time frame or course of the illness, the aetiology of the illness, the treatment and the prognosis (Cohen, 1993). In a study investigating the relationship between the degree of uncertainty in the child's chronic condition and family distress, parents of children with unpredictable symptoms (uncertainty) reported significantly more distress in their family than parents of children with very predictable symptoms (Dodgson et al., 2000). Findings also revealed family and/or social disruption in families of children experiencing intermittently unpredictable symptoms.

The current study hypothesised that children with chronic conditions that are uncertain will be associated with more distress in the family than their counterparts. The diagnosis of a child and the experience of cancer may aggravate past or present family issues or it may lead to greater cohesion and resilience among family members (Kreitler & Weyl Ben Arush, 2004). The success with which the family manages the changes and adjustments required could have a profound effect on the emotional wellbeing of the child (Noojin et al., 2000). Similarly, it is important to understand how the different parts of the family are affected by the child's illness.

2.8. Parents

Previous research explored the experiences of parents of children with cancer. Much of the research focused on parenting stress and quality of life (Eiser et al., 2005; Kazak & Barakat, 1997), psychological distress (Norberg & Boman, 2007; Pai et al., 2007; Sloper, 2000a), and how parents cope with and adjust to their child's illness (Amoateng, Kalule-Sabiti, & Oladipo, 2015; Elkin et al., 2007; Van Dongen-Melman et al., 1998).

Negative physical and emotional effects have been seen to dominate parental experiences of their caregiving role (James et al., 2002). The treatment of cancer may also have an effect on the relationship between the parents and may cause tension. The marital relationship may endure strain at some points of the treatment and improvements at other points (Long & Marsland, 2011). However, there are mixed results in the literature of the effect of a child's diagnosis on marital relationships. However, Young, Dixon-Woods, Findlay, and Heney (2002) found that only a few mothers experienced a decline in the quality of their relationships with their partners. This shows that there are other factors that contribute to how parents will cope with their child's illness. In the same way, many parents change their previous parenting methods, while others retain the methods they used prior to the diagnosis (Williams, McCarthy, Eyles, & Drew, 2013). Parents may spoil their child to co-operate with treatment, while others continue to spoil the child after treatment(Bracken, 2010).

During this time, parents 'switch worlds' (and roles) and move from the safe world of the known, the familiar and the predictable into an unusual world of uncertainty and threat (Cohen, 1993). Parents are often compelled to re-evaluate their priorities and the way they lived their lives prior to the

diagnosis (Schweitzer, Griffiths, & Yates, 2012). In addition to finding out that there is a serious illness in the family and adapting to the illness, the parents are burdened with responsibilities, including accompanying the ill child to the hospital, managing side-effects, maintaining the home and sometimes having to work in addition (Kobayashi, Hayakawa, & Hohashi, 2015). When the diagnosis is first announced to the parents, their world, as it was previously understood, suddenly and inevitably becomes transformed (Cohen, 1993). Parents' reactions to their child's diagnosis may include anger, regret, blaming (Papaikonomou, 2007), disbelief, confusion, fear, feelings of inability to cope, tension (Young et al., 2002) and shock in the initial stage (Noeker & Petermann, 2015).

Even through remission, the fear remains that the disease will return (Al-Gamal & Long, 2010; Vance et al., 2004). Parents' greatest fear is that their child will die or that the illness will re-occur. In a study on parents' perception of disclosing the diagnosis of cancer to their children (Watanabe, Nunes, & Abrue, 2014), it was found during their interviews, that most mothers associated cancer with death. Uncertainty is a common feature in parents' experiences of their child's illness, particularly over their child's future health status (Vance et al., 2004).

Literature on family caregivers of ill elders or chronically ill children often describes their experience as caregiver burden or caregiver strain (Nijboer et al., 1998; Northfield & Nebauer, 2010). Caregivers are generally defined as 'primary care providers', which refers to network members, such as the partner, parent, or sibling (Nijboer et al., 1998). The current study focused on mothers as the main or primary caregivers. Caregiver tasks are frequently categorised as –

- assistance with self-care and mobility;
- symptom management of the patient;
- emotional support; and
- financial management; and/or
- conducting medical care tasks (Nijboer et al., 1998).

In young children, these tasks may be even more intense for parents. 'Caregiver burden' refers to stress that may be experienced by people who are caring for another person (usually a family member) with a certain illness (Tull, 2017). For example, the caregiver may experience financial strain, stress, the burden of bathing and feeding the ill person, etc. However, the terms strain and burden may have a negative connotation, and mothers would not necessarily describe their experience of caring for an ill child as a burden.

Nijboer et al. (1998) previously noted that some caregivers perceive the care as a burden, while others consider it a challenge and that the term 'burden' reflects a negative approach towards experiences of caregiving. Mothers may construct their experiences differently, and may also have a

rather positive experience of caring for their child. The terms 'burden' and 'strain' subtly echo a negative experience of caregiving; however, research has shown that there are positive aspects related to the caregiving experience (Northfield & Nebauer, 2010). In the research by Li and Loke (2013), caregivers reported that their relationship with the care-receiver and the whole family improved due to the caregiving process, and reciprocity between care-giver and care-receiver. Furthermore, caregivers may gain feelings of accomplishment, such as the discovery of personal strength and the knowledge that one is needed, and a sense of reward for doing something good (Li & Loke, 2013). For some, having control over their own home was a positive aspect, while for others, the caregiver's self-efficacy was positive. In the study by Cohen, Colantonio, and Vernich (2002), caregivers mentioned companionship and a sense of it being fulfilling or rewarding. Additional positive aspects were enjoyment, duty/obligation, and meaning/importance, provide quality of life and love(Q. Li & Loke, 2013).

How couples or marriages will be affected by a child's illness will vary from family to family. Some research showed that the quality of marriage or family life improved since the diagnosis of a child (Barbarin, Hughes, & Chesler, 1985; Ell, 1996). Contradictory research however indicated that marital strain could result from the parents' tendency to place the needs of the marriage on hold during treatment, and from differences in mothers' and fathers' emotional responses to cancer (Long & Marsland, 2011).

Mothers take on the responsibility of the main caregiver and spend extended times in the hospital during the child's treatment stages (Clarke, Fletcher, & Schneider, 2005; Young et al., 2002). This period can be strenuous for the spousal relationship, causing a rift between the couple. In addition, the stress and demands of the illness result in parents focusing their attention on the child and the wellbeing of the family at the expense of the marital relationship (James et al., 2002; B. Young et al., 2002). In contrast, a stressful experience has the potential to bring the couple closer together (Zimmerman, Haddock, Ziemba, & Rust, 2001). Although the stress of the child's illness may not necessarily result in the parents' divorce, there may be a change in marital satisfaction.

Some research has been conducted in childhood cancer that focused on single parents maintaining a household and caring for a child who has cancer. Single parents may be faced with unique challenges in managing the day-to-day caregiving tasks for both the ill child and the siblings (Bemis et al., 2015). In families where both parents are present, the burden of the child's illness is shared by the two whereas single parents may carry the burden alone. For example, a single mother may need to accompany the child on hospital visits, which compromises the sole income of the family. A family's

income is strongly connected to the children's health, and maintaining the child's health may become a struggle for single parents (Brown et al., 2008).

The most common single-parent context is one with only the mother present. Klassen et al.'s (2012) literature review revealed that single mothers report lower levels of social support, social involvement and frequency of contact with friends and family compared with married mothers. However, Klassen et al.'s (2012) Canadian study found that single parents did not differ from two-parent households on caregiving demands or health-related quality of life. The study rather found that health-related quality of life was associated with lower financial savings and adjusted family income (Klassen et al., 2012). It is clear that the fear of the child dying, the demands associated with the lengthy treatment process, financial costs and pressures, as well as the negative effect on family relationships, can all lead to adverse psychosocial outcomes for parents (Klassen et al., 2007).

Moreover, the strength and quality of the family relationships are better predictors of the adaptation of the child rather than the specifics of the child's illness or the 'aggressiveness' of their medical treatment. Parents' psychological functioning is one of the critical factors influencing the interaction between the cancer course and the child's developmental process, their physical (Pai et al., 2007) as well as their psychological functioning (Noojin et al., 2000; Pai et al., 2007). Northouse (2005) argues that distressed family caregivers hinder the adjustment of patients, and how well families cope could affect how well patients cope – each affects the other. Therefore, parents play a vital role in helping children cope with cancer-related stressors (Hildenbrand, Alderfer, Deatrick, & Marsac, 2014). Furthermore, parents' perceptions of their own wellbeing could influence how they perceive the health of their child (Svavarsdottir, 2005). In addition to blaming, a feeling of incompetence may arise as parents are facing an unfamiliar event.

Therefore, parents of children with cancer should be included in interventions targeted at improving the adjustment and wellbeing of the patient, namely the child. However, parents are not the only role players affected by the child's cancer diagnosis; siblings of the ill child are also affected.

2.9. Siblings

Parents also face the challenge of disclosing the diagnosis of cancer to the child and to the siblings. Disclosing a cancer diagnosis to young children is a difficult decision for the parents (Watanabe et al., 2014) and the same difficulty can be anticipated when disclosing to siblings. Siblings of the ill child are affected by the cancer diagnosis as they are also faced with changes within the family (Kobayashi et al., 2015).

In addition, siblings observe their brother or sister experiencing many painful procedures and changes in his or her appearance. Some older children may feel the need to take care of their ill sibling and assume responsibility for domestic tasks (Knafl et al., 2013).

During the hospital visits and long stays for mothers who accompany the ill child, parents strive to maintain as much of a normal life as possible for the siblings (Fletcher, 2010). Siblings describe that they miss their family's usual activities and routines and that they often feel neglected (Sloper, 2000a), anxious and lonely (Hamama, Ronen, & Feigin, 2000). Parents tend to overprotect and spoil the child with cancer, and sometimes favour the child with cancer over other children (Long & Marsland, 2011), or treating the siblings differently (Havermans & Eiser, 1994). This may leave siblings feeling resentment towards the ill child or wishing they had the same illness that would gain them attention.

Siblings also face the fear that their brother or sister might die (Fletcher, 2010; Havermans, & Eiser, 1994; Nolbris, Enskär, & Hellström, 2014). As a result, siblings also experience anticipatory grief. Nolbris, Enskär, and Hellström (2014) identify four categories of grief experienced by siblings of childhood cancer patients:

- anticipatory grief after receiving information about the cancer diagnosis;
- grief and concern about the ill sibling's loss of a normal life;
- grief about being unimportant and forgotten in the family; and
- grief that continues after the sibling's death as a kind of bond.

Children may move from one category to another or between the different categories of grief beginning from the diagnosis of their sibling (Nolbris et al., 2014).

Another study reported post-traumatic stress as a long-term effect after the completion of a sibling's cancer treatment; however only one quarter (22%) of the sample complied strictly with the criteria for post-traumatic stress disorder (PTSD) (Kaplan, Bradley, & Melissa, 2014). According to Long and Marsland (2011), siblings endorse higher levels of negative emotion, lower levels of positive emotion, and reduced quality of life than their peers. A cancer diagnosis however does not necessarily lead to increases in sibling psychopathology. Siblings may however experience secondary trauma and show some symptoms of PTSD depending on their family context. How the siblings adjust to and cope with their brother or sister's illness may result from factors such as family functioning, parenting and marital quality.

For some siblings, having information and supportive relationships are resources that help them to cope with the situation (Houtzager, Grootenhuis, & Last, 2001; Sloper, 2000a). Sloper (2000a) investigated the experiences and support needs of siblings of children with cancer. The research found that six months after the diagnosis, siblings reported a number of problems, including loss of attention

and status, loss of their own and their families' usual activities and routines, loss of certainty and security, and loss of companionship of the ill child. However, problems had resolved 18 months after diagnosis for some, while for others, problems remained or new ones had arisen. Support is vital for siblings to comprehend what is going on in the family and why things have to change. Experiences of siblings of children with cancer are not only characterised by negative effects. Siblings have previously reported benefits and positive effects, including feeling more mature, adopting a different value to life and becoming more caring, understanding and compassionate (Havermans & Eiser, 1994; Sloper, 2000a) and closer family relationships (Sloper, 2000a). However, some siblings articulated no benefits or changes or even negative consequences of the illness (Havermans & Eiser, 1994).

2.10. Coping and adjustment

Literature above showed that the wellbeing of a child and how the child will adjust to his or her illness are largely dependent on family factors. How the family will adjust to the illness has a direct influence on how the patient will adjust and cope. In the current study, coping refers to the stress management processes employed by mothers to mitigate stressors associated with caring for a child with cancer.

According to Long and Marsland (2011), the family's health is determined by the degree to which the unit functions as a whole, over and above the functioning of its individual family members. The family system will collectively experience stresses associated with illness while engaging in interdependent coping as individual members (Ell, 1996). However, family members respond to stressors not only as individuals but also as an interactive system (Brown et al., 2008). Thus, there is a mutual relationship between chronic illness and parental adaptation, in that the child's illness affects the parents' functioning, and parental functioning in turn influences the child's adaptation.

According to Patterson and Garwick (1994), during the adaptation phase, families attempt to restore homeostasis by acquiring new resources and coping behaviours, reducing the demands with which they must deal, changing the meaning of their situation or of themselves as a family, and/or changing their views of the world. Patterson and Garwick further argues that the functioning of the family, the caregivers and the child prior to the diagnosis of a chronic disease is likely to predict psychological adaptation to the current situation. 'Family functioning' refers to the patterns of relationships connecting members of a family system, which is not a property of the individual but of the whole system (Patterson & Garwick, 1994). Different factors play a role in how well a family will cope and adjust to the stressor (i.e. the illness of a child). One such factor is the availability of resources (financial, social, and supportive). For example, Knafl et al. (2013) found that single-parent families and those with low incomes had significantly more difficulty adapting to a child's illness compared to dual-parent families and those with higher incomes. In addition, personal resources of individual

members of the family also influence the management of stress (e.g. the coping strategies of individuals). The age of the child is also an important factor in how the child understands, copes with and will adjust to the illness. For example, an adolescent girl would likely find the side-effects of chemotherapy more disturbing than a toddler. Control over one's body has unique significance for young children because the body is an important tool for achieving developmental tasks (Engel, 2000). In addition, Engel argues that children who face physical limitations resulting from the disease or its treatment, may be at a disadvantage in terms of meeting the demands of this developmental period. In the current study, only mothers of children between the ages of 12 months and 12 years were included, because children in this age group are still largely dependent on their parents.

Coping styles (cognitive and behavioural response patterns used to manage life problems) have been identified as one of the variables that protect one from the adverse effects of stress (Overholser & Fritz, 1991). In a mixed method assessment of coping with paediatric cancer, Hildenbrand et al. (2014) found from qualitative data that children utilise a range of coping strategies during cancer treatment, such as relaxation, seeking social support, distraction and cognitive restructuring. On the other hand, Hildenbrand et al.'s quantitative results showed a significantly greater number of strategies endorsed per family, including cognitive decision-making, direct problem solving, seeking understanding, acceptance, cognitive and behavioural avoidance, and negative actions. Children also used approach-oriented coping strategies, which include direct problem solving, problem-focused support, and emotional expression, while some children endorsed avoidance strategies, such as cognitive avoidance and distraction.

The family environment influences some associations between parent and child distress in families of children with cancer (Robinson, Gerhardt, Vannatta, & Noll, 2007). In families with high cohesion (Robinson et al., 2007; Varni, Katz, & Dolgin, 1996), children may receive support from and model well-adjusted family members, rather than from their distressed parent. According to Varni et al. (1996), the relationship dimensions of cohesion and expressiveness are the most consistently predictive of child adaptation in children newly diagnosed with cancer. In particular, aspects of the psychosocial environment of the family, such as commitment, help, support and the open expression of feelings, facilitate child's adjustment to newly diagnosed cancer and its biomedical treatment. The interaction of the family with its environment is also an important element of family functioning and adjustment to a stressful situation. As argued by (Ell, 1996), the family's ability (or inability) to provide support for patients is likely to be influenced by its ability to acquire external support to mitigate family stress caused by the illness.

Another strategy in the management of cancer is the family's construction of 'a new normal', which is characterised by a new routine, and with a sense that things are different from before the child's diagnosis (Clarke-Steffen, 1997). However, 'normalcy' in this context may not necessarily refer to the way things were before or to keeping up with other families with healthy children. Instead, families strive towards routines and psychosocial contexts that are predictable, reliable and comfortable (Knafl et al., 2013). According to Knafl et al., this state of normalcy, also known as 'normalisation', is typically equated with successful family management; however, it is worth noting that the absence of normalisation is not always an indicator of poor adaptation. For example, a family whose child has cancer may think that they are living a normal life and managing the illness while acknowledging that other families may not think so (compared to their norm). Parents are often so preoccupied that 'living in the present' is a common coping strategy in managing uncertainty in childhood chronic illness (Cohen, 1995).

Family counselling has been found an effective coping mechanism for families of children with cancer, more especially counselling interventions tailored according to specific stressors experienced in different treatment phases (Noeker & Petermann, 2015). Counselling is often categorised with social support or support services offered to families. Having people to talk to about problems and having people who make you feel better about yourself are generally useful as coping requirements elicited by most stressors (Cohen, 1988). Social support will be discussed later in this chapter (see 2.12.) as an important element of the current study.

It is worth noting that coping changes over time and in accordance with the situational contexts within which they occur. Parents and families may adjust differently to the different stages of cancer. For example, marital quality and parenting may change over the treatment course (Long & Marsland, 2011). The couple may spend more time apart during the child's hospitalisation, causing a rift in the marital relationship. Therefore, more support may be required at a certain point of the child's treatment whereas counselling may be needed at the beginning stages for some parents to adjust to and deal with the initial shock and reconstruction of the lives.

2.11. The role of the mother

According to Arendell (2000), definitions of mothering share a common theme, which is the social practices of nurturing and caring for dependent children. Motherhood is "constructed and maintained within the context of ongoing interpersonal interactions between mothers, fathers, and children" (Cowdery & Knudson-Martin, 2005, p. 335). In the current study, mothers were those women who had given birth to and were caring for a child who had been diagnosed with cancer.

Cowdery and Knudson-Martin (2005) identified certain processes that perpetuated two models that explain mothering (the relationship between mothers and their children):

- mothering as a gendered talent; and
- mothering as conscious collaboration.

2.11.1. Processes that maintain mothering as a gendered talent

Partners believed that mothers had a natural connection and natural knowledge, fathers stepped back, mothers organised time around children, and mothers took continual responsibility (Cowdery & Knudson-Martin, 2005). According Cowdery and Knudson-Martin's model, the relationship between mother and child is determined or maintained by perceptions mothers and father have about what the role of mother entails and the perception that this connection comes naturally. These processes that maintain mothering as a gendered talent are inculcated by social norms and the construction of gendered roles within families.

2.11.2. Processes that maintain mothering as conscious collaboration

Partners assumed responsibility is shared, and they compensated for biological differences: fathers took on tasks without mothers' instructions, fathers were open to learning, and mothers did not intervene (Cowdery & Knudson-Martin, 2005). Cowdrey and Knudson-Martin argue that processes that maintain mothering as a conscious collaboration are not reliant on social norms but on how the mother–father dyad construct their roles, so as not to conform to the gender roles and norms. Gender roles are a result of shared beliefs that are socially constructed and imposed on the individual. These roles and expectations influence general parenting, child rearing and child care practices. Of paramount importance is the influence of culture beliefs, institutions and practices (Ickes, 1993). Men and woman are differentially socialised into the gender roles prescribed by their cultures.

Although gender role expectations have changed over the years, mothers remain primarily responsible for the care that any child requires(Clarke et al., 2005). Within the family context and in our societies, mothers are generally responsible for caring for the household and the wellbeing of the members of the family. While women generally directly invest in their children from conception, men's investment in children is more indirect and depends greatly on men's ability to provide resources (Ickes, 1993).

When a child is diagnosed with an illness such as cancer, mothers as the primary caregivers experience drastic outcomes and role changes. For some families, the diagnosis of the child and the demands of the illness require that roles be dramatically reconstructed within the family, whereas other families experience few role changes (Clarke-Steffen, 1997). The role of 'mothering' might not necessarily change when a child is ill; however, the role may intensifies and certain tasks are added.

As Young et al. (2002, p. 1844) concludes, "the biographical shift to mother of a child with cancer required a fundamental redefining of mothers' self-identities, bringing some new technical and nursing roles, whilst intensifying some of their existing roles and obligations". In their study examining the healthcare activities assumed by mothers of children with cancer, Clarke et al. (2005) found that mothers are also responsible for the additional work resulting from certain vulnerabilities, pain, suffering and behaviour changes of their children resulting from the cancer and the associated treatment.

Mothers were also responsible for the healthcare tasks and intricate nursing care activities, such as making sure that the child takes medication and goes for regular check-ups (Clarke et al., 2005). As a result, mothers might have to adjust their work schedules, take unpaid leave, or quit their jobs altogether in order to care for their child with cancer (Fletcher, 2010). In contrast, fathers may feel that they have to work overtime to meet the financial needs of the disease (Clarke-Steffen, 1997). During the visits and lengthy hospital stays, mothers are also isolated from their families. This might also have an influence on their relationships with other members of the family and on their marriage. Some mothers find it difficult to care for their ill child and also plan activities for the rest of the family (Brown et al., 2008). Managing all these obligations may have severe ramifications on mothers' mental and physical wellbeing. Healthcare providers' awareness of these challenges faced by mothers will help them provide relevant support for mothers of children with cancer. Consequently, it is crucial to identify the support that is available to mothers and to investigate their support needs.

Research has shown that mothers of children with cancer experience higher levels of distress than fathers (Bayat, Erdem, & Gül Kuzucu, 2008; Frank, Brown, Blount, & Bunke, 2001; Sloper, 2000b) and more psychological distress than mothers of healthy children (Pai et al., 2007). Mothers also experience more psychosocial problems than most fathers of children with cancer (Van Dongen-Melman et al., 1998). The lengthy treatment processes of cancer and the general stress related to caring for a child with cancer have also led to the investigation of post-traumatic stress in parents of children with cancer (Dolgin et al., 2007; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005). In their study, Dolgin et al. (2007) found that mothers of children with cancer displayed moderate elevations in negative affectivity and posttraumatic stress symptomatology (PTSS) during the period following diagnosis (on average two months) and a steady decline in distress at 3–6 months' follow-up. This may be explained by the increased responsibilities presumed by mothers in the administration of care.

There are also different stress predictors for mothers and for fathers (Sloper, 2000b), and mothers and fathers perform different roles in negotiating the stressors associated with a chronic illness (Frank et al., 2001). For example, mothers' confidence in their own ability to deal with the strain of the

illness demands is related to their distress, whereas his employment situation appears to be a risk factor for the father (Sloper, 2000b). Both mother and child may come out of the experience of cancer with a sense of strength largely due to the efforts of the mother (Papaikonomou, 2007). Papaikonomou further suggests that, although mothers participating in her research served as a buffer for the event, fathers were there all the way but their role was less clear. However, males are generally expected to be task-oriented in their management of stress, and females are reinforced for expressing emotions (Frank et al., 2001).

A mother caring for a child with cancer experiences an emotional interdependence with her child, which includes managing the co-operation and treatment of the child (Schweitzer et al., 2012; Young et al., 2002) and act as 'broker' of information for the child (Young et al., 2002). From the social ecological framework, the mother–child relationship can be explained by the proposal that "the more proximal a component is to the centre of the circle (the child), the closer the relationship to and greater the influence on the child" (Pai et al., 2007, p. 407). By maintaining physical proximity, mothers act to 'keep watch' and provide 'comfort' to their children (Young et al., 2002), especially during their treatment phase.

Research shows that maternal resistance and adaptation to stress play a significant role in the ability of a child to adjust to the treatment regimen and the stress associated with a diagnosis of cancer (Noojin et al., 2000). The mother's attitude and coping abilities have a momentous influence on the family system and even more so on the child's adjustment. Furthermore, a mother's perceived confidence in her coping ability is strongly related to the selection and implementation of more active and instrumental coping, such as information seeking, problem solving and seeking social support. "More specifically, the mother's ability to cope with stress is believed to influence the quality of family relationships both through her attitude and behavior" (Noojin et al., 2000, p. 90). Conversely, maternal confidence in her ability to cope has been found to decrease with time after the child's diagnosis.(Noojin et al., 2000).

The current study is closely aligned with research by Young et al. (2002), who conducted a similar study on conceptualising mothers of children with cancer in the United Kingdom. The aim of their study was to understand the social processes surrounding mothers who care for sick children, including the obligations upon which their roles are founded, and how their reflexive constructions of their parenting role mediate their experiences. Young et al. used semi-structured interviews and drew on sociological literature on motherhood, childhood, caring and chronic illness to suggest a helpful and informative way of understanding mothers of children diagnosed with cancer. However, little attention

was given to the role of the support system of the mothers and how these systems or services contribute to the construction of their experiences.

Young et al.'s (2002) findings show the importance of supporting mothers in ways that enable them to fulfil their role as parents of a child in crisis; however, social support was not the focus of their study. In addition to exploring the experiences of mothers, the current study also aimed to understand the support available to mothers and the support needed by mothers. Maternal involvement in support services provided to the child in order to enhance her own coping and confidence is important (Noojin et al., 2000). In the South African context, literature on mothers and families of children living with cancer is lacking. Research in this context is needed to assist in the provision of interventions for mothers of children with cancer.

2.12. Social support

'Social support' is a concept that encompasses different dimensions, and its meaning differs from discipline to discipline. Social support is thus not unidimensional, but multifarious and complex (Cooke et al., 1988).

The concept has been explored in numerous ways to determine the types of support (Cohen, 1988), the categories of support providers, mechanisms by which support protects people against the negative effects of stress, and even the best definition of support (Papaikonomou, 2007). Literature shows that there is little agreement among scholars on a clear definition of 'social support' (Cohen, 1988; Cohen & Syme, 1985; House, Umberson, & Landis, 1988; Petro, Galvão, Rocha, & Nascimento, 2008; Williams, Barclay, & Schmied, 2004). However, Cobb (1976) defines 'social support' as information leading the subject to believe that he or she is cared for and loved, is esteemed and valued, and that he or she is a member of a network of communication and mutual obligations. This definition places the value of support in mutual relationships and exchanges of information with others.

Furthermore, a distinction is made between structural and functional support procedures (Cohen, 1988; Cohen & Syme, 1985; Cohen & Wills, 1985). 'Structural support' refers to measures describing the existence of and interconnections between social ties, while 'functional support' assess whether interpersonal relationships serve certain functions (e.g. provide comfort or give emotional assistance) (Cohen, 1988, p. 271).

Cohen and Wills (1985) identified the following typologies of social support presented in various discussions of support: esteem support, informational support, instrumental support and social companionship. **Esteem support**, also referred to as **emotional support**, refers to the fact that a person is esteemed and accepted. **Informational support** refers to help in defining, understanding and coping with problematic events (usually provided by healthcare professionals). **Instrumental support** is the

same as **material support**, such as the provision of financial aid, material resources and needed services. **Instrumental support** is also referred to as **tangible support** (Altay, Kilicarslan, Sar, & Kisecik, 2014).

Social companionship refers to spending time with others in leisure and recreational activities, which may reduce stress by offering a time away from the stressful situation, and providing affection.

Esteem support and the information that one is cared for and loved, can also be referred to as emotional support. The two conceptualisations of social support overlap, although used differently in the classification of the types of social support. In the current study, social support is defined as the perceived availability of friends, family members and other individuals or organisations that provide psychological and material resources. Social support is not an isolated entity, but is derived from relationships with members of one's social network (Papaikonomou, 2007), which come from one's social network, such as family members, friends and hospital staff. Therefore, the assessment or investigation of social support includes determining as many as possible aspects of the various kinds of social support as well as the many potential sources of social support (Cooke et al., 1988).

It is important to study the support needed by and provided to parents of children with chronic illnesses and to understand its influence on the child's welling and the functioning of the family. A family's ability to provide support for patients is likely to be influenced by its capacity to attain external support to mitigate illness-related family stress (Ell, 1996). Therefore, the provision of cancer information is of importance to the parents (especially mothers as primary caregivers of the child), which in turn influences the support and care they will provide to patients (the children).

Social support has been found to be an effective buffering (protective) mechanism in stressful situations (Cobb, 1976; Cohen, 1988; Cohen & Wills, 1985), such as having a child who is diagnosed with cancer. Research shows that social support and related social interactions are important resources in terms of a person's health and general wellbeing (Ell, 1996). Among these resources and individual resilience factors, the availability of social support is essential for the maintenance of psychological and physical wellbeing among parents of children with cancer (Norberg & Boman, 2007). In a review of literature developed to understand the caregiving experiences of parents of children with cancer, Klassen et al. (2007) found that psychological distress in parents was related to low perceived social support as well as low satisfaction with support. Perceptions of support or of the availability of support have an effect on how people will receive or ask for help. Park et al. (2013) reiterated in the argument that perceived support is only beneficial in the context of both support-approving cultural norms (interdependence) and support-requiring situational factors (stressful events). Park et al. found that this effect appeared to be especially strong for those who have 'support-accepting personal styles'.

Although seeking and using available social support is necessary, it may not always be easy (Brown, 2006). For example, parents may find it difficult to ask for help, whether it be financial assistance, practical help or even emotional support. Mothers are also more likely to seek information than fathers (Barbarin et al., 1985).

One could argue that support is received from particular groups within the network of the patient or the caregiver. Parents of children with cancer have reported that support from their extended family members served to assist them both emotionally and on a practical level (Schweitzer et al., 2012). The support needs of caregivers will also differ according to the context of the caregivers, the resources at their disposal, their beliefs and their culture. In their study, Altay et al. (2014) found that mothers needed primarily emotional and information-related support. Altay et al.'s study aimed at identifying mothers' social support needs and their experiences of nurses in the South African context. Furthermore, all mothers in Altay et al.'s study indicated they required social support, mostly during the time of the first diagnosis.

The interaction of interdependence, stressful events and support-accepting personal styles, bring the effectiveness of social support systems. Norberg and Boman (2007) also argue that the available support in the case of long-lasting stress recedes as time passes because chronic stressors seem to influence the social support network in a negative way. However, a severely stressful event may lead to growth, positive change and a higher satisfaction with social support (Norberg & Boman, 2007).

Providing social support to the family members of children with cancer is deemed integral in nursing care delivery (Petro et al., 2008), and should be important to all healthcare professionals involved in paediatric oncology. Furthermore, social groups have been shown to reduce anxiety in siblings of children with cancer (Houtzager et al., 2001). This may be due to the information that siblings receive relating to their family relationships, emotional reactions and a better understanding of their sibling's illness and treatment. The improvement in childhood cancer survival has also resulted in families more frequently requiring professional and social support regarding how to adjust to the illness experience and long-term effects of childhood cancer (Svavarsdottir, 2005).

