THE PSYCHOSOCIAL INFLUENCES ON A FAMILY OF A CHILD DIAGNOSED WITH CANCER

by

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"I thank Christ Jesus our Lord,

Who has given me strength,

that He considered me trustworthy,

appointing me to His service."

1 Timothy 1:12

M MARAIS

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ABSTRACT

Title: The psychosocial influences on the family of a child diagnosed with cancer

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Cancer affects everyone; it does not distinguish between age, race, gender or social background. When a child is diagnosed with cancer, it does not only affect the child, but also the family system as a whole. The focus of this study was on the psychosocial aspects that are affected in the family system once a child diagnosed with cancer. These psychosocial aspects included the emotional impact, the spousal impact, the role changes that occur in the family system, the financial impact, the impact on siblings as well as the impact on religion and spirituality. These aspects were investigated by the researcher during the applied study.

This applied study used a qualitative approach with a collective case study research design. The research population of this study included families who have a child diagnosed with cancer, who was treated at Nicus Lodge Cancer Treatment Centre in Pretoria which is a CANSA affiliate. The staff at Nicus Lodge selected participants who met the criteria based on purposive sampling, on behalf of the researcher. The researcher used semi-structured interviews and an interview schedule in order to obtain the participants' experiences of their child diagnosed with cancer and the psychosocial effects it had on them as a family system. Nine participants participated in the study. The interviews were recorded with the permission of the participants and then later transcribed. Creswell's steps for qualitative data analysis were implemented. By utilizing these measures and tools, the researcher was able to formulate findings from which conclusions and recommendations could be made.

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From the findings, the following themes and sub-themes were identified, demonstrating the psychosocial effect that a child diagnosed with cancer has on the family system and answering the research question: **Theme 1:** Protective measures with the sub-themes of religion, support structures and personality. **Theme 2:** Restrictive measures with the sub-themes of role changes, single parent, multiple children and date of diagnosis. **Theme 3:** Financial related aspects with the sub-themes of employment/unemployment, supportive employer, transport and medical aid. The findings demonstrated that many different aspects of a family system are affected when a child is diagnosed with cancer. It also demonstrated that a family system that had the necessary protective measures, were able to cope more effectively and maintain their quality of life when their child was diagnosed with cancer. The findings furthermore showed specific focus areas that a social worker in the health care setting, specifically in the oncology field, should focus on which hinder family systems from coping effectively. These focus areas enable the social workers to provide adequate supportive services to the families of a child diagnosed with cancer.

Supportive services are imperative when dealing with a family of a child diagnosed with cancer, and this is one of the recommendations of the study and a focus area for future studies. Recommendations from this study can be used by social workers in the health care field to better understand the challenges that families of a child diagnosed with cancer experience and how to effectively address their needs. Social workers can also utilize the recommendations to find ways to make their services known to the communities and improve their intervention and supportive services to these families. It is important for social workers to improve awareness in the community and to provide them with the necessary resources to cope better with the situation. To better understand this paper, certain key terms were used by the researcher.

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List of key terms:

- Psychosocial;
- Cancer;
- Paediatric illness/oncology;
- Child;
- Family system;
- Family functioning; and
- Medical social work / social work in health care.

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1 CHAPTER 1: GENERAL BACKGROUND

1.1 Introduction

Cancer is one of the major killers throughout the developed and developing world, including South Africa (National Cancer Registry [NCR], 2009:12). There are over 200 different types of cancers. According to Lauria, Clark, Hermann and Stearns (2001:1) "cancer is not one disease state but rather many, all characterized by the presence of an uncontrolled proliferation of a certain cell in the body." The presence of numerous cells in the body causes different types of cancers. As medical treatment of paediatric chronic- or life-threatening diseases has improved and more and more children survive, the physical and psychosocial consequences of such treatment have become increasingly relevant in paediatric healthcare (Bregje et al., [Sa]:137). This increased survival rate resulted from more aggressive treatment regimens; however, these cause many side effects needing symptom management, including fatigue, loss of appetite, microsites and gastrointestinal symptoms (Williams et al., 2009:95). The increased side effects of treatment often have a negative effect on the quality of life of the patient, as well as the entire family involved (Williams et al., 2009:95). Wolfe-Christensen, Mullins, Fedele, Rambo, Eddington and Carpentier (2010:108) confirmed this and added that "families of children with cancer face numerous challenges over the course of the child's treatment."

Whether large or small, and regardless of their diversity, all families faced complex challenges, including balancing interrelationships among family members, celebrating achievements, communicating expectations, values and beliefs, emotionally and materially supporting family members, and providing for material and economic needs (Western Australian…, [sa]). Families varied in their ability to fulfil many of these important functions. Relationship quality, the health of each family member, the presence of life stress, work and finance each contributed to how people manage the many demands of family life. Family functioning also showed to have strong associations with the social, economic and psychological environment of the immediate family and wider community (Western Australian…, [sa]) which needed to be addressed by a multi-disciplinary team.

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In a hospital setting a multi-disciplinary team is involved with the care of the patients, specifically cancer patients. The multi-disciplinary team includes the oncologists, radiotherapists, chemotherapists, psychiatrists, physiotherapists, occupational therapists, clinical psychologists and social workers. Social workers "…use their knowledge and skills to provide social services for clients" (Barker, 2003:410). Social work can further be defined as the "…applied science of helping people achieve an effective level of psychosocial functioning and effecting societal changes to enhance the well-being of all people" (Barker, 2003:408). This study's results enabled the researcher to understand the psychosocial influence of a child diagnosed with cancer on family functioning. It is the researcher's opinion that both the child diagnosed with cancer as well as the whole family are affected by the diagnosis and therefore social work intervention is vital. Family disruption and disintegration can be prevented if the different psychosocial influences of a child diagnosed with cancer on family functioning are identified. This prevention intervention can be done after the research was completed, by means of programs that can be developed based on this research. This is in line with developmental social work, which can be defined as "…the practical and appropriate application of knowledge, skills and values to enhance the well-being of individuals…in their social context" (Patel, 2005:206-207). Developmental social work also involves doing research in fields that will enhance the well-being of people and this correlates with the researcher's aims by completing this applied study.

The rationale for this study was to explore the psychosocial influence of a child diagnosed with cancer on family functioning. The statistics indicated that there was a high prevalence of emotional distress, as well as psychological distress among family members when a child is diagnosed with cancer, therefore this study was conducted in order to determine the exact psychosocial influences thereof. The results of the study aimed to understand the experiences of the participants regarding the psychosocial influences of a child diagnosed with cancer on family functioning, in order to enhance social work services on a preventative and therapeutic level. The definition of key concepts will be discussed briefly in order to provide a better understanding of cancer, the family system, the ill child and social work intervention.

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1.1 Definition of key concepts

1.1.1 Psychosocial

Psychosocial relates to "the interrelation of social factors and individual thought and behaviour" (http://www.oxforddictionaries.com/definition/english/psychosocial). It involves "both psychological and social aspects relating to social conditions in mental health" (http://www.merriam-webster.com/dictionary/psychosocial). Psychosocial can be defined as a term referring to "the mind's ability to, consciously or unconsciously, adjust and relate the body to its social environment and it involves aspects of both social and psychological behaviour (The free…, [sa]). It also includes the interaction between social and psychological factors. For the purpose of this study psychosocial effect is defined as the interaction between a person's social and psychological behaviour as well as the social and psychological factors that influence a person's behaviour.

1.1.2 Cancer

Cancer is a disease caused by an uncontrolled division of abnormal cells in a part of the body. It can also be defined as a malignant growth or tumour resulting from an uncontrolled division of cells (http://www.oxforddictionaries.com/definition/american_english/cancer#cancer).
Cancer is "a disease characterized by various malignant neoplasms composed of abnormal cells that tend to proliferate rapidly and invade surrounding tissue" (Free Dictionary, sv 'cancer'). Cancer is also defined as "an abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize" (Medterms…, [sa]). Cancer is not just one disease, but a large group of almost 100 diseases and "its two main characteristics are uncontrolled growth of the cells in the human body and the ability of these cells to migrate from the original site and spread to distant sites" (http://medical-dictionary.thefreedictionary.com/Cancer).

For the purpose of this study cancer can be defined as abnormal cells that divide uncontrollably, and which can metastasize to other parts of the body which is either malignant or benign growths or tumours.

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1.1.3 Paediatric illness/oncology

Paediatric illness can be defined as "a chronic health problem if it lasts over twelve months, affects the child's normal activities and requires a lot of hospitalizations and/or home health care and/or extensive medical care" (Goldbeck, 2006:1121). It is also seen as the "branch of medicine dealing with the physical, chemical, and biological properties of tumours, including study of their development, diagnosis, treatment, and prevention" (http://medical-dictionary.thefreedictionary.com/Pediatric+oncology).

For the purpose of this study paediatric illness/oncology will be seen as a chronic health issue in a child that affects his/her ability to partake in normal activities and requires hospitalization or home care for a period longer than twelve months.

1.1.4 Child

A child can be defined as a "young human being below the age of puberty or below the legal age of majority" (http://www.oxforddictionaries.com/definition/english/child). According to the Children's Act No.38 of 2005, a child is a "person under the age of 18 years." Eckard and Hutchings (2006:33) state that the law considers minors as "…a person under the age of 18 years [who] is incapable of independent action, and consequently a person's capacity to act is restricted up to that age."

For the purpose of this study a child can be defined as a person under the age of 18 years whose parents or legal guardian make decisions on behalf of the child which are in the best interest of the child, especially when it comes to medical treatments and procedures because the child is seen by law to be unable to make these decisions independently.

1.1.5 Family system

The family system can be defined as the "social interactions, patterns, and interdependence that exist between members of families, especially as they pertain to the impact of one member's illness on the others in the family" (http://medical-dictionary.thefreedictionary.com/family+systems).

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A family can be defined as a “collective body of persons who live in one house, and under one head or manager; a household, including parents, children, and extended family” (Accurate…, [sa]). Another author defines a family as "a group of people held together by bonds of love and affection, a man and a woman, married and unmarried, with or without children, gay and lesbian couples, singles, with and without children, and even larger groups of individuals in various communal living arrangements” (Adoption…, [sa]).

For the purpose of this study a family will be defined as a social unit consisting of parents (one or more adults) and their children living together in the same household, held together by a bond of love and affection.

1.1.6 Family functioning

Family functioning can be defined as “a family's ability to deal with day-to-day life, unforeseen crises, and the normal changes that occur in families over time (Peterson & Green, 2009:3). Family functioning also includes various roles which are seen as recurrent patterns of behaviour by which individuals fulfil family functions and needs (Epstein, Bishop, Ryan, Miller & Keitner, 1993:235). Individual members of families occupy certain roles such as parent, child, sibling or grandchild. Along with roles come certain social and family expectations for how those roles should be fulfilled (Epstein et al., 1993:235).

For the purpose of this study family functioning will be defined as the family’s ability to deal with everyday situations, crises and threats as well as the roles of the different members to ensure stability within the family system, and the interaction between different family members.

1.1.7 Medical social work / Social work in healthcare

Medical social work is defined as the social work practice within the healthcare setting in order to aid ill patients and their families to resolve social and psychological problems associated with their illness (Barker, 2005:266-267).

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For the purpose of this study, medical social work will be defined as mentioned above. The researcher agrees with this definition and finds it complete. A brief overview of childhood cancer and the effect that it has on the family system will follow, with an in-depth discussion on the matter in Chapter Two.

1.2 Literature review

When a child is diagnosed with cancer, it is not only the child who is affected, but also the whole family system. The parents now have to adjust to the new situation, as well as continue with the family's functioning as it was before the diagnosis. This places a lot of stress on the parents, as well as other family members. The onset of symptoms in children, the confirmation of a diagnosis of cancer and in most cases the prolonged and intensive treatment, make huge demands on the emotional and interpersonal resources of both the patients and their family members (Hill, Kondryn, Mackie, McNally & Eden, 2003:752). This is confirmed by Bregje, Houtzager, Oort, Josette, Hoekstra-Weebers, Huib, Grootenhuis, & Last ([Sa]:135), who state that psychological consequences of chronic or life-threatening illness in childhood do not concern only the patient, but also extend to family members. Farnik, Brozek, Pierzchala, Zejda, Skrzypek and Walczak (2010:151) agree with this statement and add that "chronic disease may not affect only patients' functioning, but other family members as well", especially that of the parents.

The parents need to make important decisions on behalf of their child and have to operate between the patient (the child) and the healthcare professionals (Farnik et al., 2010:151). The parents experience feelings of anxiety and distress as well as limitations in their daily routine when their child is diagnosed with cancer (Farnik et al., 2010:151). Work activities are limited due to the fact that the parents have to ensure that the child is taken for the necessary treatments, which can be time consuming (Farnik et al., 2010:158). Williams, Ridder, Setter, Liebergen, Curry, Piamjariyakul and Williams (2009:95) indicate that paediatric chronic illnesses such as cancer create problems for the family, such as the burden of care over a long period of time, physical, financial and emotional strain on resources, as well as strain on the marital relationship.

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The parents are also limited with the time available to spend with their other healthy children and siblings of the child diagnosed with cancer (Farnik et al., 2010:151). Siblings of a child with cancer have been reported to suffer from the intensive treatment and the changes it brings about in their daily routines, emotional state, social life and of course, family relations (Bregje et al., [Sa]:137). The family system has to cope with these changes brought about by the diagnosis of cancer of a child in the family. The coping process comprises both cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the individual's resources (Bregje et al., [Sa]:139). An individual can undertake actions to solve the problem that causes distress (behaviour focus) or try to change cognitions regarding the stressful situation in order to reduce negative emotions that result from it (emotional focus) (Bregje et al., [Sa]:139).

The nature of the stressful situation can demand a certain way of coping. The ways in which parents cope with the consequences of childhood cancer can be regarded as an important factor in their adaptation to the cancer experience. According to the model of stress and coping developed by Lazarus and Folkman, coping consists of actions, behaviours and thoughts aimed at dealing with the demands of events and situations that are appraised as stressful (Maurice-Stam, Oort, Last and Grootenhuis, 2008:449). When a family is confronted with the life-threatening illness of a child, there is little its members can do to change the situation or exert direct control. Siblings are particularly helpless because they are least directly or actively involved in the treatment process. "Negative manifestations of increased risk in siblings include feelings of loneliness and isolation, anxiety, depression, vulnerability, anger, worry about the ill child, school problems, withdrawal or shyness, somatic complaints, low self-esteem and (internalizing and externalizing) behaviour problems (Williams et al., 2009:97). Siblings can experience role changes in the family system, as well as personal role changes in terms of what is expected of them.

Family roles and the dynamics of the family change, once the child is diagnosed with cancer. Williams et al. (2009:96) confirm this and add that family roles are reciprocal; any significant change in one role (parent, brother, sister) alters related roles. When there are role changes in the family, the family must redefine their role patterns, and this may cause family disruption as well as distress.

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When a child is diagnosed with cancer, the family members' roles will undoubtedly change and the family system needs to cope with this. In order to understand the above mentioned factors, the researcher will discuss the theoretical framework from which a social worker working with families of a child diagnosed with cancer can operate to assist these families.

1.3 Theoretical framework

The theoretical framework that the researcher used throughout this study is the psychosocial approach. The psychosocial approach is a perspective which is most closely associated with traditional social work practice and is grounded in the notion of multi-determinism (Dorfman, 1996:27). However, "psychosocial" is a broader concept, encompassing a theory of causality as well as providing a clinical model that includes multidimensional assessment and treatment (Dorfman, 1996:28). The researcher worked with the psychological and social factors of the families that have a child diagnosed with cancer. The "psycho" factors include personality, coping strategies, intellectual capacity and ego functioning and the "social" factors include family history, peer relationships and involvement in social institutions (Dorfman, 1996:28).

By doing this study the researcher was able to identify the influence of having a child diagnosed with cancer had on family functioning and thus be able to provide guidelines for healthcare social workers in practice, as well as other health professionals. The researcher is of the opinion that the social workers working in the health field need to be aware of the different aspects that are influenced in the family system once a child is diagnosed with cancer. The family system needs to be addressed as a multi-dimensional system in order to provide these families with the necessary resources and skill sets to cope effectively in their specific situations. More details on the theoretical frameworks follow in Chapter Two, paragraph 2.32.3. By understanding the need for information in this field, and the approach which the researcher utilized, a problem statement and the rationale for the research could be identified.

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1.4 Rationale and problem statement

Health professionals often ask questions about the reality they face in healthcare or the reality they want to understand better. Cancer is a reality in today's society, one which health professionals are faced with on a continuous basis. The goal of this research problem was to produce a clearly posed question based on a well-developed knowledge of previous research and theory, as well as on the researcher's own ideas and speculations (Fouché & De Vos, 2005:100).

The researcher proposed to identify the psychosocial influence of a child diagnosed with cancer on family functioning. The researcher identified this specific research problem when she consulted with health professionals involved in the care of children diagnosed with cancer. The health professionals included the nursing staff, doctors and child psychologists at the CANSA Centre, who over time have observed the emotional and psychological influences of a child diagnosed with cancer on the family's functioning, as well as the family members' relationships between one another. This was in line with social work's core business, namely to promote the psycho-social wellbeing of people, which includes emotional well-being of all people, especially children in need. Earlier studies on paediatric chronic illness focused on the adjustment of children, but more recently, investigators have added the difficulties that parents can experience in adapting to their children's illness. Medical problems in children precipitate worry and anxiety for parents, in addition to difficult practical considerations (Frank, Brown, Blount & Bunke, 2001:293).

Parents have to arrange their schedules to accommodate hospital and clinic visits while attending to traditional work assignments and other family obligations (Frank et al., 2001:293). The researcher noted that studies done on the effect of a child diagnosed with cancer in the past mainly focused on the effect it has on the siblings, the marital relationship, or the parents' experience of having a child diagnosed with cancer. There is a gap in the literature with regard to the psychosocial influence of a child diagnosed with cancer on the family's functioning. There is limited information available on all the aspects which form part of this psychosocial influence on the family's functioning, as a combined unit.

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There is also limited information on this topic from a social work perspective, which entails a holistic look at the family's functioning and not only one aspect thereof. The researcher furthermore noted that previous studies used a quantitative approach in order to obtain the information needed. The researcher wanted to obtain rich, in-depth information with regard to this phenomenon and will thus not compare different groups' experiences with one another, but tried to understand the phenomenon from the family's personal experiences. The researcher included all experiences, not only negative experiences or only positive experiences. By doing this study, the researcher was able to formulate a better understanding of the psychological and social influences regarding a child diagnosed with cancer and the influence the diagnosis has on the family's functioning. This understanding enabled the researcher to develop ways of limiting negative risks for the patient (the child) and the family members involved may experience, and build on their positive attributes. Thus, the problem that was focused on by the researcher is the psychosocial influences of a child diagnosed with cancer on family functioning. In order to do this, the researcher developed a research goal, objectives and research question.

1.5 Goal and Objectives of the study

The goal of the study is:

To explore the psychosocial influences on the family of a child diagnosed with cancer.

To attain the goal of the study, the following objectives were pursued:

- To conceptualise paediatric oncology as a phenomenon;
- To describe the experiences of the family of a child diagnosed with cancer;
- To determine whether the socio-economic circumstances of the family are affected once a child in the family is diagnosed with cancer;
- To explore the emotional experiences of family members when their child is diagnosed with cancer;
- To explore the quality of life of the family once their child is diagnosed with cancer;

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- To explore the influence on the marital relationship of the parents of having a child diagnosed with cancer;
- To explore the family interactions once a child is diagnosed with cancer;
- To explore any changes in the family roles once a child is diagnosed with cancer; and
- To explore the experiences of the siblings of the child diagnosed with cancer.

1.6 Research question

The research question is the core of the research study and all the research processes strive to answer the research question. Todres (2005:108) describes it as a "life-world-evoking question" where the experience of a life-world is described as richly as possible. In the context of this study, the following research question was asked: *What are the psychosocial influences on a family of a child diagnosed with cancer?* In order to answer the research question, the researcher utilized specific research methodology, which will now be discussed.

1.7 Research methodology

A qualitative research approach was used for this study in order to accurately research the phenomenon of the psychosocial influences on a family of a child diagnosed with cancer. A case study research design was followed in order to discover the meaning that people make out of a social phenomenon. This enabled the researcher to compare different cases to one another, using the collective case study design to find similarities and differences. In order to select appropriate case studies, the researcher formulated specific criteria for the research population.

The population focussed on families who had a child diagnosed with cancer who was receiving treatment and were clients of CANSA Nicus Lodge. Non-probability, purposive sampling was used as the staff at Nicus Lodge selected participants according to specific criteria to participate in the research (Maree & Pietersen, 2007:176). Nine participants were selected for this study.

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In order to obtain in-depth information from the population, person-to-person, semi-structured interviews were used to collect data from the selected participants. The researcher had the opportunity to let the interviews flow into different directions as guided by the participants, but followed certain themes in the interview schedule that focussed on different aspects of psychosocial functioning of a family of a child diagnosed with cancer. See Appendix 1: Interview Schedule. The interviews were transcribed and data was analysed. Themes were generated from the data and discussed fully in Chapter Three. The research methodology is discussed in detail in Chapter Three. During the interviews with the participants the researcher had to be aware of certain ethical issues that could arise – these will be discussed briefly in the next paragraph.

The feasibility of the study was ensured before undertaking the empirical study through ethical clearance from the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria (see Annexure A). The researcher also obtained permission to conduct the study from the CANSA treatment centre, granted by Dr Annemarie Oberholzer (RN; D Cur) of CANSA-TLC Coordinator at the Northern Business Unit (see Annexure B). It was also ensured that each respondent gave informed consent to voluntarily participate (see Annexure C) in this study.

More detail pertaining to the research methodology is captured in Chapter Three.

