

**MULTI-FACTORIAL CHALLENGES OF FAMILY CAREGIVERS OF
PAEDIATRIC ONCOLOGY PATIENTS REGARDING DELAYING ACCESS TO
HEALTHCARE**

by

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MINI-DISSERTATION

Submitted in partial fulfilment of the requirements for the degree

Masters of Social Work in Healthcare
MSW (HEALTHCARE)

in the

Department of Social Work and Criminology
Faculty of Humanities
University of Pretoria

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December 2018

DECLARATION OF ORIGINALITY

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ACKNOWLEDGEMENTS

I wish to express my deepest thanks to, my supervisor, Dr. Charlene Carbonatto, for her dedication, patience, and keen interest to assist me to complete my mini-dissertation. Her guidance, scrutiny and advice helped me to accomplish this study.

- I express my sincere thanks to Steve Biko Academic Hospital for allowing me to conduct this study.
- I owe a deep sense of gratitude to Professor Reynders and his team from Paediatric Oncology for his inspiration and enthusiasm regarding this study and enabling me to complete my research.
- I thank all the ex-colleagues and friends of Steve Biko Academic Hospital (Morose, bhuti Willie, my friend Nancy, sisi Fikiswa, and Mr. Motsepe), for their support throughout my studies. I also wish to mention Sihlobo Sam Gift for his kindness and assistance.
- It is my privilege to thank Mr. Mathibedi for his constant encouragement throughout my research.
- I am extremely thankful to my family, my parents Mr. and Mrs. Mabhoza for their unconditional love and consistent support: Nditi A Faku!
- I am exceptionally thankful to my editors Messrs. Deirdre Blignaut and Elize Nagel for their patience and support.
- Lastly, I wish to thank my current employer, CHOC, for their unwavering support and understanding.

ABSTRACT

Title: Multi-factorial challenges of family caregivers of paediatric oncology patients delaying access to healthcare

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Childhood cancer is the leading cause of disease-related death. It remains a global health problem. Early diagnosis of cancer is essential for effective management of the illness. With the increase of late detection of childhood cancer, one would ask the question: “What delays family caregivers to access healthcare for their child?” South Africa has a strong legislative policy foundation for a developmental approach to childcare and child protection and high-quality health services (Children’s Act 38 of 2005; Bill of Rights, section 28; National Department of Health, 2014:3). It remains a concern why family caregivers of paediatric oncology patients delay access to healthcare.

The goal of the research study is to explore and describe the factors challenging family caregivers of paediatric oncology patients in delaying access to healthcare.

The research question driving this study was as follows: *What are the factors faced by the family caregivers of paediatric oncology patients, which result in late diagnosis of cancer in children?* The health belief model is deemed appropriate in underpinning the study (this is a theoretical framework guiding the study).

The objectives of the study are as follows:

- to conceptualize and describe paediatric oncology, treatment, access to healthcare systems and the role of family caregivers;
- explore and describe the challenges faced by family caregivers of paediatric oncology patients in the community and the health system;
- explore and describe the factors that lead to delayed access to healthcare of paediatric oncology patients;

- explore and describe the cultural challenges of paediatric oncology family caregivers and to make recommendations to the oncology team to improve accessibility to paediatric oncology care.

This study followed a qualitative approach in exploring and describing the factors that delayed family caregivers of paediatric oncology patients to access healthcare. Applied research was selected and deemed suitable as possible practical solutions for the challenges faced by caregivers of paediatric oncology patients. The case study design, particularly the collective case study design, was employed using semi-structured interviews with an interview schedule and a digital voice recorder.

The interviews were transcribed verbatim and themes were generated from the data.

The following themes and sub-themes emerged from this study:

Theme 1: Understanding cancer. Definition of cancer as understood by participants; signs and symptoms experienced by the child; action taken when child got sick; information gained from healthcare professionals regarding the sick child at local healthcare facilities; first knowledge of child's cancer; and history of cancer in the family.

Theme 2: Access to healthcare. Distance to local clinic and hospital; transport, easy access to emergency services and road accessibility; access to traditional healers in the community; and access to a clinic and/or hospital and oncology care.

Theme 3: Religion, culture and spirituality. Religion and change in belief since diagnosis; cultural rituals in family during illness or treatment; beliefs about disease and traditional medicine (*muthis* and/or *mbizas* used; and belief in Western treatment and hospitals.

Theme 4: Communication and language. Experience of communication with health professionals; language spoken, level of understanding of diagnosis when explained and other challenges.

Theme 5: Socio-economic status. Employment status, source of income, housing, environment and access to basic needs.

Theme 6: Delayed access to healthcare. Healthcare providers, understanding cancer, negligence by parents, traditional healers, time and money and transport.

Theme 7: Impact of cancer. Impact of cancer on caregiver, siblings and family and role changes.

Theme 8: Intentional and non-intentional delays. Income, awareness of cancer, emotions, bargaining, family beliefs, beliefs in Western medicine, no support systems and other factors.

Theme 9: Medical and related costs. Medical aid, payment of medical bills, hospital fee structure and financial challenges.

Theme 10: Caregiver responsibility regarding decision-making and support from the father.

Theme 11: Recommendations: Recommendations from the participants.

The findings of the study showed that there is a significant gap in knowledge about childhood cancer among family caregivers and healthcare professionals in the local healthcare system. It also revealed that the distance to local healthcare facilities disadvantaged users to access healthcare facilities easily. Furthermore, emergency service delays and poor infrastructure were found to have an impact. Moreover, oncology healthcare centres are not easily accessible.

Religion was found to be the source of strength for many people and has a potential influence to delay access to healthcare, as people mostly believe in miracles of healing. In terms of spirituality, participants believed in the power of God and their faith seemed to be strengthened as they prayed for healing. As far as culture is concerned, participants understood traditional healing and made a choice to believe either in it, or in Western medicine. However, traditional medicine did not feature strongly. The findings further showed that open communication and language were vital to promote the relationship between patient and service provider. There were instances where the attitudes of healthcare professionals were experienced negatively.

Socio-economic status challenged participants as far as affording basic healthcare was concerned. The Government's proposed NHI brings hope to many in need of medical care. A number of factors delayed access to healthcare, which include spiritual healers, time, money and transport. However, this study showed that caregivers did not intentionally delayed access to healthcare, except for those who

preferred to first experiment with other medicine such as traditional medicine from traditional healers.

The findings also showed that cancer affects the family systems on a psychological, emotional, economic and social level. Most participants did not have medical aids and struggled to navigate the healthcare system successfully. Because of the challenges they went through, the study revealed that some bad decisions were made regarding the healthcare of the child. The recommendations from the participants were on the importance of health education regarding childhood cancer, screening to improve the early detection of childhood cancer, encouraging caregivers and providing them with support.

It is very difficult to obtain optimal healthcare for children if parents and/or caregivers have no insight and are uneducated about childhood cancer. Access to healthcare is also impeded in many communities, through factors such as lack of basic services, lack of roads and infrastructure, and shortage of emergency services and/or malfunctioning emergency vehicles.

Religion seemed to be the source of strength for many participants and contributed to the ability to cope with the child's ill health. Clear communication and open relationship in healthcare facilities was a crucial factor.

Diagnosis of cancer affected the families, their function and structures, which seemed to lead to unintentional delay in accessing healthcare. Additional factors also contributed towards the delay in access to healthcare.

The use of laymen's terms instead of medical jargon may encourage a positive relationship between patient and service provider, based on trust and openness. Education of healthcare professionals from primary healthcare on early warning signs of childhood cancer to improve early detection. Childhood cancer to receive more attention in terms of aggressive awareness campaigns and screening. Furthermore, the implementation of NHI in order to improve accessibility and better care for all. Those infected by childhood cancer need psychosocial support to enhance coping mechanisms.

Key terms: Cancer, caregiver, challenges, child, delayed access, factors, healthcare, oncology, paediatric, patient, social worker.

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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ALLO	Allogeneic
AUTO	Autologous
CANSA	Cancer Association of South Africa
CHOC	Childhood Cancer Foundation of South Africa
CSF	Cerebral Spinal Fluid
IARC	International Agency for Research on Cancer
ICCD	International Childhood Cancer Day
HIV	Human Immunodeficiency Virus
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
NHI	National Health Insurance
PET	Position Emission Tomography
SADEC	Southern African Development Community

1. CHAPTER 1: GENERAL INTRODUCTION

1.1 INTRODUCTION

The death of children continues to make a serious impact in all countries throughout the world. Globally, several countries indicated that the child mortality due to cancer remains a public health concern. In developed countries (such as Canada, America and France), cancer is reported as a leading cause of disease-related death that impacts physically and psychologically on the affected children and families (Dang-Tan & Franco, 2007:703). A report released recently by the International Agency for Research on Cancer (IARC) (2016) indicates that the global occurrence of childhood cancer may be significantly higher than previously thought. In Africa, childhood cancer is prevalent; approximately more than 60 percent of people diagnosed annually, including children (WHO, 2010). In South Africa, as reported by Stefan and Siemonsma (2011:80-85), childhood cancer has never been conclusively researched. Despite this growing cancer burden, it remains a relatively low public health priority in Africa, partly because of limited resources and other pressing public health problems, including communicable diseases such as acquired immunodeficiency syndrome (AIDS), human immunodeficiency virus (HIV), malaria, and tuberculosis (Jemal, Bray, Forman, O'Brien, Ferlay, Center & Parkin, 2012:4372). Dang and Franco (2007:703) confirm that few studies are done related to childhood cancer.

Early detection of cancer in children is fundamental for supportive care to be provided. Children are a vulnerable group in need of care in all spheres of life. They can be more at risk and exposed to any form of ill health including cancer. To address this issue the Government of South Africa provides a strong legislative policy foundation for a developmental approach to childcare and protection of children (Children's Act 38 of 2005; Bill of Rights, section 28). These policies outline the needs of children and prescribe how family caregivers should take action to ensure good care for children. It is generally contended that South Africa fulfils its commitment in the Constitutional Rights of Children to Healthcare, yet children are still diagnosed with advanced stages of cancers and die (Children's Act 38 of 2005; Bill of Rights, section, 28). Children who are diagnosed late with cancer poses a challenge to the paediatric oncology team who provide treatment and must ensure

the survival of these children (Stefan & Siemonsma, 2011:80-85). Various factors contribute towards the phenomenon of late diagnosis of cancer in children. Some of these factors include caregivers' health beliefs, education, and socio-economic determinants. Healthcare professionals in primary and secondary levels of care with limited skills and knowledge of childhood cancer may also contribute to a misdiagnosis at early stages (Francis, Battle-Fisher, Liverpool, Hipple, Mosavel, Soogun & Mofammere, 2011 and Vasuthevan & Mthembu, 2013:5).

Steve Biko Academic Hospital in Pretoria is the only public tertiary hospital in Pretoria that offers comprehensive paediatric oncology care. This study explores the factors that possibly contribute to delays in accessing healthcare, especially in response to the significant increase of children diagnosed with cancer at late stages in the hospital. The dilemma pertaining to late diagnosis of childhood cancer is also noted at the Chris Hani Baragwanath Hospital in an interview with Dr. Mahlatshane (2016), who indicated that it is an issue in the hospital and that they are concerned about the late presentation of children in advanced stages of cancer when survival is poor.

This study will add value to the subject field of oncology and fill a gap in research about children with cancer, specifically the challenges faced by family caregivers of paediatric oncology patients regarding the late diagnosis of cancer. The study also contributes to bridging the gap in mutual understanding among the families, caregivers, and oncologists in the Paediatric Oncology Department of Steve Biko Academic Hospital. Ultimately, the study attempts to answer questions on issues influencing the late diagnosis of children with cancer in the cancer care sphere. The following key concepts apply to this study and is described below:

- **Family caregiver**

'Family caregiver' is defined as "anyone who provides any type of physical and/or emotional care for an ill or disabled loved one at home" (Net of Care Information for Family Caregivers, 2016:555). In this study, 'family caregiver' is the caregiver of the child who has cancer. This person is usually a parent, grandparent or family member.

- **Paediatric**

'Paediatric' is defined by Mosby's Dictionary of Medicine, Nursing and Healthcare Professionals (2013:1350) as "a branch of medicine concerned with the development and care of infants and children. Its specialties are the particular diseases of children and their treatment and prevention." In this study the words 'paediatric patients' refer to children who are cancer patients.

- **Oncology**

This concept is defined as a "study or science dealing with the physical, chemical and biological properties and features of neoplasms, including causation, pathogenesis, and treatment" (Stedman's Medical Dictionary for Health Professionals and Nursing, 2008:1107). For the purpose of this study, 'paediatric oncology' refers to the field of specialization focusing on the child with cancer.

- **Cancer**

'Cancer' refers to a malignant growth characterized by a continuing, purposeless, unwanted, uncontrolled and damaged growth of cells that differs structurally and functionally from the normal cells (Stephens & Aigners, 2016:3). In this study 'cancer' refers to a life threatening condition in children.

- **Healthcare**

'Healthcare' is defined by the Concise Oxford English Dictionary (2011:568) as "the organized provision of medical care to the individual or community," for the purpose of promoting, maintaining, monitoring or restoring health. The concept is also defined by Holmes (2009:24) as "the prevention, treatment, and management of illness and promotion of mental and physical well-being through the services offered by medical and allied health professionals." 'Healthcare' in this study refers to health services for paediatric oncology patients.

- **Patient**

The word refers to someone "who is suffering from disease, injury, an abnormal state, or a mental disorder, and is engaged in related treatment" (Stedman's Medical Dictionary for the Health Professionals and Nursing, 2012:1259). 'Patient' in this study refers to a child who is diagnosed with cancer and is receiving oncology care.

1.2 THEORETICAL FRAMEWORK

1.2.1 The origin of the model

The increased number of children diagnosed with advanced cancers at Steve Biko Academic Hospital may be investigated by means of various theoretical frameworks. In this regard, the researcher has selected the health belief model, as this theoretical framework was deemed appropriate in addressing the research question guiding the current study.

The model grew out of applied research problems and serves as a solution to practical problems and real concerns that limit the success of various programmes of public health issues. This model is linked with social cognitive theory, which suggests that human functioning can be “a product of reciprocal and intrapersonal, behavioural and environmental determinants” (Bandura, 2011:359). The health belief model is a model that is “commonly used to provide an explanation of health-related behaviour and identify aspects that could assist a person in improving their health actions” (Dennill, Rendani-Mkosi 2013:156). This paradigm developed by Rosenstock in Rosenstock, Strecher and Becker (1988) has been incorporated into other models, such as the health action model cited in (Dennill, Rendani-Mkosi 2013:156). The health belief model suggests better clarity of health behaviours and the possible reasons for non-conformity with recommended action (Hayden, 2014:38).

The researcher strongly holds the view that the health belief model provides the best insight to understand the health beliefs of family caregivers better, how they perceive and act on children’s health, particularly in the case of following guidance from healthcare professionals for children with cancer. This may inform health professionals what factors contribute towards family caregivers delaying access to healthcare. It is important to understand that people perceive and interpret ill health differently (Saca-Hazboun & Glennon, 2011:281). The response to ill health can be influenced by various contributing factors and behaviours that include knowledge about health issues, experiences, lifestyles, religions, and culture (Van Dyk, 2008:202; Truter, 2007; Porterfield & McBride, 2007:327; Van Rensburg, 2012:635 and Kingsley, 2010).

1.2.2 The components of health belief model

This study recognizes that people always have a reason to behave the way they do. Knowledge about health issues would influence the caregiver's decision-making regarding healthcare. In the case of paediatric oncology, knowing early symptoms can be crucial. Haan (2005:8) maintains that caregivers need to make an informed decision concerning their healthcare and even regarding lifestyle issues. In order to do this, caregivers need to be able to read, write and make informed decisions. As such, Green and Murphy (2014:1) suggest that health behaviour can be motivated by various perceptions. The following are important components of the health belief model:

- Perceived susceptibility to ill-health (lifestyle, no insight about health issues, ignorance);
- Perceived severity of ill-health (life-threatening, death);
- Perceived benefits of behaviour change (early detection of childhood cancer allows better management and save lives); and
- Perceived barriers to taking action (may include transport, distance to healthcare centres and traditional beliefs).

The issue of a caregiver's cultural and religious beliefs cannot be underestimated in healthcare. Partida (2007) suggests that people's culture, beliefs, attitudes and behaviour influence children diagnosed late with cancer, and emphasises the observation of cultural factors in clinical encounters.

In addition, understanding the cultural backgrounds would broaden the minds of health professionals and make them aware of how caregivers perceive and react to health issues.

One would ask the question whether caregivers understand what the concept of cancer and the importance of early diagnosis of childhood cancer is. It is imperative to understand the contributing factors that result in family caregivers of paediatric oncology patients presenting children to healthcare very late. The health belief model would contribute to bridging the understanding-gap between the family caregivers and oncologists of the Paediatric Oncology Department.

In general, people may have a negative attitude towards modern medicine because of their own belief systems or not having been exposed to medicine and medical procedures. Syme (2007:329), emphasise the importance of health awareness campaigns to share knowledge about childhood cancer and change perception about the condition. This raises the question about whether there are visible health campaigns about childhood cancer, or whether the health system of South Africa is reliable and accessible.

The researcher believes that using the health belief model would give an opportunity to probe and explore the factors prohibiting caregivers from accessing healthcare. Understanding that cancer is a life-threatening condition and that early detection improves survival rate, should encourage early access to healthcare. The researcher, therefore, will be able to explain the problem better from the caregivers' point of view. In this study, conclusions will result from factors identified that delay caregivers of paediatric oncology patients to access healthcare.

1.3 CONTEXTUALIZATION OF TOPIC

Diagnosis of children with cancer in advanced stages concern the researcher and is viewed as a crisis since oncology treatment modalities could not be of assistance resulting in children dying. Childhood cancer is seen as an increasing health issue in child mortality (Dang-Tan & Franco, 2007:703). The researcher's fundamental motive is to assist in addressing the phenomenon of late diagnosis of childhood cancer. The researcher observes health promotion interventions done on 15 February every year as International Childhood Cancer Day (ICCD). The ICCD campaign's ultimate goal and unified message is "Advance Cures and Transform Care." These campaigns focus on inequality and disproportion of access to healthcare and that children from low-income and middle-income countries have not yet had access to specialised care (<http://www.internationalchildhoodcancerday.org>).

The goal of ICCD sounds idealistic, but sends a message. A report released by the International Agency for Research on Cancer (IARC) (2016), emphasizes the increase of childhood cancer and suggests that the global occurrence of instances of this disease may be significantly higher. Stefan and Siemonsma (2011:80-85),

suggest that in Africa, and specifically South Africa, childhood cancer has never been conclusively researched. This study, therefore, is aimed at collecting information to fill a gap in research about children with cancer, focusing on the challenges faced by family caregivers of paediatric oncology patients where cancer was diagnosed late.

1.4 RATIONALE AND PROBLEM STATEMENT

Late diagnosis of cancer reduces the likelihood of affected children receiving effective oncology care, resulting in death. Childhood cancer is a leading cause of disease-related death in children in developed countries. It remains a central public health issue because of its physical and psychological impact on the affected children and their families (Dang-Tan & Franco, 2007:703). The phenomenon of children being diagnosed with late-stage cancer at Steve Biko Academic Hospital, Paediatric Oncology Unit, has motivated the researcher to conduct this study. The phenomenon of late diagnosis of childhood cancer is regarded as a serious issue by Dr. Mahlatshane (2016), at the Chris Hani Baragwanath Hospital. He indicates that late presentation of children at an advanced stage of cancer is among issues in the hospital that cause great concern due to its impact on child mortality rates. The Health Strategic Plan (National Department of Health, 2014:3) states that the department's vision is to ensure that all citizens have access to high-quality health services, promoting health status through the prevention of illness and promotion of a healthy lifestyle.

Issues concerning child mortality and life expectancy should receive more attention. There are policies in place to address the compliance issues from all the levels of operation, from primary, secondary and tertiary levels of care. The Government of South Africa provides strong legislative policies for the developmental approach to childcare and protection of children (Children Act 38 of 2005; Bill of Rights, section 28). These policies are binding laws to family caregivers to comply with in order to provide in the needs of children.

It is arguable how efficient South Africa is in fulfilling its commitment to the Constitutional Rights of Children to Healthcare, since children are still diagnosed in the advanced stages of cancer. It remains a concern as to what delays the family

caregivers to access healthcare, particularly for children diagnosed with cancer at advanced stages. The researcher believes that this study will answer questions on issues influencing the late diagnosis of children with cancer in the cancer care sphere. This study will contribute to bridging the understanding-gap amongst the families, caregivers, and oncologists and it will make recommendations for possible interventions to improve access to the healthcare.

The research question of the study is as follows:

- What are the factors faced by the family caregivers of paediatric oncology patients, which result in late diagnosis of cancer in children?

In order to provide an answer to the research question, the goal and objectives of this study will follow in the next section.

1.5 GOAL AND OBJECTIVES

1.5.1 Goal

The goal of the research study is to explore and describe the factors challenging family caregivers of paediatric oncology patients in delaying access to healthcare.

1.5.2 Objectives

For the researcher to achieve the goal, certain objectives have been formulated (Fouché & De Vos, 2011:94) which outline the following actions:

- To conceptualise and describe paediatric oncology, treatment, access to healthcare systems and the role of family caregivers.
- To explore and describe the challenges faced by family caregivers of paediatric oncology patients in the community and the health system.
- To explore and describe the factors that lead to delayed access to healthcare of paediatric oncology patients.
- To explore and describe the cultural challenges of paediatric oncology family caregivers.
- To make recommendations to the oncology team to enhance accessibility to paediatric oncology care.

1.6 RESEARCH METHODOLOGY

The researcher utilised a qualitative approach, as it seeks to explore and describe the multifactorial challenges facing the caregivers of paediatric oncology patients that result in delayed access to healthcare. This approach also supports formulating possible recommendations to the oncology team in order to enhance accessibility to paediatric oncology care. The qualitative approach enables the researcher to follow a certain pattern in order to draw a conclusion about the study (Fouché & Delport, 2011:64). The applied research allowed the researcher to gain information that contributes towards improving the policies and referral systems relating to paediatric oncology care within the healthcare system, providing practical solutions to enhance accessibility.

The population of this study was family caregivers of paediatric oncology patients with children under their care who were newly diagnosed with cancer at Steve Biko Academic Hospital. The researcher identified Steve Biko Academic Hospital, Paediatric Oncology Department as a department where children with cancer are frequently diagnosed. The sample size of the study was ten participants, which the researcher believed, provided clear information for the study. Additionally, the findings of the study were not compromised by overly insensitive size (Strydom, 2011:225). As explained by Bless, Higson-Smith, & Ashraf (2006:84), a sample is a subset of the whole population which is actually investigated by the researcher and whose characteristics are generalised to the entire population.

Methods of data collection included an interview schedule and a semi-structured one-to-one interview. This was voice recorded with the permission of the participants. Non-probability purposive sampling was used, as there were no documented lists of family caregivers of paediatric oncology patients. According to Bless, Higson-Smith and Sithole (2013:393), this sampling technique indicates that “the probability of each element of the population being included in the sample is not known.” Sampling information found in Babbie (2007:183), and the purposive sampling technique outlined in Bless et al. (2013:177), make provision for selecting family caregivers as participants who could provide in-depth information about the study. The criteria for selection were as follows:

- A family caregiver of a paediatric oncology patient.
- A newly diagnosed paediatric oncology patient at Steve Biko Hospital Paediatric Oncology Department.
- Caregiver must be accompanying the child during treatment.
- Caregiver must be staying in the CANSA or CHOC lodge.
- Caregiver can be of any gender, age, marital status, culture, ethnic group or religion.
- Caregiver must be conversant in English and/or Xhosa, which are the languages in which the researcher is fluent.

1.7 CONTENTS OF REPORT

Chapter 2: This chapter provides the literature review on paediatric oncology, the child patient, oncology treatment, role of family caregivers, factors delaying family caregivers and access to healthcare, intentional and non-intentional delays, gender and bargaining.

Chapter 3: In chapter three, the research methodology and research findings are included.

Chapter 4: The summary, conclusions and recommendations will follow in chapter four.

The next chapter will focus on the literature study.

2. CHAPTER 2: PAEDIATRIC ONCOLOGY

2.1 INTRODUCTION

A theoretical overview of the multi-factorial challenges of caregivers of paediatric oncology patients will be discussed in this chapter. The researcher will briefly review the field of paediatric oncology, the role of the caregiver, suspicious cancer signs and symptoms to be aware of and factors that contribute to the late diagnosis of cancer; socio-economic factors, and intentional as well as non-intentional factors. The chapter will further deal with gender and bargaining issues. The researcher structures this chapter by means of reviewing different studies pertaining to the topic. Subsequently, paediatric oncology is conceptualized.

2.2 CONCEPTUALIZING PAEDIATRIC ONCOLOGY

The field of oncology can be confusing to many family caregivers who have never been exposed to or never had a history of cancer in their families. The medical jargon, new faces, language, threatening environment (particularly with children), complicate an already stressful situation. Spinetta, Jankovic, Masera, Ablin, Barr, Arush, D'Angio, Van Dongen-Melman, Eden, Epelman, and Martins (2009:905-907), indicate that the environment of cancer care is overwhelming and that parents need to be informed or educated. Hence, there are protocols that need to be adhered to and decisions to be made regarding treatment that need to be followed without delay. In essence, paediatric oncology care remains a field that needs to be improved from primary to tertiary care, in order for the families and communities to learn about childhood cancer and be able to adopt healthy lifestyles.

It is crucial to have an idea of the different types of childhood cancers that are most predominant. Siegel, Miller & Jemal (2015:27) identify the main types as follows:

Leukemia is the leading and most common childhood cancer, including benign brain tumour, followed by other cancers of the brain and nervous system, which are the second most common cancers. Neuroblastoma includes soft tissue sarcomas, one-half of which are rhabdomyosarcoma, renal (Wilms) tumors, non-Hodgkins lymphomas, including Burkitt lymphoma and Hodgkin lymphoma.

Childhood cancer is classified using different staging systems that assess cancer in three ways: The size and extension of a tumor (T), regional lymph node involvement (N), and the presence of distant metastases (M). T, N, and M classifications determine the staging. As soon as the staging part is accomplished, it makes it easy for the paediatric oncologist to propose treatment (Siegel, DeSantis, Virgo, Stein, Mariotto, Smith, Cooper, Gansler, Lerro, Fedewa, Lin, Leach, Cannady, Cho, Scoppa, Hachey, Kirch, Jemal & Ward, 2012:253).

Childhood cancers can be treated with the combination of therapies, namely surgery, radiation, and chemotherapy. These treatment modalities are administered based on the type and stage of cancer. Oncology treatment is practiced in specialized tertiary hospitals such as Steve Biko Academic Hospital and is coordinated by a team of experts, including paediatric oncologists and surgeons, paediatric nurses, social workers, and psychologists (Siegel et al., 2012). Although cancer can be treated and managed, it is also important to understand that cancer has a tendency to come back (DeSantis, Lin, Mariotto, Siegel, Stein, Kramer, Alteri, Robbins & Jemal, 2014). It is imperative to gain a better understanding of childhood cancer and the suspicious clinical characteristics and malignancies. A guide for early recognition appears in the following table showing suspicious childhood cancer signs as quoted from Fragkandrea, Nixon, and Panagopoulos (2013:187).

Table 2.1: Suspicious childhood cancer and clinical characteristics and malignancies based on Fragkandrea et al. (2013:187)

Malignancy	Frequency %	Main clinical characteristics
Leukaemia(acute lymphoblastic leukaemia; acute myelogenous leukaemia)	34.1	Pallor, fatigue, malaise, especially if persistent and associated with signs of bone marrow infiltration (unexplained fever, recurrent infections, haemorrhagic diathesis) and/or lymphadenopathy 10-12
Central nervous system tumours (brain, cranial nerves, spinal cord)	22.6	Persistent headache (mainly in the morning), nausea and vomiting, ataxia, visual disturbances (diplopia, squint, papilledema, proptosis), neurologic deficits (cranial nerve palsies, motor and sensory

Malignancy	Frequency %	Main clinical characteristics
		signs), seizures, developmental delay or regression, unexplained deteriorating school performance, personality changes, torticollis, signs of raised intracranial pressure (increasing head circumference, bulging fontanelle, irritability).
Lymphoma (Hodgkin, non-Hodgkin)	11.5	Lymphadenopathy, fever or “B symptoms” (night sweats, fever, weight loss), pallor, fatigue, petechiae or bruising, abdominal mass, hepatosplenomegaly, nausea and vomiting, constipation, abdominal pain.
Neuroblastoma	7.6	Palpable mass (abdomen, neck), anorexia and failure to thrive, fever, bone pain, lymphadenopathy, pallor, malaise, irritability, leg weakness, ocular symptoms (periorbital ecchymosis, proptosis, squint, opsoclonus-myoclonus syndrome, heterochromia of the iris, Horner syndrome), back pain, subcutaneous nodules, obstructive symptoms of the bowel and bladder, neurologic deficits soft tissues.
Soft tissue sarcomas (mainly rhabdomyosarcoma)	6.1	Palpable mass, symptoms caused by pressure on adjacent structures, lymphadenopathy (depending on location of tumor), squint or proptosis (orbital location), vaginal bleeding (vaginal location).
Renal tumors (mainly Wilms tumor)	5.6	Abdominal mass, abdominal pain, hematuria, vomiting, constipation, fever, hypertension.
Germ cell tumour	3.1	Palpable mass (scrotum), respiratory symptoms (mediastinal location), abdominal distension and pain (abdominal location), constipation, enuresis, precocious puberty or amenorrhea, vaginal bleeding, leg

Malignancy	Frequency %	Main clinical characteristics
		weakness, neurologic symptoms (central nervous system location).
Osteosarcoma	3.1	Localised bone pain, palpable mass, swelling or deformity, pathological fracture.
Ewing sarcoma	2.1	Localized bone pain, palpable mass (depending on location), prolonged fever, fatigue, weight loss, compression of local structures (bladder, spinal cord), symptoms due to bone marrow infiltration
Retinoblastoma	2.1	Leukokoria (cat's eye reflex), squinting, vision loss
Hepatic tumor	1.1	Abdominal distention or mass, symptoms depend on type of tumor
Histiocytosis	>0.5	Bone pain (localized or generalized), rashes (eczema resistant to treatment), fever, weight loss, lymphadenopathy, hepatosplenomegaly, chronic ear discharge or otitis media, proptosis, diabetes insipidus.
Nasopharyngeal carcinoma	>0.5	Cervical lymphadenopathy, persistent nasal obstruction, epistaxis, persistent otitis media, tinnitus, headache, fever, trismus, dysphagia, cranial nerve palsies.
Other	<1	Clinical characteristics depend on location and histology (various malignant epithelial carcinomas [e.g., thyroid, lung, breast, bladder, skin], melanomas, or unspecified neoplasms).

“NOTE: Symptoms are listed in order of how often they are encountered in malignancies and on their clinical importance ((i.e., how specific the symptom is for the diagnosis of the respective malignancy)” Fragkandrea et al., 2013:187). Tumors are presented in order of most common to least. This implies that if caregivers of paediatric oncology patients can become aware of early signs of childhood cancer, they will be able to consult healthcare professionals at the onset of symptoms since

they would be sensitised about health issues. Children's cancer symptoms would be detected early and may therefore be better diagnosed, treated and managed.

2.3 DIAGNOSIS AND TREATMENT OF CHILDHOOD CANCER

Cancer can be diagnosed using different methods and procedures. As indicated by Siegel et al. (2012:253), prior treatment is determined by different factors including size and extension of a tumor (T), regional lymph node involvement (N), and the presence of distant metastases (M). As soon as the staging part is accomplished, the paediatric oncologist suggests the relevant treatment. Subsequently, diagnosis and treatment of childhood cancer will be discussed below:

2.3.1 Diagnosis of childhood cancer

Cancer can be diagnosed with multiple tests that can determine what type of cancer is that, to what extent cancer is spreading from the point of origin to other parts of the body. Every test done is tailor-made for each individual. It is important to learn that all these tests are done under the supervision of a paediatric oncologist. Besides that, doctors may also do tests to learn which treatments could work best for the type of cancer (American Society of Clinical Oncology, 2018). The Society indicates that there are certain descriptors that doctors consider in order to choose a diagnostic test. These include the following:

- The type of cancer suspected
- Child's signs and symptoms
- Physical examination
- Child's age and medical condition
- The results of earlier medical tests

The American Society of Clinical Oncology (2018) and Visser (2010:85) describe common tests that doctors use to diagnose childhood cancer:

- **Blood tests:** Blood tests are done to help diagnose some blood cancers, such as leukaemia and lymphoma and are continually done to measure the number of different types of cells in a child's blood. Levels of certain cells that are too high or too low can indicate the presence of certain types of cancer, and include the white blood cells that are involved in the body's defense against infections,

red blood cells that carries oxygen around the body and platelets that help to control blood clotting. It is important to understand that oncologists have to interpret the results carefully knowing that non-cancerous cells can also cause abnormal cells (National Cancer Institute, 2016).

- **Biopsy:** Doctors normally recommend a biopsy when they suspect abnormalities during physical examination and other tests. A biopsy is the removal of a small amount of tissue for examination under a microscope. This test is mostly sufficient to make an accurate diagnosis. Other tests can suggest that cancer is present, but except for certain types of brain tumors, only a biopsy can make a definite diagnosis. The type of biopsy performed depends on the location of cancer. The sample removed during the biopsy is analysed by a pathologist, who specialises in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease (American Society of Clinical Oncology, 2018).
- **Bone marrow aspiration and biopsy:** These two procedures are similar and often done simultaneously to examine the bone marrow. Bone marrow is the spongy, fatty tissue found inside larger bones. It has both a solid and a liquid part. A bone marrow aspiration removes a sample of the fluid with a needle. A bone marrow biopsy is the removal of a small amount of solid tissue using a needle. This procedure may be done in a hospital, clinic, or in a doctor's room. The doctor ensures that the patient receives a local anesthetic to numb, sometimes sedate, in order to block the awareness of pain. When these procedures are done simultaneously, it usually takes about 30 minutes to complete (American Society of Clinical Oncology, 2018).
- **Lumbar puncture (spinal tap):** A lumbar puncture is a diagnostic procedure in which a healthcare provider uses a needle to obtain a specimen of cerebral spinal fluid (CSF) to look for cancer cells, blood, or tumor markers. Tumor markers are substances found in higher than normal amounts in the blood, urine, or body tissues of people with certain kinds of cancer. CSF is the fluid that flows around the brain and the spinal cord. Similar to bone marrow aspiration and biopsy, patients are generally given an anaesthetic to numb the lower back before the procedure (Visser, 2010:85).

- **Ultrasound:** An ultrasound, also called sonography or ultrasonography, is an imaging test. It uses high-frequency sound waves to create pictures of internal organs. The sound waves hit the organs and bounce back to a device called a transducer. The transducer turns the sound waves into images for the doctor to examine on a computer (American Society of Clinical Oncology, 2018).
- **Computed tomography (CT or CAT) scan:** A CT scan creates a 3-dimensional (“3-D”) picture of the inside of the body using x-rays taken from different angles. A computer then combines these images into a detailed, cross-sectional view that shows any abnormalities or tumors. A CT scan can also be used to measure the tumor’s size. Sometimes, a special dye called a contrast medium is given before the scan to provide better detail on the image. This dye can be injected into a patient’s vein or swallowed as a pill. When possible, it is best to have this test done in a paediatric speciality centre where paediatric radiologists supervise the process. However, treatment centres are aware of the potential risks of radiation exposure from a CT scan (American Society of Clinical Oncology, 2018).
- **Magnetic resonance imaging (MRI):** An MRI uses magnetic fields, not x-rays, to produce detailed images of the body. This type of imaging can also be used to measure the tumor’s size. A special dye called a contrast medium is given before the scan to create a clearer picture. This dye can be injected into a patient’s vein or given as a pill to swallow (American Society of Clinical Oncology, 2018).
- **Positron emission tomography (PET) or PET-CT scan:** A PET scan is usually combined with a CT scan, called a PET-CT scan. At times, this diagnostic procedure is called a PET scan. This type of scan is a way to create pictures of organs and tissues inside the body. A small amount of a radioactive sugar substance is injected into the patient’s body. This sugar substance is taken up by cells that use the most energy. As cancer tends to use energy actively, it absorbs more of the radioactive substance. A scanner then detects this substance to produce images of the inside of the body (American Society of Clinical Oncology, 2018).

2.3.2 Treatment of childhood cancer

Children who have cancer are treated in specialised centres, in South Africa childhood oncology is treated in tertiary teaching hospitals. In most cases, you will find that a multidisciplinary team works with a child and the family to provide care. It is very common that these centres employ a holistic approach, making use of other healthcare professionals such as dietitians, physical and occupational therapists, social workers, psychologist, and counsellors. Special activities and programs are also organised to create a user-friendly environment for the child and family. As indicated by Siegel et al. (2012), the type of treatment is determined by the stage, size and extent of a tumor involved, regional lymph node involved and the presence of metastasis.

The American Society of Clinical Oncology (2005-2018) and Visser (2010:85), describes the following treatments commonly used to for childhood cancer:

- **Surgery**

The fundamental goal of surgery in children with cancer is to remove the entire tumor and the margin (tissue around the tumor), leaving a negative margin, meaning no cancer remains in the healthy tissue. Surgery is the removal of the tumor, either cancerous or non-cancerous, and some surrounding healthy tissue during an operation. In most cases, children with a tumor will need surgery as a part of their treatment. Doctors would subsequently recommend chemotherapy, radiation therapy, or other treatments in case cells remain after surgery. Although this treatment may have side effects, it is usually recommended for tumors. Its side effects depend on the location and type of tumor and whether it has metastasized. Prior to this treatment the multi-disciplinary team ensures that the child and family are well prepared of its advantages and disadvantages in order to cope after the procedure.

- **Chemotherapy**

This type of treatment is predominant amongst children with cancer. Chemotherapy entails a list of drugs used to destroy cancer cells such as (but not limited to) amsacrine, cytosar, cisplatin, prednisone, VCR, and bulsuphan (Visser, 2010:79). This treatment is only given by a paediatric hematologist-oncologist, specialising in

treatment of cancer with medication. Drugs may be given through injections, in the veins (intravenously) and orally. It is common that special objects used include broviac, a port to administer, for some of these drugs. These are tailor-made tools for administering medication and are developed specifically for children to alleviate the suffering of pain during the treatment period. It is important to understand that a chemotherapy regimen consists of a specific number of cycles given over a set period.

A patient may receive one drug at a time or combinations of different drugs given at the same time (American Society of Clinical Oncology, 2005-2018). This treatment has various side effects, which may be long-term or last a lifetime (Visser, 2010:28-35). The Society indicates that side effects depend on the individual and drug dosage, and may include fatigue, the risk of infection, nausea and vomiting, hair loss, loss of appetite, and diarrhea.

- **Radiation therapy**

Although radiation therapy forms part of the treatment of childhood cancer, it is not preferred because healthy organs and tissues in the radiation field are at risk for damage and may develop second cancers, particularly in young children. In most cases, doctors recommend that radiation therapy is omitted (in most cases they recommend limited period to receive this treatment) whenever possible. This therapy is the use of high-energy x-rays, or other particles such as photons, to destroy cancer cells and is provided by a radiation oncologists specialising in giving radiation therapy to treat cancer. The most common type of radiation treatment is called external-beam radiation therapy, which is radiation given from a machine outside the body. When radiation treatment is given using implants, it is called internal radiation therapy or brachytherapy. Like chemotherapy treatment, the radiation therapy regimen or schedule usually consists of a specific number of treatments given over a set period. It also has certain side effects that include fatigue, mild skin reactions, upset stomach, and loose bowel movements. The worst side effects go away soon after treatment is completed (American Society of Clinical Oncology, 2005-2018).

The above three treatment modalities are generally used in the treatment of childhood cancer. However, other types of treatment regimens have been introduced that also has the potential to effectively treat childhood cancer. These include therapeutic drugs and immunotherapy. In this kind of treatment, more than one type of treatment is used (American Society of Clinical Oncology, 2016):

- **Immunotherapy**

This type of treatment is also called biologic therapy, and is designed to boost the body's natural defences to fight cancer. It uses materials made either by the body or in a laboratory to improve, target, or restore immune system function. Examples of immunotherapy include cancer vaccines, monoclonal antibodies, and interferons. It may work by stopping or slowing the growth of cancer cells, stopping cancer from spreading to other parts of the body and helping the immune system work better at destroying cancer cells. There are several types of immunotherapy including monoclonal antibodies, non-specific immunotherapies, oncolytic virus therapy, T-cell therapy and cancer vaccines. Similar to other treatments of cancer, this treatment also has side effects which include fatigue, fever, chills, nausea, flu-like symptoms and pain at the injection site. Doctors often use targeted therapy with chemotherapy and other treatments (American Clinical Society of Clinical oncology, 2005-2018).

- **Stem cell transplant/Bone marrow transplant**

In most cases, before doctors recommend stem cell transplantation, they will first discuss with the patient and family the advantages and risks of this treatment and consider several factors, such as the type of cancer, results of any previous treatment, and the patient's age and general health before it is done. A stem cell transplant is a medical procedure in which bone marrow affected by cancer is replaced with highly specialised cells, called hematopoietic stem cells that develop into healthy bone marrow. Hematopoietic stem cells are blood-forming cells found both in the bloodstream and in the bone marrow. Today, this procedure is more commonly called a stem cell transplant, rather than bone marrow transplant, because it is the stem cells in the blood that are typically being transplanted, not the actual bone marrow tissue. There are two types of stem cell transplantation, namely allogeneic (ALLO) and autologous (AUTO). ALLO uses donated stem cells, while

AUTO uses the patient's own stem cells. In both types, the goal is to destroy all of the cancer cells in the marrow, blood, and other parts of the body. This is done by using high doses of chemotherapy and/or radiation therapy and then allowing replacement blood stem cells to create healthy bone marrow. In these types of treatment, side effects depend on the type of transplant and general health factors of the patient (American Society of Clinical Oncology, 2005-2018).

Childhood cancer can be diagnosed and treated in different ways. This researcher believes that caregivers can be confused and sometimes even become impatient when children go through the diagnostic process. Once more, viewing all the types of treatment practice in paediatric oncology, side effects seem to be understood as part of treatment. Visser (2010:28) states that in the CHOC Handbook for Parents, guidelines are given on how to deal with the diagnostic process and side effects of treatment. The researcher believes that with this information, much have been done in the field of paediatric oncology to provide advice and guidelines to manage the disease. Therefore, it is important to convey this information to parents and to raise awareness for early detection that will ultimately allow the paediatric oncologist to suggest effective treatment.

2.4 THE ROLE OF CAREGIVING IN PAEDIATRIC ONCOLOGY

The concept of caregiving is easy to grasp because it is such a familiar part of life. It is described as an "unexpected career that connotes a dynamic process whereby an individual move through a series of stages, requiring adaptation and restructuring of responsibilities over time" (Klassen, Raina, Reineking, Dix, Pritchard & O'Donnell, 2007:808). The caregiving role is a very strenuous activity that demands drastic adjustment and fast learning. Family caregivers of paediatric oncology patients are faced with numerous responsibilities and duties, for instance, decision-making needs to be done without delay, information must be gathered, adjustments in the environment made, and family systems at home needs to be reorganized due to long hospitalization. In most cases, women fulfil this this role with sincere and intense conviction. Empirical studies revealed that men may feel less prepared to partake and may encounter challenges as compared to women. Worldwide caregivers are women; however, an increase of male caregivers for older patients is seen (Surbone, Baider, Weitzman, Brames, Rittenberg & Johnson, 2009:258).

Research studies suggest that diagnosis of cancer exposes families to a crisis situation and to social upheaval (Bayat, Erdem & Kuzucu, 2008:247 and Vrijmoet-Wiersma, Van Klink, Kolk, Koopman, Ball & Egeler, 2008:694-695). Despite the impact of the so-called unexpected career upon the family, caregivers of paediatric oncology patients remain a fundamental component of paediatric oncology. The CHOC Handbook for Parents, Visser (2010:70), indicates that parents may choose different approaches to cope with the information, namely the 'selective awareness' and 'watchful and wary' approaches. With the selective awareness approach, family caregivers do not refuse to believe medical information, but choose to believe only selected parts of the information. Caregivers opting for this approach, avoid information that may possibly expose them to emotional strain.

The watchful and wary approach is mostly seen where caregivers keep a very close eye to the treatment children receive. These caregivers spend time searching for medical information and ensuring that the child receives the best treatment available. With the watchful and wary approach caregivers feel that they are in control of the situation, as they participate fully in patient management. The researcher argues for the watchful and wary approach in terms of education for caregivers. Educated caregivers have an opportunity to gain understanding and may even use the internet to enhance their knowledge. These caregivers stand a chance to interact with health professionals and discuss treatment given. However, illiterate and poor caregivers are unlikely to search for information and question treatment. For this reason, it is improbable that they would explore the second approach.

2.5 FACTORS CONTRIBUTING TO LATE DIAGNOSIS OF CHILDHOOD CANCER

Generally, access to healthcare plays an important role to improve ill health and contribute towards early detection of any disease. In the case of paediatric oncology care, early detection is of primary importance, as it prevents that children are diagnosed late and die. Subsequently, the factors contributing to delayed diagnosis are discussed below:

2.5.1 Knowledge and information

Education is an important factor in attaining optimal health. Haan (2005:8) maintains that people need to make informed decisions concerning their healthcare and even regarding lifestyle issues. In order to do this, they need to be able to read and write. In other words, the relationship between health and effective education enables people to address health issues. Knowledge contributes towards improving people's life.

Porterfield and McBride (2007:327) concur and believe that the educational status of family caregivers of paediatric oncology patients can contribute towards understanding the illnesses and that special needs of children receive effective care. Being uneducated or illiterate makes it impossible for family caregivers of paediatric oncology patients to learn about childhood cancers which may lead to unintentionally delay diagnosis (Porterfield & McBride, 2007:327). A study conducted in women with cancer shows that women with higher levels of education are diagnosed in earlier stages of cancer than those with lower educational levels (Ali, Mathew & Rajan, 2008:706). This strengthens the notion that the education level of family caregivers is fundamental to promote a better understanding of the illness and access to healthcare.

Family caregivers, as subjects under investigation, need to be educated to enable them to recognise the early symptoms of childhood cancer. A research study conducted in India to educate women shows a drop in the mortality rate of infants and children under five, within four years of that health education campaign (Haan, 2005:8). This supports the belief that literacy is a crucial factor in attaining optimal health (Vasuthevan & Mthembu, 2013:7).

The WHO (2010), recognizes two major components of early detection of cancer, namely: education to promote early diagnosis and screening as crucial in the prevention of late diagnosis of childhood cancer. These components could enable family caregivers of paediatric oncology patients to recognise possible signs of cancer, take prompt action that leads to early diagnosis, and increase awareness of possible signs of cancer. Information about childhood cancer becomes fundamental to sensitise family caregivers of paediatric oncology patients.

Caregivers having insight about childhood cancer are more likely to make an immediate decision regarding healthcare and plan for supporting the sick child (Kilicarsonlan-Toruner & Akgun-Citak, 2013). Dennill et al., (2013:187) maintains that family caregivers of paediatric oncology patients who have low literacy levels need support in order to access healthcare services.

2.5.2 Communication and language in healthcare

Communication plays a crucial role in the field of paediatric oncology and may be defined as the “exchange of information, between individuals, for example, by means of speaking, writing, or using a common system of signs and behaviors; rapport a sense of mutual understanding and sympathy” Schiavo (2013). Parents usually expect to hear only of improvement in the child’s condition (Schiava, 2013). A research study in parents of children diagnosed with cancer showed that the parents expressed the importance of the physician keeping them informed, and being approachable and available. Furthermore, parents needed the physicians to be open to their comments and to actively seek their opinions (Pyke-Grimm, Stewart, Kelly & Degner, 2006:356).

Research studies suggest that linguistic diversity demands language access services (provided by a linguist) in healthcare to translate or interpret English into the language understood by parents and caregivers (Smith & Pietryk, 2008; Partida, 2007; and Dennill et al., 2013:187). As such, the researcher believes that clear communication in the field of paediatric oncology is crucial and requires healthcare professionals to learn communication skills to successfully provide information to caregivers about the child’s condition, prognosis, and treatment plan. In so doing, a healthy relationship between the medical practitioner and family caregivers will be formed to bridge the communication barrier.

2.5.3 Access to healthcare

Access to levels of healthcare may influence late diagnosis, influenced by the capacity of professional’s function in lower levels of healthcare (primary, district and regional). The geographical proximity and access to healthcare centres providing paediatric oncology care may pose a challenge to the family caregivers, since oncology treatment may not be easy to find. Specialised treatment can only be

administered in specialised institutions such as tertiary levels of healthcare (Siegel et al., 2012; Peters, Garg, Bloom, Walker, Brieger & Hafizur-Rahman, 2008). Clearly, the ability to survive childhood cancer would be determined by geographic proximity to tertiary levels of care (<http://www.Internationalchildhoodcancerday.org>). For poor people, traveling costs may exhaust financial reserves even before starting oncology treatment (Hanna & Kangolle, 2010:11).

Healthcare in South Africa varies from the most basic primary healthcare offered free of charge by the state, to highly specialised care in both the public and the private sectors. The public sector experience serious restraints where budget and service providing are concerned. Resource capacity is often sub-optimal and hospital wards overpopulated (McIntyre, 2010:14). On the other hand, the private sector only serves middle to high-income citizens who may have medical schemes. The challenge it poses to the poor is that of high expenditure, since it operates on a 'pay as you go' basis (McIntyre, 2010:14). In addition to formal healthcare structures, traditional indigenous medicine is practiced in South Africa. McIntyre (2010:14) confirms that eighty percent (80%) of South Africans consult with traditional healers.

Transport to healthcare facilities in South Africa poses a serious problem. In order to address the transport issue, arrangements were made between the healthcare systems of Gauteng and Mpumalanga and interlinked transport was introduced. For example, patients travelling from Rob Ferreira Hospital (Mpumalanga), to Steve Biko Academic Hospital (Gauteng) are provided with transport. Despite these efforts to assist with the transport of patients and caregivers, it remains unclear how reliable local healthcare centres are in detecting early symptoms of childhood cancer and how fast they refer cases. As indicated earlier, the capacity of health professionals may contribute to the delay, thus resulting in the late diagnosis of childhood cancer.

2.5.4 Cultural and religious influence in healthcare

2.5.4.1 Culture

Seeking treatment can be influenced by how people perceive health, cultural values attached to ill health and how the community views childhood cancer (Saca-Hazboun & Glennon, 2011:281). It is worth noting that culture and religion influence

how people respond to health and interpret ill health. Understanding these dynamics in the light of the cultural backgrounds may provide further answers to the question as to why children are diagnosed late with cancer. Van Rensburg (2012:635) holds the view that multicultural beliefs and attitudes such as consulting a traditional healer versus beliefs about biomedicine often influence people in their search for healthcare.

Nonetheless, culture remains important as “an inescapable part of being human and helps us make sense of the world. It shapes our identity and is central to the way we experience ourselves, our collectively, and the world” (Albertyn, 2009:170). Partida (2007) suggest that people’s culture, beliefs, attitudes and behaviour towards healthcare cannot be underestimated as factors influencing the late diagnosis of childhood cancer. In addition, understanding various cultural backgrounds would broaden the minds of health professionals and give them insight into caregivers’ perception of health issues.

The diversity of families in society poses certain challenges. Various types of families structures exist, which include multigenerational families (more than two family generations living under the same roof) single-parent families, same-sex parent families, foster families, adoptive families, immigrant or non-citizen families, and families separated by distance, divorce, or separation. The culture of these families may pose potential barriers in accessing healthcare due to diverse perceptions and beliefs pertaining to healthcare (Albertyn, 2009:65 and Jones & Watson, 2012:216). In this regard, decision-making is strenuous for the family caregivers as far as the best treatment for a child’s concerned. Cousino and Hazen (2013) aptly remark that since “Parents must face the devastating news of their child’s diagnosis, the associated medical risks, and in some instances, their child’s potential for a shortened life expectancy.”

It is common that people trust their indigenous healthcare systems, which include *Inyanga*, *Izangoma*, *Abathandazeli*, prophets, and others. In particular, traditional families, black African culture and men may influence decision-making processes regarding the treatment of a sick child. Specifically, in patriarchal settings men dominate and make unopposed decisions. They are regarded as heads of the households and would decide about the care given to children, and women would

be expected to agree with them (Goldman, Hain & Liben, 2012:118). In other words, if the head of the household decides to consult the traditional healer or *Inyanga*, others are expected to follow with no opposition.

2.5.4.2 Religion

The important role that religious beliefs may play in late diagnosis of childhood cancer cannot be ignored. When faced with disease, disability, and death, caregivers would like their emotional and spiritual needs addressed. Religion, therefore, becomes the source of strength for many African caregivers as it reflects how life is perceived (Koenig, King & Carson, 2012). Mbiti (2015:15) suggests that religion gives family caregivers of paediatric oncology patients a sense of belonging and security, as well as guidance how to act in situations. Silbermann and Hassan (2011) assert that healthcare professionals need to understand the background of paediatric oncology patients. By so doing, strong relationships can be formed which, in turn, assist the paediatric oncologist to guide a patient's choices.

In most cases, religion is observed when individuals uphold certain principles to their beliefs, for instance, with regard to certain days, rituals and food habits. Tjale and Villiers (2004:212), suggest that engaging with caregivers would improve understanding of their religious backgrounds. In South Africa, there are different religions that family caregivers observe and practice. The government of South Africa has recognised and published the new Traditional Practitioners Bill in 2004 to acknowledge that people are different, do things differently and can affiliate in the religion of their choice (Keonig et al., 2012). The most prominent religious groupings are discussed below:

- **Christianity**

This is a dynamic and broad religion in terms of practice. Some Christians believe that diseases and illness are the results of the sins committed and that it is a punishment from God for disobeying. On the other hand, the scriptures from the Christian New Testament show that sickness either is caused by sin or not and through prayer could be healed (Todoran, 2012:291). The belief that Jesus laid hands on people or used oil to anoint and heal the sick remains a popular aspect of this religion with certain believers. This may explain why people travel to Nigeria

from South Africa to seek healing by the famous prophet Joshua. Illness makes people desperate and they would do or believe anything as long as they believe it would improve health.

Van Niekerk (2012) argues that faith in religion has a strong influence in the way caregivers respond to health issues. In addition, in 2010, the Treatment Action Campaign (TAC) opposed the Christ Embassy Healing School, whose claims of healing led to the death of many people. Followers were lead to believe in healing through faith and treatment of illness was discouraged. In this light, the beliefs of some sects formed within Christianity may lead to late diagnosis in children with cancer. Since family caregivers believe in powerful prayers for their child's healing and will visit healthcare centres only when the illness persist (Tjale & Villiers, 2004:90).

Because of the existence of many church denominations and sects, there are many controversial issues in this religion when it comes to healthcare. For example, groups like Jehovah's Witnesses do not believe in medical treatment such as blood transfusion and organ donation (Tjale & Villiers, 2004:90). This could pose a challenge, as a child diagnosed with leukaemia may need blood transfusion is part of treatment. Some Christians may claim that miracles happen which bring them closer to God and may even lead to the belief that they are healed without aid from medical science (Cobb, Puchalski & Rumbold, 2012:8). It is important that the belief system of the parents must be investigated and discussed.

- **Muslims and Islam**

Islam is considered one of the three main religions in the world. The word 'Islam' means submission to God's will and Muslims believe that one should surrender to the will of God by obeying the laws and commandments of Allah (the Arabic name for God) (Tjale & Villiers, 2004:95). For a better understanding of this religious connection, Tjale and Villiers (2004:95) comment that the followers of Islam are called Muslims. The two complement one another, for instance, Islam believes in prayer (five times a day) and fasting during the holy month of Ramadan. In addition, Muslims are believed to have faith in Allah and the Angels, the Holy Book: The Old and New Testaments are considered to be Holy Books, but the Holy Qur'an is

believed by Muslims to be their only Holy Book, and the only source of Islam (Al-Aoufi, Al-Zyoud & Shahminan, 2012).

Many Muslims believe that illnesses, diseases, and disabilities are sent by God or according to Allah's (God's) will. Muslims also believe in their traditional healers called gift healers. These healers are believed to cure various illnesses and be blessed with supernatural powers (Ross, 2007). The Islamic literature refers to illnesses resulting from sins. According to families and traditional healers of this religion, someone contracting illness should acknowledge or 'receive' it with patience and gratitude, to earn the favour of God (Ross, 2007). In the case of paediatric oncology patients, caregivers having this belief are unlikely to bring children to the healthcare system on time, because of their specific perception of illness.

Tjale and Villiers (2004:95) point out that Muslim practices include food restrictions and expressions of religious feelings through fasting, which may contribute to the late diagnosis. These practices may be overruled by hospital protocols. As such, it is likely that caregivers may opt to delay access to healthcare intentionally and may only later resort to the healthcare centres for help. It is important that the belief system of the parents must be investigated and discussed with the parents so that the role it will play is understood.

- **Indigenous African beliefs**

The majority of Black South Africans are known to consult traditional healers either exclusively or in conjunction with Western, allopathic healthcare professionals (Sodi & Bojuwaye, 2011). Another common practice is that African people may first consider lay care or asking advice from friends and the community to attempt healing with home remedies (Tjale & Villiers, 2004:152).

In South Africa there are different types of alternative practitioners. For example, traditional healers, which include the herbalist *linyanga* in Zulu and *ixhwele* in Xhosa and diviners that are known by different names in the various South African cultures, namely *amaqgirha* in Xhosa, *ngaka* in Northern Sotho, *selaoli* in Southern Sotho and *mungome* in Venda and Tsonga. A diviner or *sangoma* is a person who divines illness through the ancestors in the cultural context. In their communities, they are

respected because of their mystical powers. Herbalists specialise in the use of herbs and other medicinal preparations for treating illness. A herbalist's curative expertise includes preventive and prophylactic treatments, rituals, as well as preparations for luck and fidelity (Sorsdahl, Stein, Grimsrud, Seedat, Flisher, Williams & Myer, 2009:57).

Lastly, a prophet is another type of alternative medical practitioner. This is a faith healer, healing people by laying hands on patients, praying and providing holy water. It has been estimated that there are approximately 200 000 traditional healers practicing in South Africa, in 1995, with the number increased in recent statistics. African traditional healing intertwines with cultural and religious beliefs and is holistic in nature (Sorsdahl, et al., 2009:57). Most traditional healers are commonly rooted in communities and easily accessible.

The geographical proximity of these healers allows the family caregivers to consult them at any time for diagnosis and treatment. Moreover, their mystical powers remain respected, trusted, and expected to diagnose the problem and heal illness. In essence, traditional healers are understood by caregivers as they commonly speak the language caregivers speak. It is important to note that traditional healers somehow relate to what family caregivers want to hear or understand. Van Rensburg (2012:635) emphasises that traditional healers are expected to diagnose the problem, and as a result, people will go far, shopping around for healers. Under these circumstances healthcare is often delayed. Truter (2007:56) stresses that the role indigenous beliefs play, should not be underestimated in primary healthcare in many developing countries. It is important that the belief system of the parents must be investigated and discussed with the parents so that the role it can play is understood.

Belief in ancestral power is associated with Seeking treatment can be influenced by how people perceive health, cultural values attached to ill health and how the participants' viewed childhood cancer (Saca-Hazboun & Glennon, 2011:281).

h black African people. Van Dyk (2008:202) and Truter (2007), state that ancestor worship plays a dominant role in the lives of many South African people, due to the fact that ancestral spirits constitute part of the structure of African religion. People believe that upsetting the ancestors leads to disharmony, and as a result, sickness

occurs. Ill health is a misfortune explained as spiritual forces directed by witches or angered ancestors (Ojua, Isho & Ndom, 2013:177). Syed, Syed Sulaiman, Azhar, Hassali, Thiruchelvum and Lee (2015), state that disbelievers are more susceptible to acquire ill health and further believe that a “handful of patients link HIV and AIDS and its cause to a form of divine punishment or a curse due to human sins or unacceptable deeds of morality, as explained by their faiths.”

In the case of paediatric oncology patients, this may pose a challenge, as traditional practices would be performed to appease the ancestors and more consultations with spirits may follow in order to find the problem. During this process, the health of the child deteriorates and the child will be diagnosed only in the advanced stages of cancer. A study conducted in HIV and AIDS patients, found that a traditional healer, Zebulon Gwala, who was interviewed by Cullinan and Thom (2009:152) had a famous HIV and AIDS concoction (*ubhejane*). Gwala was of the opinion that he helped his patients through the dreams sent to him by ancestors who, he claimed, guided him in with treatment. He could not divulge the ingredients used in his medication. Similar situations may be found where family caregivers would be desperate for the healing of a child with cancer. It is important to note that, when faced with life-threatening conditions like cancer, any type of cure will be accepted by caregivers who are desperate to relieve pain or discomfort. The potential threat lies in how long this alternative care continues and what potential danger it poses for the child with cancer.

Tjale and Villiers (2004:147), suggest that it should be taken into consideration that sickness can be interpreted differently in Black African societies. Believing in ancestors can influence how parents understand the diagnosis, as the spirit of these deceased members of a larger kinship group they believe, remains with living members and has an influence on their lives, such as bringing cancer upon them. Literature reflects how childhood cancer can also often be misdiagnosed, for example, a study conducted in diagnostic difficulty and error in primary health showed that young children presenting with non-specific symptoms such as back and chest pain are misdiagnosed as ‘muscle strain’ or growing pains and injuries (Kostopoulou, Delaney & Munro, 2008).

In other instances, non-specific symptoms that may lead to early detection of cancer are overlooked (Silal, Penn-Kekana, Birch, Harris & McIntyre, 2012:120). This often causes family caregivers to doubt the diagnostic skills of health professionals. In most cases, family caregivers, particularly those who believe in ancestral power, would start consulting their ancestors for healing. Many traditions and rituals would be performed to request healing from these spirits. As such, the likelihood of cancer growing during this period is high. Again, children are taken to healthcare centres only when symptoms persisted, since no positive response from ancestors were received. Diagnosis of cancer is delayed and will likely result in the child's death.

- **Indigenous treatment – traditional medicine**

UNICEF (2016) defines traditional African medicine as “a holistic discipline involving the use of indigenous herbalism combined with aspects of African spirituality.” In Africa, herbs are used as reliable medicine, with approximately eighty percent of Africa's population using traditional medicine for their basic health needs (McIntyre, 2010:14). Caregivers of paediatric oncology patients use indigenous medicine because they may understand this medicine better. Abdullahi (2011:115) believes that this type of medicine recognises people's relationships and norms.

Truter (2007:59) suggests that traditional medicine forms part of the family caregiver's culture and customs. Caregivers, who lack trust in the ability of modern medicine, are likely to believe in what they know. Caregivers' trust in modern medicine depends on their knowledge about it. Some family caregivers may choose traditional medicine, because it is available and known by people in the community (Truter, 2007:59). The concern is how effective these medicines manage cancer. The fact that the majority of people in South Africa believe in traditional healing, was recognized by the Department of Health when they promulgated the Traditional Health Practitioners (Act 22 of 2007). An institution, namely the Traditional Health Practitioners Council, was also formed to support and promote traditional healing (DoH, 2016).

2.6 GENDER

In many cultures, men generally make decisions and the opinions of women may not be regarded as important. Women's roles, being a mother and/or a wife, are

confined to domestic functions. They have little in the decision-making process regarding the healthcare of children (Rao, 2012). Men and women may have different ideas about children's healthcare as well as different opinions regarding treatment, yet the final decision lies with the men. For instance, amongst African people, particularly in traditional families, the decisions about healthcare for a sick child are influenced by men. This is also common in patriarchal settings, where men are regarded as the heads of the households and would direct the care, while women would be expected to follow without any opposition (Goldman, Hain & Liben, 2012:118).

It is argued that the nature of family ties has an impact on the perceived roles of the women in society. In a study that was conducted in family ties and economic behaviour, the findings revealed that in times where jobs were scarce, men would more likely get jobs than women. Although this happened in good faith to maintain family ties, women's democratic rights were affected (Alesina & Giuliano, 2010:100). Women could not get respect like a man would. UNICEF (2012) argues that women can seek healthcare for their children; however, their actions would be influenced by the quality of the relationships with the fathers of the children.

Jones & Watson (2012:216) believes that the understanding of cancer either by men or women may greatly be influenced by their cultural beliefs of illness, health, wellness, and death. In addition, where family caregivers travel long distances for healthcare, men would provide financial support and make decisions. Thus, with the recent evolution of gender equality policies and inclusion of women, women have a democratic right to play the roles that used to be dominated by men (Burnet, 2008:362). UNICEF (2012), states that seeking treatment for children with cancer may also be influenced by the nature or function of the family and that decisions can be discussed within the family. However, during that decision-making process, the likelihood of delaying access to healthcare is possible as in most instances parents may not share same perspectives on healthcare issues.

2.7 BARGAINING

Bargaining can be associated with a common response to life-threatening illness. Doka, (2013:74) suggests that bargaining is a "feeling that by omitting or committing

certain actions, one can avoid or forestall further illness or death.” In the case of paediatric oncology, family caregivers’ tendency to bargain may be common immediately after the diagnosis of cancer. They would ensure that children complied with suggested oncology treatment and develop hope for a cure. On the other hand, bargaining can be seen when the condition of the child deteriorates (poor prognosis), caregivers start to be discouraged and many display elements of mistrust to healthcare system. Ross (2014), views the feeling of vulnerability and helplessness as common in caregivers of paediatric oncology patients; they would do anything or blame themselves for responding in a certain way. They ask themselves so many why questions, like why my child has cancer, why me God (Ross, 2007). Birchley (2014) suggests that family caregivers may start to shop for a better clarity of the illness and sometimes negotiate for what they think could better the child ill health.

2.8 NON-INTENTIONAL OR INTENTIONAL DELAY TO HEALTHCARE

The phenomenon of late-stage diagnosis of childhood cancer may result from non-intentional or intentional delays. **Non-intentional** delays to seek healthcare may be caused by several factors, which family caregivers may have no control over and which may include unemployment, low grant income, and limited social networks informing them about healthy lifestyle choices (Goudge, Gilson, Russell, Gumede & Mills, 2009:18). It is important to note here that child support grants, provided by the state for children under the age of eighteen, amount to only R370 per child per month. Some caregivers may struggle to access information about health issues which makes it difficult to recognise early warning signs of cancer. Family caregivers, therefore, may appear to have no sense of urgency about health issues.

Peters, Garg, Bloom, Walker, Brieger & Hafizur-Rahman (2008), affirm that geographic access, poor infrastructure, and traveling long distances to healthcare may contribute to non-intentional delays to healthcare and believe that family caregivers of paediatric oncology patients could face these barriers.

Intentional delay to access healthcare is where family caregivers understand the implications of the late diagnosis of children with cancer, but they would opt to consult with faith healers or traditional healers instead of going directly to the

hospital. Because of some caregivers' poor education and socio-economic status, they may be challenged by language and find it very difficult to communicate with health professionals. This results in the child being presented very late or not at all, because they fear to be confronted by healthcare professionals for perceived lack of care (Silbermann & Hassan, 2011). Traditional healing would be preferable to avoid questioning of healthcare professionals.

Some African people believe in healing in the name of Jesus (Tjale & Villers, 2004:21). The belief that Jesus laid hands on people or used anointing oil to heal the sick, play an influential role in unintentional delay to healthcare. Caregivers may tend to shop or bargain for healing. During the shopping period, access to healthcare is often delayed (Van Rensburg, 2012:635). Van Niekerk (2012) argues that faith in religion has a significant influence on the way in which caregivers respond to health issues. As such, they may wait until the children are extremely ill before visiting the doctors or healthcare systems (Kingsley & Bandolin, 2010). The fact that people are diverse in terms of culture and religion, as well as in their responses to health issues, ultimately causes delays in reaction react to symptoms of illness.

2.9 SOCIO-ECONOMIC FACTORS

No matter how rich or poor a country is, there is no guarantee that every citizen has immediate access to healthcare systems. The WHO (2010), indicates that there are three interrelated problems that may prohibit countries to offer quality healthcare to everyone. Firstly, the availability of resources is a challenge where immediate access to every kind of technology and various interventions are not common. Secondly, the overreliance on direct payments at the time people need care impacts negatively on access to healthcare, since over-the-counter payments for medicines and fees for consultations and procedures can often not be met financially. Even if people have some form of health insurance, they may need to contribute in the form of co-payments or co-insurance and this may have severe financial implications. Thirdly, inefficient and inequitable use of resources is identified as a problem. The WHO (2010), estimates that in the USA between 20% to 40% percent of resources, that should have been used to improve quality of health services, were wasted. With that said the government of South Africa has acknowledged the inequity in access

to healthcare and that the proposed National Health Insurance (NHI) will promote universal coverage of healthcare needs for all citizens. McIntyre (2010:26) describes this initiative as follows: “NHI is a system of universal healthcare coverage where every citizen is covered by healthcare insurance, rich or poor, employed or unemployed, young or old, sick or very healthy, black or white.”

In the case of family caregivers of paediatric oncology patients, the rapid increase by medical schemes in the private sector may pose a challenge. If a medical scheme client whose funds have been exhausted demands hospitalisation, expensive drugs, and procedures, family caregivers will have to resort to public services. Unfortunately, they will still be responsible for the previous medical costs which will put a financial burden on an already struggling family (McIntyre, 2010:14). In the State of the Nation of 2018 (SONA, 16/02/2018), Mr. Cyril Ramaposa, the president of the Republic of South Africa announced the implementation of NHI in April 2018. The President further mentioned cancer as the area that needs priority. Statements like this brought hope to the field of oncology in that resources will be made available for the disadvantaged. Unfortunately, certain provinces such as KwaZulu-Natal, suffered due to oncology services coming to a standstill because of ill-maintained or non-functioning equipment and oncologists not being available in public hospitals. It is believed that the introduction of NHI would ease the burden of inaccessibility of healthcare facilities particularly for the underprivileged. Accessible healthcare will benefit all citizens, including those with no medical aids. People will then have freedom to access healthcare and children with cancer will be diagnosed and treated in time.

2.9.1 Income and its impact on healthcare

In some families, access to healthcare is determined by their income. When a family does not earn an income, or earns very little, the priority may be diverted to buying food. Healthcare accessibility became a luxury. Kingsley (2010), states that late diagnosis and access to healthcare are influenced by those factors. The family caregivers who are working and have medical schemes are concerned about exhaustion of funds. They experience difficulties to take time off at work to consult doctors, since they may face loss of income due to absence from work.

On the other hand, family caregivers may not want to visit doctors fearing scary diagnosis that may mean emotional and financial burdening (Tjale & Villiers, 2004:34). As such, they may wait until the child is extremely ill before visiting healthcare centres (Kingsley, 2010). Tjale & Villiers, (2004:21) state that people have different beliefs: Some African people put their faith in traditional healing and are often reluctant to go to medical doctors for fear of being disowned by ancestors, while others associate hospitals with death and prefer to die at home.

In addition, poverty and unemployment may frustrate family caregivers of paediatric oncology patients and may lead them to behavioural problems, such as alcohol and other substance abuse, violence and crime. Children living in these circumstances may become vulnerable as their health is neglected (Vasuthevan & Mthembu, 2013:6). The health sector of South Africa, regulated by legislation and policies, made a commitment to the progressive realisation of basic rights which include the right to access healthcare, and have autonomy, equity and dignity. These rights allow opportunities and freedom for citizens to choose where and from whom they may obtain healthcare services. The concerning issue will be, the availability of these healthcare facilities in order to give the freedom of choice (Gray, Vawda & Jack, 2011:8).

In order to gain access to healthcare, the researcher maintains that healthcare services should be made affordable. All citizens should have equal access regardless of their socio-economic statuses. At present those who have means receive better care as compared to those who are poor. Implementation of universal healthcare will cover all citizens.

2.9.2 Cost of treatment

Treatment costs mean distress in low-income families. Social grants become the only source of survival. In these families, healthcare of children is compromised because of affordability issues. Children with cancer may even become more vulnerable due to the financial demands of illness (doctors' follow-ups, transport and food, etc.). Reinhard, Given, Petlick and Bemis (2008:4330), believe that even those families with income may experience high levels of stress due to the demands of chronic illness. With the long-term treatment of childhood cancer, families may

experience difficulties to afford the costs of treatment. In a study conducted on family caregivers of persons with a congenital disease, findings revealed that medical costs were beyond their means and socioeconomic status and caused high levels of stress (Connor, Kline, Mott, Harris, Jenkins, 2010). The research concludes that the cost of treatment brings more pressure to those with no income, and may introduce a negligent mentality to many family caregivers struggling to make means met. Children with cancer in such circumstances are prone to late diagnosis of cancer because the parents have no means. In a nutshell, cost of treatment can affect both privileged and underprivileged.

2.9.3 Affordability

The history of the healthcare system in South Africa is marked by a period during which the healthcare system provided services to people based on their race. The apartheid government favoured white people. The democratic government that came into power in 1994 was faced with challenges to restructure the healthcare system to serve all its citizens equally. Understandably, change takes time since certain processes need to be followed, taking into account amending policies to address inequalities in health services (McIntyre, 2010:1).

The government of South Africa has acknowledged the shortfalls in the health system. As a result, the NHI was proposed to balance health inequality between the rich and the poor, in fact, to achieve universal financial risk protection and access to healthcare. Moreover, the NHI proposes strategies to address current challenges facing both public and private health sectors (McIntyre, 2010:1). As compared to other developing countries in sub-Saharan Africa, South Africa is ahead with policies and programmes to provide better healthcare for all citizens.

The extent of poverty has a potential influence in prohibiting the family caregivers of paediatric oncology patients to access healthcare. Late diagnosis would be a common phenomenon among indigent families (meaning the poor of the poorest families). The child with cancer may probably bring more stress and misery (Peters, Garg, Bloom, Walker, Brieger & Hafizur-Rahman, 2008). It is important to understand that there is a relationship between poverty and health.

Peters, Garg, Bloom et al. (2008), believe that poverty leads to ill health. Mayosi and Benatar (2014), view that the government of South Africa has attempted to fight poverty in the country, by introducing social grants as a response to an unbearable situation where children were dying of hunger. However, 45 percent of the population still lives in poverty. One would ask her/himself, what holds South Africa to remain with this percentage after 24 years of democracy. In this regard, family caregivers of paediatric oncology patients would be left with no alternative other than consulting with their own traditional healers (Van Rensburg, 2012:635).

McIntyre (2010:1) indicates that the introduction of NHI will provide strategies addressing the inequality within the healthcare system of South Africa. The Patient Classification Policy Manual (2012:5; 3-19), was introduced to consider and qualify the users of the healthcare systems. This policy regulates and guides the healthcare system to provide healthcare services to all without any discrimination. It provides guidelines about how patients should be registered and classified before they are admitted in state hospitals such as the Steve Biko Academic Hospital. This is done to ensure that patients are categorised according to their ability to pay for the services. The policy regulates how healthcare payment structures should determine the fees.

All citizens and non-citizens are given equal access to healthcare. For instance, there are patients who pay and others who receive a free service. This is established by the means test, as guided by the policy. All non-South Africans are classified as private patients and receive some health benefit as South African citizen immigrants, those with work permits or temporary residents, as well as persons of SADEC countries. In SA, free service is granted to recipients of social grants, however, civil pensioners are classified according to the income they receive. It also indicates that children under the age of six are exempted from paying medical fees. The majority of paediatric oncology patients in a hospital such as Steve Biko Hospital may fall under this category. This policy promotes equality, everyone in the country obtains healthcare, though the Means test is used to ensure that everyone affords healthcare services.

The researcher can conclude that this manual serves as a payment structure that the healthcare services uses to determine the medical fees of each individual. As indicated, it accommodates everyone including Non-South African citizens.

2.10 SUMMARY

In this chapter, multifactorial challenges of family caregivers of paediatric oncology patients have been placed into context. The chapter provides a broader understanding of the various factors that are possibly faced by caregivers of paediatric oncology patients delaying access to healthcare. Literature confirmed several factors hinder family caregivers to access healthcare.

The next chapter will discuss the research methodology and empirical findings.

3. CHAPTER 3: EMPIRICAL STUDY

3.1 INTRODUCTION

This chapter outlines the research methodology of the study and includes a detailed description of the approach, type, and design of research. Furthermore, sampling, data collection and analysis methods, as well as the quality of the data, pilot study and ethical considerations are included. The focus in the second half is on the empirical findings through a thematic analysis, followed by the summary.

3.2 GOAL AND OBJECTIVES

3.2.1 Goal

The goal of the research study is to explore and describe the factors challenging family caregivers of paediatric oncology patients in delaying access to healthcare.

3.2.2 Objectives

For the researcher to achieve the main goal, the following objectives directed the study formulated (Fouché & De Vos, 2011:94):

- To conceptualise and describe paediatric oncology, treatment, access to healthcare systems and the role of family caregivers.
- To explore and describe the challenges faced by family caregivers of paediatric oncology patients in the community and the health system.
- To explore and describe the factors that lead to delayed access to healthcare of paediatric oncology patients.
- To explore and describe the cultural challenges of paediatric oncology family caregivers.
- To make recommendations to the oncology team to enhance accessibility to paediatric oncology care.

3.3 RESEARCH APPROACH

The researcher used a qualitative approach for this study, in order to explore and describe the challenges facing the caregivers of paediatric oncology patients where access were delayed. Such an approach enables the researcher to follow a certain pattern in order to draw a conclusion about the multi-factorial challenges faced by

caregivers of paediatric oncology patients (Fouché & Delpont, 2011:64). The researcher engaged with ten (10) participants, which represents the sample size of the study, in order to gain in-depth insight into the challenges that delay the caregivers to access oncology care.

Creswell (2007:37) views qualitative research as “the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem.” The researcher’s study focused on the family caregivers of paediatric oncology patients that she believed provided rich data for this research study. The information obtained from different views of family caregivers of paediatric oncology patients, assisted in understanding the plight of these children and their caregivers better.

3.4 TYPE OF RESEARCH

The researcher focused on applied research to investigate the challenges faced by caregivers of paediatric oncology. In line with Neuman’s description of applied research (2012:12), possible solutions for a practical problem are offered. This type of research was deemed suitable for the study, as it assisted in understanding the challenges faced by the caregivers of paediatric oncology patients. The findings of the study will assist the decision-makers of the department of Health to drawing conclusions about late diagnosis of childhood (Terre Blanche, Durrhem & Painter, 2006:45) and develop practical strategies in solving the problem in the community (Bless et al., 2013:59).

Applied research enables the researcher to gain information that contributes towards improving the policies and referral systems relating to paediatric oncology care within the healthcare system. The nature of this study was explorative and descriptive, using multiple cases in order to gain different views about the subject. This enabled the researcher to gain a broader understanding of the challenges accessing healthcare the caregivers of paediatric oncology patients experience (Bless et al., 2013:60, 61). This research type assisted the researcher to make the oncology team aware of these challenges in order to devise strategies to eradicate the problem.

3.5 RESEARCH DESIGN

The researcher believes that a case study design will provide an opportunity to investigate the phenomenon through analysing multiple cases producing rich data (Bryman, 2012:66).

The selection and utilisation of this design enabled the researcher to understand the problem from different viewpoints of the caregivers (Neuman, 2011:42). The researcher selected the collective case study design and approached ten (10) family caregivers of paediatric oncology patients as subjects for the study (De Vos et al., 2011:321-322). The rationale behind the collective case study was that different views would provide rich data to gain insight in the challenges facing family caregivers to gain healthcare access for paediatric oncology patients (Wisker, 2008:216).

3.6 RESEARCH METHODOLOGY

In this section the study population, sample, sampling technique, methods of data collection, data analysis and quality of the data are discussed.

3.6.1 Study population

The population for this study comprised of family caregivers of paediatric oncology patients newly diagnosed with cancer at Steve Biko Academic Hospital, Paediatric Oncology Department, Pretoria. The family caregivers stayed at the Cancer Association of South Africa's (CANSAs) facility, Nicus Lodge and at the Childhood Cancer Foundation South Africa's (CHOC) house in Capital Park, Pretoria during the course of treatment of their children.

3.6.2 Sampling

The sample size for this study were ten (10) participants. The researcher believes they gave clearer information for the study; in fact, the researcher is aware of insensitive and overly insensitive sizes that can compromise the findings of the study (Strydom, 2011:225). The researcher utilized non-probability purposive sampling, as there was no documented list of family caregivers. According to Bless et al. (2013:393), this sampling technique indicates, "the probability of each element of the population being included in the sample is not known" (Babbie, 2007:183).

Moreover, the purposive sampling technique Bless et al. (2013:177), will make provision for selecting participants who can provide in-depth information about the study. These family caregivers shared the common characteristic of being conveniently available (Davies, 2007:62).

Strydom and Delpont (2011:394), made the researcher aware that choosing a relevant sampling technique in qualitative research ensures collection of the richest data. Purposive sampling provided an opportunity for the researcher to use her judgment to interview caregivers who were knowledgeable about the question at hand (Brink, 2006:133). The researcher purposely targeted caregivers with distinct characteristics of the population being studied (Davies, 2007:62). The researcher, therefore, applied the following selection criteria for participants:

- The participant must be a family caregiver of a paediatric oncology patient.
- The paediatric oncology patient must be newly diagnosed at Steve Biko Hospital Paediatric Oncology Department.
- The caregiver must be accompanying the child during treatment.
- The caregiver must be staying at the CANSA or CHOC Lodge.
- The caregiver could be of any gender, age, marital status, culture, ethnic group or religion.
- The caregiver must be conversant in English or Xhosa, which are the languages the researcher is familiar and confident with.

Immediately as the two ethical clearances were obtained from the Faculty of Health Sciences and Faculty of Humanities, the head of Paediatric Oncology Department at Steve Biko Academic Hospital was informed about the progress of the study. He then gave permission to make use of the nurses in the unit to help identify the prospective participants using an information letter. The caretaker of CANSA Lodge, Ms. Van Deline, was informed about the study and was asked for permission to use a private venue to conduct the interviews. Nurses of the Paediatric Oncology Department played a crucial role in recruiting potential participants using the information letter. After collecting all the details of the potential participants from the nurses, it became clear that all the recruited potential participants were staying at CANSA Lodge, with none at the CHOC House. An appointment was made with

each potential participant where the letter of informed consent was discussed and the interview time and dates were arranged.

3.6.3 Data collection

The researcher made use of semi-structured interviewing with an interview schedule as the method of data collection. Bless et al. (2013:392), define interview as “a data collection technique based on the series of questions related to the research topic to be answered by research participants.” Greeff (2011:352) indicates that this method of data collection forces the researcher to think of difficulties that may be encountered. This data collection method assisted the researcher to probe and received rich data about challenges faced by family caregivers of paediatric oncology patients and their access to healthcare.

This method is based on guiding the researcher to focus on certain themes, which will correlate with the reviewed literature and focus on factors contributing to the late diagnosis of childhood cancer (Delpont & Roestenburg, 2011:186). The researcher conducted interviews in English and used a digital voice recorder for interviews with the permission of the participants. A private venue at the CANSA Nicus Lodge was arranged with the Lodge manager to conduct the interviews, as this is where the family caregivers were residing during the hospitalisation of the children. The researcher used the interview schedule to guide the interview, the voice recorder during the interviews and a notebook to write down essential data and observations made directly after the interview. These methods of data collection employed ensured trustworthiness of data and assisted the researcher to keep sufficient records of the data collected.

3.6.4 Data analysis

In this study, data gathered was transcribed and analysed as it emerged from the responses of the participants during the interview. The themes generated were substantiated with the literature review. In order to ensure the quality of reporting, the researcher followed the process for qualitative data analysis stipulated in Schurink, Fouché and De Vos (2011:403-418) as follows:

- **Planning for recording data**

According to Schurink et al. (2011:404), the researcher should plan for the recording of data systematically in a manner that is suitable to the setting. This was done before data collection began. For the researcher to plan data recording, she prepared the informed consent forms for the participants to sign before engaging in the interview and scheduled an appointment with each participant. The researcher used a digital recorder to record the information during the interview sessions. A notebook was also used to write down significant information after the interview.

- **Data collection and preliminary analysis**

The researcher did a preliminary analysis during the interview time to ensure that the interview schedules were fully completed by each participant. A notebook was used to write down any significant information or non-verbal cues revealed during the interview. The researcher applied probing to ensure that she received in-depth information from the participants. Preliminary analysis was also done by listening and transcribing the responses of the participants from the digital audio recordings into transcripts (Schurink et al., 2011:405).

- **Managing the data**

All the physical transcript sheets and records were filed separately. Pseudonyms were given to each participant to protect their identity and the date and time of interview was recorded. Each file was labelled with the pseudonym. The data was transcribed verbatim from the digital recordings and stored on the computer, with the document protected using a pin code to assure the safety of the information. This is only accessible to the researcher (Strydom & Delpont, 2011:408).

- **Recording and writing memos**

The researcher perused all the collected data during the interview period, in order to get a sense of the collected data and internalise it (Schurink et al., 2011:409). Subsequently, themes and sub-themes that emerged during the interviews were identified.

- **Generating categories and coding the data**

At this stage, the researcher identified “salient themes, recurring ideas or language and patterns of belief that link people and settings together, as the most intellectually challenging phase of data analysis and one that can integrate the entire endeavor” (Schurink et al., 2011:410). A preliminary table was developed reflecting main themes and sub-themes to form a framework for discussing the findings. This is called a ‘first order’ analysis category of meaning, which comes from the participants. A framework tailor-made for discussions and analysis took place by using the actual quotes of the participants.

- **Testing emergent understanding for an alternative explanation**

The researcher perused the data more than once trying to understand the exact meaning of what the participants wanted to say. This assisted the researcher to gain a better understanding of the problem-faced caregivers of paediatric oncology to delay treatment. Consultation was made with others with knowledge about research, participants themselves were consulted to check the accuracy of the information, and that the understanding is the same as that of the researcher. The literature review revisited to gain a better understanding of explaining connectivity of data in-depth. This according to Schurink et al. (2011:416), could be done to critically challenge the knowledge that may be known about the study subject.

- **Interpretation and developing typologies**

At this stage, data analysis brought into context the existing theory revealing conformation to existing knowledge (Maree, 2007:111). The researcher interpreted data from the participant’s point of view and the themes and patterns in the findings were incorporated and substantiated using the literature review to support the explanation (Schurink et al., 2011:418). Typologies established in literature and quotes linked to other authors’ observations were incorporated in the literature review.

- **Presenting data**

This was the final stage of data analysis, where the researcher presented the data by means of a report using themes, sub-themes, and categories generated from the findings. The exact words of participants were quoted verbatim. The researcher

summarised data, used participants' responses, and supported it with current literature (Schurink et al., 2011:418).

3.6.5 Quality of data

Trustworthiness in research ensures the quality of data. The following constructs indicate how the study proved its genuineness and trustworthiness:

3.6.5.1 Credibility

Credibility focuses on the question of compatibility regarding the genuineness of the findings, "in which the goal is to demonstrate if the inquiry was conducted in such a manner as to ensure that the subject has been accurately identified and described" (Strydom & Delport, 2011:420). The researcher is in a position where her own experiences, perceptions, beliefs, and ideas do not influence the findings of the study. In other words, the findings were exactly what the participants revealed in the interviews. According to Strydom and Delport (2011:420), this enhances the validity of the study. Credibility employs strategies such as member checks and triangulation. In terms of ensuring trustworthiness, the researcher employed member checking and through follow-ups to ask participants whether the information transcribed and interpreted was accurate (Fox & Bayat, 2007:107). This exercise was performed during debriefing after the interviews and during data processing.

The researcher obtained ethics clearance from the Faculty of Humanities' Research Ethics Committee and the Faculty of Health Sciences' Ethics Committee. Permission was also obtained from the CEO of Steve Biko's Academic Hospital and the head of the Paediatric Oncology Unit to conduct the study and to engage with the staff of the unit. Recruitment of the participants was made possible with the assistance of healthcare professionals, specifically the nurses in the unit, using an information letter. Participants were introduced regarding the purpose of the study. The researcher received training in research methodology at honours and masters level. The researcher's supervisor has extensive qualitative research experience and is a senior lecturer at the Department of Social Work and Criminology, University of Pretoria.

3.6.5.2 Transferability

Transferability indicates a situation in which “the researcher asks whether the findings of the research study can be transferred from a specific situation or case to another” (Strydom & Delpont, 2011:420). Although transferability of one qualitative study to another may be a problem, a strategy of triangulating multiple cases was adopted to generalise the collected data in order to enhance the study (Strydom & Delpont, 2011:420). For this study, transferability is supported by the fact that it followed a qualitative inquiry where multiple cases of paediatric oncology family caregivers were studied, coming from different areas and backgrounds. Various methods of data collection were used, including a semi-structured interview, an interview schedule, voice recording, field notes, and observations.

3.6.5.3 Dependability

Dependability refers to judging the process, which the researcher follows, its stability or consistency. The more the consistency in the process, the more dependability are the findings. This relates to a situation where “positivist notion of reliability assumes an unchanging universe where inquiry could, quite logically, be replicated” (Strydom & Delpont, 2011:420). The research process was also scrutinized by external reviews to ensure consistency in the research process and that the researcher has been consistent. All the research notes, the records of the data collected, transcripts kept in the audit tray. In fact, all the activities of the research process are kept to maintain the consistency in reporting. The researcher adhered to the process proposed and approved to conduct the study. Ethical clearances granted to enforce the researcher to comply and maintain consistency. This is practiced to ensure the trustworthiness of this study.

3.6.5.4 Conformability

Conformability relates to the researcher’s objectivity (Shurink et al., 2011:421). In other words, research findings must be shaped by participants and not clouded by the researcher biases. Peer debriefer used to assist the researcher by being a soundboard with regards to the interview schedule compiled and the themes generated. The peers had a critical eye about this study and were well informed. The researcher used participants for member checking to review findings from data analysis to confirm its accuracy (Lietz, Langer & Furman, 2006:453). The use of

member checking assisted the researcher to be assured of the accuracy of the information (Fox & Bayat, 2007:107). The researcher also did member checking with the participants during the interviews where the researcher examined the information provided, to obtain additional insight and reactions, to validate some of the information. The atmosphere was made to be conducive and allowed openness, this gave an opportunity to reflect on the information provided and assess whether the answers reflected what participants wanted to say. Participants' direct quotes were reflected and the researcher (true reflection) did not confuse the information provided.

3.7 PILOT STUDY

Terre Blanche, Durrhem and Painter (2006:94), refer to pilot studies as “preliminary studies on small samples that help to identify potential problems with the design, particularly the research instrument.” The researcher carried out a pilot study at the CANSA Lodge with two participants who met selection criteria. Twelve prospective participants were recruited and two (2) were selected for the pilot study. The participants went through the process of interviews. This was done to validate all the multi-methods of data collection used in this study. The pilot pre-test was aimed at testing the appropriateness of the interview schedule and whether the digital recorder functioned optimally to capture each interview session. The venue and time the interview takes were also tested. This assisted the researcher to establish the duration of each interview that eventually lasted 30-45 minutes since the interview schedule generated rich data. The researcher has performed this exercise to assess whether the interview schedule generates relevant information (Strydom & Delport, 2011:394-395) and to identify the problems that may be encountered. Pilot pre-test confirmed that the results from the two (2) interviews generated similar data. The researcher then gained confidence that the schedule is trustworthy for the purposes of this study (Bless et al., 2013:222).

3.8 ETHICAL CONSIDERATIONS

It is crucial for anyone involved in the study to be aware of the general agreement between the participant and researcher (Babbie, 2014:62). The following statement supports this view: “Research ethics places an emphasis on the humane and sensitive treatment of research participants who may be placed at varying degrees

of risk by research procedures” (Bless et al., 2006:140). To ensure this, the researcher complied with the following ethical considerations described by Babbie (2014:64) and De Vos et al., (2011:15):

3.8.1 Voluntary participation

In this research study, the researcher ensured that participants understood that their participation in the study is voluntary (Babbie, 2014:64). If they decide not to participate in the research study, their decision will not affect their relationship with the hospital staff or treatment of their children in any way (Mariana, Marc, Alan, Cristino, Van Eyssen, Uys, Van Zyl & Hesseling, 2014:199).

3.8.2 Deception of subjects/respondents

As mentioned earlier, the purpose of the research study was explained to the participants honestly (Babbie, 2014:71). The researcher expressed transparency about the study and no deceitful information was provided that led to the refusal to participate in the study (Strydom, 2011:118-119). Participants freely participated.

3.8.3 Informed consent

A letter of informed consent was read to each of the participants in English and explained in Xhosa, where necessary. This was done before the study commenced to ensure that no participant felt coerced to participate in the research study and to explain that participation in the study is voluntarily (Patton, 2002 cited in Strydom, 2011:119 & Neuman, 2012:59). Additionally, the informed consent contained detailed aspects of confidentiality, avoidance of harm or discomfort, debriefing, recording of the interview, as well as storage of data for archival or future research purposes as recommended by Neuman (2012:59).

3.8.4 Violation of anonymity and confidentiality

Participants were guaranteed anonymity and that their information would be regarded as confidential. They were also informed that responses would be identified by an allocated number, rather than a name, for each participant. Participants were assured that the data of this study will be shared with the university research supervisor for academic purposes only (Babbie, 2014:68). To ensure privacy, a secluded room at the CANSA Lodge was obtained with permission

from Ms. Vera Van Dalen. It provided a relaxed atmosphere in a safe environment to participate in the study.

3.8.5 Avoidance of harm

The purpose of the study was explained very clearly to each participant to ensure that they understand what was expected of them. The researcher complied with the ethical obligation of protecting participants from any emotional harm that may emerge from the research study. The participants signed the Informed Consent Form as an indication that they understood their involvement in the study and that their participation will not result in any harm to them. One participant had an emotional experience and the researcher referred this person to Ms. Matlala, the social worker in the Paediatric Oncology Unit, for counselling.

3.8.6 Debriefing participants

The researcher allowed an opportunity for debriefing after the interview. This was done to allow participants to share their experiences of the interview and, where possible, to provide the researcher with the opportunity to address any misconception or possible form of harm that might have occurred unintentionally during the interviews. Strydom (2011:122) believes that any academic study is a learning experience for both participants and researchers. Debriefing sessions were the best times to complete the learning experience that began with the agreement to participate. During debriefing the researcher also checked whether the data collected was accurate and the answers given reflected what participants wanted to say.

3.8.7 Providing incentives or compensations

Compensation means remuneration for participation in the study. Strydom (2011:121) believes that it is “reasonable to reimburse participation for cost incurred, such as time away from work or free time spent in the project.. In this study, family caregivers of paediatric oncology patients were made aware that their participation in the study is voluntarily and there is no form of compensation that will be given. All caregivers participated freely in this study.

3.8.8 Action and competence of researcher

Strydom (2011:123) indicates that “researchers are ethically obliged to ensure that they are competent, honest and adequately skilled to undertake the proposed investigation.” The researcher has been in the field of Social Work for nine years and understands what ethical conduct entails for this research study. She is equipped with adequate interviewing skills to handle interview situations professionally. Furthermore, the researcher is a Social Worker registered with the South African Council for Social Service Professions (SACSSP) that honours integrity as one of the codes and principles. Moreover, the researcher already started to obtain experience in qualitative research during her undergraduate BSW degree. The supervisor, a senior lecturer guided her throughout the study.

3.8.9 Release or publication of the findings

The findings of the research study display the data collected and the literature review is used to support the themes generated. The finding is published in the form of a written mini-dissertation made understandable and accessible to the public (Strydom, 2011:126). The researcher’s mini-dissertation will remain the property of the University of Pretoria, although affiliated to the Paediatric Oncology Unit at Steve Biko Academic Hospital. A manuscript will be submitted, working hand in hand with supervisor as co-author for possible publication. With this publication, the researched hopes to provide scholars in the broader psychosocial sphere with fresh insight in this field of study (Oliver, 2010:145). The researcher aims to publish the findings of this study in a journal presented at a conference, which encourage other researchers to pursue their own investigations based on the recommendations of this study.

3.9 EMPIRICAL FINDINGS

This section will present, analyse and interpret the qualitative data that was collected. It will start by presenting the biographic profile of the participants, thereafter the themes and sub-themes generated from the data will be deliberated in length. This means the findings will be presented and discussed making use of different themes and sub-themes generated from the data collected. Direct quotations from research participants and literature will complement these themes to substantiate the findings.

3.9.1 3.9.1 Biographic profile of participants

The biographic information of the participants is described in the table below:

Table 3.1: Biographic data

Participant pseudonym	Gender	Age	Marital status	Place of origin	Level of education	Employment status	Age of the child	Gender of child	Church	Race
1	Female	33	Divorced	Mpumalanga	Grade 10	Stopped working	5	Boy	Christian church	Black South African
2	Female	43	Married	Original-Zimbabwe	Form 4/ grade 11	Stopped working	11	Boy	AFM	African
3	Female	30	Single	Mpumalanga	Grade 12	Unemployed	1	Girl	Christian church	Black South Africa
4	Female	23	Cohabitation	Mozambique	Grade 12	Unemployed	4	Boy	Assembly of God	African
5	Female	42	Widow	Mpumalanga	Grade 11	Self employed	9	Boy	Zion Christian Church	Black South African
6	Female	24	Single	Limpopo	Grade 12	Employed	2	Boy	Christ is the way	South African
7	Female	34	Single	Limpopo	Grade 12	Unemployed	10	Boy	Zion Christian Church	South Africa
8	Female	28	Married	Gauteng	Grade 11	unemployed	9	Girl	Lesotho Evangelical church	Black South African
9	Female	35	Married	Angola-	Diploma Certificate	Employed	8	Girl	AFM	Black African
10	Female	33	Married	Mpumalanga	Grade 11	Unemployed	8	Boy	Zion Christian Church	Black South African

The above table reflects the demographic information of the participants in this study. The demographic variables portrayed in the table are the gender of the participant, age, marital status, whereabouts, level of education and the status of employment. The table also shows the age and gender of the children of the caregivers interviewed. Children of the participants ranged from one to eleven years of age and their gender includes more boys than girls. The majority of the participants were coming from South Africa, while the rest is from African countries that include Zimbabwe, Angola, and Mozambique.

The participant with the highest level of education was a National IT diploma, four participants completed grade twelve, while others could not manage to get a senior certificate. Three participants completed grade eleven and the lowest level of education was grade ten. The majority of the participants were unemployed (five out of ten), two participants were employed, and the other two had stopped working (equivalent to unemployed) and only one was self-employed. The religions of the participants showed that all are Christians affiliated with different churches. Biographical findings are discussed in a sub-section below:

3.9.1.1 Gender

The figure below shows the gender of participants

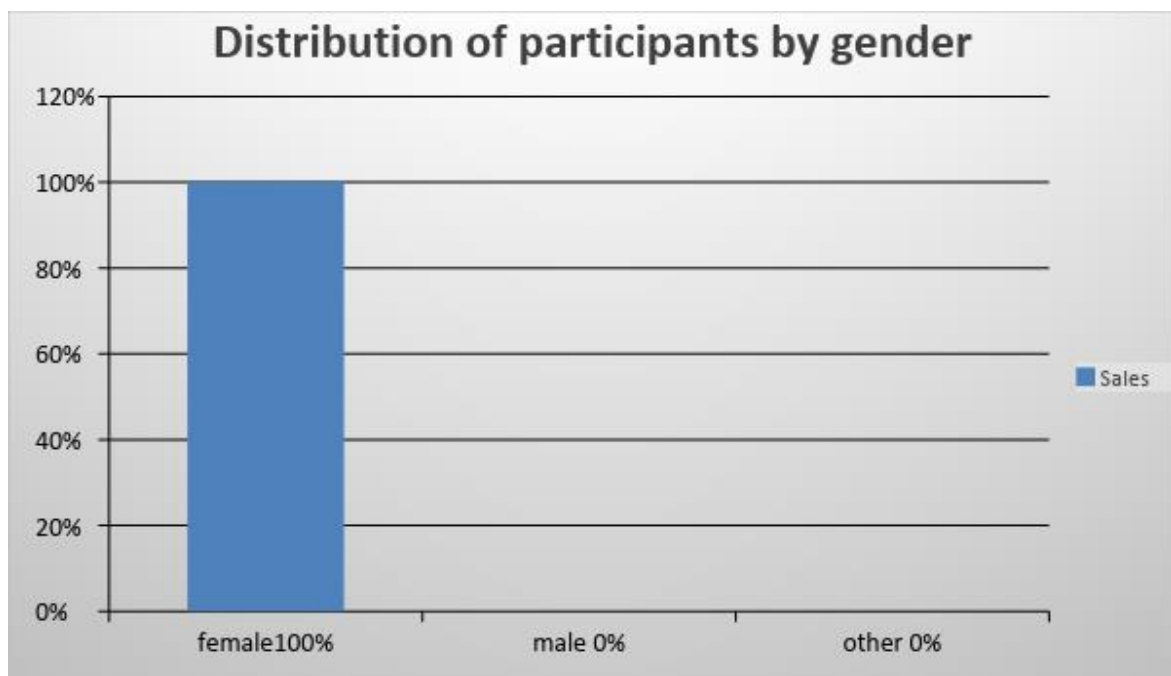


Figure 3.1: Gender (N=10)

The figure above indicates the gender of all the participants in this study as females. It reflects the fact that females are generally known as natural caregivers. It is not surprising that females dominated this study; research done by Schneider, Steele, Cadell and Hemsworth, (2011) corroborates that women scores higher compared with men for meaning in caregiving.

3.9.1.2 Age

The figure below depicts the age of participants.

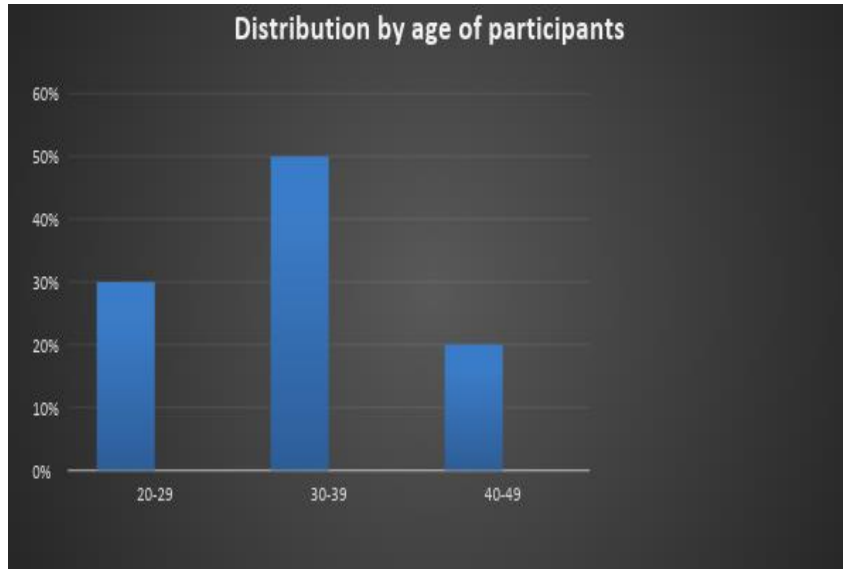


Figure 3.2: Age (N=10)

In this study, no age limit of participants was set; the researcher included any participant willing to contribute to the study. Between 20-29 years of age, three participants were included in this study (one 23 years, another 24 years and the third 28 years old). The majority of participants fall the age range of 30-39 years (two were 33 years, one 34 years and two were 35 years old). Only two participants were between the age of 40-49 (one 43 years and one 42 years old). It was interesting that no participant was below the age of 20 years where the researcher would require consent of a parent or guardian. In a nutshell, the age ranges of participants were between twenty-three (23) and forty-three (43) years.

3.9.1.3 Marital status

The figure shows the marital status of participants:

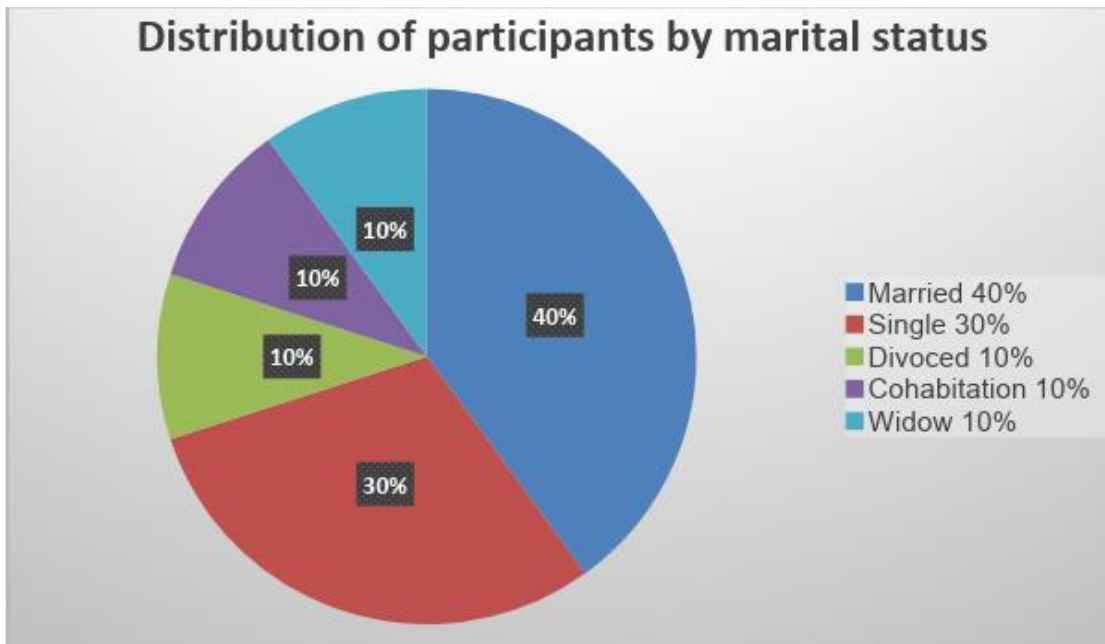


Figure 3.3: Marital status (N=10)

The figure above shows the marital statuses of participants. Four participants were married, three were single, one participant was divorced, one participant lives in a cohabitation arrangement and one participant is a widow. Married participants represent the highest distribution, followed by single participants.

3.9.1.4 Place of origin

The figure below shows where participants originated from:

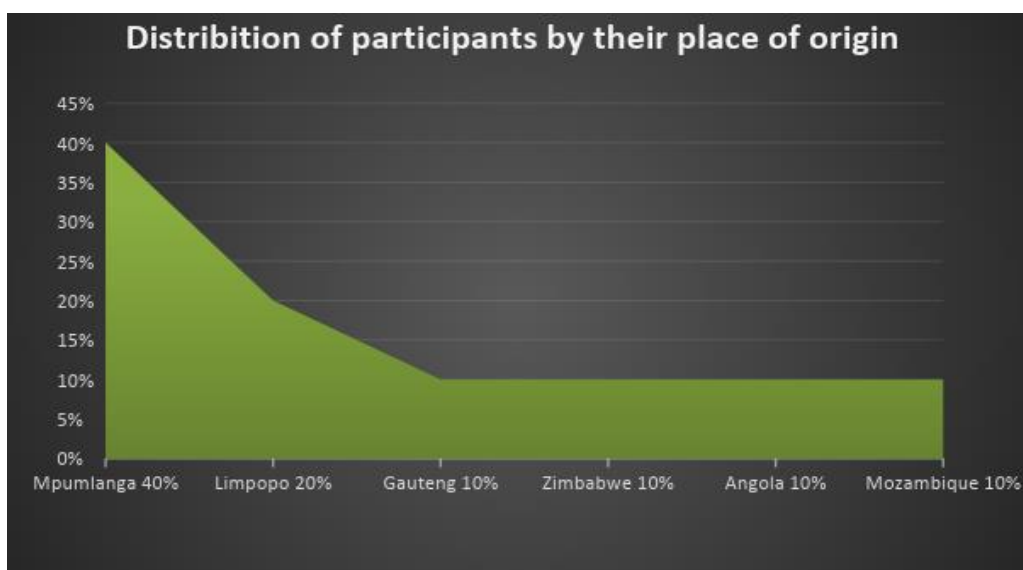


Figure 3.4: Place of origin of participants (N=10)

The graph above demonstrates that participants come from different provinces in South Africa and from neighbouring countries. The majority of the participants came from Mpumalanga (four out of ten (40%), two participants (20%) from Limpopo, one from Mozambique (10%), one from Zimbabwe (10%), one from Angola (10%) and one from Gauteng (10%). This presentation indicates that although the population is drawn from Steve Biko Academic Hospital in Pretoria, there were participants who came from neighbouring countries seeking healthcare of their children. The largest number of participants come from South Africa, namely from Mpumalanga, Limpopo, and Gauteng. Thirty percent (30%) of participants come from neighbouring countries. The WHO, (2010) affirm that childhood cancer is not a serious problem just in South African, but a worldwide phenomenon. The participants from neighbouring countries moved to South Africa to look after their sick children because their partners worked in South Africa. However, one participant from Zimbabwe indicated that she was unable to find professional help in Zimbabwe. Her husband advised her to bring the child to South Africa for medical assistance.

3.9.1.5 Level of education

The level of education of participants is shown below:

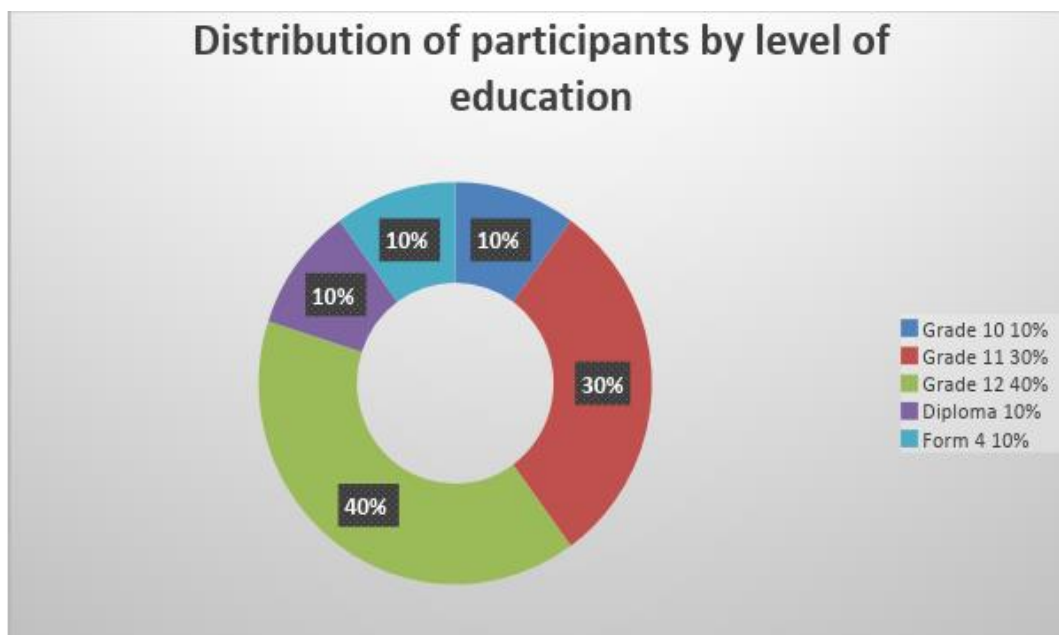


Figure 3.5: Level of education (N=10)

This figure above illustrates that the participants in this study presented different levels of education. The study demonstrates that 40%, reflecting the majority of the participants, completed grade 12. Thirty percent (30%) of the participants completed grade 11 (30%), and one participant only grade 10, reflecting the lowest level of education. According to the educational standards of South Africa, these participants are less educated since some could not complete grade 12, which makes tertiary education possible if exemption requirements are met. Those with grade 12 did not progress to higher education. As such, they are unlikely to get better jobs. One participant from Zimbabwe achieved Form 4, equivalent to grade 11 in South Africa, while only one participant managed to get a tertiary qualification.

The researcher concludes that the participants in this study were not highly educated. Porterfield and McBride (2007:327), confirm that being uneducated places family caregivers at a disadvantage to learn about childhood cancers.

3.9.1.6 Employment status

The employment status of participants is illustrated below:

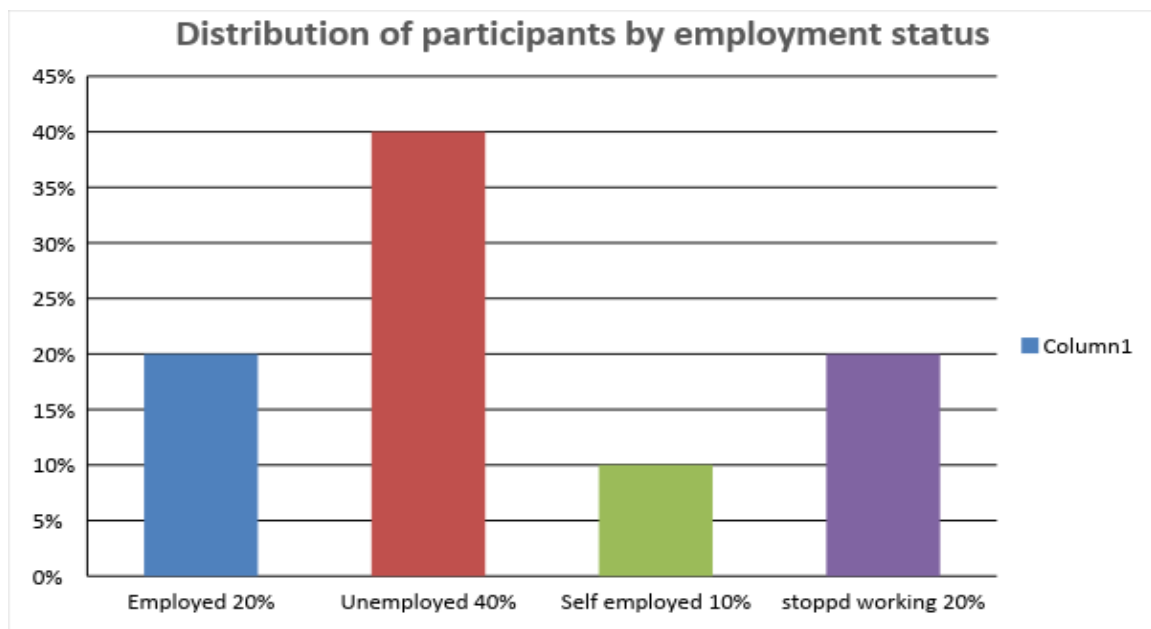


Figure 3.6: Employment status (N =10)

This figure above illustrates the employment status of the participants. The study shows that four out of ten participants were unemployed; this may be suggestive of a poor health-related lifestyle and poverty. These results are strongly affirmed by

Peters, Garg, Bloom, Walker, Brieger and Hafizur-Rahman, (2008) who hint that late diagnosis would be a common phenomenon, since the child with cancer may probably bring more stress and misery. One participant was self-employed, selling used tyres in the community, two participants had to quit their jobs in order to take care of the sick child, one participant does domestic work, but on a temporary basis, two participants were fully employed (one works as a clerk at Clicks and another one works at SADF as an IT operator).

Peters, Garg, Bloom et al. (2008), believe that poverty leads to ill health. Reinhard, Given, Petlick and Bemis (2008:4330), state that families with income, also experience high levels of stress due to the demands of chronic illness. The researcher predicts that these participants' lifestyles may be further compromised by health issues associated with their socioeconomic situation. Kingsley (2010), suggest that late diagnosis could be influenced by the fact that these participants found it difficult to take time off to visit doctors due to potential income loss, particularly those who had to stop working later. This may imply that participants who stopped working and those who are self-employed found it difficult to prioritise children's health because they feared losing their sources of income.

3.9.1.7 Church denomination

The church denomination of participants is shown below:

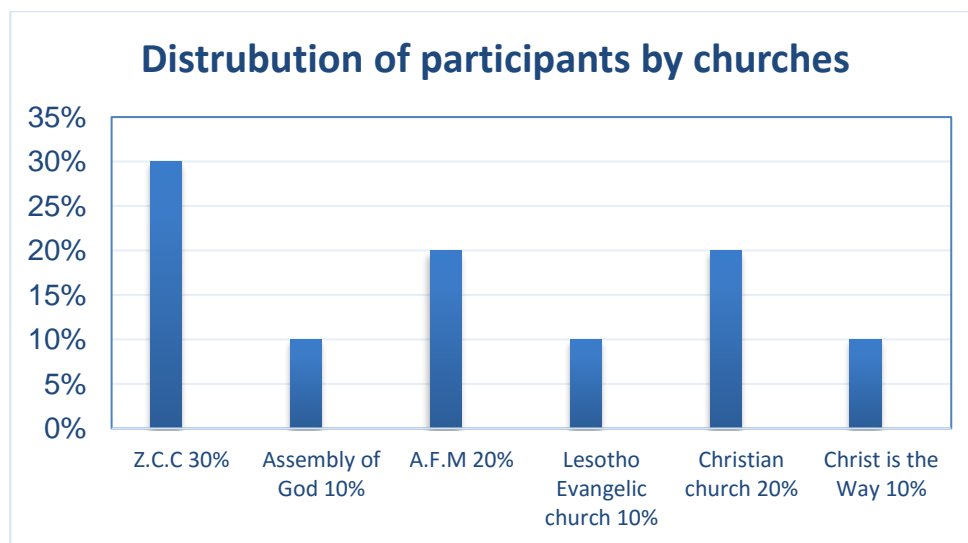


Figure 3.7: Churches (N=10)

The graph above demonstrates that all participants in this study were Christians affiliated with different churches. The majority in this study represent members of ZCC and constitute a higher percent (30%) among other churches. This may mean that the church in question understands the importance of taking children to healthcare for early detection, not expecting church members to relying on their religion for healing. Alternatively, it could be that the number of ZCC members is higher due to the size of the church. The African Faith Mission who promotes healing in the name of Jesus constitute 20% of the participants. This belief is also common in the Assembly of God, where faith in Jesus is seen as the only way. These participants constitute 10% in this study, and may more likely delay medical treatment because of their faith in the power of prayer and reliance on miracle healing.

Forty percent (40%) of the participants came from four different dominations who believe in faith healing. The members of these churches may have a tendency to 'shop' for treatment and healing by attending healing crusades where oils and water are often used. Members of these churches are unlikely to take children to medical facilities for early detection of cancer. Cobb, Puchalski, and Rumbold, (2012:8), state that Christians may claim that miracles happen which strengthen their faith in God, where healing occurs without treatment and medicine.

3.9.1.8 Gender of child patients

Figure 3.8 shows the gender of the child oncology patients.

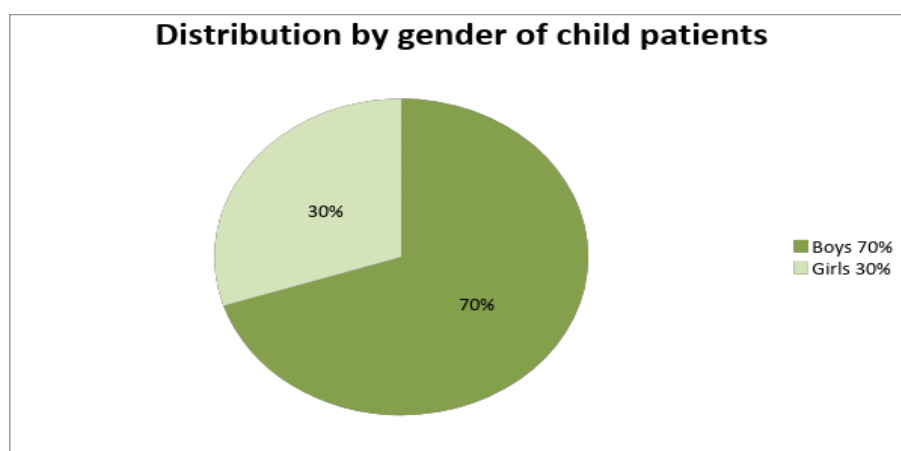


Figure 3.8: Gender of child patients (N=10)

This figure above illustrates the gender of paediatric patients. The study showed that 70% were males and only 30% were females diagnosed with cancer.

3.9.1.9 Age of child oncology patients

The following table shows the age of the child patients.

Table 3.2: Distribution by age of children

Frequency	Age	Total number
0-1	1	1(B)
1-2	2	1 (B)
2-3
3-4	4	1(B)
4-5	5	1(G)
5-6
6-7
7-8	8	2 (B/G)
8-9	9	2(B/G)
9-10	10	1 (B)
10-11	11	1(B)

(N=10)

The table above demonstrates the age of the children diagnosed with cancer. Only 40% of the paediatric patients were between 0-6 years, while 60% were between the ages of 8-11 years. The ages indicate that the majority of the children fell above the age of 6 years where free treatment of children is offered at state hospitals or where a payment streamline system at Steve Biko Academic Hospital is used.

A thematic analysis outlining themes and sub-themes generated from data follows.

3.9.2 Themes and sub-themes

In this section, the themes and sub-themes that emerged from the research interviews will be presented and discussed through a thematic analysis. All the interviews were conducted in Xhosa or English and transcribed in English. Direct quotes of participants will support these themes and literature will be used to substantiate the themes generated.

The following table provides a summary of themes and sub-themes:

Table 3.3: Themes and sub-themes

THEMES	SUB-THEMES
<p>1. UNDERSTANDING CANCER</p>	<ul style="list-style-type: none"> • Definition of cancer as understood by participants • Signs and symptoms experienced by the child • Action taken when child become ill • Information gained from healthcare professionals at local healthcare facilities. • First diagnosis of child cancer • History of cancer in the family
<p>2. ACCESS TO HEALTHCARE</p>	<ul style="list-style-type: none"> • Distance to local clinic and hospital • Transport, easy access to emergency services and road accessibility • Access to traditional healers in the community • Access to clinic, hospital and oncology care
<p>3. RELIGION, CULTURE AND SPIRITUALITY</p>	<ul style="list-style-type: none"> • Religion and change in belief since diagnosis • Church attendance before and after diagnosis • Cultural rituals in family during illness or treatment • Beliefs about disease- traditional medicine – Muthis/Mbizas used • Beliefs in Western medicine and hospitals
<p>4. COMMUNICATION AND LANGUAGE</p>	<ul style="list-style-type: none"> • Experience of communication with health professionals • Language spoken • Level of understanding of diagnosis when explained. • Understanding diagnosis and medical terms
<p>5. SOCIO-ECONOMIC STATUS</p>	<ul style="list-style-type: none"> • Employment status • Source of income • Housing and environment • Access to basic needs
<p>6. DELAYED ACCESS TO HEALTHCARE</p>	<ul style="list-style-type: none"> • Healthcare providers understanding of cancer. • Negligence of parents • Traditional healers • Time • Money and transport
<p>7. IMPACT OF CANCER</p>	<ul style="list-style-type: none"> • Impact on caregiver, siblings and family • Role changes

THEMES	SUB-THEMES
8. INTENTIONAL AND NON-INTENTIONAL DELAYS	<ul style="list-style-type: none"> • Income • Awareness of cancer • Emotions • Bargaining • Family beliefs • Beliefs in Westernised medicine • No support system
9. MEDICAL AND RELATED COSTS	<ul style="list-style-type: none"> • Medical Aid • Payment of medical bills • Hospital fee structure • Financial challenges
10. CAREGIVER RESPONSIBILITY REGARDING DECISION-MAKING AND SUPPORT FROM FATHER	<ul style="list-style-type: none"> • Decision-making and support from the father
11. RECOMMENDATIONS	<ul style="list-style-type: none"> • Recommendations and advices from participants

3.9.2.1 Theme 1: Understanding cancer

This theme focused on understanding cancer. It is divided into six sub-themes that include the definition of cancer as understood by participants, signs, and symptoms experienced by the child, action taken when the child got sick, information gained from healthcare professionals regarding the sick child at local healthcare facilities, first cancer and history of cancer in the family. This theme emerged from the comments of the majority of the participants and further sub-themes emerged. Subsequently, the sub-themes generated from the interviews are discussed and reflect the words of the participants verbatim. No language editing was done and errors in grammar and vocabulary in general remain unchanged.

Sub-theme 1.1: Definition of cancer as understood by participants

The majority of the participants attempted to define cancer according to their own understanding. Below are the quotes from the participants:

Participant three: "I can say cancer is a challenge to say how strong or how weak are you and where your hope is."

Participant six: "... cancer it's an abnormal cells that are building up in person's body."

Participant two: "I don't know because no one tells me exactly all about cancer, but for my own view, I can say simply blood cells, if you are a human being you

have got two types of cells, red cells and white cells I don't know what is going on those cells to make cancer."

Participant seven: "I think to me, the way I know cancer by now if I have known few months ago, think my child should be much better by now, and even my stress would be gone by now."

Participant one: "... That one its difficult, eshhhhh ... I don't, it is a disease that can be cured But seriously I ... don't know what is it."

Participant four: "I leave that behind I don't want to be stressed."

Participant eight: "That one is difficult but, people say cancer is dangerous but it is treatable if it is noticed early."

Participant five: "No, I do not what know cancer is." (laughed)

Participant ten: "Cancer is a devil spirit, I really don't know what it is."

Findings show that only participants two and six had an idea that cancer involves abnormal cells, but did not understand what happens to white and red blood cells in a person's body. Their descriptions were acceptable because they are not medical practitioners. The majority of the participants have little or no insight into childhood cancer. The observation was that some participants are curious to know more, although others showed fear to learn more, and denial of childhood cancer featured strongly during interviews. One participant ignored her child's condition and she said the following: "*I don't want to be stressed.*"

Tjale and Villiers, (2004:34), affirm that fear may be caused by the fact that caregivers were scared that diagnosis may imply further emotional and financial burdens. This finding is confirmed by CHOC parent handbook (Visser, 2010:70) that associate this type of response as a selective approach, as parents may avoid information that may have a potential negative impact. One participant indicated that she wished she had more knowledge about childhood cancer before it was diagnosed. The researcher inferred that the majority (seven out of ten) of the participants had no insight in the nature of cancer. Haan (2005:8) finds this as no surprise and confirms that it was at no stage that participants would understand cancer and further comments on the educational factor as crucial to influence decision-making. The researcher came to the conclusion that participants of this study do not know cancer at all. One participant defined cancer as: "*a challenge to see how strong or how weak you are and where is your hope.*"

The researcher regards this response as a confirmation of the impact of religion where the participant believes that if faith in Christ is strong, cancer will be healed. This finding is affirmed by Koenig et al., (2012) who believe that when faced with disease, caregivers need tending to their emotional and spiritual needs. Therefore, religion becomes a source of strength and support for caregivers.

The study's findings are corroborated in the theoretical framework of this study. Health behaviour is motivated by perceptions of the severity of illness (Green & Murphy, 2014:1). WHO (2010), identifies a gap of knowledge and suggests that if people knew about the two major components of early cancer detection, namely; education and screening as crucial in the prevention of late diagnosis, prompt action would have been taken. One participant aptly remarked: "That one is difficult (referring to cancer), people say cancer is dangerous but it is treatable if it is noticed early." This participant did research on the internet to enhance her understanding of cancer: *"I found that when a child had that thing (referring to lump) she may have TB or cancer."*

Pecchioni & Sparks, (2007:149) support this finding and confirm that literate people can easily access information and that they would make use of the internet to enhance their knowledge.

This finding has shown that very few participants could define cancer and presented insufficient knowledge about cancer in general. In line with the health belief model of this study, the researcher concludes that the lack of information and knowledge about possible warning signs of childhood cancer played a role in accessing healthcare.

Sub-theme 1.2: Signs and symptoms experienced by the child

Throughout the interviews, it was evident that children presented with symptoms of childhood cancer. However, the participants were unable to recognise these warning signs and symptoms of cancer:

Participant eight: "Because she has lump, I google it and then I found that when a child had that thing she may have TB or cancer yes."

Participant five: "I saw lump thing here" (pointing the neck and back of the ear).

Participant four: "... my aunt, she has a breast cancer, the breast was this big (showing) and it was heavy painful, I think maybe it is cancer I was not sure but to my son didn't have any clue because I didn't know that there's cancer for children, the cancer I know is brain, breast and leg cancer that's all."

Participant nine: "... she did not present with anything, she only presented sometimes with pain in the stomach."

Participant one: "Fever, diarrhoea sometimes, losing weight, sleeping, and feeling tired all the times."

Participant seven: "All the symptoms that were written there, I saw them, like those the cloths coming from the nose, the bruises, unable to walk, headache, sweaty, moody things, all of the symptoms' I have seen but I never think it could be the cancer."

Participant six: "... yhaa, at first it was legs his joints were painful he stopped walking, this other day he started limping actually as days went by he takes two steps and sit down he stopped eating, every time he eats he vomit and he had a high fever and then he was drinking water more especially at night, he would wake up at night and drink water and the other thing the hands were pale and they were starting to be swollen and also the stomach it was hard, when you touch his stomach he will cry."

Participant ten: "... my son has got a swollen stomach, at Tembisa there, they said its nothing it's just a flu but another doctor said you must go to Steve Biko may be they will see something."

Participant three: "Something growing in her stomach, he cries at night and stopped urinating."

Participant two: "Totally no, I was so surprised when they say its cancer, if a child is growing up you can see some symptoms maybe stomach, if he eats not vomit, but totally no sign."

Participant one, three, six, and seven recognised these signs. The findings are very similar to the Guide for Early Recognition where Fragkandrea et al. (2013:187), indicate that these children presents with suspicious warning signs, clinical characteristics and malignancies of childhood cancer.

Participant seven became very emotional when she realised that throughout all the hospital visits, her child showed all the symptoms of cancer. She expressed it as follows:

"All the symptoms that were written there, I saw them, like those clots coming from the nose, the bruises, unable to walk, headache, sweaty, moody things, all of the symptoms' I have seen but I never think it could be the cancer."

Participant six supported and shared common feelings and repeated the early warning signs the child presented with:

“... at first it was legs his joints were painful he stopped walking, this other day he started limping actually as days went by he takes two steps and sit down he stopped eating, every time he eats he vomit and he had a high fever and then he was drinking water more especially at night, he would wake up at night and drink water and the other thing the hands were pale and they were starting to be swollen and also the stomach it was hard, when you touch his stomach he will cry.”

The fact remains that these participants never knew that their children displayed possible signs of cancer. It seems apparent that all children of these participants presented with warning signs and symptoms of cancer, however, participants were not aware that it could be cancer. Sadly, these children may be diagnosed with advanced stages of cancer.

Participant two added that it was difficult to notice how the human body is affected by cancer. This is what she said:

“We are not delaying the kids to ... ok, how can I know is a problem like this, I don't know any, am walking but my blood inside has cancer but am saying am healthy, don't know , by two years to come maybe there's something like this growth am talking about but already in my blood there's already cancer, I am not delaying its because I don't know that I have cancer, why because my skin looks good, inside me I don't have any problem what I got I don't , just like HIV, you got HIV inside where's you are not aware blood cells and soldiers are going down, the time I have serious headache, I go to the clinic they tell me I am HIV maybe three years ago but I was walking and not sick, the sisters will say you took long. And I didn't know.”

This participant shared her frustration about how little she understands about cancer. The American Cancer Society (2007) strongly supports this finding and believe that this is one of the main reasons of delayed access to treatment. They add further contributory factors such as the child's age at diagnosis, the parent's level of education, type of cancer, presentation of symptoms, tumor site, cancer

stage, and first medical specialty consulted. This view is supported by the fact that people are not used to get regular health check-ups.

This study strongly indicates that participants have no knowledge of childhood cancer that may ensure prompt action. Participants, who are unaware of warning signs, cannot take any action to avoid late diagnosis of cancer. As the health belief model in this study indicates, participants with limited knowledge about early warning signs of cancer will not be motivated to take action as the reason or benefit for doing so is not clear to them. The researcher concludes that health education is needed to recognise these signs. Where health screening is not available, the detection of cancer at an early stage is very difficult.

Sub-theme 1.3: Action taken when child got sick

This sub-theme concentrates on the actions taken by participants in trying to relieve symptoms. Different people may have different reactions when faced with ill health. They may try all sorts of things in order to relieve pain. Some actions taken by the participants at home when the child got sick are reflected below:

Participant six: “It was ... three weeks no he went for ... he first started swelling and stop walking we always take him to the clinic for consultation when the pain medication is finished, I will say after three weeks.”

Participant ten: “... when I saw my son is sick I felt a pain, I went to school to inform the school about taking the child to the hospital. I didn't wait.”

Participant seven: “Yes, even at church they did another traditional thing because they thought is certain pain, then blood came and never stops, I remember they tried to place another herb on the wound to stop bleeding but the blood was just running, none stop, so all the symptoms, like a little scratch, bruise like bigger, and have no appetite, and the child was always complaining about the headache. By then I didn't have any knowledge of cancer.”

Participant five: “I thought that it was flu and took him to the clinic, they give him medicine, I remember it was alcophyllex, after they gave that medicine that thing (referring to lump) started to grow, I was so surprised what is this thing and where is coming from.”

Participant nine: “I gave her painkiller, second time I did massage on the stomach, I warm up same olive oil and I felt little lump below I thought maybe its flu, that when I took her to the sick bay.”

Participant two: “I thought maybe, it is because he is losing weight, is nothing, I took him to the clinic he was weak, they say its shortage of blood so they gave

me paper and say you must go to the hospital now because the child does not have blood, when I arrived to the hospital the doctor take blood and make some test, malaria, HIV whatever and then they order a blood for him.”

The words above reflect different views of the participants trying to relieve pain, and hoping to cure the symptoms at home. Participant ten (10) felt it was very important to inform the child’s school about his ill health, so that his absenteeism at school may be explained and excused. This participant showed a sense of urgency and panic about her child’s ill health. Participant nine (9) took significant action to relieve pain as reflected below:

“I gave her painkiller, second time I did massage on the stomach, I warm up some olive oil and I felt little lump below I thought maybe its flu, that when I took her to the sick bay.”

From these words, it is clear that the majority of participants never thought of a life-threatening disease. They believed that they could use home medication, remedies and massages to relieve pain. These actions delayed professional care at a clinic or hospital and may have continued if the child’s condition did not deteriorate. Another participant opted for prayers instead of seeking medical help. Apparently, a doctor explained the severity of this condition and that prompted her to seek medical care in Zimbabwe and later in South Africa.

Participant two (2) told the researcher that the child’s ill health was seen as normal growth of the child, and as a result, symptoms were never taken seriously. This is very common in remote rural areas, where it is believed that weight loss is a sign of growing up. This finding is strongly supported by Tjale and Villiers (2004:147) who affirm that in Black African societies, sickness is interpreted in a unique way. Common beliefs misled this participant and symptoms of cancer were not identified. As indicated by participant seven, her first reaction was to take the child to church and she relates what happened as follows:

“... at church they did another traditional thing because they thought is a certain pain, then blood came and never stops, I remember they tried to place another herb on the wound to stop bleeding but the blood was just running, none stop.”

Mbiti (2015:15); Koenig et al., (2012), confirm this and elaborate that religion may give people a sense of belonging and security, and may become their main source

of strength when faced with illness. The study shows that in desperation and helplessness, the participants of this study took random actions to help the sick child. It became clear that their decisions lacked insight in the warning signs of childhood cancer. Even those who could define cancer, only became more knowledgeable of the condition whilst they were in the hospital with the children.

A similar study about women with cancer showed that women with higher education levels were diagnosed at earlier stages of cancer than those with lower educational levels (Mathew & Rajan, 2008:706). In the course of this study, it became clear that children were more vulnerable where participants relied on home remedies to relieve pain and where no sense of urgency existed when they were faced with life-threatening diseases, resulting in late diagnosis of cancer.

Sub-theme 1.4: Information gained from healthcare professionals regarding the sick child at local healthcare facilities

Information gained when participants consulted healthcare providers when children's illness persisted, is an important sub-theme. Different views expressed by the participants are reflected below:

Participant nine: "The first doctor was very friendly, he detected the mass but he said it may be malignant or non-malignant, he referred us to scan that detected the mass."

Participant five: "At my hospital they say, when they check the blood of my son, the blood, red cells and white cells are low so they transferred us here, the doctor sent us to Steve Biko."

Participant four: "I went to the doctor, he was a good doctor, he was able to tell me to be strong and so that I can face the world now, it's time to face the world. He said my child is going to live for a month. Even at Tembisa only one month for him to live, I must arrange the papers fast so that he can be transferred that's why they didn't delay, they say it's a dangerous cancer."

Participant ten: "It's just a flu, I will make an operation to check what is the cause of this" and the child will be referred to Steve Biko."

Participant three: "... the first doctor I saw I ask him, is it possible for the small child to have cancer? he said no."

Participant two: "Many (referring to consultations), the first one we come to Steve Biko, that other side, they did X Rays they measure how big it is and they said I must come back after a week until they admit him for operation, the they said they will take biopsy."

Participant seven: “Yes, they told me what they were seeing no blood so they will send us to Pretoria there are specialists, remember told you that they were two choices whether going to Charlotte Maxeke.”

Participant eight: “It was October, the doctor told me that the child has tonsils and then get me a referral to the hospital, he said they will take those things out, when I arrive there they gave us antibiotics and painkillers only and they said they will book her for biopsy so that they can see the problem.”

The above quotes show different views about the information that healthcare professionals gave when children were taken to local healthcare centres. Participants three, eight and ten indicated that the healthcare professionals they consulted had limited knowledge about cancer’s early warning signs. Siegel, De Santis, Virgo, Stein et al. (2012), confirm that oncology specialists are difficult to find and some doctors at lower level facilities may have limited knowledge. However, the majority of the participants indicated that healthcare professionals easily referred them when children showed symptoms like anaemia, some hinted at the possibility of cancer and showed willingness to obtain a second opinion at the Steve Biko Academic Hospital. The Guide for Early Childhood Cancer (2010:187), strongly agree that these healthcare professionals were knowledgeable about possible early warning signs.

The study indicates challenges in terms of knowledge about childhood cancer where healthcare professionals and participants are concerned. Many people would wonder, how long the healthcare professionals **take** to treat the child at primary healthcare level and refer to Steve Biko Hospital as well, as how long the participants takes to treat the child at home. This finding is corroborated by McIntyre (2010:14) who suggests that approximately eighty percent of Africa's population relies on traditional medicine for their basic health needs. However, herbs regarded as reliable medicine by some healthcare professionals presented a serious shortcoming in the successful treatment of cancer. The researcher concludes that two factors played a role in the high mortality rate of paediatric cancer patients, namely, that children are taken to local healthcare centres too late and that some medical or healthcare professionals delay the diagnosis of cancer.

Sub-theme 1.5: First knew that child has cancer

The majority of the participants mentioned that they only learned that their children have cancer at Steve Biko Academic Hospital. Only three participants had children diagnosed at their local hospitals, however, these diagnoses were still to be confirmed at Steve Biko. The participants presented the following views:

Participant eight: “They told me on Friday, it was Friday at Witbank but they wanted to confirm it at Steve Biko.”

Participant five: “Prof told me my son has cancer but he will make other tests to see whether the cancer is on the brain or what, so after that, they didn’t not come back to tell me, I ask the doctor at the clinic here, so the doctor told me its blood cancer.”

Participant four: “At Tembisa hospital.”

Participant six: “No I just learn here at Steve Biko.”

Participant one: “It was here (referring to Steve Biko Academic Hospital), they took me to 1.1 (ward) they did not tell me what’s going on at 1.1, when time goes by I ask one sister, I can’t remember her name, she told me they did not tell you that this ward is ward of cancer, I went to the toilet and ask God why, first it was me now my child. ... I was very stressed until they made group us and cough out and I become fine.”

Participant seven: “The day I came to Pretoria, and that time I did not believe it was a shock about what I was hearing that day, that your son has a cancer but since you are you are going to Pretoria, the doctors will also do the tests to confirm and then they will explain what it is.”

Participant six: “I cried a lot, at Kalafong, what happen is that they examine him, they took blood and then he went for an X-ray, after taking his blood they say his blood is very low, for the kids at his age it should be 13 and above but he is at 6 so they say he might have sickle cell anaemia where cell are not hard they are sort of right angle the cells that forming in his body so I ask is it a manageable condition, when I went out of the room I went to Google and I typed sickling cell anaemia and then they explained they say sometimes it can be related to cancer but I was scared because the doctors never confirmed anything about cancer.”

Participant three: “It’s when I went to MRI at Steve Biko, the doctor told me that she has got cancer.”

Participant two: “Here at Steve Biko and send me to this ward (referring to paediatric oncology) after operation.”

These comments confirm that children were diagnosed with cancer at Steve Biko Academic Hospital. Doctors at other facilities may have suspected cancer, but could

not confirm it until a conclusive diagnosis was made at a tertiary level hospital. Participants indicated how and who presented the diagnosis for the very first time. Research studies support this and affirm that healthcare professionals in primary and secondary levels of care with limited skills and knowledge of childhood cancer may fail to diagnose cancer in its early stages (Francis, Battle-Fisher, Liverpool, Hipple, Mosavel, Soogun and Mofammere, (2011) and Vasuthevan & Mthembu (2013:5).

In addition, Siegel, De Santis, Virgo, Stein et al. (2012), also support this finding confirming that oncology care is only administered at tertiary healthcare institutions. This means that at the primary and secondary levels of healthcare paediatric oncologists are rarely, if ever, available. This study confirms that children were diagnosed with and treated for cancer at a tertiary institution.

Sub-theme 1.6: History of cancer in the family

Sometimes, people may learn about illness by experiencing it in the family. The participants of this study were asked about a history of cancer in their families in order to establish any previous experience with this disease. Participants responded as follows:

Participant one: “No we don’t have.”

Participant four: “... my aunt, she has a breast cancer, the breast was this big (pointing the breast) and it was heavy painful, I think maybe it is cancer I was not sure but to my son didn’t have any clue because I didn’t know that there’s cancer for children, the cancer I know is brain, breast and leg cancer that’s all.”

Participant nine: “... yes, I was aware.”

Participant one: “No. my child is the first one.”

Participant six: “I would say yes before my mom passed away she had a lump in the breast, when they took her for the X-ray, they say might be a possibility of breast cancer, every time she went for check-ups, so she passed away. “I remember when I was in great 8, I had a friend of mine passed away because of blood cancer I remember the first day that we come here I was so scare, crying I thought that my child is gonna die and then what if this chemotherapy does not help and all that we know that when people explain they say there’s no cure.”

Participant seven: “No, I never see someone with cancer before, I just hear people say this person has cancer.”

Participant five: “... mhhh yha, his late father has liver cancer, he died in 2011.”

Participant eight, three, ten and two: “No we don’t have it.”

The quotes confirm that the majority of participants had no history of cancer in their families. Some, as a result, could not think of previous experience related to cancer. The researcher inferred that whether family history of cancer could be traced or not, participants had little or no knowledge of childhood cancer and would at no stage have suspected the possibility of cancer. Even where cancer was not conclusively diagnosed, but a family history of cancer had been established, participants chose denial and bargaining, as they had no insight into childhood cancer. Only participants four, five and six confirmed that relatives may have had cancer because some had lumps and pains in their breasts, or cancer of the liver. Participant nine revealed that she is a cancer survivor.

These findings suggest that even as these participants had experience or a family history of cancer, it never occurred to them that childhood cancer exists. The following response expressed by participant five confirms this: *“to my son didn’t have any clue (relating to cancer).”* Other participant said: *“I did not know that there’s cancer for children.”*

The comments in the previous paragraph came from participants who had cancer in their families. These findings are contrary to those of Spinetta et al., (2009:905-907). They state that family caregivers who have never been exposed to or never had a history of cancer in their families may be confused about the condition. However, in this study even those with suspicions of cancer were clueless and confused when faced with childhood cancer. Only participant nine in this study was aware of this condition. She survived breast cancer and had a bilateral operation of the breast. Her response was: *“I don’t believe that my child has cancer, it may be something abnormal.”*

This quote confirmed that even those participants, who have personal experience of cancer, would either deny or be confused when cancer is diagnosed in their children. They have no understanding of the early warning signs of childhood cancer. The researcher observed that participant nine experienced denial and was in the bargaining phase of loss. Doka, (2013:74) affirm that caregivers may be prone to bargaining, and describes this phase as a “feeling that by omitting or committing certain actions, one can avoid or forestall further illness or death.”

Vasuthevan and Mthembu, (2013:7) and Porterfield and McBride (2007:327), exclusively points at education as a factor vital in achieving and maintaining optimal health. The study findings clearly indicate that the majority of participants had no history of cancer in their families and that they did not have any insight into early warning signs of childhood cancer. It also became clear that even those with knowledge about cancer, did not have knowledge about childhood cancer. The lack of understanding of childhood cancer was a hindering factor in accessing healthcare and links with the health belief model's idea of social cognition and reasons why people delay access to healthcare. People are motivated to take action when they understand the benefit of health action. Lack of insight is a barrier and impacts negatively on access to health services.

3.9.2.2 Theme 2: Access to healthcare

This theme focuses on the availability of healthcare facilities in rural areas and distances or time it took participants to reach them. The time it takes ambulances to arrive, road accessibility and alternatives are also investigated. Seven sub-themes are derived from the main theme and are presented as follows:

Sub-theme 2.1: Distance to local clinic and hospital

The distance to healthcare centres may influence early consultation when children became ill. Three participants stated how strenuous it was to reach the local hospital and clinic. They said the following:

Participant one: "It is very far (referring to clinic), it is three-hour drive and there's lot of traffic, its hectic especially in the morning. The roads are tied."

Participant five: "Home to the clinic or local hospital I think it's 40 to 50 kilometres away not sure."

Participant three: "... it is very far, for instance I spend R50 to go to the hospital."

The above quotes indicate that some participants were very far from primary healthcare facilities. The distance these participants travelled just to have access a clinic is quite astonishing. Participant one commented on the cost of travelling great distances to the clinic. She reported that roads were good, but the journey very long. Van Rensburg, (2012:635) shows concern about these distances, and he believes that traditional healers may be the only option as they function within the

communities where participants reside. However, some participants close to healthcare facilities said the following:

Participant seven: “The clinic is near; even the hospital is also near.”

Participant six: “Less than a KM to the clinic, we walk, less than 3 minutes.”

Participant ten: “... it is a walking distance.”

Participant eight: “... am talking about the clinic, it does not take me too long, even the hospital is not far. When going to the clinic I can go there with foot but the hospital I have to take a taxi but it's not that far, the taxi fare is not much.”

Participant nine: “Am not far from clinic, it may take 30-45 minutes if am driving.”

Participant two: “... there's no distance but these short distances are too costly, for instance I pay R30 per day and when coming here you carry food, it can take up too R100 per day, so if you are self-employed like that it means all of your profit for one day you are using for that kid, what about other kids, what about rentals, it's just too much.”

Participant four: “... yhaa it is easy, if no traffic no problem.”

The above quotes show that some participants had the opportunity to consult healthcare centres, but their concern remained the time and costs associated with travelling to those facilities. The findings pose a challenge to those participants who live very far from healthcare centres. Van Rensburg, (2012:635) confirms that they consult the closest available healthcare providers. In most cases, traditional healers become their only option. The study shows that traditional healers were visible in communities and easily accessible. Participant two and three hinted that taxi fares were expensive, even if the distance was short. Participant two confirmed that taxis were costly.

Findings indicate that the majority of the participants were dependent on public transport. This means that socio-economic circumstances affected the decision to go to the hospital or clinic. This predicts challenges in terms of financial status and inaccessibility of local healthcare centres. The researcher concludes that participants very far from healthcare facilities were prone to delay access to healthcare, due to financial problems. The majority of participants experienced easy access to healthcare centres, but commented that taxi fares posed a financial challenge. It becomes clear that sick children are vulnerable because of the existence of these barriers delaying participants to access healthcare.

Sub-theme 2.2: Transport, easy access to emergency services and road accessibility

Participants were asked about their experience to obtain emergency services when their children became ill, to get transport to the clinic or local hospital, as well, as how accessible the roads were for transport to reach them. Seven out of ten (70%) participants mentioned that transport to the centres was never a problem, as roads are tarred or gravel roads in good condition. In fact, road accessibility was never a problem for the majority of the participants. The ambulance could also reach their homes, but the issue identified was that of the time it took the ambulance to arrive. Significant comments made by participants are reflected below:

Participant seven: “To hospital, yes there is always a transport to the town, but the clinics are 24 hours and all the roads are perfect.”

Participant nine: “we call the ambulance; we also got an emergence in the area we just call.”

Participant two: “Everything is near, good roads, everything is fine.”

Participant eight: “... it is easy (referring to roads), that gravel road is not too long, yes. It (transport) is a problem because for example we were at Witbank Hospital, my child was supposed to be here on Saturday on Friday but we did not manage to come on Friday, we come in here on Saturday because they were complaining about the shortage of transport, they don't have enough transport to bring us here.”

Participant ten: “It is very easy taxes can come to our area.”

Participant five: “It takes too long because they say right now we have a problem with the ambulance, wait maybe three or four hours. Sometimes when we call ambulance, they say we must take the person to the main road, because that place is not a location, its village, the roads are not okay, so it's difficult for the ambulance to come near the house, you must take that person, maybe we must carry that person with the wheelbarrow or whatever, we can take him on the back.”

Participant three: “... it delays (referring to ambulance) you have to hire people with car.”

Participant six: “... the ambulance takes time to come, sometimes you can wait more than 2 hours mhhh.”

Participant nine complimented on how developed was the place where she stays, she said: “Within the environment, there's a sick bay, helipad, actually staying next to the airport of the Air force.”

The above quotes indicate that only participant five mentioned difficult circumstances to access healthcare centres due to no roads. She had to devise other modes like a wheelbarrow to take the child to the main road in order to get transport to the hospital. This participant experienced immense problems with transport, road accessibility and the distance to the main road.

In situations like these, participants may take longer before they visit healthcare centres due to the financial strain paying for transport for a sick child. Hanna and Kangolle, (2010:11) support the findings and state that for poor people traveling costs may exhaust any financial reserves even before starting oncology treatment. Participants faced with these challenges are more likely to contribute to the late diagnosis of advanced stages of cancer in their children.

Emergency services for and a lack of ambulances in certain areas posed a challenge, with the ambulance arriving late or not at all. Numerous participants reported frustration with the lack of emergency services, and waiting for an ambulance for hours. At local community hospitals, there was no emergency services in place. This study identifies these factors as barriers playing a role in delaying access to healthcare and impacting upon finances where transport to local hospitals were expensive. While these challenges were reported by some participants, others indicated that no accessibility issues at the clinic or hospital was experienced. They were within walking distance, the roads were perfect and they had their own private vehicles. The researcher believes that participants residing far from healthcare facilities, having poor socio-economic statuses and poor infrastructure, were those who faced the greatest challenges to cope with ill health of their children.

Sub-theme 2.3: Access to traditional healers in the community

Participants were asked to share their experiences where traditional healers in their communities were visited. Their responses were as follows:

Participant eight: "There are so many."

Participant five: "No I don't believe at traditional doctors I believe, first of all I took him to the church before I took him to the hospital, we pray after that I the priest told me I must go to the clinic, he says you can go, so I go, I don't trust the witch doctor."

Participant one: “I do not know them ... but there’s a lot of them, I can see them.”

Participant seven: “They do have, many of them.”

Participant six: “Their quiet a lot, especially those coming from Zimbabwe.”

Participant ten: “There is too much of that.”

Participant three: “Not where am staying, on the old side, there are a, lot.”

The above quotes indicate that in the community where participants reside, traditional healers are available and easily accessible. This may imply that if these participants believed in traditional medicine, they would have had the opportunity to consult them. Van Rensburg (2012:635), is of the opinion that beliefs and attitudes influence people’s choices about healthcare and that participants who had access to the services of traditional healers may have been tempted to consult them.

However, not all people believe in traditional healers, but in this study participants were aware that in their communities they do have these kinds of health service providers. Participant six (6) indicated that traditional healers are more visible in communities, specifically those coming from neighbouring countries. Only participant two and four indicated that they did not know of any traditional healers in their communities, but these participants were from Mozambique and Zimbabwe. Access to traditional healers seems to be influenced by the belief system, as participant five indicated that the availability of traditional healers means nothing when people do not believe in them.

The researcher concludes that traditional healers are part of the healthcare system; however, it depends on a person’s belief which medicine to trust. Literature studies reveal that about 70% of people in Africa believe in this kind of medicine. Koenig et al., (2012), believe that when faced with disease, disability, and death, it is common that caregivers would be vulnerable and that any available services may be consulted. The findings indicated that participants in this study did not consult traditional healers.

Sub-theme 2.4: Access to clinic, hospital and oncology care

In this sub-theme, members were asked what kinds of healthcare facilities they have in their communities. The majority (nine out of ten participants or 90%) said that they have clinics and hospitals although for some those facilities were too far away. From these participants, none mentioned oncology care, only one participant

originally from Angola, currently working and staying at SANDF in Pretoria, indicated that she was not far from the clinic and oncology care; some 30-45 minutes away. The researcher probed further to find out what kind of services participants received in those hospitals. They were asked to respond in this regard and participant eight expressed in detail about the problems she was faced at the health facility she visited:

“They told me that there have shortage of equipment, and they don’t have specialist for cancer, there’s no oncologist, that’s why am here” (meaning Steve Biko Academic hospital).

This participant’s child was treated in South Africa, as there were none available in Zimbabwe. McIntyre (2010:14) confirms that the public sector is not always capacitated with resources and that it is overcrowded. Therefore, children would be presented to a tertiary healthcare system when illness persisted.

Participant nine was referred to Steve Biko Academic Hospital due to the fact that she was very close to all hospitals from primary to tertiary levels:

“At 1 Military Hospital, preliminary they were not sure whether its cancer or what, for her being a child, they told us that the best paediatric oncologists are at Steve Biko, if they can refer to Steve Biko where there’s paediatric oncology.”

This participant was in the fortunate position that she could access all the hospitals easily because of her geographical proximity to specialists. Participants six and four learned that Tembisa and Kalafong Hospitals do not treat cancer, however they could not walk into Steve Biko Academic Hospital without a referral:

“No it’s only at Steve Biko because at first it was at Kalafong and they move us to here” (referring to Steve Biko Academic hospital)

“No they think it’s a cancer, so ‘we cannot treat the cancer because we can’t.’”

These responses confirmed that local clinics and hospitals in their vicinities did not provide oncology care, only the tertiary level hospitals did. In this study, only one participant lived very close to Steve Biko Paediatric Oncology Care Centre in Pretoria. Siegel et al. (2012), and Peters, Garg, Bloom, Walker, Brieger, and Hafizur-Rahman (2008), confirm that oncology care is only available at tertiary level,

these researches are sympathetic to the fact that and find that there is no paediatric oncology services in primary and secondary level hospitals.

The issue of accessibility can be linked to the health belief model that indicate practical problems and concerns that limit the success of various public health programmes. The existence of these barriers limited caregivers to access healthcare for their children. These factors contributed to the fact that participants rather resorted to home remedies. Therefore, children were vulnerable due to delays in the diagnosis and treatment of cancer.

3.9.2.3 Theme 3: Religion, spirituality and culture

The way people perceive health, their cultural values and perception of childhood cancer may influence their choice of treatment (Saca-Hazboun & Glennon, 2011:281). Seeking treatment can be influenced by how people perceive health, cultural values attached to ill health and how the participants' viewed childhood cancer (Saca-Hazboun & Glennon, 2011:281).

This theme explores religion, spirituality, and culture of the participants. It is divided into five sub-themes and includes religion and change in belief since diagnosis, church attendance before and after diagnosis, cultural rituals in the family before and during treatment and beliefs about disease and the use of traditional medicine (*muthis* or *mbizas*) and beliefs in Westernised treatment and hospitals.

Sub-theme 3.1: Religion and change in belief since diagnosis

This sub-theme reflects how participants relate to changes in their religion and belief when faced with the diagnosis of cancer. The following prominent responses were recorded:

Participant one: "Yes there was a change in my belief, since my child come to the hospital I just teach myself to pray in the morning at night when I sleep the thing that I was not doing."

Participant five: "... emmmmh most of the time, I just get inside the house and pray for my son to get better, and then I tell God that my son will not have that cancer."

Participant ten: "I am worried, this situation made me to pray day and night to ask God to heal my son. My belief in God has increased and is very high."

Participant six: "... yes there are because he has to get his treatment, I can't just say no he is going to be healed by the blood of Jesus until the doctors says he is fine now he can then I have to go along from what the doctors"

Participant four: "Yhooo, since I find out I am struggling to pray sometimes I feel like thing is too much to me, its heavy, if is fine playing am fine when he starts with temperatures what ... what, vomiting, diarrhoea I start to worry again."

Participant eight: "It didn't change, you know sometimes in life we don't have to lose hope so fast because sometimes the Lord want to test your belief, want to see how so I haven't lose hope for now, everything it still gonna be ok."

The above quotes show that all the participants embraced Christianity. However, the diagnosis of cancer challenged their normal practices of religion. Participants one, two, five and ten indicated that their children's diagnosis strengthened their spirituality and religious practices. Participant eight indicated that the ill health of the child was just a test from God and that **she** still believed that God will not forsake them.

On the other hand, participant four indicated that she had difficulty connecting with her God as found it almost impossible to pray. Nonetheless, participant six revealed that she changed from believing exclusively in religion, to trusting healthcare professionals, particularly doctors, as well. Van Niekerk, (2012) confirms this finding and agrees that faith has a strong influence on caregivers' responses to health issues. Ross, (2014) affirms these findings and states that participants may ask themselves repeatedly why their children were diagnosed with cancer or why God would allow this kind of struggle. Participant seven, as an example, started to doubt the practices in church and strongly mistrusted the current Priests:

"Since I find out I am struggling to pray sometimes I feel like thing is too much to me, its heavy honestly, there was time where I was doubting that, it is maybe that old church, because Priests are coming and going, maybe this new generation is not performing the same way as the old ones, that is why sometimes they tell me things that I cannot see them coming like before, sometimes I have some doubts."

While some participants may have faced a crisis in faith, participant eight confirmed her unshaken belief in God and saw cancer as a test of faith:

“... spiritually, sometimes I have a problem when I pray, my problems ended up being solved.”

Participant nine affirmed her Christian beliefs and indicated that her church formed part of her support system:

“I have a group that I belong to, whenever I have a challenge I contact the group around me, we join hand in prayer and we communicate and that challenge fade away.”

She claimed, “... my religion remains the same.”

The study's findings show that faith often intensified since their children were diagnosed with cancer. Religious practices like prayer and support from the Christian community became important factors providing comfort and courage in times of pain and adversity. Cobb, Puchalski, and Rumbold, (2012:8) state that Christians' may believe in miracles and that their perception of the omnipotence of God strengthens their faith.

Findings also revealed that some participants started to doubt their faith in the face of adversity. The researcher believes that the findings of this study clearly indicate drastic changes in participants' religious beliefs; in some cases, their faith was strengthened and in others weakened. Although some participants bargained later, their faith seemed to be ultimately revived.

Sub-theme 3.2: Church attendance before and after diagnosis

This sub-theme focuses on church attendance of participants before and after children diagnosed with cancer. The views of the participants are reflected below:

Participant eight: “Now, I am no longer going to my church, I didn't see it here, I go when am home, I don't attend any church now.”

This participant found no church in Pretoria sharing her beliefs and preferred not to attend any gatherings in the city.

Work commitment and responsibilities associated with prolonged hospitalisation of a sick child made church attendance impossible for some participants. They shared their opinions as follows:

Participant six: “It’s long time since I went to church because I am working on Sundays and last time we were short staff, it was very difficult for us to get day offs, you will find that we work 7 days a week and get one day off.”

Participant three: “I didn’t have much time to attend now because I am here (referring to hospital) but before I was attending but am fine.”

Participant ten: “The different is, now I stay longer in the hospital, when I am at home every Wednesday the pastors and other women we fellowship.”

Participant four: “Now is not the way I used to go to church, because was going Monday to Friday and Sunday, am always here, most of the time they teach us thing during the week, Sunday it’s only a service.”

These quotes show that the ill health of children isolated these participants from social support structures such as the church. The researcher believes that these participants’ faith and spirituality were challenged as they missed meaningful interaction with and spiritual support by church members and leaders. However, two participants revealed that church attendance improved:

Participant two: “You know what, they are good, they support you, because myself I see neighbours, church members are better than relatives, they give you power, you share with them, we pray for success of medical treatment. They support you more. It has improved (referring to church attendance) as compared to before, as human being, you can think too much but if you have support spiritually, your level remains high.”

Participant one: “I am going to the church now, if am not here (referring to hospital) I do not want to lie I am going there.”

Participant seven referred her church attendance as dropped informed by the fact that she had to follow some certain rules in order to attend church. She belongs to Z.C.C church, she said: “Now I am too scared, like in my church there are some rules if you are in a certain stage, you cannot come to church, you cannot use church things, so since my child get sick, I never go to church.”

The researcher believes that participant seven was alienated from her church because of certain purity laws associated with Z.C.C. practices.

Participant five did not experience dramatic changes in church attendance since her child’s hospitalisation, at the time of the interview, had been relatively short. She remarked:

“I go to church with him, because he like church, sing and also attending the Sunday school, I told him I’ll buy you church uniform, that one is brown, white and shoes, I say will buy for you my son because I can see you love church.”

The study shows that church attendance of certain participants was affected by unavoidable circumstances, specifically long hospitalisation. Significant impact on spiritual support and coping mechanisms were reported by participants since long hospitalisation made regular church attendance very difficult. Despite this, it became clear from the comments of participants that their spirituality and faith generally improved.

Sub-theme 3.3: Cultural rituals in the family during illness or treatment

It is common for African people to perform certain rituals to communicate with deceased family members or ancestral spirits, requesting their intervention during illness. Van Dyk (2008:202) and Truter (2007), state that ancestor worship plays a dominant role in the lives of many African people because ancestral spirits constitute part of the structure of African religion.

Participants in this study claimed that they do not do or believe in rituals, as some of the responses reflected:

Participant three: “I believe in God no other things, I don’t do other things.”

Participant ten: “We don’t do or belief in any other than believing in God.”

Participant six: “Not in my family.”

Participant nine: “... our perception is that let’s take a look on what kind of cancer is this and google to find what are the causes of cancer, what kinds of food that may contribute to cancer and try to minimise and also believing in God.”

Two participants had partners who believed in ancestral spirits and performed cultural rituals. The comments below reflect these participants’ views on the subject:

Participant seven: “That one is the only challenge I heard from the father of the child’s side, but in my side, I grew up parents showing me one way to live, they are Zions since I was born, so the only thing they do is to go to the church and report to the church, they will come and pray, so to the child father’s side they do something that we do not believe on.”

Participant eight: “I think I will talk about my husband’s side they believe in those things. You won’t tell someone what not to do in his place but what I do when they do such things I don’t go there. She has to go. They didn’t say about their

belief, they said I should pray. They didn't do anything they just told me to pray, they didn't talk about their rituals.”

Participant seven (7) indicated that the parents of the sick child often differ in their opinions about cultural practices. The mother may sometimes participate in rituals against her will or belief system when she is desperate for healing her child. The fact that participant seven (7) was not married to the father, made it easier for her to refuse participation in rituals. Participant eight (8) mentioned that because they were not living with the elders of the paternal family who believes in cultural practices, she could convince her husband to not participate in traditional healing rituals without much interference from his family's side.

The researcher observed resistance and criticism against cultural rituals where participants were Christian. Syed et al., (2015) comment that proponents of ancestor worship are against non-believers professing that illness in children may be a direct consequence of their lack of faith in the spirits.

In this study, only participant one participated in cultural practices and said:

“In my family like now its December time we have to buy goat just thanks the ones who slept long time ago thing like that ... we don't cut (referring to cutting face) but wear animal skin only.”

This participant expressed her confidence in her family's cultural rituals, and said that her son participated in these family activities but refrained from eating meat because he developed an allergy for it. This participant said that since the child became ill, hospitals were regularly visited while healing rituals were performed.

The researcher identified a well-known phenomenon in traditional families, namely that the blame for an undesirable situation in that family is often placed on the woman who married into that family. The comments made by a participant illustrate this clearly:

Participant two uttered different view from that of other participants, she revealed: “You know what, relatives and family can put you down, but church members can support you, why because in families they are different types of problems, this type of illness some people they say it's a genetic, its coming long back, the uncles may be had it, some they say mother has a problem, in our

culture we don't have this, may be its coming from your family or from your mother. Relatives talk too much."

Findings indicate that the majority of participants in this study did not believe in cultural practices since they were of the Christian faith. In certain participants' relationships, parents did not share a common faith and in one instance decision-making was based on the marital status of the parents. This means that the mother's side of the family made decisions about healthcare for the sick child. The researcher concludes that as much as the participants of this study were Black Africans, they seem to be liberated in terms of religion and the majority were Christians who did not believe in cultural practices. Few participants believed in cultural practices.

Sub-theme 3.4: Beliefs about disease – traditional medicine-Muthis/Mbizas used

Saca-Hazboun and Glennon, (2011:281) understand that people perceive and interpret ill health differently. According to Van Dyk (2008:202); Truter (2007); Porterfield and McBride (2007:327); Van Rensburg (2012:635) and Kingsley and Bandolin (2010), various factors and behaviours contribute to these views, amongst others knowledge about health issues, experiences, lifestyles, religions and culture. The participants in this study expressed different perceptions of illness: Significant views are reflected below:

Participant Six: "Sometimes I feel like it's a sort of black magic. ... as Christian we believe that diseases are not coming from God are they are created in the underworld. I know about Muthi's when your child is diagnosed with cancer he has a weak immune system where he can just get infected, sometimes when they make Muthis they make them out of stuff that you don't even know, the baby just drinks he is gonna get sick and most of the time traditional healers does not use clean places or sterilised things."

Participant four: "I think it's a eishhhhh ... hayi (meaning no in English) I don't believe someone did this, I just think is like a flu to me because he is always sick with different diseases so that's why I accept."

Participant eight: "I don't know but this witchcraft thing sometimes confuses us, let me say I take my child to ... the Sangoma will tell the neighbour did this, your grandmother did that, that thing brings confusion to us, so I ..."

Participant five: "On that time I was, I did not think it is cancer, I thought they bewitched my son but when time goes on its cancer because when I look at these children here, I see most of them they have that disease, I say I must accept."

Participant four: "God Knows."

Participant seven: "People are talking but it depends on how do you see that thing your belief and what you have experienced."

The above quotes present different beliefs of participants. The researcher found that where disease is present, participants tried to establish its origins and cause. Participants five, six and eight believed that the children's condition had to do with witchcraft. Participant six was of the opinion that disease originate in the underworld; as a result, she associated the child's condition with black magic. Participant four was numbed and confused by the child's condition.

All findings show desperation and ignorance about cancer where some participants, due to a lack of knowledge, will believe any explanation offered, true or false, for their children's condition.

The researcher found that children's ill health caused a lot of confusion to participants. They believed farfetched explanations about disease; some even consulted traditional healers, ultimately delaying proper healthcare.

Sub-theme 3.5: Beliefs in Western medicine and hospitals

This sub-theme explored beliefs of participants in Western treatment and hospitals, reflecting the following responses:

Participant six: "Yes I do because it's checked and it's been tested before I can be given to patients."

Participant four: "One day, sister Vera at Lodge she called me and ask me how am I coping, I said its difficult but am trying, she said do you know the disease I said yes, she asked what is it, I said rhabdosarcoma, she asked what do I know about that I said I don't know anything, she said there's a chance that the child can survive because its muscles its easy, once you treat, it's better to take 5 years to come than coming every month. I think he can survive, I started to be relieved."

Participant one: "... there are some people who can lie to you because of, before I brought my son to the hospital there were people saying that may be my child is bewitched, they were telling me many stories that is why I said only God knows why my son is like this and I won't take my son to any Sangoma or anywhere, I will just take him to the clinic."

Participant three: “Not that I believe, it’s because the tumor was growing, now it’s getting small, also side effects are not yet shown as they said.”

Participant five: “Right now, I believe it because I see changes because my son is eating, running and playing football. yes, because now I see the changes since he came.”

Participant ten: “Yes I do. It’s because my son’s stomach is very light now.”

Participant seven: “Yes, cause even if I’m the Christian, we doing half, half in the family, it depends which disease you are in, if you are just sick but you are strong you can go to the church and do church things but if that disease get worse and worse we have to consult the doctor and hear what the doctor say.”

Participant two: “It helps the kid, the only thing I want to know what is cancer, what causes, if I see sugar diabetes or hypertension I can see where it comes from but what exactly cancer is and is caused by what? If can see sugar diabetes I know, what causes this cancer? I have some questions, with my kids it started as a growth like pimple at first but that pimple grows and they say its cancer.” the challenge is that believing in this Western medication somehow confuses because, these kids the more they come for treatment they get sick. What is this, I don’t understand it. What is this cancer?”

Participant one: “I believe in Western, when I tell God that God please help me to do this I know he can do it. The only thing that I believe my child is going to be cured because I have seen that its better than the first time but now things has changed when they do those things I have to take my son away because in the first time they do that my child was 2 years, they just cut a goat, the following day he will develop things like he has burned I did know what was that. So since I came here I just put mind back that this thing was of long time I didn’t think that it can be cancer. When they do that I have to take him away and came back when they are finish he won’t eat anything.”

The quotes above show that participants believed in Western medicine in a way, specifically where it yielded positive results. Participant two believed in Western medicine, but also felt the need to get information about its nature, causes and treatment as reflected in her words: “... *what exactly cancer is and is caused by what?*” and “... *these kids the more they come for treatment they get sick. What is this, I don’t understand it.*”

Response such as these reflect that some participants are not familiar with Western treatment, such as possible chemotherapy. Other participants, for example participant six, believed in Western treatment because it is clinically tested and proven to help the patients. Upon learning about cancer, participant four was

assisted by family members to understand the treatment. She indicated that she was relieved that treatment could prolong the child's life.

Participants five (5) and three confessed that they initially did not believe in this treatment, but that the speedy recovery of the children made them trust in it. The quote by participant seven indicates that the child was diagnosed late, as this participant believed deeply in church practices, and took the child to a healthcare facility only when the condition worsened. The researcher strongly believes that the impact of these beliefs on cancer treatment is detrimental to the survival of children with cancer. This finding is supported by a study by Van Niekerk (2012), in 2010, where the Treatment Action Campaign (TAC) opposed the Christ Embassy Healing School, who claimed to heal people but caused their death. This church discouraged medical treatment and preached that faith alone could heal illness.

Participant three (3) indicated that the positive results from Western medicine made her believe in it. Participant four (4), who was told that her child was going to live for a month, started to trust treatment with Western medication when her child survived beyond the prognosis.

The study findings highlight that participants shared common beliefs in terms of Western medication. The majority strongly believed in Western medicine particularly when they observed speedy recovery. However, findings also indicate that Western medication may cause confusion, where treatment commenced and children would either improve or deteriorate. Participant two voiced her concerns and indicated that many of her questions remained unanswered. This clearly shows that education about the diagnosis and treatment of cancer is a necessity in South Africa.

The findings also indicate that some participants believed in Western medication as a second option when children became severely ill. Participant seven could attest to this and believed that both religion and Western medication should be taken into consideration during illness. The researcher concludes that participants believed in Western medication and hospitals, in conjunction with religious belief (prayers). The fact that Western medication is clinically proven convinced participants to trust it.

3.9.2.4 Theme 4: Communication and language

Communication is defined as the "... exchange of information, between individuals, for example by means of speaking, writing, or using a common system of signs and behaviors; a spoken or written message; act of communicating; rapport; a sense of mutual understanding and sympathy" (Schiavo, 2013). This theme is divided into four sub-themes that include the experience of communication with health professionals, language-difficulties in understanding, level of understanding of diagnosis when explained. Participants reflected their experiences regarding communicating with healthcare professionals. Below discussed:

Sub-themes 4.1: Experience of communication with health professionals

The majority felt that communicating with healthcare professionals was never a problem, the challenge was presented with medical terminology. However, doctors were willing to explain as the responses below indicate:

Participant one: "Communication with healthcare providers was never a problem; it was fine they teach me a lot."

Participant nine: "I find a bit difficult to understand medical terms but most of the time I ask the doctor for clarity. I now understand what is happening to my child."

Participant seven: "That happened in Polokwane, I was blank and when I was trying to ask, to know what is going on, I don't know some nurses felt like, I'm telling them what to do because I wanted to know what is going on and what is going to happen, and what you can see tell me as the nurse."

Participant six: "Would say they are nice and the first I was so lonely and in denial, they spoke with me and they told me that it's not their first time there are cures with cancer it does mean your child is going to die, they explain everything."

Participant five: "At my hospital, one of the nurse at the clinic she called me, when, the first time I went to the clinic with my son and transfer us to the hospital and then, they called me and said how is the boy, do you get help from hospital, I told them he doing well, now they transfer him to Pretoria, they said ok, its good he is gonna be okay."

Participant eight: "I once had that problem, I am still using treatment for epilepsy, I once had ... I wasn't there I was supposed to collect treatment on such a date I went there on the following week, they (referring to nurses) shouted at me but I didn't blame them because it was my fault."

The above quotes show that most participants were satisfied with the way healthcare professionals communicated with them; participants one, five and six

confirmed their understanding and sympathy. Sciava (2013) believes that these characteristics are crucial for successful communication. Participant nine experienced two-way communication and could ask doctors to explain medical terms.

Participant seven and eight found it difficult to communicate with nursing staff, and became frustrated since no information about the child's condition was given. According to participant, certain nurses had a negative attitude and participant eight reported that a nurse shouted at her because she missed the appointment date.

The observation was that it was a manner of approach. The two findings was contrary to the definition of communication as indicated by Schiava (2013). Due to this attitude of nurses' participant four opted to just "listen to what they are saying, am not arguing with them" to prevent any potential conflict. In a similar research study of parents of children diagnosed with cancer by to Pyke-Grimm, Stewart, Kelly and Degner (2006:356) these findings are supported and indicate that the parents expressed the importance of the physician keeping them informed, being approachable and available, being open to comments from the parents and actively seeking parents' opinions.

The researcher concludes that there is a need to improve the attitude of some healthcare professionals. A two-way communication is fundamental in healthcare systems. The most significant part was that there were those healthcare professionals willing to clarify what they were saying so that participants gained understanding about what was happening to their children, thus mutual understanding improved. As commented by Pyke-Grimm, Stewart, Kelly, and Degner, (2006:356), parents would like to be informed as they play a fundamental role in patient management. Communication assists both parents and health professionals to understand the children's condition and treatment plan. Communication creates a conducive environment where parents feel important and free to ask questions when they do not understand. The researcher emphasises that there is a need to improve the attitudes of some professionals and that English should not be the only language for communication; translation to other languages may also improve understanding.

Sub-theme 4.2: Language spoken

Language plays a pivotal part in understanding issues correctly, specifically in the Department of Paediatric Oncology as caregivers may become confused by medical jargons. The participants in this study revealed how they managed to understand healthcare professionals:

Participant ten: “I understand a little bit, if I want clarity on something if the doctor is white, I try to explain in a way and they understand, communication is not a problem, no It was never difficult because I do understand English, they explained everything.”

Participant two: “The language of cause, me I don’t know the medical language but you can speak other languages so it’s not more difficult.” “All over, usually the language of medical is difficult to a patient, you can’t hear what they are saying but if you ask what this is and that they can explain to you” (Meaning these medical terms are difficult, even in Zimbabwe is the same, people may experience the same problem).

Participant nine: “I find a bit difficult to understand medical terms but most of the time I ask the doctor for clarity. I now understand what is happening to my child.”

Participant six: “... no It was never difficult because I do understand English yhaa, they explained everything.”

Participant four: “To be honest I don’t know that because I don’t like to Google it hit me more, so I leave it like that.”

Participant one: “Yhaa I understand mmmmmh hhhh I do understand.” “It was well explained to me because even when they started chemotherapy I was there, I even had to leave the job because I was working I won’t send my granny. I want to see for myself, the first time they told me that my son has cancer, the just give me chemo I ask them what are giving, they said its chemo if this chemo will respond to this, it means your child has non lymphoma cancer. They try to explain non lymphoma.”

Participant eight: “Ehhhhhhhh (deep breath) I felt so bad (emotional) it was not easy to accept that my child has cancer. The doctor made it clear and used the language I could understand Zulu/Xhosa.

Participant three: “There was no problem.”

Participant five: “They spoke my language when they called me.”

Participant seven: “Sometimes I ask my neighbour who is a teacher to explain.”

The above quotes show that English was used as the mode of communication, however, when it comes to medical terms, participants needed more clarity so that they could understand the conditions of their children and treatment plans. In the

case of this study, the English language was never a problem, only medical terms needed to be simplified. Participant four (4) opted to ask for no information, because she did not want to frustrate herself. This finding is supported by CHOC parents' handbook (Visser, 2010:70) which states that parents may choose different approaches to understand information, either a selective approach or a watchful and wary approach. Participants five (5) and six (6) indicated that they never experienced a problem as the doctor could explain in the participants' language. This means that healthcare professionals understand that people are diverse as far as language is concerned and that English is not the only way of engaging.

Participant eight (8) indicated that although she did not understand the medical terms, she was confident that the doctors would simplify and explain the information. In addition, participant seven indicated that educated neighbours and family members assisted by explaining in her language about the child's condition. This finding is partially supported by research studies suggesting that linguistic diversity demands language access services (for example, a linguist or interpreter in healthcare services (Smith & Pietryk, 2008; Partida, 2007 and Dennill, Rendani-Mkosi & King, 2013:187).

The researcher concludes that clear communication is fundamental to enhancing participants understanding of children's conditions, as medical terms posed a serious problem. Children with cancer may receive the wrong treatment or do not comply with treatment because terms used may not convey the intended message to participants who may have no insight in medical jargon.

Sub-theme 4.3: Level of understanding of diagnosis when explained

This sub-theme focuses on the level of understanding of the diagnosis when explained to the participants. Significant views came from the participants:

Participant four: "No, they think it's a cancer, so we cannot treat the cancer because we can't" I say yes what next, I must go to Steve Biko, "I was not worried I thought maybe I thought it was not a big deal."

Participant nine: "I find a bit difficult to understand medical terms but most of the time I ask the doctor for clarity. I now understand what is happening to my child."

Participant seven: "I think I made peace with it, I accepted that my child has this disease."

Participant ten: “The doctor told me that my son has cancer, my heart was very painful, she said your son will be fine, she called the Social Worker, she said all these children in this ward has cancer, then I understood. I can say the doctor explained well and I got the counselling.”

Participant three: “The details were that the child will be fine, they will shrink the tumour to the smallest size.”

Participant two: “For that thing they took inside, the doctor come with results before operating the growth, they had to test what’s going on inside, this growth is going bigger every day, so they told us the results show cancer, for the first time it was tough, touches you but seeing other children even adults, I ask myself why Jesus bring this to my child has this cancer, it hurts me.”

Participant eight: “They called me to the office and sat me down, they told me that they tried all the best to help my child but the level she was at that time is not on their side they did that scanner and suspect that she has cancer.”

Participant one: “They just told me, because that time I was scared I didn’t understand ... I didn’t understand.”

Participant three become so selective in understanding, this participant could only remember that doctor sensitised of mixing medications and mentioned information about vaccination. This is what she said: “I mustn’t mix things like taking the traditional medicine mixing it with the treatment they will be giving in the hospital; they also said that I must stop the vaccines because it will interrupt the medication.”

Participant two indicated that she could listen to what the doctors were saying, it was difficult to internalize, she felt like running away because she heard that cancer is a bad disease. This is what she said: “... it was very difficult I went outside I relaxed I started to communicate with them. So later on, I saw that it’s not that difficult.”

The above shows that participants in the diagnosis phase could either listen to, or be selective of the information doctors provided. In some instances, conversations seemed one-way communication: only participant nine could ask questions for clarity. To participant seven, communication confirmed what has been bothering the child. Findings show that some participants could omit what they wanted to hear and leave the sickness part to the doctor. This finding is strongly supported by CHOC (2010:70), parents’ handbook which states that parents may choose the selective approach to prevent any situation that may expose them to potentially negative information. The researcher concludes that the majority of participants

could not understand from the onset of the children's condition due to mixed feelings experienced at the time.

Sub-theme 4.4: Understanding diagnosis and medical terms

This sub-theme focuses on other challenges participants experienced when trying to understand the healthcare professionals. Significant responses revealed the following:

Participant seven: "Yes that is where at least, because I even recorded her (referring to a doctor), I don't know to understand what is this because that was the only day they told me, you know what you have been here trying but your child has this, that is where I was surprised no ways, how come the whole week they have been taking my kid's blood and the whole month the doctor was also taking my child's blood, so how can you take blood now to the same lab and come to tell me my child has cancer, there is no way."

Participant four: "This time I was so surprised I never had about such name."

Participant six: "No it's not a problem because every time when you are in the ward the sister would come and ask what is the problem of the child and then right down when the doctor come he will tell you that I heard that your child has 123 and give medication and he will be ok."

Participant three: "Doctor says my child has a blood cancer, and I didn't know what they were talking about, they said your son will be treated and will get better."

Participant five and others questioned and showed concern about this cancer and how it is diagnosed eluded that the terms doctors use surprises and participant five never learned about such names, she said: "What is leukaemia." "The other thing I don't understand, because they say they will tell, the Professor said to my son has cancer, they will run some test, they will come to me to tell where is the cancer, it is from the head or what so I don't know where is it."

Participant ten: "Doctor in the clinic, she said to me, the cancer is in the blood he said, it's blood cancer what is it, she said it's Leukaemia, Whatever, what, what something like that."

Participant eight: "They didn't explain anything at Witbank they just told me that they are transferring us to Steve Biko just because my child has ... they suspect that she has cancer. At Steve Biko they told me that they are going to do test and she is going to the operation on Thursday so that they see the actual problem."

These quotes show that participants had no insight about childhood cancer and its diagnosis. It came as a shock to learn that children have cancer. Some participants

did not have any strength to engage due to mixed feelings. Another issue kept on concerning was that of the medical terms that make it even more confusing to other participants. Participant two emphasised that the usage of medical terms was problematic to many, because the patient could not understand these terms. However, participant six indicated that sometimes nurses in the ward will inform the doctors of a participant's difficulty in understanding the child's problem. He would later come and clarify. Participant seven managed to get information by recording the sessions. According to this participant, it helped to understand the disease.

Spinetta et al., (2009:905-907), strongly support these findings and confirm that medical jargons, threatening environment, and protocols that need to be adhered to, have an impact on caregivers who may not understand clearly, yet need to make a decision about treatment.

Despite the challenges other caregivers experienced, participant one indicated that the child's condition was explained in such a way that she was able to make an informed decision about caregiving. Klassen, Raina, Reineking, Dix, Pritchard and O'Donnell, (2007:808), confirm this finding and suggest that caregivers faced with unexpected adaptations and restructuring of responsibilities had to stop working and become a full-time caregiver.

These findings show that information about diagnosis confused most participants; even if the doctors explained, some participants did not understand. Participant eight had a typical lay understanding of medical terms and she, said that when the doctors explained the condition, the only thing she heard was that they were going to perform surgery in order to diagnose the problem. In her mind, she could imagine surgery, but she never asked for an explanation, only to find out later that the child was going for a biopsy. This clearly indicates that some participants were not confident enough to ask questions from healthcare professionals.

Participant six was confused by all the medical terms. She relied on nursing staff to obtain information from the doctors about the child's condition. The findings show that some participants would rather ask the nurses who will later connect them with doctors. The issue of medical terms remained challenging called 'big words' by participant seven. The study findings remain concentrated by the fact that

participants do not engage into two-way communication, this may be informed by the fact that participants may be threatened and confused by medical terms used. Lastly, the view voiced by participant eight sounded common. The researcher has been observing that people tend to be disorganised in such that it become difficult to understand whatever is discussed due to mixed emotions.

The researcher concludes that participants do not always understand doctors. As in most cases, their understanding is clouded by disturbing emotions (anger, frustration, disorganised, numb), because of loss and despair. Medical terms identified as a problem prohibited understanding the conditions of the children. The willingness of health professionals to explain more than once may assist the participants to gain a better understanding and learn to communicate openly with healthcare professionals. If English can be translated, two-way communication will be enhanced.

This can be linked to the health belief model where it becomes clear that people are encouraged to communicate only if they receive positive responses from health professionals. This means that if people see positive attitudes, friendliness and approachable health professionals, they may be more open. The use of laymen's or non-professional's terms will also make the health professionals seem more approachable.

3.9.2.5 Theme 5: Socio-economic status

This theme focuses on participants' economic and social positions, in other words how they make living and pay their medical bills. It consists of four sub-themes, namely: Employment status, source of income, housing and environment, and access to basic needs.

Sub-theme 5.1: Employment status

In this sub-theme, participants were asked to talk about the nature of employment. The following emerged:

Participant one: "I am unemployed. I live with social grants, I have two children and receive two social grant."

Participant seven: "No I'm unemployed for now."

Participant six: "I am employed as shop cashier assistance at clicks."

Participant nine: "I am an IT operator at SADF."

Participant three, four, five, eight: "No."

Participant ten: "I am not employed."

Participant two: "I have stopped working because of the kid, the first time he started sickness he needed more time and the father is working as such he is self-employed."

The above quotes indicate that most of the participants were unemployed. Only participants six and nine were employed. Peters, Garg, Bloom, Walker, Brieger & Hafizur-Rahman, (2008) strongly confirm these results and hint that late diagnosis will be a common phenomenon where the child with cancer may probably bring more strain and despair. Study results showing that only 20% of participants were employed, indicate that unemployment is a phenomenon that may affect the whole country. Despite the fact that legislation in South Africa protects the rights of children to receive health (Children Act. 38 of 2005; Bill of Rights, section 28), the issue of unemployment undermines the ability of caregivers to take prompt action. Some participants had to wait for social grants (child support grant of R380) to aid them.

The researcher believes that the issue of unemployment is a serious problem that affects the whole country. Having a sick child under these circumstances guarantees dysfunction. As indicated by Peter et al. (2008), unemployment was among the factors challenging participants to bring children to healthcare facilities. The following sub-theme indicate participants source of income.

Sub-theme 5.2: Source of income

In some families, access to healthcare is determined by the income. When a family earns very little or nothing, the main priority is buying food and healthcare becomes a luxury. Kingsley and Bandolin (2010) believes that late diagnosis is influenced by the fact that people find it difficult to take time off to visit doctors due to work, income loss and concerns about medical bills. Participants of this study were asked to share how they make a living; this is what they said:

Participant eight: "We survive from my husband salary."

Participant one: "I have two children and receive two social grants."

Participant five: "Not working but I'm selling vehicle tires, which is the source of income. It's not too much and from social grants."

Participant four: "His father provides for us he owns a salon."

Participant ten: “I survive, sometimes I have to do other people’s washing and I also receive Child Support grant of two children.”

Participant three: “My parents support me and child support grant of two children.”

Participant six: “I do have other sources of income; my sister gives me allowance for the kids, also Child support grant and also the father gives money.”

Participant two: “The father mostly sells on the street bananas so that we can eat.”

From the above quotes, it became clear that the majority of the participants were recipients of a child support grant. Other participants receive financial support from parents, husbands, and siblings. Participant five said that she was self-employed selling used car tyres and received a grant. Participants two and four reported that their husbands provide for them, one sold fruit on the street and another one owns a salon. Participant ten reported that she does domestic work and receives a child support grant for two children. Though participant six had a source of income, the means test used at the South African Social Security Agency (SASSA) allowed her to apply for a social grant. Participants two and four did not qualify for social grants, as they were not the citizens of South Africa. Vasuthevan and Mthembu (2013:6), indicate that participants living under such economic circumstances may become frustrated and children may become vulnerable as their health may be neglected. Mayosi and Benatar (2014) state that the government of South Africa attempts to fight poverty in the country by introducing social grants as a response to an unbearable situation where children were dying of hunger. As a result, those participants who were unemployed could put food on the table. Peters, Garg, Bloom, Walker, Brieger, and Hafizur-Rahman (2008) suggest that late diagnosis will be a common phenomenon in these families since a sick child may probably bring more stress and misery. The researcher believes that children living in desperate socioeconomic conditions are vulnerable to ill health.

Sub-theme 5.3: Housing and environment

Participants were asked about their housing environment. They had to describe their environments and also where and with whom they resided (family composition). The following responses were given:

Participant eight: “Own a house with three rooms, it’s me, my husband and my two daughters.”

Participant one: “No It is my house, it’s an RDP house, it’s me and my son, we used to stay with grandmother but now she has moved because I am here.”

Participant three: “I own, it’s a new stand, already built five rooms, two adults and two children.”

Participant five: “I am living in my own place, right now I have one room we are six, four children and two adults.”

Participant ten: “we own, it’s me, my husband and three children.”

The above quotes show that participants in this study own houses or rooms and some live with their families. Five out of ten participants indicated that they own houses, though others were still renovating and building the houses. One participant owned an RDP house. These participants believed in family cohesion. Participant five indicated that despite the limited space, her family of six lived in one room, finding solace in love and living together. There were those participants who still stay in their parents’ home. Participant six found it challenging to live in this multi-generational house, and said:

“Yesss ... because we are staying together as family. It’s not easy because I have my own kids and staying with family with no kids, you find that at the end of the month they don’t bother to contribute on the electricity, water and municipality bills. When you sit down and say I am not contributing, at the end of the month your kids are going to suffer, they don’t contribute on food, you still have to buy because you have kids.”

Albertyn (2009:65) and Jones and Watson (2012:216) partially support this quote and elaborate that the culture of these families may pose potential barriers in accessing healthcare due to diverse perceptions and beliefs pertaining to healthcare. Participants two and four rented and participant nine lived at her workplace. The researcher observed that only participants who came from other African countries rented housing. These findings show that 50% of the participants own their own homes. Some families were too big to be comfortably accommodated in one room.

The findings clearly indicate poverty. Participant one benefited from RDP housing to improve her living conditions. Peters, Garg, Bloom, Walker, Brieger and Hafizur-

Rahman, (2008), support this and affirm that poverty has a potential influence in prohibiting the family caregivers of paediatric oncology patients to access healthcare, as participants may have no means to urgently respond to health issues. The researcher believes that these kinds of settings may bring warmth and family cohesion, but may be unhealthy where a sick child is confined in an environment of a family living in one room. The researcher believes that serious questions need to be asked about the conditions in which some families live.

Sub-theme 5.4: Access to basic needs

People in South Africa are entitled to basic needs that include, water, electricity and sanitation. Participants of this study were asked about access to these needs. The following was reflected:

Participant three: "I own, it is new stand, there's no electricity no water but we stay."

Participant two: "Yes, that is not a problem."

Participant ten: "I have a tap in my yard, we have electricity and toilet outside."

Participant eight: "We do have water but outside, electricity and outside toilet."

Participant nine: "We have water, electricity everything is in place and good."

Participant one: "I have a tap in the yard and toilet inside as well as electricity."

Participant five: "Yes, we do have water, electricity, we make our own toilets regarding sanitation."

Participant Six: "We have water, sanitation, electricity mhhh"

Participant seven: "We have water, electricity but toilet outside flush."

Participant four: "We have water, electricity and toilet outside."

The quotes above show that only one participant (number three) did not have access to water and electricity due to the fact that her house was new and under construction. Because there was no electricity, she could not buy a fridge to keep food fresh and had to purchase food daily. All other participants had access to water and electricity. The challenged posed to the majority of participants was sanitation. Sixty percent (60%) of the participants had a toilet outside that could not be flushed. These outdoor toilets may create an environment for opportunist disease. Participants did not have the means to build indoor flush toilets because they were unemployed.

Only three participants had access to the very basic needs that include water, electricity and an inside flush toilet. Some participants were temporally renting in peri-urban areas, others in developed areas. The researcher concludes that participants had access to basic needs, but sanitation remains a problem. The phenomenon of unemployment affect participants and the researcher believes that children living under these circumstances are prone to health neglect, as parents' action would be focused on providing necessities for living.

Theme 6: Delayed access to healthcare

This theme focuses on factors that delayed participants to access healthcare and is divided into the following sub-themes: Healthcare providers' understanding of cancer, neglect of parents, traditional healers, time, and money and transport.

Sub-theme 6.1: Healthcare providers understanding of cancer

Participants expressed different views regarding healthcare providers' ability to diagnose and treat children with cancer at healthcare facilities. The following responses are significant:

Participant eight: "The doctor told me that the child has tonsils and then get me a referral to the hospital, he said they will take those things out, when I arrive there they gave us antibiotics and pain killers only and they said they will book her for biopsy so that they can see the problem. She was getting better for two days or three days, I took her back to the hospital up until the fourth time, they admitted us, they gave her treatment for TB then after that was when they were supposed to do that biopsy and they postponed for the following week up until the child was somehow. They just do the scanner only."

Participant five: "I took him to the clinic he was weak, they say its shortage of blood so they gave me paper and say you must go to the hospital now because the child did not have blood, when I arrived to the hospital the doctor take blood and make some test, malaria, HIV whatever and then they order a blood for him. If the doctor can't see anything from the child, or see something else, so he must take that patient to other hospital, so that they can do the tests so they can help that person fast."

Participant four: "... mhhhhh first of all I was living at Mozambique, at my husband house so, my son started to sick, I thought maybe it is something just ... I take him to a clinic, at the clinic, they gave me a medicine called Amoxyllin, so I gave him I think may be when he drinks that medicine can get better but it didn't work. I went there again, they gave me something, I change the hospital, I

went to KaHlalukana, they gave me something, I change the hospital , I go to its a city Shokwe, they gave me something, I went to home I called my mother, I decided to bring my son to my mother so my mother say yes, I called his father to take him, my mother take him to Tembisa Hospital, at Tembisa they say he has a low blood we must donate blood, so they manage to say they yes we can help, they say blood didn't match, we need his mother, I went there, I arrived early , they need me there so arrived early I managed to go there, when I get there they said no blood, they can't take the blood anymore we must take him to theatre, they did biopsy after that we can tell what's going on, after theatre he was at ICU because he was bleeding too much so they make arrangement for us to come here they say it's a cancer, its only month to leave, so I said ok I will send the papers, his father was there when they transfer them. That's why am here."

Participant one: "I went to Pretoria north clinic and they just take me to Steve Biko and they transfer me here because my child was very sick."

Participant seven: "Like to me, my son was fat and suddenly he started to lose weight but not sick, then I took him to the doctor wanted to know why my child is losing weight ,cause I'm used to my fatty son ,and I was not staying with him, so every time when I'm coming home can see him ,so at first I thought he is growing, when we are growing we no longer the same body, then I took him to the doctor he was not sick."

Participant six: " Ok the first time when my child was limping, we went to the chemistry we bought him medication for pains, he drink it and he was ok, as days went by he was sick he had a high fever, we took him to the clinic so they just gave medication and say we should come back after some time, so we went to the doctors again like where you pay when you are going to consult, they just gave us medication and say he is gonna be ok and then we told the doctor that he has gall stones somewhere here (showing the grown) they say its caused because of the issue that he is sick but with panado he is going be ok, we told them that he no longer walking they just say no he will be ok all that, I think we went to the doctor four times because every week we took him there as long the medication was finished but was not getting better. So this other day we took him to Lodium clinic we told the sister ... the sister say this child is teething so that's why he has high fever just continue with panado and calpon he will be ok. But then we told them he is not walking, the sister say I cannot write a letter for you to go to the hospital because it's the first time you come here maybe if you come more often and we see that we are going anywhere with these legs then we can refer you to Kalafong, the child went and become worse, this other day we call the pharmacist guy we told him that we have the child that is very ill is not walking and has a high fever, he said come to the pharmacy I will give you this tablet

called pencillin, put him in his buttocks, if the fever does not go down it means he could have an infection, you should take him straight to the hospital. And so, I was at work when they call me that he was not fine because his stomach was getting bigger and it was hard and he was no longer eating, he was vomiting only drink water, we took him to Kalafong, we got there around 5:30 in the evening, they help us around 10 o'clock, we had to wait for the doctor and explain everything from start mhhhh. Sometimes before they give treatment, they do bloods test then you have to wait and they have to confirm everything and which treatment the child is going to take all that."

Participant ten: "When my son got sick I took him to Tembisa hospital, he stayed there for two months trying to be treated but there were no good results until the doctor transfers me here at Steve Biko."

Participant three: "No, the first time I notice that the child has growth I went to the clinic, nothing happen, they said there is a mass in the scrotum, they did nothing, I went to the special doctor, there was nothing happen, he refers me to the hospital, still nothing happen to improve child's condition, I stayed, for a week, they did biopsy and discharge me, so he then stop urinating that's where I went to my mother's place where they took me to the doctor again, the doctor refers us Steve Biko."

Participant two: "In the first time it was difficult, operation they took that staff in the brain and send it to the laboratory and to come again until they operate, until they send me to chemotherapy after three weeks, the doctor come with results."

The findings show that the majority of the healthcare providers presented no insight in childhood cancer or early warning signs of childhood cancer. They seemed to continue dispensing ineffectual medication such as painkillers. Participant four indicated that her child was misdiagnosed and treated for TB (tuberculosis) and tonsillitis. When healthcare professionals found that the treatment was ineffective, the child was referred to Steve Biko Academic Hospital where she was later diagnosed with cancer. This clearly indicates that a child's condition often deteriorates significantly before he/she is referred to tertiary care.

Participants four and six shopped for children's healthcare, participant six went to an extent of shopping four healthcare providers without a diagnosis. The signs these children presented with could not hint or raise anything to the healthcare professionals to think that it may be cancer. As other healthcare providers could associate child's ill with teething and made the participant believe that fever, therefore, is acceptable when the child's teeth. Children were given pain medication

some the antibiotics. In fact, a quote by participant six display how healthcare professionals understand illnesses, they seem to generally think.

Other children because they were very sick, healthcare professionals could not do anything in primary healthcare they were referred to Steve Biko Academic Hospital. In a way, these children were fortunate because they could not be delayed as participant one and three indicated. In some instances, doctors could not see anything wrong with the child. This could convince and confuse participant seven to think that the child was sick or not as the doctors could not find ill health. Fragkandrea et al. (2013:187), affirmed these findings and recognise that some of these healthcare providers indeed show no insight about childhood cancer, they further developed a guide for early recognition to help the healthcare providers understand suspicious childhood cancer signs and symptoms (pg. 10-11).

These quotes are also similar with a study conducted on diagnostic difficulty and error in primary health showed that young children presenting with non-specific symptoms such as back and chest pain misdiagnosed as 'muscle strain' or growing pains, thus their symptoms often misdiagnosed as injuries (Kostopoulou, Delaney & Munro, 2008). In addition, Silal et al., (2012), supported and highlighted that even non-specific symptoms that may lead to early detection of cancer may not be detected. Subsequently, Fragkandrea et al. (2013:187), came up with a guide for suspicious cancer and malignancies.

Researcher inferred that children were vulnerable, and participants trusted the healthcare providers. Lack of insight by healthcare providers shows a hazard in the healthcare system. This suggests that some children can even die before reaching the tertiary institutions, one would ask a question how many children went by those healthcare providers their illnesses undetected and die because they were misdiagnosed and given wrong medication. These findings clearly proved that healthcare providers with no insight about early warning signs of childhood cancers are a barrier to achieve optimal healthcare for paediatric oncology care.

Sub-theme 6.2: Negligence of parents

It is likely that children suffer under the care of their parents due to the fact that parents may have no interest to partake in parental care of the children. Literature

studies cite that among other factors neglect factor may contribute towards delaying participants to access healthcare informed by several factors include fears of a scary diagnosis that may mean emotional and financial burdening, indigenous belief, fear of being disowned by ancestors, others associate hospital with death and prefer to die at home (Tjale & Villiers, 2004:21). Kingsley and Bandolin (2010) affirmed that these factors may influence participants to take action regarding the child's health and would wait until the child is extremely ill before visiting healthcare centres. Subsequently, it was only 10% of the participants noticed neglect as a significant factor prohibited caregivers to take prompt action. The construct of this study unfolds that there was at no stage participants perceived susceptibility to ill health because they may not be aware of early warning signs of childhood cancer and that healthy lifestyle may not be their habit. Due to such participant three uttered significant view, she said:

“I think it's their carelessness, they don't want to take care of their babies because if I know that there's something troubling, you will follow the rules of the medication unless there's problem with the transport it's a belief to traditional healers, they don't take the kids to the hospital until they get sick. It's careless.”

This quote supports literature studies above that neglect or carelessness is among the factors however there are other factors that may influence delay access to healthcare. She further mentioned an issue of transport as a delaying factor. The constructs agree and confirmed that barriers like those shows vulnerability and participants could be seen as neglecting children.

The researcher can conclude that the issue of neglect can be debated in many ways, only if participants were aware of childhood cancer and child being sick but not taken to healthcare facilities can be judged as neglecting if they did not bring children to healthcare. Alluding from sub-theme 6.1 above, if healthcare providers do not have insight about early warning signs of childhood cancer, participants would trust healthcare professional's judgment, whatever treatment given even if it is continual taking painkillers and antibiotics as long it is instructed by expects it will be followed. It is very normal that healthcare providers are trusted and believed by individuals. Therefore, neglect factor can be looked at, in different ways.

Sub-theme 6.3: Traditional healers

Africans are known to consult traditional healers in preference to or conjunction with Western, allopathic healthcare professionals (Tjale & Villiers 2004:152) and (Sodi & Bojuwaye, 2011). It is common that Black African people may initially delay healthcare, by asking advice from friends and other members of the community and use remedies at home. The participants were asked to give their views on traditional healers:

Participant eight: “The one for the Sangomas, people will say I want to do this one first before consulting the clinic, this one is intentional. I don’t believe in such thing so I don’t want to know anything about them.”

Participant six: “Other people most of them they don’t believe in Jesus or God they believe in something else, like Sangomas, ancestors, they say we must go there, may be they will assist us, they delay to go to the hospital and then when they come here it’s too late for children, that child may not make it so after that they blame the hospital, so they forget that it’s because of them, if you take your child as soon as possible or, your child may get help.”

Participant four: “Traditional things, someone would say I know how to heal, I run and go there, nothing.”

The quotes above show that participants know and understand traditional healers’ services, but they believe that it is an individual’s choice whether to consider traditional healing. Tjale and Villiers (2004:152) support this finding. Participant four indicated that when people faced ill health they became vulnerable and people could shop for healing, but in the end there may be no positive results. According to participant six this kind of shopping only delay professional healthcare for children. By the time children were taken to hospital, they were already very sick and the hospital was blamed for not helping. Truter (2007:59) confirms this and states that traditional medicine form part of many family caregivers’ culture and customs. The author also remarks that caregivers who lack trust in the ability of modern medicine are likely to rely on indigenous medicine.

The researcher concludes that ill health exposes individuals to psychosocial dysfunction and vulnerability. Lack of knowledge about health issues, and particularly early warning signs of childhood cancer, may lead to indigenous consulting because traditional healers are often conveniently close to where people

live. The researcher believes that if traditional healers may be made aware of suspicious early warning signs of cancer, they will contribute to the field of oncology, as they will be able to advise caregivers to consult health professional and modern medicine. As Truter (2007:59) confirms, people tend to trust and believe to what they know than what they do not understand. The advice of the traditional will be possible believed by the caregivers to consult healthcare.

Sub-theme 6.4: Time

Time is a precious commodity in life. For instance, cancer, when detected early, is better managed and its survival rates higher. This sub-theme emerged during the data collection process where participant nine strongly believed that time contributes towards delaying the child's access to healthcare services. She said the following about her experience:

“I would say may be time, time, I will use my own example now, my child started to complain about pain I took the child to the sick bay with the complaint, they sent us to x-ray because I have said she was struggling with stomach cramps and explain that she does not go to the loo, I don't know how they said it's may be constipation. I don't how they did X ray only, as well as lactostomy- laspa, it was on May by then, I went on course I left the child with the aunt believing that the stool will be loose, only to find it was not constipation, I come back after three months, the fourth month I came back the child was still complaining, I took her back to the sick bay, they gave her another treatment paraffin liquid , they told me I must bring her back if there are no changes, so it happen no changes, going back to access to healthcare, within those three months as I was not at home I could not monitor the child situation, I can say that I was of the reason that can delay access.”

This quote reveals that for caregivers who are working, time is challenge as they are pressed by work schedules and deadlines. In fact, children in working families are likely to be exposed to health neglect, as their parents may be goal driven and often neglect parental responsibility. Parents leave very early in the morning and come back tired very late in the afternoon. It is not clear whether they do have enough time for children. Helpers may report to parents. Kingsley (2010) supports this finding and confirms that, among other factors causing late diagnosis of childhood cancer, individuals find difficult to take time off and visit doctors due to work schedules, fears about income loss and concerns about medical bills. The

researcher believes that children's delayed access to healthcare is a direct consequence of the inability of parents to make time to take children to healthcare centres.

Sub-theme 6.5: Money and transport

Money is a general means of exchange; it plays an essential role in life. Without money, there seems to be no way to life. Caregivers faced with money problems are confronted with many difficulties in their daily existence. The action of taking a child to hospital or a healthcare centres becomes a luxury. Where only a little money is available, it is used to fulfil only in basic physiological needs, such as buying food. Participants in the study responded to this problem as follows:

Participant two: "Some would delay, just because you come to the hospital, how can I go to that hospital without money, all of this needs money, if I get this and that and plus that money."

Participant eight: "I will just because of the lack of transport or money. Sometimes you can see that the child has a problem but you won't notice what problem is, how serious it is."

Participant five: "Yes, because children needs something, it's difficult if they need something and I' don't get it so you say I don't have money give me time to buy that thing, the kids get disappointed, you can even see their faces, so it's very difficult."

Participant four: "Money, if you don't have money for transport what should I do, because I can borrow but I cannot replace the money because I am not working sometimes when it is an emergence I have to knock and ask for money and I will give it later, so I will call his father and tell him will pay."

Participant nine: "I don't think can be money because public hospitals are there."

Participant one: "If there's no money yhhhaaaa, but that thing has never happen to me, because of when I know the date is 27 that the date for treatment I have to take some amount and put it somewhere so that I can never forget that."

Participant six: "No, when it's come to travelling, we don't have any challenge most of the time we have money for emergencies and most like is that the father earns every week yhaaaaa. It doesn't strain."

Participant ten: "It's too much, its stressful this money is big."

Participant three: "If I am at home and I don't have money I stay until I have money."

The quotes above indicate that participants had a problem with money for transport. As participant, eight said, due to her financial strain, the child's sickness was not

regarded as serious. Participant four showed more concern and commented that she would rather make debt to ensure that the child's health needs are met. For other participants (numbers six and nine) money was not a problem. Participant five was embarrassed and felt helpless as she thought the child would look upon her and thought that she could not provide. She indicated that children became disappointed when parents cannot provide for them. Participant ten added that the issue of not having money is stressful. According to participant three, the feeling of helplessness made her stay at home until she had money.

Van Rensburg (2012:635) affirmed these findings and strongly believes that under these circumstances family caregivers of paediatric oncology patients would be left with no alternative other than following their own healthcare beliefs.

These findings show that children would have delayed access to healthcare and be diagnosed very late as participants would have no money for transporting children to healthcare centres. Vasuthevan & Mthembu (2013:6), confirm this by stating that children living in this situation are vulnerable and their health is prone to be neglected. Fortunately for participant one, she managed to budget because she saw the importance of treatment compliance.

The researcher concludes that money is a barrier to access healthcare at the onset of illness. Participants had to wait at home until they had money for transport in order to take children to healthcare facilities. The issue of money is a great concern for individuals as healthcare facilities are often far from where they live. This is linked to the health belief model where it is perceived that delayed access to healthcare are caused by barriers such as lack of money and transport which seriously impact children with cancer.

Theme 7: Impact of cancer

Dang-Tan and Franco (2007:703) and WHO (2014) reports that cancer is a leading cause of disease-related death. It impacts physically and psychologically on the affected children and families. Participants in this study expressed how cancer affected their families. Only two sub-themes focus on the impact of cancer; how it affects the caregiver, siblings, and family and role changes in a family affected by cancer.

Sub-Theme 7.1: Impact on caregiver, siblings and family

Cancer brought crisis in the families and significantly impacted on caregivers and siblings. Participants of this study reported the following:

Participant eight: "... This thing starts to affect me, now am starting to worry, my husband has to cook for himself when he comes from work, do the washing and on the other side am no longer staying with my little one and am starting to that thought of remembrance. I think cancer is affecting families because, like now I am with this one others are suffering, they don't get my attention."

Participant nine: "It has a huge impact right now because I am not the first one in the family, we are really worried when this cancer is going to end, who is next, and we want the solution. It does affect everybody but we are encouraging one another, in our family we believe in God too much, we support each other in Godly way."

Participant six: "... Yhoooooo Its very hard because at first your child is used to eat everything simba's all that but now he has cancer he is taking chemo, chemo is making his system to be weak at the same time you have to give him something that can protect his immune system from infections and my child loves meat so much, he doesn't like veggies so at first when we got here they put him on soft diet, mash potatoes, carrots, he doesn't eat those I had to force him to eat vegetables sometimes when they discharge us we got home they bought chicken, the one like Nandis, he likes meat, I had to stop him from eating those because of the spices and sources that they use they are not healthy for him, he would cry. The impact is that I have to be careful of what I give and also make sure when I prepare his food I prepare in a clean environment, everything is clean yhaa. It had, I had to stay with child in the hospital, I remember when they discharge us, I said tomorrow I am going to work, you can't go to work the child is still sick, we have to see first look, I said no you trying to control my life and all that. We had arguments mhhhh."

Participant two: "If this cancer was spreading, the challenge I face is that, most of the time, the kid says this (repeat) two weeks will be good after starting the treatment he became sick and refuse food. My parenting got challenged, you buy this he doesn't want to eat (you bring bread, he refuses to eat, you became angry) it challenges parenting, there's no problem with cancer because this disease does not spread, to other children because I was going to worry that I will be a caregiver for ever, so with my family I don't have a problem. Shortage of money, me losing the job adds burden because with father's income we were going to plus and add another than subtract, it causes new problems."

Participant four: "Mhhh, it's too much, you know sometimes when you have to go to church I have to lift him until I arrive to church, during church, he does not

want to sit or relax there so that I can enjoy preaching, so sometimes it's too difficult there but am trying. I left his young brother there he is staying with my mother and when they discharge me I go there only Saturday to see him not the way he wants, when I go he cries, so I have to hide."

Participant five: "Mhhh it affects us ... because ey, when we start to forget about what happened that year so it's coming back again, my daughter the 12-year-old last time when she goes to school she says to my son, do you know Mandoza, he died of cancer hee, you will also die, my son came back and told me that Princess told Mandoza died of cancer I say no I say no its not cancer maan, it's a lie, but when we look at him also, all of us we feel pain. They are affected (referring to siblings) when he is not at home they are not happy they miss him, sometimes they cry and they miss the brother."

The quotes above show that cancer affected the families psychologically, emotionally and physically. Dang and Franco, 2007:703 and WHO, 2014, strongly support these findings and affirm that cancer has detrimental effects on the siblings and family at large. Participants confirmed that cancer caused worries, and created fear and a lot of uncertainties about when this cancer will be cured, particularly with those participants with the history of cancer in the family. Hospitalisation demanded urgent adjustment and adaptation. Findings showed that families had to change their normal eating habits to accommodate the needs of the patients.

The findings also revealed that cancer diagnosis brought isolation; siblings miss their sisters and brothers and kept on asking about when they are coming back home. According to participant five cancer brought about numerous emotions because she did not know how to respond to siblings when asked questions about cancer. In addition, participant six said that family relationships are were at risk of becoming strained, since members felt lonely and argued about caregiving.

Another finding show the loss of employment, as indicated by participant one. The researcher recognised that participants were deeply hurt by the cancer diagnosis and that their lives changed drastically to accommodate their current situation. In circumstances where both parents were working, the mother had to stop working. According to participant two, cancer thing added problems in the family. Participant six indicated that ill health demanded a change to a more healthy lifestyle and healthy eating and that her family needed to adjust and accommodate the needs of the sick child.

According to participant four, the behaviour of the child also became problematic. Her child became moody and did not want to eat certain foods. Participants revealed that their parental styles were challenged. Lastly, participant five said that siblings sometimes feared that the brother may die, knowing that one of the kwaito music artist (Mandoza) died of cancer. Siblings were always affected by uncertainties and fears of death because of the ill health of their brother. Klassen, Raina, Reineking, Dix, Pritchard and O'Donnell, (2007:808) affirm these findings and call caregiving an "unexpected career" that can be defined as "a dynamic process whereby an individual move through a series of stages, requiring adaptation and restructuring of responsibilities over time."

The researcher concurs and concludes that cancer brought misery to the families. In some families, cancer caused despair, as they did not know how and when the chain of cancer in the family would be broken.

Sub-theme 7.2: Role changes

Participants were asked about role changes since the child's illness. The quotes below reveal that roles had to change: the mother had to make changes to become a caregiver. She had to delegate home responsibilities to others because of the child's hospitalisation.

Participant eight: "I think cancer is affecting families because like now I am with this one others are suffering, they don't get my attention."

In a situation like this, siblings may become vulnerable and struggle to adjust to changes they were unprepared to make, since the mother had to relocate to play a caregiving role. This may lead to squabbles, as sibling left at home may feel unloved and isolated. However, the age of the siblings determined understanding of what is happening. Participant three said that her family had to make arrangements and share responsibilities:

"With the father we had to change roles, he cooks for them, taking them to school and do all the house chores other children miss her so much, and that care for the children had to be shared with the aunt if the father is not there at home, so things changed."

This quote show that the family's balance and functioning where overturned which caused stress. The husband had to perform all the domestic chores mostly done by women.

Lastly, participant one indicated that mothers were left with no option but to be caregivers:

“Mommy is the good thing all the time even the children when they cry they call the mom they don't call the dad.”

This quote shows that it was uncommon to find fathers in the hospital playing caregiving roles and is supported by Brames, Rittenberg and Johnson (2009:258) who states that men may feel less prepared for the role of caregiver and may encounter challenges as compared to women. Worldwide, caregivers tend to be women; however, there seems to be a slight growth in the number of male caregivers, but mostly for older patients.

This study finding shows that cancer affects the family in different ways; it caused stress and demanded drastic changes. Participants were unprepared, as they had to become caregivers, change their lifestyles, and make difficult decisions. Roles had to change even if they compromised the function of the family, for instance, some participants had to leave their jobs and play caregiving roles. Some participants shifted roles, as one partner had to carry more responsibilities and accommodate family needs including those of the sick child. Findings show that participant's roles were not confined to domestic functions, but that these women were also able make the decision regarding the treatment of the child.

The researcher concludes that the caregiving role surprised all the participants and it has exposed the families to social dysfunction. This can be linked to the health belief model where the impact of cancer is perceived as a threat in the family as the family may live under the fear of death. The severe impact of cancer in the family may never be fully measured. Family members need to adapt and develop new ways of living to accommodate the sick member.

Theme 8: Intentional and non-intentional delays to healthcare

There are various reasons that influence delayed access to healthcare and may be intentional and or non-intentional. This theme is divided into seven sub-themes that includes income, awareness of cancer, emotions and bargaining, family beliefs, beliefs in Western medicine, and the lack of a family system.

Sub-theme 8.1: Income

Participants' reflected on how income played a part in delaying treatment:

Participant eight: "If you don't have money to go to the hospital, that means the child will stay at home and will get even worse, if you have money, I don't think there's a problem to go to the hospital."

Participant five: "Yes, because the chemotherapy is very expensive I look at the box of the medication or pills, it is R200 and more, we are many here, people may count those monies, people may delay because of expenses."

Participant Four: "Money, if you don't have money for transport what should I do, because I can borrow but I cannot replace the money because I am not working sometimes when it is an emergence I have to knock and ask for money and I will give it later, so I will call his father and tell him will pay."

Participant two: "If I am at home and I don't have money I stay until I have money. Some would delay, just because you come to the hospital, how can I go to that hospital without money, all of this needs money, if I get this and that and plus that money."

The above quotes show that income contributed significantly towards participants' delay. They indicated that they stayed at home until they got money, yet realised that this caused the child to become even weaker. Participants indicated that treatment for cancer was very expensive. Only participants two and five indicated that they could afford treatment. Participants reported that this factor was beyond their control and is regarded as non-intentional delay by the researcher. This finding is supported by Goudge, Gilson, Russell, and Gumede (2009:18) who state that unemployment and low grant income possibly limit caregivers' visits to healthcare facilities.

Some participants said that the income issue is the only reason why people delayed to seek healthcare:

Participant nine: “I don’t think can be money because public hospitals are there. I don’t think its finances, it’s just a negligence and neglect of responsibilities from the caregiver.”

Participant one: “If there’s no money but that thing has never happened to me, because of when I know the date is 27 that the date for treatment I have to take some amount and put it somewhere so that I can never forget.”

Participant six: “I can say income it’s not, because we as black people when the children are sick we have this mentality just give panado, the child will be ok, we take panado as a cure to every sickness.”

Participant seven: “I do not think it’s intentionally, because it depends on people’s lifestyle, if you do believe that I don’t go to doctors, it’s a belief, if you believe that going to Nyanga’s or church they do this and that, my child will be fine or if I use something from Nyangas because totally you do not go to doctors and why now.”

The views of these participants shown that other participants might not be realistic about the money issue due to the fact there are public hospitals in their areas where they can consult doctors. Another view was that people tend to use over-the-counter medicine for every illness; as a result, they would continue taking painkillers and a child’s illness would persist. Participant seven indicated that there was a need to transform people’s thinking about health issues and about childhood cancer. As mentioned by participant seven, people’s lifestyles amounts when it comes to health issues. Haan (2005:8) affirmed this believes that knowledge about health issues contributes towards making a decision. Porterfield and McBride (2007:327) strongly support this view and are of the opinion that a lack of knowledge about health issues may disadvantage caregivers. The researcher believes that participants had no intention to delay access to healthcare, but lack of knowledge limited mainly caused delayed action.

Regardless of what other participants said, participant five indicated that hospitals intentionally delayed treatment for children:

“Hospitals delay us because they want to be sure and then to be sure of the medication will give to our children because if they give them wrong medication we will blame them, they delay intentionally. Non- intentionally, for me, I don’t see anything?”

This quote indicates that some participants took the initiative to bring children to the clinic or hospital; the challenge they faced was that some healthcare professionals delayed to refer them to oncology treatment. Literature studies confirm showed no surprises on this finding and confirmed that some healthcare professionals at primary and secondary levels of care with limited skills and knowledge of childhood cancer may contribute to delays by failing to diagnosis in the early stages of cancer (Francis, Battle-Fisher, Liverpool, Hipple, Mosavel, Soogun & Mofammere, 2011 and Vasuthevan & Mthembu, 2013:5).

The participants' quotes revealed differences regarding income; some participants believe that having no money prohibited from going to healthcare facilities. They said that they could not even borrow money because they may not be able to repay it. Other participants were of the opinion that healthcare facilities were available, but that some people would rather opt for using over-the-counter pain medication, as they believed that it would be an effective cure.

A significant finding is revealed that a person's mentality may impact healthcare for a sick child: Participants believed that some people would not take a sick child to hospital, simply because it is not their way of responding to health issues.

Findings clearly show that income, the tendency to use painkillers, lifestyle and mentality, as well as limited knowledge and skills of some healthcare professionals the primary and secondary levels of care are the factors recognised as non-intentional delays. The researcher concludes some finding were interesting: The issue of painkillers was never seen as serious by the researcher, but the responses of the participants provided a learning experience.

Sub-theme 8.2: Awareness of cancer

Participants were asked whether they were aware of childhood cancer prior to the diagnosis of the children. Significant views are reflected below:

Participant two: "I knew nothing, completely nothing: maybe may not come if they know because they will know what cancer is and because we don't know we are here to the hospital thinking that we will get help fast, that's why we rush, if they give us date we come to make sure our children get chemotherapy or medicine before cancer spread, and we don't know this cancer where it stands.

If we know, we may sit at home because there's nothing that they can do about it but now we came here because we don't know my son will get better and my son one day will grow up, cancer will go forever."

Participant six: "What I know is that when you had cancer you need to take chemotherapy and the side effect of chemo is vomiting and bleeding and hair loss, the type of cancer I knew it was breast cancer, leukaemia and prostate cancer yhaa."

Participant nine: "She did not present with anything, she only presented sometimes with pain in the stomach."

Participant four: "I knew nothing, completely nothing."

Participant eight: "I though may be, the vein just shifts and I gave her grandpa, I say go to school my child you will be alright, when she comes from school that thing was getting bigger that's when I said this one I had to do something but I didn't know what it was, but before that I tried a lot of medication and multivitamins so that she got appetite."

Participant seven: "Again it depends on the knowledge, how do you know about those things."

The above quotes show that participants were not aware of childhood cancer, as a result, they thought they could trust pain medication. Participant eight said she bought multivitamins to bring relief to the child. Participant seven confirmed that it was likely for other participants to behave the way they did, as they did not have knowledge about certain health issues.

The findings showed that the majority of the participants confirmed that they were not aware of childhood cancer at all. Subsequently, they did not know that early detection of cancer allows better management and an improve of the survival rate (Fragkandrea, et al., 2013:187). Some children presented with those signs, but unfortunately, participants were unaware of those clinical characteristics that suggesting cancer.

The researcher concludes that participants with no insight into childhood cancer were incapable of making correct decisions about the healthcare sick children needed. This correlates with the issue of lack of knowledge about health issues. There is nothing that could have sensitised the participants about this life-threatening condition since some healthcare professionals could not understand the signs of cancer the children were presenting.

Sub-theme 8.3: Emotions

Participants of this study were asked to share experiences when they were told that their children have cancer. Significant responses emerged:

Participant five: “Yhooooo, on that time I felt like I'm dreaming, they are not talking to me, it's not me, it's not happening to my son this one not cancer, they make a mistake, so I asked another lady at the lodge , what type of cancer your child has?, she says my son has blood cancer, that ward where son sleeps those children have cancer, it's impossible not my son, I looked at them, I asked again another lady, she told me all of us, our children has cancer, I took a phone and called my older daughter, I cried, I told her my son has cancer, we all cried but she says ok mom, please call me when they explained to you what cancer is that I will Google to find out the danger of that cancer, she said mom you must be strong for him, you must not cry in front of him, he will think he will die.”

Participant ten: “Mhhhhh ... was so stressed, my heart was painful but I received counselling I understand now.”

Participant three: “I was like down but there was nothing I can do.”

Participant six: “I was in denial because, in fact I was shocked and also in denial, I say may be it is a mistake and it can't happen, so when we got here we went to oncology clinic, the doctor says, there's a possibility of cancer and then the Social Worker came, other day she come she was busy talking I don't want to talk to this person, she came to me I couldn't chase her away, we spoke she says your child is diagnosed with cancer I said no its still under investigation, this one I told her this time in my mind I keeps saying there's a mistake, there's no way that my child has cancer.”

Participant four: “Nothing because I was breastfeeding I was not allowed to cry, because they say if you cry the milk become sour, the child cannot eat that milk he will cry, so it's not good for you its better you hold yourself.”

The above quotes present the agony that participants went through when they comprehended that their children have cancer. It is evident in the study that the majority of participants had no insight about cancer and it never crossed their minds that their children may have such a condition. Their reactions revealed numbness, shock, denial, puzzlement and disbelief when they received the diagnosis.

These are normal reactions when one receives bad or unexpected news. These findings are affirmed by Ross (2007) who contends that feelings of vulnerability and helplessness are common in caregivers. Additionally, they blame themselves for

responding in a certain way. Birchley (2014), support these findings and strongly believe that participants in this state become more vulnerable and may go as far trying to look for more clarity and sometimes negotiate what they think would be better care for the child. New findings revealed that when breastfeeding, participant four said that she was not supposed to be emotional about the sick child as it was said by some health professionals that grieving would impact on the behaviour of her baby. She had to hold her emotions in check because she feared to cause problems for the baby.

The study findings confirmed that participants rarely expected a diagnosis of this nature, and in trying to internalise and digest the bad news; they had to go through a series of emotions. The researcher concludes that the participants in this study were overwhelmed by the diagnosis and they had to learn faster about treatment plans.

Sub-theme 8.4: Bargaining

Doka, (2013:74) suggests that bargaining is a “feeling that by omitting or committing certain actions, one can avoid or forestall further illness or death.” Bargaining can be associated with a natural response to life-threatening illness. It is common that when individuals faced with an unexpected situation ask themselves why they are in that situation, their strength is challenged. The participants had the following views on this matter:

Participant two: “... everyone is in church, the spirit is in higher level, everyone prays, the problem come when faced with challenge, you ask God why my child, but like if I go to traditional healer it's better that church, why God gives me this problem, you will say there may be better, no you need to stick to one thing not to change may its God who gave this to see how are going to pray to him.”

Participant seven: “I didn't believe what I was hearing, but my son's name was there but I could not believe at all, I think more than four hours, shocked and asking why now and why my child, worst part my only child.”

Participant five: “I just sat, I said God knows before I have this boy, I prayed about this boy because I have two girls, immediately the sisters told me I gave birth to baby boy, I said thank you God but I am saying why God give me a boy after that he want to take him away from me Why, why you gave me a boy, I said if it is in God's will I must try to accept and give him love and then give him love more than before.”

Quotes above show how participants bargained when the bad news was disclosed that a child had cancer. Apparently, this was the last thing participants ever thought of. They could not imagine the fact that children faced a life-threatening disease. Their strength and faith seemed challenged and typically asked questions such as "... why now and why my child, worst part my only child?" This participant who asked this question felt like she has losing all hope in life since it was her only child. Her bargaining was based on pleading God to heal her son. Participant five shared the sentiments of participant seven: she asked God why He gave her, her only boy only to take him away again. These were the painful emotions these participants had to go through. Participant two also bargained but she remembered that she was a child of God, but she later consoled herself by accepting that it was God giving her the sickness to challenge her faithfulness.

Todoran (2012:291), affirm this finding and confirms that Christians believe that illnesses can be healed through prayer. Ross (2014) also affirmed these findings by concurring that participants may ask themselves many whys in times of distress. This indicates that the participants experienced a crisis of faith in times of grief. As Visser (2010:50), affirms:

"... even a man of God did not find an easy; simple answer but had to admit that God's ways are often beyond our comprehension; that we sometimes have to accept there are no simple answers or even no answers at all."

The researcher concludes that these participants bargained and could not imagine that they were losing their children because of cancer. Participants became aware that cancer is a life-threatening disease and were now experiencing the realisation phase. The response and actions of individuals revealed the grief process and their utter vulnerability.

Sub-theme 8.5: Family beliefs

Truter (2007:59) suggests that traditional medicine forms part of the family caregiver's culture and customs. Caregivers who lack trust in the ability of modern medicine are likely to rely on indigenous medicine. The perception that caregivers have of modern medicine depends on their knowledge about it. The researcher believes that this an important aspect of the study. No issues identified that could

be linked with family beliefs, participants remain objective that they do not do any rituals. The main challenge of the participants is that they lack knowledge about childhood cancer, its early signs and symptoms as well as its treatment.

Sub-theme 8.6: Beliefs in Western medicine

In this sub-theme, participants were asked whether they believed in Western medicine. Significant responses were given:

Participant nine: "I do believe" (referring to Western medicine).

Participant six: "I do believe because it helps a lot."

Participant eight: "Now I have got that hope that my child will be alright."

Participant ten: "Yes I do."

Participant one: "I The only thing that I believe my child is going to be cured because I have seen that its better than the first time ... but now things has changed when they do those things I have to take my son away because in the first time they do that my child was 2 years, they just cut a goat, the following day he will develop things like he has burned I did know what was that. So since I came here I just put mind back that this thing was of long time I didn't think that it can be cancer. When they do that I have to take him away and came back when they are finish he won't eat anything."

Participant seven: "Yes, I think is the lucky we could because if I was too stuck in the church, maybe my child could be disable by now."

Participant two: "It's working, why, because it moves this thing (showing the tumour), doctors come again and they told us this thing (tumour) won't come again because of this treatment. For the first time, when this growth started we had operation, they said it's a minor operation, I believe that this treatment is good."

These quotes strongly show that participants believed in Western medicine. Participant seven thought that they were fortunate to get this medicine and believed that her child would have been disabled were it not for its positive effects. This implies that this participant developed trust in Western medicine more than anything else she tried. Participant two indicated that Western medicine were trusted as soon as positive results were seen. The researcher believes that most people believe in Western medicine when they had with experience of using it, but in general, people do not understand it.

Sub- theme 8.7: No support system

Research studies suggest that the diagnosis of cancer causes a crisis situation and social upheaval in families (Bayat, Erdem & Kuzucu, 2008:247; Vrijmoet-Wiersma, Van Klink, Kolk, Koopman, Ball & Egeler, 2008:694-695). Despite this crisis, caregivers, as fundamental components of paediatric oncology, had to carry on with their normal activities while providing care for sick children. The question is where these caregivers get support in order to withstand the situation. The participants of this study were asked about family support; and this is what they reported:

Participant eight: "When things are not going well he will tell me that don't stress things will go well as long we support each other."

Participant four: "My mother, my father and my husband."

Participant nine: "Yes, family, neighbours, church members."

Participant ten: "My cousin sometimes calls."

Participant six: "It's him, his mother and my sister."

Participant five: "Its him" (Referring to step father).

Participant one: "Eishhhh ... being a mother is hard but I try harder if I don't try no one can try and no one can do."

Participant two: "The father, no one is helping us, he helps me to raise the children."

Participant seven: "I do get support from my sister; she is her second mother and family."

These quotes reveal that the family served as a primary source of support and participant appreciated the help and comfort that they received from significant others as well as siblings, cousins, and aunts that are mentioned in this study. The researcher realised that when participants were faced with ill health of the children, they needed support in order to face the situation. The majority of the participants mentioned that their husbands played a crucial part in supporting them, even if we're not present in the hospital. Other systems like churches and neighbours who assisted the participants were also mentioned.

Participant one described the burden that caregiving added to the life of a mother. For this reason family and other sub-systems including the church and neighbours form the support structures of these participants. Koenig et al, (2012) and Mbiti

(2015:15), support these findings and confirm that when caregivers are faced with disease they would need support.

Theme 9: Medical and related costs

This theme focuses on how the participants pay the medical costs. It is divided into four sub-themes that include medical aid cover, payment of medical bills, payment structure and other financial problems.

Sub-theme 9.1: Medical aid

Participants revealed the following:

Participant one, two, three, four, five, eight, ten: "I don't have."

Participant nine: "Yes I do, my own and the SADF medical aid deducted from my salary, I also have my husband medical aid but I don't use it much."

Participant seven: "The child is covered from his biological father."

Participant six: "At the moment no."

The above quotes indicate that most participants did not have medical aid cover. This may be because these participants were unemployed and as a result, they could not afford nor qualify for any cover. Only participant nine had medical aid cover. Participant nine had her own medical cover as well as cover from her husband. Participant seven was also unemployed, but indicated that the father of the child provided medical cover for the child. Though ten percent (10%) of the participants had medical aid cover, they were all treated in state hospitals. This could be explained by the accreditation of paediatric oncologists at Steve Biko Academic hospital. Participant nine, who had medical cover, found it unnecessary to take her child to a private hospital. She had an option to choose either private or public healthcare. Participant nine previously received treatment at the Military Hospital where she was advised about a good paediatric oncologist.

McIntyre (2010:1) believes that the introduction of NHI will balance health inequality between the rich and the poor, and to achieve universal financial risk protection and access to healthcare. It is evident in this study that participants with no medical aids took longer to go to a hospital such as Steve Biko Academic Hospital where there were paediatric oncologists. Participant nine confirmed that "*it never took long*" for her to access paediatric oncology care. The researcher found that participants

without cover did not have a choice of various facilities for consultation since they could not pay for doctors or specialists. Those with cover would consult either private or public doctors and their medical aid cover would pay. In a situation like this, researcher believes that the children of parents with no cover were more vulnerable as the parents did not have the means to access healthcare. They had to first go through primary and secondary healthcare without diagnosis or direct referral to the tertiary institution. This was not the case with individuals with medical aid cover.

Sub-theme 9.2: Payment of medical bills

Participants of the study were asked how they paid medical bills. Their responses reflected the following:

Participant eight: “Like I said before, we survive with my husband salary.”

Participant five: “I am not paying anything because, I’m not working, so I came here with a transfer from the hospital.”

Participant four: “Mhhh ... I am still struggling but after this treatment when I come once a month, I will be able to pay because I will find work.”

Participant nine: “The Military pays for the child medicals here at Steve Biko.”

Participant one: “No he is not paying anything.”

Participant six: “No, at the moment I don’t pay any bills, government pays.”

Participant ten: “I have been not paying, but last Monday the sister in the clinic told me that I owe something. So I went to the administration to make arrangement to pay R150 every month.”

Participant three: “It’s free I haven’t received any bill so far.”

Participant seven: “His father pays medically.”

Participant two: “I pay cash, it is very strenuous, most of the time we don’t have money, the kid is ill, coming in and out but the time they wanted to admit the hospital want money, but I don’t know but they say cancer is at a high risk to many people even in the world, not only one countries they saying I suppose be treated freely, we don’t know what is going on, if you see HIV, it is better than cancer or diabetes because HIV you can take ARVs and you can go home and do anything, what about these kids, you are a father a breadwinner in the family always here, most of the time the family suffers.”

The above quotes show that the above participants in this study did not have medical aids and the majority has not yet received nor paid medical bills. This may be because children were below the age of six years and newly diagnosed and for

these reasons were not charged medical fees. Participant six and three assumed that they did not have to pay in a public hospital. In a public hospital, particularly the Steve Biko Academic Hospital, parents of children under the age of six are not required to pay. Participant ten received medical bills and was frustrated about payments because she was unemployed. She had to arrange to make payments for the medical bills.

In some instances, where the husband or father is working, caregivers such as participant seven indicated that medical bills were paid by the father. Participant nine was referred from a military hospital and indicated that the referring hospital paid the bills at Steve Biko. Due to these social function imbalances that participants are faced with, McIntyre, (2010:1) suggest that the National Health Insurance (NHI) will eradicate health inequality between the rich and the poor and provide universal financial risk protection and access to healthcare. Participant two expressed the frustration of the family that were faced with the financial demands of healthcare for the sick child. She compared cancer to other chronic illnesses that received public attention. As mentioned in the SONA, 2018, the cry of this participant was heard, as the President of South Africa, Mr. Ramaphosa, announced that cancer needs to receive priority.

Jemal, Bray, Forman, O'Brien, Ferlay, Center and Parkin (2012:4372) and Dang and Franco (2007:703) strongly support this finding and are concerned about the reasons for cancer receiving relatively low public health priority in Africa. Uncertainty exists whether it is because of limited resources and other pressing public health problems, which include communicable diseases such as acquired immunodeficiency syndrome (AIDS), human immunodeficiency virus (HIV), malaria, and tuberculosis. Furthermore, they believe that not enough research have done related to childhood cancer.

The study findings show that the majority of the participants could not afford to pay medical bills and some were not paying medical bills. The findings indicate that the majority of the participants were the recipients of social grants. The medical bills of one participant with medical aid were paid by the referring hospital. This clearly shows that those who have means received even more benefits and access to paediatric oncology care was never delayed. Those participants paying from their

pockets found it very difficult to balance their budgets. As suggested by McIntyre, (2010:1) the imbalance in healthcare systems has to come to an end and all people need equal access to healthcare.

Sub-theme 9.3: Hospital fee structure

Payment structures differ according to the individual's living and income status. The Classification of the Patient Classification Policy Manual, Gauteng Department of Health (2012:13-19), provides guidance for participants' classification for payment structure at Steve Biko Academic Hospital. Participants of this study were diverse coming from various countries with their employment statuses and incomes all different. Incomes, of the families and age of the child were mostly disparate. The payment structure is an attempt to provide an equitable method whereby participants could pay for according to their means. The payment structure for participants from SADEC countries which includes Angola, Mozambique, and Zimbabwe, is based on a means test. However, participant four from Mozambique, was classified in terms of section 3(i) of the National Health Act 61 of 2003 was classified as a private patient as she was in South Africa specifically for healthcare for her child. This is what she said:

“Mhhh ... I am still struggling but after this treatment when I come once a month, I will be able to pay because I will find work.”

This quote indicates that this participant was aware of the medical bills that needed to be paid. She was excluded from the free service because the child became ill while in Mozambique and the fact that the child was under the age of six was not taken into consideration.

The 11-year-old child of participant two from Zimbabwe, became ill in South Africa. He was classified as a private patient and participant two was supposed to pay before the child was admitted. However, staff at Steve Biko Academic Hospital apparently understood her inability to pay, and her child was admitted without the upfront payment. At this hospital no patient is turned away untreated, even if they are unable to pay due to poor social circumstances. Participant nine, classified as a non-South African citizen, had a work permit; a means test was done and she received health benefits as a South African citizen.

The payment structure of each participant was tailor-made according to individual and household income. For example, participant ten received medical bills amounting to R6000. According to this participant, her husband was employed at a construction company and they were also receiving a child support grant for two children. For this family the means test was applied and they were subsidised as the household income amounted to less than R50 000 per annum. This payment structure indicates that South Africa is implementing policies to bridge health inequality.

The findings show that participants paid according to what they could afford. The principle of Ubuntu was applied for those participants without means of paying upfront and their children were admitted and treated at a tertiary facility.

Sub-theme 9.4: Financial challenges

Participants were asked about other financial problems that they experienced in healthcare. The following emerged:

Participant five: “Yes, because children needs something, it’s difficult if they need something and I’ don’t get it so you say I don’t have money give me time to buy that thing, the kids get disappointed, you can even see their faces, so it’s very difficult.”

Participant four: “Yhoouo, its transport most of the time, to come every week it’s too much for food because he does not want to eat hospital food. So every day I must buy food. It is too much, its stressful this money is big.”

Participant ten: “I pay R100, for a return for two its R200, travelling is the main problem, I have to wait for people to give me money or wait for grant payment.”

Participant one: “When I come here in the hospital I usually pay R37 to come and R37 to go back. When coming for check-up, am not managing because now am not working, that money for social grant that am using to buy food I have to keep it for transport.”

Participant seven: “Now sometimes I am struggling especially in the middle of the month, sometimes I need things for him, and then I have to wait until all the people who support me financially get paid.”

In the above quotes, the researcher identified that only participant secondary needs; her vehicle was involved in an accident, and that impacted on her available finances. Mostly, other participants struggled with providing in basic needs for their families.

This finding indicates that even caregivers, who can afford treatment, may at some point experience challenges that will impact on taking the child for treatment on time.

The above quotes show that participants mostly found it difficult to cope with transport fees to hospitals because of their poor economic status. Some participants were dependent on social grants, and for this reason, they often had to wait for grants payments to pay for medical treatment. However, the cost of transport mostly affected the majority of the participants.

In conclusion: The findings indicated that transport fees was the main problem and contributed towards delaying participants to visit healthcare centres since participants had to wait for child support grants and additional earnings. Participants had to accommodate children's moods during illness and in most cases children refused to eat hospital food. Participants had unexpected food expenses in order to feed their children. Geographic proximity also posed a challenge, as participants had to spend money on traveling. Lack of resources that include ambulances from home to provincial hospitals, was also reported as a contributing factor that delayed caregivers to access oncology care.

3.9.2.6 Theme 10: Decision-making and support from the father

This theme focus on the responsibility of the caregiver pertaining to decision-making regarding treatment and support fathers gave. The participants responded with the following:

Participant two: "All of us but the father is the one first who should first understand this and tell me the doctor says this and I should do this and that, so we are there to understand each other because there's nothing we can do but what we want is the way forward."

Participant nine: "I would say me however I consult with my husband and he will ok it."

Participant ten: "it's my husband, who gives me money to go the hospital."

Participant eight: "No one, only myself and my husband."

The above quotes confirm that gender remains a prominent issue in decision-making. The fact that the husband remains the provider of the family meant that they made the final decisions about healthcare. This may also indicate that if the

man disagreed with the wife in terms of health beliefs, the wife's decision could be ruled out. Rao, (2012) confirms these findings by stating that in many cultures, men generally make decisions and the opinions of women may not be regarded as important. Women's roles, being a mother or wife, are confined to domestic functions, and they are generally not allowed to make the final decision regarding the healthcare of children. In addition, Goldman, Hain and Liben (2012:118) are of the opinion that it is common in patriarchal settings, where men are being regarded as heads of the households, that caregiving is delegated to women who would be expected to accept male leadership without any opposition.

Some participants had strained relationships with the father of the child, while others had different health beliefs than those of the father, and would make healthcare decision themselves. The following quotes reflect these situations:

Participant one: "The decision I made decision for myself because the father is there but ... since we have been here he never been here, he will just call and say how is he you see, so I think he don't want to be part of my son."

Participant seven: "On that one, I am too fast, because even coming here I made my decision, because we were arguing about ancestors and the father was saying why don't you try it here. Why Pretoria, because it will be more money since here they found out that it is cancer, I did not believe in shortcuts and saving too much, I know I have nothing but when it comes to life I do not mind."

Participant three: "They support the decision I made like deciding to take the child to the hospital I'm the one, am the caregiver."

UNICEF (2010), support these quotes and confirm that women have the ability to seek help regarding healthcare of their children, however, their actions would be influenced by the nature of the relationship with the fathers of the children.

These findings show that fathers only became decision-makers when they participated in raising the child, and where parties were not married, the decisions were made by the mother. Burnet (2008:362) affirms that with the recent evolution of gender equality policies and inclusion of women, women had a democratic right to partake in the roles that used to be dominated by men.

Participant eight and four showed fear regarding decision-making and preferred doctors to take decisions on their behalf. These two participants chose to be passive

in patient management because they were anxious about the outcomes and trusted the judgment of the doctor, and this was what they said:

Participant eight: “Eiiish, sometimes you can make a decision and after such a decision a problem occurred, you will regret, I should have done that instead of that.”

Participant four: “It’s a doctor, they know about the illness.”

These comments show that participants relied mainly on healthcare professionals to make decisions about treatment for the child, but still had reservations whether those decisions were the right ones. This may have caused them to stay at local healthcare facilities, ultimately delaying early oncology care at a tertiary hospital. In addition, participants were asked who influenced decision-making regarding the child’s treatment. Responses were as follows:

Participant six: “Myself, because now my child is in ICU, when he got there, what happen is that I was with him here all the way and the other time the doctors called me and say they are taking him for scan to neurosurgery to see the brain because he keeps on fitting, they wanted to see what’s the problem, I had to sign a consent I never called him there’s a problem all of that so that they can take him there, when the child come back they say the child has water on the brain because of the infection water is not flowing properly that’s why he keeps on fitting so we have to take him for theatre, you have to sign this consent and all that I went and sign I never call anybody at home to say I say 123 because I know that when I am calling them they will be worried, let me just sign this and will deal with this and I will tell them after.”

Participant four: “I make a decision after I tell them because I can’t say to the doctor I must sign here for blood and I say wait I need to call someone, I have to sign and tell them later.”

Participant nine: “The family gives the input, we measure according to how it is going to help because at the end of the day the problem will remain with us.”

Participant one: “No, If they told me something like to get blood I will just call her and tell that today they are going to do this to my son. She will say as long its fine with you its fine because you know that it’s going to be good for him.”

These quotes clearly indicate that participants took decisions without any delays. Participant four and six described how they made the decision at the hospital without the influence of others. Klassen, Raina, Reineking, Dix, Pritchard and O’Donnell, (2007:808) support this finding by stating that family caregivers of paediatric

oncology patients are faced with numerous responsibilities and duties, for instance, decision-making, that needs to be made without delay. Although some participants could still ask for their husbands' opinions, it became clear that the husbands were only informed about the decision that had been taken. As indicated by three participants, in planning for healthcare both parties engaged, but decisions regarding treatment were made without consulting the fathers. Findings show that the mother preferred to inform the father and the rest of the family when the decision had already been made and treatment administered. This included consent to blood tests, scans, and X-rays. Participant four and six added that they did not want to delay treatment and worry others at home.

In a healthy relationship, fathers or spouses play a significant role in the lives of the children. Participants in this study were asked about the role of the father in the sick child's life. Participants who were in a functional relationship with partners had the following views:

Participant eight: "His role, the father makes sure that the child is happily financially, she has everything she needs."

Participant five: "He is a good man because he gives him support he loves him, he protects him."

Participant four: "To take care, sometimes, they are going together to play, they are friends actually."

Participant ten: "He supports me, he is my husband, he is the father of the house, and he gives me money."

Participant three: "He is there."

Participant six: "I would say he is supportive, he would ask me since he has cancer what food he is suppose to eat and what are the food that can boost him."

Participant two: "He is there for us, to take care mostly of the kids, when the kid says I want that, he is supposed to provide."

These quotes confirm that fathers in healthy relationships with wives or partners care for and love their children. However, there were participants, who were frustrated with the fathers of the children:

Participant one: "I can't see it, no role the father plays he is supposed to be supportive by now, the person who is supportive is my mom instead of him."

Participant seven: "The father only support financially if you tell him, he cannot just volunteer."

These participants sounded bitter when they talked about the father of the children, and it was observed that they had a very strained relationship.

The quotes revealed that decision-making regarding treatment and role of the father/spouse influenced decision-making. Responsible fathers were informed about the child's treatment and participated in the process.

Findings show that men generally dominate the decision-making process as the heads of the households, with exception to cases where partners are no longer in a relationship, mothers would make the decision. This is a traditional way of showing respect for the head of the household. In this study, women made decisions regarding the treatment of the child and gave consent in all treatment procedures, and husbands and partners would be informed later of the outcome. Some participants opted to rely on medical professionals, as they trusted that they knew better about the illness. Findings also show that fathers would only be involved in decision-making and play a role if they were on good terms with the mother of the child.

3.9.2.7 Theme 11: Recommendations from the participants

Recommendations to other caregivers were solicited from the participants who offered the following advice:

Participant eight: "I think such person should support the child, and they should tell the child that everything is going to be ok, even if you are sad don't show the child the problem."

Participant five: "I will tell them to pray for our children, don't be scared, when you cry you can make your child weak."

Participant four: "... cancer was there long time ago but they were treated in traditional but now it's not working with traditional because long time, they were very strong not now they are gambling things, they can lie to you, they need money, you give the child that medicine and that medicine nothing change it become worse, you think to come to the hospital it's too late, cancer already spread."

Participant nine: "Firstly I will share my experience and try to encourage her and assure that the child will be fine."

Participant one: "All I can give is that If you believe that child can be cured and if you ask people can answer you, because of there are some coming there with

no trust that their children can be cured. I just share my story, showing with my child's pictures before coming to Steve Biko, I tell them to believe."

Participant two: "If you have a kid even your husband or mother anyone in the family, I can just simple say if you see any symptoms of illness just go to the hospital and get tested and get those treatments very early than late."

Participant seven: "Like they must not rely on one option, they must check and put it in their minds, then believe, you will have that braveness to go through it, you won't listen to what they are saying, and they must consider second option. Okay, so if the medical is not working, they can also rely on their traditional."

Participant six: "I would say, it's not the end of the world and they also have to understand their children's diagnosis meaning that the child has cancer does not mean the child is going to die. They need to stay positive and also change their lifestyle."

Participant ten: "I can say your son is gonna be alright just trust God, I will read verses for her and encourage her."

Participant three: "I will give advice that she must go to the clinic to get some treatment for the baby in order for the baby to be fine."

The majority of the participants revealed the importance of support and believed in using their experiences to enhance the ability to cope of other caregivers. Participant one believed that support for fellow caregivers will enhance coping with the reality of the situation. The comments of participant six indicate her positive attitude in the face of cancer. The quote by participants five and eight and five show how their skills in handling the situation developed: they believed that a child needs support, not shame.

The findings clearly indicate that caregivers of paediatric oncology patients can play a pivotal role to help other caregivers new to the journey. The experiences of participants can be trusted and believed by the new caregivers. Participant two and three now understood that cancer can be genetic and their advice to others is to fight cancer at an early stage as they learnt the importance of early detection. Participant four discouraged the use of traditional medicine. Participant seven seems open-minded about medicines (traditional and Western), and believes that either of these medicines would work. Other participants believed in the power of prayer and read healing scriptures.

The above quotes show that participants encouraged one another through religious belief and promoted a positive attitude towards trusting the treatment. Participant four explained that she discourage the use of *muthis* because she came to realise that traditional healers often gambled with people's lives and lie about curing. Participant one offered to show pictures of her child before coming to Steve Biko Academic Hospital to improve caregivers' ability to cope in times of hopelessness where they may have little faith and trust. Furthermore, participant two encouraged fellow participant to ensure a healthy lifestyle for all family members.

Klassen, Raina, Reineking, Dix, Pritchard and O'Donnell, (2007:808) state that caregiving is one of the most stressful and unexpected careers and caregivers need support in order to cope during this dynamic process of caregiving and the various emotional phases it entails. Caregiver-to-caregiver support, therefore, will minimise some of the stresses encountered on their journey. According to the health belief model, caregivers are always surprised by the impact of caregiving to a paediatric oncology patient, since they do not understand cancer and its challenges. Caregiving of child with cancer is perceived as a severe task by the health belief model.

The researcher concludes that it is the difficulty of the task of caregiving that makes family caregivers of paediatric oncology patients vulnerable at the beginning of the journey because they do not know what they are faced with. The support they receive from each other may add value and minimise their stress levels. Caregivers understand that through talking and sharing, stress can be alleviated.

3.10 Summary

This chapter focussed on the research methodology and the research findings, namely the thematic analysis of the eleven themes generated from the data. These themes included: Theme 1: Understanding cancer; Theme 2: Access to healthcare; Theme 3: Religion, culture and spirituality; Theme 4: Communication and language; Theme 5: Socio-economic status; Theme 6: Delayed access to healthcare; Theme 7: Impact of cancer; Theme 8: Intentional and non-intentional delays; Theme 9: Medical and related costs; Theme 10: Caregiver responsibility regarding decision-making and support from the father; and Theme 11: Recommendations.

The next chapter focuses on the key findings, conclusions and recommendations of the study.

4. CHAPTER 4: SUMMARY, KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This chapter summarises how the goal and objectives were met and provides an answer for the research question. Key findings are discussed, conclusions are provided and recommendations are made.

4.2 GOAL AND OBJECTIVES

The goal of this study was to explore and describe factors challenging family caregivers of paediatric oncology patients in delaying access to healthcare. The goal of the study was achieved through the following objectives:

- To conceptualise and describe paediatric oncology, treatment, access to healthcare systems and the role of family caregivers.
- To explore and describe the challenges faced by family caregivers of paediatric oncology patients in the community and the health system.
- To explore and describe the factors that lead to delayed access to healthcare of paediatric oncology patients.
- To explore and describe the cultural challenges of paediatric oncology family caregivers.
- To make recommendations to the oncology team to enhance accessibility to paediatric oncology care.

The following summary reflects on each objective achieved in this study.

Objective 1: To conceptualise and describe paediatric oncology, treatment, access to healthcare systems and the role of family caregivers

This objective was addressed in chapter two, where the researcher conceptualises paediatric oncology and describes the following: the types of childhood cancers, signs and symptoms; diagnosis and treatment in paediatric oncology; the role of caregiving in paediatric oncology; factors contributing to late diagnosis of childhood cancer; access to healthcare; cultural and religious influences in healthcare; gender; bargaining; non-intentional or intentional delays to access healthcare; socio-economic factors as well as affordability of healthcare.

The literature study provided an understanding of the field of paediatric oncology and suggested that individuals are encouraged to take action when they understand the benefits of seeking help. Literature revealed several types of childhood cancers, its diagnosis and treatment as well as clinical characteristics of suggestive malignancies. It became clear that treatment of cancer is not easy to find, as it is only available at tertiary levels of care. In communities' healthcare systems function mainly at primary healthcare level. These facilities, as well as traditional healthcare providers are mostly accessible, but they do not render specialised services required for cancer in children.

Literature suggests that people should first realise the severity of the health problem in order to take action. Where caregivers of paediatric oncology patients do not understand health problems, they are unable to recognise childhood cancer symptoms. Health education events or awareness talks about childhood cancer appear once a year in communities and are not given much attention like other illnesses such as HIV and AIDS. Thus, little or no information reaches the community at large about childhood cancer. Caregivers would therefore not perceive ill health of children as a life-threatening situation. Literature review confirmed that information and knowledge are fundamental to achieve optimal health.

The role of family caregivers, various factors that prevent caregivers of paediatric oncology patients to access oncology care and the challenges that led to delays in access to healthcare were also discussed.

Objective 2: To explore and describe the challenges faced by family caregivers of paediatric oncology patients in the community and the health system

This objective focused on aimed at the challenges faced by the family caregivers of paediatric oncology patients in the community and the health system as far as delayed access to healthcare is concerned. The empirical study in chapter three explored and described these challenges faced by family caregivers in the community and the health system. This included the following themes: Understanding cancer, access to healthcare, socio-economic status, delayed

access to healthcare and intentional or non-intentional delays. All were factors that delayed access to healthcare.

Furthermore, participants experienced difficulties living far away from healthcare facilities and having poor infrastructure or no roads. One participant ensured that the sick child reached the hospital, by using a wheelbarrow to transport the child to the main road. However, some participants were close to healthcare facilities, shortage of equipment, specialists and resources were prohibiting factors. Patients would wait in local hospitals because there was no ambulance to transport them to a tertiary hospital. It was evident that even when emergency services were called, the ambulance would arrive late or not at all. The study revealed that in the community only primary and secondary levels of healthcare were available, but no tertiary level of healthcare with oncology units.

Furthermore, challenges of getting appropriate information from healthcare professionals about the disease lead to some participants making use of search engines such as Google to get information about the child's ill health. In theme 1 and sub-theme 1.4 it became clear that certain healthcare professionals in local healthcare centres had no insight in childhood cancer signs. Children were misdiagnosed and treated for different conditions which caused delayed oncology care. Participants revealed that only when children presented with low blood pressure, they were referred to Steve Biko Academic Hospital. Those with persistent illness that cannot be related or associated with any illness were given pain medication. Theme 1, sub-theme 1.3 reflected how participants continued to take medication at home, hoping for a cure. Due to healthcare professionals' limited knowledge about suspicious clinical characteristics and caregivers' ignorance about early warning signs of cancer, children's access to medical services were delayed. Before seeking medical treatment caregivers opted to first pray for the child, hoping for a miracle cure. Only when the illness prevailed, the child was taken to Steve Biko Academic Hospital where the diagnosis of cancer was made.

The empirical results showed that there was a correlation between the findings of this study and the Health Belief Model used to conceptualise challenges that faced caregivers of paediatric oncology patients to access healthcare. As discussed in chapter one, the components of the Health Belief Model were linked to their

behaviour. If caregivers had been knowledgeable about childhood cancer signs and symptoms, they would have taken prompt action understanding that early detection allows better management of illness.

During interviews with participants, it became clear that caregivers of paediatric oncology patients do not have insight in childhood cancer. The theoretical framework guiding this study confirms that caregivers have certain health beliefs, but no verified knowledge of or insight into childhood cancer that would have motivated them to seek medical advice about oncology care for children. Under these circumstances children remained vulnerable.

Objective 3: To explore and describe the factors that lead to delayed access to healthcare of paediatric oncology patients

The third objective was successfully achieved through conducting the empirical research and literature study, exploring the factors that led to delayed access to healthcare for children with cancer. Religious belief was identified as an important source of strength and security for certain individuals. Participants did not have knowledge about childhood cancer, and did not understand the severity of the disease. Limited knowledge about childhood cancer was a barrier, which prohibited and delayed participants to act at the onset of symptoms. Even those participants who had a history of cancer in their families, did not know that children could have cancer.

Unemployment and poverty proved to be important factors contributing to delayed access to healthcare. About 60% of the participants were unemployed and dependent on a child support grant. For this reason, they waited until the grant was paid out before taking children to hospitals or clinics. Most participants did not have a medical aid scheme. Access to healthcare for children with cancer was not delayed for 20% of the participants who were employed.

Objective 4: To explore and describe the cultural challenges of paediatric oncology family caregivers

The fourth objective of this study was to gain a better understanding of the cultural practices that would have delayed family caregivers of paediatric oncology patients to access healthcare. The empirical study confirmed that most participants do not

believe in traditional African ways, such as worshiping ancestors and seeking medical treatment from traditional healers. However, one participant confirmed her family's belief in the practice of indigenous medicine and cultural rituals involving ancestral spirits to seek healing and protection. This practice, however, did not cause any delayed access to healthcare for the child, because the participant also believed in Western medicine.

Even though women would consult their husbands about healthcare concerning the sick child, in this study it was a matter of respect, as in traditional African families the man is the head of the household. One participant did not share the same cultural beliefs as the father of her child. He attempted to force his beliefs on mother and child, but was unsuccessful, since he was neither married to or on good terms with the mother. She exercised her traditional rights of being single, followed her Christian beliefs and went to hospital.

Objective 5: To make recommendations to the oncology team to enhance accessibility to paediatric oncology care

These recommendations for possible interventions in the paediatric oncology field to enhance access to paediatric oncology care are made later in this chapter.

4.3 RESEARCH QUESTION

The research question guiding the study is formulated as follows:

What are the factors faced by the family caregivers of paediatric oncology patients, which result in late diagnosis of cancer in children?

This research question was answered through the qualitative research findings as discussed in chapter three, including 11 themes, indicating the factors faced by family caregivers of paediatric oncology patients, which result in late diagnosis of cancer in children. These themes and sub-themes are depicted in table 4.1 below:

Table 4.1: Themes and sub-themes

THEMES	SUB-THEMES
1. UNDERSTANDING CANCER	<ul style="list-style-type: none"> • Definition of cancer as understood by participants • Signs and symptoms experienced by the child • Action taken when child become ill

THEMES	SUB-THEMES
	<ul style="list-style-type: none"> • Information gained from healthcare professionals at local healthcare facilities • First diagnosis of child cancer • History of cancer in the family
2. ACCESS TO HEALTHCARE	<ul style="list-style-type: none"> • Distance to local clinic and hospital • Transport, easy access to emergency services and road accessibility • Access to traditional healers in the community • Access to clinic, hospital and oncology care
3. RELIGION, CULTURE AND SPIRITUALITY	<ul style="list-style-type: none"> • Religion and change in belief since diagnosis • Church attendance before and after diagnosis • Cultural rituals in family during illness or treatment • Beliefs about disease- traditional medicine – Muthis/Mbizas used • Beliefs in Western medicine and hospitals
4. COMMUNICATION AND LANGUAGE	<ul style="list-style-type: none"> • Experience of communication with health professionals • Language spoken • Level of understanding of diagnosis when explained • Understanding diagnosis and medical terms
5. SOCIO-ECONOMIC STATUS	<ul style="list-style-type: none"> • Employment status • Source of income • Housing and environment • Access to basic needs
6. DELAYED ACCESS TO HEALTHCARE	<ul style="list-style-type: none"> • Healthcare providers' - understanding cancer • Negligence of parents • Traditional healers • Time • Money and transport
7. IMPACT OF CANCER	<ul style="list-style-type: none"> • Impact on caregiver, siblings and family • Role changes
8. INTENTIONAL AND NON-INTENTIONAL DELAYS	<ul style="list-style-type: none"> • Income • Awareness of cancer • Emotions • Bargaining • Family beliefs

THEMES	SUB-THEMES
	<ul style="list-style-type: none"> • Beliefs in Western medicine • No support system • Other factors
9. MEDICAL AND RELATED COSTS	<ul style="list-style-type: none"> • Medical aid • Payment of medical bills • Hospital fee structure • Financial challenges
10. CAREGIVER RESPONSIBILITY REGARDING DECISION-MAKING AND SUPPORT FROM FATHER	<ul style="list-style-type: none"> • Decision-making and support from the father.
11. RECOMMENDATIONS	<ul style="list-style-type: none"> • Recommendations from participants

4.4 LIMITATIONS OF THE STUDY

The following may be regarded as limitations of this study:

- Firstly, gender limited the study to gain different views as only black female caregivers participated in the study, males were not available.
- Secondly, sampling was exclusive to the Steve Biko Academic Hospital population. More perspectives may have added different and/or additional views if oncology family caregivers were interviewed from other hospitals providing paediatric oncology care in Gauteng.
- Thirdly the findings cannot be generalised, but can be applied to similar populations.
- Lastly, interruptions occurred during the interview process. Lodgers not participating in the study unintentionally entered the interview room. The researcher believes this was due to the fact that not all lodgers were informed about the usage of the room as a private office. In future, a do-not-disturb note should be put on the door to alert lodgers that unauthorised entry is prohibited.

4.5 KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

Conclusions regarding the research methodology and literature review are firstly provided, followed by the key findings, conclusions and recommendations of the research findings, structured into the eleven themes.

4.5.1 Conclusions regarding the research methodology

This study embraced the qualitative approach. It enabled the researcher, through rich data collected in the form of the voices of the participants, to understand the factors faced by family caregivers of paediatric oncology patients, who contributed to delaying access to healthcare of paediatric oncology patients. The relevance of applied research is seen in the descriptive nature of this study, allowing the researcher to focus on a specific problem in practice, namely, factors that contributed to the family caregivers of paediatric oncology patients delaying access to healthcare. The population of this study was drawn from Steve Biko Academic Hospital, particularly the Paediatric Oncology Department. The ten participants were selected using non-probability purposive sampling, which was deemed suitable, as there was no list of caregivers listed in the department. Purposive sampling allowed the researcher to use her judgement to select family caregivers who met the selection criteria. The participants of this study were all black females.

The case study design was a suitable research design. Specifically, a collective case study design provided an opportunity to study multiple cases focusing on the factors that present the obstacles family caregivers are faced with when caring for paediatric oncology patients. Participants had an opportunity to express their opinions openly. The researcher could understand the phenomenon through recording the participants' own experiences about their particular challenges.

A semi-structured one-to-one interview with an interview schedule was used as guide during the interview. This method allowed the researcher to obtain rich data from the family caregivers in face-to-face situation. A digital voice recorder used to capture the interviews, assisted the researcher to listen to and, transcribe the interviews, in order to record and understand what the caregivers were faced with.

The researcher analysed the data using the spiral process of qualitative data analysis. During this process, the researcher generated themes and sub-themes that were presented in the form of a thematic analysis.

4.5.2 Conclusions regarding literature review

A literature study was conducted to gain a better understanding of the topic. This brought in-depth understanding of paediatric oncology and provided an understanding of the different types of childhood cancer, and suspicious clinical characteristics, which would assist caregivers, families and other healthcare professionals to understand childhood cancer. Furthermore, the factors were explored that played a role in family caregivers of paediatric oncology patients delaying access to healthcare.

Literature revealed different levels of healthcare. From the primary to the tertiary level of healthcare children were misdiagnosed, because some healthcare professionals from primary healthcare have limited knowledge about the early warning signs of childhood cancer. Geographic proximity to healthcare facilities influenced access, as did knowledge about the disease. Individuals who were uninformed about childhood cancer did not realise the life-threatening nature of childhood cancer and were unlikely to make informed decisions about seeking help.

Literature underlines the influence of people's health beliefs based on religion and culture. These beliefs clash with Western medicine and treatment that are often perceived as a curse because it goes against cultural beliefs and practices. The influence of religion cannot be underestimated, as it is the source of strength for many African people, with certain prominent religions interpreting ill health differently. This provides an understanding of how ill health, based on religious and cultural beliefs, could be misinterpreted by many people.

The literature review revealed socio-economic factors as prohibiting attainment of optimal health. This included income, living conditions, cost and affordability of treatment. These factors could contribute immensely in delaying access to healthcare, as people would wait until they have finances to pay for health services. Furthermore, literature showed communication as a fundamental factor to provide a sound healthcare service. It became clear that uninformed individuals and communication barriers, as well as certain healthcare professionals' inability to

communicate effectively would contribute to the challenges faced at healthcare facilities.

Literature also revealed hope in terms of balanced healthcare systems, where poor and rich would be able to receive equal healthcare services, with the introduction of a National Health Insurance (NHI). Literature studies confirmed that the health beliefs are different in different cultures. If individuals do not have knowledge about health issues, nothing can sensitise them to take action to ensure proper and timeous healthcare.

The health belief model perceives various factors as potential barriers and a threat to obtain optimal health. The issue of accessibility had a tremendous influence to delay healthcare. People are unaware of cancer and its early warnings signs, socio-economic factors are perceived as barriers and children remain vulnerable to suffer where adults delay to take health action. The theoretical framework of this study concurs with literature: Where people are exposed to certain factors, they are vulnerable and are more than likely to be demotivated to take action about health issues. However, if these factors are addressed, people will understand illness and value the benefit of early detection.

4.5.3 Key findings, conclusions and recommendations regarding the empirical study

Key findings will be discussed in accordance with each theme outlined in chapter three, followed by the conclusions and recommendations for each specific theme.

4.5.3.1 Theme 1: Understanding cancer

4.5.3.1.1 Key findings

This theme is supported by various sub-themes: Definition of cancer as understood by participants; signs and symptoms experienced by the child; action taken when child became ill; information gained from healthcare professionals at local healthcare facilities; first diagnosis of a child's cancer; and history of cancer in the family.

The first theme explored the understanding of participants in this study of childhood cancer. The study showed that participants did not have any insight into childhood

cancer as some could even associate cancer with evil spirits. Early signs and symptoms of childhood cancer remained undetected by the participants. As participants did not understand, the signs of childhood cancer the first action they took was to give painkillers and herbs to relieve symptoms and pains at home. The persistence of ill health sensitised the participants to consult with local healthcare facilities. Findings revealed that children were initially diagnosed with different common illnesses and treated accordingly. Only when the treatment was not working were they transferred to Steve Biko Academic Hospital. The findings revealed that some healthcare professionals would indicate that cancer is not common for children. According to the study's findings, participants learned about childhood cancer at Steve Biko Academic Hospital for the first time. It is also revealed that even those participants with a history of cancer in the family, did not have knowledge that children may also have cancer.

This theme can be linked to the health belief model, in that it relates to social cognition. It clarifies the reason why people delayed access to healthcare; people are motivated to take action when they understand the benefit of health action. The model makes it clear that if people have insight about the early warning signs of childhood cancer, they will be motivated to seek help. In the course of this study, it became clear that nothing could have motivated or sensitised participants to consult a health practitioner immediately, as they did not understand the signs and symptoms of children's cancer.

4.5.3.1.2 Conclusions

- Children with cancer experienced a delay in being diagnosed and in accessing treatment due to the lack of knowledge of parents/caregivers unable to recognise early warning signs of childhood cancer.
- African female family caregivers in this study did not consult traditional healers, but this was not the main reason why they delayed access to healthcare, as initially assumed in this study.
- The team of healthcare professionals at primary healthcare level had limited information about childhood cancer and the early warning signs, misdiagnosed the child, gave irrelevant treatment and contributed to delaying early diagnosis and treatment.

4.5.3.1.3 Recommendations

- The Department of Health and other non-profit organisations such as CHOC and CANSA working with childhood cancer should join forces and plan major awareness campaigns to educate the public on the early warning signs and symptoms of childhood cancer as part of Early Childhood Development (ECD).
- Healthcare professionals/providers at the primary healthcare level should be educated and empowered to detect the early warning signs and symptoms of childhood cancer and to make appropriate referrals.
- Healthcare professionals should understand that they play a major role in health education. They should promote the awareness of childhood cancer at primary and secondary level clinics and hospitals as well as in the media.

4.5.3.2 Theme 2: Access to healthcare

4.5.3.2.1 Key findings

Various sub-themes were generated from this theme, including: Distance to local clinic and hospital; transport, easy access to emergency services and road accessibility; access to traditional healers in the community and to the availability of and access to a clinic, hospital and oncology care.

The second theme explored participants' access to healthcare. Findings revealed that participants could often not access healthcare facilities due to distances travelled, since they relied on public transport. The findings revealed that emergency services delays and poor infrastructure had an impact. The findings also revealed that traditional healers were visible and easily accessible in the communities, even those coming from neighbouring countries. The findings showed that some participants have access to local clinics and hospitals. However, they lived very far from facilities providing oncology care, which is only found at the tertiary level of healthcare. The study findings revealed that oncology care was an unknown service to many participants.

The health belief model identified access to healthcare as a barrier, as some participants struggled with distances and poor, while some individuals, according to their cultural and/or religious beliefs chose to consult a traditional healer. They delayed taking health action due to these circumstances. Therefore, children may

be susceptible to ill health and, due to these factors, cancer diagnosis and treatment only occur at a very late stage of the illness.

4.5.3.2.2 Conclusions

Access to healthcare is impeded in many communities by factors such as a lack of basic services, where roads and infrastructure is non-existent, and access to transport limited. Emergency services are not functioning, as they should. In times of need these services will be unavailable. The situation becomes worse due to the unavailability of ambulances, insufficient maintenance of emergency vehicles and the lack of emergency personnel. Distances and accessibility to tertiary levels of healthcare posed a serious problem and made it difficult for people to take prompt action when faced with life-threatening illness. These factors hampered access to healthcare and specifically for children with cancer who were more vulnerable in such hopeless situations.

4.5.3.2.3 Recommendations

- Healthcare services, specifically at tertiary level, for serious life threatening illnesses, must be made more accessible to the community.
- Primary healthcare clinics must train their personnel to be more knowledgeable about childhood cancer, warning signs and early detection, as part of Early Childhood Development (ECD) and so that children can be referred to the tertiary level healthcare services and treated in the early stages of cancer with better resultant survival rates.
- Basic services such as roads and infrastructure must be put in place by municipalities and government in communities where it is lacking, allowing easy access to transport for all.
- Emergency services in the public health sector must be improved, with more emergency personnel and ambulances in order to improve response time.
- Health promotion and awareness campaigns about childhood cancer and its early warning signs must be prioritised and be made visible in communities to sensitise people to this illness and to seek treatment in time.
- A cell phone “please-call-me” system should be introduced for emergencies by the Department of Health. This system can be introduced as the Government Healthcare Emergency Call Centre for Assistance.

- Childhood cancer needs to become a health priority area in the Department of Health in order to improve early detection, treatment and survival rate of childhood cancer.
- There should be better health screening and referral services for children at clinics.

4.5.3.3 Theme 3: Religion, culture and spirituality

4.5.3.3.1 Key findings

Sub-themes in this theme were: Religion and change in belief since diagnosis; Cultural rituals in family during illness or treatment; Beliefs about disease- traditional medicine – Muthis/Mbiza's used; and Beliefs in Western medicine and hospitals. In exploring religion, spirituality and culture of participants, the findings revealed that participants were all Christians. The diagnosis of children with cancer improves their relationship with God and became 'prayer warriors', grounded in Christ, who acknowledged the importance of prayer groups to maintain their spiritual level and ease the burden of ill health. The findings revealed no cultural rituals were performed during the illness. Cultural rituals in families pointed towards different beliefs of the mother and father of the child. Some fathers of the child patient performed cultural rituals, such as slaughtering a goat honouring the late members of the family and asking them to protect children from illness and evil spirits. Mothers did not share these cultural beliefs. Findings revealed that some participants believed cancer to be black magic' or witchcraft, or a test from God to strengthen faith. Others were confused about what to believe, though participants believed in Western medicine and treatment, the church was their first refuge when children became ill.

The health belief model encourages the observation of religious aspects and diversity of religion and health issues. Sometimes people experience crisis in faith when faced with sickness. People are motivated to take health action when they become aware of its benefits and explore further treatment. In many cases in this study people turned to religious practices because it was the only thing that they were exposed to. Subsequently, some consulted health practitioners only when they realised that prayers and rituals made no significant difference in the sick children's conditions.

4.5.3.3.2 Conclusions

Religion was a source of strength that contributed towards participants' ability to cope with cancer. In some instances, it precluded recognition that cancer is a life-threatening disease, and where individuals would not seek healthcare services. Although it gave individuals a sense of hope, it also brought a lot of confusion whether to believe in Christ or their God, depending on their religion, or in Western medicine. Eventually it seemed that participants believed in both their religion and in Western medicine to heal their child. Spirituality was a factor that enhanced peoples coping mechanisms and would typically become more intense after diagnosis of cancer. Cultural practices were not a predominant factor that contributed to delayed access to healthcare in this study. In terms of the health belief model, religion can contribute in delaying individuals to access healthcare. People believing that God will perform miracles, will put faith in Him believing that there will be a miracle healing. This factor may have impeded participants' to consult health practitioners in time before the child become critically ill.

4.5.3.3.3 Recommendations

- Cancer awareness strategies should become priority to enhance African people's knowledge about childhood cancer and treatment.
- Knowledge about Western oncology treatment needs to be improved amongst Africans.
- Church leaders, including pastors and prophets, need to be educated about childhood cancer and not encourage people to delay treatment and only resort to their faith, but to rather combine the two to complement each other. Health issues should be discussed to raise awareness of treatment and enhance faith in Western medicine.
- Community leaders, traditional leaders and healers need to be educated and become more knowledgeable about childhood cancer, warning signs and early detection, as part of contributing to Early Childhood Development (ECD).

4.5.3.4 Theme 4: Communication and language

4.5.3.4.1 Key findings

This theme generated three main sub-themes: Experience of communication with health professionals, language spoken; level of understanding of diagnosis when explained; and understanding diagnosis and medical terms.

The fourth theme explored the experience of participants' communication with healthcare professionals. The findings revealed that some participants experience two-way communication with healthcare professionals. The English language was used when diagnosis communicated. Findings were clear that participants found the usage of medical terms enormously challenging. They find them very difficult to understand and called them "big words." Some participants said that oncologist could simplify the terms, whereas others found medical terms very problematic. Findings revealed that some participants recorded the session with the doctors so that they could reflect on what was discussed.

Findings further showed that nurses were mediators between the caregiver and the doctor; participants approached them to communicate their concerns. Findings revealed that the participants' understanding of the diagnosis was very limited and was made worse by medical terms, confusion, mixed emotions, and feelings of being overwhelmed. Findings revealed that few participants could manage to ask questions to clarify what they do not understand. Findings showed that healthcare professionals at the Steve Biko Academic Hospital were friendly and participants experienced a sense of understanding and sympathy from them. However, it became clear that healthcare professionals at local healthcare centres were less friendly and approachable, and often had negative attitudes towards caregivers.

This can be linked to the health belief model that states that people are encouraged to communicate only if they receive positive responses from health professionals. If people interact with health professionals with a positive attitude, friendliness and an approachable demeanour, they may be more open to advice and suggestions. The use of laymen's terms may even encourage a positive patient-service provider relationship, based on trust and openness.

4.5.3.4.2 Conclusions

Clear communication and a positive attitude in healthcare facilities are crucial at all levels. Healthcare professionals should maintain positive relationships with caregivers of patients, show empathy and translate medical terms in laymen's terms to promote open communication and enhance understanding. The family will then be more confident to approach healthcare professionals. Thus, healthcare professionals need to be easily approachable and friendly to the people they serve. In the field of paediatric oncology communication with the parent/caregiver is crucial, as there is a lot of unexpected bad news. Caregivers need to understand the importance of treatment compliance, challenges along the journey of care, and they should understand that they face a life-threatening disease and possibly death of the child. Family caregivers should be aware of the medical treatment the child receives and its side-effects in order to reduce unnecessary anxieties.

4.5.3.4.3 Recommendations

- Medical terms need be explained in laymen's terms and simplified to enhance easy understanding by parents/caregivers. A positive patient-service provider relationship, based on trust and openness, should be encouraged.
- Healthcare professionals need to be more approachable and make time to explain the condition to patients and family.
- Family caregivers need to be empowered to communicate with doctors. They should understand that they have a right and responsibility to know about the child's illness and treatment plans.
- There should be an empowerment programme to assist the public better with healthcare professionals.

4.5.3.5 Theme 5: Socio-economic status

4.5.3.5.1 Key findings

Four sub-themes informed the main theme: Employment status; source of income; housing and environment, and access to basic needs.

The fifth theme explored the socioeconomic statuses of the participants. The study findings revealed that the majority of participants were unemployed and the recipients of child support grants. Only two participants were employed. Findings

revealed that those self-employed were doing jobs such as selling tyres and domestic jobs. Findings showed that unemployment factor prohibited some participants to take prompt action to seek healthcare. Findings revealed that most children were vulnerable for this reason. Findings were clear that for some participants coming from neighbouring countries, unemployment brought crisis and imbalance in their social sphere. Five out of ten participants indicated that they own houses, though others were still renovating and building the houses. Ten percent (10%) of the participants own RDP houses. Findings revealed that participants believed in family cohesion and a big family of six could occupy a room and live together. Though this environment may bring discomfort to a sick child, it clearly showed love and closeness in a family. The findings revealed that participants had access to basic needs that included water, electricity, and sanitation though some were still using outdoor toilets.

This can be linked to the health belief model stating that if people do not have the means, are unemployed, and dependent on low social grants, they may not be motivated and inclined to seek help. The framework states that people can be a product of reciprocal and intrapersonal, behavioural and environmental determinants as suggested by social cognition.

4.5.3.5.2 Conclusions

Living circumstances of the participants undermine the ability to take action regarding healthcare. Participants were mainly unemployed and dependent on child support grants. Due to these factors, participants were disadvantaged and discouraged to take health action. It is unfortunate that children with cancer in these families will be more vulnerable as only basic needs such as food can be bought. Under these dire circumstances, healthcare becomes a luxury.

4.5.3.5.3 Recommendations

- Health awareness campaigns should target the poverty-stricken.
- Community enrichment programmes should educate parents about childhood healthcare and illnesses to ensure early detection and prevention.

4.5.3.6 Theme 6: Delayed access to healthcare

4.5.3.6.1 Key findings

This theme had six sub-themes: Healthcare providers' understanding of cancer negligence of parents', traditional healers; time money and transport.

The sixth theme explored several factors that cause delayed access to healthcare. Findings revealed that healthcare providers in the local hospitals do not have enough knowledge to identify early warning signs of childhood cancer. The findings showed that children would be misdiagnosed and given medication for a prolonged period. Only a few children who presented with blood disorders could be referred to hospital without delay. Other children who were presented very ill to the local hospital were also not delayed. Findings revealed that over-the-counter medication such as Panados and Grandpa were mostly dispensed for the treatment of pain.

Neglecting or careless parents pose a real problem in treating children with cancer. Findings show that some participants' neglected was mainly caused by the fact that no money was available to take children to the healthcare centres. Some participants found it difficult to take time off due to busy work schedules and as a result, children could not be monitored properly until they became extremely ill. Relief was provided when participants reached their local healthcare facilities and hospital-to-hospital transport was arranged to Steve Biko Academic hospital.

According to the health belief model, should healthcare professionals have been aware of the warnings signs their response to children's ill health could have been different. Children, therefore, were vulnerable due to delayed access to healthcare and late diagnosis. The researcher also believes that primary healthcare needs to be enhanced in terms of educating healthcare providers. This will bridge the understanding gap between primary and tertiary healthcare services. Cancer in children will be detected early and cases can be referred to tertiary facilities without any delays.

4.5.3.6.2 Conclusions

Knowledge gaps where the fact that healthcare professionals were unable to identify early warning signs of childhood cancer emerged as detrimental towards

early detection of cancer in children and to provide access to oncology care. When caregivers have insight and become aware that they are faced with life-threatening disease, they are more likely to take health action despite their circumstances.

4.5.3.6.3 Recommendations

- Health professionals at primary healthcare level need training about childhood cancer in order to detect it early and make appropriate referrals.
- Education of the public about the early warning signs of childhood cancer is essential.
- All healthcare professionals should be trained in the early warning signs of childhood cancer, in order to ensure early detection.

4.5.3.7 Theme 7: Impact of cancer

4.5.3.7.1 Key findings

This theme generated two sub-themes: Impact of cancer on the caregiver, siblings and family, and role changes that occur under these circumstances.

The seventh theme explored the impact of cancer. Findings revealed that cancer impacted the caregiver, siblings, and family as it cause a crisis situation in the family, increases stress and demands drastic changes in the family. Findings revealed that participants were faced with an unexpected career called caregiving that demands hospitalisation, adaptation, adjustment and fast learning from the caregiver. Cancer paralysed the functioning of the family as some participants lost jobs and became the caregivers. Siblings are affected emotionally and psychologically. Family roles had to be changed even if they compromised the normal functioning of the family. As an example, the mother had to relocate to Steve Biko Academic Hospital to fulfill the caregiving role, whereas the father had to take responsibility for domestic activities, while remaining the provider for the family.

In some instances, significant others in the family would provide support for the children. Cancer brought socioeconomic family dysfunction and misery. To those participants with a history of cancer in the family, it brought more stress as participants worried about finding a solution. An interesting finding revealed that

some participants thought cancer as contagious. They also anticipated strenuous ongoing caregiving of the other children.

4.5.3.7.2 Conclusions

Diagnosis of cancer brings about role changes in the family system. It affects the family emotionally, psychologically and economically. The families had to learn to adapt to the new circumstances. Siblings and partners were also affected by the child's cancer and hospitalisation caused separation, isolation, anger and strained relationships.

4.5.3.7.3 Recommendations

- Psychosocial support and support groups should be provided at local healthcare facilities, to assist caregivers and family members by educating them about childhood cancer and treatment, the psychosocial implications for the family and to help them to cope with the challenges.

4.5.3.8 Theme 8: Intentional and non-intentional delays

4.5.3.8.1 Key findings

Sub-themes included income; awareness of cancer; emotions, bargaining; family beliefs; beliefs in Western medicine and a lack of support systems emerged clearly during the investigation.

The eighth theme explored intentional and non-intentional delays. Findings revealed numerous factors that cause non-intentional delays. Firstly, the findings showed that income prohibited some participants to visit healthcare centres. The study indicates that participants felt that the issue of income was unrealistic. They believe that some individuals (caregivers) have the inclination to use pain medication instead of consulting healthcare practitioners. The lack of awareness about childhood was a non-intentional factor that cause that no sense of urgency existed to attend to illness as participants were unaware of the severity of cancer as a disease. Some participants revealed that they would refuse transfer to Steve Biko hospital if the child diagnosed in the local hospital because they have learned that cancer is not curable. They would rather wait for the child to die at home. This statement points

to the fact that some of these participants were not aware of cancer and that if cancer was detected early it could have been managed better and/or even cured.

Findings revealed that participants experienced disturbed emotions when children were diagnosed with a life-threatening disease. The news was unexpected and brought grief. They experienced a range of emotions including shock, numbness and denial.

Some participants started to bargain; typically asking God their children are diagnosed with cancer. Others started to doubt their religion; they blamed the current priest for an apparent inability to heal a child with cancer.

Import for this study, findings showed no family beliefs or practices of the participants that delayed treatment. However, a lack of awareness about the disease caused delays in diagnosis and treatment of childhood cancer. Participants in this study believed in Western medicine. Findings show that some participants confident that Western medicine brings hope to disease management. Participants have support systems and the family system was observed as a principal source of strength. Other factors revealed that the use of Sangomas, prolonged 'shopping' for healing, were factors that intentionally delayed cancer diagnosis and treatment. Some individuals chose to start with traditional healing before accessing healthcare.

4.5.3.8.2 Conclusions

Non-intentional delay to access healthcare is informed by various factors. The issue of cancer awareness and income affected the participants. Mostly, it became clear that if participants were aware of childhood cancer, they would have tried all means possible, like borrowing money or making debt, to ensure that they get professional help. In some cases, participants still believed in traditional medicine and would opt for that instead of Western treatments.

4.5.3.8.3 Recommendations

- There is a demand for childhood cancer awareness in South Africa.
- The Department of Health and related NGOs and NPOs should plan aggressive campaigns and educate the public about childhood cancer and treatment.

4.5.3.9 Theme 9: Medical and related costs

4.5.3.9.1 Key findings

Four sub-themes emerged from the main theme: Medical aid; payment of medical bills; hospital fee structures and financial challenges.

The ninth theme explored the medical and related costs. The findings revealed that most participants did not have medical aid. They could not afford or qualify for any medical aid cover. Only one participant had medical aid cover and access to healthcare never delayed. Medical bills of the child paid by the Military Hospital (referral hospital). Though she had the medical aid, the child benefitted to the workplace medical support. The study shows that most of the participants were not paying hospital fees. Very few could make arrangements for payment according to the hospital fee structure. The payment structure for each participant was determined by a means test, based on affordability, to classify them. The children of the participants were treated regardless of whether the parents had medical aid or not. Other related costs included extra expenses where participants had to buy food because children did not want to eat hospital food. Furthermore, transport to the hospital regularly incurred extra costs.

4.5.3.9.2 Conclusions

There is still a need to improve healthcare services to accommodate all people. Those with medical aid cover still access healthcare with no delays as compared to those without. The issue of health inequality remains a questionable issue in terms of accessibility, as children with cancer are prone to be diagnosed late, as parents cannot afford medical aid and have to go to the local healthcare centres where cancer is unlikely diagnosed. Health belief perspectives recognise these medical factors as barriers to obtain optimal healthcare and emphasise the need to implement systems to address the phenomenon of late diagnosis.

4.5.3.9.3 Recommendations

- National Health Insurance should be implemented to provide medical cover to all people.

4.5.3.10 Theme 10: Caregiver responsibility regarding decision-making and support from father

4.5.3.10.1 Key findings

Findings showed that men in general dominate decision-making as the heads of the households, with exception to cases where partners are no longer in a relationship and mothers would make all decisions. In this study, women made decisions regarding the treatment of the child and gave consent in all treatment procedures, and husbands and partners would be informed later of the outcome. This theme identified decision-making as a major responsibility of the caregiver with support from the father. Findings revealed that some participants relied more on the healthcare professionals in decision-making. They believed that these professionals know better about the illness and its treatment. There was conditional support received from fathers, supportive fathers and unavailable fathers. The supportive father is aware of the needs of the child and provides necessities, while the unavailable father is aware of paternity, but his support is based on whether he is on good terms with the mother of the child.

4.5.3.10.2 Conclusions

Decision-making is the main responsibility of the caregiver and who fully participated in patient management. Though they did not lead the decision, their influence played a crucial part in decision-making regarding treatment. In most cases, this responsibility of caregiving came unexpectedly. The father's support depends on whether he is still in a relationship with the mother of the child. According to the health belief model people are always motivated to participate when a benefit exists. In this case, the benefit is a healthy relationship characterised by mutual love. Some fathers were not motivated to take parental responsibility due to the lack of a relationship between the parents. Unavailable fathers can be barriers to easy access to healthcare. The situation becomes more serious as the mother may not have other visible means of support. The child's access to healthcare will then be delayed.

4.5.3.10.3 Recommendations

- The hospital should offer support groups at the hospitals to help the caregivers cope.

4.5.3.11 Theme 11: Recommendations from participants

4.5.3.11.1 Key findings

Recommendations by participants may be regarded as advice to other caregivers of children diagnosed with cancer. They reflect what participants believed can console other caregivers in similar situations. The findings revealed that the majority of participants believe in the importance of support systems and use their experiences to enhance other caregivers coping mechanisms. Some participants recommended religious belief as coping mechanism. Others contended that caregivers should not show deep sorrow in front of the children, as they believe it would weaken the sick child's faith and possibly create despair. Family should also be involved in screening programmes to allow early detection of diseases. This is in line with the health belief model because this model serves to provide practical solutions to problems such a late diagnosis of cancer and it assist with explaining what were the challenges faced caregivers to access healthcare. Caregivers to support other caregivers may alleviate the unnecessary stress of caregiving on the journey of oncology care. Caregiving of a child diagnosed with cancer is challenging at all levels and the individuals are always unprepared to take on this unexpected role. The support of other caregivers may bring meaning and relief for parents or family members tasked with the responsibilities associated with a young oncology patient.

4.5.3.11.2 Conclusions

Support of caregivers is seen as fundamental in alleviating the stressful circumstances experienced by caregivers in the field of paediatric oncology. Caregivers are faced with numerous responsibilities formerly unfamiliar in their lives. The literature studies cite that caregiving can be seen as an unexpected career where an individual move through a series of stages, requiring adaptation and restructuring. The support, therefore, would help the caregivers to adjust, adapt and develop new ways of living. Participants believe that religious support and caregiving experiences may impact positively to enhance other caregivers' coping mechanisms and strategies.

4.5.3.11.3 Recommendations

- The establishment of formal caregivers support groups in the field of paediatric oncology is necessary to assist caregivers in coping with the challenges of oncology treatment.

4.6 RECOMMENDATIONS FOR FUTURE RESEARCH AND POLICY

The findings of the study confirms that there is a lack of knowledge about childhood cancer; people need to understand childhood cancer, early warning signs, and symptoms, as well as the importance of early detection in order to improve the survival rate of children. It is recommended that future studies investigate the effectiveness of health promotion programmes for childhood cancer. The reasons for the failure of the Department of Health to attend to childhood cancer from primary level need to be explored. South Africa provides a strong legislative policy foundation for a developmental approach to childcare and protection of children. There is a need to put these policies into practice and ensure accountability and compliance.

4.7 CONCLUSIVE REMARKS

Childhood cancer remains a global health concern. The aim of this study was to fill a gap in research on children with cancer and why their access to treatment is often delayed, resulting in late diagnosis. The multifactorial challenges faced by the family caregivers of paediatric oncology patients in delaying access to healthcare were reflected through the themes generated. The study helped bridge the understanding-gap between the families, caregivers, and oncologists in the Paediatric Oncology. The rights of children to access healthcare, should be respected, as they are a vulnerable group, susceptible to many forms of ill health. It is therefore crucial that awareness about the early warning signs of childhood cancer be raised.

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6. APPENDICES

6.1 APPENDIX 1: CHANGE OF TITLE

UNIVERSITY OF PRETORIA
DWARSVORM / LATERAL FORM
 RECOMMENDATION REGARDING TITLES AND ETHICAL CLEARANCE OF THESES/DISSERTATIONS/mini-DISSERTATIONS,
 SUPERVISORS/CO-SUPERVISORS

THIS FORM MUST PLEASE BE TYPED AND SUBMITTED IN DUPLICATE.
Please note: THE NECESSARY ETHICAL QUESTIONNAIRE AND RESEARCH PROPOSAL SHOULD BE ATTACHED TO THIS FORM.

Student number: 15261329 Title: Ms Surname: Mabhoza Initials: N Course: MSW (Healthcare) Department: SOCIAL WORK & CRIMINOLOGY Postal address: 565 Adcock Street Unikop Flat 502, Gezina 0084 Tel No: 0720475287	a) SUPERVISOR: Dr CL Carbonatto Please state staff number (If a person outside the University is nominated, a CV and motivation should be attached to the proposal) b) CO-SUPERVISOR: N/A Please state staff number (If a person outside the University is nominated, a CV and motivation should be attached to the proposal)	ROUTE 1. SUPERVISOR: Signature: <i>[Signature]</i> Date: 10/12/2018 2. DEPARTMENTAL RESEARCH/POSTGRADUATE COMMITTEE: Signature: <i>[Signature]</i> Date: 10/12/2018 3. HEAD OF DEPARTMENT: Signature: <i>[Signature]</i> Date: 10/12/2018 4. CHAIR OF CLUSTER: APPROVED Signature: _____ Date: _____ 5. STUDENT ADMINISTRATION: (to be submitted to the Ethics Committee/Postgraduate Committee where applicable) Signature: _____ Date: _____ 6. FACULTY RESEARCH ETHICS COMMITTEE: (to approve ethical clearance) FACULTY POSTGRADUATE COMMITTEE: Where applicable (to approve research proposal, change of title, appointment of external supervisor/co-supervisor, change of supervisor/co-supervisor) Signature: <i>[Signature]</i> Date: _____ 7. RESEARCH COMMITTEE: Signature: _____ Date: _____
Please ensure that the title is grammatically correct. Please do not type the full title in capital letters. For notification of the faculty board, please mention: THESIS: _____ DISSERTATION: _____ MINI-DISSERTATION: X OLD TITLE: Multi-factorial challenges of caregivers of paediatric oncology patients regarding delaying access to health NEW TITLE: Multi-factorial challenges of family caregivers of paediatric oncology patients regarding delaying access to healthcare		
APPROVAL: <input type="checkbox"/> Ethical clearance to be considered by the Ethics Committee <input type="checkbox"/> Appointment of external supervisor/co-supervisor (motivation and cv attached) <input type="checkbox"/> Change of supervisor/co-supervisor <input type="checkbox"/> Research proposal and title to be considered by the Postgraduate Committee (where applicable) <input checked="" type="checkbox"/> Editorial change of title <input type="checkbox"/> Other (mention): _____		

September 2013 LATERAL FORM / DWARSVORM
Faculty of Humanities Postgraduate Committee and Ethics Committee

6.2 APPENDIX 2: ETHICS APPROVAL - FACULTY OF HUMANITIES



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

1 November 2017

Dear Ms Mabhoza

Project: Multi-factorial challenges of caregivers of paediatric oncology patients regarding delayed access to health
Researcher: N Mabhoza
Supervisor: Dr CL Carbonatto
Department: Social Work and Criminology
Reference: 15261329 (GW20171027HS)

Thank you for the **well written** application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 26 October 2017. Data may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance

Sincerely

A handwritten signature in black ink, appearing to read 'Maxi Schoeman'.

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

cc: Prof A Lombard (HoD)
Dr CL Carbonatto (Supervisor)

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Dr L Blokland; Ms A dos Santos; Dr R Fassell; Ms KT Govinder; Dr E Johnson; Dr C Panebianco; Dr C Puttergill; Dr D Reyburn; Dr M Taub; Prof GM Spies; Prof E Tajard; Ms B Tsebe; Dr E van der Klashorst; Dr G Wolmarans; Ms D Mokalapa

6.3 APPENDIX 3: ETHICS APPROVAL CERTIFICATE - FACULTY OF HEALTH SCIENCES

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

31/08/2017

Approval Certificate New Application

Ethics Reference No: 350/2017

Title: Multi-factorial challenges of caregivers of paediatric oncology patients regarding delayed access to healthcare.

Dear Ms Notshanti Mabhoza

The **New Application** as supported by documents specified in your cover letter dated 23/08/2017 for your research received on the 23/08/2017, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 30/08/2017.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (**350/2017**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Additional Conditions:

- Approval is conditional upon the Research Ethics Committee receiving approval from the Faculty of Humanities Research Ethics Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers; MBChB; MMed (Int); MPharMed, PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

☎ 012 356 3084 ✉ fhsethics@up.ac.za 🌐 <http://www.up.ac.za/healthethics>
✉ Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60, Gezina, Pretoria

6.4 APPENDIX 4: PERMISSION LETTER TO CONDUCT RESEARCH -
HEAD OF PAEDIATRIC ONCOLOGY



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences
Fakulteit Gesondheidswetenskappe

29th May 2017

Dear Ms N Mabhoza

RE: Permission to conduct research in the paediatric oncology unit.

I have read your research proposal and feel that it will be in order to conduct research in the paediatric oncology unit at Steve Biko Academic Hospital. This is subject obviously to the fact that the patients and their parents are fully consented and the adhering to the research question as laid out in the Protocol.

I trust this is in order

Yours sincerely

David Reynders

www@up.ac.za

Prof David Reynders • Head of Clinical Unit, Paediatric Oncology • MBChB, FCP(SA), MPCPCH, Cert. Medical Oncology (Paed)
• Steve Biko Academic Hospital, Paediatric Oncology Clinic, Level 4, Room B6L5022, Malherbe Street Gezina, 0084
• PO Box 667, Pretoria, 0001, RSA
• Tel +27 12 354 5276 • Fax +27 (0)86 511 7707
• David.reynders@up.ac.za

6.5 APPENDIX 5: PERMISSION LETTER TO CONDUCT RESEARCH - STEVE BIKO ACADEMIC HOSPITAL



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

**STEVE BIKO ACADEMIC
HOSPITAL**

Private Bag x169 Pretoria 0001

Enquiries: Dr AP van der Walt
Tel no: +27 12 354 2336
Fax no: +27 12 3542151
E-mail: andrevdw@gpg.gov.za

For attention:
Notshanti Mabhoza
C/o Faculty of Humanities
Department of Social Work and Criminology
University of Pretoria

GP study ref. number: None

Dear investigator

**Re. REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT STEVE BIKO
ACADEMIC HOSPITAL**

**TITLE: FACTORS CHALLENGING CAREGIVERS OF PAEDIATRIC ONCOLOGY
PATIENTS REGARDING DELAYED ACCESS TO HEALTH CARE**

Permission is hereby granted to conduct the above-mentioned research at Steve Biko Academic Hospital subject to approval of the research protocol by the University of Pretoria, Faculty of Health Sciences Research Ethics Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'AP van der Walt'.

Dr AP van der Walt
DIRECTOR CLINICAL SERVICES

13 July 2017



6.6 APPENDIX 6: LETTER REQUESTING PERMISSION



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work and Criminology

17/05/2017

Ref. Dr CL Carbonatto
Tel. 012 4202410
E-mail: charlene.carbonatto@up.ac.za

The Head of Paediatric Oncology: Prof Reynders

Steve Biko Academic Hospital

Pretoria

Dear Prof Reynders

REQUEST FOR PERMISSION TO CONDUCT EMPIRICAL RESEARCH IN YOUR DEPARTMENT

STUDENT NAME: NOTSHANTI MABHOZA 15261329

The abovementioned postgraduate student is registered for the MSW (Health Care) programme in this department and is also an employee at Steve Biko Hospital, Social Work Department.

The postgraduate student is required to write a mini-dissertation, resulting from a research project, under the supervision of Dr. CL Carbonatto of this department. The research will only proceed once a departmental research panel and the Faculty of Humanities ResEthics Committee, as well as the Faculty of Health Sciences ResEthics Committee has granted ethics approval for the study. The following information regarding the study is shared:

The **title** of the study is: Factors contributing to late diagnosis of cancer amongst children.

The **goal** of the study is: To explore and describe the factors challenging caregivers of paediatric oncology patients regarding delayed access to healthcare

Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotheo
Kgoro ya Modiro wa Leago le Bosenyi

The objectives of the study are:

- To conceptualise and describe paediatric oncology, treatment, access to healthcare systems and the role of family caregivers.
- To explore and describe the challenges faced by family caregivers of paediatric oncology patients in the community and the health system.
- To explore and describe the factors that lead to delayed access to health care of paediatric oncology patients.
- To explore and describe the cultural challenges of paediatric oncology family caregivers.
- To make recommendations to the oncology team to enhance accessibility to paediatric oncology care.

The target population of the study are: Family caregivers (10) of Paediatric Oncology patients newly diagnosed with cancer.

A qualitative, case study research design will be implemented, using semi-structured face-to-face interviews with the caregivers and an interview schedule as data collection method. The interviews will be conducted at the Medical Block Office in the Oncology Department at the hospital.

This study will not result in any demands on your staff and no costs will be incurred by this request. Confidentiality will be ensured and the identity of the caregiver and patient will be kept anonymous by using pseudonyms, such as a number assigned to each participant before the interview. A letter of informed consent will be used to explain the details of the study to the participants for their voluntarily consent to partake in the study and to voice record the interview with their permission for data capturing. Appointments for interviews will follow after they have signed. All data will be safely stored and as an employee of the hospital the student will abide by all the rules regarding confidentiality and privacy. The study has a potential benefit in providing recommendations for future interventions to enhance the accessibility to paediatric oncology care. The student undertakes to provide you with a copy of the final report.

It would be appreciated if you will consider the above and grant permission to the student to proceed with the project, at your earliest convenient date.

Yours sincerely,

Faculty of Humanities
Department of Social Work and Criminology
Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotheo
Kgoro ya Modiro wa Leago le Bosenyi

MS NOTSHANTI MABHOZA

RESEARCHER



DR CHARLENE CARBONATTO

SENIOR LECTURER AND SUPERVISOR

Faculty of Humanities
Department of Social Work and Criminology
Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotheo
Kgoro ya Modiro wa Leago le Bosenyi

APPENDIX 7: WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI - ETHICAL PRINCIPLES FOR MEDICAL RESEARCH DATA INVOLVING HUMAN SUBJECTS

Clinical Review & Education

Special Communication

World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects

World Medical Association

Adopted by the 16th WMA General Assembly, Helsinki, Finland, June 1964, and amended by the: 25th WMA General Assembly, Tokyo, Japan, October 1975
32th WMA General Assembly, Venice, Italy, October 1983 41st WMA General Assembly, Hong Kong, September 1989
48th WMA General Assembly, Somerset West, Republic of South Africa, October 1999 52nd WMA General Assembly, Edinburgh, Scotland, October 2000
53rd WMA General Assembly, Washington, D.C., USA, October 2002 (Note of Clarification added) 55th WMA General Assembly, Tokyo, Japan, October 2004 (Note of Clarification added)
59th WMA General Assembly, Seoul, Republic of Korea, October 2008 64th WMA General Assembly, Fortaleza, Brazil, October 2013

Preamble

1. The World Medical Association (WMA) has developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data.

The Declaration is intended to be read as a whole and each of its constituent paragraphs should be applied with consideration of all other relevant paragraphs.

2. Consistent with the mandate of the WMA, the Declaration is addressed primarily to physicians. The WMA encourages others who are involved in medical research involving human subjects to adopt these principles.

General Principles

3. The Declaration of Geneva of the WMA binds the physician with the words, "The health of my patient will be my first consideration," and the International Code of Medical Ethics declares that, "A physician shall act in the patient's best interest when providing medical care."
4. It is the duty of the physician to promote and safeguard the health, well-being and rights of patients, including those who are involved in medical research. The physician's knowledge and conscience are dedicated to the fulfillment of this duty.
5. Medical progress is based on research that ultimately must include studies involving human subjects.
6. The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments). Even the best proven interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality.
7. Medical research is subject to ethical standards that promote and ensure respect for all human subjects and protect their health and rights.
8. While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects.
9. It is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects. The responsibility for the protection of research subjects must always rest with the physician or other health care professionals and never with the research subjects, even though they have given consent.
10. Physicians must consider the ethical, legal and regulatory norms and standards for research involving human subjects in their own countries as well as applicable international norms and standards. No national or international ethical, legal or regulatory requirement should reduce or eliminate any of the protections for research subjects set forth in this Declaration.
11. Medical research should be conducted in a manner that minimizes possible harm to the environment.
12. Medical research involving human subjects must be conducted only by individuals with the appropriate ethics and scientific education, training and qualifications. Research on patients or healthy volunteers requires the supervision of a competent and appropriately qualified physician or other health care professional.

jama.com



JAMA Published online October 19, 2013 E4

APPENDIX 8: PRINCIPAL INVESTIGATOR'S DECLARATION FOR THE STORAGE OF THE RESEARCH DATA AND DOCUMENTS

2017 -07- 17

Principal Investigator(s) Declaration for the storage of research data and/or documents

I, the Principal Investigator(s), NOTSHANTI of the following trial/study titled Factors Challenging Caregivers of paediatric oncology patients regarding delayed access to healthcare will be storing all the research data and/or documents referring to the above mentioned trial/study at the following address: The Interview Schedule, letter of Informed consent as well as audio recording and transcripts will be submitted to the University of Pretoria, Department of Social Work and Criminology.

START DATE OF TRIAL/STUDY: 01/09/2017 END DATE OF TRIAL/STUDY: 01/09/2018

I understand that the storage for the abovementioned data and/or documents must be maintained for a minimum of 15 years from the commencement of this trial/study.

UNTIL WHICH YEAR WILL DATA WILL BE STORED: 15 years

September 2017 until September 2032

Name NOTSHANTI MABHOZA

Signature [Signature] Date 17/07/2017

6.9 APPENDIX 9: INTERVIEW SCHEDULE

MSW (Health care) – N. Mabhoza - Interview Schedule

Participant profile

- Age and gender
- Marital status
- Race, culture, ethnic group
- Religion
- Level of education
- Age and biological sex of child diagnosed with cancer

Socio-economic status

- Employed / Unemployed
- Nature of employment
- Source of income - Salary - Dependent on grant - Self employed
- Housing details - informal or formal structure, rented or owned
- Where residing – with whom
- Challenges since cancer

Medical and related costs

- Medical Aid cover/ none
- Payment of medical bills by whom
- Hospital fee structure - child under 6 years – free?
- Other financial challenges – accommodation, travel

Access to healthcare services

- Distance - clinic and hospital from home
- Transport – infrastructure available
- Roads - access healthcare centres
- Environment – accessibility to water, sanitation, electricity
- Access to traditional healers in community
- Access to clinic, hospital, oncology care

1

- Telephonic or e-mail contact with healthcare centres
- Other challenges

Communication

- Experience of communication with health professionals or team
- Language spoken - difficulties understanding/ communicating with health professionals
- Level of understanding of diagnosis after explained
- Challenges

Understanding of cancer diagnosis

- Understanding of cancer
- Symptoms experienced by child
- Signs of the cancer noticed before your child was diagnosed
- Visits to healthcare facility when the child was sick
- Consultation of alternative or indigenous healthcare providers – treatment details
- First consultation with medical practitioner
- How you first knew that your child has cancer
- Details of diagnosis made – when , where, how, who
- Understanding of the diagnosis explained to you
- History of illness in family
- Other challenges

Religion, spirituality and culture

- Religion and church
- Spirituality
- Change in beliefs since diagnosis - motivate
- Church attendance –before and after diagnosis
- Cultural rituals in family during illness or treatment
- Beliefs about disease – westernised treatment and hospitals
- Traditional medicines - Muthi's , Imbiza used
- Challenges

Caregiving

- Who is the main caregiver of the child?
- Who else helps you with looking after the child
- Do you receive support from the father/ partner/spouse?
- Who provides you with support during child's illness
- Who makes decisions regarding treatment
- Role of father/ partner/ spouse
- Who helps you in raising child
- Anyone influenced your decision regarding child's treatment
- Other challenges for you as caregiver

Challenges for family / siblings

- Parents relationship influenced
- Parents relationship with sick child
- Parents relationship with other children
- Time spent with healthy children
- Negative behaviour /jealousy amongst children
- Effect on healthy children's school performance/ extra mural activities
- Relationship between sick child and healthy child
- Impact of cancer diagnosis on family
- Role changes in family due to the child's illness

Factors - Intentional or non-intentional - in delaying access to healthcare

- Income
- Awareness of cancer
- Emotions – shock, denial
- Bargaining - shopping around for other diagnosis or healing at other service providers
- Family beliefs
- Beliefs with regards to westernised medicine
- No support systems
- Sense of urgency on health issues – understanding
- Factors playing a role in delaying treatment

3

- Other factors

Recommendations

- Do you have any suggestions, recommendations or advice for other family caregivers in similar situations as you with a child with cancer?

6.10 APPENDIX 10: LETTER OF INFORMED CONSENT IN ENGLISH



Faculty of Humanities
Department of Social Work and Criminology

Researcher: Notshanti Mabhoza
E-mail: tshantimo@gmail.com
Cell no: 0720475287
Tel no: 012 354 4481

LETTER OF INFORMED CONSENT

1. Title of the Study:

Multi-factorial challenges of caregivers of paediatric oncology patients regarding delayed access to healthcare

2. Purpose of the Study:

The purpose of the research study is to explore and describe the multi-factorial challenges of caregivers of paediatric oncology patients regarding delayed access to healthcare. The information collected will assist the researcher to get a better understanding of the challenges caregivers of children with cancer experience in accessing healthcare and will contribute to understanding why late diagnosis of children with cancer occurs.

3. Procedure

This serves as a request for your permission to participate in the study. The researcher will explain to you the content of the letter of informed consent which will be written in English and Xhosa. This will be done to ensure that you understand what the research is all about and what is expected of you. You will be given an opportunity to ask questions for clarity, so that you can make an informed decision about engaging in the study. Thereafter you will sign the consent form before the interview commences. A semi-structured interview will be utilized as a data collection method and an interview schedule will be used to collect data. An audio recorder will be used to record the interview with your permission. The duration of the interview will be approximately an hour. The researcher will ask you questions from the interview schedule and you will be given an opportunity to answer.

4. Risks and discomforts

You will not suffer any risks or discomforts, but may get tired. Debriefing will be provided by the researcher after the interview. If counselling is required, you will be referred to the social worker at the Paediatric Oncology Unit.

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Departement Maatskaplike Werk en Kriminologie
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Kgoro ya Modiro wa Leago le Bosenyi

5. Benefits

The researcher hopes that the study will provide a better understanding of the factors contributing to late diagnosis of cancer amongst children and the factors challenging caregivers of paediatric oncology patients regarding delayed access to healthcare. The study has a potential benefit, that the findings of the study may be used to recommend interventions to deal with the challenges of caregivers and enhance the accessibility to paediatric oncology care. There are no direct benefits for participating in this study.

6. Remuneration

You will not receive any compensation from the researcher for your participation in the study.

7. Participant's rights

You may withdraw from participation in this study as participation is voluntary. No participant will be coerced to participate. If you decide not to participate in the research study, your decision will not affect your relationship with the hospital staff or treatment of your child in any way.

8. Confidentiality, anonymity and privacy

If you consent to participate in this study, be assured of the following:

- The information collected from you will be handled with confidentiality. No one will identify your responses, as your name will not be recorded or appear in the research study. A number will be assigned to you before the interview to protect your identity.
- Your feelings and opinions will be kept confidential and will not be linked to your identity in any way.
- Only the researcher and her supervisor will have access to the data.
- An audio-recording will be made of the interview with your permission, but will not include your name to ensure confidentiality.
- Interviews will be conducted in a quiet and private room to ensure privacy and confidentiality.

9. Data Storage

The information obtained from the participant will be stored in the Department of Social Work and Criminology at the University of Pretoria for a period of 15 years for archival or further research purposes.

10. Data usage

The data gathered will be used to compile a research report in the form of a mini-dissertation that will be available at the university library and will provide a valuable input in the paediatric oncology sphere.

11. Details of the researcher

Faculty of Humanities
Department of Social Work and Criminology
Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotheo
Kgoro ya Modiro wa Leago le Bosenyi

If you have any concerns or questions regarding the study, please do not hesitate to contact:

Notshanti Mabhoza (principal researcher) at **Cell no:** 0720475287 or **Tel no:** 012 354 4481

E-mail: tsyantimo@gmail.com

You may contact the researcher should you need clarification on issues pertaining to this study or if you experience emotional harm. The researcher will refer the research participants to the Social Worker at the Paediatric Oncology Unit if required.

Declaration

I understand my rights as a research participant. I understand what the study is about, how I will participate and why it is being conducted. I hereby voluntarily consent to participate in this study.

Signed on _____ (date)

at _____ (place)

Signature of participant _____

Signature of researcher _____

Faculty of Humanities
Department of Social Work and Criminology
Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotheo
Kgoro ya Modiro wa Leago le Bosenyi

6.11 APPENDIX 11: LETTER OF INFORMED CONSENT IN ISIXHOSA



Faculty of Humanities
Department of Social Work and Criminology

Igama lomphandi: Notshanti Mabhoza
Idilesi: 565 Adcock Street, Flat 502 Unikop, Gezina
Cell: 0720475287
Eyomsebenzi: 012 354 4481
Igama leziko: Idyunivesithi yase Pitoli

Incwadi yemvume yolwazi

1. Isihloko Sophando:

Izinto ezibangela ukufunyanwa kade kwesifo somhlaza ngo gqirha ebantwaneni

2. Injongo Yophando (Isifundo)

Injongo yoluphando kukuchaza izinto ezibangela kufunyanwe kade isifo somhlaza ebantwaneni. Ulwazi olufumanekileyo luzakunceda ukuqondisa imiceli-mngeni ejongene nabalondolazi bosapho abajonge izigulane eziselula, neziphansi kwecandelo lakwa-Oncology. Ekugqibeleni, oluphando luzakuphendula imibuzo kwimiba ethi ibe negalelo.

3. Inkqubo

Esi sisicelo semvume yakho sokuba uthabathe inxaxheba koluphando. Umphandi uza kuchazela umxholo ngaleleta yemvume ezakubhalwa ngesiNgesi nangesiXhosa . Oku kuya kwenziwa ukuqinisekisa ukuba othatha inxaxheba uyaluqonda uba uphando lungantoni na, nokuba kulindelwe ntoni kuye. Uya kunikwa ithuba lokubuzwa imibuzo, ukuze ukwazi ukwenza izigqibo enolwazi malunga nenxaxheba koluphando. Emva koko uyakutyikitye isivumelwano phambi kokuqala kodliwano-ndlebe.

Udliwano ndlebe lwabucala luzakusetyenziswa njengohlobo lokuqokelela ulwazi kunye noxwebhu lodliwano-ndlebe. Oludliwano-ndlebe luzakuqokelelwa ngohlobo loshicilelo (audio recorder). Oludliwayo-ndlebe luzakuthatha ithuba elingange yure. Umphandi uzakubuzwa imibuzo eshicilelwe kuxhwebhu lodliwano-ndlebe, emva koko uzakunikezwa ixesha lokuba uphendule.

4. Ubungozi nokungaphatheki kakuhle

Esi sisiqinisekiso sokuba ekubeni yinxalenye yoluphando awuzujongana nabungozi okanye ukungaphatheki kakuhle, kodwa kungenzeka udinwe. Xa kuthe kwenzeka wangaphatheki kakuhle

Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
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Kgoro ya Modiro wa Leago le Bosenyi

uzakuthunyelwa kumagumbi onontlalontle becandelo elijonjene nabantwana abagula sisifo somhlaza (Paediatric Oncology Unit) uyofumana iingcebiso.

5. Inzuzo

Umphandi unethemba lokuba esisifundo sizakucacisa ngcono imiba ebangela ukufumaneka kade kwesifo somhlaza ebantwaneni. Imiphumela inganegalelo elikhulu; ingancedisa ekucebiseni ngedlela ezingasetyenziswa ekuphusihliseni nasekuphuculeni ukhathalelo lwecandelo lwabantwana abagula sisifo somhlaza.

6. Imbuyekezo

Awuyikufumana nayiphi na imbuyewkezo ngokuthabatha inxaxheba koluphando.

7. Amalungelo omthathi-nxaxheba

Abathathi nxaxheba bavumelekile ukuyeka naninina ukuthatha inxaxheba njengokuba ukuthatha inxaxheba kungesosinyanzelo. Abathathi-nxaxheba abayi kunyanzelwa ukuthatha inxaxheba, ukuba ubani ukhetha ukungathathi nxaxheba. Isiqgibo sakhe asiyi kuba nanto yakwena nobudlelwane bakhe nabasenzi besibhedlela okanye nokunakekelwa komntwana wakhe.

8. Imfihlo, ukungaziwa nabucala

Ukuba uyavuma ukuthatha inxaxheba koluphando, uqinisekiswa oku kulandelayo:

- Ulwazi oluqokelelwe kuye liya kugcinwa luyimfihlo.
- Akukho namnye oyakwazi ukuba impendulo zezakho, kuba igama lakho aliya kuvezwa koluphando. Koko uyakinikwa inombolo phambi kodliwano ndlebe ukukukhusela.
- Imvakalelo nezimvo zakho ziyakugcinwa ziyimfihlo, zisetyenziselwe uphando kuphelo.
- Ngumphandi nomphathi wakhe abayakuba nolwazi ngencukacha.
- Udliwano ndlebe lakushicilelwa ngemvume yakho, kodwa igama lakho aliya kuvezwa ukuqinisekisa imfihlo.
- Udliwano nondlebe luyakuqhutyelwa kwigumbi labucala ukuqinisekisa imfihlo.

9. Iinkcukacha zomphandi

Ukuba unayo nayiphi na iinkxalabo okanye imibuzo malunga nesifundo, nceda musa ukuthandabuza qhagamshelana:

Notshanti Mabhoza (ngumphandi oyintloko)

Inombolo yeselula: 0720475287

Faculty of Humanities
Department of Social Work and Criminology
Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotho
Kgoro ya Modiro wa Leago le Bosenyi

E-mail: tshantimo@gmail.com

Bayacelwa abathathi-nxaxheba ukuba baqhagamshelane nomphandi ukuba bafuna ukucaciselwa ngemiba ephathelelene nesisifundo okanye xa bejongene nokwenzakala ngokweemvakalelo. Umphandi uyakudlulisele abo bathathi-nxaxheba bathe benzakala ngokwemvakalelo ku nontlalontle wecandelo lokunakekelwa kwabantwana abanesifo somhlaza ukuba kunemfuneko.

10. Ukugcinwa kwencukacha

Ulwazi oluqokelelweyo kwabathatha inxaxheba luyakugcinwa kwicandelo lobuntlalontle lwe dyunivesithi yase Pitoli, kwisithuba seminyaka elishumi elinesihlanu ngenjongo zophando mpepha.

11. Ukusetyenziswa kwencukacha

Incukacha ezifunyenweyo ziyasetyenziselwa ukwenza ingxelo eya kugcinwa kwi-thala lencwadi lwe dyunivesithi. ngenjongo zokunika igalele kwi candela lokunakekelwa kwabantwana abanesifo somhlaza.

Ukuvuma

Ndiyavuma ukuba ndiyaqonda amalungelo wam ngokuthatha inxaxheba engesosinyanzelo koluphando. Ndiyaqonda ukuba ulophando lungantoni, lwenzelwantoni, luzokwenziwa kanjani.

Ityikitywe ngomhla _____ (umhla) e _____ (indawo)

Ukutyikitya mthathi- nxaxheba _____

Ukutyikitya komphandi _____

Faculty of Humanities
Department of Social Work and Criminology
Fakulteit Geesteswetenskappe
Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotho
Kgoro ya Modiro wa Leago le Bosenyi

6.12 APPENDIX 12: DECLARATION LANGUAGE EDITOR

212 Smith Street

Muckleneuk

Pretoria, 0002

18 December 2018

The Supervisor, Master's Student and Technical Editor

Department of Social Work and Criminology

Faculty of Humanities

University of Pretoria

Dear Dr Carbonatto, Mss Mabhoza and Nagel

This letter is a declaration stating that I, Deirdré Rautenbach (ID 6707020099085), have edited the mini-dissertation of Notshanti Mabhoza (15261329) titled *Multi-factorial challenges of family caregivers of paediatric oncology patients regarding delaying access to healthcare*.

Yours sincerely

Deirdré Rautenbach

(+27) 82 896 5018

(+27) 12 343 6441

deirdre.blignaut@gmail.com

6.13 APPENDIX 13: DECLARATION TECHNICAL EDITOR

EC Nagel
PO Box 900
WINGATEPARK
0153

The Supervisor and Master's Student
Department of Social Work and Criminology
Faculty of Humanities
University of Pretoria

Dear Dr Carbonatto and Mss Mabhoza

This letter is a declaration stating that I, Elize Nagel (ID 5811160004086), has done the technical editing of the mini-dissertation of Notshanti Mabhoza (15261329) titled *Multi-factorial challenges of family caregivers of paediatric oncology patients regarding delaying access to healthcare*.

Yours sincerely

Elize Nagel
(+27) 83 288 2601
(+27) 12 420 3633
elize.nagel@gmail.com