Although mothers may receive support from healthcare professions and other organisations like CHOC, the rate of those receiving social support may be lower than their needs (Altay et al., 2014), which shows that mothers of children with cancer may place their own needs in the background, while focusing on the needs of the child. Moreover, there is a need for psychosocial support within hospitals where children are being treated. Healthcare providers could assist family caregivers in creating an optimal environment for healthy growth and development to take place by connecting them with the

relevant support services and resources (Dodgson et al., 2000). In the South African context, psychosocial support for parents and families of children diagnosed with cancer has developed with more services being provided by non-profit organisations like the Cancer Association of South Africa (CANSA) and the Childhood Cancer Foundation South Africa (CHOC) than within hospitals. However, research is lacking on the needs of mother of children with cancer in South Africa.

Research on the support needs of mothers caring for children with cancer is needed to develop well-defined interventions or practical skills and to evaluate the outcomes for patients and caregivers. Clarke et al. (2005) suggest that increased knowledge to support caregivers, in addition to financial support, is warranted to improve the health of ill children and their primary caregivers. Petro et al. (2008) allude to the needed for further research to focus on understanding what families need most during the cancer trajectory, or on each member of the family core.

2.13. Summary

Research, particularly in the field of psycho-oncology and nursing, has covered the effect of childhood cancers on the ill child as well as the families of these children in many aspects. However, the current study covered aspects that highlighted role changes in the context of cancer, especially how mothers are affected by their children's illness. When highlighting the role of mothers, it is important to place them within the context of their family in order to understand their role. The above review refers to aspects deemed important by other researchers in correlation with the current study. These aspects were the biomedical versus biopsychosocial understanding of cancer, the child with cancer, parents, siblings, the family (as an entity), and mothers as the focus of this study. An added aspect in the current research was the concept 'social support', which the researcher deemed important in understanding the effect of cancer on mothers of children with cancer and in developing interventions. The biomedical model has been criticised for its explanation of cancer from a medical point, neglecting the psychological, social, environmental and cultural aspects of health and diseases. Therefore, the review highlighted the role of mothers, although not physically sick themselves, health concerns and other issues that have been seen to occur because of mothers' 'new caregiving role'. Much research has been done in the health psychology and family systems; however, limited research has been done on the social support needs of mothers of children with cancer, especially in South Africa.

Chapter 3: Theoretical framework

3.1. Introduction

In this chapter, the theoretical framework underpinning this study is discussed. 'Postmodernism' is an umbrella term covering various theoretical stances, including social constructionism (Du Preez & Eskell-Blokland, 2012). This chapter begins with a discussion on postmodernism, followed by modernism as the foundational framework of social constructionism. The chapter then provides a distinction between constructivism and social constructionism as is often discussed in literature, followed by a detailed discussion of social constructionism and its application in the current study.

3.2. Postmodernism

The term 'postmodernism' suggests that the approach emerged from 'modernism', an intellectual movement derived from modernity, which is rooted in the era of the Enlightenment (Burr, 1995; Du Preez & Eskell-Blokland, 2012). The Enlightenment project aimed to seek truth, and to understand the 'true nature of reality', through the application of reason and rationality (Burr, 1995).

Postmodernism developed as an alternative perspective to the modernist notion of the world. According to Anderson (1997, cited in Becvar & Becvar, 2008), postmodernism developed as an alternative method of inquiry among scholars from various disciplines who were in the midst of questioning the meta-narrative, the certainty and the methods and practices of modernism. These scholars were exploring alternative conceptions and descriptions. Postmodernism rejects both the idea that there can be an ultimate truth and the idea that the world as we see is the result of a hidden structure (known as 'structuralism) (Burr, 1995).

Modernism is characterised by a search for an objective truth through scientific knowledge with the assumption that observers can separate or be detached from that which is observed (Du Preez & Eskell-Blokland, 2012). Postmodernism opposes the possibility of a single or final truth and "celebrates the possibility of difference, diversity and multiplicity" (Du Preez & Eskell-Blokland, 2012, p. 42). Modernistic terms and phrases such as 'truth', 'discovering reality', 'rationality', 'individual knowledge objectivity' and 'evidence' are also opposed. Furthermore, postmodernism discards the notion that the world can be understood through grand theories or metanarratives; instead it emphasises the co-existence of multiple and various situation-dependent ways of life (Burr, 1995).

Gergen (2001) postulates that the 'emerging voices of postmodernism' convey a transformation from individual reason to communal rhetoric, from an objective to a socially constructed world, and from a truthful picture of language to pragmatic practice. Reality is not out there to be discovered or observed; it is constructed through a linguistic fore-structure that directs and interprets the observations

made (Gergen, 2001). Thus, the underlying assumption in the current study was that the 'true' experiences of mothers of children diagnosed with cancer can only be understood from their constructions of their stories, which is a by-product of their social interactions (R. A. Young & Collin, 2004). Furthermore, how one constructs reality is also influenced by history and one's culture.

Social constructionism is one of the approaches that developed from the postmodern philosophical framework (Du Preez & Eskell-Blokland, 2012). According to Harper and Spellman (2006), social constructionism can be seen as the incorporation of many of the ideas associated with post-structuralism and postmodernism in psychology. Furthermore, social constructionism is linked to postmodernism "as a set of lenses that enforces an awareness of the way in which we perceive and experience the world" (Galbin, 2014, p. 84). The link between social constructionism and postmodernism can be attributed to their seemingly shared commitment to postulating a closed and impenetrable gulf between the objective identity of things and our experiences or representations thereof (Baert, Weinberg, & Mottier, 2011).

3.3. Constructivism and social constructionism

The terms 'constructivism' and 'social constructionism' are often used interchangeably (Gergen & Gergen, 2008); however, literature shows the distinct and sometimes overlapping processes between the two. Constructivism focuses on meaning-making and the constructing of psychological and social worlds as occurring in the individual mind through cognitive processes, while social constructionism emphasises that these worlds are constructed through social processes and interaction (Gergen & Gergen, 2008; Young & Collin, 2004).

Costantino (2008) postulates that constructivism rejects the notion that there is objective knowledge out there in some external reality for the researcher to retrieve mechanistically. Instead, through interaction with the participant and the phenomenon, knowledge is influenced by the researcher's disposition and values (Costantino, 2008) . However, the social context in which this knowledge production takes place is not taken into consideration. The assumption of constructionism is that the mind of an individual (the participant) represents a mirror of reality, and that the world cannot be known directly, but can be known by the construction imposed on it by the mind (Young & Collin, 2004). Costantino (2008)argues that constructivism is especially relevant to education as it deals with how people learn and how teaching should be carried out in a context where the learner is a co-constructor of knowledge.

Furthermore, participants may construct their own meaning in different ways even in relation to the same phenomenon (Gray, 2013). The same participant may interpret the same phenomenon in

different ways at different times. Constructivism is thus often combined or associated with the interpretivist framework (Creswell, 2007; Gray, 2013; Wagner et al., 2012).

In contrast to the constructivist thought, social constructionism argues that social and psychological worlds are made real or are constructed through social processes and interactions (Young & Collin, 2004), and not in the human mind. Social constructionism is thus interested in topics that have to do with the shared social aspects of all that is psychological (Galbin, 2014). While constructivists recognise that individuals construct their own views of the world, social constructionists go further to argue that these individual constructions are developed in a social world where different constructions have different social powers (Harper & Spellman, 2006). Some researchers (such as Costantino, 2008; Young & Collin, 2004) refer to this dual process as 'social constructivism'.

Social constructivism "addresses the ontological–epistemological questions of constructivism in describing the bodies of knowledge developed over human history as social constructs that do not reflect an objective external world" (Costantino, 2008, p. 119). However, constructivism differs from social constructionist because of its dualist assumptions (R. A. Young & Collin, 2004). Although constructivism and social constructionism have different emphases – constructivism being more micro and social constructionism more macro – they both pay attention to deconstruction and the role of language (Becvar & Becvar, 2008).

In addition, reality and knowledge are at the centre of both perspectives, which speaks to ontology and epistemology. Reality can be defined as a quality relating to a phenomenon that we recognise as having an existence independent of our own volition (we cannot wish it away) (Berger & Lukemann, 1966). Knowledge however is defined as "the certainty that phenomena are real and that they possess specific characteristics" (Berger & Lukemann, 1966, p. 13).

Therefore, one can argue that cancer is a reality experienced by the patients and their family members, and this phenomenon can only be understood through the 'knowledge' of the patients and their family members. Thus, the current study focused on the mothers of children with cancer as the sources and custodians of information. The argument is that participating mothers of children with cancer constructed their individual experiences of their children's illness in relationships with others in their social context and in collaboration with the researcher.

3.4. Social constructionism

Literature shows that there is no single or clear definition of social constructionism or agreement among scholars on what social constructionism is (e.g. Burr, 1995; Cunliffe, 2008; Gergen, 1985; Gergen & Gergen, 2008). Within the social constructionism literature, different authors emphasise different

aspects of the framework and none is superior to the other. However, there are certain underlying characteristics or assumptions of social constructionism.

McLeod (1997, cited in Galbin, 2014) notes the following features or assumptions of social constructionists:

- they reject the traditional positivistic approaches to knowledge;
- they take a critical stance towards taken-for-granted assumptions or knowledge about the social world;
- they uphold the belief that the way we understand the world is a product of a historical process of interaction and negotiation between groups of people;
- they maintain that the goal of research and scholarship is not to produce knowledge that is fixed and universally valid, but to open up an appreciation of what is possible; and
- they represent a movement toward redefining psychological constructs, such as the 'mind', 'self', and 'emotion', as socially constructed processes.

The focus for social constructionists is thus on how meaning and a real sense of an event are created between people in their taken-for-granted ways of conversing and in responsive dialogue (Cunliffe, 2008, p. 202). Young and Collin (2004, p. 377) summarise the epistemological stance of social constructionism in this manner:

> As an epistemology, social constructionism asserts that knowledge is historically and culturally specific; that language constitutes rather than reflects reality, and is both a pre-condition for thought and a form of social action; that the focus of enquiry should be on interaction, processes, and social practices.

Of importance to social constructionism, in relation to the current study, is its emphasis on how the social world is constructed by relational practices.

The current study argued that a mother's construction of her experiences is largely influenced by her relationships within the family and social network (e.g. friends, hospital staff and family). As such, the focus was on how the participants created meaning in their interaction with their children, their family and society, within the context of caring for children with cancer. This aspect was determined through what the mothers said, how they constructed meanings in the interview and what they chose to reflect about in their individual reflections. The argument upheld was that language and knowledge are socially constructed rather than mirror reflections of an objectively knowable reality. Moreover, what one takes to be knowledge of the world and self originates from human relationships (Gergen & Gergen, 2008).

Our 'knowing' or what we know is entrenched in and sustained by culturally and socially situated processes. Therefore, the truth cannot be objectively known, and absolute or universal

knowledge cannot be achieved since there is no context-free, neutral base for truth claims (Jorgensen & Phillips, 2002). Truth is subjective and co-created, and reality is constructed through language (Andrews, 2012). In this sense, language is seen as more than just a way of connecting people; instead, people exist through language (Galbin, 2014). However, this does not mean that nothing exists outside of linguistic construction. Whatever exists merely exists, irrespective of linguistic practice (Gergen, 2001).

Some critics argue that social constructionism is not scientifically and politically usable because it cannot determine what is true or not. As stated by Jorgensen and Phillips (2002), every result is one among many other possible stories and experiences of the world. The current research argued that there is not one reality for all mothers of children with cancer. Each mother's story is influenced by her unique context and co-created with others in her environment. The aim was not to discover the essence or truth of what it means to care for a child with cancer, but rather to discover different stories and experiences of the phenomenon.

In addition, social constructionism also focuses on meaning and power (Galbin, 2014). Power in this sense does not refer to repressive force, but rather power in knowledge production. Power also influences the knowledge we have and how that knowledge is produced. In this study, power bestowed upon the mothers to produce knowledge of their personal stories and experiences in collaboration the researcher.

Social constructionism was thus appropriate in this study as it enabled collaboration between the research and the participants in the construction of their experiences. My interpretation in the discussion section was a co-construction of the mothers' experiences.

3.5. The role of mothers as socially constructed

The role of mothers in the family comprises ideologies, historically and culturally influenced. For example, children were previously thought to be small adults (in all but their legal rights); however, in recent times, children have become innocents in need of adult protection (Burr, 1995). Furthermore, feminist constructionism views mothering and motherhood as dynamic social interactions and relationships that are located in a societal context organised by gender and in accord with the prevailing gender belief system (Arendell, 2000). This perspective focuses on the construction of shared meanings and the historical, cultural and situational contexts within which people behave.

According to White (1995, cited in Stanton, 2005, p. 63), social constructionism is concerned with how what is taken to be right is often culture- and gender- as well as class-specific. As echoed by Dallos and Stedmon (2006), our constructions are shaped by the dominant ideas that a certain culture

(or group or community) holds as central or important. In turn, these dominant ideas, such as 'good mothering', will shape the expectations and actions of individuals in society.

Research has been conducted to investigate the construction of the mother's role in families (Arendell, 2000; Collett, 2005; Cowdery & Knudson-Martin, 2005). According to Collett (2005), taking on the role of a mother is much like adopting other roles. For example, when a child is ill, the mother automatically assumes the role of the primary caregiver in addition to other care tasks in the family. One can argue that this understanding that mothers are primary caregivers is also a socially constructed ideology equivalent with the general role of mothers within the family context. Jorgensen and Phillips (2002) argue that such ideologies further unequal relationships of power and that the criticism of the dominant ideology aims to unmask power with truth. The ideology of motherhood "is related to power structures within social contexts, and frames mothering in terms of historical time and place, race and social status, and constructions of gender "(Cowdery & Knudson-Martin, 2005, p. 336).

Furthermore, Cowdery and Knudson-Martin (2005) identified two models of mothering: one holds that mothering is a gendered talent, and the other argues for mothering as conscious collaboration, and both these views are socially upheld. The following processes maintain mothering as a gendered talent:

- the belief that mothers have natural connection to their children and knowledge on caring for their children;
- stepping back from care tasks;
- mothers organising their time around children; and
- mothers taking continual responsibility (Cowdery & Knudson-Martin, 2005).

The socialisation of mothering as a gendered talent results in compliance with the societal role expectations, and certain behaviours become automatic. Conversely, there are processes that maintain mothering as a conscious collaboration. Such processes include:

- partners' assumption that responsibility for children was shared;
- compensation for biological differences;
- fathers taking on tasks without mothers' instructions or request;
- fathers being open to learning to perfom care activities; and
- both mothers and father developing a direct relational connection with their children.

Even in conscious collaboration, mothers become the primary caregivers while fathers assist when possible. In the current study, the experience of mothering a child who has cancer was seen as a social construction and not as an objective fact classifying all mothers of children with cancer. Knowledge was thus taken from looking at the world from someone's perspective (that of a mother of a child with cancer), and was in the service of some interests rather than others (Burr, 1995).

Social constructionist approaches consider people's thoughts, feelings and experiences to be the products of systems of meanings that exist at a social rather than an individual level (Terre Blanche, Durrheim, & Painter, 2006). As such, in the current study, the experiences and meanings of being a mother were assumed to be constructed and maintained within the context of ongoing interpersonal interactions between the parents and children.

Young et al. (2002) explored the experiences of mothers in the context of their children's cancer diagnosis, with the idea that mothers experience much of the consequences of the illness, although they are not ill themselves. The current study also explored the practices of mothers as socially constructed in the context of their children's illness, focusing on the participants' constructions of their experiences.

3.6. Summary

In this chapter, a discussion of social constructionism as the theoretical framework underpinning the current study was provided. Social constructionism as a movement of thought has its origins in postmodernism, and thus a discussion of postmodernism was provided as an introduction. Postmodernism cannot be discussed in isolation from modernism as the framework developed as a criticism of modernism; thus, the two schools of thought were contrasted. Constructivism was contrasted to social constructionism with a focus on the assumptions of both theories, and the application of social constructionism in this study. The chapter ended with the concept of mothering as socially constructed.

Chapter 4: Research methodology

4.1. Introduction

This chapter begins with an explanation of research methodology. The qualitative research approach as the method of enquiry in this study, making use of the case study design. The research objects and research questions will be provided along with the strategy utilised to achieve the research objectives. The research design will state how the research was conducted, the method of inquiry, the method of data collection, and the techniques for analysing data (Wagner et al., 2012). Also discussed in this chapter are the ethical considerations adhered to in this study and the issues of trustworthiness and credibility.

4.2. Defining research methodology

The methodology of a research specifies how the researcher went about practically studying what was set out to be studied (Terre Blanche et al., 2006). The research methods are some of the ingredients of research, while the methodology provides the reasons for using a certain research recipe or certain methods (Clough & Nutbrown, 2012a). Thus, methodology represents an ongoing task of justification and asks why certain methods were used. Furthermore, the purpose of the methodology is to show how the research questions are articulated with questions asked in the research field, whereas the effect of the methodology is a claim about significance.

In qualitative research, the methods are often unique to a particular study and/or context in which the research occurs (Wagner et al., 2012). In addition, constructionism makes no obligatory demands on either theory or method (Gergen & Gergen, 2008). However, in the current study, a case study approach to inquiry was used from within the qualitative research design. In order to lay out the design of the research study, a discussion of qualitative inquiry follows as a foundation.

4.3. Qualitative inquiry

Qualitative research is defined as "a means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2009, p. 22). One of the elements which gives qualitative research its unique character is its aim to provide an in-depth and interpreted understanding of the social world of research participants (Ritchie & Lewis, 2003). This is achieved by learning about the participants' social and material circumstances, their experiences, perspectives and histories.

According to Creswell (2009), qualitative research is interpretative research where the inquirer is involved in a sustained and intensive experience with the participants. Thus, in the current study, meanings were created through the researcher's interaction and co-constructions with the participants

in the interviews. In remaining consistent with these goals, the researcher alternates between using first person in the section discussing the role of the researcher (section 4.8.) and the discussions of each participant in the case studies (Chapters 5,6,7), and third person when discussing the overall study and the integrated comparative analysis.

Qualitative research concerns itself with understanding the processes and the social and cultural contexts of individuals, which subsequently shape their behavioural patterns (Wagner et al., 2012).

In addition, qualitative research is built on a naturalistic approach that seeks to understand phenomena in its context (Maree, 2007), and relies primarily on human perception and understanding (Stake, 2010), mainly that of the research participants. Thus, the research is conducted in real-life situations and not in an experimental or an artificial situation. Furthermore, qualitative research covers various approaches with different ontological beliefs (what there is to know about the social world) and epistemological stances (how to find out about it) (Ritchie & Lewis, 2003). The process of research involves

- emerging questions and procedures;
- data usually collected in the participant's natural setting;
- data analysed inductively; and
- the researcher making interpretations of the meaning of the data (Creswell, 2009).

The inductive process of analysis usually builds from particular to common or general themes. and is driven by what is in the data (Braun & Clarke, 2012). The ontological view of qualitative research is that the world consists of people with their own attitudes, beliefs and values, assumptions and intentions, and that the way of knowing reality is by exploring the experiences of others regarding a specific phenomenon (Maree, 2007). Therefore, the constructions and voices of the participants are the means through which we explore, understand and know their reality. This form of inquiry was suitable for the current study because of its focus on how the individual views and understands the world and how he or she constructs meaning out of his or her experiences (Maree, 2007). Qualitative research was also suitable for the current study due to its richness and depth of exploration and description of data (Wagner et al., 2012).

In qualitative research, the role of the researcher is that of an instrument or tool of data collection, observing action and contexts and often using his or her own personal experience in making interpretations (Stake, 2010). In order to explore the experiences of mothers of children with cancer, an exploratory design within the qualitative approach was adopted, using a case study design.

4.4. Research questions and design

Terre Blanche et al. (2006) define a research design as a strategic framework for action that serves as a bridge between the research questions and the execution of the research. The research design provides the plan of how the research will be executed in order to answer the research question. The research design stipulates the underlying philosophical assumptions, the selection of respondents, the data collection techniques to be used and how the data will be analysed (Maree, 2007). However, qualitative research designs do not usually provide the researcher with a fixed formula or recipe to follow (De Vos, Strydom, & Delport, 2005). Rather, the choice of the researcher will inform the research design to be applied.

The main aim of the current study was to explore the experiences of mothers of children with cancer, focusing on their constructed roles within the family context. The main research question answered by the research study was: How do mothers of children with cancer experience their children's illness?

In order to answer this question and to achieve the aims of the research, the following sub-questions needed to be answered:

- How have their roles changed in the family since the child's diagnosis?
- Which kind of support did participating mothers have?
- Which kind of support was needed by participating mother?

Within the social constructionist framework, the research questions become broad and general so to allow the participants to construct the meaning of a situation (Creswell, 2003) and these meanings are usually forged through interactions with others. It is important to distinguish between the main research questions (those that are answered by the study) and the field questions (those that are asked to the participants) (Clough & Nutbrown, 2012b). The above questions were the research questions governing the study; the interview questions are provided in the data collection section (see section 4.7).

The current study aimed to gain a good understanding of the dynamics of a specific situation (the experiences of mothers of children with childhood cancer) and to provide a description of that case. The case study approach is suitable for investigating all possible aspects of the experiences of mothers caring for children with cancer and for providing rich descriptions of their experiences.

4.5. Case study approach

The term 'case study' can be used to describe a unit of analysis or to describe a research method (Maree, 2007). According to Bromley (1990, p. 303), case study research is "a systematic inquiry into an event

or a set of related events which aims to describe and explain the phenomenon being studies". The case being studied could also refer to an individual, a group of individuals, an event, an entity under investigation (Hird, 2016), a process, an activity, or a programme (De Vos et al., 2005).

The qualitative case study approach enables the exploration of a phenomenon within its context using multiple sources of data (Baxter & Jack, 2008), which may include in-depth interviews with the participant and other collaterals or sources of information (Wagner et al., 2012). Through the recognition that the contexts and variables of some phenomena we wish to study cannot be controlled, the case study method thus evolved (Hird, 2016).

According to Yin (2003, cited in Baxter & Jack, 2008), a case study design is to be considered when:

- the focus of the study is to answer 'how' and 'why' questions;
- you cannot manipulate the behaviour of those involved in the study;
- you want to cover contextual conditions in the belief that they are relevant to the phenomenon under study; or
- the boundaries between the phenomenon and context are not clear.

Moreover, there are different types of case studies, dependent on the intentions of the researcher. Creswell (2007) distinguishes three types of case studies, namely the single instrumental case study, the collective (multiple) case study, the intrinsic case study. The **single instrumental case study** focuses on one issue and one case is selected to illustrate that issue. In a **collective or multiple case study**, one issue is still elected; however, multiple case studies are selected to illustrate the issue or concern. Lastly, there is the **intrinsic case study**, which focuses on the case itself because of its uniqueness or unusualness. In the current study, the multiple case study was applied where three cases were used to illustrate how mothers of children with cancer construct by their experience of the 'event'.

The case study method was also suitable in the current study due to its consistency in relation to the social constructionist framework. Consistent with social constructionism, the case study approach "supports the deconstruction and the subsequent reconstruction of various phenomena" (Baxter & Jack, 2008, p. 544). This method is reflexive and retrospective; however, this does not affect the logic of the inquiry, rather it allows for different considerations that may or may not be relevant to the study (Bromley, 1990).

However, case study methodology has been criticised for its dependence on a single case and it is therefore claimed that case study research is incapable of proving a generalising conclusion (Maree, 2007) and that the method lacks objectivity (Hird, 2016). Generalisation was however not the purpose or the intent of the current study.

Another common pitfall associated with case study is that researchers tend to attempt to answer a question that is too broad or a topic with too many objectives for a single study (Baxter & Jack, 2008). Hence, boundaries where set for the case being studied. Although mothers were the focus of the current study, the research questions investigated them in relation to their family. The cases were further bounded in terms of the inclusion criteria, which are discussed in section 4.6. below (participants and participant selection).

4.6. Participants and participant selection

Three mothers were selected utilising two sampling techniques: purposive sampling as the first stage and snowball sampling as the second stage of sampling. In **purposive sampling**, participants are selected on the basis of some defining characteristics that make them the custodians of the data needed for the study (Maree, 2007; Terre Blanche et al., 2006). Therefore, the researcher based the selection of participants on selection criteria to identify the most suitable individuals (Wagner et al., 2012).

The selection criterion in the current study was mothers between the ages of 25 and 40 years, caring for a child who was diagnosed with cancer. The children were aged between 1 year and 10 years, and were still largely dependent on their mothers as primary caregivers. However, the age criterion was the current age of the child and not the age of the child at diagnosis. Two of the children were in remission at the time of the interview, while one was due for a transplant in the following year due to the cancer moving to another stage. The mothers had to reside in Pretoria and had to be able to communicate in English.

Snowball sampling is generally used when members of the population being studied are difficult to locate (Wagner et al., 2012). Snowballing involves asking people, usually those who have already been interviewed, to identify other people they know who fit the selection criteria (Ritchie & Lewis, 2003). The researcher contacted the manager of the Reach for a Dream Foundation in Pretoria, who agreed to assist in recruiting participants. This non-profit organisation fulfils the dreams of children who have been diagnosed with a life-threatening illness such as cancer. The organisation has a database of mothers or caregivers of children whose dreams they have fulfilled or are yet to fulfil. The manager of the Reach for a Dream Foundation in Pretoria posted an advert on the organisation's database, calling on mothers who would be interested to participate in the study and those who could refer to other mothers who might have been interested. From the database, a total of total of eight mothers were initially interested in participating. However, the research study was restricted to Pretoria and none of the prospective participants resided in Pretoria. Through snowballing, three other potential participants were recruited. One mother, from the Reach for a Dream pool, referred the researcher to

an eligible participant, who connected the researcher to other three possible participants who met the criteria.

According to Wagner et al. (2012), there are no rules concerning an appropriate sample size in qualitative research, however the samples are usually small. Creswell (2002, cited in Wagner et al., 2012 pg. 88) recommends that a sample of 3–5 be used in case study research. A total of four women were initially sampled; however, only three of the participants were interviewed. During the process of data collection, one of the participants could not commence with the interview due to her child being hospitalised.

4.7. Data collection

The data was collected using semi-structured interviews as well as a reflective document provided by the participants. Participants also shared their Facebook pages as part of the 'data corpus' to provide background information and to give an understanding of the complexity of the phenomenon being studied. For the participants, Facebook provided a space for reflection, a way to lobby for support, and a way to provide information to others. However, the data set comprised the reflections and the interviews only. 'Data corpus' refers to all the data collected for the research study, while the 'data set' refers to all the data from the data corpus that is being used in the analysis of the study (Braun & Clarke, 2006).

Interviews provide the opportunity for an in-depth understanding of the personal context within which the research phenomenon is located (Ritchie & Lewis, 2003) and allows one to see through the participants' eyes (Maree, 2007; Wagner et al., 2012). In the current study, face-to-face interviews were audiotaped and later transcribed verbatim. The interviews were conducted at Unisa Main Campus as the participants found the facilities to be close to their home or work. The participants where provided with an information sheet (Appendix A) and the consent form (Appendix B) prior to the interviews. The information sheet provided a brief introduction and the purpose of the study, as well as the ethical approval from the university.

Data collection took place as semi-structured interviews. Semi-structured interviews are generally used in order to get a detailed picture of a participant's perception or account of a particular topic (De Vos et al., 2005). Semi-structured interviews have been said to be particularly suitable in instances where the researcher is mainly interested in the complexity or process, or where an issue is controversial or personal (De Vos et al., 2005). Hence, the semi-structured interview was suitable for the current study, which focused on the complexity of a personal issue. The interviews were guided by a schedule that defined the line of inquiry and enabled the researcher to probe and explore deeper and

collaborate data emerging from the reflections (Wagner et al., 2012). Table 4.1 below shows the interview schedule that guided the interviews.

Table 4.1: Interview guide

<div style="border:1px solid black">

Interview guide

If you were to tell me a story about your reflection, where would you begin?

1. Tell me about the day you found out that your child is ill?

   • What was your initial reaction when you found out that your child has cancer?

2. Describe your life around the time your child got sick

3. What and how have things changed since then?

4. How did your role change within the family? E.g. caregiver tasks, staying at home with your child or working, family relationships

5. What kind of support did you have in your family and outside your family?

6. What kind of support do you wish you would have received?

7. How did this whole experience change your life?

</div>

Participants were notified of the guide at the beginning of the interview and that the guide would not restrict the interview. The questions where open-ended and allowed the researcher to probe and clarify the participants' answers. According to Creswell (2003), the more open-ended the questioning, the better, as the researcher listens carefully to what participants say or do in their life context. The questions where broad and general, allowing the participants to construct the meaning for their situation. However, not all questions in the interview schedule were asked as the participants touched on them at some point during the interview. The questions in the interview schedule were guided by the literature as well as the general aims of the research.

In addition, participants provided a reflective document, which did not follow any particular guide or format. The participants constructed the reflection in a way that reflected their own structure of events and their thought processes. According to Maree (2007), qualitative interviews aim mainly to obtain rich descriptive data that will help to understand the participant's construction of knowledge and social reality. Although some people are not articulate or insightful in writing, the reflection documents allowed the researcher to capture the language and words of the participants.

4.8. The role of the researcher

In qualitative research, the researcher is considered the tool or instrument of data collection. Sciarra (1999) proposes that since truth is mind-dependent and based on contextual agreement, the qualitative

researcher regards as true the agreed-upon meanings by individuals within a given society. Therefore, meanings are created through the interaction of the researcher and the researched. In the current study, the participants were the experts from whom I learned and with whom I co-constructed a journey.

My background as a researcher shaped my interaction with the participants. I therefore did not enter into the interaction with a blank mind. I entered the participants' world with my background in research and the knowledge I had gained from literature and observations in society. I positioned myself as co-constructor in the process of creating meaning, and inspected my expectations before and after the interviews, to see how I might have influenced the constructed stories of the participants. My expectations were aligned to previous literature on mothers of children with cancer, the gap in research and my perceptions.

Qualitative research requires openness on the side of the researcher, which enables one to enter deep into the lives of the research participants, which in turn generates some critical questions regarding the role of the qualitative researcher (Sciarra, 1999). Sciarra (1999) emphasises this emotional involvement as crucial to the qualitative research process of entering the meaning-making world and understanding the experiences of another. I did not hold back my emotions when the participants showed their emotions, which allowed an interaction of emotions.

4.9. Data analysis

Thematic content analysis was used as the method of analysing the interview transcripts as well as the content of the reflections written by the participants. Braun and Clarke (2006, p. 82) define thematic analysis as "a method for identifying, analysing and reporting patterns (themes) within data". In other words, it is a way of searching and identifying what is common in the way a topic is talked or written about and of making sense of those commonalities (Braun & Clarke, 2012). Furthermore, thematic analysis has been said to be one of the different qualitative analytic traditions that come under the umbrella of interpretive analysis (Terre Blanche et al., 2006).