1.8 Ethical issues

Certain ethical issues were considered during the research project. Permission was obtained from Nicus Lodge to use their facilities and the families of their patients to collect the data. See Appendix 2: Permission letter from facility. Informed consent was obtained through signed informed consent forms (see Annexure C) that described the research and prepared the participants. The participants were aware that the research was voluntary and that termination of the interview could be done at any time.

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Confidentiality was maintained through keeping participants' names private and assigning numbers to each participant during the research study. Participants had the opportunity for debriefing after the interview from the staff at Nicus Lodge to ensure that no harm was done. The researcher was attentive to the participants' emotions in order to prevent emotional harm. The ethical considerations are discussed in-depth in Chapter Three. The researcher will now briefly discuss the limitations of the study, an in-depth overview will be given in Chapter Four.

1.9 Limitations of study

As can be expected in any research project, limitations did occur. Only a limited number of participants were available to partake in the study at the time that sampling for the research project took place. The researcher interviewed two participants for the pilot study and nine participants partook in the main study. This was a limitation due to the fact that only a small number of the population's views were explored which made it difficult to generalize the outcomes to the greater population.

Due to the limited availability of participants, not all racial groups were included in the study. All the participants were black, except for one who was coloured. They did however differ in ethnic groups, but the results could thus not be extended to the white- or Indian population. The results are therefore mainly based on a homogenous group and not a culturally diverse group. All the participants were struggling financially and were therefore being assisted financially by the CANSA centre, Nicus Lodge, for the duration of their child's treatment. Therefore the results of the study could not be generalized to people who were financially independent.

Due to the qualitative nature and small sampling, the results of this study cannot be generalized or transferred to the greater community of families of a child diagnosed with cancer. The results from this study are the personal views of this sample and their descriptive experiences.

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1.10 Contents of research report

Chapter 1: General background

This section introduced the research with a brief literature study, the theoretical framework, the rationale and problem formulations, the goal and objectives, an overview of the research methodology utilized during the course of the research and the limitations of the study.

Chapter 2: Literature review: Cancer, children and families.

An in-depth literature review will discuss the phenomenon of cancer and the psychosocial influences it has on the family system of a child diagnosed with cancer and the theoretical framework which was applied.

Chapter 3: Research methodology and empirical findings

The empirical chapter commences with a description of the research methods that were applied. The research findings include the results from the interviews, as well as an analysis of the themes identified. This section is divided into three sections according to the themes identified, namely protective measures, restrictive measures, and financial related aspects. Narratives from the interviews and literature are used to substantiate the findings.

Chapter 4: Summary, Conclusions and Recommendations

This chapter summarises how the goals and objectives were met, provide conclusions and make recommendations for integrated social work practice and future research, specifically for social work in oncology.

The following chapter will include an in-depth literature review.

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2 CHAPTER 2: LITERATURE REVIEW: CANCER, CHILDREN AND FAMILIES

2.1 INTRODUCTION

"It is estimated that more than one in three people will develop cancer at some time in their lives" (Davies, Kinman, Thomas & Bailey, 2008:232). "Cancer literature concurs that the experience of cancer can be extraordinarily distressing, not just for patients but also for their partners and family members" (Pikler & Brown, 2010:44). When the cancer patient is a child, not only is he/she affected, but the parents and siblings as well. This is supported by Bauman, Drotar, Leventhal, Perrin and Pless (1997:224), who indicate that a child's serious illness can place psychological and social burdens on both the child and the family members. The authors further mention that although the child diagnosed with cancer endures the major psychosocial burdens of their chronic health condition, studies have documented increased psychological risk among their parents (Bauman *et al.*, 1997:224). Families are affected directly by their child's diagnosis of cancer due to the fact that many families believe it is their duty to be present, to offer emotional support and to provide them with physical assistance in everyday tasks (Nortfield & Nebauer, 2010:567), above their normal parenting roles.

Approximately 14 000 children and adolescents are diagnosed with cancer each year in the United States (Long & Marsland, 2011:57). Due to this high prevalence of paediatric cancer, more family systems are affected as well. As a result of the medical advances that are made in treatment of cancer, survival rates are increasing. This is supported by research conducted by Long and Marsland (2011:57) who indicate that "the significant biomedical advances over the past several decades have increased the survival rate for these children to over 70%." Although treatment methods are improving, they also have negative effects such as complex therapy regiments that necessitate hospitalization as well as out-patient therapy, multiple medical procedures to monitor treatment responses such as drawing blood repeatedly and lumbar punches (Long & Marsland, 2011:57). Furthermore, despite the fact that the survival rate for cancer has improved, cancer still poses a significant threat to life; its onset is often acute and its treatment is intensive and demanding (Von Essen, Sjödén & Mattsson, 2004:474).

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It is also a chronic condition: treatment may extend for several years, and it is associated with a range of adverse long-term effects, including disability and infertility, which places extreme physical demands on children and their parents (Von Essen *et al.*, 2004:474). Cancer does not only affect a person physically, but also emotionally. People with cancer exhibit a wide range of emotions – most patients adapt well while others experience serious distress in response to the illness (Shapiro, McCue, Heyman, Dey & Haller, 2010:1). Parents of children diagnosed with cancer have to cope with the diagnosis themselves, as well as support the child who was diagnosed with cancer. This may place stress on the family system and affects their level of coping. The aspect of dying influences the patients to have to cope with multiple losses, including the loss of health, independence, function, role and future loss of relationships, which increases the amount of grief that a patient experiences (Jacobsen, Zhang, Block, Maciejewski & Prigerson, 2010:257). This influences the psychosocial functioning of the child diagnosed with cancer, as well as the parents of the child.

In order to understand the psychosocial influences on the family of a child diagnosed with cancer, this chapter will focus on the following aspects: conceptualization of cancer, the diagnosis, the different treatment options that are available as well as the side effects of these treatment options, the emotional impact, the spousal impact, the financial impact, the impact on siblings, the impact on religion and role changes within the family system. Furthermore it will focus on the social worker working with families of children diagnosed with cancer in order to enhance their psychosocial functioning as discussed from a developmental social work perspective. Having mentioned the above, the conceptualization of cancer, the diagnosis, the treatment options and the side effects of treatments, will receive attention first.

2.2 CANCER

“Cancer is one of the most challenging and baffling diseases that a human being faces” (Jagannathan & Juvva, 2009:352). Almost every family will have at least one member in each generation that become ill with cancer (Lauria *et al*., 2001:4).

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Survival rates for certain cancers have improved significantly since the 1960s due to both earlier detection and treatment advances (Lauria *et al.*, 2001:4). Paediatric illness can be defined as "a chronic health problem if it lasts over twelve months, affects the child's normal activities and requires a lot of hospitalizations and/or home health care and/or extensive medical care" (Goldbeck, 2006:1121). To understand how cancer affects a person or family's life, we first need to understand what cancer entails.

2.2.1 Conceptualizing cancer

Cancer starts with one cell that has lost control over its growth – normal cells divide in a highly controlled manner to form new cells. Cancer cells also divide and form new cells, but at a more rapid rate and they also do not cease dividing (Lauria *et al.*, 2001:4). When cells continue to divide they transfer through the lymph or the bloodstream to different parts of the body and consequently damage the affected body tissue or organ (Lauria *et al.*, 2001:4). This is called metastasis. Different metastases mean the cancer is located in different areas of the human body, thus different treatment methods are used for different cancer types.

2.2.2 Treatment options and possible side effects

Major advances continue to be made in surgery, radiation therapy and chemotherapy, which are the main treatment forms for cancer. New treatment options have also been developed, such as biologic immune modifiers, high-dose chemotherapy with marrow or stem cell transplantation, use of growth factors, monoclonal antibodies, vaccines, gene therapy and angiogenesis inhibitors (Lauria *et al*., 2010:11). This is supported by Noll, Gartstein, Vannatta, Correll, Bukowski and Davies (1999:71) who state that the "long-term survival rate of children and adolescents diagnosed with cancer has improved dramatically during the past 2 decades. This is a direct result of improved therapies that include surgery, chemotherapy and radiation." Before considering any form of medical treatment, the patient as well as the parents needs to understand what it entails, in order to make an informed decision. It is also important to remember that each case is unique and that treatment options may vary.

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This places strain on the parents of a child diagnosed with cancer due to the fact that the parents need to make this decision on behalf of the child because of his or her minority status. "These procedures and the many side effects of treatment, which can include hair loss, weight gain, mood swings, susceptibility to infections, fatigue, nausea and the impact on quality of life (QOL) not only for the child with cancer, but also for the whole family" (Long & Marsland, 2011:57). These authors also state that in addition to the strains of meeting these treatment demands, families have to adapt to the unpredictable and uncontrollable nature of cancer treatments, as well as confront the possibility that the child may not respond to these treatments and suffer long-term consequences of treatment (Long & Marsland, 2011:57).

The balance between the efficacy of the treatment and side effects of the drugs is an important focus of the design and development of therapies and different treatment options (Fallowfield, 2002:873). The treatment will be viewed as not suitable should the side effects be worse than the positive effect that the treatment may have. Active treatment (chemotherapy or radiation therapy) may be substituted for palliative treatment, should the quality of life of the patient be lowered due to the treatment and the patient who inevitably becomes terminally ill. The four most common forms of treatment which include surgery, radiation therapy, chemotherapy and hormonal therapy, will now each be discussed:

2.2.2.1 ***Surgery***

Lauria *et al.,* (2001:11) state that "cancers are sometimes cured by the removal of the primary tumour, such as a simple mastectomy, without any further intervention." Palliative surgery is employed when a cancer is incurable by resection, but removal of the tumour mass may alleviate suffering by removing an obstruction or prevent bleeding (Lauria *et al.,* 2001:11).

Cytoreductive surgery is the "removal of a large tumour mass (debulking), a procedure that may enhance the effectiveness of a second therapeutic modality such as radiation therapy or chemotherapy (Lauria *et al*., 2001:11).

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Laser surgery involves the use of a laser focused on a specific tumour site to relieve obstruction, aid in further surgical removal or combined with chemotherapy or radiation therapy (Lauria *et al.,* 2001:12).

2.2.2.2 ***Radiation therapy***

According to Lauria *et al.,* (2001:12) radiation therapy entails "beams of energy produced by orthovoltage and cobalt via linear accelerators target high-energy x-rays or subatomic particles (such as electrons) directly to the malignant tumour". Lauria *et al.,* (2001:13) further indicate that an important consideration in radiation therapy is the "ability of normal tissue adjacent to the malignant tissue to tolerate radiation." The side effects of irradiation can be nausea and vomiting, bladder problems (diarrhoea, constipation and a burning sensation when urinating), mouth and throat problems (loss of speech or development of double chin), skin reactions, such as dry skin and breakouts, and possible hair loss. In some cancer treatment regimes, radiation therapy is combined with chemotherapy in order to make the treatment more effective.

2.2.2.3 ***Chemotherapy***

Chemotherapy is the treatment of cancer by means of chemical drugs. The chemical drug targets the cancer cells in order to kill them or to prevent/slow down their growth (Lauria *et al*., 2001:14). Chemical agents made from plants, bacteria and other sources have been used to destroy tumours by inhibiting cell division and selectively destroying proliferating cells (Lauria *et al*., 2001:14). Chemotherapy is administered in five different ways, namely: intravenously which is the direct injection or an infusion of the chemical drug, intra-arterially which is administered directly into the supply artery of the affected organ, orally in the form of tablets, intramuscularly which is an injection directly into the muscle as well as subcutaneous which is an injection into fatty tissue (Lauria *et al*., 2001:15). The side effects of chemotherapy can include nausea and vomiting, cystitis, discoloration of urine, diarrhoea and constipation, hair loss and stomatitis (Lauria *et al.*, 2001:4). Chemotherapy is a toxic form of treatment and affects the healthy surrounding cells as well. In some types of cancer, chemotherapy may not be effective, and then hormonal therapy is prescribed.

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2.2.2.4 *Hormonal therapy*

According to Lauria *et al.,* (2001:16) hormonal therapy is less toxic than chemotherapy and it offers the possibility of significant objective responses in breast and prostate cancer, but may not be curative. The reason for hormonal therapy is that certain malignant cancer cells are known to have hormone receptors which enable the hormones to be absorbed by the cells (Lauria *et al*., 2001:16). Hormonal therapy is then suggested to treat specific types of cancer which are known to have hormonal receptors.

In summary, the researcher discussed what cancer entails, as well as some of the possible treatment options that are available to the patients. These treatment options include chemotherapy, radiation therapy, surgery and hormonal therapy. The researcher further mentioned the most prominent side effects of these treatment options. These side effects affect most of the patients who receive active treatment. Not only does the treatment affect the child receiving the treatment for cancer, but the whole family as well. Long and Marsland (2011:57) confirm this by adding that childhood cancer is a highly stressful experience that can challenge and disrupt the family system and its members. The degree to which the patients experience the side effects, however, differs from individual to individual and from family to family. Some patients may experience extreme nausea but less diarrhoea, while other patients may lose all their hair, or have no hair loss. These side effects also have an emotional impact on the patient as well as the family members. The child may become depressed due to hair loss or because they are constantly feeling ill and this also has a negative effect on the family system. The side effects have a direct impact on the patient's daily life, sometimes causing them not to be able to do the things they were able to do prior to treatment, and due to the fact that they are minors it directly affects the psychosocial functioning of the parents of the child diagnosed with cancer's lives as well. In other cases patients easily come to terms with the side effects, knowing they are temporary and that the end goal justifies the means and this includes families that had good coping mechanisms prior to the diagnosis. Northfield and Nebauer (2010:568) confirm this by adding that the level of family functioning and closeness prior to the child's diagnosis of cancer affects the family's ability to survive the experience.

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Patenaude & Kupst (2005:9) indicate that for there to be an open communication about the difficult emotions of a life-threatening illness, it is advisable to have psychological experts at hand to help families explore and cope with these challenging issues. "The presence of psychologists, social workers and psychiatrists on paediatric cancer services, in turn foster an awareness of behavioural challenges faced by children with cancer" as well as foster an awareness of cancer's psychosocial impact on the whole family, including parents and siblings of the child diagnosed with cancer (Patenaude & Kupst, 2005:10). The role of the social worker is then inevitably to attend to the emotional needs of the patients and parents during the time of treatment, providing the patients as well as their parents, siblings and family members with support and information. The social worker needs to ensure that the patients as well as the parents of the minor realize why the patient is receiving treatment and that it is in the patient's best interests that he/she completes the courses. The patient and parents need to receive adequate information in order to be able to make an informed decision – this is especially important when the patient is a minor and the parents need to make the decision on his/her behalf. The social worker will assist by preparing them to deal with the consequences, such as becoming ill, missing school, depression, physical symptoms and even possible death, and providing them with support during their time of grief. It is imperative for the parents to be supported during this time in order to assist them with coping with the situation in order for them to be able to provide sufficient support, advice, guidance and love to the child diagnosed with cancer. The next section will specifically focus on the psychosocial influences on the family of a child diagnosed with cancer and how the social worker can apply the psychosocial approach in therapy.

2.3 APPLICATION OF THE THEORETICAL FRAMEWORK

A social worker's role when working with individuals and groups is to ensure that no long-term trauma remains when they are faced with a life changing event, such as a child being diagnosed with cancer.

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Barber (2002:37) agrees with this and adds that social work seeks to enhance the social functioning of individuals, singularly and in groups, by activities focused on their social relationships which constitute interaction between individuals and their environments. As discussed previously, when a child is diagnosed with cancer, it does not only affect the child, but the whole family system. The theoretical framework that social workers can utilise to assist with the psychosocial functioning of a family of a child diagnosed with cancer is the psychosocial approach. This will be discussed, including the advantages and disadvantages of the model.

2.3.1 The Psychosocial Approach

The theoretical framework that the researcher utilized throughout this study was the psychosocial approach. As mentioned in Chapter One, the psychosocial approach focusses on the psychological and social aspects of families and individuals in crisis.

The psychosocial approach is applicable to the study because it is holistic and complex, but also flexible due to the fact that the approach is open to new ideas and methods of treatment (Dorfman, 1996:27). It considers the meaning which people attach to illness and health and the cultural influences which shape a range of activities dealing with health and illness (Dorfman, 1996:27). The researcher determined these meanings that the participants attach to their circumstances and took into account the constant interplay between disease process and psychological and social functioning. The model encourages caregivers to not only focus on the patient but also on the family and significant others in the patient's life and his/her environment (Dorfman, 1996:27), and this is exactly the focus of the study – to determine the influence of a child diagnosed with cancer on family functioning. People are not seen to be passive victims of the disease, but rather that the people can participate in their own recovery as well as promoting their good health. In relation to health, it means considering the psychological and social impact of an illness or condition. Serious illness often damages an individual's self-esteem and may reduce their ability to have an active social/family life. The psychosocial approach looks at coping strategies to maintain self-confidence and social networks (Dorfman, 1996:27).

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It is the researcher's opinion that social workers working in the health field, specifically in the oncology field, need to understand how families are influenced when a child is diagnosed with cancer. By understanding this phenomenon, the social workers will be able to formulate intervention strategies which are general enough to be applied to greater society, but also individualized to a point where they will address families' specific needs. By developing these interventions, these families will be enabled and empowered in order for them to be able to contribute to society, instead of being dependent on others and the government for assistance. Thus it can be said that the psychosocial approach mobilizes families to take control of their lives and situation in a positive and productive manner.

An advantage of this model is the fact that the model sees the system as a whole and addresses different areas, as mentioned above (Dorfman, 1996:27). Therefore this model addresses many different aspects at one point in time, providing a holistic approach to social adaptation and reintegration. A disadvantage of this model is that due to the fact that it addresses various aspects, it may not address each individual's needs – what is important to one person, may not be important to another person.

This model can especially be useful once a child has been diagnosed with cancer and the psychosocial effect that it has on the family. It will address all the various aspects that are affected once a child is diagnosed with cancer, such as the effect on the marriage, siblings, religion, employment, financial status, emotional status, and so forth. By addressing each of these aspects, the model will assist the families that are affected by the diagnoses of cancer in their child, to come to terms with the diagnoses. The above mentioned aspects that are affected in a family once a child is diagnosed with cancer, will now be discussed in detail.

2.4 PSYCHOSOCIAL FACTORS OF CANCER

Psychological distress following a child's diagnosis of severe chronic disease involves risks of long-term psychological and psychosocial problems for parents and families (Goldbeck, 2006:1121).

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The author further states that "careful assessment of parental psychosocial status, psychological well-being and functioning is especially useful, because a chronic illness always demands parental participation and adaptation to the new situation" (Goldbeck, 2006:1211). During the treatment period, parents need to deal with many emotional, practical and financial concerns. Von Essen *et al.,* (2004:474) confirm this and add that changes in the family's routine are inevitable as the child diagnosed with cancer needs special attention, care and frequent hospitalizations. The researcher is of the opinion that the psychosocial functioning of the whole family of a child diagnosed with cancer is affected. This is supported by Monterosso, Kristjanson, Aoun and Phillips (2007:689) who indicate that when a child is diagnosed with cancer, it contributes to a number of problems including physical exhaustion of the parents, neglect of other children's needs, general health problems, social and physical isolation, strain on spousal relationships and inability to take holidays. Therefore in order to understand the psychosocial effect on the family we need to investigate the different areas affected when a child is diagnosed with cancer. The psychosocial factors that the researcher identified as those who are most likely to be affected by a child diagnosed with cancer include the emotional impact, the spousal impact, the financial impact, the impact on siblings, the impact on religion, as well as the role changes in the family. These factors will subsequently be discussed in detail.

2.4.1 The emotional impact

As mentioned above, not only do the physical effects of the diagnosis have an impact on the patient, but the emotional effects also have a definite impact. It is the researcher's opinion that in most cases, people focus mainly on the physical side of the treatments and their side effects, causing them to neglect the emotional well-being of the patient and the other family members involved. The social workers working in the health field and specifically in the oncology field, need to emphasize the importance of both the patient's emotional well-being and that of the family system to the significant others as they need to understand that if the patient's emotional well-being is low, it may have a negative impact on the effectiveness of the treatments the patient is receiving, as well as having a negative effect on the other family members.

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Emotion can be defined as an "affective state of consciousness in which joy, sorrow, fear, hate, or the like, is experienced, as distinguished from cognitive and volitional states of consciousness" (Free Dictionary, sv 'emotion'). Well-being of a person is seen as the "state of being healthy, happy or prosperous" (Free Dictionary, sv 'well-being'). For the purpose of this study, emotional well-being is when the patient and family members experience different emotions due to the child's diagnosis of cancer and his/her physical well-being. When a child is diagnosed with cancer, it has an emotional impact on the child and the family system's well-being. The researcher is of the opinion that if this goes untreated by professionals, such as social workers, it can cause long-term difficulties, such as Post-traumatic Stress Syndrome (PTSS). During a study done by Dolgin, Phipps, Fairclough, Sahler, Askins, Noll, Butler, Varni and Katz (2007:778) they found higher levels of PTSS among parents of children during active treatment. Long and Marsland (2011:59) found in their study that mothers and fathers reported heightened mean levels of distress during the first year after their child's diagnosis. The authors also found that parents reported more prolonged distress that can persist for years, as assessed by symptoms of depression, anxiety and PTSS (Long & Marsland, 2011:59). Von Essen *et al.,* (2004:474) add that common complaints among parents of children with cancer include: sleep disturbances, hyper vigilance, difficulty concentrating, anger, guilt, uncertainty, loneliness, problems with parenting the sick child and healthy siblings, an inability within the family to meet each other's emotional needs and even symptoms of PTSS. This is further supported by Nolan, Hodgin, Olsen, Coleman, Sauter, Baker, Stanfield, Emerling and Hruban (2006:373) who state that qualitative studies have found that intense emotional strains such as anger, grief, powerlessness, loneliness and helplessness were common in families with a critically ill patient.

Due to the fact that parents assume the care-giver role in many of the cases when a child is diagnosed with cancer, they have to balance the role of caregiver with the role of parent. Young, Dixon-Woods and Heney (2002:211) indicate that "performing many of these caring tasks, demands that parents engage in emotional work on behalf of children. Their care-giving role is a complex one, involving a range of nursing, technical and emotional tasks along-side routine childcare."

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Many mothers battle with enlisting their child's cooperation with treatment, including getting them to take medicines and submit to unpleasant procedures (Young *et al.*, 2002:211). Papaikomomou and Nieuwoudt (2004:296) found that during the treatment time the parents of a child diagnosed with cancer experience enormous emotional and physical stress. Treatment caused a great deal of uncertainty, loss of control and anxiety to the parents in their study (Papaikomomou & Nieuwoudt, 2004:296). The authors furthermore found that during the initial treatment phase, the parents do not really know what the treatment entails and can become very anxious as a result, as well as the fact that they have to rely on medical professionals to make decisions on their behalf which leaves them with a feeling of loss of control (Papaikomomou & Nieuwoudt, 2004:296). Parents can also experience emotional distress when they are unable to protect their child diagnosed with cancer from distressing medical experiences and this leads to feelings of helplessness and powerlessness by the parents (Woodgate & Degner, 2013:359). It is the researcher's opinion that all of the above-mentioned factors contribute to the parents' emotional well-being and their ability to cope effectively with their child's diagnosis.

As mentioned above, once a child is diagnosed with cancer, it does not only emotionally affect the patient, but his/her parents and family members as well. Parents need to cope with their own emotional distress with regard to their child's diagnosis, as well as tend to the child's emotional needs. According to the resources the researcher consulted, the child diagnosed with cancer, as well as the family members, can experience a range of emotional effects such as depression, anger, PTSS, hopelessness, fear, anxiety, loneliness and uncertainty. It is the researcher's opinion that personality also comes into play here and can have an impact on how a person copes with a stressful life event, such as the diagnosis of cancer in a child. There are many ways to measure personality, but psychologists have mostly given up on trying to divide humanity neatly into types. Instead, they focus on personality traits. The most widely accepted of these traits are the Big Five (Pappas, 2013:20):

- Openness;
- Conscientiousness;
- Extraversion;
- Agreeableness; and
- Neuroticism.

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The Big Five are the ingredients that make up each individual's personality. A person might have a dash of openness, a lot of conscientiousness, an average amount of extraversion, plenty of agreeableness and almost no neuroticism at all. Or someone could be disagreeable, neurotic, introverted, conscientious and hardly open at all. It is the researcher's opinion that the fact that different people have different personality types, and thus different combinations of the Big Five attributes, cause people to react different to life-changing events, such as a child being diagnosed with cancer. In order to understand how a person's personality traits affect his/her ability to cope with such a situation, we need to understand what each of these traits entail. The five traits will now be discussed to improve this understanding, starting with Openness.

❖ Openness

Openness is shorthand for "openness to experience." People who are high in openness enjoy adventure. They are curious and appreciate art, imagination and new things (Pappas, 2013:20). The motto of the open individual might be "Variety is the spice of life." People low in openness, are just the opposite - they prefer to stick to their habits, avoid new experiences and probably are not the most adventurous eaters (Pappas, 2013:20). Changing personality is usually considered a tough process, but openness is a personality trait that has been shown to be subject to change in adulthood (Pappas, 2013:20). It is the researcher's opinion that for someone who has this trait, it would be easier to adjust to difficult situations, such as the diagnosis of cancer in a child because they are more open to new experiences and expect things to change.

❖ Conscientiousness

People who are conscientious are organized and have a strong sense of duty (Pappas, 2013:25). They are dependable, disciplined and achievement-focused (Pappas, 2013:25). You will not find conscientious types jetting off on round-the-world journeys with only a backpack; they are planners who will prepare thoroughly. People low in conscientiousness, are more spontaneous and freewheeling and they may tend toward carelessness (Pappas, 2013:25).

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Conscientiousness is a helpful trait to have, as it has been linked to achievement in school and on the job and relates to responsibility (Pappas, 2013:25). It is the researcher's opinion that someone who is high in conscientiousness will have difficulty adjusting to the diagnosis of cancer in their child, because it would not "fit" into their plan and what they thought their future entailed. It will be more difficult for them to adjust their goals and views regarding their family system and the change that is inevitable in such a situation.

- **Extraversion**

Extraversion versus introversion is possibly the most recognizable personality trait of the Big Five. The more of an extravert someone is, the more of a social butterfly they are (Pappas, 2013:30). Extraverts are chatty, sociable and draw energy from crowds. They tend to be assertive and cheerful in their social interactions and recharge by verbalizing to others and spending time with others (Pappas, 2013:30). Introverts, on the other hand, need plenty of alone time, perhaps because their brains process social interaction differently (Pappas, 2013:30). Introversion is often confused with shyness, but the two are not the same. Shyness implies a fear of social interactions or an inability to function socially (Pappas, 2013:30). Introverts can be perfectly charming at parties — they just prefer solo or small-group activities. It is the researcher's opinion that someone who is more extraverted, will cope better with a diagnosis of cancer, because they verbalize their thoughts, needs and emotions, and thus people who provide them with support, know how to support them more effectively. People who are introverted will need to recharge individually and privately and may thus not utilize resources and support effectively.

- **Agreeableness**

Agreeableness measures the extent of a person's warmth and kindness (Pappas, 2013:35). The more agreeable someone is, the more likely they are to be trusting, helpful and compassionate (Pappas, 2013:35). Disagreeable people are cold and suspicious of others, and they are less likely to cooperate (Pappas, 2013:35).

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It is the researcher's opinion that someone who is more agreeable, will adjust better to the news of a cancer diagnosis in their child, because they are more helpful and compassionate, and will go out of their way to assist their child as needed, no matter the costs. Someone who is disagreeable will be suspicious of others' opinions and may second guess professionals' opinion regarding their child's diagnosis.

- **Neuroticism**

People high in neuroticism worry frequently and easily slip into anxiety and depression. If all is going well, neurotic people tend to find things to worry about (Pappas, 2013:40). One 2012 study found that when neurotic people with good salaries earned raises, the extra income actually made them less happy (Pappas, 2013:40). In contrast, people who are low in neuroticism tend to be emotionally stable and even-keeled (Pappas, 2013:40). Unsurprisingly, neuroticism is linked with plenty of bad health outcomes. Neurotic people die younger than the emotionally stable, possibly because they turn to tobacco and alcohol to ease their nerves (Pappas, 2013:40). It is the researcher's opinion that a person who displays low levels of neuroticism will cope better should their child be diagnosed with cancer, due to the fact that they are more emotionally stable and will handle the news better than someone who is prone to anxiety and depression.

Other measures for personality types include the famous Myers-Briggs Type Indicator. A questionnaire based on the work of early psychologist Carl Jung categorizes people into groups based on four areas: sensation, intuition, feeling and thinking, as well as extraversion/introversion (Pappas, 2013:41). Sensing and intuition refer to how people prefer to gather information about the world, whether through concrete information (sensing) or emotional feelings (intuition) (Pappas, 2013:41). Thinking and feeling refer to how people make decisions. Thinking types go with logic, while feeling types follow their hearts (Pappas, 2013:41).

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It is the researcher's opinion that although personality types are not scientifically able to say who will cope better in a difficult situation, it does serve to provide us with some guidelines as to who are at risk of depression, anxiety, and burnout and possibly even PTSS. Along with personality, a person's ability to deal with grief also affects his/her emotional status and how they cope with life-changing events.

Each person experiences their own form of grief and if differs from person to person in terms of where they are, at a given time. The Kübler-Ross model, commonly known as the Five Stages of Grief, was first introduced by Elisabeth Kübler-Ross in her 1969 book, On Death and Dying. The progression of states is Denial, Anger, Bargaining, Depression and Acceptance. Refer to Table 1: Five Stages of Grief (Based on the Grief Cycle model first published in On Death & Dying, Kübler-Ross, 1969. Interpretation by Chapman 2006-2013.)

Table 1: FIVE STAGES OF GRIEF

Five Stages of Grief - Elisabeth Kübler-Ross	
EKR stage	**Interpretation**
1 – Denial	Denial is a conscious or unconscious refusal to accept facts, information, reality, etc., relating to the situation concerned. It is a defence mechanism and perfectly natural. Some people can become locked in this stage when dealing with a traumatic change that can be ignored. Death of course is not particularly easy to avoid or evade indefinitely.
2 – Anger	Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them. Knowing this helps keeps you detached and non-judgemental when experiencing the anger of someone who is very upset.

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3 - Bargaining	Traditionally the bargaining stage for people facing death can involve attempting to bargain with whatever god the person believes in. People facing less serious trauma can bargain or seek to negotiate a compromise. Bargaining rarely provides a sustainable solution, especially if it is a matter of life or death.
4 - Depression	Also referred to as preparatory grieving. In a way it is the dress rehearsal or the practice run for the 'aftermath' although this stage means different things depending on whom it involves. It is a sort of acceptance with emotional attachment. It is natural to feel sadness and regret, fear, uncertainty, etc. It shows that the person has at least begun to accept the reality.
5 - Acceptance	Again this stage definitely varies according to the person's situation, although broadly it is an indication that there is some emotional detachment and objectivity. People dying can enter this stage a long time before the people they leave behind, who must necessarily pass through their own individual stages of dealing with the grief.

❖ ***Denial***

"I feel fine"; "This can't be happening, not to me". These are examples of phrases that will be used by a person who is in the Denial phase. Denial is usually only a temporary defence for the individual. This feeling is generally replaced with heightened awareness of situations and individuals that will be left behind after death or who experienced a traumatic event, such as the diagnosis of a child with cancer (Kübler-Ross, 1969:67). It is the researcher's opinion that a family of a child diagnosed with cancer may experience denial at first once they hear the news from the doctor the first time. They may want a second opinion or attribute the symptoms to an illness which is less severe.

❖ ***Anger***

"Why me?; It's not fair!"; "How can this happen to me?"; "Who is to blame?". These are examples of phrases that will be used by a person who is in the Anger phase.

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Once in the second stage, the individual recognizes that denial cannot continue (Kübler-Ross, 1969:71). Because of anger, the person is very difficult to care for or to support in a time of crisis, due to misplaced feelings of rage and envy (Kübler-Ross, 1969:71). Any individual that symbolizes life or energy, or any form of normalcy, is subject to projected resentment and jealousy. It is the researcher's opinion that many parents will experience this stage once their child is diagnosed with cancer. They will ask questions such as why would something so life-threatening happen to an innocent child, it can even cause them to challenge their faith and religious ideas.

❖ ***Bargaining***

"He is so young, just let him live a little longer"; "I'll do anything for a few more years"; "I will give my life savings if..." These are examples of phrases that will be used by a person who is in the Bargaining phase. The third stage involves the hope that the individual can somehow postpone or delay death (Kübler-Ross, 1969:79). Usually, the negotiation for an extended life is made with a higher power in exchange for a reformed lifestyle (Kübler-Ross, 1969:83). Psychologically, the individual is saying, "I understand I will die, but if I could just have more time..." In the case of a child diagnosed with cancer, the parent will bargain with a higher power to give them more time with their child. It is the researcher's opinion that the parents would want to negotiate to have their child survive in order to spend more time with them, especially if they are very young or if the parents had a close relationship to the child prior to the diagnosis.

❖ ***Depression***

"I'm so sad, why bother with anything?"; "The doctors told me there is nothing more that they can do... What's the point?"; "I miss my loved one, why go on?" These are examples of phrases that will be used by a person who is in the Depression phase. During the fourth stage, the person begins to understand the certainty of death, either of him/her or his/her loved one (Kübler-Ross, 1969:86). Because of this, the individual may become silent, refuse visitors and spend much of the time crying and grieving (Kübler-Ross, 1969:91). This process allows the person to disconnect himself/herself from things of love and affection. It is not recommended to attempt to cheer up an individual who is in this stage.

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It is an important time for grieving that must be processed. It is the researcher's opinion that even though this process needs to be experienced, it may interfere with the parent's ability to take care of his/her child emotionally and physically, therefore they need the necessary resources and support to get them through this part of the grieving process.

❖ ***Acceptance***

"It's going to be okay"; "I can't fight it, I may as well prepare for it" These are examples of phrases that will be used by a person who is in the Acceptance phase. In this last stage, the individual begins to come to terms with their mortality or that of their loved one (Kübler-Ross, 1969:99). It is the researcher's opinion that even though most parents may reach this phase, it will be at different times and in different ways, and it is the social workers' responsibility to assist them with this process in order to reach a point where they can accept the situation and provide their ill child and family with the necessary support and understanding to cope effectively.

Kübler-Ross originally applied these stages to people suffering from terminal illness, later to any form of catastrophic personal loss (job, income, freedom). This may also include significant life events such as the death of a loved one, divorce, drug addiction, the onset of a disease or chronic illness, an infertility diagnosis, as well many tragedies and disasters. Therefore it is the researcher's opinion that these stages of grief coincide with the diagnosis of a child diagnosed with cancer and what their primary caregiver may experience during this time.

Kübler-Ross claimed these steps do not necessarily come in the order noted above, nor are all steps experienced by all patients/people, though she stated a person will always experience at least two. Often, people will experience several stages in a "roller coaster" effect — switching between two or more stages, returning to one or more several times before working through it (Kübler-Ross, 1969:105). Significantly, people experiencing the stages should not force the process. The grief process is highly personal and should not be rushed, or lengthened, on the basis of an individual's imposed time frame or opinion. One should merely be aware that the stages will be worked through and the ultimate stage of "Acceptance" will be reached.

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It is important for a social worker in a health care setting working with children and families where a child was diagnosed with cancer, to understand the emotional effect the diagnosis has on the child diagnosed with cancer as well as the family in order to provide supportive counselling and guidance for the child and family involved. It is the researcher's opinion that the social workers need to take into account the personality type of the person, his/her ability to deal with grief and life altering situations, and the ability to move beyond the circumstances, as well as the fact that for each person, this is an individual process. Due to the fact that the diagnosis of a child has such a profound impact on the child, his/her parents and other family members, it is unlikely that a person's marriage or relationship will not be affected, whether it is positively or negatively.

2.4.2 The spousal impact

A spousal relationship entails two people who are in a consensual relationship and share experiences, events and emotions Long and Marsland (2011:59). When spouses have children they have a dual responsibility to take care of the child's physical, emotional, psychosocial and psychological well-being. When a child is diagnosed with cancer the spouses need to go beyond their normal parenting role to support the child during this time of crisis. This can place a lot of strain on the relationship and can prevent them from spending quality time on their relationship. Da Silva, Jacob and Nascimento (2010:250) state that the diagnosis of cancer and the treatment decisions associated with it may cause uncertainty, stress and anxiety among parents. The authors also found that emotional tension can affect parents' relationship during the trajectory of the child's illness (Da Silva *et al.*, 2010:250). Long and Marsland (2011:59) indicated that many parents report increased marital distress once their child was diagnosed with cancer. The authors also found that parents reported heightened levels of distress during the first year of their child's diagnosis (Long & Marsland, 2011:59). During their study they found that parents of children on active treatment indicated that the "tag team parenting" lead to reduction in spousal interaction and shared decision-making (Long & Marsland, 2011:59). According to qualitative literature there are both themes of strains and improvements in spousal relationships when a child is diagnosed with cancer.

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Some couples indicated that the event brought them closer together, while other couples indicated the pressure was too much and it resulted in divorce. This is supported by Long and Marshland (2011:81) who indicate that the challenges include "the tendency for partners to put the needs of the marriage and partner on hold during intense treatment stages, as well as incongruence between partners' coping styles" while other partners indicated that their spouse is their main form of support and their closeness enhanced over time (Long and Marsland, 2011:59). Monterosso *et al.,* (2007:692) found that parents reported difficulties in personal relationships, including separation and divorce. Da Silva *et al.,* (2010:251) found that some relationships are weakened by the stressful event of a child being diagnosed with cancer, while others were strengthened during the cancer illness experiences. The authors found that changes occurred in spousal relationships during the course of the child's illness and these changes could be either positive or negative (Da Silva *et al.*, 2010:251).

The positive changes were evident when the couples realized their potential and resources to manage the child's illness, whereas the negative changes were evident when the couples felt that their marital relationship weakened (Da Silva *et al.*, 2010:251). According to the authors' study, the following positive changes were noted in couples whose child was diagnosed with cancer: "better perception of the partner's personal and behavioural traits, increased ability to resolve conflict, improved interpersonal confidence, greater flexibility in the relationship and more cohesive support" (Da Silva *et al.*, 2010:256). Grootenhuis and Last (1997:477) add that parents also reported good support systems, new values and attitudes, re-evaluation of goals, new perceptions on their out-look on life, increased closeness in the family and strengthened marital relationships, as positive responses when their child was diagnosed with cancer.

Da Silva *et al.,* (2010:256) also found the following negative changes in the course of their study, namely: sexuality and intimate relationships decreased, less time for leisure activities, feelings of isolation due to more time spent with the child and less time as a couple and increased tension and friction between couples due to feelings of lack of support (Da Silva *et al.*, 2010:256).

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Grootenhuis and Last (1997:477) furthermore add that increased marital distress, impaired sexual relationships and higher prevalence for marriage counselling was reported in families whose child was diagnosed with cancer. When a couple's child is diagnosed with cancer, they have to provide emotional and practical support during the time of disease and treatment (Sjövall, Attner, Lithman, Noreen, Gunnars, Thome, Lidgren, Olsson & Englund, 2010:467).

It is the researcher's opinion that the one parent is usually with the child diagnosed with cancer, while the other parent is either with the other children and running the household, or working in order to finance all the treatments. This prevents the parents from spending quality time together. Spouses also tend to feel guilty about spending quality time together when their child is sick and in hospital, therefore they tend to put romance on hold during the treatment period. Grootenhuis and Last (1997:477) found that the number of hospitalisations were predictive of decreased marital quality and maternal depression. The child's functional impairment proved to be related to maternal depression and to increased problems in parents – when a child had a relapse or second malignancy, more emotional problems were noted in the parents (Grootenhuis & Last, 1997:480).

In order for families to maintain their self-esteem and social interaction and functioning, parents may change or modify their family roles to manage their child's illness (Da Silva *et al.*, 2010:251). "The conflict, pressure from work, and difficulties in balancing roles and assuming new tasks in the family contributed to stress in their relationships" (Da Silva *et al.*, 2010:257). Families have low self-development due to restricted time to be with their partner, with friends or acquaintances, or to develop their personal interests due to the fact that they have to take care of their sick child (Goldbeck, 2006:1128). It is important for spouses to have time to interact with other family members and friends, because they are the spouses' main form of support during a time of crisis. Goldbeck (2006:1128) states that parents of a chronically ill child utilize social and emotional support from their families and their partners. Literature suggests that spouses who have a strong, supportive relationship cope better than spouses who have marital problems prior to the diagnosis of cancer in their child.

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Da Silva *et al.,* (2010:251) state that "differences between fathers' and mothers' coping have implications for individual family members and the whole family." It is also the researcher's opinion that communication plays an important role in the effectiveness of the spouses' coping methods. This is supported by Goldbeck (2006:1128) who states that maintaining open communication within the family has been described as an effective and important parental coping style to facilitate adaptation to the new situation with an ill child.

It is the researcher's opinion that it is important for a social worker in a health care setting, working with children and families where a child was diagnosed with cancer, to understand the effect that it has on a marriage or spousal relationship in order to provide supportive counselling and guidance for the child and family involved. The social worker needs to focus on the changes that may occur in the spousal relationship, the strain that parents experience, the guilt feelings which they may experience and the support structures that the parents will need. These aspects are important to maintain a healthy family dynamic and good quality of life within the spousal relationship. As mentioned above, in order for spouses to maintain or improve their relationship, some changes may need to be made within the family system, these changes can include changes in employment, parenting roles and responsibility division. This will be discussed next in role changes in the family system.

2.4.3 Role changes in the family system

Each family has their own way of functioning and coping within a nuclear family system. There are many different roles in a family system, such as: mother, father, husband, wife, child, brother, sister, provider, caregiver and dependent/minor. In some families the father/husband is the provider and the mother/wife is the caregiver – the father will work and provide financially for his wife and children, while the mother stays at home and looks after the household and the children. In other families both parents are employed and jointly provide financially for the family. When a child becomes ill and is diagnosed with cancer, these roles may change – the father may need to work more often due to increasing medical bills or the mother needing to work less to be with the ill child.

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It is normal for the mother to take more time off from work and take care of the ill child – taking the child for doctor's appointments, treatment procedures and staying with the child during hospitalization. Long and Marsland (2011:77) agree with the researcher's above mentioned opinions and indicate that a substantial body of qualitative work reports that accommodating treatment demands for the child with cancer requires reorganization of roles and reallocation of responsibilities among family members. The roles in the family change due to the child becoming the main priority, while still attending to the rest of the family's needs. This is supported by Long and Marsland (2011:77) who state that "the ill child becomes the focus of attention" and who furthermore found in their study that the parents of children, both on and off treatment, indicate that the needs of the ill child are prioritized over those of other family members. Chui and Chan (2005:373) support this and add that "the lack of knowledge about the illness and treatment and uncertainty about the prognosis lead to increased stress and tension." Although care giving responsibilities are shared between parents, most mothers either work part-time or do not work at all, while the fathers worked full-time (Svavarsdottir, 2004:153). Role changes and increased responsibilities place additional burdens on the family system (Chui & Chan, 2005:373).

Scavarsdottir (2004:158) found that the parents participating in the study indicated that the most difficult and time-consuming tasks involved in parenting a child diagnosed with cancer was providing emotional support to the ill child as well as the other children in the family system. The separation of a member because of hospitalization and restrictive visiting hours heighten the emotional strain on the family (Chui & Chan, 2005:373). Svavarsdottir, (2004:159) found that mothers find it difficult and time-consuming to manage behavioural problems, coordinate, arrange, organize and manage services for family members, to provide personal care for the child with cancer and to structure and plan activities for the whole family. Young *et al.,* (2002:211) support this by adding that "childhood illness appears to amplify traditional gender-divisions of labour as mothers relinquish other roles to take on most of the care-giving tasks associated with the illness." This places further strain on the existing roles of the family as the mother has less time to take care of the other children. Mothers find it difficult to perform basic caring tasks for their other children and may experience guilt and regret about this (Young *et al.*, 2002:211).

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Goldbeck (2006: 1129) confirms this by saying that mothers mostly have the role of primary caregiver of the child, and may experience persistent parenting stress with the ill child. Young *et al.,* (2002:211) further state that fathers too are in the difficult position of negotiating the expectations of being the main breadwinner along with their own need to be with their ill child and other children. Goldbeck (2006: 1129) supports this by adding that fathers often return to work several weeks after their child's diagnosis and thus may experience less parenting stress in terms of taking care of the sick child, but more financial stress due to being the main provider. Da Silva *et al.,* (2010:257) mention that while the mother may feel tired from taking care of the sick child, the father may also feel tired from work. "Mothers focused on involvement in the child's life, represented by being physically present, while fathers advocated for and supported the child and his wife" (Da Silva, 2010:257).

In some families they are able to absorb the changes relatively easily. It is possible for families who are financially stable, have good medical aids and have good relationships and support systems to adjust better to their child being diagnosed with cancer. Woodgate and Degner (2003:361) support this by adding that some families were able to continue to maintain their usual responsibilities, roles and activities once their child was diagnosed with cancer. There are however also families who have more difficulty with coping with the diagnosis of cancer in their child. "The conflict, pressure from work, and difficulties in balancing roles and assuming new tasks in the family contributed to stress in their relationships" (Da Silva, 2010:257). It is important for a social worker in a health care setting, working with children and families where a child was diagnosed with cancer, to understand the different role changes in the family in order to provide supportive counselling and guidance for the child and family involved. As mentioned above the parents often have to change their roles in terms of who the main breadwinner is and staying employed or resigning in order to become the primary care-giver for the child. This change in the family system has a financial impact on the family system, which will now be discussed in detail.

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2.4.4 The financial impact

Children rely on their parents financially due to the fact that they are unable to provide for themselves. This involves clothes, food, accommodation, school fees, extracurricular activities such as extra classes, sport, culture, as well as social activities and school camps. When a child becomes ill, the parents need to pay for medical services which can be very costly. Monterosso *et al.,* (2007:692) confirm this by adding that during their study they found that parents mentioned difficulties in procuring funding for various forms of care. Should the family have medical aid, medical services will be covered, but sometimes only to an extent, the parents then need to pay for the services not covered by the medical aid. When the family does not have any medical aid, they need to pay for these services privately or go to a government facility. See Table 2: Comparison between medical aids.

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Table 2: COMPARISON BETWEEN MEDICAL AIDS

Medical aid	Bestmed	Medihelp	Discovery	GEMS
Source	http://www.bestmed.co.za/modules_fe/Bestmed2013/2014bestmed-beat1.asp	http://www.medihelp.co.za/docs/default-source/product-brochures/2014-prime-1-eng6C923C0E9784EB5D6A8AAD89.pdf?sfvrsn=8	https://www.discovery.co.za/portal/individual/executive-plan	http://www.gems.gov.za/default.aspx?sNRTTskW85bVh5I2ayP/yg==
Fees	**Principle member R955. Child dependent R402 per child.**	**Principle member R1146. Child dependent R342 per child.**	**Principle member R3075. Child dependent R584 per child.**	**Principle member R652. Child dependent R276 per child.**
General exclusions	(PMB's not applicable) All travel expenses for doctors and patients. Medical aids, orthopaedic, surgical and medical appliances. Accommodation in an old-age home or institution providing general care and nursing services to persons, e.g. the infirm aged and chronically sick patients, or similar institutions. Orthopaedic and surgical appliances during hospitalisation.	Travelling and accommodation/lodging costs, including meals as well as administrative costs of a beneficiary and/or service provider. Appliances: blood pressure apparatus, peak flow measurement apparatus, motorised mobility aids/devices, commode, toilet seat raiser, hospital beds for home use, devices to improve sight, mattresses and pillows, bra's without external breast prostheses, insulin pumps and consumables, back, leg, arm and neck supports, crutches, orthopaedic footwear, elastic stockings and CPAP apparatus.	No specific exclusions stated, dependent on scheme benefit and option type.	Excludes frail care accommodation, travel expenses for doctor's appointments and mbulance services from hospital facility to home.

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In-Hospital Benefits	All in-hospital benefits, clinical funding protocols apply, hospital stay and theatre fees 100% scheme tariff, take home medicine 100% scheme tariff, limited to 7 days' medicine, consultations and procedures 100% scheme tariff, surgical procedures and anaesthetics 100% scheme tariff, pathology 100% scheme tariff, diagnostic imaging 100% scheme tariff, specialised diagnostic imaging 100% scheme tariff.	State and private hospitals and day clinics, includes Intensive and High-care wards, ward accommodation, theatre fees, treatment and ward medicine, surgery and anaesthesia, 100% of the UPFS/contracted/scheme tariff/medicine price/cost, procedure-specific co-payments may apply. Unlimited: Standard radiology, pathology and technologist services. Unlimited: Specialised radiology, in and out of hospital, on request of a specialist and subject to clinical protocols.	Unlimited cover at any private hospital and private ward cover of up to R1 400 each day. We pay the first R2 450 of your MRI or CT scan from your day-to-day benefits. We cover the balance of the scan from your Hospital Benefit, up to the Discovery Health Rate (except for conservative back and neck scans, where specific rules apply).	All costs for operations, medicines, treatments and procedures for cosmetic purposes. Includes accommodation in a general ward, high care ward and intensive confinement event, but subject to annual hospital limit and registration. Allied health services. GEMS Network GP. Alternatives to hospitalisation (hospice, sub-acute hospitals and private nursing). Subject to annual hospital limit and sub-limit of R16588 per family per year. Includes post-surgical home nursing.
Out-of-Hospital Benefits	**Out-of-Hospital Benefits:** Most out-of-hospital expenses, such as visits to a GP or Specialist, are paid in full by you directly to the service provider. The following out-of-hospital benefits are paid for by the Scheme: Medical event - Wound care benefit limited to R2300 per family (including dressing and negative pressure wound therapy treatment and related nursing services out of hospital). Medicine: CDL chronic medicine 100% scheme tariff, 35% co-payment for non-formulary medication. Non-CDL chronic medicine - no benefit.	**Out-of-Hospital Benefits:** MRI and CT imaging R15500 per family per year. Bone marrow/stem cell transplants 100% of the medical scheme tariff/cost.	No specific exclusions stated, dependent on scheme benefit and option type.	No specific exclusions stated, dependent on scheme benefit and option type.

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Day-to-day Benefits	CDL chronic medicine - 100% scheme tariff and 35% co-payment on non-formulary medication. Non-CDL chronic medication - no benefit. Wound care benefit (incl. dressings and negative pressure wound therapy (NPWT) treatment and related nursing services - out of hospital) - limited to R2300 per family.	**Day-to-day benefits:** include GP's, specialists and emergency units. Overall annual day-to-day limit R2250 per year. Chronic non-PMB medicine - for member's account. MEDICINE: From day-to-day benefits. Acute medicine (including over-the-counter medicine, immunisation, contraceptives and homeopathic, herbal, naturopathic and osteopathic medicine) 80% of the medicine price. Sub-limit of R1060 per year and subject to overall day-to-day limit. Pathology and medical technologist services out of hospital, standard radiology out of hospital is for member's own account.	**Day-to-day benefits:** GP consultations, day-to-day cost-effective medicines (schedule 3 and above), blood tests, maternity costs and some durable external medical items will be covered if you use a provider in our network. GP consultations, day-to-day cost-effective medicines (schedule 3 and above), blood tests, maternity costs and some durable external medical items will be covered if you use a provider in our network.	Examinations requested by specialist are covered subject to list of approved services, if referred by GEMS Network. GP and the visit is pre-authorised. Unlimited Specialist services. Consultations, visits and all other services. Subject to GEMS Network GP referral.

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Oncology	Oncology programme (preferred provider) 100% scheme tariff. Treatment subject to in-hospital treatment.	PMB cases and Management programs. Radiotherapy, including brachytherapy, chemotherapy and associated adjuvant medicine 100% of the contracted/scheme tariff/medicine price/cost. Co-payments apply for voluntary non-network services and/or deviating from protocol. Radiotherapy including, brachytherapy, chemotherapy and associated adjuvant medicine - for member's account.	Covers first R400 000 of approved cancer treatment in full over a 12-month cycle. You will be required to pay 20% of the cost on all further treatment once costs for cancer treatment go over R400 000. Paid up to 100% of the Discovery Health Rate.	Chemotherapy and radiotherapy: Excludes new chemotherapeutic medicines that have not demonstrated a survival advantage of more than 3 months in advanced and metastatic solid organ malignant tumours unless pre-authorised. Pathology: subject to annual hospital limit. Radiology (advanced): Subject to list of approved services. Radiology (basic): Subject to annual hospital limit.

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Chui and Chan (2005:373) indicate that "hospitalization takes a toll on family finances because of the immense health care expenses as well as a loss of income." Parents who take care of their child are unable to work the hours they used to and thus are not able to maintain the same level of income. Time and costs associated with informal care-giving for cancer patients can be substantial (Sjövall *et al.*, 2010:467). Young *et al.,* (2002:211) indicated that "a key obligation generated by the diagnosis of childhood cancer is the need of parents to be physically close to the sick child at all times". This is supported by Sjövall *et al.,* (2010:467) who indicate that "the burden of care-giving may include not being able to perform employment work as usual, leading to both psychosocial as well as financial consequences. Parents also tend to take more sick leave or family responsibility leave when a child is diagnosed with cancer in order to take the child to doctor's appointments, treatments and hospitalization. Sjövall *et al.,* (2010:472) further state that sick leave by parents of a child diagnosed with cancer, should be estimated with the addition of indirect costs of cancer due to the fact that a person has a limited amount of sick leave allocated and once it is depleted they need to take unpaid leave. Young *et al.,* (2002:212) also mention that parents sometimes engages in costly strategies to ensure that their child receives the necessary treatment. Heath, Lintuuran, Rigguto, Tikotlian and McCarthy (2006:444) "found that 74% of parents reported experiencing a great or moderate degree of economic hardship following the diagnosis of cancer in childhood".

The economic hardship also caused emotional stress for the family, which in effect placed strain on the marital or spousal relationship. In a study done by Heath *et al.,* (2006:444) it was noted that families reported an increased financial burden associated with vehicle expenses such as parking, petrol and additional maintenance, as well as additional food such as ordered meals, meals away from home and maintaining multiple residences, airfares to see specialists and babysitters for the other children when both parents were with the ill child. Therefore it is the researcher's opinion that the financial, emotional and spousal effect of a child being diagnosed with cancer is interchangeably linked – one is affected by the other.

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It is important for a social worker in a health care setting, working with children and families where a child was diagnosed with cancer, to understand the financial effect of a child diagnosed with cancer on the family in order to provide supportive counselling and guidance for the child and family involved. As mentioned above, not only the parents of a child diagnosed with cancer are affected by the diagnosis, the healthy siblings are also affected. This will be discussed in the following section.

2.4.5 The impact on siblings

When a child is diagnosed with cancer, he/she receives most of the attention, care and involvement of the parents. The other siblings receive less attention and care due to the fact that the ill child's diagnosis is now the centre of the family's functioning. This is confirmed by Nolbris, Abrahamsson, Hellström, Oloffson and Enskär (2010:298) who state that when a child is diagnosed with cancer, all attention is turned to the ill child. Very little research has been done on the effect of a child diagnosed with cancer on the healthy siblings and the topic remains poorly understood (Long & Marsland, 2011:59). Research indicates that siblings endorse higher levels of negative emotions, lower levels of positive emotions and reduced quality of life than their peers (Long & Marsland, 2011:59). Siblings may become jealous of their ill sibling due to the fact that he/she receives more attention and interaction from their parents and other family members. Siblings may feel unimportant and rejected.

Monterosso (2007:692) found that "parents acknowledge that siblings of ill children were often affected emotionally". Further research showed that cancer-related stressors may influence sibling distress (Long & Marsland, 2011:59). It has been noted that proximity to the ill child, hospital confinement and prioritization of the ill child's needs over those of other family members can compromise relationships with the spouse and other children (Long & Marsland, 2011:78). The mother may also experience role conflict due to the fact that she wants to be with her ill child when he/she is in hospital or receiving treatment, but she also wants to be with her other children at home (Long & Marsland, 2011:59).

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Hill et al., (2003:753) state that "it is generally accepted that family relationships are likely to be affected by a serious illness in a child, with implications for the subsequent adaptation of family members" such as siblings of a child diagnosed with cancer. Nolbris *et al.,* (2010:298) indicate that the bond between siblings is unique and full of different emotions. "Siblings may also experience much emotional distress if they know their ill brother/ sister may be suffering from uncontrolled symptoms, especially if they are unable to comfort them" (Woodgate & Degner, 2003:359). Woodgate and Degner (2003:359) add that worrying about their ill brother's/sister's changing physical appearance, personality and mood also contributes to their siblings' distress.

The sibling's role also changes continuously within the family system – at times the sibling may enjoy less time with his/her sick sibling, less time with his/her parents and fewer family activities and vacations. The sibling may also need to take more responsibility in and around the house, such as doing more chores, taking responsibility for school work and having to support his ill sibling emotionally. If the main care-giver is at hospital most of the time, the sibling has to come to terms with seeing the parent less often and receiving less attention and quality time. It is important for a social worker in a health care setting, working with children and families where a child was diagnosed with cancer, to understand the effect of a child diagnosed with cancer on his/her siblings in order to provide supportive counselling and guidance for the children and family involved. It is inevitable that change will occur in the family system in terms of the spousal relationship, financial independence, the impact on the siblings and the emotional impact. Along with this, the researcher is also of the opinion that a child's diagnosis of cancer will affect the spiritual/religious levels of a family system. This will be discussed in the next section.

2.4.6 The impact on religion and spirituality

Spirituality is a broader concept than religion and can be defined as "a person's beliefs and values regarding the search for transcendent meaning in life" (Nolan *et al.*, 2006:239). Religion can be defined as "a set of beliefs and practices that characterizes a faith community searching for transcendent meaning in a particular way" (Nolan *et al.*, 2006:239).

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With a patient facing life-threatening illnesses, spirituality can be defined as the ability to transcend physical discomfort, accept death, surrender to transcendence and feel at peace (Nolan *et al.*, 2006:239). It is the researcher's opinion that some people rely on their faith or spirituality to see them through a time of crisis, where other people may lose their faith during such time. Nolan *et al.,* (2006:239) found in a study that "patients reported that their spirituality gave them the strength to face life-threatening illnesses" and they described their trust in a higher power to see them through their journey and were grateful for the many blessings in their lives, despite illness-related burdens. It is also possible for a person who does not have spiritual beliefs, to start believing during a time of crisis, such as being diagnosed with a life-threatening disease or having their child diagnosed with cancer. It is important for a social worker in a health care setting, working with children and families where a child was diagnosed with cancer, to understand the effect of a child diagnosed with cancer on religion and spirituality in order to provide supportive counselling and guidance for the children and family involved.

As a short summary, the researcher discussed what emotional well-being entails, as well as the different emotions that are experienced by the patients and their significant others. The social worker's role is to attend to the emotional needs of the patients, encourage them to come to terms with their diagnosis and introduce them to the different services that the social worker can offer the patient. These services include counseling, therapy, placements in care facilities as well as bereavement counseling for the family members should the patient pass away.

2.5 SUMMARY

This chapter provides readers with an overview of cancer, the different treatment options that are available as well as the possible side effects connected with the treatments. The researcher also elaborates on the psycho-social impact of a child diagnosed with cancer on the spousal relationship, on the healthy children, on finances and religion/faith and role changes. Different authors' views are explored in order to conduct a thorough research study.

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The above-mentioned aspects are linked to the psychosocial approach, indicating the role of the social worker when working with a family whose child has been diagnosed with cancer. The following chapter, Chapter Three, will focus on research methodology and empirical findings.

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3 CHAPTER 3: RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

3.1 INTRODUCTION

As indicated in Chapter One, the researcher has identified a gap in the knowledge base of social work with regard to the psychosocial influences on the family of a child diagnosed with cancer. With the increasing number of children who are diagnosed with cancer, it has become necessary to understand the phenomenon as well as the different aspects involved with this complex disease, such as family functioning, emotional well-being, financial impact and the impact on siblings.

The focus of this chapter is to analyse and interpret the qualitative data gathered from the participants through interviews. The aim is to establish if there are any psychosocial influences on the family of a child diagnosed with cancer, and if there are, what these influences are, based on the data gathered by the researcher. The researcher will firstly outline the goal and objectives of the study. Thereafter a discussion will be conducted regarding the research methodology. This will be followed by an analysis and interpretation of the research findings. The research question for this study is formulated as follows: **What are the psychosocial influences on the family of a child diagnosed with cancer?**

3.2 GOAL AND OBJECTIVES OF THE STUDY

3.2.1 Goal of the research

The goal of the study was to explore the psychosocial influences on the family of a child diagnosed with cancer.

3.2.2 Objectives of the research

The researcher identified the following **objectives** which clearly described the major focus of the study (Kumar, 2005:50). By reaching these objectives the researcher attained the goals set in the study.

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The objectives included:

- Conceptualizing paediatric oncology as a phenomenon;
- Describing the experiences of the family of a child diagnosed with cancer;
- Determining whether the socio-economic circumstances of the family are affected once a child in the family is diagnosed with cancer;
- Exploring the emotional experiences of family members when their child is diagnosed with cancer;
- Exploring the quality of life of the family once their child is diagnosed with cancer;
- Exploring the influence on the marital relationship of the parents of having a child diagnosed with cancer;
- Exploring the family interactions once a child is diagnosed with cancer;
- Exploring any changes in the family roles once a child is diagnosed with cancer; and
- Exploring the experiences of the siblings of the child diagnosed with cancer.

3.3 Research approach

The researcher utilized the qualitative approach for this study. Rich descriptive data was collected with regard to the phenomenon of children diagnosed with cancer and the psychosocial influence thereof on the family (Nieuwenhuis, 2007:50). This was done with the intention of developing an understanding of what was being observed or studied (Nieuwenhuis, 2007:50). Through qualitative research the researcher gained a first hand and holistic understanding of the phenomena and the gathered data is presented in the form of words and quotations from documents and transcripts. The participants gave their perceptions, experiences and feelings regarding the psychosocial influence of a child diagnosed with cancer on the family during face-to-face interviews that were conducted with each participant (Patton, 2002:39). Due to the fact that this was a sensitive topic, qualitative research was ideal to capture the personal experiences of the participants.

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3.4 Type of research

There are two types of research, namely basic research and applied research. Applied research is primarily used when "the researcher's primary motivation is to assist in solving a particular problem facing a particular community (Bless Higson-Smith & Kagee, 2006:45)." The aim of the study was to explore the participants' perceptions regarding the psychosocial influences of a child diagnosed with cancer on the family. By doing this study the researcher focused on the problem of a lack of knowledge with regard to the psychosocial influences of a child diagnosed with cancer on the family. The researcher intended to gather crucial information on experiences and perceptions from research participants regarding psychosocial influences of a child diagnosed with cancer on the family, in order for other social workers in the health field working with similar cases, to be able to address this issue in the future.

3.5 Research design

The research design that was used for this study is the case study design. This was because the researcher wanted to explore the challenges and experiences which parents of a child diagnosed with cancer encountered since the diagnosis and throughout treatment. The case study design also gives an in-depth description of the case. The researcher examined human experiences through the descriptions that were provided by the people involved (Brink, 2011:113). Due to the fact that the researcher wanted to understand the meaning that the participants attach to their experiences the researcher used a form of case study to understand the situation of a small number of people "in order to obtain an intimate familiarity with their social worlds and to look for patterns in the research participants' lives, words and actions in the context of the case as a whole" (Fouche & Schurink, 2011:320).

The type of case study that was used in this study was the collective case study design. According to Fouché and Schurink (2011:322), "collective case study is an instrumental case study extended to a number of cases".

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The researcher was more interested in the group's opinion than the individual's opinion hence the reason for choosing this type of research design. The case study design enabled the researcher to gain information on the experiences and challenges facing this group of parents of a child diagnosed with cancer and the effect it has on the family system.

The purpose of the study was to describe what people experienced with regard to a certain phenomenon, as well as how they interpreted the experience and the meaning they attached to that experience (Brink, 2011:113). This design enabled the researcher to gather the perceptions of the participants with regard to their own personal experiences and the meanings they attached to it. By looking at multiple perspectives on the same situation, the researcher was able to make generalizations of what something is like from an insider's perspective (Leedy & Ormrod, 2010:141). This enabled the researcher to develop concepts and themes which were applicable to practice which will be discussed later in this chapter (Brink, 2011:113).

3.6 Research methods

The researcher utilized the following research methods:

3.6.1 Research population and sampling

It is important for the researcher to make a clear distinction between a universe, population and a sample. The universe of this study included all the families who have a child(ren) diagnosed with cancer in South Africa. The universe therefore refers to all potential subjects who possess the attributes in which the researcher is interested (Strydom, 2005b:192). The research population of this study included all the families who have a child(ren) diagnosed with cancer, who were being treated at CANSA treatment centre in Pretoria at the time. This population was a group of potential participants to whom the researcher wanted to generalize the results of the study (Welman, Kruger & Mitchell, 2005:55). The sample of the study comprised of elements of the population considered for actual inclusion in the study and was viewed as a subset of measurements drawn from the population of interest (Strydom, 2005b:194).

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The sample was selected based on the following criteria:

- Participants had to have a child/children diagnosed with cancer;
- Participants had to be the parents, grandparents, siblings of the child diagnosed with cancer;
- One participant per family was selected;
- The child with cancer had to be younger than 18 years;
- The child with cancer had to be alive at the time of the study;
- The child with cancer must have undergone treatment for cancer at CANSA;
- The family from which participants were chosen needed to consist of a mother, father and at least one sibling; and
- The child with cancer must have been residing with the family.

Non-probability sampling was used due to the fact that the researcher did not use ransom selection of population elements (Maree & Piertersen, 2007:176). Furthermore the purposive sampling method was utilized in this study, which is a technique/method of non-probability sampling. The participants were a group of people who provided data to the researcher who had a very specific purpose in mind (Maree & Pietersen, 2007:176). This method was chosen due to the fact that the researcher wanted to do research about the psychosocial influences on the family of a child diagnosed with cancer – only families who had a child diagnosed with cancer were able to participate and provided their opinions with regard to this specific topic. Ten participants were planned for the study or until data saturation was reached – data saturation was reached at nine participants.

3.6.2 Methods of data collection

The researcher used one-on-one interviews with a semi-structured interview schedule to collect data from the participants. One-on-one interviews revolve around "understanding the experience of other people, and the meaning they attach to that experience" (Greeff, 2005:293). It is focused and discursive and allows the researcher and participants to explore an issue (Greeff, 2005:293).

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A semi-structured interview schedule can be defined as “a set of predetermined questions that might be used as an appropriate instrument to engage the participant” and it also allows the researcher to adjust the questions as necessary, while still keeping to the main questions (Greeff, 2005:296). The researcher was able to gather the perceptions of the participants during the interview. The interview had a specific focus but the participants were allowed to answer the questions in any way that they saw fit. The semi-structured interview schedule was used to gather information from the participants. The advantage of using the semi-structured interview was that the researcher was able to follow up on avenues of interest to the study which contributed to a fuller picture about the psychosocial influences on the family with a child diagnosed with cancer.

The researcher also made use of observation of the participants throughout the interviewing process, as well as field notes about participants’ verbal and non-verbal behaviour, body language and emotions. This enabled the researcher to obtain in-depth information with regard to the phenomenon being studied and enabled the researcher to formulate themes and sub-themes. This in turn enabled the researcher to formulate generalizations from the data gathered.

The researcher booked the conference room at the CANSA Centre, which had a table and chairs in, to conduct the interviews. The researcher and the participant were the only people in the room and the researcher conducted the interview, which was recorded for quality purposes, with the permission of the participant. The researcher asked a participant from each family – for instance the mother or the primary caregiver – to participate in the interview. Each participant was interviewed separately. Each interview lasted 15 minutes – 20 minutes after which the researcher transcribed each interview and assigning numbers to each participant in order to maintain their anonymity and thus protect their privacy.

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3.6.3 Methods of data analysis

The data was processed and analysed utilizing the nine steps of qualitative data analysis as identified by Creswell in De Vos (2005:334), namely:

- *Planning for recording of data*

The researcher should plan for the recording of data in a systematic manner that is appropriate to the setting, participants, or both, and that will facilitate analysis, before data collection commences (De Vos, 2005:334). The researcher recorded the interviews with a tape recorder, with the permission of the participants, after which the recordings were transcribed. The researcher also made short field notes after each interview.

- *Data collection and preliminary analysis*

Data analysis in a qualitative inquiry is twofold. The first aspect involves data analysis at the research site during data collection, while the second aspect involves data analysis away from the site, following a period of data collection (De Vos, 2005:335). The research had a certain amount of data due to the literature that was studied, but the researcher gained more in-depth knowledge and personal experiences as the interviews progressed. During the interviews the researcher was able to analyse what is said.

- *Managing or organizing the data*

During this phase the researcher has to organize the data into file folders, index cards or computer files. Besides organizing files, researchers assign their files to appropriate test units, e.g. a word, sentence, an entire story, for analysis either by hand or by computer (De Vos, 2005:336). The researcher organized the data collected into certain categories in order to simplify the analysis of the data and saved on computer and back-up files.

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- *Reading and writing memos*

The researcher can list the available data on note cards, perform the minor editing necessary to make field notes retrievable, and generally 'clean up' what seems overwhelming and unmanageable (De Vos, 2005:337). This was done during the interviews in order to prevent losing any data.

- *Generating categories, themes and patterns*

The researcher can make sense of the information gathered regarding the categories, themes and patterns. This can be done by interpretations based on hunches, insights and intuition, interpretation within a social science construct or idea, or a combination of personal views and a social science construct or idea (De Vos, 2005:338). The researcher identified possible themes and patterns during the interview process while collecting the data from the participants. These themes coincided with the literature information that was obtained prior to the study and discussed in detail in Chapter Two.

- *Coding the data*

Coding data is the formal representation of analytical thinking (De Vos, 2005:338). The researcher may have had a different and new understanding about the information when coding the data. As the data is gathered, the researcher's knowledge about the topic grew and thus new ideas were formed regarding the phenomenon which was investigated.

- *Testing the emergent understandings*

During this phase the researcher searched through the data during which the researcher challenged the understandings, searched for negative instances of the patterns and incorporated these into larger constructs, as necessary (De Vos, 2005:338). While the researcher collected the data she challenged existing views and patterns previously attained.

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- *Searching for alternative explanations*

The researcher must search for other, plausible explanations for this data and the linkages among them (De Vos, 2005:339). The researcher did not only use the literature that was reviewed as possible explanations for the topic being studied, but searched for different answers that also explain the phenomenon. The information as provided in the literature chapter in Chapter Two was seen by the researcher as most relevant to this specific study.

- *Representing, visualizing*

This is the final phase in the process and it involves presenting the data in text, tabular or figure form (De Vos, 2005:339). The researcher did this by means of writing the report which includes tables and figures representative of the data gathered. Visual representation of the data will be seen later in Chapter Three where it will be discussed in detail.

3.6.4 Trustworthiness in qualitative research

According to Lincoln and Guba (1985) (in Lietz, Langer & Furman, 2006:444) trustworthiness is established when findings as closely as possible reflect the meanings described by the participants. Padgett (1998) (in Lietz *et al*, 2006:444) further explains that trustworthiness is not something that just naturally occurs, but is the result of 'rigorous scholarship' that includes the use of defined procedures. As stated by Padgett (1998) (in Lietz *et al*, 2006:444) threats to trustworthiness can include problems such as reactivity and biases on the part of the researcher and the participants. These threats to trustworthiness can be managed by the researcher by engaging in a variety of strategies. These strategies include prolonged engagement, triangulation, peer debriefing, member checking, negative case analysis, audit trail and reflexivity (Lietz *et al*, 2006:444).

There are different strategies applicable to a specific study, including Reflexivity and Member checking and prolonged engagement. The first strategy used by the researcher was that of **Reflexivity**.

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Reflexivity is defined by Horsburgh (2003) in Lietz *et al.* (2006:447) as "active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation." Furthermore it is stated that reflexivity involves deconstructing who we are and the ways in which our beliefs, experiences and identity intersect with that of the participant. In this study the researcher engaged in reflexivity by planning the data analysis. The researcher acknowledged how her own identity could help or hinder the interpretation of the narrative data. She did this by questioning her own perceptions and feelings with regard to the psychosocial influences on the family of a child diagnosed with cancer, and whether this identity might interfere with her ability to hear and understand the participant's experiences. The researcher established that she believed that there would definitely be psychosocial influences on a family if their child should be diagnosed with cancer, although this may differ from person to person, and from situation to situation. The researcher is therefore of the opinion that the psychosocial influences on a family of a child diagnosed with cancer need to be determined, in order to assist the family with coping effectively. The fact that the researcher could identify this beforehand made it possible for the researcher to put her thoughts and feelings aside and only concentrate on the participant and her answers. This prevented the researcher from being biased towards the participant.

The second strategy that was implemented by the researcher was that of **Member Checking and Prolonged Engagement**. Member checking, also known as "respondent validation, allows participants to review findings from the data analysis in order to confirm or challenge the accuracy of the work (Lietz *et al*, 2006:543). The researcher contacted the participants when her data was interpreted and asked them what their opinion was with regard to the results, and whether or not they agree with the findings. The participants agreed that there were psychosocial influences for them as a family when their child was diagnosed with cancer, and that their circumstances influenced their ability to maintain their previous level of functioning, or prevented them from maintaining their previous level of functioning.

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3.7 Pilot study

The feasibility of the study was determined by means of a pilot study. The researcher conducted a small study prior to the actual study to determine whether the methodology, sampling, instruments and analysis were adequate and appropriate (Bless et al., 2006:155). The researcher is of the opinion that the pilot study was a preparatory study that had to be completed before the actual research could take place. In this study specific attention was given to the feasibility of the study and testing of the data-collection instrument (See Annexure D).

- *Feasibility of the study*

The feasibility study assisted the researcher with the practical planning of the study, as well as to identify possible unanticipated problems (Strydom, 2005c:208). This particular study was feasible due to the fact that the researcher obtained permission from CANSA Centre to do the study (see Annexure B). Letters explaining the purpose of the study were left at the centre and any persons interested could then contact the researcher if interested in participating (see Annexure C). The researcher was able to recruit participants easily with assistance of the manager at Nicus Lodge. The costs involved in the study were limited; as the costs were only related to administrative tasks. The venue for the interviews did not have to be hired, it was available at the centre and the participants were interviewed there on a voluntary basis. The time that was utilized for this study was substantial, due to the preparations that needed to be done, the interviews that needed to be conducted, the transcriptions, the analysis of the data, as well as writing the report.

- *Testing of the data-collection instrument*

The researcher selected two participants who were representative of those the researcher expected to interview (Miller in Strydom, 2005c:209). The researcher tested the primary and secondary questions with two participants. The feedback was then utilized to improve and modify the questions for the actual study. The pilot study enabled the researcher to fine-tune the interview schedule, as well as to indicate the necessary changes that needed to be made in order to obtain valuable information and data.

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3.8 Ethical issues

The researcher attended to the different ethical issues which offer rules and behavioural expectations about the most correct conduct towards participants (Strydom, 2005a:57). This study received ethical clearance from the University of Pretoria's Faculty of Humanities, Research Ethics Committee (see Annexure A). Within this study the following ethical principles were applicable:

3.8.1 Avoidance of harm

The researcher protected the participants from physical and emotional harm by informing the participants of any potential harm beforehand and providing them with the necessary information regarding the study (Strydom, 2005a:58). The researcher furthermore informed the participants that they were welcome to withdraw at any stage should they feel uncomfortable. It is the researcher's opinion that emotional harm could have been a problem; therefore the researcher referred the participants to the social worker at the facility to conduct a debriefing session after the interview, where they discussed their feelings, thoughts and emotions to prevent any potential long term emotional harm.

3.8.2 Informed consent

The researcher provided the participants with accurate information with regard to the goal of the study, procedures, advantages and disadvantages, dangers and credibility of the researcher beforehand, so that they were able to make an informed decision (Strydom, 2005a:59). The researcher explained all the different aspects by means of a letter of informed consent (see Annexure C), to the participants in order to ensure that they knew what the study entailed and what is expected of them. The participants each signed an informed consent form that indicates that they understood everything and that they voluntarily agreed to the interview.

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3.8.3 Deception of clients and/or participants

The researcher did not deliberately misrepresent facts in order to make the participants believe what is not true, and thereby violate the respect to which every person is entitled (Strydom, 2005a:60). The researcher explained exactly what the purpose of the study was beforehand and what the study entailed.

3.8.4 Violation of privacy/anonymity/confidentiality

The researcher ensured that each participant's right to decide when, where, to whom and to what extent his/her attitudes, beliefs and behaviours were revealed; was respected (Strydom, 2005a:61). The researcher handled the information obtained in a confidential manner to protect the participants' privacy (Strydom, 2005a:61). The researcher furthermore ensured that the participants' identity will not be made public to other people (Strydom, 2005a:61).

3.8.5 Debriefing of participants

The researcher provided the participants with the opportunity to work through their experiences and its aftermath to minimize any possible harm (Strydom, 2005a:66). The researcher referred the participants to the social worker at the centre who provided debriefing sessions to the participants after the interview to ensure that no harm came to the participants.

While the previous section focuses on the Research Methods, the next section focuses on the research findings and an interpretation thereof.

3.9 RESEARCH FINDINGS AND INTERPRETATIONS

The primary aim of this chapter is to present, analyse and interpret the qualitative data collected by means of the semi-structured interviews with families of a child diagnosed with cancer. This section will focus on the profile of the participants, as well as the biographical profile of the participants and the actual analysis and interpretation of the qualitative research findings. Please refer to Table 3: Profile of Participants and Table 4: Biographical profile of participants.

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3.9.1 Profile of Participants

Table 3: PROFILE OF PARTICIPANTS

Participant	Profile
Participant 1	Participant 1 stays in a rural area in a brick house. She is single and has 3 children who are of school going age. She is a cashier but had to quit her job in order to take care of her ill child. The father of the children does not support them emotionally or financially. Participant 1's main form of support is her mother. She relies on government grants for financial assistance. Participant 1 indicated that her religion was very important to her and is her source of comfort during difficult times.
Participant 2	Participant 2 stays in a rural area in a brick house. She is married and has 3 children who are of school going age. She is a care taker at a crèche and was able to remain employed after the diagnosis of cancer in her son. The father of the children does not support them emotionally or financially. Her partner does however provide emotional and financial support. Participant 2's main form of support is her partner and her sister. She relies on her salary and her partner's salary for financial assistance. Participant 2 indicated that her religion was very important to her and is her source of comfort during difficult times.
Participant 3	Participant 3 stays in a rural area in a brick house. She is married and has 4 children of whom only the ill child is of school going age. She was a cleaner but had to quit her job in order to take care of her ill child. The father of the children supports them emotionally and financially. Participant 3's main form of support is her husband. She relies on her husband's salary for financial assistance. Participant 3 indicated that her religion was very important to her and is her source of comfort during difficult times.

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Participant 4	Participant 4 stays in a rural area in a brick house. She is single and has 1 child aged 3 years. She is a house wife and this enables her to continue to take care of her ill child. The father of the child does not support them emotionally or financially. Participant 4's main form of support is her mother and grandmother. She relies on government grants for financial assistance. Participant 4 indicated that her religion was very important to her and is her source of comfort during difficult times.
Participant 5	Participant 5 stays in a rural area in a brick house. She is single and has 2 children who are of school going age. She is currently unemployed and is able to take care of her ill child. The father of the children does not support them emotionally or financially. Participant 5's main form of support is her grandparents. She relies on her grandparents for financial assistance. Participant 5 indicated that her religion was very important to her and is her source of comfort during difficult times.
Participant 6	Participant 6 stays in a rural area in a brick house. She is married and has 3 children of whom only the ill child is of school going age. She is a teacher for Grade11 and Grade12 pupils. She is currently on annual leave in order to take care of her ill child. The father of the children supports them emotionally and financially. Participant 6's main form of support is her husband. She relies on her salary as well as her husband's salary for financial assistance. Participant 6 indicated that her religion was very important to her and is her source of comfort during difficult times.

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Participant 7	Participant 7 stays in a rural area in a brick house. She is single and has 2 children who are of school going age. She is a full-time mother and is able to take care of her ill child. The father of the children does not support them emotionally or financially. Participant 7's main form of support is her mother. She relies on government grants for financial assistance. Participant 7 indicated that her religion was very important to her and is her source of comfort during difficult times.
Participant 8	Participant 8 stays in a rural area in a brick house. She is single and has 2 children who are of school going age. She is a full-time mother and is able to take care of her ill child. The father of the children does not support them emotionally or financially. Participant 8's main form of support is her mother and boyfriend. She relies on government grants and her mother for financial assistance. Participant 8 indicated that her religion was very important to her and is her source of comfort during difficult times.
Participant 9	Participant 9 stays in a rural area in a brick house. She is divorced and has 3 children who are of school going age. She is a manager at a department store and her niece takes care of her ill child. The father of the children supports them emotionally and financially. Participant 9's main form of support is her parents. She relies on her salary for financial assistance. Participant 9 indicated that her religion was very important to her and is her source of comfort during difficult times.

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Table 4: BIOGRAPHICAL PROFILE OF PARTICIPANTS

Participants	1	2	3	4	5	6	7	8	9
Gender	Female	Female	Female	Female	Female	Female	Female	Female	Female
Age of participant	26	36	44	25	25	43	22	30	34
Age of child diagnosed with cancer	7	4	13	3	6	14	5	2	7
Other daughter(s)	2	1	3	0	2	0	0	1	1
Age of other daughter(s)	10, 5	14	27, 24, 20	0	12, 9	0	0	6	12
Other son(s)	0	1	0	0	0	2	1	0	1
Age of other son(s)	0	8	0	0	0	26, 23	3	0	9
Race	Xhosa	Venda	Coloured	Pedi	Zulu	Swazi	Zulu	Pedi	SiSwati
Religion	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian
Marital status	Single	Married	Married	Single	Single	Married	Single	Single	Divorced
Employment status	Unemployed	Employed	Unemployed	Unemployed	Unemployed	Employed	Unemployed	Unemployed	Employed
Type of cancer of child	Leukaemia	Sarcoma	Lymphoma	Blastoma	Kidney	Sarcoma	Blastoma	Ischaemia	Leukaemia
Date of child when diagnosis was made	2014-06	2013-05	2014-06	2014-01	2014-03	2014-06	2014-04	2013-11	2013-08

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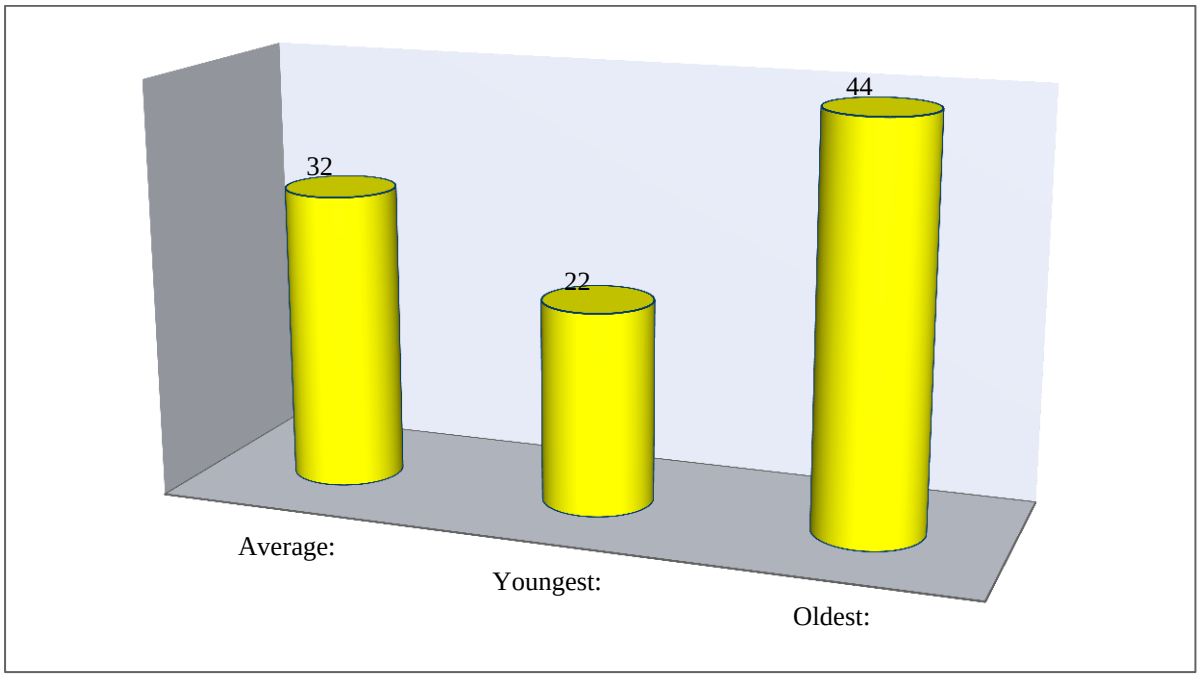
The biographical details of the participants were collected during the interview as part of the questions in the interview schedule. A total of nine parents/primary caregivers of a child diagnosed with cancer participated in this study. Saturation of data was achieved after nine interviews. All of the participants were female. The profiles of the participants are as follows:

Figure 1: AGE OF PARTICIPANTS



n=9

- ***Age***

The ages of the participants ranged between 22 and 44 years of age, see Figure 1: Age of Participants. It was the researcher's observation that the participants who were a bit older, coped better with the situation in their family. This could have been due to better integrated support systems, life experience or personality. It seemed as if the younger participants were more unsure and fearful regarding the future and the diagnosis of their children.

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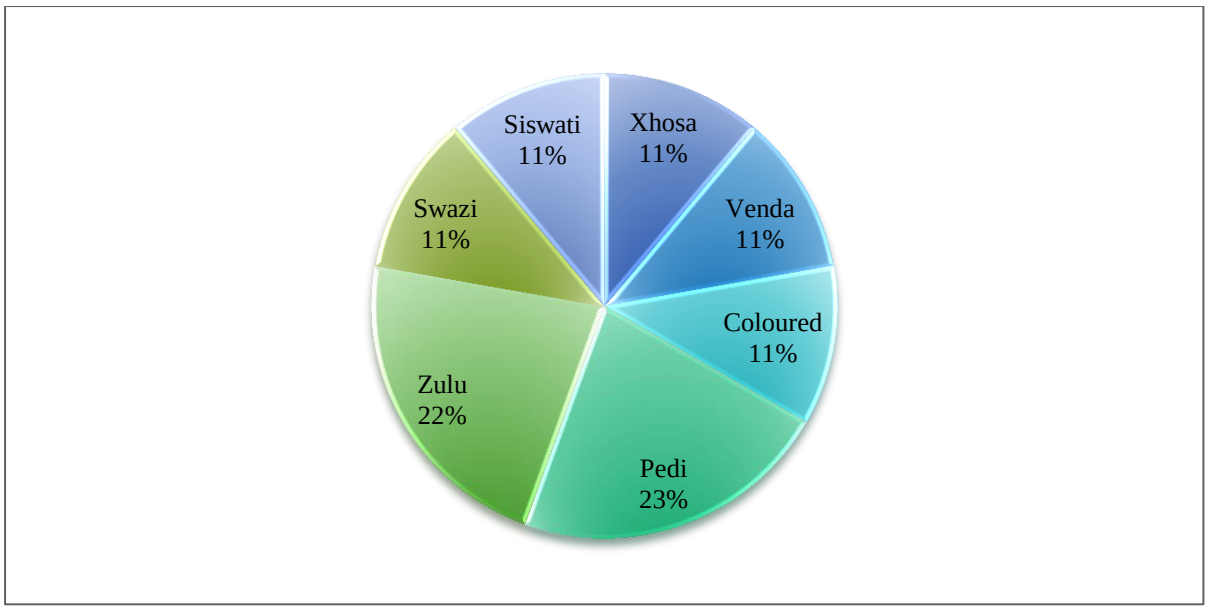
Figure 2: ETHNICITY



n=9

- ***Ethnicity***

The participants that were interviewed were from different ethnic groups. There was no preference to which ethnic group or race the participant needed to belong to, it depended on the availability of participants at the time of the study. The fact that the participants differ in ethnicity, provided a good representation of the different ethnic groups in South Africa. See Figure 2: Ethnicity.

- ***Gender***

All the participants were female. There was no preference to which gender participants were going to be selected. During this study, the main caregiver of the child was primarily the mother, the grandmother or a niece. In the instances of a single mother (either not married or divorced), the father of the child was not involved in the child's life and thus did not provide emotional or physical assistance and therefore the mother was the main provider and caregiver. Family members such as the grandmother or niece of the sick child would assist the single mother by becoming the main caregiver while the mother works. In the instance of a married mother, the father would be the main breadwinner and would be working, while the mother became the full- time caregiver. This information links up with the next section on marital status.

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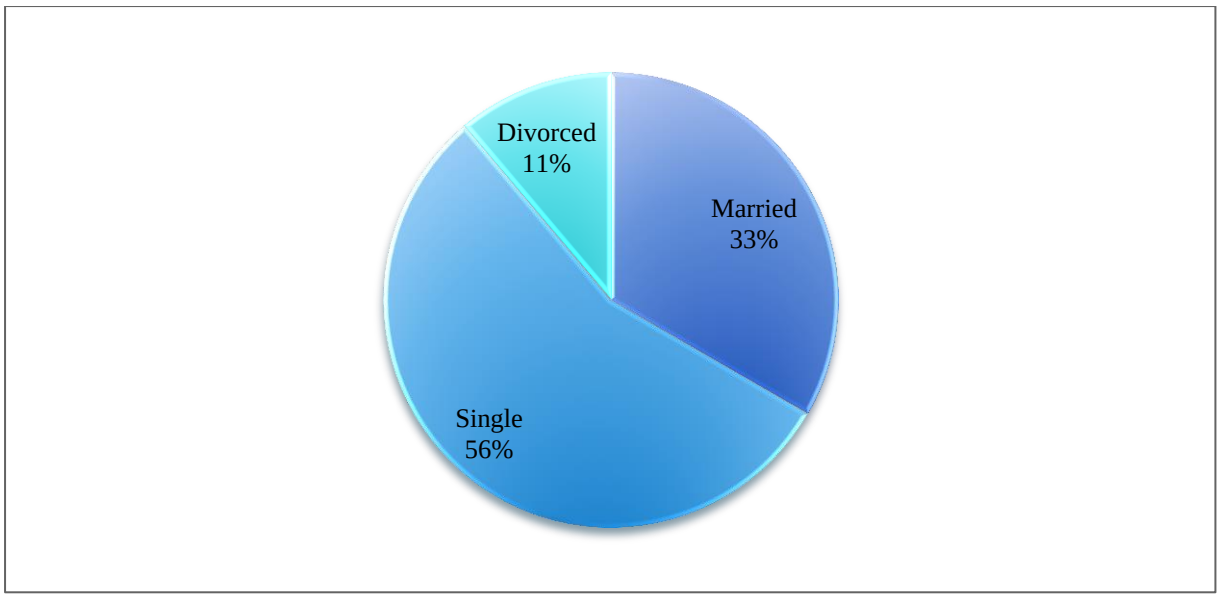
Figure 3: MARITAL STATUS

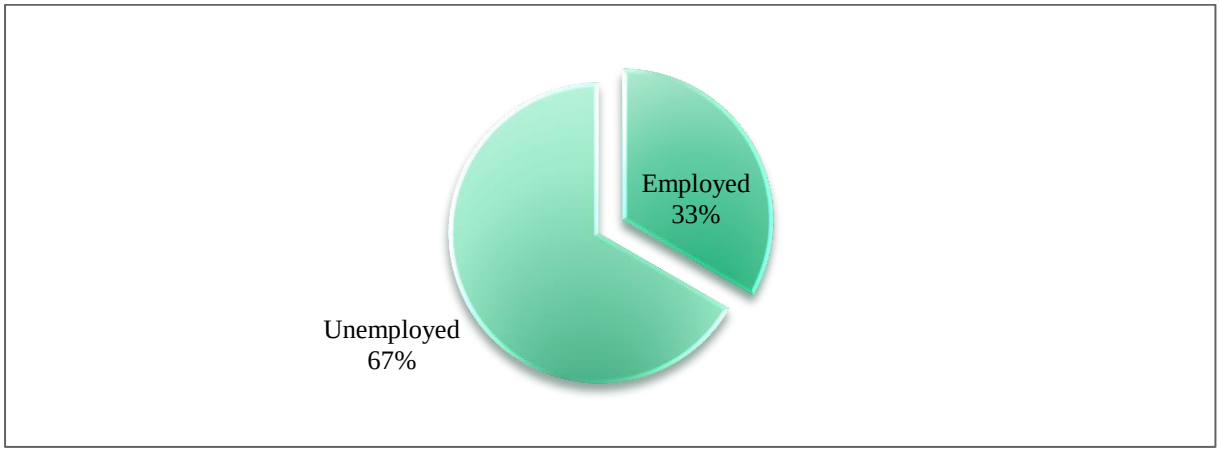


n=9

- ***Marital status***

The participants that were involved in the research were married, single or divorced. The majority (56%) were single and thereafter married (33%) or divorced (11%). Cancer affects the participants' ability to cope with their child being diagnosed with cancer and the psychosocial effects it has on the family system, such as support systems, employment, main caregiver and family responsibilities and roles – if a person is married, there is a support system which can be relied on. Refer to Figure 3: Marital status.

Figure 4: EMPLOYMENT STATUS



n=9

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- ***Employment status***

The participants of the study were categorized in groups of employed or unemployed. The participants who were employed (33% of the participants) were financially more stable, than the majority of participants who were unemployed (67% of the participant) prior to the diagnosis of cancer in their child. The participants who are unemployed either survived financially from grants or money from their family. All the participants indicated that after the diagnosis of cancer in their child, the financial strain became more intense and it was more difficult to make ends meet. Refer to Figure 4: Employment status.

- ***Healthy children***

Some of the participants had other children as well, apart from the child diagnosed with cancer. Collectively there were seven healthy girls and three healthy boys aged under 18 years of age, and there were three healthy girls and two healthy boys aged over 18 years of age. The participants involved in the study indicated that their healthy children were also affected psychosocially by the diagnosis of cancer in their sibling. The healthy children would experience feelings of shock due to the diagnosis, resentment and anger in younger children when the sick child received gifts and they would not receive gifts, feelings of abandonment when the mother spends all her time at the facility and being the main caregiver for the sick child, anxiety in older children who are able to understand the severity of the situation, as well as a negative impact on older children's school work and extracurricular activities. See Figure 5: Age and Gender of Healthy children and Figure 6: Healthy Children.

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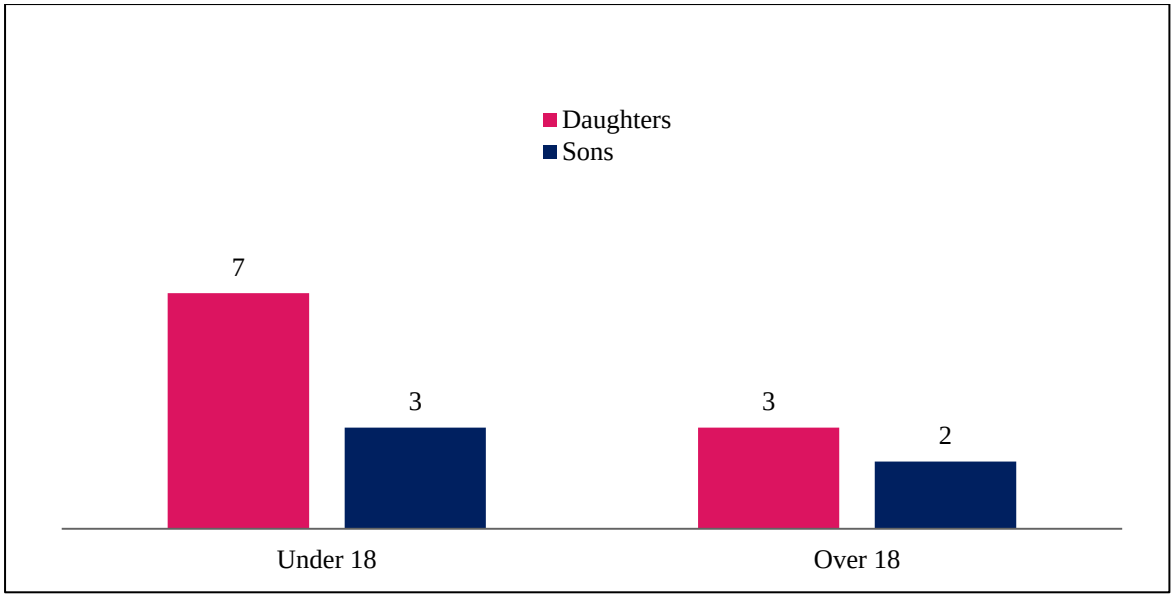
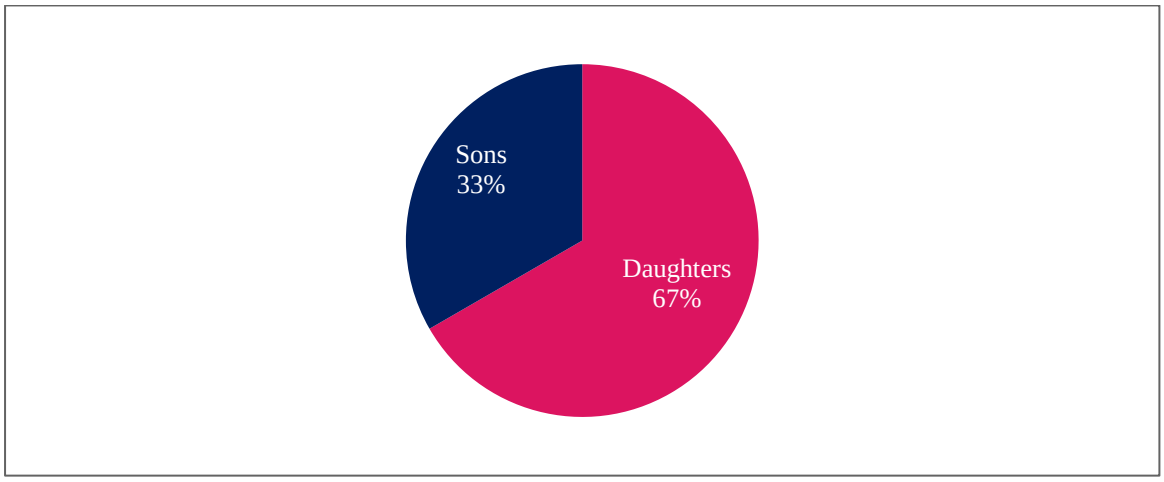
Figure 5: AGE AND GENDER OF HEALTHY CHILDREN



n=9

Figure 6: HEALTHY CHILDREN



n=9

- ***Cancer diagnosis***

All the participants had a child who is diagnosed with cancer and was currently receiving active treatment. Some of the children received chemotherapy; others received radiation therapy, while others had to undergo surgery and chemotherapy combined. The active treatment led to the primary caregiver constantly having to be with the sick child, attend to his/her needs and monitor his/her well-being, alongside the medical team.

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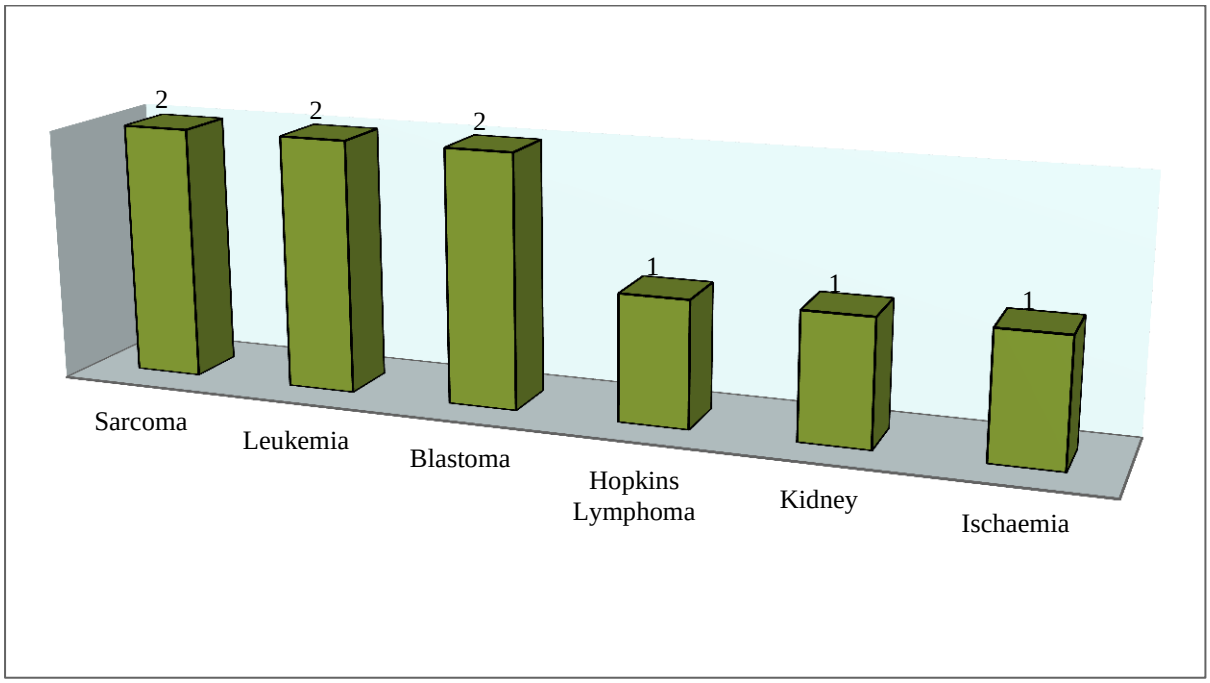
It was often reported that the primary caregiver would sleep less during times of active treatment due to stress, insomnia and the child not feeling well and having to attend to his/her needs, as well as treatment that extends until all hours of the night. The participants also indicated that during this time their appetites would change and they would either eat less or more, depending on their personality types or stress levels. Different types of cancer were present in the participants' children during the study. See Figure 7: Types of cancer.

Figure 7: TYPES OF CANCER



n=9

The diagnosis of the participants' children differed in terms of the type of cancer, as well as the time they were diagnosed. The fact that the participants' children were diagnosed with different types of cancer, and that the time of the diagnoses differed, enabled the participants to share different views on the psychosocial effects that a child diagnosed with cancer had on the family system, as well as the time period that they had to adjust to the situation. The majority of children in this study had Blastomas (2 out of the 9 ill children), Leukemia (2 out of the 9 ill children) or Sarcomas (2 out of the 9 ill children).

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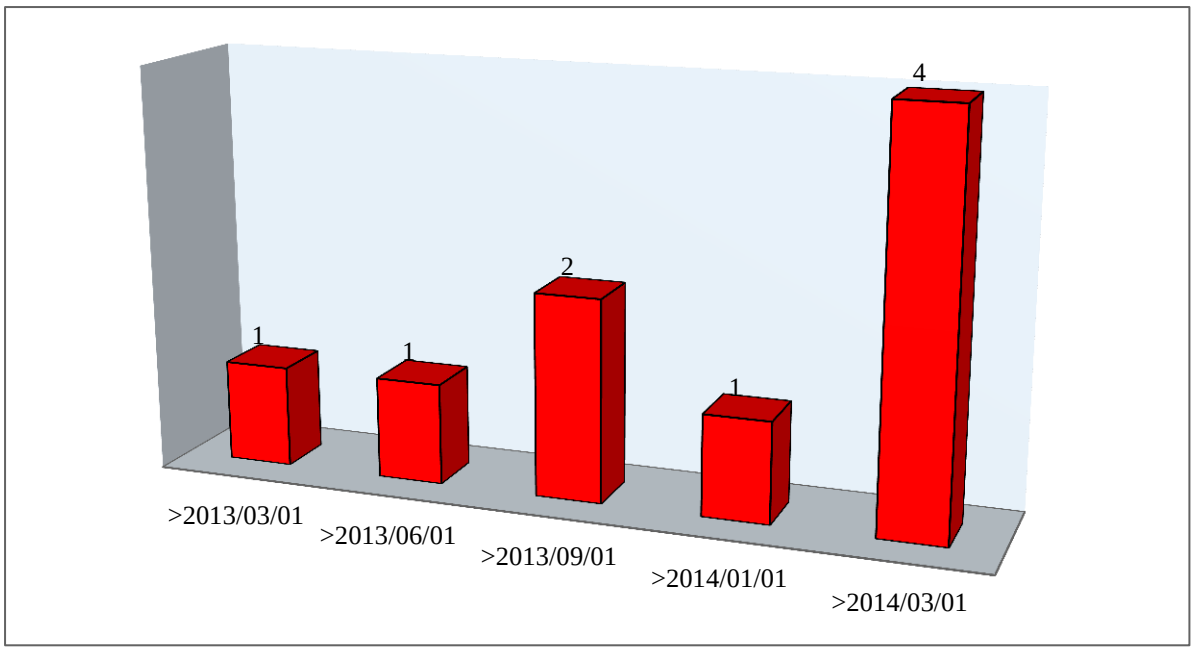
The findings suggest that all types of cancer – as seen in this study where six different types of cancer were diagnosed - entail a degree of psychosocial effects on the family system, and can thus be generalized to all families who have a child diagnosed with cancer. See Figure 7: Types of Cancer and Figure 8: Year of Diagnosis.

Figure 8: YEAR OF DIAGNOSIS



n=9

The above-mentioned figure shows the actual date of the diagnosis of cancer in the children of participants. This concludes the biographical information with regard to the participants who participated in the study.

In summary, the researcher took into account the biographical aspects of the participants, such as age, race and ethnicity, marital status, employment status, the age of the healthy children, types of cancer and date of diagnosis. This was done in order to have a better understanding of the participants' background and personal situation, which in turn assisted the researcher to formulate themes and sub-themes according to the psychosocial aspects that are affected in the family system when a child is diagnosed with cancer based on the participants' personal experiences.

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The following section will focus on the themes emerging from the data, reflecting on perceptions, experiences and feelings of the participants regarding the psychosocial effects a child diagnosed with cancer has on the family. This section will discuss the different themes and sub-themes.

3.9.2 Themes and Sub-themes

In this section the themes generated from the study will be discussed. Direct quotes from the interviews that were transcribed were used to reflect these themes. Literature was used to substantiate the findings. Parents and family members of a child diagnosed with cancer are at risk of depression, anxiety and reduced quality of life. Parents and family members of a child diagnosed with cancer are also affected by demographical variables, socio-economic status, social characteristics and personal expectations (Gil, Gibbons, Jenison, Hopkins & Von Gruenigen, 2007:1477). Iwamitsu, Shimoda, Abe, Tani, Kodama and Okawa (2003:289) add to the above statement by saying that parents of a child diagnosed with a life-threatening illness have emotional distress such as depression and anxiety which has a negative effect on their quality of life. People do however differ in their response to a difficult situation; therefore the researcher has identified different aspects that may contribute to the difference in their reactions and this was discussed according to the themes which the researcher formulated based on the data collected.

The information will be discussed according to the following three themes generated by the study:

- **Protective measures** for parents of a child diagnosed with cancer;
- **Restrictive measures** for parents of a child diagnosed with cancer; and
- **Financial-related aspects** for parents of a child diagnosed with cancer.

Each theme will be discussed according to the following structure:

- Summary of findings;
- Quotations to verify findings; and
- Literature to substantiate the findings.

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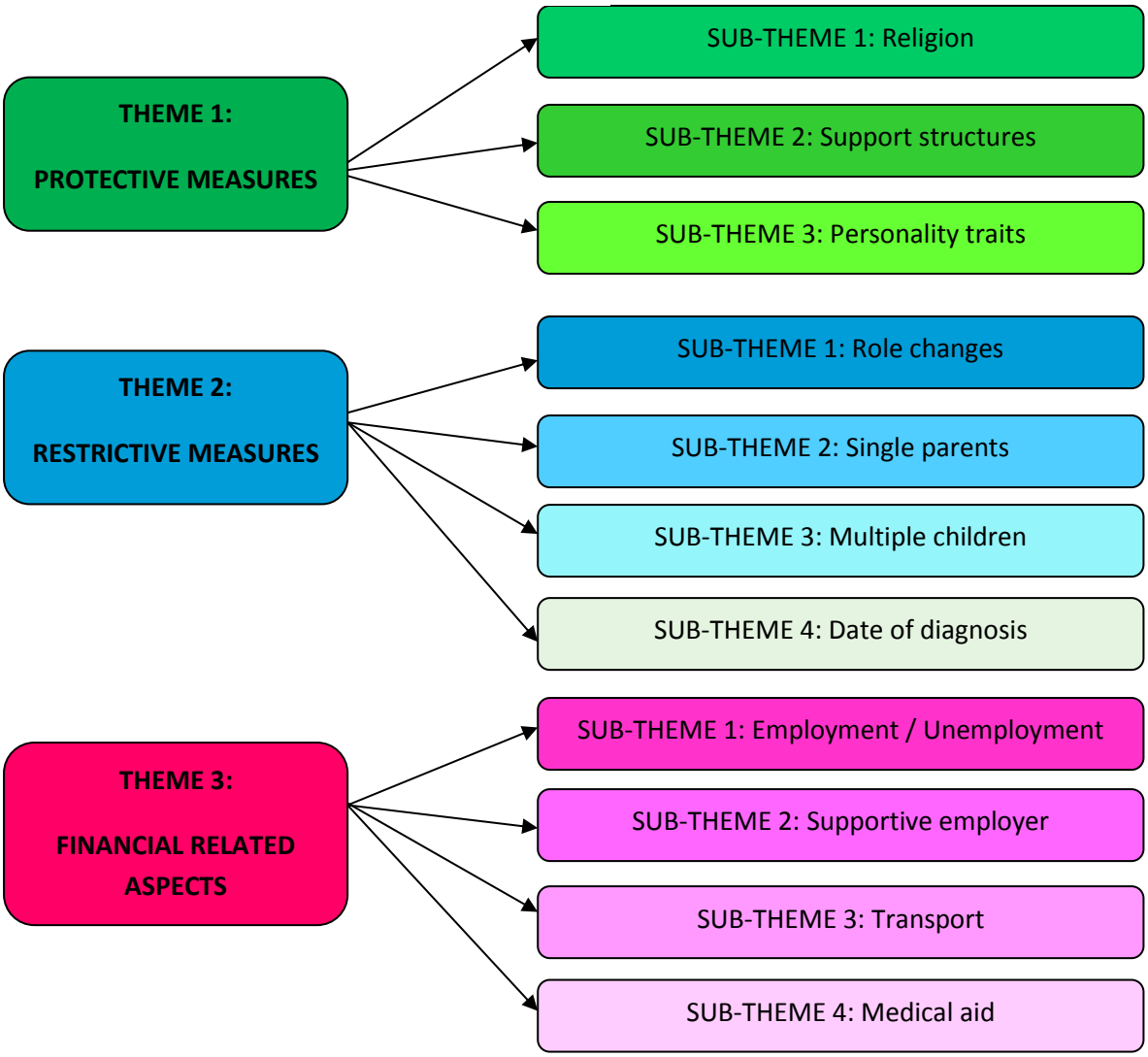
Figure 9: THEMES AND SUB-THEMES



3.9.2.1 *THEME 1: PROTECTIVE MEASURES OF PARENTS OF A CHILD DIAGNOSED WITH CANCER*

When a child is diagnosed with cancer, it generates distress in that child's family and their functioning. The way in which the family system adapts to the diagnosis is influenced by many different factors. These factors include optimism, coping mechanisms and social support, to name but a few (Matthews & Cook, 2008:716.)

The researcher found different aspects that enhanced the participants' ability to cope with the diagnosis of cancer in their children.

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These aspects will be discussed in detail. In this theme *three sub-themes* were identified, namely:

- Religion;
- Support structures; and
- Personality traits.

❖ **Sub-theme 1.1: Religion**

According to Sherman, Plante, Simonton, Latif and Anaissie (2009:125) "turning to religious faith appears to be among the most commonly cited coping strategies" among parents of a child diagnosed with cancer. Sherman *et al.* (2009:126) further state that findings suggest that families who struggle with their faith during a terminal illness of a loved one, may be at risk when it comes to coping with the illness. Stressful circumstances such as illness are likely to trigger a more intensive reliance on religious coping strategies (Sherman *et al*. 2009:126). Heaven and Ciarrochi (2007:681) indicate that "religion has the potential to provide meaning to an individual's life" and support the person through difficult times.

The following quotations confirm that religion and faith is an important factor in coping with a child diagnosed with cancer:

Respondent 1:

"Uhm, wat vir my baie gehelp het is my vertroue op die Here. Omdat die Here my al deur diep dinge gelei het." *[Uhm, what helped me a lot was my trust in God. Because God has helped me through many difficult things."]*

Respondent 2:

"Yes, God is there. My faith is strong now, because God is there for me and it is all I have."

Respondent 3:

"Yes, my faith is very important to me, God has given me the strength to go on, even though I didn't want to, or felt like I couldn't do it anymore."

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The above mentioned quotes are supported by Laubmeier, Zakowski and Bair (2004:48) who mentions that "spirituality often becomes important throughout the course of the disease and its treatment as well as during the period of remission." Several cross-sectional studies have found that spirituality among families of a child diagnosed with cancer is related to positive moods and good quality of life (Laubmeier *et al*. 2004:49). The participants in this study definitely indicated that their faith had an impact on their ability to cope with their child's diagnosis and helped them to remain positive even when they receive bad news. Laubmeier *et al.* (2004:53) further indicate that during their research study they determined that high levels of spirituality among families of a child diagnosed with cancer were associated with less distress and symptom severity and better quality of life. Cousins (1979), as sighted in Hodges (2002:110), adds that the healing dimension of spirituality is important when coping with a terminal illness. All of the participants indicated that their religion plays a very important role in their lives. It helps them to cope with the diagnosis and to come to terms with it. The participants indicated that their faith was the main aspect that kept them going and without it they would not have been able to face every new day or challenge. This has a positive effect on their emotional well-being and psychosocial functioning in return.

❖ **Sub-theme 1.2: Support structures**

According to Matthews and Cook (2009:717) "social support is a multi-dimensional concept that includes the quantity of social ties (network size, density and multiplicity), quality of relationships and perceived and actual availability of support." They further state that social networks act as a stress buffer in traumatic events (Matthews & Cook, 2009:717). Jia, Uphold, Wu, Chen and Duncan (2005:395) state that "providers of social support generally include the patients' family members, friends and others." In this case, family members and spouses are the main support system for the caregiver of a child diagnosed with cancer.

The following quotations confirm that support system is an important factor in coping with a child diagnosis with cancer:

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Respondent 1:

"Tannie Vera staan my baie by en praat altyd met my, sy staan my so baie by. En die skoonfamilie ook, hulle is altyd daar om te help." *["Aunt Vera supports me a lot and always talks to me, she really supports me. And the in-laws, they are also always there to help."]*

Respondent 2:

"My husband, it is just me and my husband, he keeps me going. We don't have other family to support us, but he is my greatest support, I wouldn't have been able to do it without him."

Respondent 3:

"My mother always comes to visit me and she takes care of my children when I have to be here for my little boy, when he is sick. She just does everything I don't have time to do anymore. She is the one that supports me."

The better the participant's support system was, the better they coped with the diagnosis of cancer in their child. This is supported by Jia *et al.* (2005:396), who found in their study that parents' satisfaction with social support, regardless of the source of support, was significantly associated with improved quality of life. Friedman, Kalidas, Elledge, Chang, Romero, Husain, Dulay and Liscum (2006:596) agree with this and add that "social support has been shown to mitigate the deleterious effects of stressful events, including cancer." Support systems are positively related to a person's emotional well-being, in other words, self-esteem and mental health of a person (Calswell, Silverman, Lefforge & Silver, 2004:57). When the researcher asked the participants what role their support systems played in their lives, all the participants indicated that their support systems were very important to them and it helped them cope when things got difficult. The support system included family members, friends, the church as well as their work and the CANSA organization where they were currently residing. This is supported by Jia et al., (2005:395) who state that "providers of social support generally include the parents of a child diagnosed with cancer's family members, friends and others."

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The participants who aren't currently employed didn't however indicate work as part of their support system. Having the necessary support system has a positive effect on their emotional well-being and psychosocial functioning in return.

❖ **Sub-theme 1.3: Personality traits**

During the interviews the researcher identified which type of personality the participants had, for instance introvert vs extrovert and optimistic vs pessimistic. The researcher identified a pattern within the participants' answers. The participants who were extroverts were also the optimistic ones, while those who were introverts were more pessimistic. It was the researcher's observation that those participants who were more optimistic, coped better with the diagnosis of cancer in their child, than those who are generally more pessimistic. It coincided with the "glass half full vs glass half empty" approach. The participants who were generally extroverted type of people, coped better with the diagnosis of cancer in their child and this could be because extroverts generally express their emotions better to other people, and can thus receive the necessary support, while introverts tend to keep to themselves and process inwardly, which may cause them to isolate themselves form their support structures. Five participants were extroverts and optimistic, while four participants were introverts and pessimistic.

The following quotations confirm that personality type is an important factor in coping with a child diagnosis with cancer:

Respondent 1:

"I don't know what keeps me going, I just keep on because I have to, for my son's sake, I have to be strong because he is just a child."

Respondent 2:

"Ek het geen vrae vir die Meester nie, ek vra nie hoekom dit met ons moes gebeur nie, ek sit net my vertroue in die Here en dat Hy deur die dokters sal werk om my kind gesond te maak." *["I have no questions for the Master, I don't ask why this happened to us, I just place my trust in God and that He will work through the doctors to heal my child."]*

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Respondent 3:

"I feel very sad, why did this happen to such a small child, it isn't fair. I feel bad because I don't know where cancer comes from, not even the doctor can tell me where it comes from or why it happens to children."

There are many ways to measure personality, but psychologists have mostly given up on trying to divide humanity neatly into types. Instead, they focus on personality traits. As mentioned in Chapter Two, the most widely accepted of these traits are the Big Five:

- Openness;
- Conscientiousness;
- Extraversion;
- Agreeableness; and
- Neuroticism.

The Big Five are the ingredients that make up each individual's personality. A person might have a dash of openness, a lot of conscientiousness, an average amount of extraversion, plenty of agreeableness and almost no neuroticism at all. Or someone could be disagreeable, neurotic, introverted, conscientious and hardly open at all. The researcher found that for those who had openness as a trait, it was easier to adjust to difficult situations, such as the diagnosis of cancer in a child because they were more open to new experiences and expect things to change. The researcher furthermore found that those who were conscientious had difficulty adjusting to the diagnosis of cancer in their child, because it didn't "fit" into their plan and what they thought their future entailed. It was more difficult for them to adjust their goals and views regarding their family system. The researcher concluded that someone who is more extraverted, coped better with a diagnosis of cancer, because they verbalized their thoughts, needs and emotions, and thus people who provided them with support, knew how to support them more effectively. Lastly, the researcher found that someone who was more agreeable, adjusted better to the news of a cancer diagnosis in their child, because they were more helpful and compassionate, and went out of their way to assist their child as needed, no matter the costs. It is the researcher's opinion that although personality types aren't scientifically able to say

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who will cope better in a difficult situation, it does serve to provide us with some guidelines as to who are at risk of depression, anxiety and burnout. It can thus be said that a person's personality traits have and impact on their emotional well-being and psychosocial functioning in return and this impact can either be positive or negative.

The key findings of Theme 1 can be summarized by applying the psychosocial approach. The participants, who indicated that they were coping with their situations, were also predominantly the participants who had a strong religious background. This directly ties up with support systems – the participants who had the necessary support were coping better with the diagnosis of cancer in their children, than the participants who did not have the necessary support. The findings from this study suggests that those who were more positive and out-going were able to cope better because their support systems knew what their needs were and how to appropriately address them, as well as the fact that people who are more positive by nature seek the positive in every situation.

3.9.2.2 *THEME 2: RESTRICTIVE MEASURES OF PARENTS OF A CHILD DIAGNOSED WITH CANCER*

As mentioned in Theme 1, there are certain aspects that enable a family system to cope better with the diagnosis of cancer in a child and to sustain the family system through a time of crisis. The same can be said for aspects that hinder the family system's ability to cope during a time of crisis. The researcher found different aspects that restricted the participants' ability to cope with the diagnosis of cancer in their children. These aspects will be discussed in detail. In this theme *four sub-themes* were identified, namely:

- Role changes;
- Single parents;
- Multiple children; and
- Date of diagnosis.

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❖ ***Sub-theme 2.1: Role changes***

The participants indicated that there were role changes in the family system due to the diagnosis of cancer in their child. In the one family system the older children would take over the responsibilities of the mother who was the main caregiver for her son diagnosed with cancer. When she was at hospital during his treatment period, the other children would attend to the chores and daily routines so that she could provide the sick child with her full attention. In another family system the grandmother became the primary caregiver of the sick child, so that the mother could continue working, as she is a single parent who relies on her income for financial security, especially now that her child is ill. In yet another family system, the niece of the mother of a sick child became the primary caregiver, also so that the single mother could continue working and providing for her family. Many of the mothers who were the primary caregivers of the ill child had to stop working so that they could attend to their sick child full-time. This caused many of the mothers to suffer an income loss and increased the financial strain on the family.

The following quotations confirm that role changes is an important factor in coping with a child diagnosis with cancer:

Respondent 1:

"I am taking care of my sister's child while she works. She can't be here and at work and she needs the money. I am not working now so I can help her. But yes, it is difficult to look after a child and to know the mom is very worried and looking at your every move. She is so sad that she can't be here with him."

Respondent 2:

"Ek en my man kry nie regtig tyd om alleen te wees nie, ons sit saam ons kind as hy chemo kry, soms tot baie laat. En my man werk so hy kan nie altyd hier wees nie. Ons dink nie eers aan man en vrou wees vir mekaar nie, dit gaan oor ons seuntjie, hy moet net beter word." *["My husband and I don't really have time to be alone, we sit with our child when he gets chemo, sometimes until very late. And my husband works so he can't always be here. We don't even think of being husband and wife to one another, it is about our son, he must just get better."]*

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Respondent 3:

"It is more difficult now, I can't go to the shop quickly, I have to get someone to watch him while I am gone. And I get worried if it takes long because I need to get back home, I need to take care of him and make sure the other children are taken care of as well. It becomes difficult. I get tired."

Family life revolves around the care of the ill child (MacDonald & Callery, 2007:211). When a child is diagnosed with cancer, then that child is the main priority for the family system and everything else is second in line. The child's health, treatment and progress are the parents' main concern, and in order to do this, things need to change. Mothers become the main caregiver, fathers often need to take on a second job to support the family, older children take over with household tasks and their daily routines are changed if the ill child is in hospital. Cancer often changes roles, which may be a challenging adjustment. This is supported by Hovey (2003:92) who states that "mothers were the primary caregivers in the families and took responsibility for the general childcare as well as doctors' appointments and other health maintenance issues."

It is important for both parents to have open communications to ensure that they have the same goals and objectives regarding the ill child's treatment and condition (Coping with family life…, Sa:23). These added responsibilities may become overwhelming and lead to feelings of frustration and resentment. The parent who is the main caregiver may feel guilty for burdening his/her partner and feel saddened and frustrated by their own limitations (Coping with family life…, Sa:23). In addition, although it may be difficult for both partners to do so, it is important to accept outside help from friends, family members, or professionals (Coping with family life…, Sa:23). Adult children may act as caregivers for a parent with cancer—a change that is often difficult for both parents and children (Coping with family life…, Sa:23). There are many different roles that can change – these changes can either be temporary (as long as needed, or as long as the sibling is ill) or long-term (depending on the length of time that the sibling is ill, or the sibling's willingness to assist, even after the crisis has passed). This will depend on the family system and their functioning prior to the diagnosis. These role changes have an effect on their emotional well-being and psychosocial functioning in return.

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❖ ***Sub-theme 2.2: Single parent***

During the interviews it became evident to the researcher that most of the primary caregivers were single mothers who were unable to work due to their role as caregiver for their ill child. The fathers of the ill children were not involved in the children's lives, didn't provide emotional or financial assistance to either the mother or the ill child and in most cases didn't even know how their children were doing or that they were ill. It is the researcher's opinion that in the case when a mother is the primary caregiver of her ill child, and she has healthy children, her responsibility is so much more. Many of the participants indicated that they felt they were neglecting their healthy children, and that they wished they had more time to spend with them, but in their current situation that just wasn't possible. The single mothers who were the primary caregivers indicated that their support system is very important, especially if they have young children who need constant care while their sibling is ill.

The following quotations confirm that being a single parent is an important factor in coping with a child diagnosis with cancer:

Respondent 1:

"My husband and I are separated; he doesn't have anything to do with my child. I am the one who takes care of her and sits by her side while she gets treatment or when she isn't feeling well. I have to take care of everything."

Respondent 2:

"I can't work because I have to take care of my child. I don't know who is going to pay the bills. I have to ask the family for money but I have to pay it back because they don't have enough money either."

Respondent 3:

"I am so tired, I don't get time to do anything else, I am always with my child because he isn't doing well, and I'm scared if I leave, or visit my other children, that he will die and I won't be here to comfort him. He needs me and I need to be here, it is very difficult, but I love him and I don't mind doing it."

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When a child is diagnosed with cancer, it places emotional, physical and financial strain on the parents of a child. If the person, who is the main caregiver, is a single parent, the strain is felt much more intensely. “One of the most important consequences is the potential fatigue and the need for a break from care giving” (Edmond & Eaton, 2004:197). It is the researcher’s opinion that when a single parent is the main caregiver, there is limited support, and thus limited opportunity for a break. Johnson (Sa:101) states that some of the most pressing issues facing a single parent includes “lack of affordable housing, affordable child care, health care/hospitalization and good-paying jobs that enable them to support their families.” Thus it is reasonable to say that a single parent with a child diagnosed with cancer, faces many difficulties. “Parents of children requiring complex care described their role in care giving as a process that began with birth of their child with an illness and continued indefinitely” (MacDonald & Callery, 2007:209). It is further stated that parents of an ill child often experience fatigue, depression, isolation and inability to work due to the fact that they are the primary caregivers, and this is heightened in the case of a single parent (MacDonald & Callery, 2007:211). Hovey (2005:85) states that mothers who are the primary caregivers of an ill child often have concerns regarding their own levels of fatigue and are worried about their child’s emotional well-being and peer relationships. Gray (2003:39) adds to this by stating that “mothers were most affected in their daily lives by the impact of a child’s needs” and this often manifested in the form of emotional distress, career disruption and stressful interfaces with the medical and educational systems. Thus it can be said that being a single parent has an effect on their emotional well-being and psychosocial functioning in return.

❖ ***Sub-theme 2.3: Multiple children***

From the 9 participants, only one didn’t have children other than the child diagnosed with cancer. Of these 8 participants that had other children than the child diagnosed with cancer, 10 of the children were under 18 years of age, while 5 were over the age of 18 years of age, as shown in Figure 5. The participants with the younger children indicated that it was very difficult to attend to all of their needs. While they were taking care of their ill child, family members such as the grandparents would take care of the healthy children.

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This was necessary in most cases due to the fact that the hospital where the ill child was being treated wasn't close to their homes, and the healthy children needed to continue with school. Feelings of guilt were apparent in the mothers who were the primary caregivers of the ill children. The younger healthy children would also complain about loss of attention from their mother, not receiving gifts like the ill child receives and feelings of loneliness. The older healthy children were more understanding and willing to assist the mother in whichever way was necessary. The siblings of the ill child also expressed concern for their sibling and wanted him/her to be healthy and come home. The younger children expressed the need for things to go back to the way they were before their sibling became ill.

The following quotations confirm that having multiple children is an important factor in coping with a child diagnosis with cancer:

Respondent 1:

"My children understand that I need to be with their brother and that he is very ill. They are very sad that he can't be home with them and they miss him. But they help out at home while I'm here so that helps me a lot."

Respondent 2:

"My baby cries, he wants to know where I am and why I am never at home. My mother says at night it is the worst when he needs to sleep. He doesn't understand that I need to be at hospital. It makes me very sad."

Respondent 3:

"My mother takes care of my children and takes them to school. They seem okay, I phone them at night and hear how their day was and how school was. But they are sad when I miss a soccer game. And they want their sister to come home. My mother takes good care of them, but I miss them too."

It is estimated that two million families in America have four or more children under the age of 18 years (Skolnik, 2013:82). It is the researcher's opinion that many families in South Africa also have large families, especially in the African cultures.

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Having multiple children places physical, financial and emotional strain on a family, to be able to attend to everyone's needs. When a child is diagnosed with cancer, the care of that child requires time, effort and sacrifices. Literature states that the continuation of care of a child with special needs, makes it difficult for parents to allocate time to siblings (MacDonald & Callery, 2007:211). It is the researcher's opinion that in the case of a single parent, this becomes even more difficult for the parent to manage. The child diagnosed with cancer's needs may increase, but this does not mean that the other siblings' needs decrease. The parent has to manage the needs of both the healthy children as well as the needs of the ill child. When the parent has to be with the ill child during treatment, it is inevitable that the healthy children will receive less attention and assistance. It is the researcher's opinion that this places emotional strain on the parent. Thus siblings of a child diagnosed with cancer's emotional well-being and psychosocial functioning is affected.

❖ ***Sub-theme 2.4: Date of diagnosis***

Some of the participants indicated that their child was diagnosed recently while others indicated that the diagnosis was not new and that they were going through another round of treatment.

The following quotations confirm that the date of the diagnosis is an important factor in coping with a child diagnosis with cancer:

Respondent 1:

"I am very, very sad, they just told me that there is nothing they can do for him. He is only five years old. Why does this have to happen? Two months ago he was still happy and running around, now he is dying."

Respondent 2:

"I am so scared, I don't know what is going to happen to him. His tummy was hurting and then the doctors told us he has cancer. They can't even tell us where cancer comes from. I just want the doctor to make him better. I don't know what I am going to do without him, he is my little boy."

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Respondent 3:

"Ons is rustig, ons weet die Here is in beheer en slegte goed gebeur met goeie mense ook. Ons hou net aan met bid en ons glo die Here sal ons help. Hy is al baie beter as wat hy was toe hy eers gediagnoseer was, so ons hoop dat die chemo gaan werk en dat hy gesond sal word." *["We aren't worried, we know that God is in control and that bad things happen to good people too. We just keep on praying and believe that God will help us. He is doing much better than he was when he was first diagnosed, so we hope the chemo will work and that he will get better."]*

Each person experiences their own form of grief and it differs from person to person in terms of where they are at, at a given time. The Kübler-Ross model, commonly known as the Five Stages of Grief, was first introduced by Elisabeth Kübler-Ross in her 1969 book, On Death and Dying. The progression of states is Denial, Anger, Bargaining, Depression and Acceptance. Refer to Table 1: Five Stages of Grief in Chapter Two. From the data obtained, while referring to the literature in Chapter Two, the parents of a child diagnosed with cancer, who had heard the news some time ago, had time to reach the Acceptance phase, whereas parents who had only heard the news recently were still in the process of reaching Acceptance. Thus it can be said that the date of the diagnosis has an effect on their emotional well-being and psychosocial functioning in return.

The key findings of Theme 2 can be summarized by applying the psychosocial approach. Role changes are inevitable in a family system where a child is diagnosed with cancer, but how it is managed depends on individual people and family systems. The participants did experience role changes, but those who had a better support system were able to manage the role changes more effectively. The single parents need to have better support systems in order to manage the diagnosis of cancer in their child effectively and to ensure that the disruption in the family system is as minimal as possible. The findings from this study suggest that the age of the healthy siblings affect their reactions towards the ill sibling and their ability to adjust to the changes in the family system.

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The same can be said of the time of diagnosis of cancer in a child – the parents who have known about the diagnosis for longer and have been dealing with the situation for longer, were coping better than parents of a newly diagnosed child.

3.9.2.3 *THEME 3: FINANCIAL RELATED ASPECTS.*

In any person's life, being financially independent affects your quality of life. It is the researcher's opinion that if a person is able to provide in his/her daily basic needs, their quality of life is higher than those who are unable to do so. When a person is facing a life threatening situation such as the diagnosis of cancer in their child, it has an impact on their financial independence and stability.

The researcher found different aspects that enhanced/hindered the participants' financial independence and his/her ability to cope with the diagnosis of cancer in their children. These aspects will be discussed in detail. In this theme *four sub-themes* were identified, namely:

- Employment/Unemployment;
- Supportive employer
- Transport; and
- Medical aid.

❖ ***Sub-theme 3.1: Employment/Unemployment***

Poverty is a very relevant matter in today's society. Many people do not have a proper education and therefore are unable to find a well-paying job to support their families. If you do not have a sustainable income, many other factors are influenced, such as sufficient food, clothes and housing, as well as the inability to afford school fees and transport. It is the researcher's opinion that there are many people who find it difficult to make ends meet, and when you add a dreaded disease to the situation, it just worsens the person's situation. Most of the participants indicated that they were barely making it through the month with the money they had, and after their child was diagnosed with cancer, their debt became unmanageable. Many of the participants solely rely on government grants to get them through the month and this is hardly enough to feed your child, never mind sending him/her to school or paying for medical expenses.

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Many of the participants also indicated that when their child became ill, they had to give up their employment in order to become the full-time caregiver for the child, which results in even less income and financial stability for the family system. Other participants had to ask a family member to become the primary caregiver for their ill child, in order for them to continue working and to sustain their family. This results in feelings of guilt on the mother's side for not being able to attend to her child's needs herself, it increased the level of emotional distress due to not knowing first-hand what is going on and in the case of small children, the bond between mother and child was affected, as they did not see each other as often as usual.

The following quotations confirm that employment/unemployment is an important factor in coping with a child diagnosis with cancer:

Respondent 1:
"No, we don't have enough money, I can't work anymore because I have to be with my child. My parents are taking care of the children. My daughter asks me why she can't get new shoes, but she doesn't understand that I don't have money to buy new shoes for her."

Respondent 2:
"My man werk sodat ek saam met my seun kan wees deur die dag. Dit gaan nou moeiliker omdat ek nie ook kan werk nie, maar my man het 'n goeie werk en God sorg vir ons." *["My husband works so that I can be with my son during the day. It is more difficult now because I can't work too, but my husband has a good job and God takes care of us."]*

Respondent 3:
"No, we use the grant. That is all money we get. I can't pay the doctors, I don't know what I am going to do. I just don't have the money, but he is sick, he needs the chemo."

Schroevers, Kraaij and Garnefski (2008:552) state that a chronic illness may strongly interfere with a people's daily lives and the ability to perform activities they normally would.

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Darity (2003:226) indicates that being unemployed or out of the labour force "has extensive destructive effects on a person's psychological well-being." The longer the person is unable to work, the more the person's well-being is affected. This is supported by Kalil (2009:16) who states that "insufficient work limits families' economic resources, in particular the income necessary to purchase the resources and goods (e.g., schools, housing, food, as well as safe and cognitively enriched learning environments) that are critical for successful development."

It is the researcher's opinion that the participants who are still working are more worried about their child's health and less involved in the treatment and care, whereas the mothers who are not working, are more involved, but have greater financial difficulties. Johnson (Sa:101) states that parents are unable to support their families on minimum-wage jobs that offers no health care benefits. It is the researcher's opinion that this is a reality for many South African citizens. If a parent is unable to work, certain aspects take priority, such as housing, food and clothing. If the parent is no longer able to financially sustain his/her family, he/she has to rely on social welfare and government grants. This is supported by Kalil (2009:16) who states that a decline in families' work hours and income is associated with an increased reliance on public assistance and greater receipt of welfare income. Whether the person is employed or unemployed affects the family's emotional well-being and psychosocial functioning in return.

- ***Sub-theme 3.2: Supportive employer***

The participants who were either employed, or whose partner was employed, indicated that their employers were very understanding towards them and assisted them as far as possible. If the employee needed time off from work or had to leave work due to a crisis, the employer was generally accommodating. It is thus understandable that an employer can only assist up to a point, and this places emotional stress on the employee. The employee is then caught in a situation where they feel torn between their responsibility to their ill child and family, and the need to stay employed in order to sustain the family system financially.

The following quotations confirm that a supportive employer is an important factor in coping with a child diagnosis with cancer:

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Respondent 1:

"My man se werk is baie goed vir ons, as die dokter laat weet dat hy moet kom, dan kan hy loop by die werk. Hulle verstaan ons kind is siek, hulle is baie goed vir ons." *["My husband's employer is very good to us, if the doctor lets him know he needs to come, then he can leave work. They understand our child is ill, they are very good to us."]*

Respondent 2:

"My work lets me visit my daughter and I can work the hours back, they just need the letter from the doctor saying it was important to go to hospital. They know I wouldn't just leave for any reason."

Respondent 3:

"I am the manager at the shop, I can't just leave whenever I want to, I have to make sure everything is okay at work, I have to be there. So I have to trust my niece that she will take care of it. It is very difficult for me not to be with my baby, but I need the money, I need to work."

Employees report that they are more productive and more engaged in their work when they are able to balance the demands of work with other aspects of their lives. Improvements in physical and mental health are also associated with workplace flexibility. Flexible work options available to the employee also improve family well-being. It is the researcher's opinion that if the employer provides flexibility in the workplace – such as being able to take time off for doctors' appointments and treatments with the ability to work the hours back at a later stage – the employee will be more willing to participate at work and complete the work that needs to be done. It is a fact that a person only has a limited amount of sick leave, annual leave and family responsibility leave per year/annum, and once this is depleted, it causes stress for the employee, especially if it is his/her child that is ill and needs attention. Thus a person's employer affects the family's emotional well-being and psychosocial functioning in return.

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❖ ***Sub-theme 3.3: Transport***

Transport was one of the main difficulties that the participants experienced during the time that their ill child received treatment. They would stay at Nicus Lodge, CANSA centre during the week, and then go home over weekends to visit their family and healthy children. All of the participants stay in areas that are far from the hospital where their child is currently being treated, and therefore transport costs are high. This also means that family members and their support system would not often visit them at Nicus Lodge, because they would not have the financial means for transport. The participants indicated that transport and medical expenses are their main expenditure, and it leaves little for anything else that needs to be paid / bought. The participants also stated that if they went home once the treatment was completed, and the child became ill, they had to travel far for medical attention should the child fall ill again.

The following quotations confirm that transport is an important factor in coping with a child diagnosis with cancer:

Respondent 1:

"Ek bly hier, my man kom kuier hier vir ons. Maar ons kan nie elke naweek huistoe gaan nie, dit is te ver en die petrol is duur." *["I stay here, my husband visits us here. But we can't go home every weekend, it is too far and the petrol is too expensive."]*

Respondent 2:

"I don't see my other children very often, I can't afford to go home every weekend, so I phone them and talk to them, but my mom is helping me and she takes good care of my other children."

Respondent 3:

"If we are at home, then it is difficult if she becomes sick, because it is far from the doctor and from the hospital. So I need to be sure she will not get sick when she goes home, because I don't have money to come to Pretoria every day. The taxi's is very expensive. And you can't take a sick child in the taxi, it doesn't work."

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For many South Africans, unemployment is a stark reality. This is supported by Kalil (2009:20) who states that studies show that black families, at all levels of the socio-economic spectrum, have fewer economic resources with which to buffer the impact of loss of income, such as in the case of a mother that discontinues her employment in order to be able to assist her ill child. If they do not have an income, they are unable to afford the daily necessities such as food and shelter. Medical fees and transport also need to be covered, but are low on the priority list. If your child is ill and you need to travel in order to receive medical attention, it is an expenditure you did not bargain on, and may place a person in a position to choose between transport and other necessities. As discussed in Chapter Two, the Minimum Wage 2013-2014 explains what the average South African person living in poverty earns per month, and how this affects their daily lives, and this supports the above-mentioned statements made by the participants. Transport thus affects the family's emotional well-being and psychosocial functioning in return.

❖ ***Sub-theme 3.4: Medical aid***

Only one of the nine participants had a medical aid. The eight participants who did not have a medical aid indicated that their medical accounts were very high and that they did not have the means to pay the outstanding accounts. The one participant indicated that they had an outstanding medical account at the hospital of R31 000.00 which they were unable to pay. The participant who did have a medical aid indicated that the funds had been exhausted, and they were now financially responsible for the medical costs. It is the researcher's opinion that people living in poverty battle to finance their basic needs, let alone medical accounts for treatment of a child diagnosed with cancer.

The following quotations confirm that having a medical aid is an important factor in coping with a child diagnosis with cancer:

Respondent 1:

"My husband pays our medical aid, but it is so expensive, there is nothing left. We have outstanding accounts that need to be paid still."

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Respondent 2:

"We don't have a medical aid, I can't afford it, I don't make enough money. So I don't know who is going to pay for everything, I am very worried about it."

Respondent 3:

"No, I don't have a medical aid. Nicus Lodge pays for the medication and the chemo, because they know I don't work. I can't pay the doctors."

The comparison between medical aids as discussed in Chapter Two, serves to indicate that in order for a person to have a medical aid, he/she needs to have a sustainable income in order to be able to afford it. If you are a minimum wage worker, there are other priorities before a medical aid, such as food, shelter, clothing and schooling. Many of the minimum wage workers in South Africa are unable to afford a medical aid, and therefore they either have to pay privately for medical services, or they need to rely on government institutions to assist them. It is the researcher's opinion that the government institutions in South Africa are overpopulated and under-staffed, with a shortage of medical services, facilities and medical stock. People who are dependent on government services often have to stand in long rows in order to obtain a consultation, and in order to do this they need to take leave from work, which results in a loss of income.

Should a person be able to afford a medical aid, there are often exclusions and self-payment gaps which is the person's responsibility to cover once the medical aid does not cover it. As indicated in Table 2: Medical Aid Comparison in Chapter Two, entry level options with a medical aid usually only covers hospital fees, therefore if the person is not admitted to hospital, the medical aid does not pay for the services/treatment/medication. If the child is diagnosed with cancer, numerous medical expenses arise, such as hospitalization fees, treatment fees (such as chemotherapy and radiation therapy), specialist fees, medication fees, surgery fees, etc. Whether the person has a medical aid affects the family's emotional well-being and psychosocial functioning.

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The key findings of Theme 3 can be summarized by applying the psychosocial approach. The findings of this study suggest that families who are employed and can remain employed while their child is diagnosed with cancer and receiving treatment, will cope better in the long-run. Parents of a child diagnosed with cancer need to be empowered and assisted in this regard as far as possible. When a person has the necessary support, he/she will be able to cope better with their situations, and this was evident in the findings of this study – the participants who had the necessary support from their employers were coping better with the diagnosis of cancer in their children, than the participants who did not have the necessary support. They were able to provide their families with the support as well as be the main breadwinner of the family. This is also directly linked to transport and medical aid, and the person's ability to able to afford it. The person needs to be seen in a holistic manner and should be supported in all areas where possible.

3.10 SUMMARY

In this chapter the researcher presented, analysed and interpreted qualitative research findings based on the responses of families of a child diagnosed with cancer and the psychosocial effect it has on them as a family system. The qualitative research results suggested that a child diagnosed with cancer had a definite effect on the family system's psychosocial functioning. The results indicated that all aspects of the family system were affected when a child was diagnosed with cancer. These aspects include the effect on the spousal relationship, the impact on siblings, the impact on the parent's employment, the impact on the parents' financial independence, the impact on the parents' emotional strain, as well as their spiritually. There were, however other factors that also had an influence on the participants' psychosocial functioning, such as their personality, whether or not they were employed, their support systems as well as their religion. It showed, for instance that when the family system had a good support system, they were able to cope better, than when they had a poor support system.

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From the qualitative findings and interpretations thereof, the answer to the research question thus seems that the family system's psychosocial functioning is affected through different aspects, such as the effect on the spousal relationship, the impact on siblings, the impact on the parent's employment, the impact on the parents' financial independence, the impact on the parents' emotional strain, as well as their spiritually.

The next chapter summarizes the conclusions and recommendations of the study on the psychosocial influences on the family of a child diagnosed with cancer. The chapter furthermore outlines the proposed interventions that need to be taken.

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4 CHAPTER 4: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

In the previous chapter, the researcher presented the reader with empirical research findings as obtained by means of a qualitative approach in an applied study. The focus of this chapter is to give a general summary of the research project and make conclusions and recommendations on the psychosocial effect on a family of a child diagnosed with cancer. The aim of this chapter is to provide an explanation on whether the goal and objectives of the research project have been achieved and to what extent. Conclusions will be made according to the key findings from the three themes and sub-themes of this research. Lastly, recommendations will be made for practice, for future research and according to the themes.

4.2 Summary

4.2.1 Objectives of the study

To attain the goal of the research study, the following objectives were pursued:

- To conceptualize paediatric oncology as a phenomenon;
- To describe the experiences of the family of the child diagnosed with cancer;
- To determine whether the socio-economic circumstances of the family are affected once a child in the family is diagnosed with cancer;
- To explore the emotional experiences of family members when their child is diagnosed with cancer;
- To explore the quality of life of the family once their child is diagnosed with cancer;
- To explore the influence on the marital relationship of the parents of having a child diagnosed with cancer;
- To explore the family interactions once a child is diagnosed with cancer;
- To explore any changes in the family roles once a child is diagnosed with cancer; and
- To explore the experiences of the siblings of the child diagnosed with cancer.

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4.2.1.1 *Objective 1: To conceptualize paediatric oncology as a phenomenon*

This objective was achieved through an in-depth literature review that was conducted and presented in Chapter Two. The theoretical foundation of cancer, treatment options and side effects and the psychosocial factors of a cancer diagnoses were described. The theoretical framework was discussed as well as social intervention from a developmental perspective. The literature review was done in order for the empirical research to be viewed in context.

4.2.1.2 *Objective 2: To describe the experiences of the family of a child diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. The literature review in Chapter Two described the different aspects of the family that could be affected when a child is diagnosed with cancer. One of these factors included how the family system was affected when a child is diagnosed with cancer. The empirical research indicated that families had less time to spend quality time together as a family, their free time was utilized differently and family members did not see each other as often, especially when the child diagnosed with cancer was receiving treatment and the primary caregiver needed to be with the child.

4.2.1.3 *Objective 3: To determine whether the socio-economic circumstances of the family are affected once a child in the family is diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. The literature review in Chapter Two described the financial impact that a cancer diagnosis has on the family due to hospitalization, treatment, medical aid being depleted and primary caregivers being unable to work. The empirical research indicated that the primary caregivers were unable to continue with their currently employment due to the fact that they had to attend to their child's needs on a daily basis and be there when he/she is treated or hospitalized. The parents that were able to continue with their employment had to ask a family member, such as a grandmother or niece, to become the primary caregiver for their child.

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4.2.1.4 *Objective 4: To explore the emotional experiences of family members when their child is diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. The literature review in Chapter Two described the emotions typically experienced by parents of a child diagnosed with cancer, such as denial, anger, bargaining, depression and acceptance. The empirical research indicated that the primary caregiver would become more emotional when their child was ill, when a poor prognosis was made or when their child was receiving therapy.

4.2.1.5 *Objective 5: To explore the quality of life of the family once their child is diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. The literature review in Chapter Two described the different psychosocial effects of a child diagnosed with cancer had on the family. Quality of life is affected by many different aspects, such as financial strain, marital relationships, employment and emotional maturity. The empirical research indicated that if the above-mentioned aspects were balanced, the person would have an over-all better quality of life.

4.2.1.6 *Objective 6: To explore the influence on the marital relationship of the parents of a child diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. The literature review in Chapter Two described the marital relationship as a concept and how it is impacted by a crisis such as a child being diagnosed with cancer. The empirical research indicated that relationships that were stable prior to the diagnosis maintained or even improved their level of intimacy and support, but those who did not have a stable relationship prior to the diagnosis experienced more pressure.

4.2.1.7 *Objective 7: To explore the family interactions once a child is diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. This objective correlates with objective two. As discussed previously, the empirical research indicated that family interactions were kept as similar as possible, but change is inevitable.

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If other children are part of the family system, their routines need to be maintained as effectively as possible. This is usually done with the assistance of other family members, should the primary caregiver be a single parent.

4.2.1.8 *Objective 8: To explore any changes in the family roles once a child is diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. The literature review in Chapter Two described the role changes that families experience due to a crisis. The empirical research showed that the main role changes were that of the primary caregiver caring for the child diagnosed with cancer and thus being unable to take care of the healthy children, especially in the case of a single parent, as well as the inability of the primary caregiver to continue working. Older children often have to take over the role of parent in the family system if the single parent becomes the primary caregiver.

4.2.1.9 *Objective 9: To explore the experiences of the siblings of the child diagnosed with cancer*

This objective was achieved through the literature review and the empirical research conducted. The literature review in Chapter Two described the impact of terminal illness on healthy children in detail. The empirical research showed that a child diagnosed with cancer becomes the primary concern in the family while they try to maintain all other aspects of family functioning, but these are often neglected, such as the needs of siblings and spending quality time as a family. Younger healthy siblings often do not understand why their parent is not at home often or why the ill child receives all the attention and gifts. Older healthy children are more understanding and supportive of the parents in terms of taking charge and assisting where they can.

4.2.2 Goal of the study

The goal of the study was to explore the psychosocial influences on the family of a child diagnosed with cancer, which was accomplished in the following manner: The literature chapter focused specifically on conceptualizing cancer and the treatment options available, as well as the possible side effects the person may experience.

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The psychosocial influences were discussed in detail, including the emotional impact, the spousal impact, role changes in the family, the financial impact, the impact on siblings and the impact on religion and spirituality. Social functioning from a social work perspective was conceptualized and looked at the specific areas where social functioning can be assessed. The theoretical framework that formed the basis of the study was the psychosocial approach.

From the empirical research the following themes were generated: protective measures, restrictive measures and financial related aspects. Each theme was divided into sub-themes. The theme of protective measures were divided into three sub-themes including religion, support structures and personality traits. The theme of restrictive measures were divided into four sub-themes including role changes, single parents, multiple children and date of diagnosis. The last theme of financial related aspects were divided into four sub-themes including employment/unemployment, supportive employer, transport and medical aid.

4.2.3 Research question

In the context of this study, the following research question was asked:

What are the psychosocial influences on the family of a child diagnosed with cancer?

The data collected during the in-depth interviews with the participants, revealed themes and sub-themes related to the psychosocial influences on a family of a child diagnosed with cancer who was receiving active treatment. These themes and sub-themes were discussed in Chapter Three. The research question was demarcated into specific areas which are the main themes of the study. These themes are visually expressed in Table 5: Themes and Sub-themes.

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Table 5: THEMES AND SUB-THEMES

Themes	Sub-themes
Protective measures	Religion Support structures Personality traits
Restrictive measures	Role changes Single parent Multiple children Date of diagnosis
Financial related aspects	Employment/Unemployment Supportive employer Transport Medical aid

4.3 Conclusions

The conclusions are based on the key findings of this study. The researcher is of the opinion that the findings are transferrable to similar populations. The data analysis of this study was done according to the qualitative processes. The qualitative approach enabled the researcher to gather valuable data on the topic under investigation by exploring the perceptions of the participants. The type of research, namely applied research, selected for this study was suitable as the study was in essence problem-orientated in the sense that the research was carried out to explore a specific problem in practice, which was the psychosocial influences on a family of a child diagnosed with cancer. Data collected by means of a one-on-one interview and a semi-structured interview schedule provided the researcher with rich data from the different participants. The collective case study as a research design enabled the researcher to explore the perceptions of more than one participant which enabled the researcher to reach consolidated findings and make some preliminary comparisons, which were presented in the common themes and sub-themes that were generated. The study was conducted in a government hospital and NGO facility in an urban area with access to resources.

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4.3.1 Theme 1: Protective measures

The research showed that there were certain factors that enabled a family to cope more efficiently with the diagnosis of cancer in their child and thus served as a protective measure for them. The participants who had these protective measures experienced the least disruption in the family system.

4.3.1.1 *Sub-theme 1: Religion*

Religion was indicated by all the participants as vital to their ability to cope with the diagnosis of cancer in their child. