The perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

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by

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DECLARATION

I hereby declare that this research report is my own original work and that all references to other sources and other authors' work have been properly cited and referenced. Furthermore, this research report has not been submitted previously for any other degree or examination.

Lowry

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DEDICATION

This work is dedicated to all the children who have passed away due to this dreaded disease…

Those whom we love and lose are no longer where they were before.

They are now wherever we are.

- *John Chrysosin*

This work is also dedicated to those children and their families who continue to fight the battle…

You are braver than you believe, stronger than you seem, smarter than you think.

- *A.A Milne*

Abstract

Children all over the world have been affected by childhood cancer and South Africa is no different. Research has been done on childhood cancer worldwide, however very little has been conducted in South Africa and particularly by social workers. This research explores the perceived influence of cultural practices on primary caregivers' coping abilities and resilience when their child is diagnosed with cancer and treated in a private hospital. The study adopted a phenomenological qualitative approach with a descriptive design. The research used purposeful sampling, with inclusion criteria, to select one participant per family, whose child had been diagnosed with cancer and was being treated at the Wits Donald Gordon Medical Centre (WDGMC). The 16 participants were interviewed face-to-face using a semi-structured interview schedule to guide the interview. The researcher used the interpretative phenomenological analysis (IPA) approach to manually analyse the data once collection had taken place. Systems theory was used in conjunction with the Sociocultural Model of Stress, Coping and Adaptation to underpin the study. Results show that the caregivers within this study have varying degrees of understanding about childhood cancer in general, including their own child's disease and treatments. Although caregivers' understanding varied, their experiences of the diagnosis and treatment of the child in their care were similar as many caregivers experienced shock and a sense of being overwhelmed, Overall, they felt it was a difficult experience to go through. There were numerous descriptions of culture by the participants and the aspect of traditional beliefs, as well as witchcraft, were raised and explored. The majority of the participants did not feel that their culture affected or significantly impacted their coping ability. This research will hopefully assist social workers and medical professionals in the paediatric oncology setting to be able to better assist primary caregivers to understand and access resources they may need in order to cope and be resilient.

Keywords: childhood cancer, caregiver, culture, coping, strengths, resilience

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CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

Globally, cancer is an extensive public health issue (Siegel, Miller, & Jemal, 2016). It is a devastating diagnosis, not only for adults, but especially for children. A cancer diagnosis is a traumatic experience for both the family and the child (Peek & Melnyk, 2010). Although research has been done on childhood cancer worldwide, very little has been conducted in South Africa, particularly by social workers, relating to the perceived influence of cultural practices on primary caregivers' coping abilities and resilience when their child is diagnosed with cancer and treated in a private hospital.

In South Africa, less than half the children affected by cancer are diagnosed and many that are, are diagnosed in the late stages of the disease (Visser, Poole, Bence & Schutte, 2010). It is believed that this may in part, in some instances, be due to the family's cultural beliefs regarding illness. It has been noted that some mothers who have a traditional belief system tend to take their children to a traditional healer for treatment first (Naidoo et al., 2016), therefore by the time they reach a medical treatment centre the cancer has spread and is now in its late stages. It is apparent that the perception of illness can be influenced by culture and so the researcher intends to explore this theory further. Culture would then possibly impact the person's ability to cope and, ultimately, their resilience.

All caregivers who care for a child diagnosed with cancer have an immensely important role. These caregivers also cope differently as this is a role that is extremely taxing emotionally (Angstrom-Brannstrom, Norberg, Strandberg, Soderberg, & Dahlqvist, 2010). Often, the way in which the caregiver coped was influenced by the way in which the child was handling, or not handling, their emotions and circumstances. Parents, therefore, felt most comfortable and capable when they perceived that their children were comfortable. (Angstrom-Brannstrom et al., 2010).

This study adopted a qualitative approach and an explorative and descriptive design. This research will hopefully assist social workers and medical professionals in the paediatric oncology setting to be able to better assist primary caregivers to understand and access resources they may need to cope and be resilient. Moreover, it is hoped that the findings of this study will have a broader impact and guide paediatric oncology units across the country, which

could then possibly adjust policies, incorporating a cultural aspect of coping and resilience when assisting families who have a child diagnosed with cancer.

1.2 BACKGROUND

Childhood cancer is a relatively rare disease but despite this, there are many types of cancers that affect children which are different to those that adults are diagnosed with. According to Visser et al. (2010), unlike with adults, children's cancers most often occur in developing cells, for example, the bone marrow, kidneys and nervous system tissues. The top five most common childhood cancers in South Africa are leukaemia (blood cancer), lymphoma, brain tumours, nephroblastoma (cancer of the kidneys), and lastly tumours that begin in the soft tissue, known as soft tissue sarcomas (Singer, 2010; Visser et al., 2010).

Childhood cancers are seen worldwide and while developed countries are able to diagnose and successfully treat between 70 to 80 per cent of childhood cancer patients, countries like those in Africa are not quite as fortunate (Edwards & Greeff, 2017). In 2012 Hadley, Rouma, and Saad-Eldin found that approximately 80 per cent of children with cancer in Africa die due to lack of access to adequate health care. This can be due to lack of availability of drugs, the lack of effective government policies with regards to childhood cancer, lack of awareness of the communities, and lack of education and adequate training of health professionals (Stefan, 2014). If there were better statistics available, the likelihood that the issues raised above would be addressed, would be greater.

Unfortunately, however, there is not a lot of information on childhood cancer statistics in Africa, as there are few formal cancer registries across the continent (Stones, de Bruin, Esterhuizen, & Stefan, 2014). In many developing countries cancer registries are poorly developed (Chirdan, Bode-Thomas, & Chirdan, 2009). South Africa has a cancer registry, but despite then having slightly more accurate statistics, not all children with cancer have access to treatment centres or are even being correctly diagnosed. A study by Ghiasuddin, Wong and Siu (2015) found that some patients assumptions and perceptions of healthcare were based on their culture and traditional values. This is true in South Africa as well. Jithoo (2010) notes that an individuals' (parent's) perceptions impact whether cultural sources of treatment are sought.

In South Africa there appears to be a lack of consideration for the impact of culture on how a diagnosis of childhood cancer is understood and processed. "Awareness of the effect of cultural differences on behaviour acquires special importance in medicine, given that cultural

factors shape our experience of illness and our reactions to it" (Die Trill & Kovalcik, 1997, p. 197). When considering the topic of coping and childhood cancer, by being conscious of the perceived influence of culture on primary caregivers we may be better equipped to manage their expectations and reactions, which may allow them to access their coping strategies more easily.

Although childhood cancer is rare, with approximately 800 to 1000 South African children diagnosed annually ("Types of Childhood Cancer," 2020), it is still a reality for families in South Africa and families experiencing this reality cope with the diagnosis and treatment in different ways. These families may cope through behavioural patterns they already have, along with cognitive aspects to help resolve stress. Each person will have a different disposition that will assist with coping (Banerjee, Bhattacharya, & Sanyal, 2014).

Primary caregivers may experience many emotions, including anger, guilt, fear and grief, which may have an impact on their mental health outcomes (Peek & Melnyk, 2010). It is therefore important to be made aware of techniques that may help parents to cope. Ways of coping could include the following: relying on family, friends and hospital staff treating the child to help when necessary, getting information and talking to the doctors - asking questions, ensuring effective communication with everyone involved, taking time out for oneself and looking after oneself physically, as well as maintaining a positive attitude (Visser et al., 2010). While these strategies are ideal, realistically they may not always be available to all families, especially considering emotional, social, spiritual and cultural aspects and beliefs, as well as socio-economic circumstances.

In the United States and Canada, for example, research into how culture affects families of children diagnosed with cancer was undertaken and in both studies it was found that families' coping strategies may be influenced by their cultural backgrounds and that further research should be carried out (Banerjee et al., 2011; Zomerlei, 2015). There does however appear to be a profound lack of research, by social workers, in this field in South Africa. South Africa is known for its cultural diversity. Cultural diversity has characteristics such as co-existence of different groups, for example, linguistic, ethnic, religious etc, each with their own different lifestyles, traditions, values and belief systems (Geyer, Peu, Roussouw, Morudi, & Uys, 2005). It is therefore likely that primary caregivers from different cultural backgrounds may employ different coping strategies to process and deal with a diagnosis of childhood cancer. The influence of culture may also have an impact on their level of resilience.

Resilience, when defined as a concept on its own, is explained by Masten (2001), as referring "to a class of phenomena characterised by good outcomes in spite of serious threats to adaptation or development" (Masten, 2001, p. 288). When a child is diagnosed with cancer it becomes a huge threat to the individual and the family. According to Rosenberg, Baker, Syrjala, Back and Wolfe (2013), parents that have a child diagnosed with cancer who are not resilient and who do not have the resources to cope, may struggle psycho-socially even more than those who are already struggling but do have these resources. It is therefore important to explore how caregivers develop and experience resilience.

It is becoming clear, that a person needs to act in conjunction with their environment in order to be resilient. Personal factors are not the only issue when it comes to developing resilience. (Bouwer, 2014). Society and culture, i.e. an individual's environment is also determining factors. According to Bouwer (2014), there needs to be a balance between personal and social resources in order for the individual to be able to better cope with adversity.

Whilst there is a clearer connection between coping and culture in so much as that our culture will impact our coping ability, the connection between culture and resilience is not as established. According to Bonanno (2005) intriguing questions have been raised as to whether or not resilience has varying meanings within different cultures, and if so, could these cultures perhaps exchange alternative ways of effective and not-so effective coping with one another, when faced with difficult situations. When a child is diagnosed with cancer the primary caregiver often sees it as extremely challenging, but many things may assist the parent to be resilient. These may include culture and coping mechanisms, and so these two concepts need to be considered in order to best assist parents through this difficult period (Bonanno, 2004).

In order to do this, we need to acknowledge that, as Ungar (2008) notes, it is unclear what non-western cultures view as resilience, and what meaning marginalised groups attach to the term resilience. We therefore need to explore what resilience means to different cultural groups within their contexts. The researcher intends to explore the contexts and cultures of the primary caregivers in non-western cultures further.

The aim of this research was therefore to establish how cultural practices affect the coping and resilience of primary caregivers whose child is diagnosed with cancer and treated in a private hospital in Johannesburg, South Africa.

1.3 STATEMENT OF THE PROBLEM AND RATIONALE FOR THE STUDY

Social workers help people to cope and deal with difficulties in everyday life. They work with a variety of different people and use different psychosocial approaches. The research that has been carried out thus far in South Africa has not been around the impact of culture, but rather on the psychosocial influences on a family of a child diagnosed with cancer (Marais, 2014). There is a dearth of research where culture is explored or researched in the South African context from a social workers' perspective, regarding childhood cancer. This is possibly due to the ambiguity and complexity of the concepts.

Culture is passed on from one generation (parents or primary caregivers) to the next (children) and is acquired via socialisation (Idang, 2015). Culture differs from person to person. In South Africa, there are many different cultures and the diagnosis of childhood cancer, as well as the notion of healing is understood differently and from different perspectives. As South Africa has eleven official languages, the word cancer may be interpreted differently in meaning within these various languages. The way a person understands terminology impacts on how they engage with it. If a person knows what cancer means they may then have preconceived ideas about it, whereas someone who has no knowledge of the term may be open to new things they are told about cancer. Jithoo (2010), a South African psychologist and researcher, explains therefore that disease is subjective by nature and therefore cancer information needs to be modified accordingly, with the patient's culture, biological state and social circumstances being taken into consideration when diagnosed.

Different cultures also traditionally believe in different types of medicine. According to (Ross & Deverell, 2010), cultural factors will influence who is consulted to treat the patient and restore their wellbeing - due to the meaning attached to different illnesses and conditions, as well as beliefs about what caused the condition. In South Africa more than 80 per cent of people consult traditional healers or traditional diviners. A traditional healer is also known as a *'sangoma'* and a traditional diviner as a *'nyanga'* (Turkington, 2017). In traditional medicine it is believed that disease is caused by social, psychological or natural causes, while Western medicine looks at the biological malfunction resulting in physiological, anatomical or chemical changes (Ross, 2010).

Adaptation to a childhood cancer diagnosis and treatment can be daunting and has the potential to cause psychological stress for the members of the family. Zomerlei (2015) noted that the strengths within a family are connected to culture and can therefore vary significantly. Very

often the coping methods of a parent or family are interconnected with their culture and the researcher will explore this further.

This study was carried out at The Wits Donald Gordon Medical Centre as it has a specialised, dedicated paediatric oncology unit. Due to this unit and hospital being so well known, patients of different cultures from all over Sub-Saharan Africa attend this facility. As the researcher had been working in the unit for the past few years, she had access to these culturally diverse patients and from her experience working with them, had become curious as to what role culture plays in primary caregivers' resilience and their ability to cope with a diagnosis of childhood cancer.

In the South African context Grant, Haskins, Gaede and Horwood (2013) noted that "traditional and biomedical health care coexist and are used alternatively" (p. 178). There are therefore many complexities when it comes to healthcare and medicine as it can include Western, traditional and alternative medicines and these may be used in isolation or in conjunction with one another. The researcher was based in a Western medical facility where the focus is on Western medicine, for example, chemotherapy and other conventional treatments and therefore the researcher chose to focus on the aspect of Western medicine, while acknowledging that traditional and alternative methods are options for many families. The researcher looked at the perceived influence of culture on the parents coping and resilience.

As a primary caregiver, their coping and resilience would have an impact, not only on the diagnosed child's coping and resilience, but the entire family as well. According to Rosenberg et al. (2014), in order to improve outcomes for families whose children have been diagnosed with cancer it may be beneficial to include interventions whereby resilience resources are promoted, as this may compliment the resources already available to these families.

No research could be found to have been conducted by social workers in the South African context with regards to childhood cancer and the impact culture has on primary caregivers' resilience and how they cope with a childhood cancer diagnosis. South Africa is culturally rich and extremely diverse, thus it seems reasonable to expect that research from a South African setting, will be more credible, as this research will consider the unique South African context. This study will aim to hopefully fill a gap in the academic literature on coping with childhood cancer based on the cultural context. The contribution of this study would hopefully assist social workers in the paediatric oncology setting to be able to better assist primary caregivers

to adjust their perceptions so that they may then be able to access emotional, social, spiritual and cultural resources they may need to cope and be resilient.

Understanding is always tied to its surroundings, which includes language, customs, geography, iconic traditions, and especially the ordinary practices of its people (Bell, 2002). The cultural system to which one belongs can therefore be valuable in guiding us as to how to deal with individuals and families in difficult situations. It is anticipated that this research will be beneficial to social work and for other mental health practitioners assisting families who have a child with cancer. Paediatric oncology units across the country could adapt policies about how to be go about counselling families of paediatric oncology patients based on the findings of this study. They may be able to tailor policies towards the cultural aspect of the patients and their families and therefore be able to help them more appropriately within their own contexts.

1.4 AIM AND OBJECTIVES

1.4.1 Primary aim

To explore the perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

1.4.2 Secondary objectives

- To determine how primary caregivers' understand the diagnosis of childhood cancer.
- To understand the primary caregivers' experiences of their child being diagnosed with cancer.
- To explore primary caregivers' perception of culture.
- To determine whether culture influenced primary caregivers' ability to cope and if so how.
- To identify primary caregivers coping mechanisms.

1.5 OVERVIEW OF RESEARCH DESIGN AND METHODOLOGY

The research was phenomenological and qualitative in approach. The researcher had pre-tested the interview schedule to make sure it was relatable to the participants. The research study used purposeful sampling to select participants whose children have been diagnosed with cancer and

are currently being treated in a private hospital. The ward clerk in the paediatric oncology unit assessed if the parent met the inclusion criteria. If the parent met the inclusion criteria and was therefore appropriate, the ward clerk gave them a participant's information sheet and asked if they would give the researcher their contact details. The researcher then made contact to see if they were willing to participate in the research. One participant per family was selected from the paediatric oncology unit at The Wits Donald Gordon Medical Centre (WDGMC). Sixteen participants were purposively selected, they were interviewed face-to-face and the researcher used a semi-structured interview schedule to guide the interview. The researcher administered the interview schedule and so the process was the same for each participant. Interviews were recorded and then transcribed.

The researcher used the interpretative phenomenological analysis (IPA) approach to analyse the data once collection had taken place. IPA methodology required an extremely intensive and detailed analysis where patterns were explored, and themes developed. The researcher also maintained a systematic record of all data collection, coding and interpretation, in order for the research process to be transparent. Theoretical frameworks that guided the study included Systems Theory, which was used in conjunction with the Sociocultural Model of Stress, Coping, and Adaptation, to underpin the study.

1.6 LIMITATIONS OF THE STUDY

There were limitations to descriptive, phenomenological research, however the researcher attempted to minimise these. Limitations included:

- It is unlikely to produce generalised data as it is participant-dependent and subjective.

  Although the data may not be able to be generalised to the average population, it should be noted that they may be transferable to primary caregivers of children diagnosed with cancer in other private hospitals.

- Participants may have improper understanding of, or reluctance to, answer questions.

  There were inclusion criteria stating that the parent should be comfortable and able to converse in English and so the participants should therefore be able to adequately express themselves. It appeared though that some participants struggled with English. The researcher attempted to minimise any misunderstanding by rephrasing the

questions when necessary so that the participant better understood the question. In hindsight however, it would have been beneficial to use an interpreter.

- Another limitation may be that due to this type of sampling being purposeful, it is entirely at the researcher's judgement and discretion as to who gets interviewed and who does not. This may lead to the researcher's influence being too prominent in this type of sampling (Creswell, 2012).

  The researcher was aware of the above limitation and so tried to ensure that participants were representative of the unit's population.

- The researcher would have had their own beliefs and values that may lead to bias.

  The researcher kept reflexive notes to try and minimise bias and to be self-aware.

According to Sutton and Austin (2015), readers need to be able to better understand the filters through which the data collection and analysis took place, and this can be done by the researcher's reflexivity being noted. The researcher needed to not ignore their own biases whilst being reflexive, but rather embrace them and reflect upon them so the reader is made aware of the researcher's position and subjectivities.

1.7 DEFINITIONS OF TERMS

Cancer / Oncology:

According to Sudhakar (2009), when normal cells begin to grow out of control, cancer develops. The author further elaborates stating that:

> there are different types of cancers; all types of cancer cells continue to grow, divide and re-divide instead of dying and form new abnormal cells. Some types of cancer cells often travel to other parts of the body through blood circulation or lymph vessels (metastasis), where they begin to grow. Generally, cancer cells develop from normal cells due to damage of DNA. (p. 1)

Childhood/ Paediatric:

According to the (Children's Act 38 of 2005, 2006) "'child' means a person under the age of 18 years" (p. 12). This definition therefore refers to children under the age of 18 years of age.

Childhood / Paediatric Cancer:

In childhood cancer the cancer is also caused by normal cells growing out of control, however, no one knows what causes childhood cancer, although there are many different theories. Childhood cancers “tend to occur in different parts of the body, look different under the microscope, and respond differently to treatment” than adult cancers (Visser, 2010, p. 1).

Culture:

Napier et al. (2014) noted that “culture can be understood as not only habits and beliefs about perceived wellbeing, but also political, economic, legal, ethical, and moral practices and values” (p. 1697).

Coping:

Coping refers to how a person attempts to prevent or diminish their perception of harm or threat or even loss. It is an attempt to reduce distress (Carver & Connor-Smith, 2010).

Resilience:

For this research, when defining resilience as a concept on its own, resilience can be understood as "a class of phenomena characterised by good outcomes in spite of serious threats to adaptation or development" (Masten, 2001, p. 228).

1.8 OVERVIEW OF THE RESEARCH REPORT

This research dissertation consists of five chapters:

1.8.1 Chapter one: Introduction

This chapter gives an overview of the study. It provides a background to childhood cancer and also covers the problem statement and rationale in detail. The aim and objectives are noted, as well as the limitations and how these were addressed. Finally, it contains the definitions of key concepts, as well as the purpose of the study.

1.8.2 Chapter two: Literature Chapter

This chapter reviews the literature pertaining to the topic and all key concepts. Childhood cancer is explored in detail, as is culture, coping and resilience. The theoretical framework, systems theory, is also discussed in this chapter.

1.8.3 Chapter three: Research design and Methodology

In chapter three the research design and methodology are discussed. The sampling procedure and data collection and analysis are discussed in this chapter. The phenomenological approach is discussed in detail. It also details the questionnaire used and explores the limitations of the study.

1.8.4 Chapter four: Results and discussion

The chapter consists of the results from the interviews which were then analysed. The themes that emerged are described and then discussed. The aims and objectives were addressed. Figures, tables and quotations were used to demonstrate the results.

1.8.5 Chapter five: Main findings and Recommendations

Main findings were presented in connection to the objectives. These included exploring the caregivers understanding of childhood cancer, culture, coping and finally resilience. This chapter also looked at their overall experience of looking after a child with cancer and what ultimately assisted them with coping. This was followed by a conclusion and recommendations for social workers, future practice and support for healthcare providers, research and theory.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter will endeavour to explore literature pertaining to how cultural practices and beliefs influence primary caregivers' coping ability and resilience when their child is diagnosed with cancer. There are various aspects to this topic that will be reviewed. These include cancer, childhood cancer, culture, coping and resilience. Although there is a lot of international research on the above-mentioned aspects, there is a lack of literature on these aspects within the South African context, in relation to one another, and carried out by social workers.

2.2 UNDERSTANDING CANCER

To understand the impact of cancer it is essential to understand what cancer is. “Cancer is characterised by an uncontrolled proliferation of abnormal cells that can affect other organs of the body” (Sawadogo, Schumacher, Teiten, Dicato, & Diederich, 2012, p. 1226).

Sudhakar (2009) notes:

> Some types of cancer cells often travel to other parts of the body through blood circulation or lymph vessels (metastasis), where they begin to grow. Generally, cancer cells develop from normal cells due to damage of DNA. (p. 1)

While treatments and side-effects for adult and childhood cancers are similar, for example, chemotherapy, radiation therapy, surgery, bone marrow transplant and immune therapy; the types of cancers differ completely. Adult cancers do not occur in the same parts of the body as children’s cancers and they do not respond to treatments in the same way. Adult cancers also look different to childhood cancers when viewed under a microscope (Visser, 2010). Another difference between adult and childhood cancer is that often there is a cause for adult cancers, while the cause is unknown in childhood cancers.

2.3 CHILDHOOD CANCER

According to Spector, Pankratz and Marcotte (2015), despite many years, even decades of study, the causes of childhood cancer remain unknown. There are various theories as to what

the cause of childhood cancer could be and what is known is that normal cells are found to be growing out of control. What causes this abnormal growth is what is unknown. Researchers worldwide therefore continue their efforts to try to find a cause (Visser, 2010). In Table 2.1 the explanations of the various childhood cancer diagnosis's are detailed. These definitions are provided by Visser et al. (2010).

Description of childhood cancer diagnosis's	
Diagnosis	**Explanation of Diagnosis**
Leukaemia	This is also known as cancer of the blood. There are three types of blood cells and in leukaemia, one of these types of cells, the white cells, become cancerous and grow abnormally. These cells divide and multiply and take over the bone marrow. There are different types of leukaemia's, for example, acute lymphoblastic leukaemia and acute myeloid leukaemia.
Lymphoma	This is when the tumour/ cancer starts in the lymph glands. The two main types of lymphoma in children are Hodgkin's Lymphoma (4%) and Non-Hodgkin's Lymphoma (7%). These are further divided into sub-categories and that determine treatments and prognosis, etc.
Ewings Sarcoma	This is a type of bone cancer, the second most common type. There are two separate types of tumours that belong to the Ewings sarcoma family. These tumours occur mainly in the pelvis, arms and legs and the ribs, but can occur anywhere in the body.
Rhabdomysarcoma	This is the most common type of tumour belonging to the group of soft tissue sarcomas. These tumours grow in muscles or sinews, or the fibrous tissues around the muscles. There are slight variants on the type of tumours which grow in these areas. They are treated with chemotherapy and then surgery, and sometimes followed by radiotherapy.

Table 2.1 Childhood cancer diagnosis's

A cancer diagnosis and its treatments, in both adults and children, are therefore very complex. Globally, cancer is an extensive public health concern (Siegel, Miller, & Jemal, 2019). Some countries, such as the United States of America, have carried out a lot of research on the topic of cancer and although cancer is on the increase in America, the five year relative survival rate over the past three decades for all adult cancers combined has increased (Siegel, Miller, & Jemal, 2016). Therefore, a positive trend can be seen within a developed country. In less developed countries, like Africa however, cancer is an emerging crisis (Busolo & Woodgate, 2015).

In the past decade, the increase of childhood cancer specifically, has seemed to have levelled off and there has been a decrease in mortality. The overall mortality rate of childhood cancer has been brought down by the fact that one of the most common childhood cancers, leukaemia, is now able to be treated more effectively and so the mortality rate relating to this diagnosis has decreased (Schwab, 2011). However, this is only one of many types of childhood cancers. There are other types of childhood cancers with less successful cure rates. These include brain tumours, neuroblastoma (cancer of the nerve cells), rhabdomysarcoma (cancer of soft tissue / muscles) and osteosarcoma (cancer of the bone), for example (Visser, 2010).

As studies of cancer in adults are more prevalent than childhood cancer, and it is already known that further studies are required regarding adult cancer, it can therefore be deduced that it is vital to do more studies relating to childhood cancer. Further studies regarding childhood cancer would be relevant as childhood cancer is the second most common cause of childhood death in developed countries (Fragkandrea, Nixon, & Panagopoulou, 2013).

2.3.1 Childhood cancer in Africa

Ultimately, further research needs to be conducted on childhood cancer, especially in resource-limited countries as this is where over 90 per cent of children die due to having cancer. Annually, nearly 100 000 children, under the age of 15 die due to childhood cancer and 90 per cent of these deaths are in resource-limited countries. This therefore makes childhood cancer an extensive international health concern (Sullivan et al., 2013). The prognosis of cancer in both adults and children is dependent on the type of cancer and its stage, or degree to which it has progressed at the time of diagnosis. The cure rate is higher in children than for most adults. Nevertheless, 90 per cent of children live in developing countries and these countries therefore

have the most cases of childhood cancer (Chirdan, Bode-Thomas, & Chirdan, 2009). The rate of childhood cancer is especially concerning in developing countries as the cure rate of children there is low (Visser, 2010). Countries such as Ghana have very poor survival rates with regards to childhood cancer (Renner & McGill, 2016) and in a study carried out in Zambia, the poor survival rates were in part attributed to "disparities in education and socioeconomic conditions, coupled with inefficient or suboptimal health care delivery" (Slone et al., 2014, p. 2). Legitimate research would be more likely if there were adequate childhood cancer registries in place as the poor survival rates would also be reflected in these and therefore, the urgency for further research, and resources needed, could be realised.

In Kenya, for example, there is no updated population-based cancer registry and therefore accurate data about the common forms of cancer is not available. They therefore largely rely on hospital-based regional registries for their information. This is helpful as, although it may not contain extensive data, the patients do eventually get to a hospital where additional data is gathered (Githanga, 2017). Ideally, Stefan (2015) says that efforts should be made to develop reliable and operational childhood cancer registries throughout the continent of Africa. By having accurate registries and therefore accurate statistics, more resources could be put towards childhood cancer and childhood cancer research in order to improve the survival rates throughout Africa. Kruger et al. (2014) is in agreement with the need for more reliable data as at present the incidence of childhood cancer is predominately unknown. If there were more accurate statistical data, health policies may also possibly get influenced and adapted in order to assist with research and the fight against childhood cancer.

Unfortunately, up until now most studies have been carried out regarding the prevention of adult cancers, rather than childhood cancers, and limited to Western and Southern Africa. It would therefore be important for other African countries to also carry out studies on childhood cancer and why the survival rates are lower than in developed countries (Busolo & Woodgate, 2015).

2.3.2 Childhood cancer in South Africa

Survival rates in South Africa are lower than the survival rates of children who are diagnosed internationally (Stones, de Bruin, Esterhuizen, & Stefan, 2014). Within the South African population, leukaemia is the most prevalent childhood cancer. Childhood cancers represent about 1 per cent of all cancers. In the South African paediatric population, 600 - 700 new cases of cancer are reported to the South African Children's tumour registry annually (Stefan &

Stones, 2012). This number is far less than it should be. Childhood cancers are considered rare and because of this they are often misdiagnosed, causing delays for primary caregivers who are desperately trying to find out what is wrong with their child (Jones, 2006).

One reason for low survival rates may be that there are misconceptions within the South African communities and so help is not always sought immediately, and there is also a lack of knowledge of childhood cancer symptoms. At Baragwaneth Hospital, an academic hospital in Gauteng, South Africa, research was carried out to see if use of childhood cancer warning signs, the Saint Siluan warning signs, would improve referrals of childhood cancer. The results were somewhat positive in that they found that the number of patients referred to the unit increased undoubtedly, however these patients were already in the later stages of the disease. The St. Siluan warning signs were therefore effectual in highlighting symptoms of cancer in patients, but not in bringing them to the hospital in the early stages of the illness (Poyiadjis, Wainwright, Naidu, Mackinnon, & Poole, 2011). The St. Siluan warning signs are recorded in Table 2.2, according to Poyiadjis et al. (2011, p. 314).

The St. Siluan warning signs of childhood cancer	
Warning Sign	**Description**
S – Seek:	Medical help early for persistent symptoms.
I – Eye:	White spot in the eye, new squint, new blindness, bulging eyeball.
L – Lump:	In the abdomen and pelvis, head and neck, limbs, testes, glands.
U – Unexplained:	Prolonged fever over 2 weeks, loss of weight, pallor, fatigue, easy bruising, or bleeding.
A – Aching:	Bones, joints, back, and easy fractures.
N – Neurological signs:	Change or deterioration in walk, balance, or speech, regression of milestones, headache for more than a week with or without vomiting, enlarging head.

Table 2.2 The St. Siluan warning signs

Unfortunately children can often not be offered any effective treatment as they have only sought help when they are symptomatic with advanced local and metastatic disease (Hadley, Rouma, & Saad-Eldin, 2012). Getz and Brodersen (2010) point out that in both adult and childhood cancer the sooner the cancer is detected, the less aggressive the treatment is. The treatment may still include surgery, chemotherapy and/or radiation therapy, but it would be milder.

2.3.3 Medical Treatments of Cancer

Although patients illnesses may seem medically similar, there are individual differences in the effectiveness of treatments and therefore the outcomes (Patenaude & Kupst, 2005). The treatment of a child needs to take place under a paediatric oncologist and not an adult oncologist. Table 2.3 presents a description of the various types of treatments that both adults and children receive. The descriptions in Table 2.3 are according to Visser (2010).

Explanation of childhood cancer treatments	
Type of Treatment	**Description**
Chemotherapy	This treatment is through medications that may be given via the mouth, by injection or intravenously (into the vein) or lastly through a drip or central line. These drugs circulate in the body and kill rapidly dividing cancer cells.
Radiation Therapy / Radiotherapy	This treatment is given by high energy x-rays which kill cancer cells in their path. The number of treatments and frequency will depend on the diagnosis.
Surgery	This is where they surgically remove all, or as much, of the cancer as possible. Surgery is usually followed by chemotherapy and/or radiation therapy to try and destroy any remaining cancer cells.

Bone marrow transplant (BMT)	Patients with various cancers who do not respond to conventional treatments may require a bone marrow transplant. This treatment is only used when it is the best possible option for cure. It is a more intensive treatment than chemotherapy. BMT is when they transplant healthy donor stem cells to the patient. The patient's own bone marrow cells are destroyed and then the healthy cells given to the patient. There are different kinds of BMT, for example, autologous, allogeneic, syngeneic and stem cell transplant.
Immunotherapy	This is when T-cells from a bone marrow donor are given to patients, however the patient's body may reject these.

Table 2.3 Childhood cancer treatments

2.3.3.1 Side-effects of cancer treatments

These cancer treatments attempt to kill the cancer cells but in fact affect multiple bodily functions and so sometimes result in numerous adverse symptoms (Chan et al., 2014). Patients receiving treatment for cancer may experience fatigue, nausea and vomiting, mouth ulcers, known as mucositis, as well as low blood counts where they require blood or platelet transfusions.

In research that was carried out by Reeve et al. (2014), it was found that although adults experience similar side-effects to children, for example, nausea and vomiting, hair loss and mouth ulcers or sores, there were additional side-effects recorded by adults.. The most common side-effects in adult cancer treatment included "fatigue, insomnia, pain, anorexia, dyspnea [breathing difficulties], cognitive problems (includes memory or concentration impairment), anxiety (includes worry), nausea, depression, sensory neuropathy [numbness], constipation, and diarrhea" (p.4). In this study emotional side-effects are noted by the adults and these too should not be ignored in children who are receiving treatment.

Often when children and adults receive treatment for cancer their white blood cells that fight infection become extremely low and so the patient needs to be kept in strict isolation. Isolation is particularly taxing on children as they want to be with friends and play. In one study, caregivers of these children mentioned that the constraints that are introduced are often very difficult, as it is then up to them to limit the child's activities (da Silva, da Silva, Bezerra Goes, Diniz Machado, & Paiva, 2015). Caregivers often feel desperately sad for their child and guilty as they are the ones who have to maintain these limitations, even though medically they have been instructed to do so.

Not only do children experience side-effects of treatment, but complications too. Children may have negative physical reactions to blood or platelet transfusions, they may have anaphylactic reactions to the chemotherapy drugs used, or even go into renal failure due to drug toxicity. Not only is this scary for the child but for the caregivers as well. These complications are acute at times and they can also be lifelong, therefore childhood cancer survivors and their caregivers have ongoing concerns. Heart problems, for example, are one of the prominent causes of ill health and, in some cases, death with regards to children who have survived cancer treatment (Franco & Lipshultz, 2015).