In the current study, this method of analysis was utilised firstly because, as argued by Braun and Clarke (2006, p. 77), "it offers an accessible and theoretically flexible approach to analysing qualitative data". Secondly, thematic analysis is in the class of methods that are independent of theory and epistemology and can thus be used across different theoretical and epistemological approaches (Braun & Clarke, 2006). However, this does not mean that the researcher was free of theoretical positioning and assumptions. Consistent with the social constructionist framework, thematic analysis involves the identification of patterns as socially produced (but no discursive analysis is conducted) and it examines the ways in which experiences, events, realities and meanings are the effects of various

discourses operating within society (Braun & Clarke, 2006). Furthermore, thematic analysis conducted within a constructionist framework, "seeks to theorize the socio-cultural contexts, and structural conditions, that enable the individual accounts that are provided" (Braun & Clarke, 2012, p. 14). The following guidelines were followed in the analysis processes, although presented step by step, it is worth noting that the process was reflexive and iterative.

- Phase 1: Familiarising oneself with the data

This phase involves immersing oneself in the data by reading and rereading textual data (e.g. transcripts of interviews and reflections) and listening to audio recordings and making notes on the data as you read or listen (Braun & Clarke, 2012). In the current study, this phase began when the researcher transcribed the audio recordings into textual data, which involved repeatedly listening to the recordings. However, this was not a linear process. The phase of immersing or familiarising oneself with the data continued throughout the analysis process to allow the researcher to capture accurately what had occurred in the data. As the research instrument, the researcher came into the analysis process with prior knowledge of the data and initial analytic interests from conducting the interviews.

In order to conduct thematic analysis, the verbal data from interviews needs to be transcribed into written form (Braun & Clarke, 2006). In thematic analysis, there is no one way or set of guidelines to follow when constructing a transcript, and constructionist thematic analysis does not require any particular level of detail in the transcript. The interviews were transcribed verbatim to include all verbal and some non-verbal utterances (e.g. crying), and were rechecked against the original recording for accuracy. According to Terre Blanche et al. (2006), the immersion and familiarisation stage of analysis should result in the researcher knowing the data well enough to know what can be found where, as well as the kinds of interpretations that can be supported (or not) by the data. This first step of analysis allowed for an in-depth understanding of the data and the identification of initial themes or patterns, which flowed into phase two of the analysis process.

- Phase 2: Generating initial codes

According to Braun and Clarke (2012), codes are the building blocks of the analysis. A code is usually a word or short phrase (Saldaña, 2009) that provides a label for a feature of the data that is potentially relevant to the research question (Braun & Clarke, 2012). Saldaña (2009, p. 45) refers to this initial coding process as the "first cycle method". First cycle methods are divided into seven subcategories: grammatical, elemental, affective, literary and language, exploratory, procedural, and theming the data (Saldaña, 2009). Because of the flexibility of qualitative research, these coding methods are not prescriptive; the selected methods depend on the nature and goals of the research study. In the current

study, a mixture of grammatical and elemental methods of coding techniques was chosen. Elemental coding methods are primary approaches to qualitative data analysis, which have basic but focused filters for reviewing the data corpus, and they build a foundation for future coding cycles (Saldaña, 2009).

Grammatical coding methods refer to the basic grammatical principles of a technique. In the current study, the process of producing initial themes began with generating a list of ideas and marking what seemed interesting in the data set. During that process, each unit of data was assigned its own code, with some pieces of data sharing similar codes. This was done on a Word document by highlighting texts and adding codes (comments) in the margin of the document. Using the macro function on the Word document, a list of codes and excerpts allocated to each theme were collated and saved in Excel.

- Phase 3: Searching for themes

Once all the text had been coded, the process of reviewing the coded data and identifying areas of similarity and overlaps between codes commenced. This phase involved sorting the different codes and collapsing them into potential themes. All the relevant coded data extracts within the identified themes were then collated. Saldaña (2009, p. 150) refers to this process as "second cycle coding", where the first cycle codes are reorganised and re-analysed to develop a sense of categorical, thematic, conceptual, and/or theoretical organisation.

Some codes were combined to form an overarching theme, other became sub-themes, while yet others were collapsed based on their relevance to the research goals. Some patterns in the data where characterised by similarity (things happen the same way), difference (they happen in predictably different ways) and some by frequency (they happen often or seldom) (Hatch, 2002, cited in Saldaña, 2009).

The themes were identified at a latent level, which is aligned with the constructionist paradigm. Latent themes go beyond the surface content of the data, and "starts to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies – that are theorised as shaping or informing the semantic content of the data" (Braun & Clarke, 2012, p. 13). It is also worth noting that at this point, the case studies were analysed using an embedded approach, which focuses on specific aspects of the case rather than a holistic approach (Creswell, 2007). This process ended with a table of possible themes and sub-themes as well as excerpts from the data that were coded in relation to each the theme.

- Phase 4: Reviewing the themes

This phase entails the refinement of the list of themes identified in phase 3 and close exploration of themes (Terre Blanche et al., 2006). At this point, some of the themes appeared to mean the same thing and were classed under one theme. According to Braun and Clarke (2006), the reviewing and refining process includes two levels. Level one is reviewing at the level of coded data extracts in order to assure that the themes of the candidates capture the outlines of the coded data adequately. Level two involves coding in relation to the whole data set, considering the soundness of the individual themes in relation to the data set. This phase provides the opportunity to rework some themes, create a new theme, find a place for those extracts that did not seem to work in an already existing theme, or to discard them from the analysis (Braun & Clarke, 2006). During the review process, some themes collapsed into each other and formed one theme, while still others became sub-themes.

- Phase 5: Defining and naming themes

'Defining' and 'refining' refer to the process of identifying the essence of what each theme is about (as well as the themes overall), and determining which aspects of the data are captured by each theme (Braun & Clarke, 2006). In this phase, the final themes were then refined and defined and a detailed analysis of each was provided. It needs to be noted that the identified themes not only tell a story about the participants but they also reveal the researcher's way of thinking and of making sense of the information provided by the participant. The themes described only reflect the stories and accounts of the participants and cannot be generalised to other mothers caring for children diagnosed with cancer.

- Phase 6: Producing the report

This phase involves the final analysis and write-up of the report, and aims to tell the complicated story of the data in a way that will convince the reader of the merit and soundness of the analysis (Braun & Clarke, 2012). The final write-up of themes and subthemes are provided in full in Chapters 5, 6 and 7 (reporting on the findings) as well as Chapter 8 (comparative analysis). Chapter 8 provides a full discussion of the findings (comparing the three cases) in comparison with previous literature.

4.10. Ethical considerations

According to Terre Blanche et al. (2006), the crucial purpose of research ethics is to protect the welfare of research participants. The following accepted philosophical principles were applied in the current research study:

Autonomy and **respect for the dignity** of persons. All participants were treated with respect and dignity. The principle of autonomy was ensured by allowing the participants to tell their stories, being an active listener and not imposing my views on them.

Non-maleficence was managed by ensuring that no harm befell the participants as a result of the research. The study did not intend to harm the participants in any way, although some discomfort was anticipated. Due to the sensitivity of the research topic, the researcher had anticipated that the study might evoke emotions that mothers have not dealt with or related issues with which they were struggling at the time of the research. Therefore, arrangements were made for participants who needed counselling as a result of the research. Participants were informed that they had the option of being referred to the campus psychotherapy clinic should they have need of counselling after the interview. One participant needed counselling and the researcher recommended the Unisa Psychotherapy Clinic where the participant would receive free counselling services. The researcher provided the contact details of the clinic and recommended that the participant make an appointment.

Beneficence obliges the researcher to endeavour to maximise the benefits that the research would afford the research participants (Shenton, 2004). The researcher believes that the benefit for the participants was in being given the space to share their experiences and being given a voice in a situation that usually focuses on the patient rather than on the primary caregiver.

The principle of **informed consent** was adhered to in the study. Terre Blanche et al. (2006, p. 72) outline the following standard components of consent: "(a) provision of appropriate information, (b) participants' competence and understanding, (c) voluntariness in participation and feedback to decline or withdraw after the study has commenced, and (d) formalisation of the consent usually in writing".

The information sheet (Annexure A) along with a consent form (Annexure B) was sent to the participants well before the interview. The information sheet provided important information that the participants needed to know about the study and what their participation meant. Participation was voluntary and the participants had the opportunity to withdraw from the study at any point before the analysis of the data, should they not feel comfortable talking about their experiences.

In terms of the principle of **confidentiality**, the data was only accessible the researcher and her supervisor and was used only for the purposes of this study. The participants remain anonymous and pseudonym was allocated to each participant and her family members (in cases where the participant mentioned family members' names). Furthermore, any identifying data of the interviewees has been changed. However, their age and child's age at diagnosis will be mentioned in the description of the case study, as it has specific relevance for this study.

4.11. Trustworthiness and credibility

In order to achieve high levels of trustworthiness, as the researcher, the researcher needed to ensure that the situation within which the data was collected would be safe and nonthreatening (Wagner et al., 2012). Furthermore, the relationship with the participants needed to be open, relaxed and trusting (Wagner et al., 2012). The interviews were conducted in a safe environment, and the participants preferred that the interviews be conducted at the university campus (Unisa) rather than at their homes or any other venue. Two of the participants thought that the location was near their place of work, thus convenient for them. One participant felt that her children might need her attention if the interview were to be conducted at home. According to Lincoln and Guba (1985), research should be designed in such a way as to ensure credibility, applicability, confirmability and dependability.

The following provisions were made to promote the **credibility** of the research as suggested by Shenton (2004):

- the adoption of research methods was well established in qualitative inquiry;
- development of an early familiarity with the culture of participants occurred before the first data collection dialogues took place; and
- the participants were contacted informally before the actual interviews could take place, which initiated a conversation between the researcher and participants and assisted to build rapport.

Triangulation entails the use of different sources of data collection methods (interviews and individual reflections) and using more than one sampling technique (in this case, purposive and snowball sampling). The following triangulation methods were also employed:

- negative case analysis: each case study was analysed separately and also cross-analysed to see if there were similarities and differences;
- frequent debriefing sessions between the researcher and her supervisor: the researcher had sessions with her supervisor in between the data collection process;
- peer scrutiny of the research by my peers, colleagues and other scholars, as well as feedback provided at academic conference presentations; and
- previous research findings were examined to assess the degree to which the results of the project were congruent (or not) with previous findings.

Applicability (or transferability) is achieved when findings fit into contexts outside the study situation, which is determined by the degree of similarity or goodness of fit between different contexts(Shenton, 2004). Consistent with the assumptions of social constructionism, the findings of the current study may not be transferrable to other contexts due to the unique experiences of each individual and her social context. However, the methods used in this study could be applicable in similar cases,

which may produce different results. Thick descriptions of the research methods as well as the research findings are provided in this report to allow applicability to other research studies. All versions of the data in their original form (raw data from interviews) are provided; however, the same data may be interpreted differently by another researcher applying different lenses.

In qualitative research, the researcher seeks means for taking into account both factors of instability and factors of phenomenal or design-induced change (Lincoln & Guba, 1985). In order to address **dependability**, Shenton (2004) suggests that the processes within the study be reported in detail, thereby allowing a repetition of the work by other researchers, although not necessarily to gain the same results.

According to Shenton (2004) the concept of **confirmability** is the qualitative researcher's concern to objectivity. Triangulation was used in this context to reduce the effect of investigator bias or for the researcher to be aware of his or her biases entering the research context. The use of two methods of data collection also ensured that my interpretations represented the voices of the constructor (participant) and not just my subjective views.

4.12. Summary

This chapter presented the methods applied in the current research study, namely the research approach, research design, sampling techniques, methods of data collection, thematic analysis as well as the ethical considerations. The chapter started with an introduction and definition of research methodology. A discussion of qualitative research as the method of inquiry in this study was then provided. Within the qualitative research method, a case study design was employed in order to answer the research questions. The chapter provided details regarding purposive sampling and snowball sampling, and semi-structured interview as the means of data collection. As the instrument of data collection, the role of the researcher in the study was also discussed in detail. An outline of the relevant ethical consideration was provided along with the measures of trustworthiness.

Chapter 5: Amanda's story

Age: 34

Ethnicity: White

Child's age at diagnosis: 3 years

Type of cancer: Burkitt's leukaemia

Interview setting: Unisa Muckleneuk Campus

5.1. Introduction

This chapter contains the case description of the experiences of a mother (Amanda) caring for a child who has been diagnosed with cancer. The analysis of the transcript of the interview conversation between Amanda and myself is reflected in this chapter, as well as the reflective document provided by her.

In presenting Amanda's story, the setting of the interview will be discussed as well as my impressions of Amanda. In describing the conversational setting and the researcher's impression of the participant, the research will refer to herself in first person. To give context to Amanda's story, the description of her son's illness is provided, progressing from before the diagnosis. Furthermore, a discussion of what emerged from the conversations is provided in the form of themes and subthemes. It is important to note that the themes presented in this chapter are only a reflection of Amanda's reality and are thus not representative of all mothers caring for a child with cancer. The themes were constructed by me, as the researcher, through my knowledge, the aims of the research and the theoretical framework underpinning the study. The chapter concludes with a summary of Amanda's case description.

5.2. The conversational setting

The interview took place at the University of South Africa (Unisa) Muckleneuk campus, in an office space. Due to Amanda's schedule, she thought it would be best to have the interview at Unisa at her convenience. The walk with Amanda from the parking area to the office room gave us time to introduce ourselves and talk informally. I escorted her to the office were the interview would be held. Amanda was familiar with the environment and seemed at ease. To provide a conversational space that would not create boundaries and barriers for communication, the furniture was placed on one side of the office, with only two chairs in the middle of the room, facing each other slightly.

5.3. My impression of Amanda

Having communicated with Amanda on the phone and via emails prior to the interview, I had an image of an elderly woman and expected her to be formal. Instead, I was met by a young mother. Perhaps it was her appearance (reddish hair, black nail polish, black clothing) and a small body structure that gave me the impression that she was young and could welcoming. Prior to meeting her, I was intimidated by the image I had in my mind and not knowing what to expect. Perhaps my intimidation stemmed from the fears of conducting my first interview as well as some of my personal biases. As a young black woman, interviewing a white woman whom I thought would be elderly, created anxiety and uncertainty.

However, in meeting Amanda, I relaxed and felt at ease. She was open and friendly. As we walked into the interview room, I asked her to take a seat on any of the two chars where she would feel comfortable. I then offered her water and juice. Although she had a bottle of water in her hand, to be polite, she accepted my offer and said that she would take the juice for later at home instead. All feelings of fear and intimidation subsided as we started the interview.

I also sensed that Amanda had spoken about her child's illness and her experiences quite often as she did not have a problem recalling certain events. She also did not show emotions as she related her story. She appeared to have a very strong character and did not feel sorry for herself. She seemed willing to do everything in her power to help other mothers caring for children with cancer. Her experience opened her up to many contacts, and she made use of them to assist other mothers going through the same trajectory.

5.4. Cancer description

George (3), the older son of two, and Will (2) seemed to be healthy infants growing up on her farm. The first signs of the problem began with George complaining about pains in his legs and showing symptoms of a fever. Amanda immediately acted on the symptoms and consulted the family's general practitioner (GP).

The symptoms were treated; however, they persisted, leading Amanda to seek medical assistance over and over. The pains and symptoms persisted, and the GP referred Amanda to a paediatrician for further assistance. Nevertheless, the pain became constant and unbearable, leading to an operation on the leg. After several examinations and blood tests, a bone marrow biopsy revealed cancer in George's cells although the type of cancer could not be determined at that stage. After a second bone marrow biopsy, George was diagnosed with a rare and aggressive type of leukaemia (Burkitt's leukaemia).

There were only three cases of this type of leukaemia in the world, with George being the first patient to be diagnosed with Burkitt's lymphoma leukaemia at that specific hospital. However, the doctor estimated his chances of survival to be 60%, which gave hope to his mother. George then began his treatment with medication flown in from France; however, doctors warned that if he does not respond to the medication he would fall into a coma and die within 24 hours.

During the treatment process, George became withdrawn and he turned into himself, which Amanda attributed to the long periods that he spent in isolation at the hospital. George had to spend his fourth birthday at the hospital as he was undergoing treatment. The effects of treatment included vomiting, aggression, depression, inability to control bowl movement, and loss of mobility and susceptibility to infection leading to George contracting two deadly infections during his chemotherapy. At the time of this research, George was in remission and was still on maintenance chemotherapy, which he would be on for a while to monitor his health.

5.5. Themes and subthemes

The following themes and sub-themes were identified in Amanda's account of her story as she journeyed through her child's illness.

5.5.1. Events leading to the diagnosis

Although the interview focused on Amanda as a mother, she narrated her story beginning with a description of the illness, how it affected the child, and events leading to the diagnosis. The events that led to her son's diagnosis reflected how the signs and symptoms that led to assist in the struggle to obtain a diagnosis for her son's illness. She described the events leading to her child's diagnosis as follows. Please note that all quotations are reflected verbatim and unedited.

> *Okay so [...] first of all he started complaining about pain in his legs, so I took him to the GP cause we lived on a farm and there's no paediatricians or oncologists or… just GPs, and [...] took him there, he gave him some antibiotics coz he had fever or etcetera as well … and [...] he didn't got −get any better so I took him the second time and again the same story and by the third time the GP said, "Okay, rather go through to paediatrician."*

> *So, we went through to Potchefstroom to see [the] paediatrician, went [...] to a hospital, he then [...] did − ran a number of tests like he tested for tuberculosis and he tested for brucellosis and …coz he had all these symptoms but couldn't be explained.*

> *So [...] I think we were there for about a week or so and then he− one of his colleagues said to him, "Rather do a bone marrow aspiration to rule out cancer."*

She also provided a description of the illness by saying:

Just a quick history about it [...] we all have bacteria in our system that helps us to digest our food and etcetera, but because he was on [...] chemotherapy and he was immune-suppressed, that bacteria escaped ... from his tummy so and started to attack all his organs so and ... so it actually occurred did not [sic] have antibiotics against this specific antib- ... bacteria.

5.5.2. Emotional roller coaster

The metaphor of an emotional roller coaster signifies the different emotions that Amanda had experienced, both negative and positive emotions. Two sub-themes were identified: different emotions and uncertainty. Her emotional roller coaster began when the doctors discovered that her son had Burkitt's lymphoma leukaemia. When she was told that her son had this rare cancer, Amanda expressed initial emotions of shock and disbelief. She was shocked as she did not think that cancer occurred in small children, or even that her own child would be diagnosed with cancer. She described her initial reaction in the following excerpts:

And that's when they saw the cancer so he then came to me, the paediatrician, and he said to me, "Okay, so they found cancer," and so [...] he asked me if [...] if I'm gona be okay ... but it's like ... first of all its shock.

It's like disbelief, like cancer is not really something that happens to small... kids, ja ja, so ...

Amanda was overwhelmed by the fear of losing her son to cancer. As a mother, she began her reflection with the fearful moment when she was told that she might lose her son. Asked which point of her journey she wanted to reflect on during the interview, she said:

So, if I have to reflect, that's the first thing I think about, is that moment when the doctor said ... we have to ... we might have to say our goodbyes ... yes.

The information provided by professionals at the hospital aggravated the fear she already had. With the rare cancer and the uncertainties around the illness, doctors were not sure if the treatment would work or not. The fear intensified when the doctor told her that she might have to say goodbye to her son. The way doctors deliver news to patients and their caregivers has an influence on how the recipients of such news will adapt to the situation. The uncertainty of the professionals regarding the type of cancer and treatment had an effect on how Amanda reacted and how she conceptualised the illness. The following excerpts show how the information from doctors aggravated Amanda's fear of losing her son:

The everlasting fear of will my child survive or will I have to bury him like some of the other onco parents had to bury their kids.

The fear become more of a reality when the oncologist told me that we have to say our goodbyes, as they do not know if George will make it. He came so close to death that he even went into silent death.

And then he also said to me ... but they've never tested it against this bacteria and if it doesn't work then [...] within 24 hours he will fall into a coma and it will pass away.

Although her child survived cancer, Amanda continues to fear for her child's future. She did not fear that her son might relapse; instead, she feared that her son might grow up a victim because of the title of 'cancer survivor'. Asked whether she feared that her child might relapse she exclaimed:

No! But I'm a bit different than most − well I think than most, so my mom is − she is running a Facebook page where we've documented his whole journey. And [...] so she asked − a few months ago she asked a couple of the onco moms, "So what do you say? Do you say my child had cancer or do you say my child has cancer?" And I'm kind of the only one that said it's over, it's done, you have to move on, and so I would say, "He had cancer," but I don't even want the world to ... meet him as the boy that survived.

It seems that she feared that cancer would become her son's identity and that he would continue to be identified as the child who had cancer. She also feared that her son would pity himself and feel that the world owes him for being associated with cancer. She continued to express her fears in the following excerpts:

I want them to meet him like okay, this is George, only if they later on find out that he's a survivor then ... then ... its fine, then I don't mind. But I don't want the world to ... meet him at first as the cancer survivor, so me and my mom, we have a lot of fights ... about this because I think she struggles more than I do with ... what he went through and what she went through with this whole cancer ordeal [...] so with her, she is like if she introduce him to someone, she would introduce him as the child that survived.

Yes ...yes ... and I'm scared because I'm scared that one day he might feel that the world owes him something because now he's a survivor, he's a victim, you are such a victim of this life and I don't want that for him. I want him to be a fighter, so this happened, unfortunately this happened, this card was dealt for us but we've dealt with it and now we move on.

Reflecting on her experiences, she described her journey as a time of great sadness, intense fear and extreme joys. She experienced emotions of sadness and empathy towards her two children: one child going through the aggressive cancer treatment and the other receiving less attention from his mother because of his brother's illness. She described her emotions as follows:

I felt a great deal of sadness for George (who was then only 3 years old) that he had to go through poison being pumped into his little body, he had to fight to stay alive and that he was the one that had to deal with all the side-effects of the cancer as well as the chemo.

I also felt very sad for Will (George's brother who was only 2 years old) that he had to stay behind on the farm living with his grandparents and not knowing when or if he will be able to see his mom or brother again. I felt sad when he visited us and had to leave again, I felt sad because he did not know what was going on. I felt sad for him as I solely focused on George and only realised how much he craved my attention that he, at the age of 2, asked me if he may also please have cancer. I felt extremely sad for boys that were not able to see each other every day or play as they used to.

The emotional roller coaster took Amanda from feelings of fear to joy and hope that her son would have a chance at life. She expressed her joy as follows:

When the oncologist told me a day after we had to say our goodbyes he came back and said George has a fighting chance. The tears ran down my face from extreme joy and extreme thankfulness. And again, the day when he started walking again. And again, the day when he ran out of hospital after his last high-risk chemo was administered.

Amanda chose to reflect on the moments that brought her hope and on the positive moments where her son completed his treatment. In explaining why she had chosen to reflect on this period she said:

The reason why I am writing my reflection on the time in hospital and not including the maintenance chemo therapy process, is because even though that I know today still his white blood cell count is low and we have to deal with every bug that is in the air, the dangerous, worst part is over and reflecting back on the 'cancer ordeal' it started the day he was diagnosed and ended the day when he rang the bell (at Unitas hospital, the kids finishes their high-risk chemo have the privilege to ring a bell).

Compared to other mothers who lost their children to cancer, Amanda felt a sense of guilt that her son survived.

Oh just very, very grateful, yes, yes, that's it, coz there's nothing else you can feel but feeling very grateful cos […] I know that he survived but I also know of moms that had to bury their kids … that were in the hospital at the same time that we were, It's like one of the moms […] her daughter passed away but the one day she came to me and she said, so, if God can heal George, he can also heal […] her little daughter and […] Palesa was her name, so and I … I

... just didn't know what to say because ... I don't know, I don't know why his life was saved but not hers.

5.5.2.1. Uncertainty

The events leading to the diagnosis of cancer marked a time of uncertainty for Amanda and her family. She struggled to obtain a diagnosis for her child and doctors could not explain what was happening to her son. She recalled:

Okay so [...] first of all he started complaining about pain in his legs, so I took him to the GP cause we lived on a farm and there's no paediatricians or oncologists or ... just GPs, and [...] took him there, he gave him some antibiotics coz he had fever or etcetera as well ... and [...] he didn't got −get any better so I took him the second time and again the same story and by the third time, the GP said, "Okay, rather go through to paediatrician."

So we went through to Potchefstroom to see paediatrician, went [...] to a hospital, he then [...] did − ran a number of tests like he tested for tuberculosis and he tested for brucellosis and ... coz he had all these symptoms but couldn't be explained ... so [...] I think we were there for about a week or so and then he − one of his colleagues said to him, "Rather do a bone marrow aspiration to rule out cancer."

Uncertainty occurred because of the rare type of cancer, which also resulted in long periods of waiting. Uncertainty was sparked by the doctors not being able to explain what was wrong with Amanda's son. The cancer was also of a rare type, which perpetuated feelings of uncertainty and thinking that she might have to say goodbye to her soon.

Ja, to give them, but the machine says that's no cancer but they could see the cancer cells, so they had to do some more tests to make sure − just to find out what type of cancer, so he had ... it's actually called "Burkitt's lymphoma leukaemia ... you cannot ... ja, there is nothing on it on the Internet ... and the doctor even said, "Don't even try to find something coz you will not."

Ja, it's very rare, I think they were three in the whole world in 2014 that had that type of cancer and he was the first one in Unitas hospital ever been diagnosed with that cancer.

Amanda describes the times of waiting, from the time her son was diagnosed, which taught her to be patient.

The hours, days, weeks of waiting. Waiting for answers, waiting for him to start chemo, waiting for chemo to finish up, waiting for him to get sick because of the chemo, waiting for him to get better, waiting for blood, platelets and plasma, waiting for the doctor's rounds. Waiting, waiting, waiting ... and all those waiting taught me how to be patient.

5.5.3. Life changes

The diagnosis came with many changes for Amanda and her family. When a child is diagnosed with a life-threatening illness like cancer, mothers as the main caregivers experience drastic changes. When her son began treatment, Amanda had to re-locate to Pretoria, starting a new life. She was going through a divorce and concurrently lost her job and did not receive any assistance from her baby's father. The following subthemes were identified in Amanda's story: social identity, changes in living environment, role changes, change in perspective and priorities in life, and life lessons.

5.5.3.1. Social identity

Social identity refers to a person's sense of who they are, based on their group membership or a group they belong to. In speech, it seems that Amanda identifies with the group of "onco-moms" and "onco-parents". These two terms are used to refer to mothers or parents of children undergoing diagnosed with cancer. Although Amanda did not regard herself as an onco mom because her son survived, she acknowledged that this term has become part of her identity. She used the term to refer to other mothers of children with cancer. When asked if she still wanted the title she exclaimed:

> No, I don't want that title [...] but I ... if I do talk to people ... what I do is that I work for the Sunflower fund, what we do is we recruit people to become stem cell donors ... so I'm in this environment 24/7, and it's easier for me to explain to people why we need it because I went through what we went through, but so ... I am not saying that I ditch that no ... I'm no longer an onco mom, I use that information that I've learned and ... use that experience that I went through to try and help.

> I don't say you have to like forget everything that you went through coz that was part of what shaped you as you are now today, but move on, you can't be stuck in that ... others and get more people on the registry and etcetera etcetera.

> And [...] because they are on cortisone treatment as well [...] one of the other onco moms, she described them as ... exactly like bipolar pregnant ladies [giggles], that's how they acted on ... the cortisone.

Although she did not want the title of an onco mom, she still used the title to help other families experiencing what she had experienced.

> And yes, sometimes I do use it for ... like not personal gain but like yesterday George was invited for a press conference at Ellis Park coz he will be shown on TV on Saturday [...] coz the Lions adopted the South African National Blood Services as their NPO for this year.

In some instances, Amanda compared herself to other mothers or her experiences to those of other mothers of children with cancer. She regarded herself as being different from other mothers caring for a child with cancer, not coping the same as other people and her situation as being different from others.

> *No, and I know that most of the moms goes on to anti-depressants when they are in hospital, just to help them to cope, and the ones that are already on anti-depressants they give them a stronger one or a second one.*

> *So obviously I chose the oncologist and […] I've asked him and he said, "No his chances is …" I think it was 60 per cent so it's very high ag…against the other kids.*

> *No! But I'm a bit different than most − well I think than most, so my mom is − she is running a Facebook page where we've documented his whole journey. And […] so she asked … a few months ago she asked a couple of the onco moms, "So what do you say, do you say my child had cancer or do you say my child has cancer?" And I'm kind of the only one that said it's over, it's done, you have to move on, and so I would say, "He had cancer," but I don't even want the world to … meet him as the boy that survived.*

5.5.3.2. Change in living environment

Due to her son's treatment, Amanda had to relocate to the city from living on a farm outside the city. This was difficult for Amanda since she had no income.

> *And ja, like on my side, I lost my job obviously because we were on a farm and now we had to move to Pretoria for his treatment.*

> *So here I moved like … the … when the paediatrician, he phoned us and said I must bring him through to the hospital so I've asked them, "So how many days should I pack?" and they said, "Just pack for like three days," so I did pack for like five days. And with that suitcase we went from Potchefstroom through to here and as the grannies and whatever from the farm came to visit I've asked them to bring some more clothes.*

> *[…] bring some, so little by little piece by piece I brought the whole house till I found a place to rent here, ja, which was also difficult because I didn't have an income, so how do you rent a place …*

5.5.3.3. Change in perspective and priorities

When a child is diagnosed with cancer, life changes for the parents and the whole family. The mother, as the main caregiver, may experience most changes due to the care required and the time spent with the child. Amanda described her journey as follows:

A time where life taught me a few life lessons, a time I have undergone huge changes of my perception regarding certain life matters ...

During this time, her child became her priority and some things did not seem to matter anymore. Other problems did not seem to be important, she described them as "trivial".

Oh ja, so what happens is ... first of all, like I explained to you that some of the things just doesn't matter in life anymore, like [...] whatever, things that used to bother you it's like [...] so ... it doesn't matter anymore, ja, so and you do ... stay in that mind-set quite ... for quite a while, but then slowly but surely, you're starting to return back into the real world.

Yes, definitely, and ... of course what happens is, as a mom or as a parent you go into survival mode, nothing else matters. [...] it's ... like the day before I took him to the paediatrician I went to the ... my lawyer to sue for a divorce, coz my husband sued me but then he withdrew and then I went to the lawyer and I sued him for a divorce. But that was obviously put on hold ... I still wanted to like not be married to him anymore, but that wasn't priority and [...] ja, so all the other things in life seem like it disappears, it's not that important as you thought it was.

Another is how trivial your "problems" or other people's problems looks when you sit there fighting with your child for his life. But also, how the trivial problems of others could be so refreshing (e.g. my stepsister came to visit the one day and she had this "I think I might like this guy" problem, which was so refreshing as the other onco parents deal with the same problems you do like bills, what is the meaning of this, what is the meaning of life, etc.

5.5.3.4. Life lessons

The cancer experience taught Amanda some lessons in life, which became part of the changes that she experienced. The experience taught her much about herself and other people. She learned to be patient due to the long waiting periods during her son's treatment. As a mother, she also learned to draw strength from her son's resilience and her son's strength during treatment. The following extracts show the lessons that Amanda had learned during her journey.

One of the biggest changes for me was I've learned to be patient, because of the hours, days, weeks of waiting. Waiting, waiting, waiting ... and all those waiting taught me how to be patient.

And you realise how strong and acceptant and resilient children can be. I was always so amazed on how these kids just kept on being kids, they play, they read books, they still acted like kids all the way while feeling so weak and so sick.

Her experiences with people and her son's resilience taught her much about other people, how they think and how they operate.

How easily they accept the hand they were dealt, dealing with everything with minimal questions (depending on the age). And how they just accept it when for example, they are being placed into isolation and despising every second of it. The resilience of a child is, well, just astonishing.

To sum it up, it was a time where I learned a lot about life, myself (like the true meaning of going into survival mode), and a time where I learned a lot about other people, how they think and operates.

5.5.4. Roles

In general, mothers are responsible for care tasks in families, especially towards children as dependents. Although a mother's caregiver role might not change when a child is diagnosed with cancer, the role intensifies according to the care needs of the child. As a mother, Amanda had to manage different aspects of her son's illness. Because of the illness and treatment, Amanda's role as a mother intensified, she was responsible for the self-care needs of her child. The following excerpts show how her care responsibilities changed.

… in age as well, so he went … totally went back on nappies and, okay, he lost the use of his legs during the first few months.

… and we had and vomiting and all that stuff as well, so we had bundles of washing to do every single day, so this was what we used to do is, I'll go home with all the washing and etcetera, go sleep because you can't really sleep in hospital because he is all there.

She became the proxy for her son in terms of making decisions on treatment. She also became her son's information broker.

So, the doctor came to me and said to me, ja, […] so … they flew in some medication from France and I had to sign the release form […] saying that … that I would pay if my medial aid doesn't pay whatever.

Yes, yes […] we were in … I think we were in hospital for three four days and he asked me, "When am I gonna stop having cancer now?"

So, I had to explain to him that so this is gonna be a long procedure and […] so ja I … I … explain to him that we gonna be in hospital for a while in and out of hospital, you don't stay in hospital the whole time obviously, but yes.

Amanda also took on the role of protector, wanting to protect her son and wondering how her son will be perceived by the world. As a protector, she was concerned with her son's future and wanted to protect who her son will grow up to be.

But I don't even want the world to … meet him as the boy that survived.

I want them to meet him like, okay, this is George, only if they later on find out that he's a survivor then … it's fine, then I don't mind. But I don't want the world to … meet him at first as the cancer survivor, so me and my mom we have a lot of fights.

Yes … and I'm scared because, I'm scared that one day he might feel that the world owes him something because now he's a survivor he's a victim, you are such a victim of this life and I don't want that for him. I want him to be a fighter, so this happened, unfortunately, this happened, this card was dealt for us but we've dealt with it and now we move on.

She also adopted the role of a fighter. During her journey with her child, she did not show emotions because she wanted to be a fighter.

But again, like ja, I know I'm just an emotional dork like now because of the hormones, but normally, I'm not even emotional. I cried twice during his whole treatment.

… and that was the day that the doctor said that he was diagnosed and when the doctor said that we had to say our goodbyes …

And that's it, for the rest of the time it was just fight, fight, fight.

5.5.5. The effect of the illness

When one member of a family system is diagnosed with cancer, the whole family becomes affected in some way or another. Amanda observed how different members of her family were affected by her son's illness, not excluding how she was affected as the main caregiver. The main themes identified was the effect of the illness with the following sub-themes: effect on the ill child, effect in the siblings, effect on the extended family, and the financial effect on the mother.

5.5.5.1. Effect on the ill child

Amanda identified some changes in her son since he had been diagnosed with cancer. In addition to the side-effects of the treatment, Amanda identified some behavioural changes in her son, which she attributed to him being isolated for long periods at the hospital.

Yes […] there's quite a few things that changed. He withdrew like […] he was not like the same, he was like … Okay, wait, let me explain, he was always a shy type of person and not really outgoing or anything, but he withdrew within himself, but I think that could have been because they were putting him in isolation.

What […] happens to them is, they … they regress … in age as well, so he went … totally went back on nappies and, okay, he lost the use of his legs during the first few months.

I felt a great deal of sadness for George (who was then only 3 years old) that he had to go through poison being pumped into his little body. He had to fight to stay alive and that he was the one that had to deal with all the side-effects of the cancer as well as the chemo (e.g. the time when he was wheelchair-bound, or the time when he was not able to leave the hospital for 9 weeks and 5 days on end, where he was not even allowed to go outside for fresh air and the numerous times he had to be placed in isolation, being stuck a room for about a week, having no contact with anyone expect for me, my mother, nurses and doctors).

5.5.5.2. Effect on siblings

Siblings of paediatric cancer patients experience changes as the family responsibilities and routines change to manage the illness. In the following excerpts, Amanda described the effect of George's illness on her other son:

Yes, yes definitely, so he's also got a younger brother. He was at that stage ... he was only two years old, and [...] so I had to leave him behind with the grandparents on the farm and [...] because there was just no way that I could look after both boys, one being in hospital, what am I gonna do with the other one?

Yes, so he came and visit us a few times and it was about halfway through he started treatment I saw something different with the brother. So, all the kids do see a psychiatrist that specialise in trauma to help them through coping through whatever they're going through and I took the little brother to her as well and she said that ... she diagnosed him with secondary trauma so coz he doesn't know, he feels like, no, Mom has abandoned me.

She expressed the sadness and empathy she felt for her son whom she had neglected as she focused on the ill child. Will, her other child, desired to have cancer so that he too could have his mother's attention. In addition to his brother being sick and his mother not being around, the sibling was also experiencing the abandonment of his biological father.

I also felt very sad for Will (George's brother who was only 2 years old) that he had to stay behind on the farm living with his grandparents and not knowing when or if he will be able to see his mom or brother again. I felt sad when he visited us and had to leave again, I felt sad because he did not know what was going on. I felt sad for him as I solely focused on George and only realised how much he craved my attention that he at the age of 2 asked me if he may also please have cancer.

He's no longer this angry little boy that he used to be [...] and I think it's because ... [...] I think it's not just the cancer or what he had to go through, but I think it's because there's finally

a father figure ... in his life, because now I think in his mind he feels like I've abandoned him, his dad had abandoned him ... so he doesn't have anyone except for granny and grand...grandfather on the farm, so and now I think he sees now and feels like okay now he is finally part of ... of a team.

5.5.5.3. Effect on family

Amanda's mother, as the interim caregiver of her grandchild, was affected by her grandson's illness. She had to move back to South Africa in order to take care of Amanda's other child. Amanda's family was separated during this time as she relocated to another town for her son's treatment. For her to be close to the hospital meant leaving her family and relocating, which had an effect on family relationships.

Yes, yes definitely, so he's also got a younger brother. He was at that stage ... he was only two years old, and [...] so I had to leave him behind with the grandparents on the farm and [...] because there was just no way that I could look after both boys, one being in hospital, what am I gonna do with the other one? So my mom came back from New Zealand to help me but ... he was so sick ... George was so sick that [...] we stayed the first ... after the first treatment we stayed in hospital for... if I remember correctly, was it for nine weeks and five days on end, so and ...so we ... took turns.

I think she struggles more than I do with ... what he went through and what she went through with this whole cancer ordeal [...] so with her, she is like if she introduce him to someone, she would introduce him as the child that survived.

5.5.5.4. Financial effect

Amanda lost her job after her son had been diagnosed with cancer. In addition to losing her job, she had to relocate to be close the hospital where her son would receive treatment and this had further financial implications.

So obviously I lost my job [... I had to move so there was no income, the dad didn't help... in financially or contributed in any way.

... little by little piece by piece I brought the whole house till I found a place to rent here, ja, which was also difficult because I didn't have an income, so how do you rent a place and ...

She relied on the trust fund she had started for financial assistance. She did not have financial security and relied on other people who contributed to the trust fund she had established for her son.

So [...] yes and [...] ... but in the end things just worked out, we started a trust fund for him and people just ... gave us money that I could've payed rent, bought some nappies because what ... happens to them is, they ... regress.

5.5.6. Coping

In coping with the different stressors induced by her experiences, various coping mechanisms were identified as sub-themes under the coping theme. Amanda did not seem to realise the different coping strategies that she used to cope with her son's illness; however, she identified that her belief in a higher being assisted her. Her social support (informal and formal) also helped her to cope with her experiences.

5.5.6.1. Coping differently

Amanda viewed herself as coping differently compared to other mothers who were at the hospital with her. Mothers are provided psychological support if need be; however, she has not used the hospital's services.

No, and I know that most of the moms goes on to anti-depressants when they are in hospital, just to help them to cope, and the ones that are already on anti-depressants they give them a stronger one or a second one.

As a smoker prior to her child's diagnosis, she smoked even more when her child was in hospital, which was a coping mechanism for her. The smoking breaks at the hospital allowed her free time from the hospital ward and a time to talk to a nurse who became her friend.

I don't know ... The one thing that I did ask [...] like one of the sisters, like we became like actually good friends because I started smoking just before he was diagnosed like obviously I smoke like a chimney.

Yes, when he was diagnosed. So, like maybe the smoking helped. But like so she was night ...she was working on night shift so we used to when it's quiet [...] in the hall, we used to go out for a smoke together, and I said to her, "Whatever is happening, just be honest with me, I don't care how good or bad news it is." And I think that's how I coped with it because everybody was always honest with me coz I asked every one of them, "Just be honest with me... no matter how good or bad it is."

It seemed that Amanda struggled to express her emotions or that she suppressed her emotions.

But again, like ja, I know I'm just emotional dork like now because of the hormones, but normally I'm not even emotional. I cried twice during his whole treatment.

Maybe, I don't know [...] coz I've never cried, I'm not a crier anyways so I'm not really an emotional type of person, but anyway that's a story for another time. I've seen ... a psychologist about this.

5.5.6.2. Social support

Social support played a pivotal role in Amanda's journey. She received different forms of support during her journey, starting with the hospital. She received emotional support from the doctor and counsellor directly after her child had been diagnosed with cancer. This helped her deal with the initial shock that she experienced.

And then he asked me if ... I was willing to talk to someone, his [...] think he said sister-in-law is like ... a counsellor.

And I said, "Yes, please," so I spoke to her on that day and she said a few things to me like, "Explain everything to him, be honest ... open and honest about what he's got and what is ... you know, just ... just be open, don't ... don't try to hide anything from him."

A lot, just ... just ... to have a few words with her, it was like 20 minutes our whatever conversation, but that really helped me through this ... initial shock and ...

Receiving information at the hospital and choosing one source of information helped Amanda to cope with and prepare herself for what was to come. She explained that she was advised by the counsellor to choose one person to listen to, which helped her single out some of the information she received.

No, coz one of the other things that [...] that lady said to me is ... the counsellor ... said to me is that ... "Choose one person to listen to and that's it," So obviously I chose the oncologist and [...] I've asked him and he said, "No, his chances is ... I think it was 60 per cent so it's very high ag...against the other kids.

Ja, ja, ja, so yes so [...] there were a lot of people that were saying this and that so just chose not to listen to them, so ja, that's it.

The honesty and openness of the nurse during their smoke breaks helped her cope better and prepare herself better.

Yes, when he was diagnosed. So, like maybe the smoking helped. But like so she was night ... she was working on night shift so we used to when its quiet [...] in the hall, we used to go out for a smoke together, and I said to her, "Whatever is happening, just be honest with me, I don't care how good or bad news it is." And I think that's how I coped with it because everybody was always honest with me coz I asked every one of them, "Just be honest with me, ... no matter how good or bad it is."

81

Yes ... Coz then you can prepare yourself and you know there's a couple of outcomes they could be or whatever, so you know, you prepare yourself mentally and emotionally but still fighting and hoping for the best obviously but ...

Amanda also received support from her family in caring for her child as she spent most of her time in the hospital and eventually re-located. However, she did not receive any support from her estranged husband.

Yes, yes definitely, so he's also got a younger brother. He was at that stage he was only two years old, and [...] so I had to leave him behind with the grandparents on the farm and [...] because there was just no way that I could look after both boys, one being in hospital, what am I gonna do with the other one? So, my mom came back from New Zealand to help me but ... he was so sick ... George was so sick that [...] we stayed the first ... after the first treatment, we stayed in hospital for ... if I remember correctly, was it for nine weeks and five days on end so and ... so we (we) took turns.

Amanda and her husband were going through a divorce when her son was diagnosed with cancer. She did not receive any support from her estranged husband. She was especially disappointed that he did not support his own son who needed his father.

Yes ... but even [...] he didn't support his own child, so [...] It's like when the doctor said we have to say our goodbyes, [...] I like I did with everyone, I sent them a message saying well, this is what the doctor said, we have to come say our goodbyes but nobody is allowed in the room because we were put in reverse isolation because that type of bacteria is very contagious.

Yes ... and the whole hall is full of sick patients so [...] yes so, he didn't even bother to ... you know, just come and stand at the door and say goodbye. He didn't bother to phone him or anything so ja, I phoned him about three days after and I said to him, "You now, what the f**k dude, this is your ... child!" [Laughs] and he is like, "Ja, I have to work" [laughs again] so ja, like ok, whatever.

Due to the financial effect of the illness, she received financial assistance from others through a trust fund that she had started.

So [...] yes and [...] but in the end, things just worked out, we started a trust fund for him and people just ... gave us money that I could've payed rent, bought some nappies because what ... happens to them is, they ... they regress.

Ja, so I meet this angel of a lady who and she ... didn't tell her bosses that I do not have an income and she rented me a place, so yes.

5.5.6.3. Spirituality/believing in a higher being

Amanda's belief system became a way of her coping with what her child was going through. She negotiated through prayer with God for her child's life, hoping that her son's life would be saved. Since her son survived cancer, she continued to show gratitude and thanked Jesus for her son's life.

> *I have realised how much as a Christian I spoke/prayed to God (never in my life have I prayed and begged so much for something as the time we were in hospital) begging God to save George's life, thanking Him every time George was doing well and praising Him for helping us get through this.*

> *I realised, no matter what you believe in. As a parent going through such an ordeal, you feel so helpless and know you need some sort of divine intervention to help you get through this, someone/something you can pray to. I personally think that no human being is strong enough to go through something like this without some sort of higher being you can communicate to. Saying this all the while I know that I am a very strong and resilient person myself, I still thank Jesus for saving George's life.*

As shown in her reflection, Amanda viewed the cancer journey as impossible to go through without believing in a higher being.

> *I personally think that no human being is strong enough to go through something like this without some sort of higher being you can communicate to. Saying this all the while I know that I am a very strong and resilient person myself, I still thank Jesus for saving George's life.*

5.5.6.4. Helping others

It seemed that Amanda helped others, going through similar experiences, as a form of coping mechanism for her. She offered herself to other mothers, helped to raise awareness and to recruit stem cell donors, and also became of help to the children in oncology wards.

> *So, I'm in this environment 24/7, and it's easier for me to explain to people why we need it because I went through what we went through, but so ... so, I am not saying that I ditch that no ...no, I'm no longer an onco mom, I use that information that I've learned and ... use that experience that I went through to try and help others and get more people on the registry and etcetera etcetera.*

> *Through him, through whatever he's gone through and getting in touch with other people so that they can come on board with ... us as well.*

[Laughs] … and of course I had the support as well. Maybe that's why … maybe that's how I cope with it, being the support. Ja … I did a few things, we did a music video that I shot in the hospital.

Amanda did not make use of support services offered by cancer support organisations; however, she was involved with one organisation in order to help other children with cancer.

And there was a guy that did this super cars for upper kids. They're still doing it. They take all these Ferraris and I don't know what type of cars … Lamborghinis, and they take kids that's been diagnosed or has been … has gone through cancer […] in a ride in these smart cars, that's called super cars for super kids and they contacted to ask if I can bring some kids or organise some kids to join and that's how I got involved with CHOC again … is I phoned them and asked them if they could bring some kids that might be willing or be interested. So that the only … yes.

5.6. Summary

In this chapter, the story of Amanda was provided according to the themes that emerged during her interview and reflection. The chapter started with a description of the conversational setting and my impression of Amanda. Prior to presenting the emerging themes, a description of the illness was provided to give context to Amanda's story and an understanding of her son's illness. The transcript of the interview between Amanda and the researcher was analysed as well as the reflection written by Amanda. The following themes and sub-themes were identified:

- **Events leading to the diagnosis**

Amanda narrated the events that occurred before her son was diagnosed with cancer, as well as the background of the illness. She described her life before cancer, and how her life changed from there on.

- **Emotional roller coaster**

The main theme of an emotional roller coaster was subdivided into two sub-themes: different emotions and uncertainty. Amanda experienced different emotions from the initial shock of the diagnosis, disbelief, fear, sadness and empathy to joy. Her journey with her son was characterised by uncertainty.

- **Life changes**

Amanda's life changed significantly during her son's treatment. The following sub-themes were identified under life changes: role changes, social identity, change in living environment, change in perspective and priorities, and life lessons.

- **Effects**

The diagnosis of Amanda's son had an effect on the whole family, including their extended family. The theme of effect encompassed the following sub-themes: effect on the ill child, effect on the sibling, effect on the family, and financial effect.

- **Coping**

Coping was a prominent feature throughout Amanda's story. Amanda suppressed her emotions; however, she employed different types of coping, such as smoking more than before the diagnosis. The following sub-themes were identified: coping differently, social support, believing in a higher being (spirituality) and helping others. The social support she had available to her assisted her in coping with her child's illness.

Chapter 6: Grace's story

Age: 37

Ethnicity: White

Child's age at diagnosis: 16 months

Type of cancer: Acute monoblastic leukaemia

Interview setting: Unisa Muckleneuk Campus

6.1. Introduction

This chapter contains the case description of a mother's (Grace) experiences of caring for a child who had been diagnosed with cancer. In presenting Grace's story, the setting of the interview will be discussed followed by my impressions of her. To give context to Grace's story, the description of her son's illness will be provided, progressing from before the diagnosis until post-treatment. In this chapter, the analysis of the transcript of the interview between Grace and myself as well as the reflective document provided by Grace is presented. A discussion of the prominent themes is provided with supporting quotations from the transcripts. It is important to note that the themes presented below reflect Grace's reality and are thus not representative of all mothers caring for a child with cancer. Furthermore, the themes were constructed by me, as the researcher, through my knowledge, the aims of the research and paradigm underpinning the study. The data could be interpreted differently by another researcher as there are multiple truths out there. The chapter concludes with a summary of Grace's case description.

6.2. The conversational setting

The interview took place at the University of South Africa (Unisa) Muckleneuk campus, in an office space. I offered to meet Grace at her home; however, she anticipated distractions at home with her two sons vying for her attention. After having communicated via emails and telephone conversations, the day of the interview was set. We met at the Unisa corridors and I escorted Grace into the interview room. I offered Grace a seat and before we began the interview, she handed me her signed consent form. To provide a conversational space that would not create boundaries and barriers for communication, the furniture had been placed on one side of the office, with only two chairs in the middle of the room, facing each other slightly.

6.3. My impressions of Grace

Prior to meeting with Grace, we had communicated several times over the phone and via emails to arrange a meeting. Having spoken before the interview it seemed as though we had met before. Due to the interview with the first participant, I was less intimated and less anxious going into the interview with Grace. She was strong in stature and seemed older than me, and my approach to her changed. In retrospect, this was not solely because of my fears but rather due to my biases. In my culture, an elderly person (whether male or female) is to be treated with a certain level of respect.

From the beginning of the interview, Grace was open and did not hold back. She showed a strong character and did not show emotions. It seemed to me that she blocked her emotions and had not dealt with what she went through with her son as well as the loss of her sister. She spoke much about her son, her husband, the illness itself, and the events surrounding the illness more than she spoke about her experiences. However, upon reading her Facebook posts, it appeared to me that documenting her son's journey and her experiences have become a therapeutic process for Grace.

Grace's family had a history of cancer. This seemed to have had an effect on how she dealt with her son's diagnosis.

6.4. Cancer description

Luke a (16 months) and Will were healthy brothers leading a normal life. Luke seemed to be a healthy chubby boy until he suddenly developed what seemed like tonsillitis. After contracting tonsillitis for the third time consecutively coupled with a fever, Luke was admitted to the hospital at his mother insistence. Several tests were conducted and after a bone marrow biopsy, Luke was diagnosed with leukaemia. Further tests were done that confirmed the diagnosis of a rare and aggressive type of leukaemia, acute monoblastic leukaemia.

The first block of chemotherapy started immediately for the duration of eight days. Due to the aggressive nature of the treatment and risk of infection, Luke was hospitalised in isolation for a month. Some of the effects of treatment included loss of appetite and not eating or drinking good, a fluctuating fever, nausea as well as mouth and throat sores.

The second block of chemo included a lumbar puncture to inject the chemo drugs into his spine fluids to attack cancer cells that could be in the fluids going to his brain. This also comprised a second bone marrow aspiration, which showed that the cancer cells were dying; however, there were still traces of some cancer cells, which increased the chances of relapse.

Luke had to complete his treatment and received a bone marrow transplant to survive the cancer. After running tests, Luke's brother was found to be a match and he donated bone marrow. The pre-transplant

chemotherapy, combined with other medication, destroyed Luke's bone marrow, affected his mobility, his ability to sit up without support, and his balance. As a result of the negative effects of the medication, the doctor changed his medication. The long periods spent lying on a hospital bed delayed his physical development, which affected his legs and walking patterns. Luke is in remission; however, regular visits are still required for check-up and inoculation.

6.5. Themes and sub-themes

The following themes and sub-themes were identified in Grace's account of her story as she journeyed through her child's illness. The themes were identified in the interview as well as the reflection written by Grace.

6.5.1. Events leading to the diagnosis

Grace spoke about and reflected much on the events surrounding the diagnosis of her son. The events before the diagnosis featured prominently in her story. She reflected:

> *I would actually begin at the beginning ... how everything had evolved [...] everything that led up to it, you know. I mean, Luke was a healthy little boy, nice and chubby, sixteen months old, running around and all of a sudden he had tonsillitis, so you think as the parent its tonsillitis.*

> *My husband was with me and the paediatrician that actually admitted him to hospital had to work from Femina that day ... so he phoned and then a sister came to our room that morning at round about eleven o'clock and she said well the doctor wants to talk to us and so I just knew that something was wrong.*

She reflected on her journey beginning with her young son's life and events that led up to her son's diagnosis. She remembered the events from when she noticed the symptoms until the day her son was diagnosed with cancer.

> *Luke got tonsillitis 3 times after each other in November 2014. He was on 3 sets on antibiotics but his fever just did not want to break. He started to become sleepy and was very pale. After the 3'd round of antibiotics I took him back to the dr and insisted that they admit him as he was not eating or drinking anything. We were admitted 17 December 2014. They did bloodwork and the paediatrician woke me up that evening saying that something is wrong and would like to do a bone marrow biopsy also known as a bone marrow aspiration. The following morning at 9am it was done and by 11am we got the call from the dr...its not looking good, its leukemia.*

> *I drove us to the hospital and we were greeted by the nurses who became our rocks and our friends. Further tests were done from the sample taken that morning and we got the results the*

following day. They confirmed that Luke had AMLieukemia. This type of leukemia is rare, aggressive and clever. So we had one chance and one chance only.

6.5.2. Talks of the illness

Grace reflected much on the illness – its effects and treatment. She related her son's journey through the illness as though it was her own. Her construction of the journey reflected especially her son's journey and the effect of the illness. In her talking about the illness she (the mother) acted as proxy for her son who could not tell his story.

> *He had his first block of chemo for 8 days straight and I remember one of the dr telling us that they cannot see any more cancel cells in his blood on Christmas day! We were so relieved. We stayed in hospital 3 days shy of a month....in total isolation as he was very very sick. I remember that we were not working between Christmas and New Year which helped a lot.*

> *The day he started his next round of chemo they did a lumbar punch where they inject chemo in his spine fluids in case there are cancel cells hiding in the fluids to the brain. They also did another bone marrow aspiration. This confirmed that the cancer was almost gone BUT there are still cancer cells there and this meant we were dealing with a very aggressive and very clever cancer. This also meant the only way for Luke to survive this is to finish his treatment and immediately doing a bone marrow transplant. like the dr explained...because not all the cancer cells are not gone means that the chances that it WILL come back is guaranteed.*

> *And because it's the clever type of cancer cells if he would relapse the chemo will most probably not work...so he have one chance. So early January 2015 we brought his little brother to hospital and all 3 of us had to get 13 viles of blood taken to be tested to see if anyone of us can be a match for Luke.*

She described her son's treatment process, which was characterised by long waiting periods. The treatment also affected her other son's life as he became a donor. However, this brought hope to the family.

> *And then the waiting started!!! 6 weeks of wait our prayers were answered when Dr advised us that his brother was a 100% match for Luke. Now the wait started to get a date for the transplant. There are only 1 private hospital in Pretoria that has a paediatric oncology ward and that is at Unitas Hospital...they also only have 1transplant room. And the waiting list to extract bone marrow at Pretoria East Hospital was also a loooong list. While waiting for a date we continued with Luke chemo. I would stay with him and then over weekends I would get a bit of a break to go home, see my other son and just be by myself.*

6.5.3. Emotions

Although Grace did not deal with her emotions during her journey with her child, the journey seemed to have been an emotional one. Fear and guilt were identified as sub-themes.

The following quotation expresses her initial reaction to her son's diagnosis:

> *It shatters you as a parent. I mean the first thing you think about is death but the more you read into it ... read about it and the experiences you realise that it's not really a death sentence.*

6.5.3.1. Fear and uncertainty

The fear of cancer was a constant theme through Grace's interview and reflection. She initially equated cancer with death and felt defined by cancer. The fear and uncertainty of whether her son would live and if she herself would be diagnosed with breast cancer persisted and affected her decisions.

> *It shatters you as a parent, I mean the first thing you think about is death but the more you read into it ... read about it and the experiences you realise that it's not really a death sentence.*

Her family history with cancer coloured how she initially reacted to the news of her son's diagnosis and also how she thought of her own health. As a result of the fear of cancer and a in a way to minimise her own chances of having cancer, she made a drastic health decision:

> *Oh no ... I've been surrounded with cancer all my life ... so it's I think it's also I'm ... terrified.*
>
> *Ja, grandpa, grandma, mom, sister ... son ... so its [...] it definitely its ... cancer defined me, that's sad but its every what if what if what if, so I must say that since my mastectomy it feels like a table mountain has been lifted of my shoulders because I know that that risk that I had [...] is not here.*

As a mother, the fear of relapse persists, even after her son's remission and survival. The fear of relapse made her even more cautious and alert to every symptom of illness in her son. When asked whether she feared that the cancer would return she responded:

> *So, I'm terrified to the extent that I actually went for a double mastectomy in February this year so ...*
>
> *... because I'm so focused on when is it gonna happen when is it gonna happen when is it gonna happen ...*
>
> *Yes, it does, but its every parent that has gone through this they have a fear that ... every time that they get a fever that you immediately think it's back.*
>
> *You and people say, "Don't think that way." Yes, we don't wanna think that way [laughter] but it's there.*

6.5.3.2. Guilt

Although her son had recovered and was back at school, it seemed that Grace carried the guilt of not being efficient in caring for her child at home. She also felt guilty for being relieved of taking care of her children at home.

> *I was tired. It just becomes too much, so I was happy to see them go to school [...] also with Luke. He, as I mentioned, he is a very feisty child. He gets bored easily so he wasn't stimulated at home and I felt guilty because I don't have the time to sit with him to stimulate him. In a sense I don't have the knowledge and I don't have the time.*

> *So, it's good for me and he loves being with other kids, so it was a good thing he loves school so I know it's a good thing.*

Although her son survived, Grace expressed the guilt that other mothers lost their children to cancer. She felt powerless not knowing how to help mothers who lost their children to cancer.

> *Now Luke is healthy and running around. You know it's also difficult dealing with the guilt ... because my child made it but my friend's four of my friend's children didn't make it [...] so you still need to work on that guilt as well ... and you shouldn't but you do.*

> *Ja, I know, ja, that there is so many kids that don't [survive]... it's just unfortunate.*

> *And their loose so it's a very difficult... I don't know how to handle that [...] so like my one friend if I phone her I'm not allowed to ask her how she is ... not allowed to, she's been on pills from a psychiatrist I don't know so well. He passed away in November so ja, it's difficult, you don't know I don't ... I'm not equipped.*

> *And how can I help ... help them, how can I be there for them coz they've lost their child.*

6.5.4. Added trauma

In addition to her son's illness it seemed that Grace and her family experienced added trauma. Her husband lost his brother prior to their son's cancer diagnosis, while her sister was also diagnosed with cancer a month before her son's diagnosis. During her son's treatment, she then lost her sister. This trauma had an effect on how they received and dealt with their son's illness; however, she took on the role of being the strong one for the family.

> *... My husband started crying. He lost his brother four months ... before that, my sister was diagnosed with cancer a month before that ... two months before that.*

> *You see, his brother suddenly passed away a mere 4 months ago, and my sister was diagnosed with breast cancer 2 months ago.*

She describes how traumatic events occurred in succession. Her son and sister were in hospital at the same time, which meant that she could not visit her sister. Her sister passed on without her being able to see her.

> *I did feel that because my sister and Luke got chemo the same ... the same time, I couldn't go visit my sister because she couldn't be [...] in a germ environment; Luke couldn't be in a germ environment and vice versa, so ja, I think the last time I saw my sister was March and she passed away in May.*

> *I think the last ... you know it was everything happened at once ... it's his brother suddenly passed away, then it was my sister, then it was Luke, then it was my sister that passed away, then it was Luke's ... while Luke's transplant was going on and now he also had some family things that was dumped on him so this has brought us ... it made us stronger and it brought us closer to each other.*

6.5.5. Roles

The role of being a mother comes with many changes to every woman; however, when a child is diagnosed with cancer, the role of a mother changes even more. Parenting styles also change as parents adjust to the changes in their ill child, while balancing relationships with the other healthy child or children. The mother's role is intensified; in addition, she has to fulfil the role of a wife. The role of being the strong one was identified as a sub-theme under role changes.

She explained her role as follows:

> *It's a lot ... to have two kids age two and three at home. They constantly want your attention but you still need to work and because of all the debt I had to start a second job so I had to do two jobs plus look after the kids ... plus I need to run the house plus I need to be a wife.*

> *To reflect ... also to be there for Will whatever he is going through, you know, take him to school, picking him up, you know, colouring and doing various things with him but after he's gotten much stronger, they bond with his dad now than what I have with him [...] but it I think it's just because he was his primary caretaker for so long.*

> *... and because he is a very feisty child [...] we now just need to adjust our parenting ... according to him and his trauma, his personality and things like that, so ja, we've learned [laughter] a whole new.*

As a mother, she also became the broker of information for her two sons, having to explain hospital procedures to them.

Yes, so and the bone marrow transplant was two days after his third birthday, so, I mean when you're three, you don't really know so we tried to explain to him what was happening, what's gonna happen, how his gonna go to the hospital, his gonna blow a little balloon and they're gonna take blood from his back and that his gonna save his brother with the doctor and God will be with them and all three of them will save his brother.

She constructed the experience as her own since she went through the process with her son. Grace constructed her son's treatment period as a "we" experience, using the term "we' when reflecting on her child's experiences:

We were admitted to hospital on the 6th of May for the pre transplant chemo. This chemo is crazy....it literally kills the bone marrow.

Little Luke went from strength to strength and we were discharged a mere 17 days after the transplant...and he has been doing great since then.

He had his first block of chemo for 8 days straight and I remember one of the dr telling us that they cannot see any more cancel cells in his blood on Christmas day! We were so relieved. We stayed in hospital 3 days shy of a month ....in total isolation as he was very, very sick. I remember that we were not working between Christmas and New Year which helped a lot.

6.5.6. Being the strong one

From the moment the doctor disclosed her son's diagnosis, Grace became the strong one in the family, to support her husband and her son alike. Although her sister was also diagnosed with cancer shortly before that, she empathised with her husband who had lost his brother prior to their son's diagnosis. As a mother and wife, she assumed the role of being the pillar of strength for her husband and child.

She described the moment the doctor disclosed the diagnosis as follows:

I vividly remember my husband standing next to me with Luke in his arms and he could see in my face that something was very wrong. When I told him the news, he just burst out crying as this was too much for him to handle.

So… he just burst out crying and I had to … even though I was shaking and freaking out inside … I had to be the strong one.

I don't know if it's fortunately or unfortunately but I had to be the strong one, ja, so its hectic its … I don't wish that on anyone.

I remember packing little Luke's bags to get to another hospital as soon as possible. I remember shaking but also trying to hide it from my husband, trying to be the strong one. I drove us to the hospital and we were greeted by the nurses who became our rocks and our friends.

She did not show emotion or deal with what she was going through because she had to be strong for her son. She acknowledged how she dealt with what was happening, as it would affect her son and his treatment directly. As a mother, she neglected her own feelings and did not want to break, in the fear that her son would be affected. She explained:

I think we're so traumatised but we can't show we traumatised because we need to focus on our kids we ... actually neglect our own [...] feelings

... and also I think Luke was sixteen months old, he barely started talking, he barely started walking, he well, he walked what six months [...] so I couldn't show emotion I couldn't deal with it because I had to put all my focus on being strong for him because if I break down he won't know what's going on. I mean that would affect him and his treatment.

6.5.7. The effect of the illness

Although only one member of the family was physically sick, the cancer affected the entire family. Grace constructed cancer as a 'we' disease when describing the time her son was in hospital. The following categories of effects were identified as sub-themes: effect on the mother, financial effect, effect on relationships, effect on the ill child, and effect on the family unit.

6.5.7.1. Effect on the mother

As a mother and the primary caregiver, her son's cancer diagnosis had a considerable effect on Grace. Due to her family's history with cancer, she felt that cancer defined her. She was surrounded by cancer all her life; however, she did not think it would happen to her son. Her son's diagnosis led to her making a drastic health decision. Due to the succession of traumatic events, she has not had time for herself.

So, I'm terrified to the extent that I actually went for a double mastectomy in February this year so ...

Cancer defined me, that's sad but its... every what if what if what if, so I must say that since my mastectomy it feels like a table mountain has been lifted of my shoulders because I know that that risk that I had [...] is not here.

With the transplant I just said to my husband, "You know what, this past six months has been hell [...] I don't get to have a break, I don't have time to just be me and reflect on what's happening, everything is just one after the other."

As a mother and wife, her caregiving tasks intensified as she started working from home. The financial effect of her son's treatment led to her working two jobs, although she was working from home.

> *It's a lot ... to have two kids age two and three at home. They constantly want your attention but you still need to work and because of all the debt I had to start a second job so I had to do two jobs plus look after the kids ... plus I need to run the house plus I need to be a wife.*

6.5.7.2. Effect on the family unit

When one member of a family is diagnosed with a life-changing illness, such as cancer, the entire family changes as members adjust their routine to the demands of the illness. In addition to the effect on the individual members of the family, the family unit is also affected. The family may be affected positively and/or negatively. Grace constructed what her family went through as follows:

> *With the transplant, I just said to my husband, "You know what, this past six months has been hell [...] I don't get to have a break, I don't have time to just be me and reflect on what's happening, everything is just one after the other."*

In Grace's case, the family roles changed as grandparents became more involved in the care of the healthy child. The family's normal routines had to change as they took turns between being at the hospital with the ill child and not deviating from the normal routines for the sibling. However, the entire experience strengthened her family.

> *So, what I've taken from this whole journey, is I'm a better person, our family is a stronger unit even though we went through hell and back [...] we're stronger people [...] and I would love to do more for the cancer kids.*

> *No, we ... it was only us and then my mom and my ...my mother-in-law so specially just when he was diagnosed that was just before Christmas and New Year so we had the one grandma stay with Luke in hospital and we as a little family – my husband myself and then Will – would go to the other family for Christmas Eve and vice versa for Christmas day so they also helped especially you know ... it also affected my husband and our marriage.*

> *So, luckily I had that support structure. With the transplant we made turns. I would be one day with him and then one day with ... at home with the little ...with Will [...] and we would swap shifts every day and it helps a lot because it gives you just that break ... to reflect also to be there for Will whatever he is going through. You know, take him to school, picking him up you know colouring and doing various things with him but after his gotten much stronger, they bond with his dad now than what I have with him [...] but it I think it's just because he was his primary caretaker for so long ...*

6.5.7.3. Financial effect

Due to the treatment of the illness, Grace had to start a second job while working at home in order to take care of the household. It seemed that she did not only support her family emotionally and fulfilling chores as a wife; she was also a provider financially. As a result of her son's treatment, they found themselves in debt.

> *I don't know, I know financially its insane and we still struggling with all the debts and because, yes, we have medical aid but over and above that then they reject it so then you get … then you need to get funds so you make loans to not be blacklisted and then you make loans to make loans to loans …*

> *So, at this stage, we're sitting with R150 000 of debt that so … that's the one thing … but I don't know who is gonna give you R150 000 just [laughter] not in today's economic climate.*

> *But you still need to work and because of all the debt I had to start a second job so I had to do two jobs plus look after the kids.*

6.5.7.4. Effect on relationships

Cancer isolated Grace from her friends and family, which had an effect on her relationships with them. Her friends stayed away from her; however, she made friends with mothers going through the same ordeal as her.

She explains her relationship with her friends and family in the following excerpts:

> *And the things is because you, like I said in my document, you lose so many friends. All of a sudden there's no one … […] and yes, it's because they don't know how to handle it.*

> *So, they just stay away but they will do more damage, so our group of friends has dropped to only a handful of people but you gain so much more … your friends in the ward and they are friends for life because you've gone through the same things […] so I do try and make contact but it's difficult for them losing their kids because some of them don't wanna be in contact because you remind them of their child.*

With her sister being diagnosed with cancer around the same time as her son, her relationship with her sister was affected. It seemed that she felt guilty that she could not visit her sister at the hospital until she passed away.

> *The same time, I couldn't go visit my sister because she couldn't be […] in a germ environment* Luke *couldn't be in a germ environment and vice versa, so ja, I think the last time I saw my sister was March and she passed away in May … but we spoke over WhatsApp and I said to her, "I'm so sorry, I wish I could be there more I wish I could support you more, do more for*

you," but she said to me, " I understand that,"… that gives me a sense of peace but I still think
that I could have done more.

She spent much of her time with her ill son in hospital, which had a negative effect on her relationship with her other son. She felt that her son had a close relationship with his father and not with her.

Yes, and also before that … when his brother was born he was one and a half years old … barely … sooo unfortunately that's the thing but I mean they [are] still young enough for me to just … not justify to correct if I can put it that way.

But after his gotten much stronger they bond with his dad now than what I have with him [...] but it I think it's just because he was his primary caretaker for so long.

Due to the demands of the illness, she and her husband spent much time apart, which had an effect on their marriage.

It also affected my husband and our marriage … for six months we didn't sleep in the same bed so it did affect it, it's only now recently that we've managed to sort of be okay but at a stage I thought, oh my soul, it's not gonna work, we're drifting further and further apart and I think it's probably the way you have to go through that because you need to find your household and then you need to find your marriage and then you need to find routine and things like that, ja.

6.5.7.5. Effect on the ill child

The treatment of cancer had a physical and psychosocial effect on Grace's ill child. The treatment of cancer is associated with some psychosocial effects depending on different factors. Children may also experience post-traumatic stress due to the time they spend in the hospital. Grace described how cancer affected her child:

So yes, and definitely it affected him as well [...] at that young age, he stopped walking completely he stopped walking so for after our first block of chemo we had to …start again

I think that was better and then after the treatment he actually became very aggressive so we took him to a … what's it a … play therapist.

They normally start showing post-traumatic stress six months after the last time they were admitted.

6.5.7.6. Effect on the sibling

Grace's other son, Will, became a match for Luke's needed transplant and he donated his bone marrow. As a young child, he did not understand what was happening to him. The procedure of donating a bone marrow could have had an effect on the sibling.

So early January 2015 we brought his little brother to hospital and all3 of us had to get 13 viles of blood taken to be tested to see if anyone of us can be a match for Luke. And then the waiting started!!! 6 weeks of wait our prayers were answered when Dr advised us that his brother was a 100% match for Luke.

Yes, his got an older brother that … they are fourteen months apart. His brother was actually his hero. He donated his bone marrow he was a 100% match yes so we were very blessed in that sense. But that was also another obstacle course because he was only two years old, ja, two and half years old.

When a child is diagnosed with cancer, parents tend to focus on the ill child while neglecting the healthy siblings. Grace spent much of her time with her son in hospital and less time with her other son, which had an effect on their relationship.

The transplant date were given to us and it was scheduled for 13 May. 2 days after Will's 3'd birthday. This meant that I would not be with him on his birthday but it also meant we can now get the transplant.

No, we … it was only us and then my mom and my … mother-in-law so specially just when he was diagnosed that was just before Christmas and New Year so we had the one grandma stay with Luke in hospital and we as a little family my husband myself and then Will would go to the other family for Christmas Eve and vice versa for Christmas day so they also helped especially, you know …

Yes, and also before that … when his brother was born, he was one and a half years old … barely … so unfortunately that's the thing but I mean they still young enough for me to just … not justify to correct if I can put it that way.

They bond with his dad now than what I have with him […] but it I think it's just because he was his primary caretaker for so long …

6.5.8. Coping

Coping was a prominent theme throughout Grace's interview. Having a positive outlook, helping others and social support were identified as sub-themes.

6.5.8.1. Positive outlook

Throughout her journey, Grace looked at her experiences with a positive eye. She was optimistic from the time her son was diagnosed even when she was fearful.

Yes, we had all the heartache and stresses the everything but I think we're better [...] and I don't wanna lose that.

So, I'm trying to see it in a positive light.

When the doctor said to us its [...] from there we packed the bags and we went to Unitas hospital from Kloof because they don't have a paediatric oncology ward so we went to Unitas and we waited and we spoke to the doctor and I've always tried to see the positive out of it, I say, "We've got one chance. Let's do it."

She saw the experience as having a positive effect on her family. The experience made them closer and stronger as a family. She sees her family as being fortunate that her other son could donate his bone marrow and save his brother's life.

It's going well, Luke is doing great the doctors are very happy [...] With my husband and myself it's going well [...] I think the last you know it was everything happened at once it's his brother suddenly passed away then it was my sister then it was Luke then it was my sister that passed away then it was Luke's ... while Luke's transplant was going on and now he also had some family things that was dumped on him so this has brought us ... it made us stronger and it brought us closer to each other.

What I've taken from this whole journey is I'm a better person, our family is a stronger unit even though we went through hell and back [...] we're stronger people [...] and I would love to do more for the cancer kids.

So, I do think we've ... we were one of the lucky ones ... we are that's why I say I can't say, "Ah, this is so bad," because we're blessed in every sense of the word, Will was a 100% match, you know, we didn't have to go look for a donor overseas.

6.5.8.2. Helping others

Grace helped others as a way of coping with her experiences. Giving was a way for her to heal and deal with her own experiences and her journey through cancer. She focused on helping other mothers caring for children with cancer. She explained:

It's very rewarding for me and I think its maybe ... a way of me healing by giving [...] I couldn't give [gifts to childhood cancer patient]) this year yet but hopefully I can get my act together and have another Christmas in July.

Because helping people, especially people going through [cancer experience] that you know people sitting in the wards I mean the wards are overflowing at the moment.

She started a non-profit organisation through which she could help other mothers of children diagnosed of cancer. Helping others became a way of healing herself.

> *And I've also started my own little non-profit organisation to do things like last year out of my own pocket and on Luke's Facebook page I said I want to have a Christmas in July for the kid in the ward so everyone ran for gifts and Christmas wrapping.*

> *And all the kids were made soup and we had bread and soup in the middle of winter and all the kids got Christmas gifts in July and so I would love to do that but [...] but this year had been ... hard because every you know we've lost so many I think I'm putting up a wall to protect myself.*

> *It's like last year there was a few mommies that the social worker at Unitas would phone me and say listen we've got a child of five and there's no money for you now they put all their money into their medical aid so that their child could get private care for their cancer.*

> *So, there's no money for cloths, food and things like that so they would say listen, the child is ... it's critical that they get dressed in a non-germ environment so I would go and buy them clothes and give it to the parents so you know I trying to do ... make a difference in that sense.*

6.5.8.3. Social support

The support available to parents when a child is diagnosed with cancer could help them cope with the demands of the illness. Grace received emotional support and instrumental help from her husband and extended family. As shown in the following excerpts, her husband took turns with the care tasks for both her sons. Her in-laws also took care of the healthy child while she was in hospital.

> *You can't buy time, [...] which is a good thing, I mean, during the whole treatment I'm one of the very blessed people with a very amazing and supportive husband so he had to go to work.*

> *So luckily I had that support structure. With the transplant we made turns. I would be one day with him and then one day with ... at home with the little ...with Will [...] and we would swap shifts every day and it helps a lot because it gives you just that break.*

> *No, we ... it was only us and then my mom and my ... mother-in-law, so specially just when he was diagnosed that was just before Christmas and New Year so we had the one grandma stay with Luke in hospital and we as a little family my husband myself and then Will would go to the other family for Christmas Eve and vice versa for Christmas day so they also helped.*

> *My husband would come to hospital to spend some time with us while our other little one at that stage 2 years old would be at his grandmothers playing not knowing what was wrong. We would made turns to be with Luke in hospital and home with his brother.*

Grace received support from her employer who allowed her to work from the hospital. She also received social support from people through a Facebook page she created to document her son's journey.

> *No, no, because there is so much, you know, I'm very happy that I started a Facebook page for Luke so I gave updates [...] and its grown to up to over 1000 people and I know that Amanda's mom started a page for George.*

> *I work from home so my company said to me I can just work from hospital so you know a lot of parents in the wards actually they lose their jobs.*

Another aim of this study was to investigate the support needs of mothers of children with cancer. When asked of her support needs, Grace expressed a need for financial assistance. Fortunately, she lived close to the hospital, she therefore did not use services offered by some organisations that accommodate mothers during their child's hospitalisation.

> *I don't know ... I know financially its insane and we still struggling with all the debts and because yes we have medical aid but over and above that then they reject it so then you get ... then you need to get funds so you make loans to not be blacklisted and then you make loans to make loans to loans ...*

> *I think that is one thing that I would have appreciated. I know for the parents that stays in Polokwane they, because there's no oncology unit there, they normally come through here so they, you know, they've got a place to stay at the CHOC houses [...] with their kids, you know, they get meals, they get transport to and from the hospital for the chemo and things like that so for me that's wonderful because we stay ... very close, ja, so we didn't need that.*

Although children are offered emotional support at the hospital, there is a need for emotional support for parents at the hospital. Parents are often provided with assistance in terms of caring for their ill child; however, they are neglected when it comes to emotional support.

> *But I do think that ... I know that there's for the older kids ... they've got psychologists that do come into the ward too but because Luke was so small they couldn't.*

> *But ja, I think the parents are very much neglected. They focus on the kids, which they have to because they are the sick ones but the support that the parents normally [...]*

6.6. Summary

In this chapter, the story of Grace was provided. The chapter started with a description of the conversational setting and my impression of Grace. Prior to presenting the emerging themes, a description of the illness was provided to give context to Grace's story. The transcript of the interview

between Grace and myself was analysed as well as the reflection written by Grace. The following themes and sub-themes were identified:

- Events leading to the diagnosis

Grace reflected on the events leading to her son being diagnosed with cancer. She related how doctors reached her son's diagnosis and also spoke of her son's life before the diagnosis.

- Talks of the illness

Grace reflected on her son's illness through her eyes. She constructed the illness as her own experience and as a 'we' experience.

- Emotions

The cancer diagnosis came with mixed emotions for Grace as a mother. Although she did not show her emotions, she was shattered by the diagnosis. Fear, uncertainty and guilt were identified as sub-themes under the main theme of emotions.

- Added trauma

In addition to the trauma of her son's diagnosis, Grace experienced added trauma. Her sister was diagnosed with cancer around the same time as her son, and subsequently passed away. Furthermore, her husband lost his brother.

- Roles

When a child is diagnosed with cancer, the mother's role changes drastically while she takes on new responsibilities. In addition to taking care of her ill child, Grace had to care for her healthy child, take care of the household and be a wife.

- Being the strong one

Grace took on the role of being the strong one in her family in order to support her family through the cancer ordeal.

- The effect of the illness

The diagnosis of Grace's son had an effect on her entire family in different ways. The following sub-themes were identified under effect: financial effect on relationships, effect on the ill child, effect on the mother, and effect on the sibling.

- Coping

The following coping styles and coping mechanism were identified under the theme of coping: being the strong one, a positive outlook, helping others, and social support. Grace became the strong one in the family, supporting her son and her husband through this journey. She had a positive outlook and optimism that helped her in dealing with her painful experiences. Helping others was a form of healing

and a coping mechanism during her journey. The social support from her friends and family also helped her cope and adjust to the demands of her son's illness.

Chapter 7: Judi's story

Age: 40

Ethnicity: White

Child's age at diagnosis: 6 months

Type of cancer: Langerhans cell histiocytosis

Interview setting: Judi's office boardroom

7.1. Introduction

This chapter contains the case description of Judi's experiences of caring for a child who has been diagnosed with cancer. The analysis of the transcript of the conversation between Judi and myself is reported in this chapter, as well as the analysis of the reflective document provided by Judi. In presenting Judi's story, the setting of the interview will be discussed as well as my impressions of Judi. To give context to her story, the description of her son's illness is provided, progressing from before the diagnosis. Furthermore, the themes that emerged from the conversation and reflection are provided. It is important to note that the themes presented in this chapter are only a reflection of Judi's reality and are thus not representative of all mothers caring for children with cancer. The themes are constructed by me, as the researcher, through my knowledge, the aims of the research and the theoretical framework underpinning this study. The chapter concludes with a summary of Judi's case description.

7.2. The conversational setting

The interview took place in a boardroom at Judi's workplace. I had visited Judi's office prior to the interview; therefore, I knew my way around the building. Upon arriving at her office, I was greeted with a warm hug and was escorted to a boardroom were Judi suggested that the interview be held. Judi anticipated interruptions in her office; hence, she booked the boardroom for the interview. We sat across each other at one end of the long boardroom table. The space created a somewhat formal setting for us. I encouraged Judi by telling her that the interview was not going to be a formal one but rather a conversation guided by a few questions.

7.3. My impressions of Judi

Upon meeting Judi the first time before the interview, she came across as a friendly woman, full of life and laughter. She had a bubbly personality and expressed her gratitude for being part of my research. In spite of her personality, it seemed that Judi had not dealt with her experiences. During the interview, she wept as she talked about how her son's illness changed her life. It seemed to me that she had not

reflected on how her life had been affected although she was not the patient. It became apparent that Judi's son's illness progressed to its second phase unexpectedly while they thought he was on his path to remission. Although her son was well and in school during the interview phase, the family was awaiting news on her son's possible donor for a transplant.

Having been interviewed by journalists about her experiences, Judi had a way of telling her story and did not expect the reflective questions I asked during the interview. She was accustomed to talking about her son's journey but not about her role in this journey. She had not taken time to reflect on her experiences and how the illness had affected her life. I then suggested that she make an appointment with a psychologist and provided her with the contact details.

7.4. Cancer description

Judi had a normal pregnancy and gave birth to a healthy baby boy (Josh) without any complications. Josh, now 5 years, was only six months old when he started experiencing health problems. His mother noticed that his nappy rash would not heal and developed into blood spots. The rash occurred in every warm place in his body and the paediatrician could not explain the rash after trying different medication. After visiting a skin specialist, the doctors suspected a rare form of cancer, however conformation of the diagnosis required a skin biopsy. The skin biopsy revealed the diagnosis of Langerhans cell histiocytosis, an auto-immune disease where one's cells attack the body.

Because his veins were too small at six months, Josh only started his chemotherapy at nine months. Some of the effects of the chemotherapy were mouth sores, pains, chills, inability to eat (making a feeding tube necessary). The treatment was successful and his port (feeding tube) was removed. Unexpectedly, the illness went into its second phase progressing to his bone marrow and formed a tumour in his head. The tumour affected Josh's hearing and his speech and made his bones weak.

At the time of the study, it had been five years of maintenance chemotherapy and intermittent radiation; however, Josh has not yet reached a sustained remission. A stem cell transplant was required to 'reboot' his immune system since his condition was considered fatal.

7.5. Themes and sub-themes

The following themes and sub-themes were identified in Judi's account of her story as she journeyed through her child's illness. The themes were identified in the interview as well as the reflection written by Judi.

7.5.1. Events leading to the diagnosis

The interviews all began with a reflection on a mother's journey through her child's illness. Participating mothers were asked where they would begin reflecting on their journey. Judi started with her 'normal life' and the events before her son was diagnosed with cancer. The following quotations show her journey from the beginning to when her son was diagnosed with cancer:

> *My live was so perfect, after a normal pregnancy and a blessed day when Josh was born without any complications!*

> *Well I think the best is to tell of when it started [...] you know me and Robin [her husband] got married and we had a − we took quite a while to get to the stage and decide to have children and then we had a − I was pregnant, little boy, normal pregnancy no problems ... and then [...] Josh was born and then nine months after his − actually about six months then the problem started [...] he was [...] he started [...] it was on his skin a nappy rash that didn't wanna heal till he had like blood spots.*

> *I took him to the paediatric [...] his doctor, and she said to me, "I mean we've tried so many medicines and stuff," so she doesn't know what to do anymore.*

> *And she advised us to go to a skin specialist and then they ... I will never forget that we were sitting there and she called two of her friends and they go through to me and then she said to me, "I think that your son's got a rare cancer and you need to start chemo," and I thought yoo girl, what are you talking about? I mean we don't have cancer in the family I mean ... and then the only way they can confirm the illness is through a skin biopsy.*

7.5.2. Emotional roller coaster

The cancer journey is an emotional one, not only for the patient, but for the mother as well. The following sub-themes were identified: different emotions, hopelessness and uncertainty. Judi experienced different emotions namely; shock, disbelief, anger, hopelessness, fear and guilt. Uncertainty and hopelessness were prominent features in the interview and thus sub-themed under the theme of emotional roller coaster.

7.5.2.1. Different emotions

Judi experienced different emotions when the doctors diagnosed her son with a rare form of cancer. She experienced an initial reaction of shock and disbelief. She also experienced fear and denial, which led her to seek a second professional opinion on her child's diagnosis.

> *I thought yoo girl, what are you talking about? I mean we don't have cancer in the family. I mean ...*

Ja, I thought they are lying, I thought what! What do they know I thought [...] you know you're going through these different phases. You going through denial and then you think, oh, let's get a second opinion.

As parents we remember the first time the news was broken to us, the emotions was overwhelming of shock, fear and denial.

Then you start googling the word because you couldn't even pronounce it so, ja, you go into a denial phase and then you go into the angry phase so, ja, its different phases you go into.

The diagnosis of cancer came with the fear of death due to the nature of the illness. When her child started day care, she felt a sense of relief coupled with fear. It seemed that she continued to fear what might happen to her vulnerable child in her absence. As a mother, she is alert and always thinking the worst of any situation, consulting the doctors on any signs or symptoms of illness.

I mean the whole situation is well [...] but ja, there is good in it because I've never for me myself I've never realised that you can [crying] ... love someone so much ... and at the same stage be scared of losing him [crying] ... I mean every ... every ... feels like a death sentence ... that ... so ja, to appreciate life more all of that [crying].

I was ... scared and relieved at the same time because scared is I was [...] anything can happen. I mean he's that weak I know you can't put him in a little glass cage for the rest of his life but [...] you know if children are ... they don't see his illness so if they do something to him that he gets hurt I mean I sit here with my tummy on a notch.

You always think the worst doesn't matter what, something happens you always think, wow, what did he break now but not okay fine its only so you know so ja, that's you think you think the worst.

I mean everything with him is in extra drive, if I can put it like that. I mean its ... if he falls, he breaks − he will physically break something so ja, that's quite you know I think you're forced to think out of the books and you know to be like the freaky mom that ... runs to the doctor for everything

Through the year of ups and downs, Judi learned to block out what she was experiencing; however, that brought the guilt of moving on.

Sometimes you feel guilty because you think yoo how you can just block that out and move to the next one but ... ja, it worked for me.

7.5.2.2. Hopelessness

The enormity of the illness brought hopelessness and a concern for the child's future. Parents lose hope when they hit a wall or when the unexpected happens to their child. Due to the uncertainty of cancer, Judi felt that their hope was crushed at certain points when they thought they had conquered.

We were overwhelmed by the enormity of the situation, in the 4 and a half years our hope was crushed a few times when we thought this is now sorted and done.

Believe me, feeling hopelessness that you can't do anything for your child is the worse feeling ever!

Josh's bones were very fragile; if he fell it could easily break. Believe me, feeling hopelessness that you can't do anything for your child is the worse feeling ever!

But in the same breath, we are ready for the life-line and another chance that Josh will be healed after he receive the transplant.

Following her son's diagnosis, Judi and her husband were concerned for their child's future; however, they remained optimistic about the future. They questioned the decisions they made on behalf of their child.

We are very scared yet optimistic of this next chapter in Josh's life, and constant wondering if we are doing the right thing ... but in the same breath, we are ready for the life-line and another chance that Josh will be healed after he receive the transplant.

We were real scared, anxious and panicking about what the future will hold.

7.5.2.3. Uncertainty

Cancer is associated with uncertainty since parents usually have no prior knowledge or experience of how to care for a child with cancer. The doctors' uncertainty regarding the symptoms that the child presents may also bring uncertainty and worry for parents. The diagnosis itself comes with uncertainty as parents do not know the symptoms and because of the rare types of cancer that may be found, doctors may also struggle to reach the diagnosis. Judi described it like this:

I took him to the paediatric [...] his doctor and she said to me, "I mean we've tried so many medicines and stuff," so she doesn't know what to do anymore.

Then Josh's illness progresses into a much bigger and dangerous phase. Each MRI [magnetic resonance imaging] scan and PET [positron emission tomography] scan feels like a death sentence when you wait for the reports to see where this has progressed to and what new damage this has caused.

I remember I asked the doctor to write down the name of Josh's condition, I couldn't even pronounce it properly. Then we started googling it to try and make sense of what this is all about.

So, we went for radiation and chemo and ja, that's been four years going up and down with that.

Emotions of uncertainty were further perpetuated when the illness moved into its second phase as they thought their child responded well to chemo. She described this period as a difficult time.

So ja, then he started chemo when he was only nine months old but it's not only start with chemo you know we went through operation for him to − for a port to be inserted that's − they use that to give children chemo because their veins is not strong enough for the chemo so we went through that and then at nine months he started with chemo and it went very well and ja, then it was resolved and … ja, we were on our way to take out the port because we thought we got our certificate we are done now with chemo and Josh is fine.

And then I said to Josh's ear specialist, "I think something is wrong with his ears because he is hitting his head the whole time."

And the doctor said, okay rather go for the operation. He will also go and look while he sleeps if he can see something and then ja, me and my husband thought, okay, this is gonna be quick we take out the port, we gonna get some coffee and I will never forget they came running to us calling us we must come quickly back to the theatre.

Because there's things growing out of Josh's ears and ja, so long story, it was that the illness went to its second phase. It went to his bone marrow, ja, and his skull.

… A difficult time for us, ja. We started our way to chemo and ja, then his whole head, there's a tumour growing in his head as well.

So we went for radiation and chemo and ja, that's been four years going up and down with that.

7.5.3. Life changes

The experience of caring for a child with cancer had changed Judi. She describes her son's diagnosis as one of her life-changing moments. The experience has made her love even more and appreciate life even more. Asked how the experience had changed her life, Judi wept and requested that we take a moment from the interview to allow her to calm down. It seemed that she had never thought about how the experience had changed her and it became very emotional for her to describe the changes.

[Crying] … ok, it changed me a lot …

... And that unconditional love for us and when somebody said the other day that when a child is going through that, everything changes, and it's so true. I mean, he has changed us as well, I mean the whole situation is well [...] but ja, there is good in it because I've never for me myself I've never realised that you can [crying] ... love someone so much ... and at the same stage be scared of losing him [crying] ... I mean every ... every ... feels like a death sentence ... that ... so ja, to appreciate life more all of that [crying].

My second life-changing event is to hear that your child has been diagnosed with cancer when he was only 6 months old.

7.5.4. Roles

As a mother and the main caregiver, Judi was responsible for the care demands of her son's illness and the management of his treatment. Her role as a mother intensified with the additional care needs associated with cancer. She worked out her son's schedule for hospital visits and found ways for her son to co-operate during hospital visits. It seemed that for Judi as a mother, it had become an automatic action to take time off work to be with her child at the hospital. The following quotations show Judi's role in her son's life and the management of her son's health demands.

Ja, they go on and life, I mean the little life that he knows and he will go on, we've worked out all the ... [...] chemo sessions and everything I mean all the scans and it works out about every twenty days Josh must get something either a scan or chemo you know something and that's his life ... he doesn't know better.

We've been, it's difficult to explain to him why we go back every time [...] we say that he must go to get his medicine and so [...] I always try to be with him when he goes there [...] and he is you know for example a stupid thing is he doesn't wanna lie down on the bed while they give him his chemo for example because ... he wants to sit up because then he's in control you know stuff like that so ja, it's difficult ... it's difficult [...] but you know what, I know it's not always right but you work with a reward. I mean now I say we go through and we're done and we gonna do this so there's always something to look forward to ... I'm not saying I'm spoiling him rotten. Don't get me wrong, but I feel so we've got this little treat. He loves mango ice-cream so the treat is if you're done with the treatment then we go and get him a mango ice-cream.

So, you know we try to − I'm trying to make it better for him to look forward to something nicer, ja.

Josh recently turned 5 and it's still very difficult to explain to him why we need to go again to the dr or when he needs to take medication or treatment, and off course he is NOT fond of needles

She described her role as more sympathetic or empathetic than that of her husband, which made her child relate better to her than to her husband. Her role as the empathetic one created a special relationship between her and her son.

Yes ... I try, I really do I think I've missed like one or two [hospital check-ups] in his life but I really try and I think, you know, he wants me there because daddy is not very sympathetic ja, what's the word, ja, I think its [empathetic]

She described a mother's role as a protector, wanting to protect her child and empathising with him. She described her husband as being practical, whereas she was emotional. Her description of herself in contrast to her husband was a re-enforcement of the socially constructed ideology of a mother's role. As a man, her husband was hard on their son and inculcated strength while she was soft and wanted to protect the child. Due to the emotional nature of a mother, her child was more comfortable showing 'weakness' and pain to her rather than to her husband. The follow excerpts show the different gender roles within a family:

Ja, ... it's been tough, it's been really tough because I think the roles as a mommy, I mean we've talked about that, you know, I want to protect and I feel sorry [for Robin]

Robin is very practical so, Robin thinks differently and I'm emotional you know, and I will think emotional about things. He thinks practical, so I think in a way we ... complement each other.

I − you know I think it goes to [...] your head especially as a mom ... I mean you are the protector of that child so and I always said that it's not [...] a cold like it's going away and its gone for a while.

... Where daddy wants to make strong and daddy wants him to survive out there so it's difficult to find the middle ...

Ja, and sometimes that happens [...] I've learned so much because Robin is so harder on him than I am. Sometimes it's good to push him, you know.

Ja, definitely ja, and I think he can ... he can tell me if he doesn't feel you know nauseous or whatever, you know, but I think sometimes he feels he can't say that to daddy, ja.

7.5.5. Different phases

The initial diagnosis brought about different emotions which Judi described as different phases. Her journey was unpredictable and characterised by high moments and low moments. As her son's illness progressed to different stages, she had to adapt and adjust to the demands of the stages, which came with different emotions for her. She experienced disbelief, shock, denial and anger.

> *Ja, I thought they are lying, I thought what! What do they know I thought ... you know you're going through these different phases; you going through denial and then you think oh. Let's get a second opinion.*

> *... then you start googling the word because you couldn't even pronounce it. So ja, you go into a denial phase and then you go into the angry phase. So ja, its different phases you go into.*

> *... and that unconditional love for us and when somebody said the other day that when a child is going through that, everything changes and it's so true. I mean he has changes us as well, I mean the whole situation is well [...] but ja, there is good in it because I've never for me myself I've never realised that you can [crying] ... love someone so much ... and at the same stage, be scared of losing him [crying] ... I mean every ... every ... feels like a death sentence [...] that ... so ja, to appreciate life more all of that [crying].*

Judi's son's illness moved into different stages as they thought that their son had conquered cancer. The second phase was categorised as the most dangerous phase, and this came with different emotions, even for his parents.

> *Then Josh's illness progresses into a much bigger and dangerous phase. Each MRI scan and PET scan feels like a death sentence when you wait for the reports to see where this has progressed to and what new damage this has caused.*

> *Ja, that was very shocking, that was very − I always say I mean the journey with Josh is now for four years and we had ... a few lows and that was when the doctor told us it went to this next phase and his bones is very weak as well so he will fell ... if he fell, he broke something.*

Judi described her journey as one filled with the good and the bad, the ups and the downs. She experienced low moments and high rewarding moments as she journeyed with her son through cancer.

> *Okay [...] the good in it for me – there is the good and the bad and the good in it [...] okay let's start with the bad. The bad is ... you know you go through these phases of feeling mad at the world, mad at God, mad at everybody.*

> *I was ... I was scared and relieved at the same time because scared is, I was [...] anything can happen. I mean, he's that weak I know you can't put him in a little glass cage for the rest of his*

life but [...] you know if children are ... they don't see his illness so if they do something to him that he gets hurt I mean I sit here with my tummy on a notch.

Just to think if he fell or something happens at school but also when he went to school and I mean you can see how he has grown I mean that for me it's so rewarding to see, wow, he's fighting this battle out there and he's really trying to ... [live his life]

I think Josh's personality I mean [...] I think from a small age you know to doctors and hospitals he is very − his social skills for me is so great I mean he will run to the doctor and hug him and everybody is always amazed of his personality.

[...] and ja, I mean I'm − I think all the mommies say, "You are so proud of him," and not all the other children are open to people and give them hugs and run to the sister and give her a hug and stuff, and Josh is very open to people and for me that's so wow, because I think that's special and it's not every child that's got that you know [...] so that's for me a high wow to see how he ... relate himself to people that's actually gonna hurt him.

7.5.6. The effect of the illness

Judi's story shows how cancer did not affect only her son's life, but also her whole family. The illness had a great effect on her; however, it seemed that she had not dealt with her pain. The illness had an effect on all areas of her life: her son, her marriage, her finances and friendships.

I mean, this illness really messes up everything [crying] your son − my son, my marriage ... everything [...] but the good in it is that's [...] you know to see Josh and his resilience to go on with life... [Crying]

I remember when Josh was getting chemo in the children's oncology ward, one of the other mommies whose child was lying next to Josh started crying next to me and said that this is so unfair, cancer is destroying her marriage, family and child ... This is so true!

Ja, and sometimes that happens [...] I've learned so much because Robin is so harder on him than I am. Sometimes it's good to push him, you know. I've ... but ja it's been difficult. It's been really difficult and you know it's an ongoing thing you know ... it's like I know every relationship is work but this is a different type of work its [...] ja ...

I don't think all the works gives the same support and unfortunately I need to work I can't not work I mean to keep all the bills in the air.

But ... yoo my family and friends yoo I mean you do loose a few ... friends along the way and not to say it's bad ...

As shown below, her son was affected physically by the illness and treatment effects. He is physically not as strong as other children and that creates limitations for him as a young boy.

> *Josh's bones were very fragile; if he fell it could easily break. Believe me, feeling hopelessness that you can't do anything for your child is the worse feeling ever!*

> *Ja, he doesn't know that I can feel better that's and his limitation for example I mean he is physically not as strong as other children and but still that doesn't keep him …*

7.5.7. Coping

Different coping mechanisms were identified in Judi's interview and reflection. Her personality type, spirituality/belief, work and social support were identified as sub-themes under the theme of coping.

7.5.7.1. Personality type

It seemed that Judi's personality helped her adjust to and cope with her son's illness. She described herself as a 'people's person', which meant that she drew strength from people around her. Her son's resilience and his personality also kept her going during this difficult time. As a mother, seeing her son's resilience and cheerful personality helped her cope. The following excerpts show how Judi's personality (and that of her son) became a way of adjusting and coping:

> *What keeps me and Robin going is that Josh is so resilient in spirit; he will go on with things as if it's normal to feel this way.*

> *I think Josh's personality I mean […] I think from a small age you know he was to doctors and hospitals he is very − his social skills for me is so great I mean he will run to the doctor and hug him and everybody is always amazed of his personality.*

> *And ja, I mean I'm − I think all the mommies say, "You are so proud of him," and not all the other children are open to people and give them hugs and run to the sister and give her a hug and stuff and Josh is very open to people and for me that's so wow because I think that's special and it's not every child that's got that you know […] so that's for me a high wow to see how he … relate himself to people that's actually gonna hurt him.*

> *Ah, you know at least he goes on with his life like nothing is wrong and I think that's our saving grace […] in all this. He will for example … he will […] I mean he will go for chemo and he will walk out of the hospital and he doesn't feel sorry for himself.*

7.5.7.2. Spirituality/believe

Spirituality or a belief in Christ was a type of coping mechanism for Judi. Although she struggled at some points with her spirituality, being angry at God for what she was going through with her child, her belief helped her in coping.

> *I'm a people's person, so I think what helped me a lot is I think the support of my family and friends […] and of course I mean I'm … I am a Christian so but ja, sometimes you go into bad spaces with that as well.*

> *Okay, let's start with the bad. The bad is you know you go through these phases of feeling mad at the world, mad at God, mad at everybody.*

7.5.7.3. Social support

In Judi's case, social support comprised support from family and friends, from professional staff members at the hospital, and support from her job. Although she lost friends along her journey, she received support from other friends and family members. The following excerpts from the transcript show the support that Judi received during her journey.

> *I'm a people's person so I think what helped me a lot is I think the support of my family and friends […] and of course I mean I'm … I am a Christian so but ja, sometimes you go into bad spaces with that as well.*

> *I mean family I haven't seen for years is suddenly in our lives and supporting us in this and that's so … that's for me wow … that's wonderful ja*

> *But … yoo, my family and friends yoo, I mean you do loose a few …friends along the way*

> *[…] but I mean yoo, the friends that stick with me is really they are good and family. I mean we are very close with each other. I mean for an extended family as well.*

> *Dr said we must keep it as normal as possible for Josh. Because of the treatment Josh is getting tired very quickly, he is in a wonderful preschool that is supporting us on this journey.*

Her job helped her focus on something different from her son's condition. It gave her the opportunity to look forward to something else and interacting with other people on a different level, having time away from the stress of her son's illness. The support from her colleagues also helped her to cope better.

> *Ja definitely, coz I think at work you are forced to think about other things and you know not to feel sorry for yourself the whole time. Ja so … the work forces me and I think that was also part of the supporting and survival thing for me as a mommy.*

It's you know, you need to stand up now, get dressed, go to work, make sure everything is ... in the air here at work as well. So that ja, for me it was because like I said to you, people gives me energy so they helped me a lot.

And ... you know it's but I think as the years move on it became very more hectic so I didn't have a choice to share it with my work colleagues as well what's going on with him and I'm very blessed. I've been... the manager that was in my life and still in my life is very supportive and you know they ... really give me the emotional and work load support that I need to cope with Josh's things and you know they are human they are, wow, I'm very blessed.

Ja, and think because you know that they give you that support you know if there's work-related things you will really go an extra mile for them and I mean it's a give and take situation the whole time.

The presence of a spouse seemed to be an important factor in terms of support for the other due to the different strengths that men and women have. The following quotations show Judi's reliance on her husband's support.

Ja, my husband as well, you know, he is ... Robin is very practical, so, Robin thinks differently and I'm emotional, you know, and I will think emotional about things he thinks practical so I think in a way we ... complement each other.

But ja, he gives me different strength in the family but because I mean we are woman we need different things.

7.6. Summary

This chapter captured the story of Judi. To provide context, the chapter begun with a description of the conversational setting, a short description of my impressions of Judi, followed by the cancer description. The themes and subthemes that were identified in Judi's interview transcript and the reflection were also provided. The following themes were identified:

- Events leading to the diagnosis

The interview begun with a reflective question where the participant had to relate her story beginning at any point of her cancer journey with her child. Judi reflected on her 'normal' life before her son's diagnosis. In providing this background knowledge, she provided context to her story and how the experience of her son's cancer changed her life.

- Emotional roller coaster

The cancer journey seemed to be an emotional one for Judi. Initial emotional reactions included shock, disbelief, denial and anger. The following subthemes were identified: different emotions, hopelessness and uncertainty.

- Different phases

The illness of Judi's son progressed into different phases, which came with different emotions and stages of adaptation for Judi as a mother. The journey had high and low moments, positive and negative sides, the good and the bad.

- Life change

Her son's diagnosis was a life-changing moment for Judi. The experience taught her to love more and appreciate life. It seemed that the thought of how much the experience has changed her life was emotional for her.

- Roles

As a mother and primary caregiver, her role intensified after her son's diagnosis. Her role was that of a protector, empathising with her child as a result. This theme shows how the socially constructed roles of mothers are re-enforced in families.

- Effect

The illness had an effect on all areas of her life: her son, her marriage, her finances, and friendships.

- Coping

Different coping mechanisms were employed by Judi in order to cope with and adjust to her experiences. The following subthemes were identified: personality type, spirituality/belief, and social support.

Chapter 8: Comparative analysis

8.1. Introduction

The aim of this study was to explore the experiences of mothers of children with cancer and to understand how the child's cancer diagnosis affected their lives. This chapter provides a comparison of the different themes that were identified in the three case studies presented in Chapters 5, 6 and 7, and also reported in previous research findings in literature. The aim of this study was not to generalise the findings; therefore, the comparative analysis focused on the uniqueness of every mother's experience even when facing a similar situation that is, caring for a child with cancer. Although there were similarities in some themes (as shown by this comparative analysis), each mother's experience of the identified theme was different and unique. Therefore, individual experiences of the same theme are discussed and contrasted with previous literature. This chapter is not an attempt to justify the findings of the study, but to provide a discussion via different constructions of the same subject. It is worth noting that the themes and interpretations presented were identified through the researcher's lenses and could be interpreted differently by another researcher. Although discussed separately, some themes may overlap.

The following themes occurred in at least two or all three stories constructed by the participating mothers of children with cancer:

- events leading to the diagnosis;
- emotions: an emotional roller coaster;
- life changes;
- the effect of the illness; and
- coping.

8.2. Events leading to the diagnosis

All three mothers reflected on the events leading up to the diagnosis of their child. It seemed important for the mothers to provide their context prior to their child's illness and the transition into the new life. Mothers spoke much about their child, showing a reluctance to speak about themselves and their experiences of their child's illness.

The events before the diagnosis have been said to be very significant for parents, and might affect their subsequent adaptation and reaction to their child's diagnosis (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001). Young, Dixon-Woods, Findlay, and Heney (2002) refer to these narratives as a biographical shift, which signifies the disruption associated with the cancer diagnosis. These narratives on the events leading to the diagnosis show the transitions of mothers from being

mothers of 'healthy' children to mothers of a child with cancer or 'onco-mommies', as reflected in the current study. The terms 'onco-mommies' (oncology mothers) and 'cancer mommies' were used by mothers to refer to themselves and other mothers of children with cancer.

In the current study, mothers contrasted their 'normal' lives before the diagnosis and their lives after the diagnosis as they re-constructed their lives and their new identity. They spoke about the symptoms of the illness, the changes they saw in the child, and the events of the day their children were diagnosed with cancer.

A previous study by Dixon-Woods et al. (2001) showed that getting a childhood cancer diagnosis is complex and relies on different role players, including parents and medical practitioners. The role of mothers in this process of getting a diagnosis is of importance as mothers are constructed as the main caregivers that are usually first to notice something wrong or unusual regarding their child's health. The signs and symptoms recognised by mothers in their children are often vague, non-specific, may seem common in children, thus making it more difficult to make the correct diagnosis at first and causing delays. The symptoms could easily be confused with more common, less life-threatening conditions (Eiser, 2004b). For example, Grace's son was treated for tonsillitis because of the symptoms with which he presented, while Judi's son showed signs of a skin rash and was treated for such. These mothers noticed something wrong with their child and sought medical assistance. Their children were subsequently treated multiple times for the presenting symptoms before the correct diagnosis was made. This process can be emotionally taxing for mothers not knowing the nature of their child's illness. The trauma of the diagnosis remains a vivid memory for many parents (Eiser, 2004b). The focus of mothers on the events that led to the diagnosis and the diagnosis itself highlighted a new identity and a new life for mothers. Although the participating mothers were not sick themselves, their children's illness becomes their own narratives and changed how they had constructed their lives previously.

Furthermore, in line with social constructionism, this contextualisation of the phenomenon being constructed provides a historical location of that phenomenon. Young and Collin (2004) argue that social constructionism does not just say that something is socially constructed; it also points to the historical and cultural location of that construction.

8.3. Emotions: Emotional roller coaster

The diagnosis of cancer enforces an emotional effect on the patient and the different members of the family. When the doctors reveal the diagnosis of the child for the first time, parents go through a range of emotions. At first, the parents usually experience feelings of shock, disbelief, fear and numbness (Kreitler & Weyl Ben Arush, 2004; Low & Rankin, 2010; McCubbin, Balling, Possin, Frierdich, &

Bryne, 2002) and a period of confusion and denial. The levels of psychological distress have been reported to be higher for mothers than for fathers, which can be attributed to differences between mothers and fathers in responsibilities and in experiences and management of stress (Eiser, 2004b). Two of the mothers in the current study experienced initial emotions of shock, disbelief, denial and fear. Disbelief and denial are common responses when parents struggle to accept the reality of the illness. Amanda went into a state of denial, thinking that cancer does not occur in children, let alone her child. In another study in the South African context (Maree, Parker, Kaplan, & Oosthuizen, 2016) some parents were shocked at the diagnosis of cancer in children, associating the illness with the elderly and with white people.

These initial emotional reactions are often encapsulated by the concept of denial in the process of grieve. Denial is a stage where people try to believe that the cancer diagnosis is not happening to them, their child or their family (Levy & Ziegler, 2017). During this stage, one may feel numb or be in a state of shock and disbelief. Although parents are not ill themselves, they may experience denial in the same way that patients do. Furthermore, denial is a normal protective emotion when a life event is too overwhelming to deal with all at once, unless it stands in the way of parents getting the child the medical care needed.

On the other hand, Judi thought that the doctors were lying and that her son could not have cancer because they did not have it in her family. Although certain types of cancer seem to run in families and cancer is sometimes seen as a family disease, there are different factors that contribute to the occurrence of cancer, especially in children. Cancers that run in the family are sometimes caused by an inherited abnormal gene that could lead to cancer (American Cancer Society, 2017). In children, the causes of cancer are often unknown, while parents are left with questions of why cancer occurred in their child (Maree et al., 2016). Although Grace had a prior experience with cancer in her family, she did not expect her own son to be diagnosed with cancer. No parent ever expects that his or her child would be diagnosed with cancer.

Cancer is associated with uncertainty since parents usually have no prior knowledge or experience of how to care for a child with cancer. Parents are confronted with the uncertainty of prognosis, the risk of treatment complications or even the death of their child (Wong & Chan, 2005). Uncertainty also featured prominently in all three participants. This was partly due to the rarity and aggressiveness of the cancer with which each child was diagnosed. Amanda's son was often sick; however, the doctor did not know what was wrong with him, which caused uncertainty for Amanda. When the doctor diagnosed her son with cancer, the news that her son might not live long perpetuated the uncertainty and fear for Amanda. Grace also experienced a great deal of uncertainty and fear. With a family history

of cancer, her son's diagnosis of cancer coupled with other situational factors worsened the uncertainty for Judi. She did not only fear losing her son, but also feared losing her life to cancer since she had lost her sister to cancer during the treatment of her son's illness. For Judi, uncertainty started when her son developed a rash that doctors could not explain even after failed treatment. Upon consulting a skin specialist, Judi's son was diagnosed with a rare cancer. The uncertainty of the diagnosis led her to search the Internet to get a sense of the illness. The sub-theme of uncertainty about the child's future is common and relates to the fear of death or relapse (Northouse, 2005; Papaikonomou & Nieuwoudt, 2004). Great fear and anxiety were found to be associated with the cancer diagnosis, in keeping with previous studies on mothers caring for children diagnosed with cancer (Björk et al., 2005; Sari, Yilmaz, Ozsoy, Kantar, & Cetingul, 2013; Shortman et al., 2013). As described by Judi, "each MRI scan and PET scan feels like a death sentence when you wait for the reports to see where this has progressed to and what new damage this has caused". Grace initially thought of her son's diagnosis as a death sentence until she read up on the illness and began to understand it.

Participating mothers feared losing their children to cancer due to the rarity of the type of malignance with which their children had been diagnosed. The fear of death may also be perpetuated by a doctor's uncertainty regarding the illness and the type of information he or she provides to parents. Amanda recalled the doctor telling her that she might need to "say her goodbyes" as her son might not make it beyond 24 hours. Such statements highlight the common association of cancer with death and the feelings of fear in mothers of children with cancer. While all three mothers experienced the fear of losing their child to cancer, Amanda and Grace also felt guilty about their child surviving cancer while other mothers had lost their children. In their study on the information needs of South African parents of children with cancer, Maree et al. (2016) found that some parents felt guilty about their child being alive, while others were concerned that they too would lose their child.

Furthermore, the end of treatment also marks a much anticipated yet fearful time for parents and caregivers. The child leaves the dreadful hospital environment; however, the exhausting fear of a relapse may still hover (Fletcher, 2010; Kreitler & Weyl Ben Arush, 2004). In the current study, mothers also expressed the constant fear of relapse, which made them paranoid of every symptom related and unrelated to cancer. Mothers become overly attentive to the slightest signs of illness. In addition, guilt is also common as parents wonder if they could have done anything to prevent the cancer. Two of the mothers felt guilty when their child survived cancer while other mothers had lost their children to cancer. Mothers empathised with those mothers who had lost their children to cancer.

Although there were commonalities in emotional effect of cancer on mothers as seen in the current study and previous literature, there are contextual and individual factors that determine the effect. It is

thus important that the individual emotional and psychological effect of each participant be understood in their context. It seemed from the current study that the participating mothers did not deal efficiently with the initial emotions that they experienced, which could cause distress at a later stage for themselves and the ill child. After the diagnosis, mothers became immersed in caring for their ill child, 'sweeping their emotions under the rug' and neglecting their own wellbeing. The neglect of their own emotional wellbeing may have a long-term effect on the mothers as the caregivers. Distress experienced by parents might have an influence on how children cope with and adjust to their sickness.

Wong and Chan (2005) found that parents were not willing to talk to friends and relatives about their children's illness; however, they were willing to share their experience with each other because they were 'in the same boat'. Support group for mothers could help mothers to share their experiences with other mothers sharing similar experiences and dealing with their emotional distress.

8.4. Life changes

This theme of 'life changes' overlaps with other themes as they relate to the different aspects of life that changed after the child's diagnosis. The experience of a child's cancer diagnosis may necessitate personal growth and often positive changes for parents (Norberg & Boman, 2007). In the current study, mothers experienced changes in various aspects of their lives. A big and inevitable change was the change from being mothers of healthy children to being 'onco-mommies'. Because of the child's diagnosis, a mother's identity changes to that of an onco-mommy, sharing experiences with mothers in the same position. As argued by Young et al. (2002), the shift from being a mother of a healthy child to becoming a mother of a child with cancer requires a fundamental redefining of mothers' self-identities, adopting some new technical and nursing roles, whilst intensifying some of their existing roles and obligations.

With a cancer diagnosis, life as was previously constructed changes to a new construction of life. In the current study, all three mothers experienced some changes in their lives after their child's diagnosis. Mother experienced changes as they re-organised their routines and family life and adapted to the new demands that came with the diagnosis of the child. When a child is diagnosed with cancer, family roles and responsibilities change to accommodate the cancer treatment and to prioritise the needs of the ill child (Clarke-Steffen, 1997; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002; Wong & Chan, 2005; Young et al., 2002). As in other studies (e.g. Sari et al., 2013), the mothers in this study were the ones responsible for their children's care needs.

Following the child's diagnosis, the role of the mother as caregiver intensifies to meet the care demands of the ill child while balancing other roles. The care tasks of mothers in the hospital and at home included: acting as proxy for the ill child, information broker, and managing the child's treatment. In

addition, two of the mothers highlighted their role as protectors, wanting to protect the child from others and to protect their future. They found a balance and a new way of living with the changes they experienced.

The theme of 'life changes' represented the extent to which life changed, particularly for mothers as the main caregivers. For example, Amanda experienced changes in her social identity, changes in living environment, role changes, change in perspective and priorities in life, and life lessons. Consistent with a previous study on parents of children with cancer, Amanda changed to a different and humble outlook on life and approached life differently after her son's diagnosis with cancer (Björk et al., 2005). She began to reflect upon what was most important in life, while other things did not matter to her any longer and new priorities were set. Consistent with Amanda's situational changes, parents have previously reported a change in living arrangements where the treatment hospital was far from their living areas (Sari et al., 2013).

On the other hand, Judi described her son's diagnosis as a life-changing moment in her life. The cancer experience changed her approach to life, it has made her love even more and appreciate life more. Her roles intensified as she managed her son's care demands and obligations while balancing her job and role as a wife. Grace also balanced her role as a caregiver, wife and a working mother. This juggling of multiple roles is often done at the expense of some aspects of one's life, such as the spousal relationship and the relationship with the healthy children in the family.

These multiple roles and responsibilities performed by mothers may affect how they adjust to and cope with their child's illness. For example Burns et al. (2016) found that the experience of role conflict after diagnosis, such as perceiving more conflict regarding family roles and their ability to meet these role expectations, was related to a deterioration in the mothers' marital adjustment over time. Although their study investigated both mothers' and fathers' individual marital adjustment when their child is diagnosed with cancer, their findings showed that mothers' perceptions of role conflict and role overload may be an additional source of stress, which heightens their initial distress, and could later spill over into their relationships. This role conflict and the effect thereof, was more so for mothers than for father. Although sometimes unnoticed by healthcare providers and policymakers, the roles of mothers are integral components to the treatment and subsequent recovery of their children with cancer (Fletcher & Clarke, 2003).

8.5. The effect of the illness

When a child is diagnosed with cancer, the entire family experiences the effect of the illness. Research has been conducted to explore the experiences of mothers as care providers of children with cancer (Fletcher, 2010) and the cost of the illness for families (Eiser & Upton, 2006). Cost does not only refer

to monetary cost, but also to costs relating to all aspects of one's life. The findings of the current study are in harmony with previous studies highlighting the cost and effect of childhood cancer on the family of the patient. The constraints generated by the treatment have been said to affect family life, such as loss of a job, financial or marital difficulties and/or siblings' rebellion (Kreitler & Weyl Ben Arush, 2004). All three participating mothers experienced financial effects in some way or another. Mothers altered their work schedule, took time from work to care for the child, while one lost her job after her son's diagnosis. This theme highlighted how costly cancer is and how the participating mothers gave their all to provide the best care for their child.

The life of the family is re-arranged to care for the child with cancer and to adapt to a new way of life. In terms of the influence on the family unit, mothers spoke about the effect on relationships with other family members. Different members of the family were affected differently by the diagnosis depending on family roles, relationships and care demands. Children incurred physical and psychosocial effects due to the illness and its treatment, which in turn had an emotional effect on the mothers. Mothers in the current study felt empathy and helplessness when their child was in pain.

Two mothers who had more than one child mentioned the effect of the illness on their healthy child as they focused most of their attention and time on the ill child. Siblings of childhood cancer patients are also affected by the illness as the family responsibilities and routines change to manage the illness. As a result of the care demands associated with cancer, siblings of children diagnosed with cancer are often inadvertently ignored. As reported previously (see section 2.9), siblings have feelings of isolation because their parents are frequently at the hospital and gone from home while they are left in the care of others (Björk et al., 2005; Kreitler & Weyl Ben Arush, 2004). Amanda's healthy son was left in the care of the extended family during the ill child's treatment, and was later diagnosed with secondary trauma. Grace's healthy son was left at home in the care of his father while his mother spent much time at the hospital with the ill child; thus, their mother-son relationship was impaired. There is limited research on how younger siblings cope with their older sibling's illness.

The two married mothers felt that the illness affected their marriage negatively as they focused their attention on caring for the ill child. Participating mothers spent much of their time away from home, at the hospital with the ill child, and when at home, the focus remained on the wellbeing of the child. Grace experienced an effect on her relationship with her husband since they did not share the same bed for six months. Mothers have previously reported a decline in the quality of their relationship with their spouse (Young et al., 2002) due to the time mothers spend caring for their ill child. Indeed the child's sickness has a major effect on the couple's relationship as reported by mothers as well as fathers (Doumit & Khoury, 2017).

The separation during the child's long periods of hospitalisation adds to marital distress and family discord (Bayat et al., 2008). Not only does the time mothers spend at the hospital create a rift in the spousal relationship, but mothers focus on care tasks even when such can be at the detriment of other relationships. The changes in the couple's relationship may be perceived as a threat to the normal family dynamics and a significant hindering factor for coping (Doumit & Khoury, 2017). Single parents caring for a child with cancer may experience different stressors on account of being the sole caregiver.

Single parents are often stretched to the limit in 'normal life' (Bracken, 2010) and even more so when caring for a child that demands extra attention. In another study exploring how single parents of children with cancer describe their caregiving experiences, single parents were found to experience several cumulative stressors in addition to the existing strain of caring for a child with cancer (Granek et al., 2012). Furthermore, meeting the care demands associated with a cancer diagnosis and the maintenance of a home can be significantly more burdensome for single parents than for both-parent families. Likewise, Amanda faced certain cumulative stressors and had to make additional sacrifices for the wellbeing of her child without the support of her estranged husband. She lost her job and moved closer to the hospital for her son's treatment, while leaving her other son in the care of her parents. At the time her son was diagnosed, she was going through a divorce. As in Granek et al. (2012), financial problems seemed to be the most pronounced burden experienced by single parents caring for a child with cancer. In addition to the already strenuous financial burden of cancer, Amanda lost her job and struggled to meet her financial needs. Moreover, her geographical shift had a negative effect on the entire family, as her other child had to be separated from his sole parent and had to live with is grandparents.

Although this is not universal, mothers usually bear most of the burden of their child's illness, the hospital visits, the disruption of schedules, and other caregiving tasks (Bracken, 2010). Moreover, the multiple roles and responsibilities performed by mothers may affect how they adjust to and cope with their child's illness. As mentioned under the theme of Life Changes (see 8.4.), role conflict and role demands experienced by mothers may have an effect on their relationships. However, confronting family roles and reorganising set roles in the early stages of the child's illness could strengthen the spousal relationships over time (Burns et al., 2016). Furthermore, the experience of a child's illness may also bring a juxtaposition of a negative effect on the marital relationship and a strengthening of the family unit. For example, although Grace's relationship with her husband was negatively affected by their child's illness and time spent apart, her family become a stronger unit. On the positive side, many families come through the cancer experience as a stronger unit for having faced the crisis together (Bracken, 2010). The theme of effect also highlighted the biographical disruption of cancer as experienced by the three participating mothers caring for their children diagnosed with cancer. A

disruption of family life, roles, relationships, finances and some aspects relating to a mother's identity was inevitable.

8.6. Coping

As indicated in the literature review chapter (see section 2.8,) parents of children with cancer face many stressors, including disruptions in daily routines, financial challenges, emotional distress, and additional stressors unrelated (or related) to the child's diagnosis. Qualitative (Dixon-Woods et al., 2001; Hildenbrand et al., 2014; B. Young et al., 2002)conducted on how parents cope with childhood cancer with some focusing specifically on how mothers of children with cancer cope with their child's illness demands (Doumit & Khoury, 2017; Elkin et al., 2007; Fletcher, 2010). The finding of the current study revealed that mothers are generally able to adapt to and construct a new life, which does not mean that they did not experience negative experiences regarding their ability to cope.

In the current study, 'coping' referred to stress management processes employed to mitigate stressors associated with caring for a child with cancer (see 2.10). This management process involves the interplay between the demands of the illness and the resources available for mothers to manage these demands. Mothers participating in the current study employed different coping strategies to mitigate the stressors they faced after their children's diagnosis. Various coping mechanisms were identified in the constructions of their stories and can be attributed to the situational factors that each participant faced.

Norberg, Lindblad, and Boman (2005) concluded from their findings that situational factors are important for the relationship between certain coping behaviours and emotional distress in parents of children with cancer. For example, in the current study, one mother whose child had relapsed, showed intense emotions during the interview, which could be partly due to the child's age at diagnosis and relapse. Norberg et al. (2005) however found contrasting results in their study. In their study, parents who had faced a relapse of their child's disease did not differ from parents with no such experience regarding coping and emotional distress. It is my argument that similar situational factors will affect mothers differently and each will have a unique experience of the same phenomenon.

As argued by Kreitler and Weyl Ben Arush (2004), parents often perceive their child's illness through the lenses of their fears, their beliefs, their knowledge, or their memories of other illnesses in the family history, and in accordance with the place the child has in their lives. Furthermore, in the current study, a belief in a higher being or spirituality played an important role in how mothers coped with their child being diagnosed with cancer. Two of the mothers constructed their belief in a higher being/spirituality as a way of coping with what they were going through. Elkin et al. (2007) found a strong relationship between religiosity and a mother's coping with a child being diagnosed with cancer, although their

study was conducted within a highly Christian population. A belief in God instils hope within the family or the caregiver that the child will survive (Björk et al., 2005) and has been shown to be a positive factor for coping with a child's cancer illness (Doumit & Khoury, 2017). A belief in God and the child's resilience provided hope for the mothers participating in the current research in a sometimes hopeless situation.

When faced with a life-threatening disease, hope and optimism could become a norm as people try to adjust to the situation. In order to adjust, one may believe the best and be hopeful for the future, especially parents who have to imagine a different future for their child. Consistent with another study on families of children with cancer (Björk et al., 2005), Grace had hope and a positive outlook to reduce her feelings of fear and powerlessness. The thought that other mothers had a more difficult time or that other families were experiencing a worse situation helped Amanda and Grace to keep a positive focus. The child's resilience was identified as an adaptive measure for some mothers. Amanda and Judi found strength in the way their child was resilient through the painful experience of the cancer, especially through the treatment phase. However, previous research focused on family resilience rather than the resilience of the ill child as a motivation for parents to cope with and adjust to their child's illness (Eilertsen, Hjemdal, Le, Diseth, & Reinfjell, 2016; McCubbin et al., 2002; Rosenberg, Baker, Syrjala, Black, & Wolfe, 2013).

There are certain factors that contribute to resilience in terms of how parents or families cope with and adjust to their child's cancer diagnosis. In their study, McCubbin et al. (2002) identified the following resiliency factors in families:

- internal family rapid mobilisation and reorganisation;
- social support from the healthcare team, extended family, the community and the workplace; and
- changes in appraisal to make the situation more comprehensible, manageable and meaningful.

In the current study, social support and the resilience of the ill child were resilience factors for the mothers. Mothers were encouraged by and admired their ill child's strength and his ability to continue with life even when facing a painful and life-threatening illness.

According to Rosenberg et al. (2013), the concept of resilience suggests an ability to withstand stress or to 'bounce back' from traumatic events. As in Rosenberg et al. (2013), Amanda and Judi described their child's brave fight with cancer and the courage their child had exhibited through the painful ordeal. Judi described that she drew strength from seeing her son live as if nothing was happening to him. Social support featured prominently in all interviews and will thus be discussed as a subtheme later in the section below (see 8.8.).

8.7. Social support

Social support in the face of a cancer diagnosis has been studied extensively in various fields of study (Altay et al., 2014; Bayat et al., 2008; Gage, 2013; McCubbin et al., 2002; Norberg & Boman, 2007; Norberg, Lindblad, & Boman, 2006; Winkeler, Filipp, & Aymanns, 2006).

Extensive research has shown that social support helps to buffer the negative effects of stressful life events on individuals. For instance, Norberg et al. (2005) found social support to be important in decreasing parents' anxiety when a child is diagnosed with cancer. Social support was also an important element for mothers in the current study. The types of social support available to mothers were discussed under the categories of emotional support, informational and financial support.

The support groups identified in the current study were family members (grandparents and spouses), friends (mainly those met during this period), medical staff and support from the work environment. For the two married mothers, their spouses were of great support and they helped the mothers cope with their care tasks, while the extended family was an additional source of support for all mothers. Support from the extended family included caring for the siblings of the ill child while the mother was in hospital with the ill child, while support from other mothers of children with cancer mainly comprised emotional support, advocacy or raising awareness. The medical staff provided information support, keeping the mother updated with the child's condition. One mother spoke about the amazing support she received from her work environment. This could have been support by her employers or her colleagues, while another mother was allowed to work from home. Being surrounded by family and friends played a positive role in the mothers' lives and helped them cope better with their child's illness. Support from the extended family has been said to be a resiliency factor for families caring for a child with cancer (McCubbin et al., 2002).

The mothers in the current study constructed a common identity that helped them in supporting one another as 'onco-mommies'. While two mothers perceived a loss of friends during the period of their child's illness, they gained friends and a network of other mothers caring for a child with cancer. However, it is worth noting that mothers may perceive a loss of friendship because of their expectation of support being offered to them and the dynamics of social support. For example, Judi explained that although she had lost a few friends along her journey, she was overwhelmed by the support she received from her family and the good friends who remained and supported her. Offering support to others was a way of coping and buffering these mothers' own stress. Helping others or altruism was a means of transforming uncomfortable feelings and thoughts about their experiences. Two of the mothers in the current study helped other mothers to care for a child with cancer who were thought to be less far along

in dealing with their pain. In a Chinese study, Wong and& Chan (2005) found that mutual support groups could be an effective intervention for parents.

The findings of the current study support the need for mutual support groups for mothers of children with cancer. Although not in a formal setting, the mothers in the current study offered emotional and instrumental support to other mothers of children with cancer. While parents need these new networks of people going through the same experiences, there might be a perception of the loss of previous relationships. In general, people have not learned how to support victims of life crises adequately (Winkeler et al., 2006) while severe stress may also influence a person's perception of the availability and value of support from others (Norberg & Boman, 2007).

The community or friends may not know how to support their loved ones facing the crisis of cancer and may therefore distance themselves. Norberg et al. (2006) found that whether parents relied on support-seeking behaviour or not seemed to be of less importance, as long as support was positively perceived. This means that anxiety and stress are lessened by the perception that support is available, regardless of whether the support is sought after or not. The community may not know how to support the family caring for a child with cancer, resulting in a perception of lack of support. On the other hand, the family going through the stressful ordeal may not request or mobilise support directly, apart from financial support.

As emphasised by Winkeler et al. (2006), the direct mobilisation of support by those in need of it, might reduce confusion by providing information about the support recipient's needs. Direct requests of support are related to positive support behaviours from others partly because it is against social norms to reject support requests from those in need. In addition, subjectively perceived support has been said to be of importance for parents of children with cancer, and should thus be considered when assisting parents experiencing distress following a child's cancer illness and treatment (Norberg et al., 2006). Therefore, a trustworthy and sustainable relationship is also important for satisfactory and efficient social support. For example, in another study examining the dynamics and processes of social support, Gage (2013) found that the most helpful logistical or material support came from the strong ties within parent's social networks. Moreover, support providers already had an intimate relationship with families, and the parents felt comfortable asking and receiving help from the support providers. Therefore, mothers may feel uncomfortable asking for help from others, especially when this involves allowing others into their private space. The relationship between support recipient and support provider is an important determinant of the quality of support, the type of support and how it will be received. For example, the participants created trust funds and mobilised for financial support through Facebook. Although they relied especially on their family for emotional support, the Facebook platform

allowed them to share their journey with friends, the larger community and anyone willing to support them through their journey, whether financially or with words of encouragement.

In terms of support needs, families have different needs and the different stages of the illness journey solicited different needs. Mothers in the current study seemed reluctant to voice their needs as mothers. They focused on the needs of the child and support for the child. This reluctance was also mentioned by Young et al. (2002), which they explained as a means of mothers demonstrating their adequacy as mothers of ill children, and as a means of avoiding drawing attention away from their children onto themselves. Although participating mothers in the current study were aware of the support services offered by healthcare professionals and other organisations, they did not use such services. Mothers generally place the management of their child's illness ahead of their own emotional wellbeing or support needs (Altay et al., 2014)

Mothers in the current study kept their emotional wellbeing in the background while they prioritised the needs of the child and managing their household. In another study within the South African context, Jithoo (2010, p. 351) also found that "communicating about the illness was generally limited to physiological and medically related matters, with emotional issues being rarely articulated". The purpose of Jithoo (2010)'s study was to investigate the perceptions of parents of children with cancer regarding their knowledge-seeking behaviour, their experience of the communication process in health care and to identify the support they may have desired. Furthermore, parents were overwhelmed with the emotional distress of their child's illness and expressed the need for psychosocial services. However, although mothers experienced emotional distress, they prioritised the need for financial support more than emotional or psychological support. As in Shortman et al. (2013), participating mothers appeared to place higher value on practical and financial assistance, rather than psychological or emotional support. For example, financial support was an immediate need for Grace rather than psychological support offered at the hospital. On the other hand, Amanda and Judi created trust funds to raise money for medical procedures. It could therefore be that the participants' emotional needs were already meet in their environment.

However, research has shown contrasting findings with regard to the support needs of parents of children with cancer. In another study (Kerr et al., 2007), the following needs were identified:

- need for information;
- need for emotional support;
- need of giving information with or without the child present;
- financial needs; and
- need for support from their co-workers.

Moreover, the two main themes in Kerr et al.'s were information needs and emotional needs. In a Turkish study, Altay et al. (2014) found that mothers primarily required emotional and information support, rather than financial support. This can be explained by the organisational and financial support that is provided, although in a limited way, to families of children with cancer in Turkey, placing the need for emotional support at the forefront. Informational needs have been highlighted as important in some research on parents' support needs (Altay et al., 2014; Arabiat & Altamimi, 2012; Kerr et al., 2007; Maree et al., 2016), while other findings show that information is not always a resource sought after (Jithoo, 2010).

These contrasting findings show the contextual difference of families, which lead to caregivers' needs. As concluded by Arabiat and Altamimi (2012), the needs of parents differ from one family to another and healthcare professionals must be familiar to these needs and acquire the skills for appropriate interventions. In addition, different types of support may be needed at different points of the cancer journey. For example, mothers might require informational support upon receiving news of their child's diagnosis (Kerr et al., 2007), while they may require financial and logistical support at a later stage when the child receives treatment.

Mothers in the current study focused on the support needed for their child and the child's needs rather than their individual support needs. Psychological support for the ill child was especially emphasised and was a choice for mothers. This highlights the identity of mothers in relationship to their children. Mothers construct their ideas of support in relation to social norms and standards of mother–child relationships and ideals. Therefore, the identity of a mother is intertwined with that of her child.

8.8. Summary

In this chapter, the findings of the study were discussed in relation to previous literature. Similar themes identified across the three case studies were discussed in detail. The following themes were identified: events leading to the diagnosis, emotions: an emotional roller coaster, changes, effect, and coping. These themes were linked to previous studies of mothers of children with cancer, and different experiences of the same themes were identified. The most prominent themes were those of effect and support. The two themes seemed linked in that much of the effect of the illness was mitigated by the support available to the family. In a way, the participating mothers constructed their stories as proxies for their families. They related the effect of the illness on the whole family according to their perspective. When asked about the effect of the illness and the support available, the participants often referred to other members of the family and not to themselves. It is thus important for healthcare

providers and organisations working with mothers of children with cancer to consider the uniqueness of every mother's experiences and provide services relevant to their needs.

Chapter 9: Conclusion, limitations and recommendations

9.1. Introduction

This chapter provides a general summary of the research study. The study will be evaluated in line with the research question and the way the problem was addressed. The strengths and limitations of the study will be discussed, and the chapter will conclude with recommendations for further research.

9.2. Evaluating the study

This study achieved its goal of exploring the experiences of mothers of children with cancer, focusing on the mothers' constructed roles within the family context and their role in the wellbeing of their ill child. The study aimed to provide a space for three mothers to express their experiences of caring for a child with cancer. The participants were given a voice in a field of research which has not been explored much in the South African context. Childhood cancer is considered a rare disease and the study aimed to explore the accounts of mothers of children with cancer in relation to this phenomenon. Therefore, themes and sub-themes that emerged from the interviews and reflective essays were discussed. This was followed by a comparative analysis of the themes from each story and previous literature. Although the stories of the participants were unique, the comparative analysis revealed commonalities in the stories constructed by mothers in the context of their children's illness. However, it is worth noting that individual experiences of each mother are unique in their social context and it cannot be generalised that all mothers of children with cancer will go through the same experiences. The main goal of the study was to answer the following research question:

> How do mothers of children with cancer experience their child's illness?

It is the researcher's view that this question was answered in Chapters 5, 6, 7 and 8 which provided the stories of all three participants supported by excerpts in their own words and a comparative analysis of the themes identified in all three stories. These chapters reflected the voices of mothers of children with cancer and provided insight into how they experienced their children's illness.

Mothers of children with cancer have unique experiences of their child's illness; however, the following themes were identified across all three participants through the comparative analysis:

- events leading to the diagnosis;
- emotions: an emotional roller coaster;
- life changes;
- effect of the illness; and
- coping.

To assist in answering the general research question and fulfilling the aims of the research study, the following sub-questions were answered:

- **How has their roles changed in the family?**

The findings revealed that, although experienced differently, mothers of children with cancer experienced some role changes within the family context. Life, as was previously constructed, changed and new meaning was given to the new life after the child's diagnosis.

While the role of mothers as caregivers may not necessarily change, the roles of the participating mothers intensified after the diagnosis of the child. As the primary caregivers, mothers accompany their children on their hospital visit and spend time away from home to be with the child during the treatment periods. The demands of the illness and its treatment require mothers to change their usual routines, while still maintaining their role as mother to the siblings of the ill child and maintaining their spousal relationships.

- **What kind of support do mothers have?**

A common form of support that the participants had at their disposal was social support – either from family, friends, healthcare professionals (nurses or doctors) or from work. The types of social support identified were emotional support, informational support and financial support. Although some lost friends they had prior to the diagnosis, some mothers gained friends going through similar experiences, and they became each other's social support network. There was also the notion of perceived support, where some may perceive others being or not being supportive. Because of the construction of cancer in our society, others often do not know how to support those facing life-threatening illnesses or how to support their families.

Interestingly, although all participants were aware of support services offered outside of the hospital, they did not make use of the services. Although support services were available in the hospital and others organisations, there were contextual differences in how or whether such services were utilised. Findings have previously endorsed the assumption that the experience of childhood may initiate a change in parents' perceived support (Norberg & Boman, 2007). This may occur in two ways: either parents grow in faith of support or they perceive a decrease in support over time.

- **What kind of support do mothers need?**

In answering the question of their support needs, mothers placed considerable emphasis on their needs in terms of the burden of the illness rather than on their psychosocial needs. Mothers were reluctant to voice their personal needs or needs relating to their wellbeing, placing their needs in the background.

The current study revealed that mothers had different needs with regard to the support they required. Literature (see Maree et al., 2016) also shows that there are different support needs expressed by parents and caregivers. One might conclude that the contextual difference of families need to be taken into consideration in how individuals are affected, how they will cope and what kind of support they will require. While information about the illness may be a need for some parents immediately after the diagnosis, some parents avoid the information regarding their child's illness (Jithoo, 2010). Mothers in the current study articulated the need for financial support in addition to psychosocial support.

It is worth noting that individuals have unique social contexts that play an important role in the way they adapt to situations. Therefore, the qualitative research has not reached consensus on the support needs of mother of children with cancer. In order to understand their needs, of this population, the mothers have to be placed and understood in their context. This means taking into context the social structures within which they find themselves, their socio-economic status, education, culture and family context. For example, the need for financial support may be due to the medical system in South Africa and medical expenses. These findings could also be due to the socio-economic status of the participants and their preference for or affordability of medical services. These factors are contextual and unique from person to person.

9.3. Strengths

This study provided the stories of three mothers of children with cancer. This study did not aim to generalise its findings to the larger population of mothers of children with cancer but aimed to give voice to the mothers and get an understanding of their experiences with their children's illness. Although not sick themselves, mothers are greatly affected by their children's cancer diagnosis.

Triangulation was also achieved through the multiple data collection methods, as highlighted in Chapter 4: Methodology (see 4.11.) Semi-structured interviews and the reflective essays provided rich data and a space for the mothers to construct their experiences in their own words, of which I made meaning through the themes identified. Semi-structured interviews allowed for flexibility between the participant and researcher (De Vos et al., 2005), although the interviews were generally guided by specific questions (see interview guide in section 4.7.), while the reflective essays provided a construction of the meaningful events in the participants' experiences, without the guiding or probing of the interviewer.

The case study design within the qualitative approach was relevant for the study and the nature of inquiry. As argued by Creswell (2009), the process of qualitative research involves data being analysed inductively, building from the particular to general themes, and the researcher provides interpretations of the meaning of the data. This approach thus allowed me to co-construct the stories of

the three mothers by providing interpretations informed by my knowledge, background, and theoretical framework underpinning this study. However, my contribution in the interview was directed by the participant throughout the interview. The themes moved from the individual stories to the comparative analysis, in the light of which the common themes identified in each participant's story were discussed. Despite the limitations mentioned, this study achieved its goal of exploring the experiences of mothers of children with cancer by giving them a voice in the context of the children's illness.

9.4. Limitations

A major limitation of the study was that of the sample. Participants were white mothers from Pretoria, and therefore the experiences documented here are not presentative of the wider population of mothers. In addition, the small sample size may have been a limitation; however in qualitative interviews, the emphasis is placed on collecting individual, detailed, in-depth information, and therefore the qualitative rather than the quantitative element of the information was important (De Vos et al., 2005).

It would have been interesting to explore the experiences of black or African mothers as cancer is often seen as a white phenomenon occurring only in white people (Maree et al., 2016). On the other hand, the healthcare practices of black women will be different considering their unique social context. As was argued by Wright and Maree (2008), understanding urban black women's healthcare practices will enable health promoters to develop interventions that are successful, and the same can be said about rural black women. Although the study cannot be generalised, it is my argument that this study can be transferrable and replicated to a larger group, which might provide information that could help health professionals in understanding the needs of caregivers of children with cancer.

Furthermore, the focus of the study on mothers of children who have already gone through treatment, excluded mothers whose children might still be in treatment.

The nature of the topic was sensitive and evoked emotions in the participants and the researcher. As cautioned by De Vos et al. (2005), the relationship between the researcher and the participants should not be a therapeutic one, and limits need to be in place so as not to evoke certain emotions in the participant. In the one case where the interview evoked emotions in the participants, counselling services were suggested and the relevant information was provided to the participant. Debriefing sessions and reflections between the researcher and her supervisor, especially during the data collection, allowed the researcher to keep track of her perceptions, emotions and possible biases.

Another limitation of the study was the once-off interview and the duration of the interviews. Although the researcher had been in contact with the participants prior to the interviews, follow-up interviews would have allowed for richer data. It is the researcher's view that single interviews fail to explore and capture the changing and uncertain nature of cancer as a journey. Cancer is not a once-off

event and therefore longitudinal studies could provide details on the caregivers' journey through the different phases of the patient's illness. Such studies could assist in the implementation of interventions at different stages of the illness and its treatment.

The setting of the interview was another observed limitation. Although the venue was convenient for the participants, the office space within the university could have been a barrier to the openness of the participants in the interview. The formal setting limited my thinking and my probing. The researcher was also conscious of the space where we were, and this could have been the case even for the participants.

9.5. Recommendations for further research

In the light of the reviewed literature, more research needs to focus on the needs of mothers as the main caregivers when children are diagnosed with a chronic illness, such as cancer. It is clear that mothers play a pivotal role in the care and wellbeing of the child and how the child will cope with the illness. It was also clear from this study and previous literature that, although not sick themselves, mothers face many stressors through their child's cancer experience. Therefore, more research needs to focus on the support needs of mothers and tailoring interventions best suited for their care needs. Within the South African context, research on the care needs of mothers of children with cancer is still lacking. As the main caregivers in the family context, research informing interventions in the healthcare system is needed.

Further research should explore mothers' use of support services provided by healthcare professionals and civil society. Information on mothers' use (or lack of use) of support services and a greater understanding of factors that are predictive of support use is needed to guide the development of interventions that are relevant in clinical practice and psycho-oncology.

Cancer is not a once-off event, but is rather a journey that goes through different stages. Therefore, a further recommendation is for research to look at how caregivers cope with the different stages of cancer. Maree et al. (2016) also found that there are different needs at different times, and no consensus was reached on which information is needed at which point of the cancer journey. The different stages of cancer may place varying demands on caregivers. Therefore, a longitudinal study following caregivers over a long period could provide information on the needs associated with the different stages. It is also worth noting that different caregivers may have different needs at a given stage of the illness; therefore, contextual factors need to be taken into account in research.

In a multicultural context, such as South Africa, research should be inclusive of the various cultures and how they construct illness and thus the caregiving process of paediatric cancer patients. The social constructionist perspective views culture as an important element in the construction of

one's reality; therefore, culture plays an important role in how cancer is perceived and how medical help will be sought. Although cancer affects both white and black children, it is still perceived as occurring only in the white population (Maree et al., 2016). Therefore, research can provide information in the healthcare practices of black people in the context of cancer and their needs. Without the understanding of black South Africans' healthcare perceptions and practices, healthcare professionals will not be able to develop strategies and health promotion interventions congruent to the population's healthcare practices and needs (Wright & Maree, 2008).

9.6. Personal reflection

In retrospect, my journey from the conceptualisation of the research topic to the completion of this degree inevitably reflects my personal journey. Throughout my journey psychology inculcated critical thinking in me and the need to understand how things are the way we understand them to be. This motivated me to move from a counselling environment and further my studies in research psychology.

My decision to enrol for a master's degree in Research Consultation was motivated by a need to move from individually based solutions. I wanted to give voice (through research) to the powerless and marginalised. The research topic came about as I reflected on my family's experience with illness and the caregiving journey of family members. The biomedical perspective of illness adopted in our medical system does not take into account the social influence of illness on patients and their families. Caregivers are provided with the knowledge needed to care for the patient outside of the hospital environment; however, their own care is often neglected. I was interested in how caregivers cope and construct meaning in the context of an illness that is not their own.

9.7. Summary

This chapter concluded the thesis by providing an evaluation of the study in relation to the research question outlined, the strengths and limitations of the study, as well as recommendations for further research. It was concluded that the needs of families and caregivers vary and that the social contexts of caregivers need to be considered when tailoring interventions. Furthermore, the importance of interventions focusing on mothers (caregivers) of children with cancer was highlighted in relation to their role in the wellbeing of the patient (namely the child).

It was also concluded that cancer is not a once-off event, but a life journey. Therefore, mothers may have different needs at different stages of their children's illness. It was thus recommended that longitudinal research is needed to focus on the needs of mothers of children with cancer at the different stages of the illness rather than once-off interviews focusing on one aspect of the journey. Such a holistic approach to the mother's narrative could provide information on the different milestones faced

by caregivers. This information will feed into the aspects that health professionals may need to consider in the care of paediatric cancer patients.

Reference list

Al-Gamal, E., & Long, T. (2010). Anticipatory grieving among parents living with a child with cancer. *Journal of Advanced Nursing*, 66(9), 1980-1990. doi:10.1111/j.1365-2648.2010.05381.x

Alonso, Y. (2004). The biopsychosocial model in medical research: The evolution of the health concept over the last two decades. *Patient Education and Counseling*, *53*(2), 239–244. doi:10.1016/S0738-3991(03)00146-0

Altay, N., Kilicarslan, E., Sar, C., & Kisecik, Z. (2014). Determination of social support needs and expectations of mothers of children with cancer. *Journal of Pediatric Oncology Nursing*, *31*(3), 147–153. doi:10.1177/1043454213520471

American Cancer Society. (2017). *Family cancer syndromes*. Retrieved from https://www.cancer.org/cancer/cancer-causes/genetics/family-cancer-syndromes.html

Amoateng, A. Y., Kalule-Sabiti, I., & Oladipo, S. E. (2015). Psycho-social experiences and coping among caregivers of people living with HIV/AIDS in the North-West province of South Africa. *South African Journal of Psychology*, *45*(1), 130–139. doi:10.1177/0081246314556566

Andrews, T. (2012). What is Social Constructionism? *The Grounded Theory Review*, *11*(1), 39–47.

Arabiat, D. H., & Altamimi, A. (2012). Unmet care needs of parents of children with cancer in Jordan: Implications for bed-side practice. *Journal of Clinical Nursing*, *22*, 531–539. doi:10.1111/jocn.12122

Arendell, T. (2000, November). Conceiving and investigating motherhood: The decade's scholarship. *Journal of Marriage and the Family*, *62*, 1192–1207. doi:10.1111/j.1741-3737.2000.01192.x

Armstrong, G. T., Stovall, M., & Robison, L. L. (2010). Long-term effects of radiation exposure among adult survivors of childhood cancer: Results from the Childhood Cancer Survivor Study. *Radiation Research*, *174*(6), 840–850. doi:10.1667/RR1903.1

Baert, P., Weinberg, D., & Mottier, V. (2011). Social constructionism, postmodernism and deconstructionism. In I. Jarvie & J. Zamora-Bonilla (Eds.), *The Sage handbook of the philosophy of social sciences* (pp. 475–487). London: Sage. doi:10.4135/9781473913868.n25

Barbarin, O. A., Hughes, D., & Chesler, M. A. (1985). Stress, coping, and marital functioning among parents of children with cancer. *Journal of Marriage and Family*, *47*(2), 473–480.

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. The *Qualitative Report*, *13*(4), 544–559.

Bayat, M., Erdem, E., & Gül Kuzucu, E. (2008). Depression, anxiety, hopelessness, and social support levels of the parents of children with cancer. *Journal of Pediatric Oncology Nursing*, *25*(5), 247–253. doi:10.1177/1043454208321139

Becvar, D. S., & Becvar, R. J. (2008). *Family therapy: A systematic integration* (7th ed.). Boston: Pearson. doi:0205609236

Bemis, H., Yarboi, J., Gerhardt, C. A., Vannatta, K., Desjardins, L., Murphy, L. K., ... & Compas, B. E. (2015). Childhood cancer in context: sociodemographic factors, stress, and psychological distress among mothers and children. *Journal of pediatric psychology*, *40*(8), 733-743.

Berger, P., & Luckmann, T. (1966). The *social construction of reality: A treatise in the sociology of knowledge*. Harmondsworth: Penguin Group.

Bishop, S., Stedmon, J., & Dallos, R. (2014). Mothers' narratives about having a child with cancer: A view through the attachment lens. *Clinical Child Psychology and Psychiatry*, 20(4), 611-625. doi:10.1177/1359104514542302

Björk, M., Wiebe, T., & Hallström, I. (2005). Striving to survive: Families' lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, *22*(5), 265–275. doi:10.1177/1043454205279303

Bracken, J. M. (2010). *Children with cancer: A comprehensive reference guide for parents*. Oxford University Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. doi:10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2012). Thematic analysis. Cooper, Harris (Ed); Camic, Paul M. (Ed); Long, Debra L. (Ed); Panter, A. T. (Ed); Rindskopf, David (Ed) & Sher, Kenneth J. (Ed). (2012). APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological , (pp. 57-71). Washington, DC, US: American Psychological Association. doi:10.1037/13620-004

Bromley, D. B. (1990). Academic contributions to psychological counselling. 1. A philosophy of science for the study of individual cases. *Counselling Psychology Quarterly*, *3*(3), 299–307. doi:10.1080/09515079008254261

Brown, R. T. (Ed.). (2006). *Comprehensive handbook of childhood cancer and sickle cell disease: A biopsychosocial approach*. New York, NY: Oxford University Press.

Brown, R. T., Wiener, L., Kupst, M. J., Brennan, T., Behrman, R., Compas, B., … Zeltzer, L. (2008). Single parents of children with chronic illness: An understudied phenomenon. *Journal of Pediatric Psychology*, *33*(4), 408–421. doi:10.1093/jpepsy/jsm079

Burns, W., Péloquin, K., Sultan, S., Moghrabi, A., Marcoux, S., Krajinovic, M., Robaey, P. (2016). A 2-year dyadic longitudinal study of mothers' and fathers' marital adjustment when caring for a child with cancer. *Journal of Psycho-Oncology, 26(10), 1660-1666*. doi:10.1002/pon.4189

Burr, V. (1995). *An introduction to social constructionism*. Social Research Reports (Vol. 26). London: Routledge. doi:10.4324/9780203299968

CANSA. (2016). *CANSA care homes – A home away from home*. Retrieved from http://www.cansa.org.za/cansas-care-support/cansa-care-homes/

Caress, A.-L., Chalmers, K., & Luker, K. (2009). A narrative review of interventions to support family carers who provide physical care to family members with cancer. *International Journal of Nursing Studies*, *46*(11), 1516–1527. doi:10.1016/j.ijnurstu.2009.03.008

Childhood Cancer Foundation of South Africa. (2017a). *Childhood cancer facts*. Retrieved from http://www.choc.org.za/childhood-cancer/cancer-facts.html

Childhood Cancer Foundation of South Africa. (2017b). *Childhood cancer registry*. Retrieved from http://www.choc.org.za/childhood-cancer/cancer-registry.html

Clarke, J. N., Fletcher, P. C., & Schneider, M. A. (2005). Mothers' home health care work when their children have cancer. *Journal of Pediatric Oncology Nursing*, *22*(6), 365–373. doi:10.1177/1043454205281834

Clarke-steffen, L. (1993). Waiting and not knowing: The diagnosis of cancer in a child. *Journal of Pediatric Oncology Nursing*, *10*(4), 146–153. doi:10.1177/104345429301000405

Clarke-Steffen, L. (1997). Reconstructing reality: Family strategies for managing childhood cancer. *Journal of Pediatric Oncology Nursing*, *12*(5), 278–287.

Clough, P., & Nutbrown, C. (2012). *A student's guide to methodology* (3rd ed.). London: Sage.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, *38*(5), 300–314. doi:10.1097/00006842-197609000-00003

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, *19*, 184–188. doi:10.1002/gps.561

Cohen, M. H. (1993). The unknown and the unknowable: Managing sustained uncertainty. *Western Journal of Nursing Research*, *15*(1), 77–96.

Cohen, M. H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. *Qualitative Health Research*, *5*(1), 63–77.

Cohen, S. (1988). Psychological models of the role of social support in the etiology of physical disease. *Health Psychology*, *7*(3), 269–297.

Cohen, S., & Syme, S. L. (1985). Issues in the study and application of social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 3-22). San Diego, CA: Academic Press.

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310–357. doi:10.1037/0033-2909.98.2.310

Collett, J. L. (2005). What kind of mother am I? Impression management and the social construction of motherhood. *Symbolic Interaction*, *28*(3), 327–347.

Cooke, B. D., Rossmann, M. M., Mccubbin, H. I., Joan, M., Mccubbin, H., & Patterson, J. M. (1988). Examining the definition and assessment of social support: A resource for individuals and families: Individuals Families. *Family Relations*, *37*(2), 211–216.

Costantino, T. E. (2008). Constructivism. In L. M. Given (Ed.), *The Sage encyclopedia of qualitative research*

methods (117-120). Thousand Oaks, CA: Sage. doi:10.4135/9781412963909.n64

Cowdery, R. S., & Knudson-Martin, C. (2005). The construction of motherhood: Tasks, relational connection, and gender equality. *Family Relations*, *54*(3), 335–345. doi:10.1111/j.1741-3729.2005.00321.x

Creswell, J. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, LA: Sage.

Cunliffe, A. L. (2008). Social constructionism. In R. Thorpe & R. Holt (Eds.), *The Sage dictionary of qualitative management research* (pp. 201–203). London: Sage. doi:10.4135/9780857020109

Dallos, R., & Stedmon, J. (2006). Systemic formulation: Mapping the family dance. In L. Johnstone & R. Dallos (Eds.), *Formulation in psychology and psychotherapy: making sense of people's problems* (pp. 72–97). London: Routledge.

De Vos, A., Strydom, H., & Delport, C. S. (2005). *Research at grass roots: For the social sciences and human service professions* (3rd ed.). Pretoria: Van Schaik.

Dixon-Woods, M., Findlay, M., Young, B., Cox, H., & Heney, D. (2001). Parents' accounts of obtaining a diagnosis of childhood cancer. *The Lancet*, *357*(9257), 670–674. doi:10.1016/S0140-6736(00)04130-1

Dixon-Woods, M., Young, B., & Heney, D. (2005). *Rethinking experiences of childhood cancer: A multidisciplinary approach to chronic childhood illness*. Glasgow, UK: Open University Press.

Dodgson, J. E., Garwick, A. R., Blozis, S., Patterson, J. M., Bennett, F., & Blum, R. W. (2000). Uncertainty in childhood chronic conditions and family distress in families of young children. *Journal of Family Nursing*, *6*(3), 252–266.

Dolgin, M. J., Phipps, S., Fariclough, D. L., Sahler, J. Z., Askins, M., Noll, R. B., Sahler, O. J. Z. (2007). Trajectories of adjustment in mothers of children with newly diagnosed cancer: A natural history investigation. *Journal of Pediatric Psychology*, *32*(7), 771–782.

Doumit, M. A. A., & Khoury, M. N. (2017). Facilitating and hindering factors for coping with the experience of having a child with cancer: A Lebanese perspective. *Journal of Psychosocial Oncology*, *35*(3), 346–361. doi:10.1080/07347332.2017.1283654

Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vézina, L. (2006). Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine*, *9*(4), 912–921. doi:10.1089/jpm.2006.9.912

Du Preez, E., & Eskell-Blokland, L. (2012). Social constructionism. In M. Visser & A.-G. Moleko (Eds.), *Community psychology in South Africa* (2nd ed., pp. 41–69). Pretoria: Van Schaik.

Earle, E. A., Clarke, S. A., Eiser, C., & Sheppard, L. (2006). "Building a new normality": Mothers' experiences of

caring for a child with acute lymphoblastic leukaemia. *Child: Care, Health and Development*, *33*(2), 155–160. doi:10.1111/j.1365-2214.2006.00638.x

Eilertsen, M., Hjemdal, O., Le, T. T., Diseth, T. H., & Reinfjell, T. (2016). Resilience factors play an important role in the mental health of parents when children survive acute lymphoblastic leukaemia. Acta Paediatrica, 105: e30–e34. doi:10.1111/apa.13232

Eiser, C. (2004). *Children with cancer: The quality of life*. London: Lawrence Erlbaum Associates.

Eiser, C., Eiser, J. R., & Stride, C. B. (2005). Quality of life in children newly diagnosed with cancer and their mothers. *Health and Quality of Life Outcomes*, *3*, 29. doi:10.1186/1477-7525-3-29

Eiser, C., Greco, V., Vance, Y. H., Horne, B., & Glaser, A. (2004). Perceived discrepancies and their resolution: Quality of life in survivors of childhood cancer. *Psychology Health*, *19*(1), 15–28. doi:10.1080/08870440310001594501

Eiser, C., & Upton, P. (2006). Costs of caring for a child with cancer: A questionnaire survey. *Child: Care, Health and Development*, 33(4), 455-459. doi:10.1111/j.1365-2214.2006.00710.x

Elkin, T. D., Jensen, S. A., McNeil, L., Gilbert, M. E., Pullen, J., & McComb, L. (2007). Religiosity and coping in mothers of children diagnosed with cancer: An exploratory analysis. *Journal of Pediatric Oncology Nursing*, *24*(5), 274–278. doi:10.1177/1043454207305285

Ell, K. (1996). Social networks, social support and coping with serious illness: The family connection. *Social Science & Medicine*, *42*(2), 173–183. doi:10.1016/0277-9536(95)00100-X

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*(4286), 129-136.

Engel, G. L. (1981). The clinical application of the biopsychosocial model. *The Journal of Medicine and Philosophy*, *6*, 101–123.

Engel, R. (2000). *Adjustment to childhood cancer: Parent-child coping & family functioning*. NY: Yeshiva University.

Fletcher, P. C. (2010). My child has cancer: The costs of mothers' experiences of having a child with pediatric cancer. *Issues in Comprehensive Pediatric Nursing*, *33*(3), 164–184. doi:10.3109/01460862.2010.498698

Fletcher, P. C., & Clarke, J. N. (2003). When your child has cancer. *Journal of Psychosocial Oncology*, *21*(3), 3–23. doi:10.1300/J077v21n03

Flury, M., Caflisch, U., Ullmann-Bremi, A., & Spichiger, E. (2011). Experiences of parents with caring for their child after a cancer diagnosis. *Journal of Pediatric Oncology Nursing*, *28*(3), 143–153. doi:10.1177/1043454210378015

Frank, N. C., Brown, R. T., Blount, R. L., & Bunke, V. (2001). Predictors of affective responses of mothers and fathers of children with cancer. *Psycho-Oncology*, *10*, 293–304.

Gage, E. A. (2013). The dynamics and processes of social support: Families' experiences coping with a serious

paediatric illness. *Sociology*, *35*(3), 405–418. doi:10.1111/j.1467-9566.2012.01491.x

Galbin, A. (2014). An introduction to social constructionism. *Social Research Reports*, *26*, 82–92.

Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, *40*(3), 266-275.

Gergen, K. J. (2001). Psychological science in a postmodern world. *American Psychologist*, *56*(10), 803-813. doi:10.1037/0003-066X.56.10.803

Gergen, K. J., & Gergen, M. M. (2008). Social constructionism. In L. M. Given (Ed.), *The Sage encyclopedia of qualitative research methods (817-820)*. Thousand Oaks, CA: Sage. doi:10.4135/9781412963909.n426

Granek, L., Rosenberg-Yunger, Z. R. S., Dix, D., Klaassen, R. J., Sung, L., Cairney, J., & Klassen, A. F. (2012). Caregiving, single parents and cumulative stresses when caring for a child with cancer. *Child: Care, Health and Development*, *40*(2), 184–194. doi:10.1111/cch.12008

Girgis, A., Lambert, S. D., McElduff, P., Bonevski, B., Lecathelinais, C., Boyes, A., & Stacey, F. (2013). Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psycho-Oncology*, *22*(7), 1557-1564. doi:10.1002/pon.3166

Gray, D. E. (2013). *Doing research in the real world* (3rd ed.). London: Sage.

Greaves, D. (2002). Reflections on a new medical cosmology. *Journal of Medical Ethics*, *28*(2), 81–85.

Hamama, R., Ronen, T., & Feigin, R. (2000). Self-control, anxiety, and loneliness in siblings of children with cancer. *Social Work in Health Care*, *31*(1), 35–48. doi:10.1300/J010v31n01

Hampel, P., Rudolph, H., Stachow, R., Laß-lentzsch, A., & Petermann, F. (2005). Coping among children and adolescents with chronic illness. *Anxiety, Stress & Coping*, *18*(2), 145–155. doi:10.1080/10615800500134639

Harper, D., & Spellman, D. (2006). Social constructionist formulation: Telling a different story. In L. Johnstone & R. Dallos (Eds.), Formulation in Psychology and Psychotherapy: Making Sense of People's Problems (pp. 98–125). London: Routledge.

Havermans, T., & Eiser, C. (1994). Siblings of a child with cancer. *Child: Care, Health and Development*, *20*, 309–322.

Herbst, M. C. (2015). Cancer Association of South Africa (CANSA) Fact sheet on Childhood Osteosarcoma. Retrieved from http://www.cansa.org.za/files/2017/08/Fact-Sheet-Childhood-Osteosarcoma-NCR-2012-web-May-2017.pdf

Herbst, M. C. (2016). *Cancer Association of South Africa (CANSA) fact sheet on known causes of cancer*. CANSA. Retrieved from http://www.cansa.org.za/files/2016/01/Fact-Sheet-Known-Causes-Cancer-Jan-2016.pdf

Hewa, S., & Hetherington, R. W. (1995). Specialists without spirit: Limitations of the mechanistic biomedical model. *Theoretical Medicine*, *16*(2), 129–139. doi:10.1007/BF00998540

Hildenbrand, A. K., Alderfer, M. A., Deatrick, J. A., & Marsac, M. L. (2014). A mixed methods assessment of

coping with pediatric cancer. *Journal of Psychosocial Oncology*, *32*, 37–58. doi:10.1080/07347332.2013.855960

Hird, M. J. (2016). Case study. In R. L. Miller & J. D. Brewer (Eds.), *The A-Z of social research* (pp. 23–25). London: Sage.

House, J., Umberson, D., & Landis, K. R. (1988). Structures and processes of social support. *Annual Review of Sociology*, *14*, 293–318.

Houtzager, B. A., Grootenhuis, M. A., & Last, B. F. (2001). Supportive groups for siblings of pediatric oncology patients: Impact on anxiety. *Psycho-Oncology*, *10*(4), 315–324. doi:10.1002/pon.528

Ickes, W. (1993). Traditional gender roles: Do they make, and then break, our relationships? *Journal of Social Issues*, *49*(3), 71–85. doi:10.1111/j.1540-4560.1993.tb01169.x

James, K., Keegan-Wells, D., Hinds, P. S., Kelly, K. P., Bond, D., Hall, B., Speckhart, B. (2002). The care of my child with cancer: Parents' perceptions of caregiving demands. *Journal of Pediatric Oncology Nursing*, *19*(6), 218–228. doi:10.1053/jpon.2002.128777

Jithoo, V. (2010). To tell or not to tell; The childhood cancer conundrum: Parental communication and information-seeking. *Psychological Society of South Africa*, *40*(3), 351–360. doi:10.1177/008124631004000313

Jorgensen, M., & Phillips, L. J. (2002). *Discourse analysis as theory and method.* London: Sage.

Kaplan, L. M., Kaal, K. J., Bradley, L., & Alderfer, M. A. (2013). Cancer-related traumatic stress reactions in siblings of children with cancer. *Families, Systems, & Health, 31*(2), 205-217. doi:10.1037/a0032550

Kayser, K., Watson, L. E., & Andrade, J. T. (2007). Cancer as a "we-disease": Examining the process of coping from a relational perspective. *Families, Systems, & Health*, *25*(4), 404–418. doi:10.1037/1091-7527.25.4.404

Kazak, A. E., & Barakat, L. P. (1997). Brief report: Parenting stress and quality of life during treatment for childhood leukaemia predicts child and parent adjustment after treatment. *Journal of Pediatric Psychology*, *22*(5), 749–758.

Kazak, A. E., Boeving, C. A., Alderfer, M. A., Hwang, W.-T., & Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology*, *23*(30), 7405–7410. doi:10.1200/JCO.2005.09.110

Kerr, L. M. J., Con, C., Harrison, M. B., Medves, J., Tranmer, J. E., & Fitch, M. I. (2007). Understanding the supportive care needs of parents of children with cancer: An approach to local needs assessment. *Journal of Pediatric Oncology Nursing*, *24*(5), 279–293. doi:10.1177/1043454207304907

Klassen, A. F., Dix, D., Papsdorf, M., Klaassen, R. J., Rochelle, Y., & Sung, L. (2012). Impact of caring for a child with cancer on single parents compared with parents from two-parent families. *Pediatric Blood Cancer*, *58(1)*, 74–79. doi:10.1002/pbc

Klassen, A. F., Raina, P., Reineking, S., Dix, D., Pritchard, S., & O'Donnell, M. (2007). Developing a literature

base to understand the caregiving experience of parents of children with cancer: A systematic review of factors related to parental health and well-being. *Supportive Care in Cancer*, *15*(7), 807–818. doi:10.1007/s00520-007-0243-x

Knafl, K. A., Deatrick, J. A., Knafl, G. J., Gallo, A. M., Grey, M., & Dixon, J. (2013). Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing*, *28*(6), 523–535. doi:10.1016/j.pedn.2013.03.006

Kobayashi, K., Hayakawa, A., & Hohashi, N. (2015). Interrelations between siblings and parents in families living with children with cancer. *Journal of Family Nursing, 21(1), 119-148*. doi:10.1177/1074840714564061

Kreitler, S., & Weyl Ben Arush, M. (2004). *Psychosocial aspects of pediatric oncology*. (S. Kreitler & M. Weyl Ben Arush, Eds.). UK: Wiley.

Levy, A. S., & Ziegler, O. (2017). *Coping with a diagnosis of cancer in children*. University of Rochester Medical Center. Retrieved from https://www.urmc.rochester.edu/encyclopedia/content.aspx?contenttypeid=90&contentid=P02723

Li, H. C. W., Chung, O. K. J., & Chiu, S. Y. (2010). The impact of cancer on children's physical, emotional, and psychosocial wellbeing. *Cancer Nursing*, *33*(1), 47–54.

Li, H. C. W., Chung, O. K. J., Chiu, S. Y., Ho, K. Y. E., & Lopez, V. (2014). The impact of cancer and its treatment on the physical activity levels and behavior in Hong Kong Chinese childhood cancer survivors. *Cancer Nursing*, *37*(3), 43–51. doi:10.1097/NCC.0b013e3182980255

Li, Q., & Loke, Y. A. (2013). The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research. *Psycho-Oncology*, *22*(11), 2399–2407. doi:10.1002/pon.3311

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, Calif: Sage.

Long, K. A., & Marsland, A. L. (2011). Family adjustment to childhood cancer: A systematic review. *Clinical Child and Family Psychology Review*, *14*, 57–88. doi:10.1007/s10567-010-0082-z

Maree, J. E., Parker, S., Kaplan, L., & Oosthuizen, J. (2016). The information needs of South African parents of children with cancer. *Journal of Pediatric Oncology Nursing*, *33*(1), 9–17. doi:10.1177/1043454214563757

Maree, K. (Ed.). (2007). *First steps in research*. Pretoria: Van Schaik.

McCubbin, M., Balling, K., Possin, P., Frierdich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. *Journal of Family Relations*, *51*(2), 103–111.

McCutcheon, V. V. (2006). Toward an integration of social and biological research. *Social Service Review*, *80*(1), 159–178.

Mitchell, W., Clarke, S., & Sloper, P. (2006). Care and support needs of children and young people with cancer and their parents. *Psycho-Oncology*, *15*, 805–816. doi:10.1002/pon.1014

Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R. J., & Van Den Bos, G. A. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psycho-Oncology*, *7(1)*, 3–13.

Nikfarid, L., Rassouli, M., Borimnejad, L., & Alavimajd, H. (2015). Chronic sorrow in mothers of children with cancer. *Journal of Pediatric Oncology Nursing*, *32*(5), 314–319. doi:10.1177/1043454214563407

Noeker, M., & Petermann, F. (2015). Childhood cancer: Psychosocial aspects. In *International encyclopedia of social & behavioral sciences* (Vol. 3, 2nd ed., 459-464). Bremen Elsevier. doi:10.1016/B978-0-08-097086-8.14066-8

Nolbris, M. J., Enskär, K., & Hellström, A.-L. (2014). Grief related to the experience of being the sibling of a child with cancer. *Cancer Nursing*, *37*(5), E1-E7. doi:/10.1097/NCC.0b013e3182a3e585

Noojin, A. B., Causey, D. L., Gros, B. J., Bertolone, S., & Carter, B. D. (2000). The influence of maternal stress resistance and family relationships on depression in children with cancer. *Journal of Psychosocial Oncology*, *17*(2), 1–15. doi:10.1300/J077v17n02

Norberg, A. L., & Boman, K. K. (2007). Parents' perceptions of support when a child has cancer: A longitudinal perspective. *Cancer Nursing, 30(4), 294-301.*

Norberg, A. L., & Boman, K. K. (2008). Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress symptoms, depression and anxiety. *Acta Oncologica*, *47*(2), 267–274. doi:10.1080/02841860701558773

Norberg, A. L., Lindblad, F., & Boman, K. K. (2005). Coping strategies in parents of children with cancer. *Social Science & Medicine*, *60*, 965–975. doi:10.1016/j.socscimed.2004.06.030

Norberg, A. L., Lindblad, F., & Boman, K. K. (2006). Support-seeking, perceived support, and anxiety in mothers and fathers after children's cancer treatment. *Journal of Psycho-Oncology*, *15*, 335–343. doi:10.1002/pon.960

Northfield, S., & Nebauer, M. (2010). The caregiving journey for family members of relatives with cancer: How do they cope? *Clinical Journal of Oncology Nursing*, *14*(5), 567–577. doi:10.1188/10.CJON.567-577

Northouse, L. (2005). Helping families of patients with cancer. *Oncology Nursing Forum*, *32*(4), 743–750. doi:10.1188/04.ONF.743-750

Overholser, J. C., & Fritz, G. K. (1991). The impact of childhood cancer on the family. *Journal of Psychosocial Oncology*, *8*(4), 71–85. doi:10.1300/J077v08n04

Pai, A. L. H., Greenley, R. N., Lewandowski, A., Drotar, D., Youngstrom, E., & Peterson, C. C. (2007). A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology*, *21*(3), 407–415. doi:10.1037/0893-3200.21.3.407

Papaikonomou, M. (2007). Childhood cancer: A parent's perspective on social support, with a case illustration. *Journal of Child & Adolescent Mental Health*, *19*(1), 65–73. doi:10.2989/17280580709486636

Papaikonomou, M., & Nieuwoudt, J. (2004). Exploring parents' stories of coping with their child's cancer: A qualitative study. *South African Journal of Psychology*, *34*(2), 283–300. doi:10.1177/008124630403400207

Park, J., Kitayama, S., Karasawa, M., Curhan, K., Markus, H. R., Kawakami, N., Ryff, C. D. (2013). Clarifying the links between social support and health: Culture, stress, and neuroticism matter. *Journal of Health Psychology*, *18*(2), 226–235. doi:10.1177/1359105312439731

Parry, C. (2003). Embracing uncertainty: An exploration of the experiences of childhood cancer survivors. *Qualitative Health Research*, *13*(2), 227–246. doi:10.1177/1049732302239600

Patterson, J. M., & Garwick, A. W. (1994). The impact of chronic illness on families. *Annals of Behavioral Medicine*, *16*(2), 131–142.

Petro, I. C. D. S., Galvão, C. M., Rocha, S. M. M., & Nascimento, L. C. (2008). Social support and families of children with cancer: An integrative review. *Revista latino-americana de enfermagem*, *16*(3), 477–483. doi: 10.1590/S0104-11692008000300023

Pilgrim, D. (2015). The biopsychosocial model in health research: Its strengths and limitations for critical realists. *Journal of Critical Realism*, *14*(2), 164–180. doi:10.1179/1572513814Y.0000000007

Quinn, W. H., & Herndon, A. (1986). The family ecology of cancer. *Journal of Psychosocial Oncology*, *4*(1/2), 45–59. doi:10.1300/J077v04n01

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. Sage. doi:2002109391

Robinson, K. E., Gerhardt, C. A., Vannatta, K., & Noll, R. B. (2007). Parent and family factors associated with child adjustment to pediatric cancer. *Journal of Pediatric Psychology*, *32*(4), 400–410. doi:10.1093/jpepsy/jsl038

Robison, L. L., & Hudson, M. M. (2014, January). Survivors of childhood and adolescent cancer: Life-long risks and responsibilities. *Nature Reviews Cancer*, *14*(1), 61-71.

Rosenberg, A. R., Baker, K. S., Syrjala, K. L., Black, A. L., & Wolfe, J. (2013). Promoting resilience among parents and caregivers of children with cancer. Journal of *Palliative Medicine*, *16*(6), 645-652. doi:10.1089/jpm.2012.0494

Saldaña, J. (2009). *The coding manual for qualitative researchers*. Sage.

Sari, H. Y., Yilmaz, M., Ozsoy, S., Kantar, M., & Cetingul, N. (2013). Experiences of parents with the physical care needs at home of children with cancer: A qualitative study. *Cancer Nursing*, *36*(5), 385–393. doi:10.1097/NCC.0b013e3182a0e221

Schweitzer, R., Griffiths, M., & Yates, P. (2012). Parental experience of childhood cancer using interpretative phenomenological analysis. *Psychology and Health*, *27*(6), 704–720. doi:10.1080/08870446.2011.622379

Sciarra, D. (1999). The role of the qualitative researcher. In M. Kopala & L. A. Suzuki (Eds.), *Using qualitative*

methods in psychology (pp. 37–49). Thousand Oaks, CA: Sage. doi:10.4135/9781452225487.n4

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*, 63–75.

Shortman, R. I., Beringer, A., Penn, A., Malson, H., Lowis, S. P., & Sharples, P. M. (2013). The experience of mothers caring for a child with a brain tumour. *Child: Care, Health and Development*, *39*(5), 743–749. doi:10.1111/cch.12005

Sloper, P. (2000a). Experiences and support needs of siblings of children with cancer. *Health and Social Care in the Community*, *8*(5), 298–306.

Sloper, P. (2000b). Predictors of distress in parents of children with cancer: A prospective study. *Journal of Pediatric Psychology*, *25*(2), 79–91. doi:10.1093/jpepsy/25.2.79

Stake, R. E. (2010). *Qualitative research: Studying how things work*. New York, NY: The Guilford Press.

Steliarova-Foucher, E., Colombet, M., Ries, L. A. G., Moreno, F., Dolya, A., Bray, F., … Shin, H. Y. (2017). International incidence of childhood cancer, 2001–10: A population-based registry study. *The Lancet Oncology*, (18), 719–731. doi:10.1016/S1470-2045(17)30186-9

Stones, D. K., De Bruin, G. P., Esterhuizen, T. M., & Stefan, D. C. (2014). Childhood cancer survival rates in two South African units. *South African Medical Journal*, *104*(7), 501-504. doi:10.7196/samj.7882

Svavarsdottir, E. K. (2005). Surviving childhood cancer: Parents' perceptions of their child's health. *Journal of Pediatric Oncology Nursing*, *22*(2), 80–88. doi:10.1177/1043454204273812

Terre Blanche, M., Durrheim, K., & Painter, D. (2006). *Research in practice: Applied methods for the social sciences*. (2nd ed.). Cape Town: Juta.

Tull, M. (2017). *Stress from caring for someone with PTSD: Recognizing and coping with caregiver burden*. Retrieved from https://www.verywell.com/stress-from-caring-for-someone-with-ptsd-2797408

Vance, Y. H., & Eiser, C. (2002). The school experience of the child with cancer. *Child: Care, Health and Development*, *28*(1), 5–19. doi:10.1046/j.1365-2214.2002.00227.x

Vance, Y. H., Eiser, C., & Horne, B. (2004). Parents' views of the impact of childhood brain tumours and treatment on young people's social and family functioning. *Clinical Child Psychology and Psychiatry*, *9*(92), 1359–1045. doi:10.1177/1359104504041923

Van Dongen-Melman, J. E. W. M., Van Zuuren, F. J., & Verhulst, F. C. (1998). Experiences of parents of childhood cancer survivors: A qualitative analysis. *Patient Education and Counseling*, *34*(3), 185–200. doi:10.1016/S0738-3991(98)00031-7

Van Veldhuizen, A. M., & Last, B. F. (1991). *Children with cancer: Communication and emotions*. Amsterdam: Swets & Zeitlinger.

Varni, J. W., Katz, E. R., & Dolgin, M. (1996). Family functioning predictors of adjustment in children with newly diagnosed cancer: A prospective analysis. *Journal of Child Psychology and Psychiatry*, *37*(3), 321–328.

Wade, D. T., & Halligan, P. W. (2004). Do biomedical models of illness make for good healthcare systems ? *British Medical Journal*, *329*(7479), 1398–1401.

Wagner, C., Kawulich, B., & Garner, M. (Eds.). (2012). *Doing social research: A global context*. McGraw-Hill Higher Education.

Watanabe, A., Nunes, T., & Abrue, D. (2014). Japanese parents' perception of disclosing the diagnosis of cancer to their children. *Clinical Child Psychology and Psychiatry*, *19*(1), 125–138. doi:10.1177/1359104512470599

Williams, L. K., McCarthy, M. C., Eyles, D. J., & Drew, S. (2013). Parenting a child with cancer: Perceptions of adolescents and parents of adolescents and younger children following completion of childhood cancer treatment. *Journal of Family Studies*, *19*(1), 80–89. doi:10.5172/jfs.2013.19.1.80

Williams, P., Barclay, L., & Schmied, V. (2004). Defining social support in context: A necessary step in improving research, intervention, and practice. *Qualitative Health Research*, *14*(7), 942–960. doi:10.1177/1049732304266997

Winkeler, M., Filipp, S.-H., & Aymanns, P. (2006). Direct and indirect strategies of mobilization as determinants of social support provided for cancer patients. *Journal of Applied Social Psychology*, *36*(1), 248–267.

Wong, M. Y., & Chan, S. W.-C. (2005). The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of clinical nursing, 15(6), 710-717*. doi:10.1111/j.1365-2702.2006.01297.x

World Health Organization. (2017). *Cancer*. Retrieved from http://www.who.int/mediacentre/factsheets/fs297/en/

Wright, S. C. D., & Maree, J. E. (2008). Health care practices influencing health promotion in urban black women in Tshwane. *Curationis*, *31*(3), 36–43.

Yaris, N., Mandiracioglu, A., & Büyükpamukcu, M. (2004). Childhood cancer in developing countries. *Pediatric Hematology and Oncology*, *21*(3), 237–253. doi:10.1080/08880010490276971

Young, B., Dixon-woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: Conceptualising mothers of children with cancer. *Social Science and Medicine*, *55*, 1835–1847.

Young, R. A., & Collin, A. (2004). Introduction: Constructivism and social constructionism in the career field. *Journal of Vocational Behavior*, *64*(3), 373–388. doi:10.1016/j.jvb.2003.12.005

Zebrack, B. J., & Chelser, M. A. (2002). Quality of life in childhood cancer survivors. *Psycho-Oncology*, *11*, 132–141. doi:10.1002/pon.569

Zebrack, B. J., & Landier, W. (2011). The perceived impact of cancer on quality of life for post-treatment survivors of childhood cancer. *Quality of Life Research*, *20*(10), 1595–1608. doi:10.1007/s11136-011-9893-8

Zimmerman, T. S., Haddock, S. A., Ziemba, S., & Rust, A. (2002). Family organizational labor: Who's calling the plays?. *Journal of Feminist Family Therapy*, *13*(2-3), 65-90. doi: 10.1300/J086v13n02

Appendix

APPENDIX 1: INFORMATION SHEET

Title: When a child has cancer: the constructed experiences of mothers of children with cancer

Name: Itumeleng Masisi

Student Number: 45596913

Supervised by: Prof. Maria Papaikonomou

You are invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The study is being conducted as part of the research requirement for the Masters in Research Consultation (Psychology). The aim of this study is to explore the experiences of mothers caring for a child diagnosed with cancer. Mothers are the primary caregivers, however their experiences are often not told.

Why are you being invited to participate?

You have been invited to participate in this study as your experience with caring for and raising a child who has been diagnosed with cancer is the main interest and focus of this study.

Do I have to take part?

It is up to you to decide whether or not to take part. You are not obligated to take part in the study, your participation is voluntary. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. Should you decide to take part, you are still free to withdraw at any time before the analysis of the research results.

What will happen to me if I take part?

You will have an interview with the researcher and will also be requested to write a reflection on your experiences. Approximately one hour of your time will be required for the interview. If you live outside of Pretoria, you will only be requested to write a reflection on your experiences through your child's illness.

What are the potential benefits of taking part?

The benefit of participating is that you will have a space to share your experiences as a mother caring for a child with cancer.

Will what I say be kept confidential?

The interviews will be tape recorded and transcribed for data analysis. The reflection will also be stored and analysed. The transcribed interviews will be anonymous and will not reflect your name or link back to you. All data will be strictly confidential and the recording and reflections will be destroyed after publication of the research findings.

Who has reviewed the study?

The study has received ethical clearance from the University of South Africa, clearance number: 14/09/2015. The study is supervised by Professor M. Papaikonomou from the University of South Africa

Contact Information

Should you require any further information you may contact Itumeleng Masisi on 0732383011/ 0767442451. You can also contact my supervisor on (012) 429 8266.

Thank you for taking time to read this information sheet and for participating in this study!

APPENDIX 2: CONSENT FORM

WHEN A CHILD HAS CANCER: THE CONSTRUCTED EXPERIENCES OF MOTHER SOF CHILDREN WITH CANCER

Researcher: Itumeleng Masisi, MA Research Consultation (Psychology) at the University of South Africa (UNISA)

I, _____ (participant name)

1. Confirm that I have read and understand the information sheet for the study and have had the opportunity to ask questions.   Yes/No

2. Understand that my participation is voluntary and that I am free to withdraw at any time. Yes/No

3. Agree to the recording of the interview.   Yes/No

Signature_____

Date _____

APPENDIX 3: ETHICAL CLEARANCE

UNISA | university of south africa
Department of Psychology

Ethical Clearance for M/D students: Research on human participants

The Ethics Committee of the Department of Psychology at Unisa has evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA and the Unisa Policy on Research Ethics.

Student Name: Itumeleng Montsokolo Lenah Masisi   **Student no.** 45596913

Supervisor: Prof. Maria Papaikonomou   **Affiliation:** Dept. of Psychology, Unisa

Title of project:

> When a child has cancer: the constructed experiences of mothers of children with cancer

The proposal was evaluated for adherence to appropriate ethical standards as required by the Psychology Department of Unisa. The application was approved by the Ethics Committee of the Department of Psychology on the understanding that all ethical principles related to informed consent, anonymity, confidentiality and the right of participants to withdraw from the study will be met to the satisfaction of the supervisor.

Signed:

Date: 14/09/2015

Prof P Kruger
[For the Ethics Committee   ]
[Department of Psychology, Unisa]

The proposed research may now commence with the proviso that:

1) The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.

2) Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Psychology Department Ethics Review Committee. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.

3) The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.

Please note that research where participants are drawn from Unisa staff, students or data bases requires permission from the Senate Research and Innovation Committee (SENRIC) before the research commences.