Not all children receive treatment, as not all children reach treatment centres. In a study that was carried out in a paediatric oncology unit in South Africa there was evidence found to indicate that parents had thought that cancer was not a disease that occurs in children, but rather the elderly. Parents had previously also believed that cancer only affected the white population and was associated with a sore, or the breast (Maree et al., 2015). These misconceptions within Africa are likely linked to traditional or cultural beliefs.

2.3.4 Impact of childhood cancer on caregivers

The daily functioning of a family is substantially affected when a child is diagnosed with cancer. The devastating diagnosis causes the family immense emotional distress (Long, Marsland, Wright, & Hinds, 2015). The emotional impact on the whole family when a child is diagnosed with cancer is therefore colossal. The word 'cancer' itself may provoke many emotions within a person – fear and anxiety, anger and even sadness. In a study carried out by Long et al. (2014) caregivers of children who had been diagnosed with cancer found that they had concerns regarding the adjustment of their child both in terms of their health and diagnosis, as well as socially. They were especially worried that the child would be viewed differently from their friends and peers who were also in the process of developing. These caregivers were

concerned that their child was particularly vulnerable due to possible threats to both their emotional and physical health.

When a child is diagnosed with cancer it is not only the immediate losses that are felt by the family, but anticipatory loss or grief. West, Bell, Woodgate and Moules (2015) found that family members suffering was due to the loss of normalcy within the family and they wished to be able to return home. Family members felt as though their lives had been uprooted. Immediate losses may include – not being able to go out as a family while the child is on treatment, not being home (parent and child) when the child is in hospital, not being able to see friends regularly or even simply go to school (child) or work (parent). Some parents leave their jobs to care for their ill child or have to work reduced hours.

Darcy, Knutsson, Huus and Enskar (2014) found that once a child was diagnosed with cancer and they started treatment everything about their usual life became unfamiliar and as a result the child felt like a stranger. Everything about the child suddenly changed from their self-esteem to independence and even energy levels. Home life became different as it had to be adapted to the needs of the sick child. These changes within the home presented the parents with a new, unfamiliar role. Often with changes comes loss, whether it is immediate or anticipatory.

The possible physical death of the child is part of anticipatory grief, and adds to the difficulty dealing with the diagnosis, along with the other modifications that the cancer diagnosis and the cancer treatment may impose (Quintana, Wottrich, Camargo, & Cherer, 2013). Anticipatory grief or losses, or perceived loss, may include – loss of the child's future or seeing the child grow up and meet milestones should the child not survive, loss of a normal childhood (depending on the length of treatment), loss of a 'normal' adult life, for example, sometimes due to treatments or the type or location of the cancer, the patient may have fertility problems or not even be able to have children and parents are warned of this, fear of potential disfigurements and therefore possibly a loss of a happy adulthood, even fear of financial losses as perhaps only one parent is now able to work. These things often go through parents' minds and even the patient's minds, depending on their age and level of understanding. Elisabeth Kübler-Ross was a psychiatrist who, through her work with patients with life threatening illnesses, including cancer patients, developed the grief model with the five stages of grief and loss. Kübler-Ross's (2003) stages of grief and loss can therefore guide the caregivers process

at diagnosis and during and after treatment, regardless of the child's outcome. The process of grief is shown in Figure 2.1.

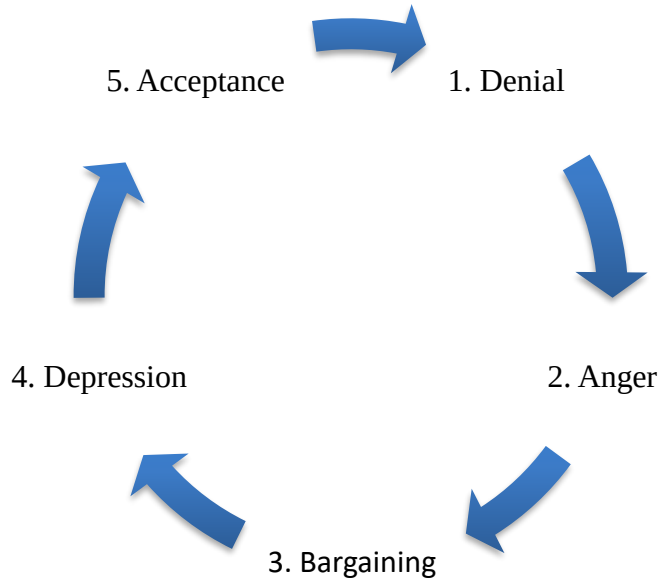

Figure 2.1. Elizabeth Kübler-Ross's stages of grief and loss

According to Mckenzie and Curle (2012), parents' use of denial and avoidance as a psychological defence mechanism was noted by the parents themselves. The parents used these mechanisms as a way of coping with the devastation of the cancer diagnosis and following treatment. Once parents are no longer able to deny the reality of the diagnosis, anger often sets in. Parents are even angry at themselves and blame themselves for what is happening to their child. Anger can be misdirected at times like these. Parents also tend to bargain, usually with God or the higher power that they believe in, saying things like – I will stop smoking if you just make my child well, or I will treat people better, etc.

The grief and loss stages make up a dynamic process, one whereby parent's move in and out of these stages without even realising it. They may even be experiencing more than one stage at a time. Parents may go through a depressive phase (Barrera et al., 2013). Again, this may be a phase experienced numerous times throughout their experience with childhood cancer. At some point it is hoped that acceptance or partial acceptance is reached. Khoury, Huijer and Doumit (2013) stated that parents may deal with having a child with cancer with acceptance, but not agreement. It is important that it is realised that accepting the situation and liking or

agreeing with the situation are not one and the same. Caregivers dealing with childhood cancer will have constantly changing emotions.

Caregivers often feel torn as they want to remain positive and strong for the child, but in fact have conflicting feelings of fear and anxiety of what is to come. These caregivers may also experience fatigue and feel that they are functioning on autopilot – they do the necessary and just keep going because they have no other option. It is often only after the experience that the true trauma they have suffered is realised. In a study carried out by Mckenzie and Curle (2012) parents felt, post treatment, that they then had to address difficult emotions on their own and so felt abandoned. These parents continued to fear relapse and the unknown once treatment has been completed. During the diagnosis and treatment of the cancer, parents felt that uncertainty was one consistent experience in their lives. This uncertainty often continued for a period of years (Bally et al., 2018).

2.3.4.1 Impact of childhood cancer on the family

When dealing with a child with cancer it has been found that families' capabilities, both emotional and physical, vary due to the increased responsibility and distress placed on the family (Aung et al., 2012). In homes where the mother and father are a couple it has been seen that caring for a child with cancer places additional stress and strain on the marital relationship. Some couple were able to maintain a united front to overcome the child's illness, however due to the circumstances became distant and detached from one another. Different types of distancing can occur including geographical (due to where the treatment is available), physical (intimacy) and emotional distance from one another. For some couples there was an exchanging of roles, which was challenging. Couples identified the first six months following diagnosis as the most taxing on their relationships, prior to them being able to assimilate and deal with the reality of the experience (Silva-Rodrigues, Pan, Pacciulio Sposito, de Andrade Alvarenga, & Nascimento, 2016).

In research carried out by Wiener et al. (2017), various means of strengthening the marital relationship were identified when dealing with a child with cancer and these included: having clearly defined roles within the family unit and having a partner that not only helps with daily medical issues of the sick child, but also a partner who assists with household chores and the needs of siblings.

Siblings also struggle to cope when their brother or sister is diagnosed with cancer. The age of the sibling will affect how they display their difficulty with coping. Siblings in school may find their academic performance suffers and they are more frequently absent (Long et al., 2018). For others distress may be displayed in terms of somatic symptoms, or depression and withdrawal. They may have difficulties communicating their distress and needs and feel abandoned as their parent/s' focus is on the sick child and the parent/s may spend many hours with their sibling at the hospital. In some instances, parents do not inform the siblings of what is happening with their ill sibling in order to protect them. This can potentially have the opposite effect as the sibling could then think that the situation is worse than it really is (Cordaro, Veneroni, Massimino, & Clerici, 2012). Open and honest communication with the well siblings is therefore imperative in assisting them to cope with the situation.

Siblings of a child with cancer become aware of how fragile the family is and that it could fall apart at any moment (Long et al., 2015). Family life may seem chaotic for the sibling of a child with cancer and they lack the normalcy of the family prior to diagnosis. This may cause the sibling to feel insecure which may affect their self-esteem. Their normal routine may be altered and at times these siblings feel neglected. By parents including the sibling of the child with cancer in the processes surrounding the illness and treatments, the siblings were able to cope and function better (Yang, Mu, Sheng, Chen, & Hung, 2016).

2.4 UNDERSTANDING CULTURE

"Culture is a slippery and ubiquitous concept" (Birukou, Blanzieri, Giorgini, & Giunchiglia, 2013, p. 3).There are numerous definitions and beliefs which affect the understanding of the term culture. Culture is multidimensional and includes both internal and external factors relating to individuals. These factors are intertwined and cannot be explained in isolation, but rather in connection to one another (Mironenko & Sorokin, 2018).

As the researcher has noted, the definition of culture is a complex one that includes various aspects, it is not a one-dimensional concept but rather one that needs to incorporate the broader picture. According to Rathje (2009), culture can be understood better in terms of its relationship with the collective and the individual. Holistically, the phenomenon of culture is a complex matrix. This matrix is pictured in Figure 2.2.

	Pleural perspective	**Individual perspective**
Collective perspective	What governs the membership to a collective?	What governs the formation of the individual's collective memberships?
Cultural Perspective	How can the customs of a collective be described?	What effect do collective customs have on individuals?

Figure 2.2. Culture as a matrix – The expansion of the traditional usage of the term "culture" to include the collective and individual perspectives (Rathje, 2009)

Rathje (2009) explains this matrix in the following way, she states that:

> By employing this tool, questions regarding the customs of certain collectives are addressed in the cultural/plural field while the collective/plural field can be used to investigate the rules of membership and participation in collectives. The cultural/individual field is dedicated to the interdependencies between individuals and culture, while the collective/individual field describes the individual's membership in discrete collectives. (p.43)

People's values and beliefs are significant in creating their reality and their reactions to their environment and circumstances they find themselves in. Even during early childhood development, children already start to give meaning to their world through interactions and actions. Therefore childhood is "a cultural phrasing of the early part of the life cycle" (Griffiths, Schweitzer, & Yates, 2011, p. 83). As children, our interactions with family, as well as our social and cultural environments have an impact on everyday experiences (Batra, 2013). These experiences are what builds a child into the adult that they become; cultural exchange therefore has an impact from a very young age. Our culture and cultural exchanges contribute to the makeup of who we are today. The above is all in accordance with Erikson's psychosocial developmental theory.

Children's views of illness may also differ from one another and their beliefs around illness are carried into adulthood. Illness and disease are therefore often explained in different ways depending on the culture and society the person comes from and vary from person to person. Across and within societies perceptions of psychological and physical wellbeing differ substantially. According to Napier et al. (2014) culture encompasses, not only racial heritage and ethnic identity, but also moral beliefs and values, as well as political, economic and ethical practices, alongside their perception of their overall welfare.

Similarly, socially acceptable ways of curing an illness may also vary. One way that is acceptable in one culture may not be acceptable in another and this may be due to their understanding of the illness (Nkosi, 2012), which in essence is due to cultural diversity. Cultural diversity refers to specific characteristics within that culture where different groups co-exist. These groups may have varying values and beliefs and their traditions and lifestyles may differ from one another (Geyer, Peu, Roussouw, Morudi, & Uys, 2005). Due to the fact that people lead different lifestyles it would make sense to say that it is likely that they may possibly handle a diagnosis of a child with cancer, and their care, in different ways.

The way in which a person responds to caring for a child with cancer will be influenced by their cultural environment. It is important therefore that researchers and healthcare providers assess and proceed according to the individuals cultural norms (Munet-Vilaro, 2004). Ultimately, knowing a family's cultural background should not deter the treatment team from treating the family as individuals. Their individuality needs to be maintained while incorporating their cultural characteristics (Die Trill & Kovalcik, 1997). These cultural characteristics will differ from family to family as culture is complex and diverse.

2.4.1 Worldwide cultures

Cultures differ throughout the world and it determines meaning within people's lives. Culture evolves with the times (Hammarberg, Kirkman, & de Lacey, 2016). Culture plays a part in not only Africa but worldwide. In the Filipino culture, for example, there are "*sumpa*" and "*gaba*" and these pertain to the beliefs that illness can be caused by a curse. When speaking of *sumpa*, it refers to a curse that has been brought upon by a human being while, *gaba* is a curse brought upon by God or a divine being due to the person having committed a social sin (Abad et al., 2014). Similarly, some South Asian parents that immigrated to America believe that cancer can only be understood through religion and therefore if their child was diagnosed with cancer, it

was a result of something bad that either their child or they had done in their past or present life (Banerjee et al., 2011).

In an Iranian study it was found that some parents hated and blamed themselves for the child's cancer as they believed that the illness may have been due to a sin they had committed and were therefore being punished for. Other parents felt guilty and blamed themselves as they thought that they had been negligent when caring for the child prior to their diagnosis and this was the reason for the child's illness. They therefore tried to go through memories to ascertain where they had gone wrong (Taleghani, Fathizadeh, & Naseri, 2012). The burden of blame often lies with the caregivers. Mothers roles specifically are increased during the period of the child's illness, as is their emotional exhaustion (Altay, Kilicarslan, Sarı, & Kisecik, 2014). It can be said that due to culture more is expected of the females or mothers than the males or fathers with regards to the sick child.

In a study conducted on retinoblastoma (cancer of the eye) in India it was found that the parent's willingness to treat the child, was related to whether the child was male or female. A male child received preferential treatment, even if the parents needed to borrow money in order to do it, while the female children often seemed to be neglected. The families may also not want an enucleation (removal) of the eye due to fear of disfigurement and this is especially true for the female children where they feel the disfigurement may hinder her prospects of getting married (Chawla, Kumar, & Singh, 2017). These findings can be linked to cultural beliefs. Gray, Szulczewski, Regan, Williams and Pai (2014) notes that in some culture's doctors don't believe in disclosing everything to the patient in an attempt to protect the patient. Western medicine can sometimes contradict this as healthcare services are focused on patient independence and making informed decisions.

In China for example, if a family believes in traditional Chinese medicines they may choose to not fully follow Western treatment, or supplement their treatment by using other remedies or other caregiving practices. (Leavitt et al., 1999). Due to the difference in cultural contexts between Western and Chinese traditions, Chinese children viewed the nature and meaning of their illness very differently to Western children. They also had different views to their treatment. Some traditional Chinese people also believe in the philosophy of fatalism and this then would mean that their fate has already been decided even prior to the diagnosis, therefore the diagnosis could not have been prevented (Ho Cheung William Li, Chung, Ho, Chiu, &

Lopez, 2012). Globally, perceptions of illness and appropriate treatments differ according to culture.

2.4.2 African cultures

Culture plays a key role with regards to the individual, the family and ultimately the communities' level of health. In the African context this is relevant where the individual's behaviour is largely influenced by the values and beliefs of extended family and the community (Airhihenbuwa & De Witt Webster, 2012). According to Owusu-Ansah and Mji (2013) the surroundings in which the African makes sense of his world is within the African culture with its relational values. These values and, fundamentally, culture will influence how they perceive illness and what treatment follows.

When a female or female child is ill in an African family, it is often the tradition in the less westernised societies that any decisions regarding the female or child's health is made by the male elders and predominately female elders or grandmothers. Some African beliefs surrounding illness can therefore be detrimental to the health of a female child.

2.4.3 South African cultures

South Africa is called the 'rainbow nation' because it is a nation full of rich diversity. There are diverse ethnic groups, cultures and languages. "During the era of apartheid, people were designated as white, black African, coloured (people of mixed race) and Asian/Indian" (Roman, 2014, p.213). There are numerous different cultures within the country, each with their own intricacies. In South Africa "eleven official languages were formally recognized (Sepedi, SeSotho, Setswana, siSwati, Tshivenda, Xitsonga, isiNdebele, isiXhosa, isiZulu, English and Afrikaans), and special attention was given to those languages considered to be marginalized (such as sign language and some of the endangered and heritage languages in the country)" (Penn & Watermeyer, 2018, p. 171). The number of languages is just a small indication of the number of various cultural groups within South Africa and there are subgroups within these cultural groups.

With regards to South African culture, people need to take into consideration different political experiences that various people may have endured as their experiences impact their overall perceptions of the world and one another. For example - a political ideology which is based on discriminatory and unjust philosophies can significantly affect citizens in every area of their life, for example the apartheid system which was formally adopted by the national government

in 1948. Airhihenbuwa and De Witt Webster (2012) noted that apartheid may have an effect on the present composition of culture in South Africa. During apartheid there was racial discrimination as different racial groups were subjected to inhumane and unjust policies between various cultures and races and this today may still impact on how people from different races and cultures, historical backgrounds and environments, perceive one another and perceive a situation. In post-apartheid South Africa long-term adversity and ramifications of the apartheid era are still evident. During apartheid, for example, there was lack of access to healthcare for people within rural communities as all the hospitals were in the main towns. Although more community clinics are today available locally, there is still a lack of advanced, main hospitals in the rural communities.

Out of apartheid in South Africa the notion of 'ubuntu' was born and it was intended to bring about possibilities of social cohesion and build the nation (Eliastam, 2015). The term 'ubuntu' is particularly used in connection with Africans in South Africa. In a study carried out by Gade (2012), two definitions of ubuntu arose, the first being that ubuntu is a person's moral quality and the second is that ubuntu is a "phenomenon (for instance a philosophy, an ethic, African humanism, or a worldview) according to which persons are interconnected" (p.487). All beings are interconnected and part of a greater system, although beliefs and values within this system may differ, especially with regards to health.

In a study of rural South African indigenous women around their concept of health, it was seen that their perspective of health was related to relationships. These women believed that people's illness was due to relationship breakdowns and that healing would only take place once the broken relationship was mended as the person needed to be in harmony with others in order for wholeness and health to be restored (Owusu-Ansah & Mji, 2013). Perceptions of health care and health in a culturally diverse South Africa are strongly connected to one's cultural values and belief (Grant, Haskins, Gaede, & Horwood, 2013).

2.5 CULTURE AND HEALTH

According to Kagawa Singer et al. (2016):

> Culture is an internalized and shared schema or framework that is used by group (or subgroup) members as a refracted lens to "see" reality, and in which both the individual and the collective experience the world. (p.6)

Asad and Kay (2015) notes that it is not a new concept that culture impacts interventions in the health care sector. A person's understanding of health and illness is constructed within their culture and that the way in which they perceive illness and their health-seeking behaviours are culture-based (Betsch et al., 2016). Both ancient and modern people depend on medicines to try and fight illness when they sick, and illness remains a serious threat to the public in both developed and developing countries, rural and urban areas and varying ethnic groups, despite advances in medicine and science. Herbal remedies have evolved over time based on culture and area in which the community are based and these herbal remedies have their own ways of treating disease and are an integral part of the communities culture and their understanding of health and illness (Pan et al., 2014).

Since ancient times, disease has been a leading cause of morbidity/mortality. Disease is also associated with a heavy economic burden. Despite current advances in science and medicine, disease remains a serious threat to public health in both developed and developing countries, urban and rural areas, and all ethnic groups.

In the United States it was noted that for generations there has not being equality in healthcare as healthcare is influenced by ethnicity, education, income and even where a person lives. Healthcare systems largely operate apart from community life and from one another (Plough, 2015). Therefore the goal should be to craft more culturally congruent healthcare and determine extensive characteristics that vary cross-culturally in the hope that this will lead to health behaviour changes and solutions (Sherman, Uskul, & Updegraff, 2011).

Asad and Kay (2015) spoke of three dimensions: cultural knowledge, cultural practice and cultural change and these three dimensions of culture are connected to healthcare. The first, cultural knowledge is connected to the creation of health interventions as this is where the persons beliefs and values and norms are of significance. Cultural practice refers to how these health interventions are implemented, and lastly cultural change is linked to health outcomes over time as culture is dynamic and evolves over time. Changes in knowledge and behaviour could be brought about by culturally sensitive health interventions and this could eventually lead to changes in policies.

Quah's (2014) understanding is that behaviours related to health and health care are linked to one's cultural context. Healthcare options afforded to people differ hugely across cultures and countries. Ultimately health care can be divided into two main categories: Western biomedicine systems (modern medicine) and traditional medicine systems. Traditional medicines often seek

herbal medicinal cures or treatments. Herbal remedies are passed down from one generation to the next. These prevalent remedies are used to treat both simple, as well as complicated ailments (Malik, Bhat, Ballabha, Bussmann, & Bhatt, 2015). In countries, such as India, this traditional knowledge of natural sources to remedy ailments is seen to compliment the Western healthcare system. Globally, organisations have therefore advocated for the preservation of traditional medical practices and their development (Angmo, Adhikari, & Rawat, 2012). Mesfin, Tekle and Tesfay (2013) noted that knowledge of traditional medicinal plants is not only useful for conservation purposes of cultural tradition and biodiversity, but also to maintain healthcare within the community and for drug development for the local people. Often modern medicine is practiced alongside traditional medicine in some Asian countries, other than China and India (Karmakar, Islam, Kibria, Hossain, & Sattar, 2012).

In a study conducted in Canada by Auger, Howell and Gomes (2016) it was noted that traditional healthcare practices treated the patient holistically, including their emotional and spiritual well-being which is often neglected in Western medicine practices. The participants in this research study therefore acknowledged their ongoing needs for access to traditional healthcare, elders and traditional knowledge keepers. There are often barriers to accessing traditional healthcare as the general population deny the value and effectiveness of traditional healing. It is therefore important to educate students going into the healthcare field regarding culture.

Students studying pharmacy in New Zealand come from different ethnic backgrounds and will therefore most likely have varying views and understandings of health and healthcare as they will probably have been exposed to different treatments (often traditional, primarily herbal treatments) and healthcare practices. Health professional educators can therefore not simply presume that all learners have the same attitudes and knowledge with regards to traditional practices and healthcare (Anwar et al., 2015). Cultural knowledge comprises of a huge resource of innovative and tested approaches and strategies that could address common issues and provide benefit to various populations with difficult, and even chronic health problems. Even indigenous diets can contribute to health, or lack thereof, and through cultural knowledge healthcare providers can more accurately assess and address health concerns amongst all populations ((Kagawa Singer et al., 2016).

In order for adequate healthcare to take place in all communities there needs to be culturally sensitive health communication. This type of communication improves understanding when

families are needing to make medical decisions and it can also assist communities that are culturally diverse to be more aware of behaviours that promote health, for example, not smoking or eating a healthy diet. One issue that lack of culturally sensitive communication could lead to is an imbalance of power between patient and family, and the doctor, as many cultures evaluate power holders in different ways (Betsch et al., 2016).

In some countries, traditional medicine providers are acknowledged and held in high esteem, for example, in India the *Amchi* is responsible for traditional healing systems. They use mainly, but not only, plants to treat illness and diseases, as well as animal parts and minerals (Angmo et al., 2012). In Chile the traditional medicine is called *Mapuche* medicine, there is an issue of integrating this traditional medicine with biomedicine or modern medicine, to an extent where it has become an emerging issue in health policy. An intercultural health approach is one that, via equivalent acknowledgement and mutual respect, attempts to bridge the gap between Western medicine and indigenous medicine and healthcare systems (Torri, 2012). According to Airhihenbuwa, Ford and Iwelunmor (2014) there is a perspective that perhaps public health interventions are not always sustainable in changing behaviours as the role and influence of culture is not adequately attended to.

"Health is a fundamental human right and if healthcare is to be universal and equitable it should not be less accessible to some sectors of society than to others" (Moodley & Ross, 2015, p. 630). Mbatha, Street, Ngcobo and Gqaleni (2012) have noted that although everyone is entitled to choose the healthcare system they use, there is bias towards Western medicine or the allopathic system, especially for individuals who are employed and have medical aids. In South Africa traditional healthcare practices cannot legally issue sick notes for employees who are absent from work. This is extremely frustrating for people who use traditional medicine and traditional health practitioners. Some institutions, under specific conditions, do however support the rights of their employees and accept traditional health practitioners' sick letters. Unfortunately, a lot of confusion is created for employees as well as policy makers regarding traditional health practitioners' sick notes due to the inconsistency and ambiguity.

In South Africa there are numerous descriptions of traditional healers and these include herbalists, faith healers and diviners and each of these healers perform their healing through varying means (de Andrade & Ross, 2005). Traditional healers are often based within a short distance from communities and so are easily accessible. They also understand their patients' culture. Traditional healers work on the combination of the mind and body to help overcome

sickness (Cheikhyoussef, Shapi, Matengu, & Mu Ashekele., 2011). Traditional healers however are not only found in South Africa but in societies throughout the world. “They [traditional healers] are often part of a local community, culture and tradition” (Cheikhyoussef, Shapi, Matengu, & Mu Ashekele, 2011, p. 1). Traditional medicines and natural products have been part of various cultures for many years, since prehistoric time. “Traditional Chinese medicine, Ayurveda, Kampo, traditional Korean medicine, and Unani have been practiced in some areas of the world and have blossomed into orderly-regulated systems of medicine” (Yuan, Ma, Ye, & Piao, 2016, p. 1).

In Africa, within the medical sector however, there can be confusion when using the term “traditional”, as most people use it to describe African traditional healers. But why can an allopathic or Western medical practitioner not also prescribe to traditional ideologies, values and beliefs, especially if these encompass respect and empathy for one’s clients? It is noted that if the medical practitioner and the patient’s worldviews are congruent or understood by the medical practitioner, the patient is more likely to accept the medical opinions and treatment suggestions made (De Andrade, 2011). In Limpopo Province there are Bapedi traditional healers who play an essential role in the rural inhabitants primary health care (Semenya & Potgieter, 2014). Various plants and animals are utilised in traditional healing and they are used to treat not only medical ailments, but cultural; or social afflictions as well. A large proportion of the South African population will consult a traditional healer at some time in their life (Williams & Whiting, 2016).

Traditional healers are trained by other traditional healers who have been called to become a trainer. Not any traditional healer can go on to train future healers, it is a speciality. Once a traditional healer has completed training various rituals are performed prior to them being able to practice (Mokgobi, 2014). Very little formal training with regards to traditional, complementary and alternative medicine (TCAM) takes place within the South African context. At most of the medical schools TCAM was covered but in a tokenistic manner. The university in KwaZulu-Natal is the one exception (Chitindingu, George, & Gow, 2014). Sodi et al. (2011) observed that the ethics that guide traditional healers’ practices are in fact congruent with those of Western-trained medical practitioners, unfortunately however there is still a perceived distrust of traditional healers by Western professionals.

In South Africa, during the unjustified apartheid era, all people of colour were not afforded the same access to hospitals and healthcare as the white people. People of colour who lived in rural

communities were far from the main cities and towns where the main hospitals were based and therefore often didn't even get any healthcare. During apartheid, and largely still today, there was and is, a pro rich distribution of public and private healthcare services. This means that there was and is socioeconomic inequity in South Africa and healthcare services are utilised by those who can afford it. "Race is found to be the largest contributor (42%) to the socioeconomic inequity in inpatient healthcare utilisation" (Buisman & García-Gómez, 2015, p. 205).

Due to past and present discrimination, poor access to healthcare services remain a reality in South Africa today. Although, there may be more community clinics, the main hospitals and healthcare facilities are still in the main cities and towns and are therefore still not easily accessible to our rural families for various reasons, for example, geographical distances and finances. According to Maphumulo and Bhengu (2019) there are still challenges facing the South African healthcare system currently and these include:

> unequal distribution of resources, management and leadership crisis, increased disease burden, pull and push factors and slow progress in restructuring the healthcare system, including strategies adopted by government to improve the quality of healthcare delivery. (p.3)

Government is trying to readdress this imbalance through the implementation of National Health Insurance (NHI). Therefore, many people and communities choose, and are dependent on traditional healing as their primary source of healthcare.

In South Africa surveys showed that many patients said they used traditional herbal medicines to treat their ailments. These ranged from diabetes to pain, HIV and even childhood illnesses (Hughes, Aboyade, Beauclair, Mbamalu, & Puoane, 2015). Traditional, complementary and alternative medicines are widely used in Sub-Saharan Africa and TCAM should be considered by stakeholders due to its essential and critical role within the healthcare delivery service sector (James, Wardle, Steel, & Adams, 2018). De Andrade and Ross (2005) noted that there are similarities between traditional and modern approaches to healthcare as both practices focus on benefiting the patients. Traditional healers also noted that they could educate Western / modern practitioners about holistic patient care. "In sum, culture has influenced, does influence, and will continue to influence health-related behaviour" (Quah, 2014, p. 6).

2.6 CHILDHOOD CANCER AND CULTURE

When cancers occur before the age of 20, which it rarely does, it tends to raise many concerns. These concerns may be cultural or societal, medical, psychological and even ethical in nature (Steliarova-Foucher et al., 2017) as a common belief is that children do not get cancer, when in fact they do. Approximately 175,000 new cases of childhood cancer are diagnosed worldwide annually (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Therefore, although childhood cancer is referred to as being rare, there is still a substantial number of children and families affected by it. Due to these families seeking support, the larger community is often then also impacted by the diagnosis.

In Kenya, for example, it was noted that the caregivers of children diagnosed with cancer received support not only from extended family, but villagers and church members as well. However, the people in their support structures did not always encourage compliance with the child's conventional treatment due to misconceptions of cancer. Parents noted that people within their communities felt that their child should rather be treated by a traditional healer as their illness was due to being bewitched (Mostert et al., 2014). In Ghana it was also noted that parents' decision-making regarding their child with cancer is often based on social determinants and their personal experiences (Renner & McGill, 2016).

In Africa, traditional beliefs were a factor that influenced the mothers' and communities' beliefs regarding cancer. The mothers reported taking their children to traditional healers first as they believed that their community felt that the cancer or illness was a result of a curse of an ancestor. Only later did they seek Western medical intervention (Naidoo et al., 2016). In South Africa one of the reasons for childhood cancer being diagnosed late was the lack of awareness of early signs of cancer by the traditional healers, as well as lack of information that is available to the public (Edwards & Greeff, 2017). Globally, including in Africa, cultures influence healthcare in different ways. It is therefore crucial to disease prevention and health promotion to centralise language and culture in health behaviour interventions, particularly in African countries (Airhihenbuwa & De Witt Webster, 2012).

In Africa, healthcare has always included the component of traditional healing (Semenya & Potgieter, 2014). Reasons for this may be that in African culture the relationship with their ancestors is what predicts good health (White, 2015). Illness is also believed to have either an abnormal or normal course in African culture. When a symptom persists over time it may be believed to be abnormal and therefore sent by ancestral spirits. This is usually the case with

illnesses such as cancer and HIV as they do not have immediate Western cures. These cases of illness are then referred to the traditional healer (Munodawafa, 2002). The type of traditional healing varies depending on the culture and region from which the person comes. Traditional healing cannot therefore be compared from one healer to another (Mokgobi, 2014). Traditional healers are believed to be the mediums through which a person's spiritual and ancestral worlds, as well as their physical and psychological beings are communicated. These areas are believed to be interconnected (Turkington, 2017). In the traditional African communities, traditional healers are seen as part of healthcare and this should not be discounted or overlooked. It is therefore important that healthcare providers are aware of their patients' different cultures and provide culturally competent care. The providers need to be aware of their own cultural differences in order to become culturally competent. This is possible through training as well as experiences (Munet-Vilaro, 2004).

2.6.1 Childhood cancer and South African culture

Healthcare providers in South Africa need to be mindful of the fact that their patients, who may be children, and their families come from different cultures. Even within the medical field there is a connecting of cultures. These cultures consist of both the conscious and unconscious networks of collective life that impacts perceptions, decisions and actions (Barnes, Plotnikoff, Fox, & Pendleton, 2000). Thibodeaux and Deatrick (2007) state that children reside and experience the world within a family context and these families exist within a society that lives within part of a culture. People learn about culture from not only family but also from school, religion, the media as well as the government. There are variables that form part of the culture to which one belongs, these include ethnicity, religion, gender, socioeconomic backgrounds, status or class as well as educational level. Culture is therefore complex by its very nature. Due to the diversity within South Africa, it can be assumed that a diagnosis of childhood cancer would be experienced or perceived differently within the different cultures and so, perhaps even treated differently. It is recognised that culture influences the interpretation and perception of sickness and disease and often these cultural values and beliefs become more prominent when illness or, cancer, strikes the family (Munet-Vilaro, 2004).

Culture can even play a role in determining whether a child is taken to a treatment centre and if they are not, why not. According to Die Trill and Kovalcik (1997) within a community, the cultural beliefs of that community may determine the value attached to children and ultimately what will be done in order to preserve or maintain their health. The family's reaction to a sick

child may be determined by their cultural values and way of life. In South Africa, for example, in traditional communities, the mothers of the ill child were helpless as their families prevented them from taking their child to a treatment centre far from home (Edwards & Greeff, 2017). At times, this delay then resulted in a delayed diagnosis, which may have led to the child having advanced disease that could not be treated. Often these children die, and the mothers are left feeling guilty and struggling to cope.

2.7 UNDERSTANDING COPING

It is important that the child and their family are assisted to cope with their feelings and stressors, regardless of the outcome. Even without a childhood cancer diagnosis you will find that everyone's coping abilities differ. There are variables that will impact the individuals coping, for example, relationships, what other stress they are experiencing, whether they are resilient or not, as well as whether or not culture has an impact on them (Rule, 2010). The concept of coping has been relevant for many years and according to Folkman, Lazarus, Gruen and DeLongis (1986):

> Coping refers to the person's cognitive and behavioural efforts to manage (reduce, minimise, master, or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources. (p. 572)

Coping refers to how a person attempts to prevent or diminish their perception of harm or threat or even loss. It is an attempt to reduce distress. These attempts may be voluntary, or automatic and involuntary (Carver & Connor-Smith, 2010). Coping comprises of extensive personal tendencies, these may be stable traits, behavioural patterns or habits and cognitive efforts that attempt to handle stressors (Banerjee, Bhattacharya, & Sanyal, 2014). There are also different types of coping, for example, problem-focused coping and emotion-focused coping. Strategies such as planning and active coping fall into the problem-focused coping category, while engaging in distracting activities that aim to reduce emotional distress or venting emotions fall into the emotion-focused coping category (Bardi & Guerra, 2010).

Problem-focused coping can help change psychological stress for the better when change takes place within the environment, while emotion-focused coping focuses on changing the way that people react to or interpret what is happening. Not thinking about the threat takes away the stress of it, even if only temporarily. If the threat is reframed in a non-threatening way then the

cognitive aspect of the stress reaction is removed as well (Lazarus, 1993). Whether the person uses problem-focused, emotion-focused, or both forms of coping, the focus of the coping effort is always on trying to meet the external demands of the situation and manage the internal conflicts they generate (LaMontagne, Wells, Hepworth, Johnson, & Manes, 1999).

Sirois, Molnar and Hirsch (2015) discuss coping in terms of adaptive and maladaptive coping strategies. There are coping strategies specific to adaptive coping, these include: reframing the stressor in a positive way, actively planning and implementing steps to handle the stressor, seeking support in others and distraction – engaging in activities that distract from the stressor. Less adaptive coping strategies were escape-avoidance strategies whereby the person disengages from the stressful event whether cognitively, behaviourally or both.

Ultimately, when confronted with an experience that is possibly onerous, but also meaningful, coping is imperative. Coping is not static but rather flexible; it is a process that unfolds between human beings and their environment. This process is impacted by age, personality, circumstances and experiences (Kupst & Patenaude, 2016). Therefore, different people will react and cope differently to the situation of having a child diagnosed with cancer.

2.7.1 Childhood cancer and coping

When a child is diagnosed with cancer and is seriously ill the entire way of life for the family changes dramatically (Greeff, Vansteenwegen, & Geldhof, 2014), and they need to try to cope with this situation. Coping with a childhood cancer diagnosis and treatment is a process. This process is versatile and consists of various aspects, it is therefore essential that extensive information is used to understand the family's ordeal through precise assessment (Hildenbrand, Alderfer, Deatrick, & Marsac, 2014).

The families' welfare and adjustment may be negatively affected by parents constant anxiety (C. M. Warner et al., 2011). As mentioned, coping is not static; it is an evolving process that is guided by the situation. In terms of a child diagnosed with cancer, the parent will usually first cope with the trauma of the diagnosis, followed by the treatment demands, for example, being in hospital or distressing side-effects like nausea and vomiting. The parents then also need to cope with their child's physical and emotional reactions to diagnosis and treatment (Hoekstra-Weebers, Wijnberg-Williams, Jaspers, Kamps, & Wiel, 2012) .

Therefore such a diagnosis causes disruption within the family, including parental role confusion, as well as distress of the parents regarding what will happen with the child and their future (Peek & Melnyk, 2010). In a study conducted in Brazil it was noted that the most noteworthy aspect for parents who had a child with cancer was that of changing roles (Silva-Rodrigues et al., 2016). Dynamics and roles changes within the family are bound to happen when a child is diagnosed with cancer, but that does not mean that it is an easy task dealing with these changes, especially as the parents or primary caregivers have additional concerns.

Cancer is a long-term illness and, in some cases, can be seen as chronic. Childhood cancer affects the entire family, not only the diagnosed child (Elcigil & Conk, 2010). The experience of childhood cancer can consequently be very frustrating, overwhelming and upsetting for a parent and the family in its entirety. These caregivers and families are often anxious when their child is diagnosed with cancer and they struggle to cope as their coping abilities decrease (Marcus, 2012). When hearing of a childhood cancer diagnosis the people involved may feel a myriad of emotions. Often people associate cancer with death and, as mentioned previously, do not think children can get cancer (Grootenhuis & Last, 1997).

A parent's emotional and psychological functioning may be impacted by how they think about, process and regulate their emotions once their child has been diagnosed with cancer. Their emotional and psychological functioning then may have an impact on how they interact with their children (Dunn, 2012). This will be the case for both parents, however they may interact differently with the diagnosed child and their siblings. It was noted in a study that fathers of children with cancer reported greater psychological distress than fathers of healthy children. This finding when viewed from a social ecological perspective, means that this is important to the functioning of not only the father and family, but it has implications for the functioning of the ill child as well (Pai et al., 2007).

There is no way to determine which strategy a person will turn to in order to cope and maintain functioning until they are placed in a difficult position. According to Rodriguez et al. (2012) other coping strategies that may be helpful for these families include cognitive reappraisal and acceptance of the diagnosis and treatments. Coping with regards to childhood cancer however carries an additional stress from those of day-to-day living as the responsibility of the caregiver multiplies exponentially, they now have additional complicated and seriously important

caregiving tasks to perform for the ill child (Jones, 2012), thereby making the coping process even more challenging.

2.7.2 Childhood cancer and coping worldwide

Research in Lebanon confirmed the challenge of coping as it noted that the participants of the study battled to cope with the diagnosis and treatment of their child. The participants felt that the battle they were fighting was two-fold: against the disease itself and secondly the changes that were the result of the cancer (Khoury et al., 2013). The changes that take place due to such a diagnosis affect the disrupt the dynamics of the whole family, this is also due to the protracted period of time the child is ill. Due to the lengthily process of cancer treatment it is sometimes referred to as a chronic illness.

In a study carried out in Brazil the research showed that parents of children with a chronic illness have high levels of stress and anxiety due to the suffering they experience. It also indicated that parents of children with cancer had significant impairment of their emotional state (Alves, Guirardello, & Kurashima, 2013). According to Rosenberg et al. (2013) the emotional and mental anguish and worriment of the parent can negatively impact the welfare of everyone in the home, including the ill child and their siblings. There are ways in which the parent can alleviate some of this distress. What was seen to assist in the coping process was open and honest communication. Communication between the patient and parent is of essence when a child is diagnosed with cancer. By talking about the cancer the parent and child cope more efficiently with the process of diagnosis and treatment (Walls, 2011). It has been seen that the parents coping is related to their child's coping and vice versa. By communicating with their children openly about cancer and giving them appropriate information, parents alleviated the distress of the child (Suzuki & Kato, 2003).

By alleviating the child's stress the parents stress was also reduced. Research studies have found, from experience, that the better the child copes, the better the parents cope. This was found to also be the case in a study that was conducted by Angstrom-Brannstrom et al. (2010) in Sweden. When the child was able to cope with the process of treatment, the parent's anxiety and distress was decreased and they felt comforted by the fact that their child was able to cope. Parents were grateful to see that their children were able to adjust to the situation, even in the face of fear.

Parents of children with cancer tend to cope with the situation differently and this is often due to the different roles they hold within the family. Gage-Bouchard, Devine and Heckler (2013) agree with this and say that mothers usually look for social support and adopt more active coping mechanism whereas fathers do not. According to Brody and Simmons (2007), during a childhood cancer diagnosis both parents may experience a conflict within their usual role they fulfil. Parents who are the providers in the family, often the fathers, feel conflict between having to work and being able to stay with the ill child, whether in hospital or at home. In an American study it was seen that most fathers were active in 'doing' practical things in order to cope with the experience rather than focusing on the emotional aspect. This approach seemed to give fathers a sense of control and a distraction from an overwhelming and emotional situation (Hill, Higgins, Dempster, & McCarthy, 2009).

Acceptance is however, often reached over time, as caregivers say that the process gets easier with time and they find a 'new normal'. Caregivers and parents use varying coping mechanisms to achieve this.

2.7.3 Childhood cancer and coping in South Africa

In a study conducted in South Africa it was noted that various things could assist the family of a child with cancer to cope. These included: religion, support structures and certain personality traits. It was noted that if the participant had a strong support system, and those who were more positive, and outgoing were able to cope more effectively. The outgoing participants were also able to make their needs known (Marais, 2014).

According to Naidoo et al. (2016), there were three prevalent coping strategies that became apparent amongst rural South African mothers whose children were diagnosed with cancer. These were acceptance, prayer and lastly, optimism. Coming to terms with the diagnosis of childhood cancer was assisted by their acceptance of the child's health status. Prayer and optimism gave the mothers the reassurance that they would triumph over these challenging times in their lives. Coping is therefore possible, although not easy, but the ways in which caregivers cope varies.

In another study also carried out in South Africa it was seen that there are various challenges that parents have to contend with, which complicated their ability to cope. Families enter a crisis mode, and this makes caring for a child with cancer an even more arduous and exhausting experience, for everyone involved, especially as it is a long-term task. Coping becomes a

challenge. The changes that take place during this time are so vast that it is not possible to go back to how things were before the diagnosis (Maree, Parker, Kaplan, & Oosthuizen, 2015). Each family views the situation differently, and therefore although there may be similarities, families ultimately cope with their circumstances differently.

2.8 THE INFLUENCE OF CULTURE ON COPING

Cultural beliefs have an impact on how one copes. A person is guided by their values and beliefs daily and depending on these beliefs they are able or unable to access various resources within themselves. Their choice of coping strategy is shaped by their cultural context (Aldwin, 2004). A diagnosis of childhood cancer is a significant event in each family members life. These significant aspects of their lives and how they deal with and process them is impacted by their culture. Social resources that are accessed and available to these primary caregivers are also influenced by culture (Chun, Moos, & Cronkite, 2006).

A diagnosis of childhood cancer may possibly call the family's cultural beliefs into question. If culture is something that is usually relied on to help them deal with difficult times it may mean that their ability to cope is diminished. This can be problematic when being in a very vulnerable position of serious illness. Across cultures there are differing meanings assigned to health, illness and even disability (Ravindran & Myers, 2012). According to Gray et al. (2014), each and every family has its own ‘culture’ and therefore the way in which healthcare providers broach culturally sensitive aspects such as disease, healing and death needs to be carefully considered.

2.8.1 Influence of culture on coping worldwide

How then does a parent cope within their culture and with the diagnosis? According to Kuo (2011) the sociocultural Model of Stress, Coping, and Adaptation “views coping as a function of individuals’ stress appraisal, coping resources, social support, resources afforded by their culture, and others’ reactions in the social context” (p. 1088). There do, however, appear to be norms that encourage the use of certain coping strategies within a culture. From this the association between coping and cultural values can possibly be explained. An example would be a family from a culture that is traditional and believes in turning to religion for assistance, they may cope better by turning to religion as this is viewed as a culturally normative coping strategy (Bardi & Guerra, 2010). In Chinese traditions the opposite can be observed, where it is believed that illness is God's punishment for past sin (Yeh, 2003). The caregiver may turn

away from God or feel shunned by their religion, thereby decreasing their ability to cope. These two beliefs are completely different and yet they both may need to be treated within the same healthcare system.

Korean mothers that participated in a study regarding their coping strategies and psychosocial adjustment, carried out by Han et al. (2009), also suggested that clinicians need to be more aware of the how they provide information to certain individuals or groups to prevent a negative experience due to their cultural coping style. Further studies need to be done, and they should include various coping strategies and how, within a cultural context, they assist with social, intra-familial and psychological adjustment in a family where there is continuous stress due to a child having a cancer diagnosis (Han, Cho, Kim, & Kim, 2009).

In the United States of America, a study was done regarding the Latina mothers of children who had been diagnosed with cancer and what their stressors were. Their stress levels were higher due to various factors including economic, immigration and acculturation (following meeting between cultures, it is the process of psychological and cultural change that takes place) stressors, as well as cultural factors and language barriers (Johns et al., 2009).

Depending on the caregiver's culture, they may also have varying opinions of what their role is exactly. In Iran it was found that the caregivers or parents felt the huge burden of medical tasks, for example, frequent hospital or clinic appointments, giving medications and monitoring side-effects etc. as well as caregiver tasks, in addition to dealing with their own emotional distress. Iranian caregivers also felt responsible for the siblings of the ill child and other family members and helping them to adjust to the situation (Taleghani et al., 2012).

Another American study by Wiener, McConnell, Latella and Ludi (2013) noted that cultural customs and norms should be acknowledged and considered as these apply to and affect the decision makers in the family and those who need to understand the diagnosis, treatment and possible outcomes. Some families struggle to better understand the process and treatments, due to the fact that they face far more adversity than others and this needs to be considered when dealing with families in South Africa.

2.8.2 Influence of culture on coping in South Africa

Most families in South Africa are challenged with various forms of adversity and may therefore struggle more to cope with a diagnosis of childhood cancer due to these additional stressors (Rule, 2010). Accessing how a family usually adapts may be difficult due to the diagnosis being

an unexpected and traumatic event. The family may need assistance from a social worker to identify how they can strengthen their coping and resilience (Jones, 2006). Each person within the family system may react to this trauma differently and so the social worker needs to note this and provide appropriate supportive services to each individual member of the family that will meet their specific needs in order to cope sufficiently (Marais, 2014).

According to Jithoo (2010), a South African researcher, all psychosocial care should be attainable by all members of the population, regardless of status. This psychosocial care network should take into consideration the culture of the people it is dealing with, and ideally be non-prescriptive. Families should be looked at holistically and this includes the relationships within the family system. It has been seen that families seem to cope better with the diagnosis of an illness when their relationships prior were stable and they were well supported (Rule, 2010).

A diagnosis of childhood cancer cannot be viewed in isolation but instead in the social, cultural and economic context from which these families come. Families assign a certain meaning to their circumstances and this impacts their ability to favourably fight the cancer (Brody & Simmons, 2007). Primary caregivers are the ones in the family that establish how the family functions, as well as its psychosocial and emotional environment, playing an essential role in determining how the family will handle the diagnosis. The significance of how the primary caregivers cope is therefore of great importance (Patistea, 2005).

The healthcare system too has a culture itself that must be taken into consideration and integrated into the families' experiences. The family will need to understand, interpret and ultimately comply with this system to receive the treatment that their child so desperately needs (Jones, 2006). It is important for families to be allowed to receive healthcare that is in line with their values and beliefs and many practitioners need to be made aware of the importance of cultural issues within healthcare so that they can act with cultural humility and sensitivity (Tervalon & Murray-García, 1998).

In a study carried out in Sub-Saharan Africa by Østergaard (2015) it was found that the patients had more faith and trust in the healthcare professionals if they found them to be fair and respectful in the way in which they communicated. In South Africa communication can be complicated, especially in the healthcare setting where the healthcare professionals and the patients or family may not speak the same language. Penn and Watermeyer (2018) confirm this

by stating that there are huge communication difficulties in the healthcare sector and so the need for competent interpreters is essential. “The type of interpreter used at the different sites has a profound influence on the medical interaction and on factors such as accuracy of diagnosis, patient satisfaction and level of adherence” (p. 178). In a multicultural and multilingual society such as South Africa more emphasis should be placed on the need for trained, medical interpreters, as currently there is no official system for medical interpretation .(Hunter-Adams & Rother, 2017). Currently healthcare professionals mainly rely on informal interpreters and translation.

Ultimately, “it is a well-recognised fact that cultural and linguistic factors pose barriers to a patient’s ability to access health care systems, health information, and treatment instructions, or even to adhere to treatment regimens” (Watermeyer, 2011, p. 71). By addressing the problem of communication difficulties across cultures and between healthcare providers, including allied healthcare professionals, and patients and their families, the gap between culture and healthcare could begin to be bridged.

There are numerous other health professionals and allied health that make up a multidisciplinary team that will treat the child and work with the family within a Western medical facility, for example, doctors, nurses, social workers, physiotherapists and occupational therapists. It would be helpful for the families if healthcare professionals were empowered with the correct skills and knowledge to make culturally appropriate clinical decisions and ultimately implement these interventions (Li, Chung, Ho, Chiu, & Lopez, 2011). It has been suggested that healthcare professionals can make the experience easier by providing individualised care and providing consistent and clear information (Gibbins, Steinhardt, & Beinart, 2012). This necessity remains unchanged to date. Although patients and families’ hospital stays can be made easier, there are still other stressors outside of the hospital environment that add strain. It is therefore important to take into consideration when a child is diagnosed with cancer that there is an accumulated load of stressors and burdens, as mentioned above, as well as socio-demographic stressors, and that these have a potential impact to increase psychological distress (Bemis et al., 2015).

2.9 UNDERSTANDING RESILIENCE

The understanding of resilience has improved over the past few decades and through this, further theory can be explored and hopefully useful avenues for interventions will be

discovered (Luthar, Cicchetti, & Becker, 2000). While some families manage to be resilient and emerge more resourceful and strengthened through crisis events, others are shattered and struggle to be resilient (Walsh, 2012).

2.9.1 Definition of resilience

There are numerous definitions of resilience when used in relation to human beings and often the nature of the definition is dependent on the circumstances and sociocultural context in which the research was conducted. The researchers' theoretical inclinations and the population sampled would also influence the definition that the researcher constructed (Fletcher & Sarkar, 2011).

According to Aburn, Gott and Hoare (2016), there are some similar themes when it comes to the definition of resilience, however these are not universal. They include that resilience is not a static process but rather an evolving one that includes adjustment and adaptations to be made, and encourages the person to rise above their circumstances. For this research however, when defining resilience as a concept on its own, resilience will be discussed as a phenomenon whereby, despite serious threats to the persons advancement and adaptation, there are positive resolutions (Masten, 2001).

There are different schools of thought when it comes to resilience. Some researchers / professionals feel that due to resilience being an emotional ability it is therefore also thought to be an acquired behaviour (Passi, 2014), i.e. they feel that resilience can be learnt. While others feel that it is inherent and just needs to be accessed, they argue that resilience is in all of us, our minds and brains and in our relationships and communities. Resilience is not seen as rare or a special character trait, but rather a normal human resource available to everyone (Masten, 2001). Another more culturally accurate definition of resilience noted by Ungar (2008) states that:

> in the context of exposure to significant adversity, whether psychological, environmental, or both, resilience is both the capacity of individuals to navigate their way to health-sustaining resources including opportunities to experience feelings of well-being, and a condition of the individual's family, community and culture to provide these health resources and experiences in culturally meaningful ways. (p. 225)

According to Panter-Brick (2015), resilience is when you accomplish more than simply functioning well, or more advantageously than anticipated. While Southwick (2014) says resilience is when one makes sense of the principled aspects within your life. Regardless, when prolonged, frequent stress diminishes one's resilience. While positive stress has its importance in order for healthy development to occur, in order for resilience to occur, it is important that regular, strong, protracted stress be avoided or at least buffered when possible by healthy and supportive relationships (Herrman et al., 2011).

2.9.2 Childhood cancer and resilience

According to Konnikova (2016), Bonanno, a clinical psychologist, identifies that one of the central elements of resilience, is perception. The way in which one conceptualises an event is important, i.e. whether an event is perceived as traumatic or as an opportunity to learn and grow. Events are only traumatic if that is our perception of them. For most patients and their families, the diagnosis of childhood cancer is perceived as traumatic. The entire family view this experience as a challenge and crisis in their lives. It is not only the patient who needs to be resilient but the entire family as well. Family resilience as a concept refers to a family's ability to recover and grow in the face of these challenges and crisis. Family resilience looks at the family's functioning as a whole and how they function in adverse situations (Walsh, 2012).

According to parents of children diagnosed with cancer, different definitions of resilience are simultaneously true. A cancer diagnosis and the ability to "live normally" and move forward demonstrates resilience. This resilience is shaped by personal resources such as being positive/optimistic and self-sufficient. A person's resilience is also shaped by how they are able to evolve through experiences of illness including cumulative stress and personal growth (Rosenberg et al., 2014). Each person's or caregiver's experience of childhood cancer varies.

Caregivers' personal opinions of the cancer experience will determine their definition of resilience. Factors of resilience depend on the caregiver's prior expectations of cancer, as well as their inherent traits, i.e. their baseline characteristics. Whether or not they are resilient will also depend on evolving processes such as their social support structures and coping strategies and social support. Depending on these factors, psychosocial outcomes will become evident,

for example, post-traumatic growth and absence of psychological distress (Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013).

It appears that resilience within these parents may be brought about by various elements of the cancer experience, for example, if they are in a supportive environment and find their challenges manageable (Phipps et al., 2015). Fathers specifically were more likely to display resilient characteristics that enabled them to adjust to the changes in their family life when they used productive and effective communication patterns, in conjunction with social supports (Brody & Simmons, 2007).

2.9.3 Childhood cancer and resilience in Africa

According to Theron, Theron and Malindi (2013), resilience should not be generalised across cultures and contexts and therefore there should be more research carried out on resilience and its meaning within specific cultural settings, especially Africa.

Aldwin (2010) also says that the variety of stressors that people are faced with, within their culture, differs according to whether they are male or female, their socio-economic status, and their ethnicity. The type of stressor and the challenges it presents will have an impact on the person's resilience.

2.10 THE RELATIONSHIP BETWEEN COPING, RESILIENCE AND CULTURE

Findings from a study by Bonanno (2005) raises an interesting question as to whether resilience means different things in disparate cultural backgrounds. More importantly though, he also raises the question of whether differing cultures could in fact teach each other about alternate, effective ways of coping with extreme hardships, an example of which would be childhood cancer.

2.10.1 Coping and resilience

Coping in a paediatric oncology setting happens within a process (Zander, Hutton, & King, 2010). This process takes place for all involved, from staff, to the ill child, to their family. Nothing takes place in isolation. According to Zomerlei (2015), family resilience results from a combination of things, including important experiences from prior to the cancer diagnosis, family dynamics, parental aspects, as well as extra family support. This shows that resilience is also a process that takes place over time and in conjunction with many varying factors.

Greeff et al. (2014) emphasises how a number of coping strategies may need to be incorporated in order to deal with a crisis situation. These coping strategies may be internal such as denial, optimism, acceptance, and relying on religion or external, for example, information gathering, problem solving or getting assistance from others. Our coping strategies are part of a process that therefore leads to our resilience and, ultimately, whether or not a person is able to 'bounce back' from adversity.

Personal, as well as coping, resources can be increased over time if one is exposed to ongoing, positive emotion-related experiences. These repeated constructive emotions may broaden one's mindset and become ingrained (Tugade & Fredrickson, 2007). This broadened mindset leads to resilience.

2.10.2 Culture and resilience

A childhood cancer diagnosis is a traumatic and life-changing experience (Griffiths et al., 2011). The families' coping ability, ability to adapt to change and resilience will be shaped by the families' frame of reference and ultimately their culture. Social and cultural aspects, as well as various biological and psychological aspects, are the basis of resilience. These aspects interact with each other and the result is how one deals with trying circumstances (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). How one deals with stressful experiences indicates one's resilience or lack thereof.

Wright, Masten and Narayan (2013) found that culture is an essential component of understanding resilience. Cultural evolution has put into place protective systems, in the same way that human beings equip themselves with adaptive systems, through biological evolution. It is therefore imperative that culture be considered when attempting to understand resilience. Ungar (2013) notes that the process of resilience is associated with factors that protect against trauma associated with both immediate and prolonged stressors. These factors are complex and dependent on one's culture. In a separate study Ungar (2012) also notes that context, as well as culture, configure the setting within which the processes connected with resilience take place. Some of these processes are more pivotal to growth and adaptation than others. "Resilience is negotiated, navigated, and driven by culturally specific, diverse, and often-changing goals" (Panter-Brick, 2015, p. 242).

2.10.3 Coping, resilience and culture

From the literature, it is evident that there is research pertaining to each of the elements of culture, coping, resilience and childhood cancer, however very little research on the collaboration of the terms in South Africa. It has been suggested that there is a demand for research regarding how healthcare professionals can respond to patients and families of different cultures. This research needs to investigate how culture is experienced and viewed within different cultural worlds (Rule, 2010). This study aims to hopefully contribute knowledge and understanding in this regard. It aims to hopefully determine the impact of cultural practices on the coping and resilience of primary caregivers when their child is diagnosed with childhood cancer and treated in a private hospital in South Africa.

Questions raised by Zomerlei (2015) were regarding why some families struggle while others cope well, and what resources (community, familial, individual) would assist or enable primary caregivers to cope successfully with their distress. What are the specific hindrances to resilience? The researcher hopes to determine whether culture impacts on coping and resilience of the primary caregivers in a family where a child has been diagnosed with cancer.

2.11 THE SOCIAL WORKER'S ROLE

The function of a social worker includes being able to recognise the complicatedness of people's experiences, be aware of the effect of disadvantage and vulnerability, as well as individual and structural barriers. A social worker should believe in a person's capability to develop and transform. Social workers should receive continued professional development (CPD) training in order for them to be able to accomplish the above (Scholar, McLaughlin, McCaughan, & Coleman, 2014). In South Africa social workers are required to be registered with the South African Council for Social Service Professions (SACSSP) and their professionalism is guided by a code of conduct and ethics set out by this professional body. The SACSSP also monitor social workers CPD points and these are required in order to maintain an up to date registration.

Social workers ultimately encourage and support the overall well-being of their clients and families that they engage with. Social workers address the individuals social circumstances and context in order to assist them personally, as well as the public and structural problems they may be encountering (Towns & Schwartz, 2012). There are various types of social work and areas of social work; these include statutory work, community work, medical, welfare and

adoption work, as well as marriage and family services. They may work in trauma settings or even corporate companies where they would assist a variety of clients in numerous work environments that are potentially extremely stressful (Wagaman, Geiger, Shockley, & Segal, 2015).

Social workers can also perform psychosocial needs assessments within various settings and the necessary resources their clients may need. Social workers need to be reflective in their work in order to be able to bracket their own emotions and see their client's and their experiences from their frame of reference and without personal bias or subjectivity. As Ingram (2013) notes, social workers engage in a two-way process with regards to emotions, their client's emotions and their own and so they need to be self-aware and recognise the impact that this may have on them. It is therefore emphasised that social workers need to be resilient and capable of coping with the emotional demands of their occupation (Grant & Kinman, 2012).

2.11.1 The social worker's role in healthcare

In each secondary setting where a social worker may be employed, there are unique and specific challenges that a social worker may encounter. This is particularly apparent in a health care setting (Craig & Muskat, 2013). Within a complicated health care system social workers are able to help recognise unmet needs in patients and help them to navigate the healthcare system in order to attain the best possible level of functioning (Reckrey et al., 2014). Ultimately the social work profession is guided by central values and these include the worth and dignity of the patient or person, as well as, the significance of human connections (Bogo & Wayne, 2013).

In a study conducted by Browne (2019) it was found that social workers are often the link between the various treating teams of the patient, thereby facilitating better care for not only individuals but populations as well. These health social workers take on a biopsychosocial approach and look at the patient as a whole and within their context. Viewing the patient within their context is essential as the patient's health is not limited to being in a clinic, they are part of a family and that family is part of a larger community. These families and communities can present the patient with numerous challenges, but also potentially useful resources (Allen, 2012). Although social workers are involved in various hospital settings throughout the world, they are not always fully engaged and utilised by other healthcare practitioners. Beddoe (2013) suggests that further research should be conducted in order to assess the perceptions of these other healthcare providers regarding the value and role of social workers.

2.11.2 The social worker's role in oncology

Internationally, cancer has become a prevalent disease and social workers, as well as other professionals, are involved with working with oncological patients as the benefits of psychosocial services have been noted (Yi, Kim, Choi, Kim, & O'Connor, 2018). In an oncological setting there are various psychosocial interventions which can be implemented by the social worker. These include assessments, adjustment and crisis interventions, loss and bereavement interventions and survivorship care. Social workers also coordinate appropriate resources and support both social and community, and refer to other services when necessary. Social workers support the well-being of the individual, families, caregivers and communities and contribute to continued cancer care (Pockett et al., 2016).

Social workers working in the oncology field adopt a family-centred approach within their scope of practice (Patenaude, Pelletier, & Bingen, 2015). In New York there is a cancer care program for veterans where social workers are part of the treatment team. The role of these social workers is to assess the bio-psychosocial needs of the patient and any other family member. They then may provide counselling, information and education about the cancer and the treatment process, locating support services to improve compliance to treatment, finding necessary mental health programs, as well as home care and benefits and financial counselling (Clark et al., 2012). Social work in the oncology setting therefore encompasses an extensive range of services as these social workers work with a vulnerable population who are experiencing numerous challenges (Preyde & Synnott, 2009). Social workers working in an oncology setting need to be culturally competent as they will encounter various ethnic groups (Zebrack, Walsh, Burg, Maramaldi, & Lim, 2008). Oncology social work can be challenging, but despite these challenges and stress it provides these social workers with a sense of growth (Yi et al., 2018).

Similarly, within the context of paediatric oncology, the social workers role is the same as within any other healthcare or oncology unit or setting. In paediatric oncology the social worker may also liaise and collaborate and communicate with the patients and sibling's schools, community organisations and other necessary role players to educate them regarding the impact of a childhood cancer diagnosis on the patient and siblings. Social workers working within the paediatric oncology environment form part of a multidisciplinary team (Patenaude et al., 2015).

There are numerous challenges that exist when attempting to manage cancer in multicultural environments. An essential consideration in clinical healthcare is culture as it contributes to

creating and guiding patients' health-related behaviours, beliefs, and values (Brown, Ham-Baloyi, Rooyen, Aldous, & Marais, 2016). This is the situation in paediatric oncology settings within South Africa and social workers working in this environment therefore need to be sensitive to various cultures.

2.12 THEORETICAL FRAMEWORK

Overall, more research has been done in the field of adult cancers and very little in paediatric oncology. Culture, coping and resilience are all multifaceted and complex concepts. The researcher will be using the systems theory and the sociocultural model of stress, coping and adaptation to underpin the study.

2.12.1 Systems Theory

Generally, systems theory is concerned with the structure of complex systems, with a special emphasis on how parts relate to each other and to the whole system. In the social sciences, this usually means understanding how individuals relate to each other and to their society as a whole, and the effect that social pressures have on individuals (Flamand, 2016).

"A familiar demarcation of systems in social work involves the designation of particular social systems as being micro-, mezzo-, or macrolevel depending on system size and complexity" (Friedman & Neuman Allen, 2011, p. 7). The differentiation can be seen in Table 2.4.

Differentiation between social systems	
Social System	**Description**
Micro-system	Individuals and couples.
Mezzo-system	Intermediate-size systems, including groups, support networks, and extended families.
Macro-system	Communities and organisations.

Table 2.4 Social systems

All aspects of these three social systems are affected when a child is diagnosed with cancer. Helgeson, Jakubiak, Van Vleet and Zajdel (2018) are in agreement and noted that

> Family systems theory states that (a) an event that occurs to one family member affects other family members and (b) their responses in turn affect the target family member. That is, not only does the family affect how one responds to a health threat, but the health threat affects family interactions as well. In other words, family systems theory assumes that behaviour takes place in an interpersonal context. (p. 2)

2.12.1.1 Childhood cancer and systems theory

Marcus (2012) states that it is imperative to integrate a family systems approach when dealing with families and children that are affected with childhood cancer. According to (Crespo, 2012), the tenet of family systems theory is that the whole being is greater than the separate entities that make it up. The family systems theory therefore focuses on the family as a whole and the relationships within the subsystems that constitute the family. Coping with cancer within the context of a family system means that each family members' identity within the family, and their role, needs to be managed. Each person's emotions also need to be managed. "Coping in the context of cancer describes a method of integrating the cancer experience into the existing personality of the patient or family member" (Kupst & Patenaude, 2016, p. 68).

This theory relates to the study as the researcher will be looking at the parent's ability to cope and be resilient in relation to their culture and experience of childhood cancer, as one knows that childhood cancer affects the entire family. As discussed earlier, culture includes knowledge, beliefs, arts, morals, laws and customs that a person acquires by being a member of society. By researching the realm of culture, the community or social structure from the which the individual comes, the macro level is being investigated. The mezzo-system would then focus on extended family and support organisations which may come into play when a parent is trying to cope with the diagnosis of their child. Finally, on the micro level, the researcher will use the systems theory to understand the dynamics within family, the cultural influences and how these things affect the parent.

Rosenberg et al. (2013) also found when researching parents and their coping with a childhood cancer diagnosis, that the systems theory applied. The research suggests that the entire family is impacted when there is a crisis or continual challenges. The research also showed that when a child is diagnosed with cancer pre-existing vulnerabilities may emerge. Some families will manage better within their system than others. The roles within the family system change and all members are forced to adapt to their new role when a child is ill with cancer. The roles of

the family change as the sick child now has new needs that need to be met (Chaudhry, Abu Talib, Awang, & Ahmad, 2016).

You may find that some caregivers will rely on the patient for their positivity or their spouse on a microlevel, while others may focus more on the mezzo level where they can get help from extended family and support groups, etc.

2.12.1.2 Childhood cancer and systems theory worldwide

According to Long and Marsland (2011), a child with cancer and their siblings belong to a family system and will therefore be affected by the way in which the family reacts to the diagnosis. The way in which the family manage the change within the family system may impact both the patient and siblings' outcomes. These outcomes may be positive adjustment and growth, or on the other hand may be suggestive of increased distress and even psychological problems.

Within the family system many things may change, including roles within the family. Often the mother may need to be with the child in hospital and therefore work less, where the opposite is true for the father as due to accumulating medical bills he may need to work more (Marais, 2014). The relationship between the parents may also take strain due to the uncertainty around the child's diagnosis and treatment, as well as all the additional stressors. Communication difficulties may arise between parents (da Silva, Jacob, & Castanheira Nascimento, 2010). Difficulties between the parents will affect the entire family system.

2.12.1.3 Childhood cancer and systems theory in Africa

The entire family system is affected when a child is diagnosed with cancer. How the family system functions may impact treatment decisions. In Kenya, a study showed that a parent or caregivers' inclination to stop treatment or seek alternative treatment is often impacted by people who are close to them, even community members. The parents perception of cancer and treatment can be influenced by those within the systems to which they belong (Mostert, Njuguna, et al., 2014).

In South Africa the systems theory can be linked to the concept of ubuntu. According to Gade (2012) "Bongani Finca, a former TRC commissioner, elaborated the idea that ubuntu is about interconnectedness in greater detail" (p.492). He said ubuntu is defined by the concept that

‘people are who they are because of others. Nobody lives in isolation; everyone belongs to a community. Ubuntu connects with the macro level and promotes a reliance on community for support and building character. This ubuntu is not only extended to people in South Africa but also to those who come from outside our borders to receive treatment here.

Often foreign caregivers, who come to South Africa with their child for treatment, have to rely on organisations such as Childhood Cancer Foundation of South Africa (CHOC) for physical support. This would represent the macro level of the systems theory. Every aspect of the family is affected and, on every level.

2.12.2 Sociocultural model of stress, coping and adaptation

Secondly, the Sociocultural Model of Stress, Coping, and Adaptation will be used in collaboration with the systems theory. According to Thibodeaux and Deatrick (2007), the way in which a family manages and define a diagnosis of childhood cancer is directly connected to their cultural background. A diagnosis of childhood cancer is known to be a stressful situation. This model hypothesises that an individual’s beliefs and values are shaped by their expansive cultural beliefs. These cultural beliefs also impact the way in which others’ react in, or towards, stressful experiences and circumstances (Kuo, 2011).

The framework of this model is that coping is a function of a person’s evaluation of whether something is stressful or not, what coping resources they have, what social support and resources they have available to them due to their culture, and how others react within their social setting. According to this model if the primary caregiver has cultural expectations and resources, these will impact on their perception of the diagnosis (stressor), which will then affect their judgement regarding the overall stressfulness of the situation (Kuo, 2011).

Hill et al. (2009) emphasises that beliefs within society and their assumptions regarding what is expected of men, as opposed to what is expected of women, impact on how society sees appropriate coping for the different genders. Socialisation theories of coping therefore suggest that woman use more emotion-focused coping techniques, while men use more instrumental and active coping strategies as they are believed to be more independent and assertive. By understanding how the parent copes and functions, in relation to the diagnosis and their culture, researchers will get an idea of how the rest of the family system copes and why. This may be

useful for future research regarding children and how they themselves experience their diagnosis of childhood cancer (Friedman & Neuman Allen, 2011).

2.13 CONCLUSION

According to de Pentheny O'Kelly, Urch and Brown (2011), in a society where cultural diversity is increasing globally, there are bound to be conflicts of belief systems. Healthcare providers find it challenging to change and adapt their working models to meet the demands of patients from various cultural backgrounds.

In this chapter the literature pertaining to childhood cancer, coping, culture and resilience was discussed in order to gain insight into these concepts. They were defined and then explored, not only on an international level, but within the South African context. While these concepts have been discussed individually, what is apparent is that understanding of how these concepts are linked together is not a simple process.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

Although research has been done on cancer and childhood cancer, very little has been conducted in South Africa, particularly by social workers. Perceptions of illness are influenced by culture and therefore so are people's responses to a cancer diagnosis. Despite the relative rarity of childhood cancer there are many types that affect children and it is on the rise in South Africa (Visser, 2010). The research question is therefore: What is the perceived influence of cultural practices on a primary caregiver's coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital?

In this chapter the researcher focuses on the research design and methodology that was used when carrying out this research in order to answer the research question above. First the aims and objectives are outlined, thereafter a description of the research design and methodology will be detailed. This is followed by a detailed list of the research process. Finally, the limitations of the research and ethical considerations, as well as trustworthiness and rigour, are explored and detailed.

3.2 AIM AND OBJECTIVES

3.2.1 Primary aim

To explore the perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

3.2.2 Secondary objectives

The secondary objectives included the following:

- To determine how primary caregivers understand the diagnosis of childhood cancer.
- To understand the primary caregivers' experiences of their child being diagnosed with cancer.
- To explore primary caregivers' perception of culture.

- To determine whether culture influenced the primary caregivers' ability to cope and if so, how.
- To identify primary caregivers' coping mechanisms.
- To explore the primary caregivers' understanding of resilience.

3.3 RESEARCH DESIGN

The research that was carried out was qualitative and phenomenological in approach. Qualitative research delves into the intricate realities that individuals have constructed for themselves. It deals with their everyday life experiences in a holistic way. Qualitative research bases its findings on peoples subjective realities rather than focusing on concrete phenomenon of objects (Erlingsson & Brysiewicz, 2013). Phenomenology too emphasises the subjective experiences of the participants and again, their interpretation of the world (Gavin, 2008). The researcher was looking at the impact of cultural practices on the primary caregivers' ability to cope from their perspective and from their frame of reference. A detailed exploration of the conscious daily encounters and social interactions of participants is what the researcher hoped to achieve and was the purpose of the phenomenological approach (de Vos, Strydom, Fouché, & Delport, 2011).

3.3.1 Qualitative Research Method

The researcher's aim, by using the qualitative research method, was to create knowledge and understanding of the phenomenon. This was done by exploring participants experiences and perceptions of their lives (Kornbluh, 2015). The researcher chose to make this study a qualitative one as this approach allowed the researcher to be flexible in the way in which questions were asked and also encouraged the participants to feel comfortable enough to answer questions and participate in the study.

In qualitative research, analysis of the information needs to be organised, integrated and systematic. Whilst doing this the researcher attempted to identify patterns and relationships amongst the information. From this the researcher was then able to identify themes (Neuman, 2014).

A qualitative approach involves an inseparable relationship between data collection and data analysis. The process of data collection provides ideas about directions for analysis. Possible themes and patterns may emerge during data collection and therefore making sense of these start the data analysis process whilst still collecting data. However, Schurink, Fouché and de

Vos (2011) highlight that it is important for the researcher to take caution not to rush to premature conclusions.

3.3.2 Phenomenology

According to Erlingsson and Brysiewicz (2013) phenomenology:

> is the study of phenomena and lived experience and it asks, ‘‘What is this kind of experience like?’’, ‘‘What meaning does this experience carry?’’ It is the study of lived experience emphasising pure descriptions and descriptions of essences. (p.96)

Sutton and Austin (2015) agree with this, stating, that phenomenology concentrates on exploring and understanding how the world is experienced by people. The researcher attempts to understand the participants subjective experiences by placing themselves in the shoes of the participant. A phenomenological study was deemed appropriate as this study revolved around experiences of caregivers in relation to the phenomenon of childhood cancer.

There are different types of phenomenology, namely: transcendental, hermeneutic and existential. The researcher used the transcendental phenomenology approach. Transcendental phenomenology was founded by Edmund Husserl. A basic explanation is that his belief was that that the researcher would be able to thoroughly explore the consciousness and therefore become aware of the fundamental make up of a phenomenon (Eddles-Hirsch, 2015).

Hermeneutic phenomenology on the other hand was established by Heidegger. He initially followed the transcendental approach but then discovered the hermeneutic approach. The difference between the two is that Heidegger did not agree with the researcher having to bracket his own perceptions and beliefs as he felt this was impossible. An essential difference between these approaches is in the focus of the research. Transcendental phenomenology focuses on descriptions of the participants’ experiences, from the participants’ frame of reference; while hermeneutics is interpretative in its representations (Todd et al., 2016). Finally, existential phenomenology explores the human existence and their actions in concrete situations. It also takes into account the perspective that humans have free will (Woodruff & Zalta, 2016).

The challenge of the transcendental phenomenological approach was that there was concern that the researchers own subjective feelings toward the phenomenon may be brought in. It was therefore imperative that all previous knowledge of the phenomenon that the researcher had,

be bracketed, so that they could be present to the new information they were being exposed to (Willig & Stainton-Rogers, 2010).

3.3.3 Descriptive research design

When the topic of the research is extremely complicated, descriptive research may be utilised (Goddard & Melville, 2011). This type of research encourages distinct and dense insights; and depictions of the phenomena from the participants' frame of reference (Watkins, 2012). This is therefore a descriptive study as it focuses on the primary caregivers' experiences of childhood cancer.

3.3.4 Strengths and weaknesses of a phenomenological qualitative research method

There are both strengths and weaknesses to this approach and they are detailed below.

3.3.4.1 Strengths

- A topic that had previously not had a lot of research done on it could be researched. This was true of the topic of coping and resilience with regards to childhood cancer. There is limited research in this area that been carried out by social workers in South Africa.
- The researcher was able to delve into the experience of the participant and retrieve detailed descriptions of their feelings and attitudes around childhood cancer, culture, coping and resilience. This was done by probing and asking spontaneous questions in the interviews.
- The participants experiences are looked at holistically and not in isolation. The participants were asked to detail their experiences and all areas were included from the physical, emotional and cognitive aspects.
- Through thorough analysis, complex issues can be better understood. Interpretative phenomenological analysis (IPA) was used and themes were explored more than once before being recorded.

3.3.4.2 Weaknesses

- The researcher had their own beliefs and values that may lead to bias. By keeping a reflexive diary, the researcher attempted to minimise bias.

- The data collecting and data analysing processes are very time consuming. The researcher kept meticulous notes and therefore could more easily make comparisons to previous analysis.
- Policy makers prefer quantitative results that allow them to adjust or create policies. Therefore, the researcher attempted to be thorough and detailed in the results so that policy makers could understand the importance of any changes that may need to be made.
- This qualitative research was unlikely to produce generalised data as it was participant dependent and subjective. Although the data may not be able to be generalised to the average population, it should be noted that the results may be transferrable to primary caregivers of children diagnosed with cancer in other private hospitals.

3.4 METHODOLOGY

3.4.1 Population

The population consisted of primary caregivers of children who had cancer and were seeking treatment at The Wits Donald Gordon Medical Centre. Participants were over the age of 18. The exact number of this population was unknown due to the fluidity of the paediatric oncology unit. However, approximately just over 30 new patients were seen in the unit in 2019.

3.4.2 Sample

The sample was one primary caregiver, per family, of children diagnosed with cancer. The reason for this is that there was usually one primary caregiver who stayed in hospital with the child, whilst the other continued to try and run the household, therefore the parent in hospital was more accessible and had more time to participate in the research. When, however, both parents were available and willing to participate in the research, the researcher allowed the parents to make the decision as to who participated in the interview. The parents did not have to be South African, but the child needed to be receiving treatment in the country at The Wits Donald Gordon Medical Centre.

3.4.3 Sampling Procedure

Purposeful sampling was used to recruit participants. Padgett (2008) explains that the process was deliberate in selecting participants so that they would be able to contribute the required necessary information. The aim of purposive sampling is to get enough people so that the

researcher can gather as much information possible in order to explore, interpret and understand the research question (Carey, 2013). There were specific inclusion criteria that were used to select potential participants.

The inclusion criteria included the following:

- The participant must be a primary caregiver of a child with cancer – a mother / father / step-parent / sibling / grandparent / foster parent / extended family member who is over the age of 18 years.
- Child must be treated for cancer at The Wits Donald Gordon Medical Centre.
- The primary caregiver must be familiar and comfortable to converse in English.

The ward clerk of the paediatric oncology unit assessed whether the primary caregiver met the inclusion criteria. If she felt that the primary caregiver was appropriate, she then gave them the participant's information sheet (Appendix B) and asked if she could give the researcher the caregiver's contact details. The researcher then made contact with the caregiver and once contact was made the researcher gave the caregiver the consent forms (Appendices C and D) and set up an appropriate time for a face-to-face interview.

The researcher endeavoured to make sure that the participants were representative of the ward population by choosing participants from various cultural backgrounds. According to Daniel (2012) there are both strengths and weaknesses when using purposeful sampling. They are listed in 3.4.3.1. and 3.4.3.2.

3.4.3.1 Strengths

- Provides more control with regards to who participates in the study. The researcher was able to select participants that would be more likely to meet the aim of the study.
- When research is focused on a particular target population it is more appropriate. The participants were able to discuss their experiences of childhood cancer as they were currently undergoing that experience.
- An advantage with this type of sampling was that there was deliberate choice in who the researcher interviewed and so it prevented there being a large number of participants, which could have led to a diminished in-depth picture and therefore superficial results (Creswell, 2012).

- It is a time-effective form of sampling. The researcher did not have to interview an endless number of participants to get information that would be appropriate to the study. By using purposeful sampling, the participants were chosen with the likelihood that the aim of the study would be met.

3.4.3.2 Weaknesses

- Another limitation may be that due to this type of sampling being purposeful, it was entirely at the researcher's judgement and discretion as to who gets interviewed and who does not. Researcher bias is therefore a weakness of this type of sampling (Sharma, 2017). The researcher was aware of this weakness throughout the study and therefore attempted to use reflexivity to prevent too prominent an influence or bias, as far as possible.

3.4.4 Sample size

The sample size was made up of 16 participants, one parent per family and consisted of one interview per participant. The researcher felt that they would manage to retrieve all information they needed in one interview.

3.5 RESEARCH INSTRUMENTATION

The researcher collected the information by asking open-ended questions set out in a semi-structured interview schedule or guide (Appendix A). This schedule or guide had been pre-tested.

3.5.1 Pre-testing of the research tool

The researcher also pre-tested the research schedule to make sure it was relatable to the participants. The pre-test was carried out on two caregivers who meet the inclusion criteria for this study. One was a South African mother and one was a Namibian aunt. The researcher included this mother in the pre-test as she could speak English but struggled at times to express herself properly and so the researcher wanted to make sure that the interview schedule or guide would be able to be understood by everyone. A semi-structured interview schedule or guide in a face-to-face interview was used. There were minor changes that needed to be made in the participant's information sheet, for example, changing the word 'parent' to 'caregiver'.

The researcher found that the interviews were quicker than anticipated, they ranged from 20 minutes to an hour per participant and perhaps, in some instances, more probing was needed. The question of highest level of education was added to this section as it may add an interesting dynamic to the research. The pre-test participants had very different levels of education and the researcher thought this may impact their answers. The researcher felt that perhaps the participants would therefore have varying levels of understanding of the concepts being explored.

The researcher saw the necessity of bracketing her own knowledge and opinions of the topic. This therefore made the researcher open to receiving the information that the participants had to share about the topic more objectively. The researcher found that the face-to-face interview was of value as the participants sometimes did not quite understand the question and the researcher could then rephrase it in a way in which they could understand. The question around the participants' understanding of resilience was removed as participants struggled with this question and the researcher did not want to daunt the participants with this question, but rather asked about their strengths, which links to their resilience. There was another question removed due to repetition.

3.5.2 Semi-structured interview schedule or guide

According to Carey (2013), a semi-structured interview provides the researcher with the opportunity to ask not only pre-planned questions, but spontaneous questions as well. The researcher has the discretion to ask additional questions based on their feedback to already asked questions.

The interview schedule contained questions about the demographic and biographic information of the participants, as well as questions about culture, coping and resilience. The questions asked were open-ended in order to be able to understand the participant's subjective perspectives. There are strengths and weaknesses to semi-structured interview schedules or guides.

3.5.2.1 Strengths

- The researcher could prepare the questions beforehand and therefore be prepared. The researcher took time to prepare the semi-structured questionnaire or guide and also pre-tested it in order to evaluate its suitability.
- As the questions were pre-planned, they could be made relevant to the aim of the study.

- The questions could be phrased correctly, and sensitive questions thought through. Due to childhood cancer and caregivers' experiences being a sensitive topic, the researcher was able to phrase the questions so that they were as appropriate and sensitive as possible.
- The questions could be sequenced strategically to assist the flow of the interview. The researcher was able to structure the interview guide / schedule in such a way that topics were grouped, and the interview flowed easily.
- The researcher was able to pre-test the interview schedule to make sure it was suitable to the participants. Prior to the commencement of the data collection for the research study, the researcher pre-tested the interview guide / schedule with two participants and made the necessary changes.
- A semi-structured interview schedule or guide provided a stable format to the process. The research process therefore was similar for each participant, which created consistency.
- There were inclusion criteria stating that the parent should be able to converse in English and so the participants should therefore be able to adequately express themselves.

3.5.2.2 Weaknesses

- It may seem more impersonal interviewing with a semi-structured interview schedule or guide. The researcher attempted to minimise the possible impersonal aspect of the interview by maintain eye contact with the participant and recording the interview, therefore the researcher did not have to make notes.
- Analysis of open-ended questions can be difficult. The questions were therefore not analysed only once but numerous times.

3.6 METHODS OF DATA COLLECTION

The method of data collection that the researcher used was face-to-face interviews. Open-ended questions were asked in order to gain insight and understanding of the ideas that the participant had about the phenomenon of interest (Gavin, 2008). There were both strengths and weaknesses of doing face-to-face interviews and these are now detailed.

3.6.1 Strengths

- The researcher was able to use various techniques and skills in order to get as much information as possible.
- The researcher was also able to take social cues from the participant and obtain extra information from the participants voice and tone, body language etc. This information added to the verbal answers (Opdenakker, 2006).
- The researcher administered the interview schedule and so the interview process followed the same structure for each participant.
- Pre-planned and spontaneous questions could be asked. The researcher was able to be guided by the participants responses and therefore was able to ask spontaneous questions that would add to the richness of the data.
    1. The researcher could make an effort to build a rapport and gain trust of the participant. The researcher attempted this through poise and non-verbal body language, as well as tone.
- If the participants struggled to understand a question, the researcher could read the verbal and visual cues and rephrase the question.
- "Through language people can best articulate and explain their thoughts, opinions, emotions and experiences" (Carey, 2013, p.127). As it was a face-to-face interview, the participants were given the opportunity to voice their opinions.

3.6.2 Weaknesses

- Interviews take time. The researcher was aware of this and so set aside appropriate time to do the interviews so that they would not be interrupted. Being aware that the interview would take time meant that the time needed could be managed efficiently.
- A lot of unnecessary information may be recorded if the participant goes off topic. By redirecting the participants back to the topic under discussion, the researcher attempted to minimise the amount of unnecessary information recorded.
- Honesty of the participant cannot be guaranteed. By ensuring participants were aware that their identity would at no stage be disclosed this encouraged the participants to be more truthful.
- Some participants may be introverted by nature and so not disclose a lot of information. The researcher was sensitive to the nature and personality of each

participant and used techniques, such as gentle probing, to get as much information as possible.

- Some participants may have felt uncomfortable or even intimidated by the researcher. By keeping a friendly and open disposition the researcher attempted to make participants feel as comfortable as possible.

Methods of data collection will now be detailed.

3.7 METHODS OF DATA ANALYSIS

The researcher used the interpretative phenomenological analysis (IPA) approach to analyse the data once collection had taken place. "IPA aims to understand the lived experience of a conscious, situated, embodied being-in-the-world, where "the world" is understood through a respondent's involvement in it" (Larkin & Thompson, 2012, p. 330). IPA therefore requires meticulous qualitative analysis of comprehensive participants personal experiences. This is usually done by using extensive semi-structured interviews to collect data (Smith, 2011).

The data analysis took place once it had been collected and transcribed. Patterns developed and themes were then identified. The trustworthiness of the study was addressed when analysing the data. The following four areas were considered: credibility, transferability, dependability and confirmability. These will be discussed in more detail later in this chapter.

According to Roberts (2013) IPA is a dynamic process that focuses on achieving a wealth of in-depth understanding of the participants experiences with regards to the phenomena being explored. IPA methodology required an extremely intensive and detailed analysis of the experiences by the relatively small number of participants. These accounts were captured through a face-to-face semi-structured interview process. The analysis then followed, and patterns were explored, and themes developed. IPA also inferred that the researcher cannot completely remove themselves, their thoughts and their beliefs in order to analyse the participants experience (Larkin, Watts, & Clifton, 2006). The analysed result of the data transcriptions can consequently be referred to as a combined effort by the researcher along with that of the participant (Smith, Flowers, & Osborn, 2002).

The researcher chose to use IPA because not only does it explore how the participant had understood the phenomenon being explored but it also contextualised the interpretation within

the participant's cultural and physical environments. IPA looks at the participants experiences, psychologically and sociologically, principally from that person's perspective (Carey, 2013).

Schurink et al. (2011) identify numerous stages in data analysis in the research process. The first step in beginning to analyse the data was transcribing it and storing it accordingly. This means converting the data to the form in which you intended to analysis it, for example written text and then organising it so that you can access what you needed, when you needed it.

All textual data was analysed numerous times in a systematic way. Once the data were collected and transcribed it was read and re-read and then analysed and themes identified. In IPA, for the researcher to attempt to prevent bias, it was important that she kept a reflexive journal. The researcher will become aware, via self-analysis, of any influences that may affect the process whereby the data was collected and analysed (Clancy, 2013).

Once themes were identified, connections between these themes were looked at. Similarities or differences between the themes were noted and grouped into 'clusters' or concepts. The intention at this point was to develop a group of themes that could then be subdivided into categories whereby hierarchical relationships could be suggested (Biggerstaff & Thompson, 2008). These findings then were written up. The strengths and weaknesses of IPA are discussed below:

3.7.1 Strengths

- Encourages the researcher to keep a reflexive diary so that the process is transparent. A reflexive journal was kept by the researcher, and entries considered when constructing the results.
- It is an adaptable approach, there is more space for freedom. The researcher was allowed the necessary freedom to analysis results and make connections numerous times, making the necessary adaptations.
- "Offers flexible and versatile approach to understanding people's experiences" (Tuffour, 2017, p. 5). The experiences of the participants were analysed from various angles and not constrained to only one way of looking at them.

3.7.2 Weaknesses

- There is the possibility of researcher bias. Again, as mentioned previously, a reflexive journal was kept, and supervision was used to try and maintain as much objectivity as possible.
- One cannot generalise the findings to larger populations. Although the results could not be generalised to a larger population, they may possibly be generalised to a smaller similar population of caregivers whose child was diagnosed with cancer and treated in a private hospital in South Africa.

3.8 THE RESEARCH PROCESS

The following steps were undertaken in this research process:

- A research topic was formulated.
- Literature was located and researched.
- A proposal was then constructed.
- Permission was granted from the CEO of the hospital (Appendix E), as well as the professor in charge of the paediatric oncology unit (Appendix F), for the research to be done in the unit.
- The proposal was presented at a social work department seminar and then submitted to graduate studies for approval.
- The research proposal was submitted to Wits Medical Ethics Committee for ethical clearance. Minor changes had to be made before ethical clearance was given (Appendix G).
- Caregivers were approached by the ward clerk if she felt that they were appropriate and gave them a participant's information sheet (Appendix B).
- If they were willing to participate, they gave their contact details to the ward clerk to give to the researcher and the researcher then made contact.
- A time and day for the interview was set up and the interview took place.
- The interview was recorded and later transcribed, with the participants permission.
- The transcribed interviews were then systematically analysed, and themes identified.
- The results were then written up.
- The research took place over several months.

3.9 ETHICAL CONSIDERATIONS

According to Kumar (2018), “ethics are the moral values of professional conduct that are considered desirable for good professional practice” (p. 476). Ethics in research are imperative and hold researchers accountable for their study. By having good ethical standards readers and the public can put trust in the research and therefore they may be more willing to fund future research. It should be noted that there was a welcome document in the unit that informed parents and/or caregivers of social work services and that they could arrange an appointment should they require them. The researcher was not the family social worker but arranged for another onsite social worker to manage the case if the family requested support. Due to the importance of ethics, the following ethical principles were considered and addressed in this report:

3.9.1 Credibility of the researcher

The researcher was a qualified, registered social worker. The researcher has been registered with the South African Council for Social Services Professions (SACSSP) from 2004 to present. The researcher had been working in the paediatric oncology setting since 2008 and so was knowledgeable regarding the topic of childhood cancer and dealing with families who are trying to adapt to the diagnosis. The researcher was aware of the sensitivity and confidentiality needed regarding the topic and had experience in working in such an environment.

3.9.2 Voluntary participation

It was made clear to the participants, in the participants information sheet, that their participation in the study was entirely voluntary and they did not have to participate if they did not wish to. Participants could have withdrawn from the study at any time without being penalised or victimised in any way.

3.9.3 Doing no harm

Due to the research process involving interviews of participants there was an ethical consideration that needed to be acknowledged. Within the research that is currently being discussed, ethical consideration needed to be given to the fact that it was possible that there may be psychological or emotional harm or stresses as a result of being asked to recall or recount difficult experiences. The researcher prepared the participant for this possibility by explaining the research and process beforehand and had a distress protocol in place. This

protocol entailed arranging the necessary therapy sessions with a social worker, if available, or psychologist, who would be appointed to them should they not have requested one earlier in the process. This was at no cost to the family and was onsite, at The Wits Donald Gordon Medical Centre. None of the participants made use of this service offered, however one of the participants made use of a free counselling service offered by her place of employment prior to the interview.

3.9.4 Informed Consent

The researcher needed to get informed consent from the participants (Appendices C and D). According to (Royse, 2011), the language used to educate possible participants should be age appropriate, jargon free and free of technical/ professional concepts that the average person may not easily grasp.

The potential participants were given a participant's information sheet and were fully informed about what the study entailed and its purpose, including the explanation that by doing this research the researcher hoped to be able to better understand what assists caregivers to cope and possibly make recommendations that will help primary caregivers' cope with a diagnosis in the future. And that the aim is to provide a culturally sensitive guideline on how best to help caregivers cope for healthcare professionals working with these caregivers.

The potential participants were informed regarding approximately how long the interview was going to take. Written informed consent was signed by participants prior to the commencement of the research.

3.9.5 Anonymity

The identity of the participants must be protected in order to maintain their wellbeing and this was done through anonymity and confidentiality. Due to the researcher conducting the interviews complete anonymity was not possible as the researcher knew the identity of the participants, however, anonymity was ensured with regards to reporting the results and participants are unidentifiable in the report. Anonymity implies that the participants' identity would not be disclosed at any time, including when the final report was compiled. In the final report pseudonyms were assigned to the participants and so the readers will not be able to identify a specific participant with a specific response. The information that was gathered was coded and only the researcher and the researcher's supervisor knew the participants identifying

details. Confidentiality and privacy are therefore maintained through the core research ethics principle of anonymity (Vainio, 2013).

3.9.6 Confidentiality

Confidentiality refers to the fact that although the researcher knows the participant's identity she promised not to divulge it in any paper, public forum or report (Bhattacherjee, 2012). Any information deemed sensitive will remain confidential and will not be linked to the identity of the participant. Participants were interviewed individually in a private room at The Wits Donald Gordon Medical Centre where the researcher had obtained permission to carry out the research. To prevent any concern of loss of privacy from arising, the researcher explained that the interview was confidential, and the participants identity would not be revealed in any way in connection with the results. The researcher explained that all data would be kept on a password-controlled computer and hard copies would be locked in a cupboard that only the researcher had access to. All stored data, the recordings and transcribed interviews, would be kept for five years and then would be destroyed.

3.9.7 Feedback and dissemination of results

The research participants were made aware that feedback was possible and that they were entitled to the results. They could request them in either hard copy or via email if they wanted to. In the participants information sheet, they were also made aware that the research dissertation would be submitted to The University of the Witwatersrand and might be used for academic purposes (published in journals or presented at conferences).

Feedback to the hospital regarding the results of the research would be arranged in the form of a formal presentation for the medical staff that work in the paediatric oncology unit at The Wits Donald Gordon Medical Centre.

3.10 REFLEXIVITY

The researcher is the means for obtaining the data in qualitative research, therefore there is the potential that, consciously or unconsciously, the researcher could influence how this process and the process of data analysis, happens. An example during a semi-structured interview for

instance, would be the researcher's body language (linked with emotions) towards the participants, which could influence the participants level of disclosure (Baillie, 2015).

The researcher therefore needed to bracket their own feelings and emotions when working on the research process and it was important to be self-aware and use reflexivity. According to Sutton and Austin (2015) reflexivity does not mean ignoring or avoiding your own biases, but rather looking at their world views and perspectives in such a way that they can clearly state their position so that readers are able to understand the filters that were in place when the participants were questioned or interviewed, data was collected and analysed, and the results were recorded.

The researcher kept a reflective journal, the purpose of which was to create a transparent research process (Ortlipp, 2008), and was conscious that she needed to be self-aware of preconceived ideas or perceptions regarding the research being carried out.

3.11 TRUSTWORTHINESS AND RIGOUR

Pereira (2012) stated that:

> to be judged valid, a phenomenological study must take into consideration methodological congruence (rigorous and appropriate procedures) and experiential concerns that provide insight in terms of plausibility and illumination about a specific phenomenon. (p.19)

The trustworthiness of the study therefore reflects the quality of the research. According to Hadi and José Closs (2015) it is imperative to illustrate rigour in qualitative research as the research results therefore have integrity and soundness to make an impact on both policy and practice. Rigour of a study refers to the research being methodically carried out and that it needs to be of a high standard (Baillie, 2015). Trustworthiness and rigour were addressed when analysing the data and the following four areas were considered:

3.11.1 Credibility

"A qualitative study is credible when its results, presented with adequate descriptions of context, are recognisable to people who share the experience and those who care for or treat them" (Hammarberg et al., 2016, p. 3).

The research needs to be conducted in a plausible manner and the credibility needs to be able to be exhibited (Houghton, Casey, Shaw, & Murphy, 2013). This research was conducted using the phenomenological qualitative approach. Phenomenology is a well-known and recognised approach to qualitative research that has been used for many years. The data collection and analysis methods were well thought through. In order to assist with the credibility of the research, the researcher kept a reflexive journal which assisted in keeping the process of the research transparent and assisted the researcher in bracketing their own opinions and perceptions around the topic.

The researcher also provided rich, comprehensive descriptions of the caregivers' experiences and their coping abilities during the process of having a child diagnosed with cancer. This provided insight to those who will read the results. These results were framed by a detailed literature review.

Korstjens and Moser (2018) say that credibility can be encouraged through persistent observation, meaning the data that is being analysed is read and re-read, analysed and thought through and the concepts are then revised and adjusted accordingly. The researcher should study the data throughout the process until in-depth insight is reached and final results concluded. According to Barusch, Gringeri and George (2011), throughout the process researchers should be honest and accountable in detailing the decisions they made when executing various approaches to demonstrate credibility. The study and process cannot be evaluated without accountability.

3.11.2 Transferability

Transferability refers to the potential of the findings of a study to being transferred or generalised to other contexts and/or groups (Elo et al., 2014). However, according to Leung (2015), due to qualitative research dealing in particular with certain phenomenon within specific populations or groups and contexts, it is usually not anticipated or expected that the conclusions will be able to be generalised. It may be however, that the findings of this research may be applicable to other primary caregivers of children diagnosed with cancer who are being treated in another private hospital.

3.11.3 Dependability

Dependability or reliability refers to discerning whether or not the research methods and application were appropriate and sound. Dependability looks at the integrity of the concluding

results (Noble & Smith, 2015). This can be a daunting task as there are no set rules as to how the researcher should do this exactly. One way of doing this is through coding and then re-coding the data, thereby allowing multiple observations by the researcher (Anney, 2014).

Another way in which dependability was addressed was by presenting an extensive description of the methodology used so that this study can be replicated by other researchers in other contexts (Zomerlei, 2015).

3.11.4 Confirmability

The data analysis needed to remain objective so that when the data was assessed alone it confirmed the general findings (de Vos et al., 2011). To check confirmability of the study there was a documentation process and audit trail. An audit trail documents each step completed during the collecting and analysing of the data, this strengthens confidence in the research data (Royse, 2011). Accurate transcriptions were also important for confirmability of the research. It was important that what was said in the interview was what was transcribed; hence, the large amounts of time taken to transcribe and check the data.

“The interpretation should not be based on your own particular preferences and viewpoints but needs to be grounded in the data. Here, the focus is on the interpretation process embedded in the process of analysis” (Korstjens & Moser, 2018, p. 3).

3.12 CONCLUSION

In this chapter the phenomenological qualitative approach that was used was discussed. The research methodologies that were carried out were also explored and the strengths and weaknesses of each contributing element discussed under that section. The research process was summarised. This was followed by a detailed exploration of the ethical considerations and reflexivity. Finally, the trustworthiness of the research was addressed.

CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION

The aim of this chapter is to present and analyse the qualitative data collected during the research. Demographic details of the participants will be presented first, followed by the demographics of the child for whom they are the primary caregiver. The demographics of the participants and the children in this study influence the results of the research findings and these will also be presented in this chapter. The use of various charts and quotes by participants have been incorporated in order to illustrate the findings. The researcher has compared the results to theory throughout this chapter. In this chapter participants will be identified as P1 to P16. They have been assigned a number in order to protect their anonymity.

4.2 DEMOGRAPHICS

The demographics of the participants will be presented first, and this will be followed by the demographics of the diagnosed child for whom these participants are the primary caregiver. There were 16 participants interviewed in this study.

4.2.1 Demographic information of the participants

4.2.1.1 Gender and age of participants

There were 13 females and three males who participated in this study. The majority of the diagnosed children's primary caregivers were female, which is in keeping with the generalised role of caring. Most caregivers being female may be due to the older, traditional view of the woman being the carer and the male being the provider. These views may differ from family to family though, as Alesina, Giuliano and Nunn (2013) notes that in some society's women are seen as equals to males while in others there is the different opinion that the fitting place for a woman is in the home only.

More recently though it has been noted that various family members may view their roles through different lenses. The family member may either see their role as care-based and/or career-based. If the family member sees their role as care-based then they perceive their value in their ability to be a nurturer or carer and they therefore need and want to physically and/or

emotionally look after their family members. Whereas, if they were career-based, they would associate their value with their ability to provide financially for their family. They would want to secure their families security from an economical resource aspect (Masterson & Hoobler, 2015).

Either caregiver, male or female, may identify with one of these roles and in some cases, in single parent families, the one caregiver may be forced into dual roles, for example caring for the child and being the main provider financially. In this study, all three males took on the role of caregiver due to family circumstances. The uncle, who is 28 years old, appeared not to find his role too difficult and demanding as he said,

> "Actually, I thought it was going to be a bit difficult but, no, it's way too easy (P14)."

The other two older males, on the other hand, felt they still needed to fulfil the role of provider as well and this can be seen by their following statements:

> "I have some businesses that people are calling me. So, I sent someone to do it [the business/work] for me (P1)."

. "This thing is affect me a lot madam, I'm just be honest. Finance, physically, mentally, a lot of things because most of time you rely mindset, all the things that need to be planned, you plan, what's going to be, what step should I do, where do I have to do… (P15)."

The ages of the participants varied greatly, the youngest being a 24-year-old sister and the oldest being a 76-year-old grandmother, both of whom were the primary caregivers to the diagnosed child. This demographic information was important, as the impact of the life experience of the caregiver may have a positive or negative influence on his/her ability to cope with the diagnosis and treatment process, as well as influence how resilient they may be.

Three of the participants were between the ages of 20 to 29, while a further eight of the participants were between the ages of 30 to 39. Two participants were between the ages of 40 to 49, whilst three participants were above the age of 50. These results can be seen in Figure 4.1.

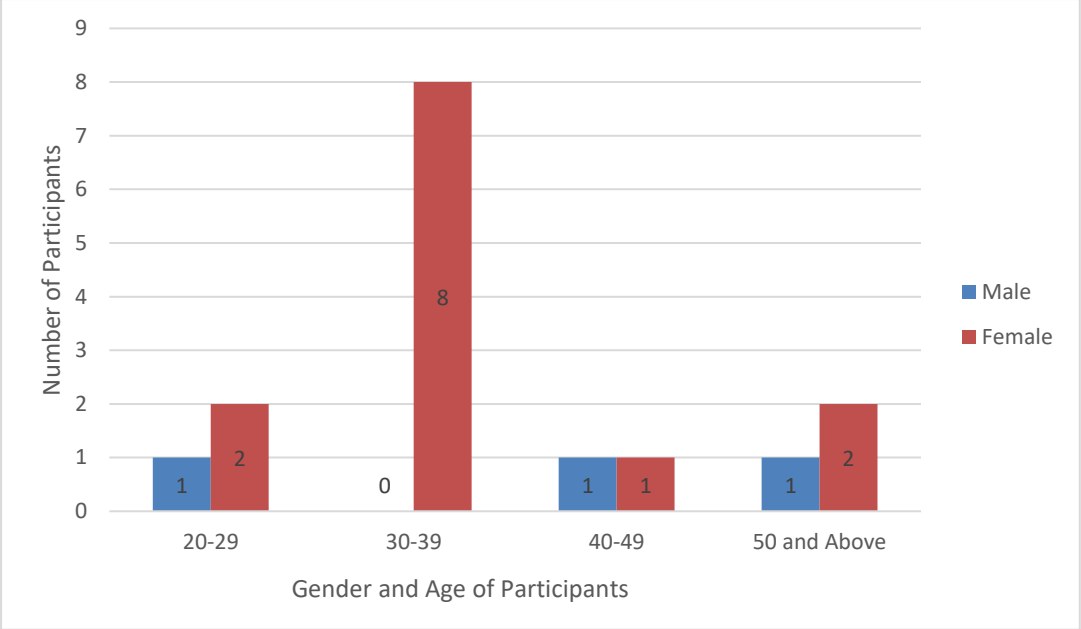

Figure 4.1. Gender and Age of participants (n=16)

4.2.1.2 Ethnicity

While one of the main aims of this study was to explore the role that ethnicity, and therefore culture, had in coping with a child who was diagnosed with cancer, the participants struggled to answer this question in detail, which therefore led to a limitation of the study. It is therefore important to explore the difference between race and ethnicity, as there is a misconception that they are one and the same.

According to Santos, Palomares, Normando and Quintão (2010), race refers to the biological aspects of a person. Race is a historical term and has been used to categorise people socially. Differences in skin colour, face and skull shapes, hair type and genetic ancestry is what is referred to most commonly. Ethnicity refers to the cultural aspects of the person and is determined by genetic similarities as well as linguistic and cultural affinities. These similarities and affinities create an ethnic community which often say they have specific social and political structures, as well as a territory.

In this study, ten of the participants, when asked their ethnicity, answered by providing their race and only two went on to speak of their ethnicity. The participants' answers show that there is confusion between the two terms, whereby people use them interchangeably. The amount of information retrieved from the participants was minimal and therefore so too was the analysis.

This study was therefore not able to adequately explore the ethnicities of the participants and connect these to culture.

It may have been difficult for the participants to verbalise their ethnicity to the researcher as she is a white female. Considering the significant role that race has had in the apartheid South Africa, participants may have been wary to discuss their race with the researcher and perhaps even feel that it should not be relevant in these times. For the researcher, what she felt was strange, was that she could see their race, for example, black, white, Indian or coloured and yet the participants seemed reluctant to label themselves by race and therefore delve deeper into their ethnicity. The researcher would not have known the deeper aspects of their ethnicities for example, Venda, Afrikaans etc. but perhaps could have probed more to find these out. Out of the 16 participants, nine named their race as their ethnicity and only one went on to elaborate on their ethnicity. In post-apartheid South Africa ethnicity and race both remain sensitive subjects. As the older generation would have lived through apartheid, they may feel judged and prejudiced as a result of their ethnicity. Out of the participants, eight participants chose to simply identify themselves as African, while a further three as South African. For the purpose of this study the 'African population' refers to the black ethnicity. One of the white females referred to her ethnicity as 'Afrikaans', this participant does not therefore view her ethnicity as simply 'white'. None of the foreign participants raised the fact that they were from a cultural group which was not South African and only one of the participants named his tribe, the Igbo tribe in Nigeria, as part of his ethnicity.

As noted by Oppong (2013), the formation of one's identity correlates with one's religion. The fact that identity and religion correlate is suggested by various studies that have been conducted. Therefore, religiosity would be applicable in determining purpose and commitment in the creating of one's identity. The likelihood is high that there is a variation between disparate demographic groups as to the weight that the relationship between religion and identity hold. One male, participant 14, identified himself as Christian, although this is not an ethnicity. He possibly chose this is his ethnicity as that is what he identifies with most. Religion is part of our identity as is ethnicity. Beyers (2017) is in agreement as he states that people identify others in relation to their religion, rather than ethnicity, and therefore there is an overlap between ethnicity and religion. Ethnicity is an important contribution to the formation of our identities. Participant 14 may have identified himself as Christian due to the fact that he didn't want to be labelled. He is an African man and also part of the younger generation and during his interview he stated that he believes in equality and due to this the researcher found

that he may have felt that by labelling himself with a certain ethnicity he would detract from what he had to contribute. He stated in his interview that:

> "I always tell myself that we are all the same, no matter, we are all the same (P14)."

Due to the participants' different understanding and perceptions of ethnicity, it was difficult to get accurate and representative results. These demographics are also likely to influence the rest of the results. Nevertheless, the results can be seen in Figure 4.2.

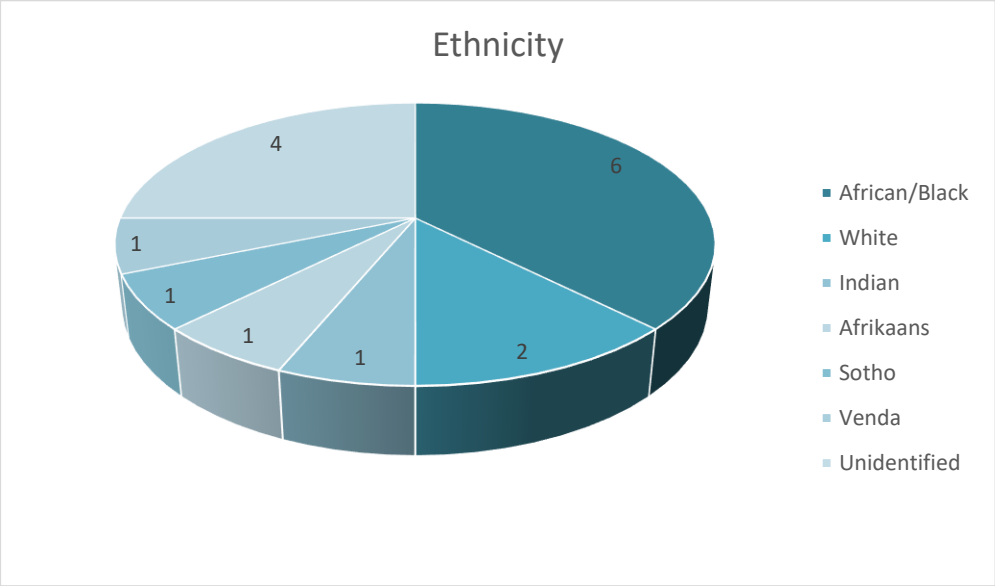

Figure 4.2. Ethnicity of participants (n=16)

Participants two and nine, as well as participant 16, stated they are South African, but they did not specify their ethnicity and so are included in Figure 4.2 under unidentified. There were also participants from other countries, including Nigeria (n=1), Swaziland (n=1) and one mother from Namibia. One of the mothers is Zimbabwean, however she has lived in South Africa for 10 years and her son, who was diagnosed with childhood cancer, was born in South Africa. Of the participants, 11 were South African, while the remaining five were born outside of South African borders.

4.2.1.3 Relationship to the child diagnosed with cancer

This study focused on the primary caregiver of the child diagnosed with cancer. Overall, 10 mothers were interviewed, while only one father was interviewed. Then there were also two

grandmothers, two uncles and one sister. These numbers are depicted in Figure 4.3. Both the uncles and the sister were from foreign countries and it appears the parents did not come and stay with their children due to work commitments and having to look after the siblings of the diagnosed child. We therefore see that in some instances the care was dependent on the nuclear family on a micro-system level, while at other times the extended family, on a mezzo-system level.

According to Rudi, Dworkin, Walker and Doty (2015), the communication methods between family members has changed and continues to evolve over time, to include formats such as text message, WhatsApp, email, Facebook and Skype. This statement is true in the paediatric oncology unit and, due to these technological advances, the children are now able to still speak to their parents via Skype and WhatsApp. Even South African families use these forms of communication when brothers and sisters or the parents are at home and the diagnosed child is in hospital. Often young children are given their own cell phones in order to be able to communicate with the outside world while in hospital.

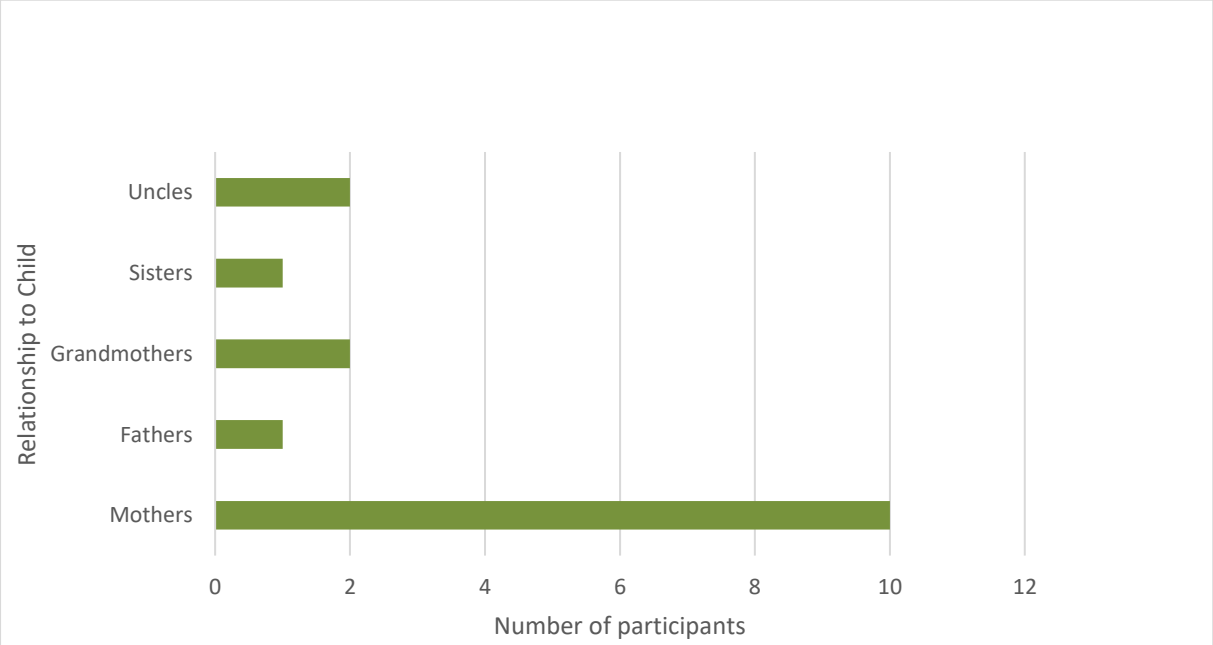

Figure 4.3. Participants relationship to the diagnosed child (n=16)

It was also noted by Munodawafa (2002) that in the African community the definition of family may include extended family and does not only consist of the nuclear family - as known in Western cultures. There may be many variations when speaking of family, where aunts and

uncles, or grandparents may be included, for example. When looking at the demographic details in this research it was evident that not only were parents' primary caregivers, but extended family as well. Two children were cared for by their uncles and two by their grandmothers. Participant one expressed having to leave a lot behind due to having to care for his nephew and that this had an impact on his family. He did say, however, that once you get the mindset right then you able to do what is necessary within the situation of caring for the child, although it is difficult.

> "So, what I am trying to say is when your ability to focus and sacrifice for the other will give you the strength to cope but it is not easy (P1)."

The second uncle and the grandmothers did not mention feeling that caring for the children was challenging, but they were comfortable with having taken on this role.

4.2.1.4 Marital status and number of children

Nine of the participants were married females; in addition, one female was single, one was widowed, and one was in the process of a divorce. Out of the three male participants, one was single and two were married. In the case where the mother or father was the primary caregiver, all had at least one other child at home. Of the 16 participants, 11 were the biological parents of the child they were caring for. Fifteen of the participants had children of their own, even if the child of which they were the primary caregiver was not their biological child but rather a relative. Of the 15 participants, six of their own children were older than the diagnosed child they were caring for and two were younger than the diagnosed child. The remaining seven caregivers had children both older, younger and the same age children (twin) as the diagnosed child at home.

All of the diagnosed children had siblings. Of the diagnosed children, three were the oldest of the children in their families, four were the middle children, seven were the youngest in their families, while two of the diagnosed children were one of a twin where the twins were the youngest in their families. This finding is important as having another child to care for at home often makes dealing with the diagnosis of a child more complicated and impacts on the parents' coping ability. Not only does the parent need to see to their ill child's well-being but that of their well child or children as well. According to Hosoda (2014), siblings are often concerned about their sick sibling and so they also feel impacted by the diagnosis. They may also, however, feel neglected by their family as everyone is attending to the sick child. Frequently,

the experience is difficult for the siblings, thereby making it even more complicated for the parents and their own coping ability and resilience.

4.2.1.5 Level of education

The level of education of the participants was important to record as the researcher wanted to explore if it had any implication on the amount of understanding there was around the child's diagnosis and illness, as well as when it came to understanding the terms 'culture' and 'resilience' - ie. their ability to cope. The levels of education varied and are displayed in Figure 4.4. The lowest level of education of a participant was grade 10 and the highest level of education was a postgraduate degree. All, except one of the participants, had matric.

People with education often have skills and knowledge about how to access resources, but this was not true for all the caregivers. Participant 16 for example, had only a matric and secretarial course but due to her self-confidence and enquiring mind, she would question the doctors and so was extremely knowledgeable about her son's condition and treatments.

Participant two who did not have a matric and was a more withdrawn participant was not extremely knowledgeable, as she may have not had the confidence to question the doctors and get additional information. When asked what she understood by the child's diagnosis her response was:

> "It's just that they sick (P2)."

Therefore, perhaps the link between knowledge and coping ability is linked more to personality type and what they wanted to know and learn about the illness and treatments, rather than level of education.

Sultan et al. (2016) noted that not only does coping ability depend on a person's personality type and characteristics but is often quite specific to gender as well. Avoidant or passive or palliative coping, for example, work and leisure, is seen to be more regularly used by male figures, or fathers; whilst family support and social support is seen to be used more by the female figures or mothers to assist in coping.

In a study carried out by Panganiban-Corales and Medina (2011) it was found that there was no significant connection between the caregiver's level of education and the stress they experienced. It was also noted that most caregivers had some level of basic education and

would therefore be able to understand simple information. The participants' educational level would however not impact significantly on coping ability.

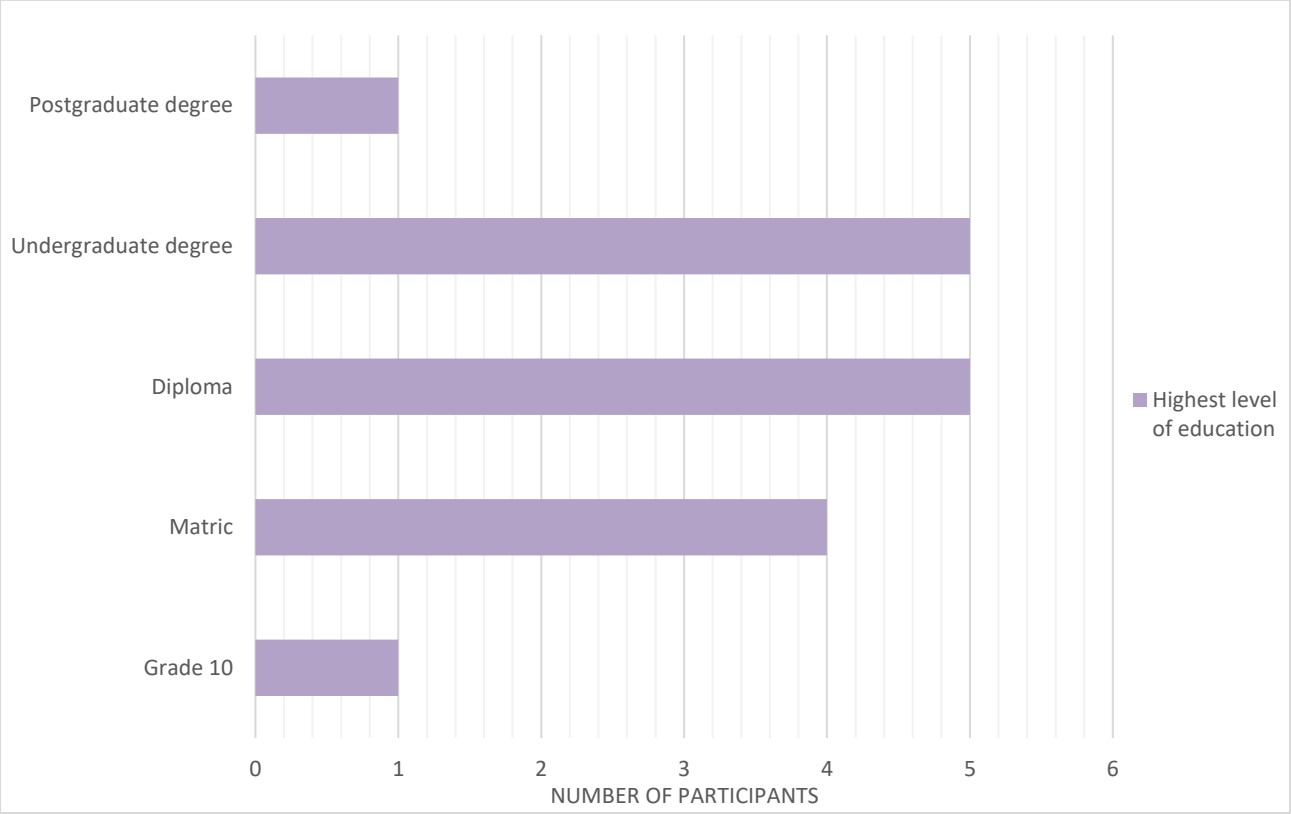

Figure 4.4. Participants highest level of education (n=16)

Of the participants, nine were employed, while the remaining seven were not employed at the time of the interviews. This aspect was difficult to link to their coping ability as, for example, the mother with the postgraduate degree had chosen to give up her job to look after her sick daughter after she had relapsed. So, although not employed she had the capacity to be employed and she was extremely knowledgeable about childhood cancer and her daughter's cancer. Participant five was employed and even said:

> "We've had from both sides an immense support in the places that we work and from that of course it has aided us in coping with everything from a, relaxing a bit more and even the financial aspect (P5)."

Participant six was a registered nurse and therefore she had heard of childhood cancer previously, but not encountered it in her professional work. Having heard of childhood cancer

did not improve her knowledge of the diagnosis' and treatments. It did, however, improve her capacity to understand medical terms when the doctors spoke with her.

Another participant, who was not employed but had a bachelor's degree, had a good understanding of her son's illness and could describe medications and the treatment process; while participant nine, who had a matric and was employed, had some difficulty understanding her child's diagnosis and treatment. It can be said that the participants' understanding did not seem to be linked to the aspects of education and employment but may have played a role in certain instances. It appeared that the participants' ability to understand the illness and treatments seemed to be more dependent on how much they wanted to know and learn about the illness and treatments. However, some caregivers were possibly scared and could not handle the full explanation of the illness and treatment process to come and so it may have been partly a subconscious defence mechanism.

The amount of knowledge they have regarding the disease can also depend on how confident they are in their own abilities to question and communicate with doctors and their medical team. It is apparent that information is gathered more easily by caregivers when the medical team communicates well and furnishes the caregivers with enough understandable information (Kilicarslan-Toruner & Akgun-Citak, 2013). The more the parents are able to communicate adequately, the more information they receive and the better their understanding.

Although one would assume that level of education and employment would increase the likelihood of a parent having adequate communication skills, this was not necessarily the case, as personality type also needed to be taken into consideration. One of the older caregivers with a limited education level did not have a good understanding of the child's illness and subsequent topics discussed. The remaining 15 participants level of education could not be directly linked to their level of understanding regarding the child's diagnosis. Kästel, Enskär, and Björk (2011) found that communication is key to a person's ability to understand and there should be mutual respect between the families and the health care team. The health care team should be empathetic and build trust. Often information provided is difficult for families to handle due to defence mechanisms they have in place and mental obstacles, rather than education levels and whether or not they were employed.

4.2.2 Demographic information of the child of whom the participant is the primary caregiver

4.2.2.1 Gender and age of child at diagnosis versus age when the interviews took place

Nine of the children were male and the remaining seven were female. Of the 16 children, 12 were older at the time of the interview than they were at the diagnosis, therefore confirming that there had been a period of time between the child's diagnosis and the interview. This time period is depicted in Figure 4.5. Thus, implying that the caregivers had therefore had some time to process the diagnosis and treatment and perhaps try to put into action some coping mechanisms.

Four of the children were newly diagnosed, and therefore the same age at both diagnosis and the time of the interview and their caregivers were still learning about the illness. They had not had a lot of time to process what was happening and ultimately what this would mean for them as a family.

Participant nine's child had been diagnosed within the month prior to the interview and when asked what she knew about childhood cancer and her child's diagnosis she said:

> "To be honest, nothing. I'm still learning but what I know is that in time she will get healed (P9)."

Participant nine explained that she didn't yet have much knowledge about the cancer. During this initial stage, when parents are still learning about cancer treatment processes, parents may often feel overwhelmed. Often caregivers are given the necessary information but struggle to assimilate it at the time due to shock and being overwhelmed. Participant 12's child had also been recently diagnosed prior to the interview and said:

> "What I've learnt since I've been here, it's actually a lot of information at once, oh my gosh, I was like so overwhelmed with everything (P12)."

So, it can be seen that participant 12 was still experiencing the shock of the diagnosis and feeling overwhelmed with all the information that had been continuously given to her and she was still processing the information and experience.

On the other hand, where there was a time lapse between the diagnosis and interview, the caregivers were more settled and noted:

> "But it does get easier (P16).
>
> "I mean there were things that completely through our lives upside down in the beginning and I think with that, there were, there was a lot more frustration than there is now, I've sort of accepted things a lot more, to just let it be and go with the flow (P5)."

These quotations demonstrate that participants, where the children had not relapsed, felt that with time the shock and feeling of being overwhelmed eased.

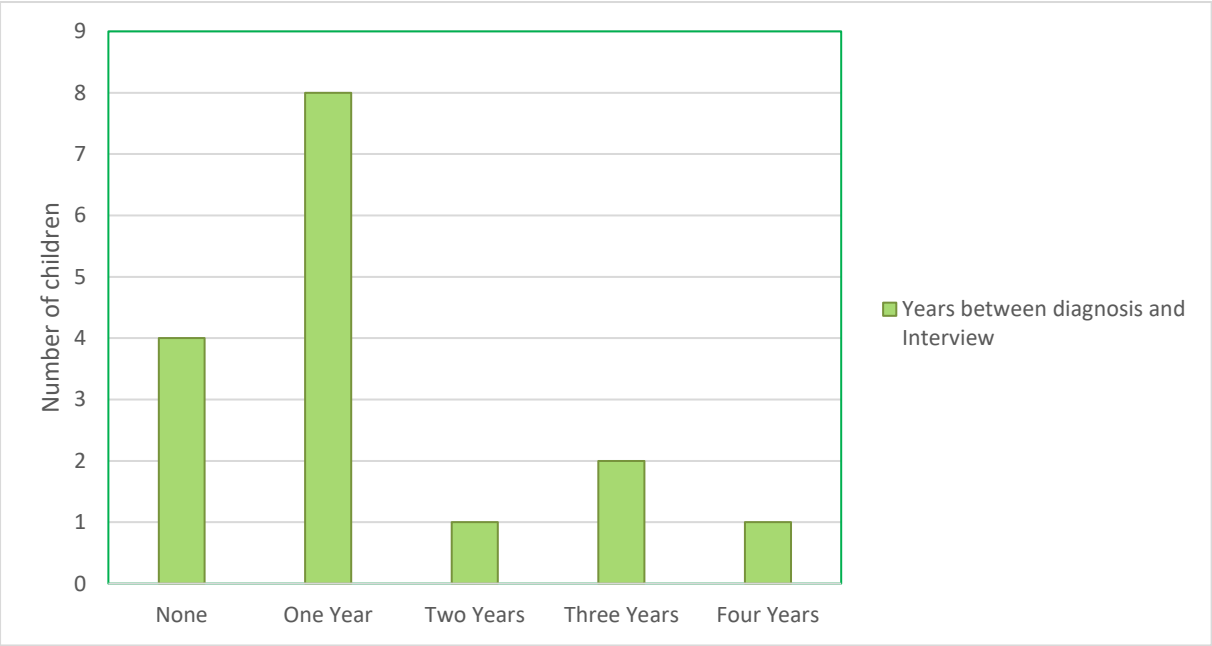

Figure 4.5. Years between diagnosis and the interview (n=16)

Caregivers' were also more easily able to assimilate the information given to them and therefore understand the process, there were fewer unknowns, and this made coping slightly easier. As noted by Kästel et al. (2011), the parents' understanding both emotionally and intellectually became easier as the treatment process progressed. Time was essential in order for parents to comprehend what was happening and so become more familiar with the processes and their new circumstances.

4.2.2.2 Ethnicity of child

The ethnicity of the children was the same as that of their caregivers, with the exception of one mother who described herself as African/Venda and her child as African/ Tsonga, as the father is Tsonga. The children were therefore described by their caregivers as the following: six African/black children, three South African, one Tsonga, one Sotho, two white, one Indian and one Afrikaans. Four of the children were from outside South African borders, one from Nigeria, one from Swaziland and two from Namibia. The African male who described himself as Christian also described his nephew's ethnicity as Christian. It is possible that the reason for the three participants saying the children's ethnicity was South African was due to lack of understanding of the word 'ethnicity'.

4.2.2.3 Schooling

Of the 16 children, 15 had been in school prior to diagnosis and were hoping to return to their nursery school or grade as soon as possible. During treatment the children are unable to attend school. Ten of the children were in primary school, one in high school, while two of the children were still in nursery school. One child had been looked after at home by her grandmother prior to diagnosis as she was only three years old and had not yet started nursery school. All participants will be able to return to school in their maintenance phase of treatment.

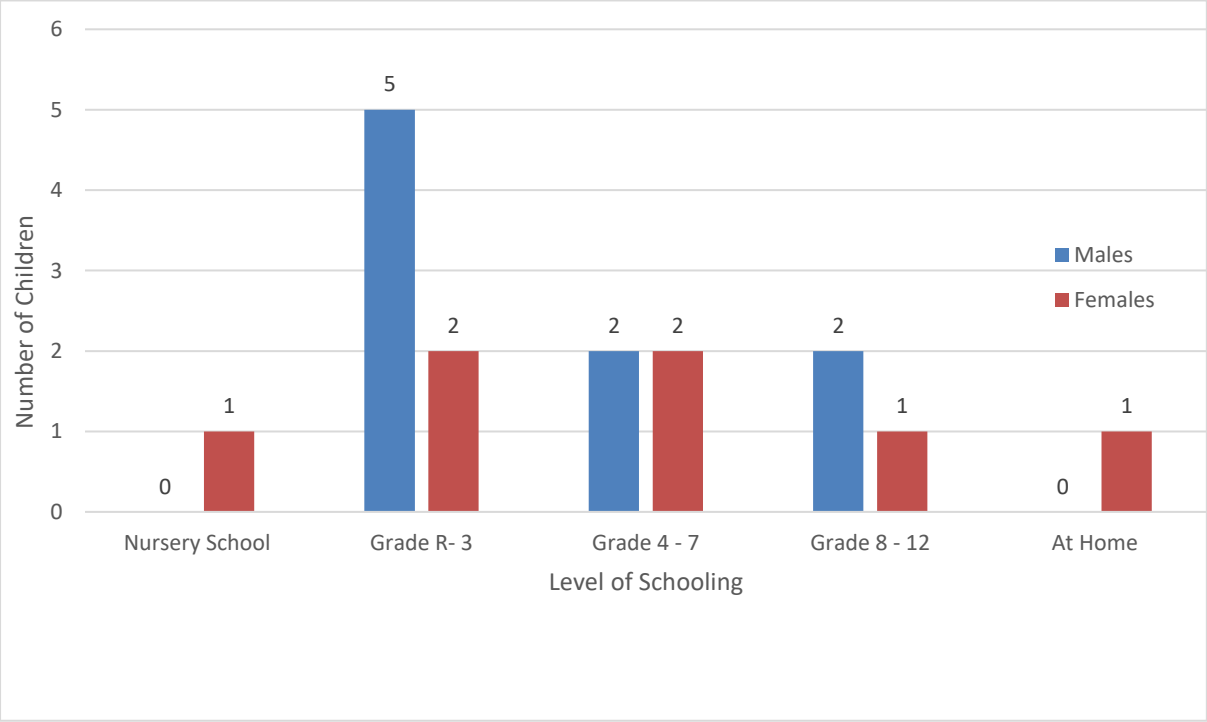

Figure 4.6. Schooling of children diagnosed with cancer (n=16)

In Figure 4.6 the number of children in the different school phases can be seen. The phases are broken up into nursery school, grade R–3 (Foundation Phase), grade 4-7 (Intermediate phase), grade 8-10 (Senior phase). Children diagnosed with childhood cancer often miss going to school and being with their peers and especially their friends. If the child is of school-going age, it adds another demand on the caregiver to liaise with the school and teachers and to keep the ill child as up-to-date as possible. It is important to note that the child is part of a greater whole, a school system or community and therefore by being removed from this system the child would have to find ways of adapting to this change. According to Compas, Jaser, Dunn, and Rodriguez (2012), when speaking to children who have cancer, they said that their biggest stressors were regarding not seeing their friends and not being able to keep up with schooling, or not being able to attend school. They also felt stressed regarding visits to the clinic or hospital and not being able to do the things they did previously. Finally, these children were concerned about their families.

Part of a child and adolescents' development is formed through going to school. Batra (2013) speaks of Erikson's developmental theory saying that people do not always recognise and appreciate that schooling and its associations have an impact on both a child's emotional and social development. This development is established through interactions with peers, teachers and the physical environment in which schooling takes place. Interactions include playing, exposure to media and technology and even reading and writing. All of these are part of interactions that take place at school. If a child is denied psychological and social space to experience these relationships, they develop self-doubt which can have a negative impact on their self-esteem (Batra, 2013).

A pilot project was carried out at Sydney's children's hospital by Ellis et al. (2013) where they connected children with cancer receiving treatment and their schools, including teachers and peers, via visual telecommunications. Initially some of the children were reluctant to participate as they were embarrassed by their appearance and also all the attention they would receive, this reluctance slowly dissipated over time. It was found that by allowing the child to be part of the school via visual telecommunications they were able to gain a sense of normalcy and were distracted from their cancer. It gave their peers the opportunity to see the child prior to their return to school and this helped to normalise their appearance for the other students. Overall the pilot study was successful and assisted in building the ill child's self-esteem.

It was also found that when peer-supporting programmes had been in place and peers' knowledge of cancer was increased, there was less fear and a more positive attitude towards the returning student. Peers were also more willing to interact with the student who had cancer (Helms et al., 2016). Internationally, it is noted that when a child with cancer re-enters school the success is largely dependent on peer acceptance (Ellis et al., 2013).

A mother of one of the older children noted:

> "She complains about school, not going to school and not seeing her friends and like not living a normal life like any other child but she, I think she's strong (P8)."

According to Visser (2010), caregivers should work jointly with the principal and class teachers at the child's school to attempt to keep the child up-to-date with schoolwork. It is important that caregivers and parents do not put their child under additional, unnecessary pressure, while still supporting and encouraging them to do what they are able to do. All children are able to return to school in the maintenance phase of their treatment. It often depends on when in the school year the child was diagnosed, as to whether or not they progress to the following grade or return to the grade they were in when diagnosed.

One caregiver said that the school had said:

> "... that they're going to like give her like some kind of test to check if she is ready to go to grade 7 (P8)."

Having to follow up with the school does add additional stress to the caregivers, but it is important for the child's development and to maintain some sense of normality and build their already fragile self-esteem. Although caregivers explain to the children that they will return to school after the intensive phase of their treatment, the children still find this difficult to process and deal with.

One mother said:

> "It's still really eating him up because ja, yesterday we asked the doctor if he'll be able to go to school in January, February and then the doctor said April and he started crying again but we assured him, that no Tshiamo you will go to school next year (P3)."

Unfortunately for children that come from outside the South African borders, they only return to school once they return home, however, this is still within the maintenance phase of treatment.

4.2.3 Diagnosis' and treatments of the ill child

4.2.3.1 Diagnosis of ill child

In childhood cancer, leukaemia is the most common diagnosis (Visser, 2010, p.11). This was confirmed to be the case in this research as eight of the children were diagnosed with some form of leukaemia, this was followed by lymphoma (n=4), Ewing's sarcoma (n=2), rhabdomysarcoma (n=1) and finally, the sister of one of the children was not sure of her diagnosis. These results are detailed in Figure 4.7.

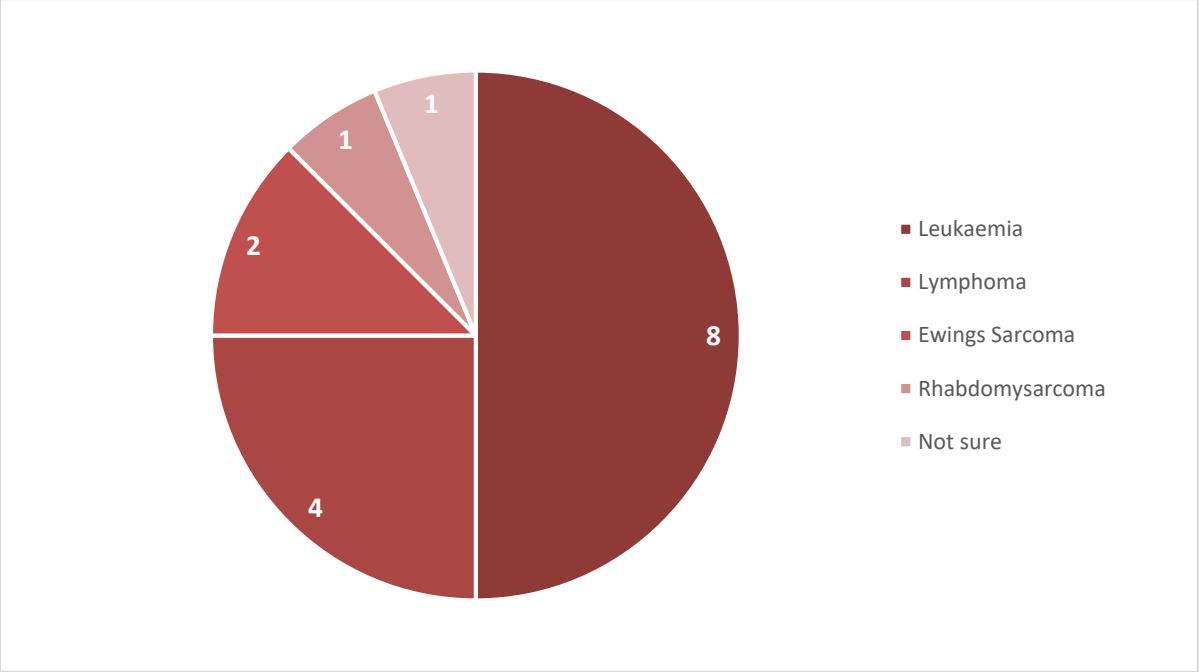

Figure 4.7. Diagnosis of ill child (n=16)

4.2.3.2 Treatments

All 16 of the caregivers were aware that the children were, would be, or had, received chemotherapy. Half of the participants were extensively aware of what treatment their child had received, while the remaining eight were simply aware that their children had received chemotherapy. The eight caregivers that only knew about chemotherapy did not know, at the

time of the interview, if their children would need any other types of intervention, for example radiation or surgery.

One uncle was aware that his nephew needed to have a stem cell harvest followed by a bone marrow transplant, as did one mother know that her son ideally needed a bone marrow transplant. Side-effects of treatment were not discussed extensively in the interviews. It should be noted that educating parents regarding their child's disease and the treatment processes that are to follow are essential in empowering the parents in their daunting journey. As Flury, Caflisch, Ullmann-Bremi and Spichiger (2011) stated in a study they conducted, parents found comprehensive written and verbal information they were given by the healthcare professionals, regarding the processes, to be helpful and assisted them in being more prepared and not so anxious of the unknown.

4.3. UNDERSTANDING OF CANCER AND THEIR CHILD'S DIAGNOSIS

4.3.1 Primary caregivers' understanding of childhood cancer, the diagnosis and treatments.

4.3.1.1 Childhood cancer

Ten of the 16 participants said that they had heard of childhood cancer prior to the child's diagnosis, however, they never thought that it would affect their family. Although they had heard of childhood cancer, they did not have a full understanding of the illness and the extent of the different types of childhood cancers. Participant one said:

> "I had [heard of childhood cancer], but I don't know, I've heard of it (P1)."

Another participant stated:

> "You know how you read on social media or you see it on TV, on movies, however, like it wasn't close to home, so I really didn't take notice, but I know that there's [childhood] cancer (P8)."

The remaining six participants said that they had never heard of childhood cancer prior to the child being diagnosed with cancer. One participant said:

> "It was the first, I didn't even know that kids can get cancer (P3)."

While another stated, when asked if she had heard about childhood cancer:

> "Nope, I thought that it was for adults, not for kids. Normally I never read about that, never been interested, never thought that it would happen to my family (P9)."

The belief that cancer is for adults, not children, is a misconception held by many in society. According to Grootenhuis and Last (1997), cancer is not commonly associated with children, but rather with death with regards to adults.

While some children are taken to medical doctors, others are taken to traditional healers for consultation, or their local or regional clinics for assessment first. Lack of awareness and knowledge of childhood cancer within these communities pose a risk to a child who then does not get diagnosed or treated correctly. Edwards and Greeff (2017), who carried out a study on childhood cancer, found that a common challenge was that African traditional healers, as well as district health care providers, were not knowledgeable or aware of childhood cancer.

This lack of knowledge may be partially due to cancer being associated more with adults and so there is less understanding of childhood cancer and ultimately it is more 'taboo'. It is later seen that the unknown causes anxiety and fear for these caregivers and that can be linked to the lack of awareness and information available to the general public around childhood cancer and the diagnosis's and treatments.

A person's understanding or preconceived ideas of a topic such as childhood cancer often comes from people around them, including from family members. Friedman and Neuman Allen (2011) speak of systems theory in relation to the size of the system. Small social systems are referred to as micro-systems, whereas intermediate social systems are mezzo-systems. Examples of mezzo-systems are extended families and support networks or groups. Lastly, the focus of the macro-system is on large social systems, including communities and organisations.

A caregiver's perception may be altered on all three levels above as they interact with people in their different systems. The information they receive from the system with which they interact, may have a positive or negative impact on their coping abilities. For example, if the caregiver has support and encouragement on all three levels, they are likely to be able to cope better in this situation.

Where a caregiver, whose community and family, for instance, has an opposing belief to the caregiver and believes that the childhood cancer is due to witchcraft and that western medicine

is not necessary, may find this has a negative effect on them, adding unnecessary stress to the situation. In some cases, the stress may become overwhelming and treatment may even be abandoned. Belief in witchcraft does not only happen in South African communities. In a study conducted in Kenya by Mostert et al. (2014), it was evident that families and parents of children diagnosed with cancer were isolated by their social groups. In this particular study, 17 percent of families were in this category. Parents also noted that it was suggested to them that their child might be cursed. Some community members also encouraged parents to abandon treatment at their current hospital and that they should pursue alternative treatments.

If a caregiver is part of a larger community, or macro-system, for example, the hospital community, they may feel safer and this in turn may assist them to cope better. Participant five said:

> "I think having got to know the staff at the hospital, the nurses, the doctors, yourself, it's become like a family on its own, you know, and like with anything starting a new job, or joining a new group or anything, you're always nervous about what you're dealing with and once you get to know it and you build that trust and those friendships and relationships there's a huge set of comfort there (P5)."

There needs to be greater awareness around childhood cancer which will lead to a greater understanding for caregivers, as well as the greater community.

4.3.1.2 Knowledge about the child's diagnosis of childhood cancer

15 of the 16 participants knew the type and name of cancer that the child had, however not all of these 15 participants knew the type of cancer in its entirety, for example, which part of the body was affected by the cancer. One caregiver did not know the type of cancer or where it was even though she confirmed that the child had cancer. Participant 13 replied when asked what cancer her sister had:

> "Mm, not sure (P13)."

4.3.1.2.1 Relapse

Five of the participants had children who had relapsed at the time of the interview and said that dealing with a childhood cancer relapse is an even more difficult experience to deal with than the initial diagnosis.

One of the mothers said, when speaking of the relapse:

> "I think for now, it's harder than the first cause I was, I was thinking that he is cancer free now, he's going to enjoy school without going in and out to hospital (P6)."

While one of the grandmothers said:

> "It hurts more because, ja, we keep on hoping that he's going to be clean and not have this hanging over his head anymore, but it just keeps coming back (P4)."

Caregivers of children who relapse experience a sense of disappointment, they feel the unfairness of the situation, not only for their child but themselves and the entire family. When a child relapses the threat to their life becomes a real concern once again and so this creates a crisis point for the child and their family (Tippy, 2016). The family feel anxious and angry, as well as scared and sad. The family is disappointed that their child has to endure further treatment knowing that often long-term survival is not attainable. They nevertheless remain hopeful, attempting to balance new treatment with the child's quality of life. Additional stressors, including poorer prognosis, possibly explain why a first diagnosis is easier to adapt to rather than the trauma of a recurrence or relapse (Rodriguez et al., 2012).

Feelings that relapse is more difficult correlates with a study carried out by Grootenhuis and Last (1997) where it was found that parents of children where a relapse has occurred were far more fearful and powerless regarding their child's prognosis than those parents where the child was in remission.

4.3.1.3 Understanding of treatments

Eight participants had an extensive understanding of what the diagnosed child had received as treatment and what they still will have to receive. One participant detailed the child's entire treatment which included chemotherapy, radiation, surgery and further maintenance chemotherapy.

4.3.1.3.1 Caregivers limited understanding

Participant 15 had a limited understanding of cancer and he had misconceptions around the diagnosis. He detailed the child's treatment for another ailment until the present as he believed that this treatment is what caused his son's cancer. This father believed that metal that had to

be used in his son's leg to rebuild it had somehow chemically changed and caused his son's cancer. He stated that:

> "We can put under consideration because this thing, we cannot say, ok yes, it's a cancer, but let's see the part, what's the cause and that metal, it might be, at my little understanding (P15)."

He firmly believed this as prior to his son having surgery on his leg he was cancer free. His thinking was based on cause and effect. However, there is no known reason for why children get lymphoma, which is the cancer that his son had.

4.3.1.3.2 Bone marrow transplant and understanding thereof

Two of the children were awaiting a bone marrow transplant at the time of the interview and the one child's uncle had a good idea as to what this entailed. There are different types of bone marrow transplants where the donor can be the patient themselves, or a sibling or person who is a match. The success of these transplants is dependent on many variables. Another child who had relapsed three times prior had damage to his kidneys and therefore had to have lower doses of chemotherapy and ultimately, the grandmother believes this is why he had relapsed for the fourth time**.**

4.3.1.3.3 Effect of communication from doctors

Participant number five was knowledgeable of her son's treatment and the treatment process but had to question the doctors in order to get the necessary information. She said:

> "Sometimes I think the doctors think you know what they know (P5)."

Of the participants, eight were aware of only chemotherapy and they were not able to explain what this entailed or even all the side-effects of such medication. This lack of knowledge and non-understanding of the treatment may lead to feeling dis-empowered and unsure of what is happening. They felt that the medical team were the experts and should not be questioned. The unknown and not knowing what to expect often causes anxiety. Healthcare providers therefore have an obligation, not only to the child, but to the child's caregivers, to disclose all information regarding the child's illness, even if it is difficult for the parents to hear (Mack & Joffe, 2014). It should be noted that it is also how the patient and caregivers are given the information. Communication between the doctor and caregivers requires an understanding of both parties'

emotional state in this complex interpersonal interaction (Kee, Khoo, Lim, & Koh, 2018). All parties in the communication will be sensitive to both verbal and non-verbal cues, and not simply what the information is. This will affect the caregivers' reactions and manner in which they cope with the information.

4.3.1.3.4 Caregivers overall knowledge of treatments

Figure 4.8 shows that all of the 16 participants were aware that their child had received chemotherapy thus far, two of the children had received radiation and chemotherapy, whilst another two had had surgery, as well as chemotherapy and radiation. Of the 16 children, two had had treatment and were awaiting transplant. A further four participants were aware that the children had chemotherapy, as well as other medical treatments that were either part of the protocol, for example, steroids, or blood thinners, given due to complications from the chemotherapy.

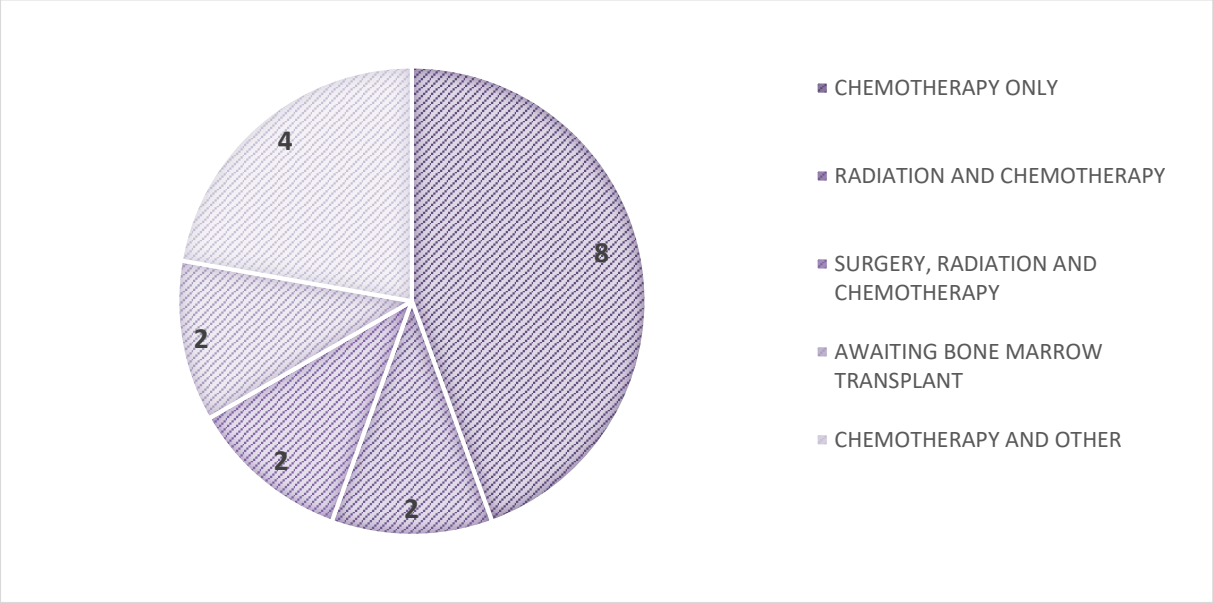

Figure 4.8. Types of treatments the caregivers were aware that the children will receive (n=16)

Overall, the participants felt that the treatment had had a positive effect, though one or two participants did have their doubts. One grandmother said of chemotherapy of a friend who had previously been diagnosed:

> "She refused chemo totally, she says she'll rather die than take chemo. And when I see what Mark* has been through, I agree with her as well (P4)."

Alternatively, however, it is also important to note that some caregivers choose not to know the details of the treatment as they feel they trust the medical team and would prefer not to nurse the child as such, but rather support them simply as their caregiver. It was therefore important that the medical team was guided by the caregiver when possible.

4.3.2 Primary caregivers' experiences of the child they're caring for being diagnosed with cancer

Caregivers in this study have confirmed that the most intense experience of anguish was when they were informed that the diagnosis of childhood cancer was confirmed. The caregivers' felt that this was due to not knowing what to expect. Both the caregivers' and children are impacted by the experience of childhood cancer (Nóia et al., 2015).

Overall, 15 of the participants described their experience as stressful and the types of stressors identified will be discussed below. Some participants felt that they had become educated around childhood cancer and taken the positives from the experience as well. One participant acknowledged that there are a lot of misconceptions, misinformation and sometimes overloading of information. He felt that this impacted his experience negatively. The participants also felt that the whole family was affected. Thibodeaux and Deatrick (2007) acknowledge that the families dealing with childhood cancer battle with this life-changing event. The whole family is affected by a childhood cancer diagnosis.

4.3.2.1 Stressful, difficult experience

Of the 16 participants, 15 felt the same, regarding the diagnosis and what follows as being a difficult experience. A participant who was from Swaziland described it being really hard as they were far from home and their supportive family, so not only did they need to interact with and understand the new environment and people, but a life-threatening diagnosis as well.

4.3.2.2 Feelings of guilt and blame

Three participants spoke of thinking that the child's cancer had been caused by something they had done. They thought perhaps that it could have been when they were pregnant. Their

feelings of guilt subsided when they came to the realisation that they could not have prevented the illness and it was not connected to what they had or hadn't done.

4.3.2.3 Being overwhelmed / shocked

Darcy et al. (2014) noted that parents whose children are diagnosed with cancer experience shock and trauma. They live in the present and with constant worry, they feel powerless and inadequate but know the treatment is imperative and had to be undertaken.

Four participants described a sense of shock when they received the diagnosis, while two others said they functioned on autopilot and did what needed to be done at the time.

Participant five said:

> "So, I think I'm still in auto pilot. I know me well enough to know that the time I'm going to break is when it's done. I'm just the type of person when something happens, I go, well this is what it is, we need to deal with it and get on with it (P5)."

While one grandmother said she wasn't even aware of the shock they were experiencing until their GP raised it with them as a family. She described her experience to another mother:

> "I said it was like falling into a big black hole and you can't get out of it (P4)."

4.3.2.4 The impact on the family

The impact that the diagnosis has on the entire family can make coping stressful and especially if there are other siblings at home that need to still be cared for, or if the caregivers stay far away from the treatment hospital. These all need to be addressed. The family dynamics change, and this can be difficult for the patient, the parents and siblings.

4.3.2.4.1 Siblings

The siblings experience disorder and chaos within their family and often parents don't keep them informed in detail regarding what is happening to their ill sibling and therefore the well sibling's understanding of childhood cancer is hazy and fragmented (Yang et al., 2016). The way in which a caregiver engages with the well sibling should be age appropriate. (Brennan, Hugh-Jones, & Aldridge, 2013) noted that siblings often look as though they are coping, even when they are not and so it is up to the professionals and their caregivers to recognise this. At

times the siblings attempt to remain self-sufficient rather than seeking the necessary help and support they may need.

4.3.2.5 Misconceptions

Five participants spoke of the misconceptions there are surrounding childhood cancer. They spoke of the reality of people's beliefs and misperceptions that childhood cancer is brought on through curses and witchcraft. Although the participants were able to discuss this topic, they did not believe in witchcraft or traditional healing when it came to their own child.

4.3.2.6 Emotionally draining

When such a diagnosis is made, we can compare the emotional stages that the caregivers go through with Elizabeth Kübler-Ross's stages of grief and loss. The caregivers may move between the various stages fluidly, moving back and forth and even being in more than one stage simultaneously. They also may become stuck in a stage and struggle to move forward. Often caregivers will start in a stage of denial. As previously discussed, many participants said they did not think that cancer was an illness that children get. Participant eight even said that:

> "You know you read on social media or you see it on TV, on movies, however, like it wasn't close to home. So, I really didn't take notice, but I know that there's [adult] cancer (P8)."

Whilst another agreed saying:

> "You know when you don't know, when you haven't met anyone with a child with cancer, you just think ah, it's one of those things (P7)."

Participant six spoke of feeling angry and wondering why her daughter had to go through all that she was experiencing and then wondering why it couldn't have been herself instead. She voiced her anger when saying:

> "I just feel she doesn't deserve to go through this, no child deserves any of this (P6)."

Caregivers may enter the bargaining and depression phases numerous times during their journey. Caregivers often feel guilty and blame themselves and this can put them at risk for depression. One mother said:

> "I also did that I asked myself so many questions. I couldn't sleep at night (P3)."

Caregivers may even go back to the stage of denial, the stages discussed are not static and caregivers can and will move in and out of them at different times, they may even be in more stage than one at the same time.

According to Kübler-Ross (2003), acceptance may replace denial at some stage in the process, after moving backwards and forwards through the numerous stages, as denial is often a defence strategy that is temporary. Often the acceptance is partly dependent on how well the child is and how the child is coping influences what stage the caregiver finds themselves in.

One participant said that when her grandson is well:

> "I feel better in my heart as well. And I think that gives you the strength to carry on more and just makes him get better and better you know (P4)."

Another participant described the experience as overwhelming, especially the first day. She said she felt extremely overwhelmed and continued to say:

> "I think we give the word cancer too much power, the word cancer and then you give the word chemo is even more frightening (P16)."

The various themes that emerged from the caregivers' experiences and their comments, these themes and associated quotations are detailed in Table 4.1.

Caregivers' experiences of the child being diagnosed with cancer		
Caregivers experience – Themes	**Number of participants**	**Illustrative quote**
Stressful or difficult experience	*15*	• *It was for the first time I saw his father crying really. (P3)* • *It's been difficult. (P9)* • *It has been a nightmare so to speak. (P11)* • *It's hard for us because we live far, it's hard to see your family members. (P13)*
Felt guilty / blamed self	*3*	• *We blame ourselves really, maybe it was something I did when I was expecting him. (P3)*
Shock / overwhelmed	*4*	• *When we first heard it was a shock. (P4)*

		• *The first day is so overwhelming because you kind of being told your child's got cancer. (P16)*
The whole family is impacted	*5*	• *Everything, it's disrupted. (7)* • *You have some kids that miss their brother as well. (P15)*
Misconceptions/ misinformation	*5*	• *I mean witchcraft, if I may put it that way…So, they might have that as another, that's another misconception. (P1)*
Fear / Emotionally draining	*6*	• *You fear that is he going to survive. (P6)* • *It's very emotionally draining. (P8)* • *It's a rollercoaster. I have never been so like, torn apart in my life. (P12)*

Table 4.1. Caregivers' experiences of diagnosis

4.3.2.7 Distress eases over time

The overall theme noted from the caregivers' experiences was one of being overwhelmed, stressed and frightened. It was a difficult experience to take in and deal with at the time of diagnosis, but according to the caregivers' opinions below, it was noted that the distress seemed to ease over time.

Participant three said:

> "It gets easier especially when you are in hospital and you see that you are not the only one with a sick child (P3)."

Whilst another participant echoed this by saying:

> "But it does get easier. I think it becomes like part of your, you, you learn what, part of a routine (P16)."

In a study conducted in China by Tsai et al. (2013) it was concluded that within the Chinese society, caregivers of children with childhood cancer were able to gradually adjust within the first six months of treatment, both emotionally and psychosocially.

Participant 11's brother was treated for childhood cancer when they were young and so she remembers this experience, she compares the two experiences, and this helps her as she says her brother was sicker than her daughter has been and yet he survived and is now a grown adult. She had therefore been more accepting that children get cancer and that her daughter had been diagnosed with cancer.

It is important to note that acceptance does not mean that the caregivers find the situation good and acceptable, but rather that they have managed to incorporate the illness and treatment into their daily lives and for the most part are able to function and cope.

As the caregiver's fear and stress eases so does that of the child as a child tends to take the lead from their caregiver. A diagnosis and the start of treatment will be anxiety provoking for the child and so the calmer the caregiver is, the calmer the child will be. Hildenbrand, Alderfer, Deatrick and Marsac (2014) noted that caregivers play an essential role in assisting their child to cope with their cancer experience and stressors they may encounter.

In a study conducted by Ångström-Brännström and Norberg (2014) they found that children found their caregivers presence comforting and that parent and child interaction creates a secure foundation for the child. Their parents assist them to see their circumstances as less dangerous and they are therefore able to endure the process. Caregivers therefore play an essential role in the emotions of the child they are looking after.

4.3.3 Primary caregivers' perception of culture and its influence on coping

4.3.3.1 Basic understanding of culture

Culture is referred to by Ahmadi (2006) as "a system of norms and values that is shared by the members of a society, a community or a group and the explicit expression of these norms and values" (p. 26). This explanation is just one definition of culture and there are many various others.

Long et al. (2014) noted that culture and the norms associated with the culture may impact the family in terms of the meaning they assign to a childhood cancer diagnosis and the role that the siblings take on within the family system.

Everyone and every family member belong to a culture and this will somehow impact on how they experience the childhood cancer diagnosis. According to the Sociocultural Model of Stress, Coping, and Adaptation, culture will impact the caregivers' perceptions as well of that

of the patient and even their siblings. Culture is always changing as through the generations they contribute to the culture. Culture is therefore not static.

Culture means different things to different people and this can be seen in some of the results where the participants gave their different opinions regarding their interpretation of culture.

All of the participants agreed that there are many cultures within a country and even the four participants from countries outside South Africa agreed that there are many cultures within their own countries. Some linked their culture to their values and their belief systems and how they live their life overall.

Participant 10 said:

> "For me, personally, culture is what I believe, what the values I stand for and how I adapt or how I live every situation referring to what I believe in and what my values are to make sure in every situation I'm not discriminating myself against what I believe and in what I stand for (P10)."

While participant five said that culture encompasses:

> "Our values and beliefs that we, you know, sort of instilled in ourselves from either onset of birth in a family or in a company, if you are part of a company. So, I think in short, a set of values and beliefs that encompass that group or individual dynamic (P5)."

One participant queried which kind of culture the researcher referred to, for example, family, individual or work/company culture, thus putting into perspective that there are different cultures for different groups of people and places.

According to participant one:

> "As time goes on we have interwoven culture and religion. But culture was existing before religion come in, except if I'm wrong (P1)."

Another participant put it simply, saying:

> "It's just your tradition, coming from your grandma, grandpa (P2)."

Culture and religion are both complex terms and can be intertwined for some people and completely separate for others. One participant said of her husband's culture that:

> "His culture was more of church based, it's coming from church more than how, or like you know how you bring up a child (P8)."

She also noted that:

> "Some of the churches nowadays they more of cultural than religion (P8)."

The participant however, felt that for her personally her culture and religion were two separate entities, which is seemingly contradictory to her husband, according to the above quotations. The relationship between culture and religion is confusing at times. Wiener, McConnell, Latella and Ludi (2013) state that many lives are based on the foundations of cultural and spiritual beliefs and practices. Tripathi and Asthana (2013) state that religion and spirituality are essential cultural factors and these factors provide meaning to people's experiences and beliefs. For example, "in Lebanon, one's religious beliefs and cultural background are so deeply intertwined that many seek solace in their religion when faced with any life crisis" (Doumit & Khoury, 2017, p. 4).

It should be noted however that not everyone belongs to a religion or is a believer in a greater deity or spiritual being. However, everyone belongs to a culture whether they identify with it or not. What can make a situation more complex and complicated is when a person views culture and religion as two individual entities with conflicting beliefs and they need to choose between the two.

One participant felt that as she was a Christian, she didn't follow her culture as she didn't believe in it in the traditional sense of the word. The community that she belonged to did however believe in traditional culture and witchcraft. She said:

> "I'm a Christian but ah for culture, cause some of our traditional culture, like the older people they believe that it, it's a witchcraft (P6)."

For her and others, religion can be what creates your identity, rather than simply just your culture, for others it may be a combination of the two. Religion forming identity may take place on various levels. On an individual level or parental level, the micro-system level, if the person is deeply religious, they therefore pass these views onto their children. Religion assisting the formation of identity may also take place on a macro-level whereby the community plays an important role and has an influence on this process. This would happen for example, when the community members are mainly religious and people adhere to the

norms of that community, thereby having religion play an essential part in identity formation (Oppong, 2013).

In this study some participants linked culture with traditional beliefs and witchcraft which will be discussed in further detail under the next point.

4.3.3.2 Traditional beliefs

In many cultures there is a stigma surrounding all cancers and Daher (2012) noted that stigmas often have a silencing effect, thereby making attempts to implement cancer awareness far more challenging. In a study carried out in Kenya, it was found that some families believed their child had been bewitched and according to Mostert et al. (2014), the cause of the cancer was due to the child having a spell or curse put on them by a witch or magic user. The person who put the spell or curse on the child may be well known to the family, or may have been consulted by someone close to the family. In cases where the child is thought to be bewitched, they would need to be consulted by a traditional healer in order for cure to take place.

Six of the participants spoke of culture and its connection with traditional beliefs as well as witchcraft. The one participant even spoke of how back home, in Nigeria, he had heard of a child with leukaemia, but it was believed by the parents that the child was from another planet and he came here to consume their money, as treatment costs a lot of money. He went on to say that it was the traditional, religious belief of the family. He also stated that:

> "Sometimes you know we Africans we have that belief is something, it might be something done by somebody. They are trying to punish me, they know this side, might be, something, somebody creates a future, so they are trying to… I mean witchcraft, if I may put it that way (P1)."

The above quotation corresponds with a study carried out in Ghana where it was mentioned that evil or bad spirits have attacked the sick person and that is why they are ill (White, 2015).

Another participant said that although they do not believe in witchcraft, there are a lot of people who believe in witchcraft and practice it within their community. She said:

> "Ja, you should go to a traditional doctor, a kid cannot just have cancer. Ja, it must be something to do with witchcraft. Ja, we get that a lot (P3)."

Witchcraft was exclusively raised by African participants and spoke mainly of it being within their extended community, also known as the macro-system. The disturbing factor was that a relative of participant seven, who is a nurse in Zimbabwe, told this participant that it is unheard of a child to have cancer and therefore people rather link childhood cancer to witchcraft. She feels that it is different with her family in South Africa, however, as she stated that they are more educated.

Participant eight felt that her and her husband, whom she is currently divorcing, have different belief systems, his being more traditional. She said that she believed in Western medication whilst her husband believes that for their child to be cured, she needs to go to the mountains to cleanse herself or drink a certain water from the stream or eat a certain broth. This situation made their journey very challenging and has created additional stress.

When asked about culture and if they follow traditions, another participant said:

> "I really, I cannot say that one, I cannot say that madam, just to be honest I cannot say that. Because culture is something that you cannot go deeper unless you go deeper with a person who knows your culture exactly (P15)."

This participant felt that he could not discuss his African culture with the researcher as he assumed, he and the researcher do not believe in the same things due to the researcher being a white female. Men and woman; and African and white; are seen differently in different cultures and although these misconceptions have evolved over time, the older generation, especially those who lived through apartheid, perhaps find it difficult to integrate into their belief systems. Woman were seen as 'lower' than the man and were expected to follow their cultures and traditions. Nevertheless, this participant was extremely respectful towards the researcher; however, culture was an aspect he was not comfortable discussing. Another African participant stated that:

> "Before we are colonised by the white man, we have our own traditional culture and beliefs. So now, we have intermarried both of them (P1)."

This participant was younger than participant 15 and from another country and therefore perhaps his perception was slightly different, and he was more easily able to adapt to more modern views of culture.

One participant summed it up by saying that:

> "Different races have different, I find have different cultural things I think and different religious beliefs (P16)."

A study carried out in low- and middle-income countries established one of the delays was that in rural areas, families have easy access to traditional healers and often consult with them initially, which leads to delays in these children receiving medical care (Magrath et al., 2013).

In this study, however, caregivers had seemed to seek Western medical advice early on when their children became ill.

4.3.3.3 Culture**s perceived influence on primary caregivers' ability to cope.**

Of the participants, 13 did not feel that culture had any influence on their ability to cope and their resilience in this situation. When speaking about if there was a connection one participant said that:

> "It has nothing to do with culture. Cause if I want to rely on culture, culture will tell you it might be since from the forefather. That is what culture always believes in. Since of the forefather or punishment (P1)."

Another mother said she did not know her culture and therefore it had not influenced her coping in any way. She said:

> "Culturally, ja like maybe you go to a traditional doctor, no, we don't do that. We don't take this medicine, no. We were not raised up like that (P3)."

The youngest participant, participant 13, from Swaziland, felt that culture was something engrained in the Swazi identity. There are certain rituals that get done when people are certain ages and that is just how it is. She said that they even pray as a country and meet in stadiums to do this and this activity was part of their culture. She says that she does what she is told and so doesn't feel that culture has impacted her coping in anyway.

Another participant spoke of culture as norms, doing whatever their ancestors previously did. He gave examples of not being allowed to sweep outside in the evening, or you can't get anything from an elder with your left hand even if you are left-handed. He grew up with these traditional beliefs, but he does not feel that any of the various beliefs has helped him to cope in his current situation.

Thirteen of the 16 participants did not feel that culture influenced their coping in anyway, however three participants did feel that culture had assisted, with one participant saying about her culture:

> "It's made me stronger; I think because of the background I came from. Look, Portuguese culture is not an easy one. We've had hard life, we've also been victimised in this country, but we just chose to ignore it and carry on with our life (P4)."

Of the participants, 12 felt that rather than their culture helping them to cope, their religion had helped them to cope. Overall it was felt that culture and religion are two separate entities. When asked if her culture had helped her to cope one participant revealed:

> "Not my culture but my religious beliefs, we very strong Christians and so from the minute he was diagnosed we just believed that God's got this and funny enough I haven't been fearful at all and I think that that's just more, it's not really a cultural thing, it's more, it's more a religious thing you know (P16)."

According to Chun et al. (2006), culture is a dynamic system and it evolves over time rather than being a static entity. Participant one explained:

> "Sometimes culture you know, as time goes on we have interwoven culture and religion. But culture was existing before religion comes in, except if I'm wrong (P1)."

Overall, the African caregivers spoke of culture in connection with their traditional beliefs, while the rest of the Indian and white caregiver/s spoke about culture in terms of Western ideas. Two African participants also mentioned that due to them being educated they don't follow the more traditional cultures, but rather their religions and Western medicine.

Participant one said, when speaking of culture and witchcraft that:

> "When you are more educated you will see the better part of it and not the other part of it [witchcraft] (P1)."

Participant eight said that her husband, whom she was currently divorcing, believed in more traditional ways of treatment and he was doing these concurrently with the chemotherapy treatment as far as she was aware, even though she was not in agreement with this.

She stated that:

> "It's more of a traditional thing they give them herbs, they give them other stuff to take, to drink… (P8)."

A study conducted by Munodawafa (2002) found that:

> 'Quite a lot of Africans who are educated, or have become Christians, will consult Western medicine, church, and traditional practitioners either concurrently, or alternatively, when faced with such abnormal illnesses or without cure (p. 9).'

It may also be true that the person's values and beliefs are what they feel is part of their culture, as participant 10 said:

> "For me, personally, culture is what I believe, what the values I stand for and how I adapt or how I live every situation referring to what I believe in and what my values are (P10)."

She also stated that:

> "I don't think my cultures influenced the way I've coped in the situation to be honest, but I feel like my personal beliefs and my personal values have really influenced the way…(P10)."

Therefore, essentially saying that her values which are part of her culture influenced her coping ability. Therefore, culture had in fact helped her to cope, possibly without her realising. This can be true as according to Bardi and Guerra (2010), personal values are affected by cultural values, which in turn influence a person's ability to cope. Culture in respect to coping is relevant to values for example, religious coping. There is therefore a connection between stress, coping and adaptation, and culture whether on a conscious level or not. This is in line with the Sociocultural Model of Stress, Coping, and Adaptation. This model also mentions that a person's coping is dependent on if they feel the event is stressful and what resources the caregivers have to support them. This can be within their cultural realm and society, macro-system, at large. Overall, culture is a complex concept and people's opinions of culture differ and that it is often hard to articulate or understand the role of culture in one's decisions.

4.3.4 Primary caregivers coping difficulties

During the interviews it was noted that all caregivers experienced things that made coping even more difficult for them. There were many struggles that they faced apart from just the diagnosis and treatment. Some of the more significant difficulties are detailed below. Not all caregivers experienced the same difficulties in the same way, however different themes emerged.

4.3.4.1 Accepting the illness

With a diagnosis of childhood cancer, caregivers mentioned feeling a loss of control and constantly feeling uncertain in their ability to protect their child's well-being and ultimately the child's life. They felt dis-empowered and had no choice but to submit their child to the treatment process and hope that their child survived (Cox, 2018). This dis-empowerment makes accepting the illness extremely difficult for caregivers to accept the illness.

Of the caregivers, 10 found it difficult to believe that their child had been diagnosed with cancer and so struggled to accept the diagnosis and sometimes the treatment that they had to follow. Most caregivers said that their experience of having a child diagnosed with childhood cancer had been difficult and one caregiver even said that it had been a nightmare.

Caregivers often struggle to accept the diagnosis as it is not known what exactly causes childhood cancers and whether or not they will survive the diagnosis and treatment process. Schweitzer, Griffiths and Yates (2011) confirm that it is difficult to accept the diagnosis of childhood cancer as the parents experience the possibility of the death of their children and this creates shock and sometimes denial. Parents now view their child as vulnerable, but realise that they need to take an active, supporting role with regards to caring for their child.

If a parent looks only at the vulnerability of their child you will find that discipline falls away and this can become problematic, not only during treatment, but post treatment should the child survive. If the child has not been disciplined and has been allowed to do anything they want while ill, they feel that they should continue to be treated that way when they have recovered. It also creates problems within the family as siblings feel that they are treated unfairly and perhaps more harshly.

In a study conducted by Williams et al. (2013), they found that children had poorer behavioural outcomes when parents and grandparents had decreased discipline and increased spoiling of both the sick child and their siblings, during and post treatment.

Another implication of the child not being disciplined is that the child may feel that they must be extremely ill and therefore fear dying, as their parents have not set boundaries in place. It is important to have boundaries as consistency leads to predictability, which leads to security for the child and the siblings as well.

4.3.4.2 Feelings of guilt

Participants also seemed to blame themselves and feel guilty that their child was in this situation. One mother said that she had learnt a lot, including that this was not her fault but rather that her son's body had "failed him" as she put it.

Other caregivers also wondered if it was perhaps something that they had done that caused the cancer with one participant saying**:**

> "Ja, we blame ourselves really, maybe it was something I did when I was expecting him (P3)."

Another caregiver said:

> "I panicked a lot when they said embryonal I worried about whether there was something I did but actually apparently, it's not, it's sort of when cells change (P16)."

Feelings of guilt can hinder the coping process. Guilt feelings are not exclusive to caregivers in South Africa, but are common among all caregivers of a child with cancer. Kim, Yi, Sang, Kim and Heo (2017) noted that in Korean mothers there were extreme feelings of guilt as they felt responsible for what their child was experiencing and questioned whether they were doing what was in the best interest of the child.

4.3.4.3 Finances

In childhood cancer circumstances, the families' income is significantly affected on all levels (Bona et al., 2014). Worldwide, families with children diagnosed with cancer find that they have additional financial burdens that they now have to contend with, and this can put strain on the family. According to a study done by Warner, Kirchhoff, Nam and Fluchel (2015), it was almost unmanageable for families to handle additional costs related to the child's cancer diagnosis. Job changes and having to be with the child in hospital unexpectedly added to this challenge. This was true for families who had already been dealing with a childhood cancer diagnosis and its treatments for at least one year.

Families in South Africa find that there is the financial burden that such a diagnosis brings. There are many extra incurred costs, for example, doctor's bills where they have charged above medical aid rates, blood tests that aren't fully covered, travel expenses when travelling to and from the hospital, a parent may need to give up work to be with the ill child, therefore decreasing the family's monthly income. Often families don't really talk about their financial difficulties and try and cope with it on their own. If families discuss financial issues, they usually focus on the direct costs rather than the indirect costs. For example, the family may mention that they have an outstanding account for a doctor or the blood lab (direct costs), rather than focusing on the petrol money used to get them to and from the hospital, or the leave days that they have had to take at work (indirect costs).

When families come from outside of South Africa, there are often additional expenses or some of these families fund the treatments themselves, which can be financially crippling. Although the foreign patients are accommodated at CHOC house where there is no cost involved or those on medical aid are put up in bed and breakfasts which is paid for by the medical aid, they struggle with finances for daily living and simple things.

One uncle from Nigeria said:

> "She said she will take me to the mall to buy a book and I don't have money, and I don't, we are limited, we are constrained financially (P1)."

Another unexpected cost that the caregivers raised was additional medications that arose due to complications of the treatment, which are often paid for out of the caregiver's pockets, especially if medical aid is exhausted. The caregivers also feel they need to buy healthier food for the child, sanitising equipment for their homes, sometimes masks and gloves, all these 'little' things contribute to the larger sum, making it more difficult for the families to cope financially.

Then there is the cost of alternative or natural medications that some caregivers give alongside the prescribed medications, this adds cost. The one caregiver whose child has relapsed for the fourth time admitted trying the natural way and are continuing to do so at present, but this also comes at a cost and she said:

> "... and cause you know money's not easy… I couldn't sleep for three hours wondering what was going to happen (P4)."

An article by Patterson, Holm and Gurney (2004) confirmed that parents incurred extra financial expenses that led to financial difficulties. These additional strains were in connection with co-payments for treatment and/or a parent having to work less, or not work at all due to the cancer treatment their child was receiving.

Lastly, there is always the concern for caregivers that if the treatment they receive here, in South Africa, does not work and they need to go overseas for treatment, the question may be who will cover that cost and how will they as caregivers find the necessary funding. At the time of the interview this was not the situation for any of these families yet, however it was raised by one caregiver who stated:

> "What astounds me is the cost of it if you look at these children who need to go to Spain or America and that for seven million rand. I don't understand, I don't understand from a human point of view, how a medical team could expect an individual to get seven million rand to give a child a chance at life (P5)."

4.3.4.4 Unpredictability and the unknown

A significant difficulty that caregivers were faced with was the unpredictability of the situation and not being able to plan, even a day in advance, as things change so quickly with this illness. One caregiver said:

> "I was struggling to cope because I was overwhelmed with everything and you don't know what to expect you know, you don't know what you are in for (P12)."

Another caregiver said that the unknown and not knowing what to expect next makes it more difficult to cope. She said that she received general information that helped but guidance as to what exactly the next step is would help her to cope better.

There seemed to be agreement around this point with another caregiver saying:

> "Because with this things it's never black or white. It's up and down, up and down, so that's scary (P7)."

Another caregiver, whose daughter has an Ewings sarcoma, which is a very rare type of cancerous tumour of the bones or soft tissue around the bones, said that this cancer that is predominantly found in boys and so finding support for her and her family has been very challenging. She said:

> "With her one [treatment protocol] it's very difficult because we don't know, we haven't had another family that's gone through it, like we've gone through it so that we could lean on them and ask them what did you do here, what did you do there. Even with, it came to us making the decision for amputation you know, there wasn't much we could go to (P10)."

There was a lack of support from within the South African community, due to the rareness of her daughter's diagnosis. Sometimes parents do not connect with others as they want the parents to have gone through the exact experience that they are going through and often this is not possible as the children\n's diagnosis's, treatments and reactions vary greatly. Parents may feel isolated. The unpredictability of the diagnosis and treatment process makes the diagnosis and treatment even more scary. When it came to the children relapsing, this was then another unknown experience for these families, although they already knew the child had cancer and had experienced some of the treatment protocols that the child had received. A relapse now changed the way forward and once again they were faced with the unknown, as well as the uncertainty of whether their child would survive or not. The unknown and unpredictability therefore made coping much more difficult for these caregivers.

4.3.4.5 Child's emotions and mood swings

Granek et al. (2014) noted that dealing with their child's emotional volatility was challenging. The children often feel frustrated, moody and angry due to their medications and/or simply feeling ill. Five of the caregivers felt that their child's emotions and mood swings made it far more difficult for them to cope with the situation. One grandmother felt extremely frustrated as the chemotherapy caused her granddaughter to have outbursts and mood swings. Whilst she realised that this is just due to the medication, it still made it harder to deal with the situation.

Another caregiver said of what makes it difficult for her to cope:

> "I would say that, the mood swings, the depression that they go through, mood swings, they cry over everything and they uh, it's very sad that they can't even live a normal life every child lives (P8)."

She continued to say that as a caregiver you have to learn to deal with stress from the child. You also have to reassure them that things will turn out OK and this in turn creates stress on the caregiver, as the reality is that they cannot guarantee that all will be OK. In a study conducted in 2016 by Jalmsell, Lövgren, Kreicbergs, Henter and Frost (2016), it was found

that children who had been diagnosed with cancer wanted information to be relayed to them in such a way that it was age appropriate, but more importantly, in a positive way in order for them to maintain hope. The impact of this on the caregiver is that they sometimes have to be the 'buffer' between what the doctor has said and what they tell their child. According to Coyne, Amory, Gibson and Kiernan (2016), although parents appreciated honest and open communication from the healthcare professionals, they wanted to determine and manage how the information was given to or shared with their child.

Children also have emotions and worries about their diagnosis and treatment and some children will ask questions like: Why do I have cancer? Why can't I go to school? Why me? The child's emotions and questions then put an additional strain on the caregiver as they are the ones who are asked these questions.

The youngest caregiver said that she wished there was someone older to help her with the child as it is difficult to deal with her when she is not feeling well and is emotional. In a study that was carried out in Brazil the "results suggest that the inexperience of those younger caregivers with the parental role can generate higher levels of stress and anxiety when they are faced with a child's chronic illness" (Alves et al., 2013, p. 360).

One father said that his son enjoys making jokes and it's difficult for him, as the dad, as his son is no longer making jokes. The child's mood is reflected in the fact that he no longer makes jokes and is most likely struggling with the diagnosis and treatments he is receiving. Throughout the years humour has been noted to be an efficient and powerful coping mechanism (Samson & Gross, 2017), and therefore the fact that the child is no longer even able to use his humour to cope shows the deep impact that such a diagnosis can have on the child and ultimately the caregivers and entire family.

Caregivers seem to struggle with the child's emotions as they are battling their own emotions at the same time and trying to keep a calm exterior. This situation is a challenge to coping. In Table 4.2 the themes that emerged regarding the caregivers' coping difficulties are listed with quotes.

Caregivers' coping difficulties (n=16)		
Caregivers coping difficulties – themes	**Number of participants**	**Illustrative quote**
Accepting the illness	*10*	• *It has been a nightmare so to speak. (P11)* • *He has been having those cramps, but none thought of cancer. Since how we grow up cancer usually doesn't come in kids. (P14)*
Feelings of guilt	*3*	• *I guess it's changed a whole lot of things about me and like you know I even feel bad sometimes with my other kids cause I really don't give them attention. (P8)* • *You feel guilty, you fear that is he going to survive, you see, and then sometimes you feel like why I'm not the one who's sick. (P6)*
Finances	*5*	• *It's very tough. The expenses, all the stuff you have to pay. Some you have to pay some of the doctors, some medical aid don't pay it, you see. (P15)* • *I must now, you know, take out money from my own pocket to buy the medication because medical aid is exhausted. That's another stress. (P8)*
Unpredictability and the unknown	*7*	• *I was struggling to cope because I was overwhelmed with everything and you don't know what to expect you know, you don't know what you are in for. (P12)* • *And the unpredictability is, is tough because you actually can't plan your life. (P5)*
Child's emotions and mood swings	*5*	• *I get sometimes frustrated. I'm not even near her – she's fighting. (P2)* • *It's hard to get to cause they are confused, same time they want to go to school, they ask a lot of questions and they always ask why me? Why do I have cancer? (P13)*

Table 4.2 Coping difficulties

4.3.5 Primary caregivers' coping strategies

Fifteen of the sixteen participants felt that they were coping adequately with the diagnosis and treatment process thus far. Their main coping strategies included the following:

4.3.5.1 Communication and support among caregivers

The greatest form of support that eight of the caregivers received appears to come from one another. They feel that they are not alone and could get advice from one another.

Two participants stated:

> "And being with parents again that their kids have cancer explaining things for me (P9)."

> "I've coped a lot now than at first when we came here cause I didn't understand anything, but the more I meet with other parents the more I understand (P.13)."

This communication and being supported by one another was a primary coping strategy for these caregivers.

Caregivers who are from foreign countries or far distances from the hospital are accommodated at CHOC (Childhood Cancer Foundation of South Africa) house. CHOC house is a 'home away from home' for patients who come from far. It is based in Saxonwold not far from the hospital, they provide a bedroom and all necessary facilities, including meals and transport to and from the hospital at no charge. By doing this, they ensure compliance to treatment for these patients who might otherwise not be able to afford the costs of coming for treatment. Three caregivers who stayed at CHOC also felt that they were able to get to know children who were further along in their journeys, and some who were in remission and now well, which was encouraging. One caregiver stated:

> "In CHOC house the man I met from Zimbabwe said his child was 6 years old when they came here for treatment now the child is 17 (P1)."

This encouraging feedback therefore gave the caregivers a more positive outlook and a belief that there is hope and that in turn gives them strength to continue and to cope.

Communication amongst caregivers also works in the sense that some caregivers feel that they could not cope with another caregiver's situation. Seeing the difficulties of other caregivers' therefore makes them feel that their situation is bearable and that they can cope through it.

One caregiver said:

> "But I do, I follow a lot of stories, A – to be there and also to appreciate where I am in my story and to know how lucky we as a family are and how lucky John* is because, because we are lucky (P5)."

One caregiver says that it is easier to be at the hospital because then you know that you are not the only one who has a child with cancer.

She also said:

> "It gets better really and then we speak, parents you know we always communicate really. Ja, so it's helping, we are supporting each other (P3)."

Other caregivers felt that they now try to approach new parents who have just started their journeys to try and help them to feel more at ease and able to cope with the situation. This in turn made the caregiver feel like they were contributing and helping others and could therefore manage or cope with their own situation.

One caregiver said:

> "I kind of now make a point of trying to find parents who are on the first day to just kind of tell them to just take one step at a time because it's just so scary (P16)."

However, not all illnesses and parents' coping strategies are the same and so to compare situations is often very difficult. One caregiver found that due to the rarity of her daughters' diagnosis the best support she found was on a group of parents overseas on Facebook.

Coulson and Greenwood (2012) found that the quantity of online support groups has grown exponentially. This growth has provided not only accessible information but also various types of support for families.

According to Gage-Bouchard, LaValley, Mollica and Beaupin (2017), families now use personal pages, on numerous social media platforms, such as Facebook, Twitter, YouTube, PatientsLikeMe, to mobilise necessary support. These types of support include documenting

their experiences and sharing stressors of being a caregiver of a child with cancer, advocating childhood cancer awareness and fundraising. Families often also express their thankfulness for all the support they are and have received through social media.

Social media allows caregivers with similar journeys to share experiences and knowledge with one another and come together and "consequently, support groups or parents of other children with cancer are important information sources for families and patients" (Kilicarslan-Toruner & Akgun-Citak, 2013, p. 181). Irrespective of where the parents are based it shows that they have a connection that other people do not. They communicate and share experiences and ideas, and this helped them to cope.

This was also seen in a study carried out by Angstrom-Brannstrom, Norberg, Strandberg, Soderberg and Dahlqvist (2010) where it was apparent that parents of children with cancers' anxiety and fears were diminished when they were able to talk to other parents within the same situation and share positive and negative experiences. When parents saw the improvements in the other parents' children, they then felt that their child could also beat the cancer, and this gave them hope which made the situation seem more manageable.

4.3.5.2 Assessing the situation and then planning

Hildenbrand et al. (2014), reported that strategies that assisted parents to cope included creating routines and plans amongst others. Caregivers in this study also coped by looking at the situation and then plan the way forward and how they were going to tackle what needed to be done for and alongside their child. When the caregivers spoke of this they made it clear that they did not mean to plan for the future, as that is very difficult when you have a child with cancer, but more a day-to-day plan of what needs to be done in order for them to be equipped for the treatment plan process and informing their child of the way forward. They also referred to planning in terms of siblings and what needed to be done to ensure they were cared for, fetched from school and fed, for example.

One caregiver said:

> "Because most of the time you rely on mindset, all the things that need to be planned, you plan, what's going to be, what step should I do, where do I have to do… (P15)."

They also referred to planning in terms of siblings and what needed to be done to ensure they were cared for, fetched from school and fed for example. At times caregivers are able to rely

on their spouse or the child's older siblings to assist with day-to-day things, i.e., they engaged their micro-system. At other times they had to be reliant on the mezzo-system surrounding them, for example, extended family or friends, to do these tasks for them.

Parents often feel torn as, while they want to give the other child attention, this is not always possible and so the siblings feel neglected even though this was not the parent's intention. A study by Labay and Walco (2004) stated that siblings did not display an increase in behavioural problems, but they did, however, show an increase in both academic difficulties and social problems. Parents could attempt to mobilise various support structures to assist the siblings so that the entire burden does not rest upon them. They could engage with the sibling's school system on a macro-level, including the sibling's teachers to provide extra support. Caregivers can also inform the parents of the friends of the siblings what is happening and so engage the mezzo-level support system as well. Empathy was an important prognosticator of externalizing and overall difficulties of siblings.

Ultimately however, it is the micro-system that is deeply affected and so this needs to be considered. A parent themselves, therefore, also needs to try and show empathy to the sibling and keep open and honest communication and keep them informed around what is happening with their sibling. While often basic and practical needs of the siblings are seen to, the emotional needs can get overlooked.

Nevertheless, caregivers felt that first assessing the situation and then planning, whether for the siblings at home, or the ill child in hospital, was another coping strategy for some of the caregivers, as this also gave them a small sense of control of a situation that was very chaotic and overwhelming.

4.3.5.3 Getting comfort from the child's strength

According to Kim et al. (2017), caregivers found they got their strength and courage from their children who they felt were courageous in dealing with their challenging childhood cancer journey. In a childhood cancer setting caregivers often perceive their child's distress as their own or they have immense empathy for their child and the distress they are experiencing (Howard Sharp et al., 2016), therefore the better the child is doing physically and emotionally, the better the caregiver copes.

Five caregivers said that when their child is feeling better and is in good spirits, they, as caregivers, feel like they are coping much better.

One mother said of her daughter:

> "She's so positive, if I cry she shouts at me for crying, she turns around, why you crying, what we need to do, what are they saying, can you help me walk now, can we do my exercises, she knows the names of her medication, she talks to the doctors about her medication. So, she's literally that anchor that helps me want to help her even more (P10)."

While a grandmother said:

> "When he is like he is now then he's practically back to normal then the whole family is happier as well (P4)."

Parents gained comfort, strength and energy from the child's spirit and vitality and how they were not giving up, but rather fighting the cancer (Angstrom-Brannstrom et al., 2010).The implications of this are two-fold however, the parents comfort when they are well may be an encouragement to the child as they know that when they look and feel well, the caregiver seems happier, thereby making them want to show this side. However, knowing their parent feels better when they feel better may also lead them to hide their emotions of sadness and their struggle with the diagnosis and treatment, in order to keep their caregiver happy. A caregiver therefore needs to be very in tune with the child in order not to miss anything, for example, a fever or general illness.

4.3.5.4 Family dynamics and support

Nine of the participants mentioned that their family was a coping mechanism for them as they felt that they could rely on, trust and fall back on them for the needed support. They felt that without this positive dynamic in their family they would not have managed to cope**.**

Even the four caregivers that had travelled from other countries felt that their families played a role in their coping and one mother felt that she would not have coped without the support of her husband who had come with her and her daughter. She stated that:

> "You know we are coping, not just by prayers but you know just me and my husband being together as a team, working together as a team, just supporting each other, so it does make it a little bit more easier to cope (P12)."

Another mother mentioned that the support she gets from her family, and their encouragement, assist her in coping with the situation of the diagnosis and treatment. It appears that a diagnosis such as childhood cancer can either tear families apart or bring them together. According to a study by Hosoda (2014), not all families experienced negative impacts of the challenges of childhood cancer on the functioning within their families. Often parents rather initiated ways to preserve their family functioning by perceiving the child's cancer in a positive way and by adapting the roles assigned within the family to meet current needs within the context.

Participants mentioned that not only had their spouses had helped them to cope, but the patient as well, and even extended family. When asked what made coping easier for her, one participant said that:

> "So, she's [diagnosed child] literally that anchor that helps me want to help her even more and I'm lucky because the other thing you see here is some of the, I've literally seen some marriages come apart in this hospital and my husband is almost, like literally my pillar of strength (P10)."

Good family dynamics and positive support from those around them became a coping mechanism that these participants relied on. It made them feel more contained and so more able to cope and incorporate their new experience into their daily lives. An overall review of the coping strategies can be seen in Table 4.3.

Caregivers' coping strategies (n=16)		
Caregivers coping strategies – Themes	**Number of participants**	**Illustrative quote**
Communication and support amongst caregivers	*9*	• *The other thing to come here and maybe we are in the room, we are two in the room, one talk to other mother whose experience about this disease is also helpful. (P6)* • *I told another mother the other day as well, uh you're stronger than me. (P2)*
Assessing the situation and then planning -	*5*	• *It was very easy for me to jump in, ok what does she need, what does the food need to be like, what does the medication need to be like, how*

pragmatic approach		*we going to run this, how we going to write things in the book, cleaning, visitors, you know. (P10)* • *Even though I heard it was leukaemia, I just had to take a breather and just analyse the situation, what's happening, what are the facts. (P11)*
Getting comfort from the child's strength	*5*	• *Watching her makes me strong. (P9)* • *She's a fighter and she really helps me a lot and to cope with it as well. (P12)* • *The thing that is encouraging me, when I saw him, today's he's well and he's fit and we talk a lot. (P15)*
Family dynamics and support	*9*	• *I think just holistically, family, friends, work, the family at the hospital, it's been, it's been a very easy journey having that there. (P5)* • *Family support is very, very essential. (P1)*

Table 4.3 Coping strategies

4.3.6 Primary caregivers' understanding of the phenomenon of resilience

All of the 16 participants acknowledged that they had strengths that were part of their personalities and therefore they are ultimately resilient. They had all 'bounced back' from the diagnosis of their child, except for one participant who felt she hadn't coped with the diagnosis yet, having said that she was able to acknowledge that she did have strengths and so was resilient in her own right.

Eight of the participants had a good understanding of resilience, as one participant explained eloquently that it's:

> "Your ability to cope with difficulty, tough times, setbacks and how quickly you bounce back. Not to say that you, you just averse to feeling anything but it's how you experience it and how quickly you move into a stabilised state again (P5)."

With the phenomenon of resilience being a fairly abstract concept, the researcher also looked at participants' strengths as indicators of their resilience and recorded the themes that emerged, namely: religion/God, spouse/partner, positivity and hope.

4.3.7 Strengths

Various strengths emerged from this discussion with the participants. Some strengths were raised more consistently than others and those are the themes that are detailed. According to Walsh (2012), some families come out of a crisis event or continuous hardship broken and despondent, whereas others come out with increased resources and strength and are able to raise and love their children.

The themes below are the themes that arose and helped the caregivers to cope better and be more resourceful.

4.3.7.1 Religion / God

The number one thing that 14 of the 16 participants identified as a strength was having a religion, or believing in God, or a higher power and that helped them to get through the child's diagnosis and treatment process. Only two of the 16 participants did not mention religion as being a strength. Gardner et al. (2017) said people who engage in positive and meaningful spiritual coping are often able to access additional support from within the spiritual community. This support can have a positive impact on their ability to adapt to the situation.

According to Ahmadi (2006), during difficult times, religion intensifies. Religion can either gain significance or lose significance for a person during their time of crisis. With a disease such as cancer, some people may turn to religion to help them to cope, while others may become doubtful of their religion. This seemed to be the case in this research as the majority of participants felt that religion was a strength that was innate and could not be taken away from them in any way.

According to Brewer-Smyth and Koenig (2014), through intrinsic and extrinsic support, resilience may be promoted. These forms of social support may be implemented via religion and spirituality. Religious beliefs that provide meaning to a crisis event are intrinsic forms of support, as is a relationship with the Divine. Support that is received from the religious community is extrinsic support.

Numerous participants however also felt that religion was a complete separate entity to culture in general. The question of whether culture and religion are related to one another is a complex one. Bardi and Guerra (2010) noted that in embedded cultures, coping by seeking God's help is natural and encouraged as people are required to follow traditions, which includes following their religion. One participant felt that culture and religion are intertwined to some extent, but ultimately because you are of a certain culture, does not automatically mean you practice a specific religion.

Whether culture and religion carry the same weight when it comes to traditions and beliefs then comes into question.

One participant said:

> "In as much as, let me assume now we are Christians, we marry through the religious way in the church, but we accept and know someone is married when his bride is culturally married in the traditional way (P1)."

Most participants felt they became stronger through prayer and this allowed them to cope better and empower themselves.

4.3.7.2 Spouse/partner

According to McCubbin, Balling, Possin, Frierdich and Bryne (2002), it is evident that spouses are an imperative origin of support for one another and the family's togetherness is often strengthened through a diagnosis of childhood cancer. This seemed to be true amongst the caregivers who had spouses. One participant stated:

> "And then there's, I get my strength from my husband, he's really supportive and from Sam* (P3)."

Five of the participants spoke of how their connection or relationship with their partner was a strength that they felt had helped them coped. They felt that having a good relationship was one of their strengths or gave them strength.

In a study carried out by Brody and Simmons (2007) it was noted that fathers felt that during these challenging times relationships within their family system were improved and strengthened and this may have been due to relying on one another for support and

encouragement and spending more time with one another. Having a good support structure in place contributes to the person's ability to cope.

Masten and Monn (2015) noted that an individual and family's resilience are intertwined. Therefore, as the participants mentioned that they gain strength from one another, this helps them to be resilient. Individuals form part of various systems, including the family system and the interactions between these systems affect each other. The resilience of the entire, connected system will influence the resilience of each individual system in accordance with the systems perspective (Masten, 2018). When there is positive interaction between family risks and family protection, there can be family resilience. Resilience is possible at numerous family system levels (Henry, Sheffield Morris, & Harrist, 2015), including the micro-system level, which would mean that support from a spouse could have an impact on resilience.

4.3.7.3 Positivity and Hope

According to Hullmann, Fedele, Molzon, Mayes and Mullins (2014), the people who were able to grow through the experience of a child with cancer were the ones who were higher in hope and were therefore more easily able to find meaning within the experience.

Six of the participants felt that they are positive and so that is their strength. Others mentioned that having hope was a strength. In a study conducted by Barrera et al. (2013), caregivers repeatedly mentioned that in order to maintain hope they needed to avoid others who were negative in any way. One participant said:

> "Keep the faith and keep hope alive and never, you know, think the worst, even though it will come cause, I mean we are all human (P8)."

Participant six therefore links her religion and faith to hope and this is not uncommon. Peteet and Balboni (2013) noted that:

> Cancer is most frightening when it endangers hope. Not only does a diagnosis of cancer force the question of what a realistic object of hope is (e.g., cure, more time, quality of life, or a good death), but it also raises the questions of what are one's deepest hopes and ultimate basis for hope. (p. 281)

Religion or spirituality is able to assist and guide some people in regaining hope in that they find a sense of purpose and meaning of life within their religion. Religion allows a person to

feel that someone greater than themselves is in control (Souza, Frizzo, Paiva, Bousso, & Santos, 2015). If one has hope, it is easier to remain positive.

One participant spoke of being positive and said:

> "So, anything that was coming negative, no, I'd put it aside but rather look for something that is positive (P11)."

As noted by De Graves and Aranda (2008), "hoping for the best and fighting for a cure gave these families a sense of doing all in their power to save their children (p 296)."

Essentially having hope assisted caregivers to move beyond the feelings of uncertainty and being paralysed by the fear of the cancer diagnosis. Hope assisted parents to adapt and adjust to the uncertainty of their current circumstances and attempt to find a 'new' normal, as well as attach new meanings and value to their situation (Bally et al., 2018, p. 94).

4.3.7.4 Physical strengths

One participant mentioned that exercising, for example running and doing weights helped him to cope with the situation. Not only did it distract him from the situation at hand, but helped to keep him physically strong and healthy, so he was able to care for his nephew.

4.3.7.5 Cognitive strengths

One participant mentioned that she felt that being a realist was her strength, she looks at the situation at hand and then deals with it accordingly; while another participant felt that being able to multitask was her strength and that being able to do this had helped her to cope with the diagnosis and be resilient. Another participant explained that her ability to be given information and asked to create a plan and carry it out is her personal strength that has helped her with the diagnosis and treatment process.

One participant said that his strength is that he sees everyone as equals and so he is comfortable around everyone, it makes communicating with doctors easier and he is able to ask questions freely and be open. He feels it is his mindset and that it makes things easier. He said:

> "Ok, my personal strengths, actually like, I always tell myself that we are all the same, no matter, we are all the same. And there's no need to fear anyone or be uncomfortable around anyone (P14)."

4.3.7.6 Emotional strengths

Participant 12 felt that she had a fighting spirit and that was her strength, while participant nine mentioned needing to be strong for their child and how this had helped them to be able to cope and ultimately it made them resilient.

Whilst it was difficult for the participants to remain emotionally strong all the time, all the above themes and subthemes contributed to them successfully being strong for some of the time. An overall review of the caregivers understanding of resilience and their strengths (subthemes) can be seen in Table 4.4.

Caregivers' understanding of the phenomenon of resilience (n=16)		
Caregivers understanding of resilience – Themes	**Number of participants**	**Illustrative quote**
The ability to cope with or 'bounce back' from a difficult situation/experience	*8*	• *I think resilience is the ability to get over all the problems you go through. (P4)* • *It means never giving up, not giving up, just try by all means to try to, to like you know keep going. (P8)* • *No matter what is thrown at you, you carry on. (P10)*
Caregivers strengths – subthemes		
Religion/God	*14*	• *I pray a lot. (P11)* • *It's only God who knows. (P15)* • *So, our children are the same, we pray, we pray together, it's strength that must come from inside. (P10)*
Spouse/partner	*5*	• *My husband is so supportive. (P6)*

		• *At least my husband also came and he's here and if it wasn't for him as well, then ja, I probably, I don't know. (P12)* • *My husband is almost, like literally my pillar of strength. (P10)*
Positivity and hope	*6*	• *I try to, to look always on the positive side of the negative things that you are facing. (P1)* • *I've got hope. (P6)*
Physical strengths	*1*	• *So exercise and that it makes me to cope, instead of being depressed. (P1)*
Cognitive strengths	*4*	• *I can do many things at one time. (P7)* • *I'm the type of person that you need to give me all the information before I have to do something, and then if you tell me to execute, I'm very good with that. (P10)*
Emotional strengths	*2*	• *I'm a fighter and in general I'm a positive person. (P12)*

Table 4.4 Understanding of phenomenon of resilience

4.4. CONCLUSION

The purpose of this study was to investigate the perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital. It can be seen that culture is a complex and a somewhat subjective concept, whilst resilience is not always well understood. It was noted that 13 of the 16 participants did not feel that culture influenced their coping ability. These findings may be partially influenced by the researcher being a white female. At least one participant was not willing to engage and delve into an in-depth discussion around culture as he felt that the researcher may have a different understanding of culture, and the meanings attached to his own culture in particular. Other participants may have felt the same concern around the researcher not understanding their culture, however they did not verbalise it. Twelve of the participants felt however that religion assisted them with coping.

It was clear that these caregivers belong to systems on the micro-, macro- and mezzo-level and that these systems are also all affected by the diagnosis. These systems can, however, also impact how a family or caregiver cope and how resilient they are, depending on interactions

that take place. As stated in the Sociocultural Model of Stress, Coping, and Adaptation, a person's ability to cope is dependent on many variables. Variables such as whether the person views the experience as stressful, their culture and resources, as well as society's reaction can have an impact on the person. These variables would impact their coping, adaptation and therefore resilience. In this research most of the participants felt that they were resilient but struggled to put into words exactly what the term meant for them. Due to all of the above it therefore makes it difficult to generalise these results to the overall population.

CHAPTER 5

MAIN FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1. INTRODUCTION

Culture in South Africa is a very complex concept and when you combine this concept with a caregiver's coping ability and resilience, the complexity increases. The caregiver's understanding of culture, coping and resilience varied, and this was reflected in the results. This chapter will outline these findings, which will be followed by the conclusions and finally recommendations for practice and support, as well as for both future research and implications for theory.

5.2. MAIN FINDINGS

Research on this topic is minimal and even more so within the South African context, for example, Marais (2014) explored the psychosocial influences on a family of a child diagnosed with cancer, but did not explore the cultural aspects. The aim of this study was therefore to explore the perceived influence of cultural practices on the primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital. The following objectives were explored and then analysed with themes recorded below.

5.2.1 Objective One: To determine how caregivers understand the diagnosis of childhood cancer

Ten of the caregivers were aware of childhood cancer prior to their child's diagnosis and were knowledgeable about the diagnosis of childhood cancer. Some of the participants had a particularly good understanding about the type of childhood cancer that their child had, while one or two were still learning about it. Out of the 16 participants, 15 were able to name their child's type of cancer, while one was unsure. The caregivers did say that there were misconceptions around childhood cancer within their communities, where some community members believed the cancer was caused by witchcraft. None of the caregivers themselves believed that their child's cancer was caused by witchcraft. Two of the children were awaiting bone marrow transplants and one of the caregivers' knowledge regarding the transplant was good, while the others understanding was limited at the time of the interview.

The caregivers' level of education and employment status did not appear to impact on their ability to understand the childhood cancer diagnosis. Some of the caregivers were not parents and the sample included two uncles, a sister and a grandmother. This too did not seem to impact on what or how much they chose to understand about childhood cancer. The caregivers' understanding was more determined by their type of personality and how they were able to engage with the healthcare team.

5.2.2 Objective Two: To understand the primary caregivers' experiences of their child being diagnosed with cancer

The findings of this research show that families are affected by a childhood cancer diagnosis in their entirety and the theme that emerged here was one of struggle and difficulty with coping with the diagnosis, treatment and entire process. All caregivers, except for one uncle, felt that this had been a difficult experience to endure. Many caregivers described the experience of their child being diagnosed as shocking and overwhelming initially. They did however feel that, with time, the process became easier for them.

All the caregivers that were parents to the diagnosed children had other children at home and they said this made it even more difficult as they had to try and see to the sibling/s as well. The siblings' routines needed to be kept as normal as possible and they still needed to attend school and have meals prepared for them, for example. Jones (2006) states that:

> When a child is diagnosed with cancer, families experience a devastating life event with immediate and long-term impact on quality of life, activities of daily living, family dynamics, self-identity, parental role, and sense of meaning in the world. (p.221)

The entire routine and everyday activities of each family member was impacted and disrupted, and caregivers often had to rely on their extended support system, if they had one, to alleviate some of the day-to-day stressors.

Three of the caregivers also initially blamed themselves that their child had to experience this and that made the situation more difficult. Only once they were made aware of the fact that this was not true, were they able to deal with the experience slightly better and start to look at it from another perspective. These caregivers experienced internal conflict, between the guilt of thinking that perhaps they did something to cause the illness and the reality of that not being true. They therefore battled to move forward to being more accepting of the illness.

In this study five of the participants had children who had relapsed, and this made their experience even more challenging. The parents felt disappointed and they tried to maintain the child's quality of life while the child was getting new, often stronger, treatment.

Prior to their child being diagnosed with cancer some caregivers said that they had heard of childhood cancer but that they never thought that their child would get cancer. Therefore, it was shocking and overwhelming when they received the child's diagnosis. Elizabeth Kübler-Ross's stages of grief and loss was applied to analyse the caregiver's experiences. The caregivers would move in and out of the various stages, and even be in different stages simultaneously. The stages are denial, anger, bargaining, depression and acceptance. The caregiver's experiences were dynamic rather than static. Day-to-day the child's health would/could change, and this would impact the caregiver's experience and emotions.

5.2.3 Objective Three: To explore the primary caregivers' perception of culture

Culture is a complex concept, particularly in a country as diverse as South Africa. Caregivers, in this research, had a relatively broad idea of the concept of culture and felt that their values and beliefs constituted their culture. Six of the African caregivers spoke of traditional beliefs and witchcraft. They felt that this was part of their culture, but not one which they prescribed to, but rather part of their broader community. Traditional healing is part of the African culture and held in high esteem in the community (de Andrade & Ross, 2005). Traditional healers are often consulted before, or in conjunction with, Western medicine. It is believed that traditional healers treat the patient holistically rather than just physically. Caregivers in this study, however, did not consult traditional healers, although they were encouraged by people within their communities to do so. A number of caregivers felt however, that as they were well educated, they did not follow traditional beliefs and therefore did not subscribe to the witchcraft aspect, or perception, surrounding childhood cancer.

The older generation of caregivers felt that their culture came from the generations before them and so they follow on, or carry, some of these beliefs and traditions with them. An older African father felt that he could not go into culture with the researcher as a white female as she does not believe the same things and therefore, she may not understand his culture. He says culture should be discussed amongst those of the same culture.

When being asked about their ethnicity, one participant responded that he was Christian, he connected his religion to his identity rather than his cultural beliefs and identity. Another

participant felt that religion and culture are intertwined, while others felt that they were separate entities.

5.2.4 Objective Four: To determine whether culture influenced the primary caregivers' ability to cope and if so, how

The majority of caregivers, all but three, did not feel that culture had influenced their ability to cope in any way. One grandmother felt that her upbringing and Portuguese heritage made her stronger as growing up was not easy for her. Another mother said that their family dynamics, which are part of their culture, helped her to cope as they are close knit.

The African caregivers spoke of culture and its influence in terms of traditional beliefs and witchcraft which they said they did not prescribe to and therefore culture did not have an impact on their coping ability. An important aspect that came through in this regard was that many of the caregivers felt that religion had helped them to cope but did not feel that religion was a part of their culture, they felt that it was a separate entity. The researcher was a white female and asking about the very sensitive topic of culture, caregivers may therefore have been reluctant to give in-depth answers and the researcher therefore may have received limited answers.

5.2.5 Objective Five: To identify primary caregivers coping strategies

The themes that emerged within this objective were two-fold. Firstly, caregivers spoke about what made it more difficult for them to cope, followed by what made it easier. Firstly, caregivers struggled to accept that the child had been diagnosed with childhood cancer, this is often the case as it remains unknown as to what causes childhood cancers. Not all caregivers had even heard of childhood cancer prior and so this was a new concept to them.

Feelings that the caregiver themselves may have caused the illness caused them to feel profound feelings of guilt. The caregivers questioned if they were possibly to blame for the child's cancer. They were concerned that it was something that they had or had not done for the child, or even, for the mothers, something they had done during pregnancy. Feeling that they may have caused the illness caused the caregivers to feel profound feelings of guilt.

Struggling with the additional financial costs that the childhood cancer diagnosis brought on for the family also made coping more difficult and added stress for the caregivers. Caregivers mentioned additional medical bills and costs such as buying special foods for the sick child.

Unpredictability and the unknown were difficult for caregivers to cope with as they were unable to plan anything as the condition of the diagnosed child could change from one moment to the next. They may also be admitted to hospital unexpectedly, which had an impact on the siblings at home who need to be seen to and so often parents have to rely on other people that they may usually not have had to do. The unknown around the diagnosis, the treatment and what to expect, was also mentioned as daunting for some of the caregivers as this was an entirely new experience.

Lastly, some caregivers felt it was far more difficult to cope when the diagnosed child was not coping or was experiencing mood swings. They also found that the children would ask questions around why they were the sick ones and it was difficult for the caregivers to handle such situations as there was no answer. The caregivers were often trying to process their own emotions and therefore find it more difficult than normal to contain the child's emotions as well.

Whilst the caregiver's grappled with the above difficulties that hindered their coping, there were also positive aspects that assisted them to cope. Many of the caregivers felt that the only person who could understand or relate to what they were going through was another caregiver of a child diagnosed with cancer, they may have connected at the hospital or through the internet. The caregivers expressed feeling less alone due to these connections. This included the caregivers who were from outside of the country and who had made connections with other caregivers in their immediate environment. One caregiver also expressed that by speaking to another caregiver where the treatment had been successful gave him hope. The caregivers tend to share experiences and ideas, and this assisted them with creating and maintaining their own coping strategies.

Although caregivers were unable to plan for the future, they were able to plan for the day-to-day necessities, sometimes hour-to-hour. They felt that by planning they had a small sense of control over an otherwise overwhelming experience. This assessing and planning also related to the caregiver being able to plan for the needs of the siblings, meals or a lift home from school, or to an extra-mural activity. The assessing would also refer to the ill child and their needs and care. By having a small sense of control some of the caregivers were able to cope slightly better than others.

Five of the caregivers expressed that if the diagnosed child was feeling well and coping, they were more likely to cope with the situation at hand. It was when the child was ill and struggling with their experience that the caregiver's ability to cope was significantly challenged.

Finally, in situations where the family system was strong to start with, these dynamics seemed to become stronger. Many of the female caregivers felt that they were able to rely on their partners for strength. It was mentioned that caregivers who felt that they had the support of not only their nuclear family, but extended family as well, felt more able to cope and so this was a coping mechanism in itself. Positive support from those around them, increased their coping abilities. The coping strategies identified pertain to the caregiver's in this study in particular and made these caregivers feel more contained and therefore assisted them in coping with the situation.

5.2.6 Objective Six: To explore the primary caregiver's understanding of the phenomenon of resilience

The phenomenon of resilience is a concept that half of the caregivers were familiar with, this may be due to the fact that it is a complex and abstract concept. The concept of resilience may be a strange or unknown one for some, and there may possibly not be a direct translation for the word in other languages. According to Stephens (2013), "resilience has been broadly defined and generally applied to create much confusion and ambiguity" (p. 125). However, all of the caregivers were able to identify strengths within themselves that in fact made them resilient.

Strengths were explored rather than resilience, as resilience is a more abstract concept, whereas strengths were more easily relatable to the caregivers. The following strengths emerged, namely**:** Religion/God - 14 of the 16 participants found solace and strength in their religion. Their religion gave them the ability to 'bounce back' and handle the situation of their child being diagnosed with cancer and the treatment processes that followed. Some caregivers felt that their strength came from their partner/spouse. Having a good nuclear family support system in place gave them the strength and ability to cope.

Some caregivers felt that their innate positivity was a strength and that they always had hope, while one participant felt that being physically active and healthy assisted him in his ability to care for his nephew and ultimately helped him to be resilient in the difficult situation he found himself. While physical strength was mentioned by a male caregiver, cognitive strengths were

raised by his female counterparts as being a strength. Their ability to manage the diagnosis and treatment from a cognitive aspect and carry out certain steps to help cope was a strength. One participant felt she had a fighting spirit, and this made her emotionally strong which ultimately made her resilient.

Whilst not all of the caregivers were resilient all of the time and struggled to cope with their experience at some part during their journeys, overall all the participants displayed strengths that made them resilient for at least part of the time. All the participants had the ability to 'bounce back' and cope with their situation, but when they were able to do this, depending on their coping strategies and support systems in place, varied.

5.3. CONCLUSIONS

The purpose of this study was to investigate the perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital. There was confusion around the term 'ethnicity' and so limited information was gathered in this regard. There was therefore a lack of information on their background cultures. The overall results indicated that the majority of caregivers did not feel that culture influenced their ability to cope or their resilience in anyway, however, many said that their various strengths assisted them to cope. These various strengths were in part intertwined with culture but perhaps the participants were not aware of this on a conscious level. The overriding factor among this group of caregivers, that assisted with coping and resilience, seemed to be their religion and belief in God. When speaking of their culture, participants said that this included their values and beliefs, linking religion to culture on a subconscious level.

Six of the African participants spoke of traditional healing and witchcraft as linked to culture and at times linked to childhood cancer by their greater communities. These participants, however, did not personally believe in or follow these practices. Personality traits seemed to influence the information gathered around childhood cancer and their child's diagnosis. Those who were confident in speaking to and questioning doctors appeared to have more knowledge about the disease.

Some of the caregiver's values and beliefs fell into the realm of culture, however they did not feel this was the case. The phenomenon of resilience was explored and only half the caregivers had a good understanding of the concept, however all caregivers noted personal strengths that

lead them to be resilient. Only one participant felt that they were not coping with the diagnosis and their child was newly diagnosed. This research also found that the mood and emotions of the child impact the coping ability of the parents. The better the child is handling the situation, the easier it is for the parents to cope.

The diagnosis of childhood cancer was stressful and difficult for the participants, however, in this study it was found that the diagnosis in fact strengthened families. The use of available resources, for example, extended family help, as well as participants' personal strengths, assisted in their ability to cope and ultimately their resilience. A number of participants felt that coping became easier as time and treatments progressed. One of the participants raised that counselling through her work had assisted her, but none of the other participants mentioned counselling or hospital support as a coping mechanism and so the numbers were not sufficient to include this in the themes related to coping.

In Figure 5.1 it can be seen that within the systems theory there are, as previously mentioned, different levels of systems. When combined with the sociocultural model of stress, coping and adaptation, it is made clearer how these affect one another. The way in which an individual (micro-system) views an event as stressful or not will determine how they interact with the event and whether they have sufficient coping resources internally or need to lean on their bigger resource structures, for example, extended family or a support group within their mezzo-system. A person's macro-system also will impact their stress appraisal as often how society perceives a situation is how an individual then too looks at it. Therefore, all systems and variables are interlinked. These systems and variables have an influence on a person's perceptions of everything including culture, religion, health and illness and their beliefs and values.

An individual's perception of life then has an impact on how they perceive and interact with specific events that take place. In this instance the way caregivers perceive the diagnosis, treatment an outcome of a cancer diagnosis of their child was explored. The ways in which caregivers were able to cope were highlighted as well as what caused them to struggle to cope are detailed. It is important to note that these also have an effect on one another.

Whether an individual is resilient or not depends on many variables, including the individuals view of resilience. It can be said that some people cope due to being resilient while others use strategies to cope and therefore become more resilient.

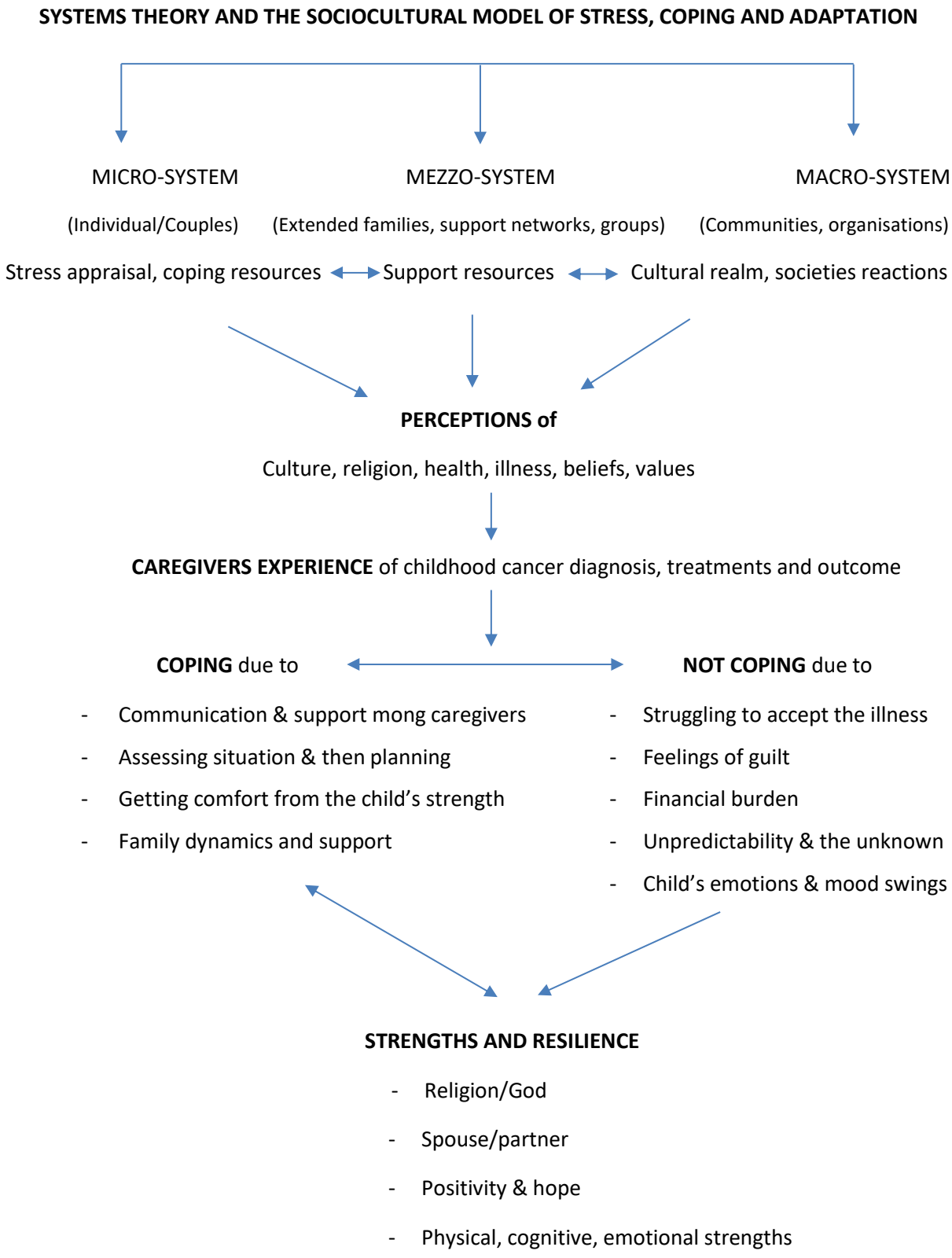

Figure 5.1. Conceptual framework of the study

5.4. RECOMMENDATIONS

Due to the sample number being small, 16 participants, the results and recommendations cannot all be generalised. It must also be noted that this was a very specific sample group of caregivers whose children were treated in a private hospital and that this sample group does not represent the larger population. Further research should also take place in the government sector.

5.4.1 Recommendations for Practice and Support for Social Workers

- Social workers or those supporting the caregivers should be aware of the possibility of the larger community believing that the child has been bewitched and the impact that may have on the caregiver and patient's family.

- Social workers could assist with educating communities and schools more broadly about the impact of childhood cancer on the entire family and how best to support these families. For example, how best to reintegrate the sick child into the school system.

5.4.2 Recommendations for Practice and Support for Healthcare Providers

- While the majority of caregiver's perceptions were that culture did not influence their coping abilities and resilience, what assisted them to cope, for example: religion, communicating with other caregivers, assessing the situation and panning the way forward, should be taken into consideration by healthcare practitioners.

- Healthcare providers should be encouraged to include the caregivers in the treatment process as from this research it was found that the unknown creates fear among caregivers. Therefore, the more included and educated they are around the diagnosis, the more likely they are to cope better with the situation.

- It is essential that it is remembered that a diagnosis of childhood cancer affects the whole family system and how that system functions. Systems theory can be looked at as a guide as to how one system impacts on another, and so all systems surrounding the child can be assessed and addressed when and if necessary.

- Healthcare providers need to be made aware regarding the fact that one coping strategy may work for one caregiver or family but not for another, just as one caregiver may not

feel influenced by culture where another caregiver might. It is important that due to the caregiver's individualisation that they are treated accordingly.

The caregiver needs to be viewed in holistically, including their psycho-social and cultural needs.

5.4.3 Recommendations for Future Research

This research aimed to explore the perceived influence of cultural practices on caregivers coping abilities and resilience when their child is diagnosed with cancer and from this research it can be seen that both culture and resilience are complex. Further research could be done in the South African context regarding what the sick child is told about their cancer and the impact that their knowledge has on the caregiver.

Further research into the social workers role in a paediatric oncology environment is also recommended as this may improve or enhance caregivers' coping mechanisms and ultimately their resilience, if appropriate strategies can be explored with them, with a social worker.

Research into the coping abilities and resilience of caregivers in the public hospitals, where resources are often limited, should be done in order to be able to more broadly generalise results.

5.4.4 Recommendations for Theory

Theoretical teaching will need to be expanded to further include South African cultures and the impact culture has on understanding the parent's reactions to a diagnosis of cancer. By using the systems theory to understand that patients and family's function within systems, they can be better supported in all realms. If the understanding of the dynamics and culture that interplay in caregivers coping, especially by healthcare professionals, is improved, the psychological distress that these caregivers experience may be minimised. These caregivers could be viewed holistically within their cultural contexts.

5.5. CONCLUDING COMMENT

A diagnosis of childhood cancer is devastating for any caregiver and family. Due to such a diagnosis many changes take place within the family's realm. These changes may be positive or negative in effect. Some of the larger community may believe in witchcraft, which is another hurdle the family may have to tackle.

When exploring culture within the South African context the complexity is enormous and people's understandings and perceptions differ, the same goes for resilience. According to Chaudry et al. (2016) resilience is being able 'bounce back' after an adverse event. While people may be able to identify resilience when they see it, they themselves, often struggle to employ resilience. It is also a challenge to measure and promote resilience (A. R. Rosenberg, Starks, & Jones, 2014).

Resilience is determined by numerous factors, including biological, cultural, psychological and social factors. How a person responds to a stressful situation is often based on how these factors interact with one another (Southwick et al., 2014). Healthcare providers therefore need to take these factors and interactions into consideration when treating a child diagnosed with cancer in order to provide holistic care. "Increased awareness of cultural factors is needed to improve clinical care and reduce health disparities" (Gray et al., 2014, p. 252).

The majority of the participants felt that religion helped them to cope, rather than culture, however as Beyers (2017) noted, "the relation between religion and culture seems to be similar to the uneasy relationship between two arguing relatives who cannot deny their connectedness, but wished it otherwise" (p.8).

We all function within a system and if we are able to find ways in which to assist that system in functioning when faced with an adverse event, such as when a childhood cancer diagnosis takes place, we are more likely to be resilient.

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APPENDICES

APPENDIX A: Self developed semi-structured interview guide / schedule exploring the influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

Research interview schedule or guide

The perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

Go through PIS and get signed consent. Start recording.

PARTICIPANT DETAILS / DEMOGRAPHICS

Gender:

Ethnicity (tribal clan/ background):

Home Language:

Age: 18-25

26-30

31-35

36-40

41-45

46-50

50 and above

Religious affiliation:

Marital status:

Children:

Residing country:

Highest level of Education:

DIAGNOSED CHILD'S DETAILS

Age at diagnosis: 1 month – 12 months

13 months – 18 months

19 months – 24 months

25 months - 2 years 6 months

2 years 7 months – 3 years

3 years 1 month – 4 years

4 years 1 month – 5 years

5 years 1 month – 8 years

8 years 1 month – 12 years

12 years 1 month – 16 years

16 years and above

Diagnosis:

Date of diagnosis:

Treatments:

Current age: 1 month – 12 months

13 months – 18 months

19 months – 24 months

25 months - 2 years 6 months

2 years 7 months – 3 years

3 years 1 month – 4 years

4 years 1 month – 5 years

5 years 1 month – 8 years

8 years 1 month – 12 years

12 years 1 month – 16 years

16 years and above

Ethnicity (tribal clan / background):

Gender:

Schooling:

GUIDING QUESTIONS

1. What do you understand about childhood cancer and in particular your child's diagnosis?
2. Tell me about your experiences since your child has been diagnosed with cancer?
3. What is your understanding of the term culture?
4. Please elaborate as to how you feel culture has influenced the way in which you cope?
5. Do you feel you have coped with your child's diagnosis? Please specify.
6. What has made your coping easier or more difficult? (Family / medical)
7. What can you identify as your strengths? (Can you explain your understanding of resilience? Ability to bounce back)
8. Do you feel you have applied them in your current situation and if so how?
9. Do you have any other comments or information that you feel you would like to share?

THANK YOU FOR YOUR TIME AND FOR SHARING YOUR EXPERIENCE WITH ME.

APPENDIX B: Participants information sheet

SOCIAL WORK
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4472 • Fax: 011 717 4473 • E-mail: socialwork.SHCD@wits.ac.za

Participants Information Sheet

The influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

Good day,

My name is Chantel Lowry and I am a post-graduate student registered for the degree MA Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research regarding how cultural practices affect primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated at a private hospital. Getting this diagnosis can be very difficult, and we do not know very much about how people in this situation cope. By doing this research I hope to be able to better understand these factors and possibly make recommendations that will help primary caregivers' cope with a diagnosis in the future.

As a caregiver of a child diagnosed with cancer, you are in a position to contribute to my research if you choose to. I would like to invite you to participate in my study. You will not be paid to participate in the study and there will be no cost to you. Your participation is entirely voluntary and you would be able to withdraw from the study at any point. If both you and your spouse would be able to participate, it will be up to you to decide who will participate as I can only accommodate one caregiver per family. If you choose to participate in my research I would interview you at Wits Donald Gordon Medical Centre at a time that is appropriate for you. The interview will last for approximately 1 hour and it will take place in a private room. At the beginning of this interview I will be asking a few demographic questions for research purposes. During this time should you encounter a question that you do not feel comfortable answering, you are under no pressure to answer it and may refrain from answering. Should you experience any upset or psychological distress I will arrange for you to see the psychologist at the Donald Gordon Medical Centre at no cost to you. Her name is

Tina Sideris and she can be contacted on 011 356 6045. As mentioned above there is a possibility of psychological distress and there is no direct benefit to you for taking part in this research.

I would like to record the interview on an audio recording device and I would like to ask your permission to do this. The reason is so that I will be able to accurately transcribe the interview later and therefore accurately record all data for analysis. By recording the interview, I will be able to listen more attentively without the distraction of having to make notes. Only my supervisor and I will have access to these recordings. The audio recordings will be kept in a locked cupboard that only I have access to and the transcripts will be kept on a password locked computer that only I have access to. Data will be stored for a maximum of two years if published and six years if not published. Thereafter, data will be disposed of.
Your name and personal details will be kept confidential and will not be revealed in the final report or at any other time. The results of the research may possibly be used for academic purposes (for example, books, journals and conference proceedings) and you will be provided with a copy of the results if you want one.

Please contact me, on 083 484 1222 or Chantelann.lowry@gmail.com, or my supervisor, Dr. Francine Masson on 011 717 4480 or Francine.masson@wits.ac.za, if you have any questions regarding my study. We will answer them as best as possible. If you have any concerns or complaints about the study, please contact **Human Research Ethics Committee (Medical)** administrators Ms Zanele Ndlovu or Mr Rhulani Mkansi on Tel 011 717 2700/2656/1234/1252, HREC-Medical.ResearchOffice@wits.ac.za.
Thank you for considering participating in my study, please do not hesitate to contact me should you have any questions, and I can answer any immediate questions you have now.

Yours sincerely,

Lowry

Chantel Lowry
Masters social work student

APPENDIX C: Consent Form

Consent form for Participation in the Research project

The perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

The purpose and procedures of the above-mentioned research have been explained to me.

I _____, hereby consent to be a participant in this research study.

I understand that:

- Participation in this research project is entirely voluntary.
- I may withdraw from this research study at any time without being penalised or disadvantaged in anyway.
- I do not have to answer all questions if I choose not to.
- Confidentiality will be kept and my identity will not be revealed to anyone other than the interviewer and their supervisor.
- A copy of my interview transcript will be kept in an appropriate place and may be used for future research. There will not be any of my identifying details on this document.
- My responses will be used in a Masters project write up and may also be presented in book chapters, books, journal articles and at conferences.
- Direct quotes from my interview may be cited in the research study report or other write-ups of the research. There will not be any of my identifying details on this document.

Name of Participant: _____

Signature: _____

Date: _____

APPENDIX D: Consent forms for audiotaping

Consent form for audio-recording of the interview

The perceived influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital.

The purpose and procedures of the above-mentioned research have been explained to me.

I _____, hereby consent for my interview to be audio-recorded.

I understand that:

- Participation in this research project is entirely voluntary.
- I may withdraw from this research study at any time without being penalised or disadvantaged in anyway.
- I do not have to answer all questions if I choose not to.
- Confidentiality will be kept and my identity will not be revealed to anyone other than the interviewer and their supervisor.
- A copy of the audio-recording will be kept in an appropriate place and may be used for future research. There will not be any of my identifying details on this document.
- The recording will be transcribed and my identity will be kept confidential.
- My responses will be used in a Masters project write up and may also be presented in book chapters, books, journal articles and at conferences.
- Direct quotes from my interview may be cited in the research study report or other write-ups of the research. There will not be any of my identifying details on this document.

Name of Participant: _____

Signature: _____

Date: _____

APPENDIX E: Permission from hospital CEO to conduct research

Wits University
Donald Gordon
Medical Centre

Patient centred Independent Academic

MEDICLINIC

16 March 2018

To whom it may concern

Re: Permission to conduct research at Wits Donald Gordon Medical Centre

This letter serves to confirm that permission is granted from the CEO, Dr Susan Tager at WDGMC for Mrs Chantel Lowry to conduct their study titled:

"The influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital."

No data collection may start at WDGMC until a Clearance Certificate has been obtained to do the study from the Wits Human Research Ethics Committee (Medical).

Yours faithfully,

Dr Sue Tager
CEO
Wits Donald Gordon Medical Centre
Tel: (+27) 011 356 6302
Mobile: 082 457 7134
Email: sue.tager@mediclinic.co.za

APPENDIX F: Permission from paediatric oncology unit's head consultant to conduct research

Wits University **Donald Gordon Medical Centre**

Patient-centred. Independent. Academic.

21 Eton Road, Parktown, 2193
P.O. Box 2072, Houghton, 2041
Tel : (011) 356 6115/6
Fax : (011) 356 6048

PAEDIATRIC PRACTICE
PR. No. 050 000 0178020
Associates : Dr J E Poole, Dr R D Wainwright, Dr S Payiadjis, Dr G Naidu, Dr B Goodwin, Dr R Schwyzer, Dr D MacKinnon, Dr B Rowe, Dr J Geel
janet.poole@wits.ac.za

25/04/2018

To whom it may concern

Re: Permission to conduct research

This letter serves to confirm that permission is granted by Professor Janet Poole, the Head of Department at the Wits. Donald Gordon Medical Centre (WDGMC) Paediatric Haematology and Oncology Units Chantel Lowry to conduct her study titled:

"The influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital."

No data collection may start until a Clearance Certificate has been obtained to do the study from the Wits Human Research Ethics Committee (Medical).

Yours faithfully,

Professor Janet Poole
Head Paediatric Oncologist
Wits. Donald Gordon Medical Centre
Tel: (+27) 11 356 6191
Mobile: 082 469 5762
Email: Janet.poole@wits.ac.za

APPENDIX G: Ethics clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mrs Chantel Ann Lowry

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180515

NAME: (Principal Investigator)	Mrs Chantel Ann Lowry
DEPARTMENT:	Social Work - School of Human and Community Development Wits Donald Gordon Medical Centre Paediatric Oncology Unit
PROJECT TITLE:	The influence of cultural practices on primary caregivers' coping ability and resilience when their child is diagnosed with cancer and treated in a private hospital
DATE CONSIDERED:	25/05/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Francine Masson
APPROVED BY:	CB Penny Professor CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	21/06/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **May** and will therefore be due in the month of **May** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Lowry
Principal Investigator Signature

21/06/2018
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX H: Turnitin report

00400616:Chantel_Lowry_Final.docx

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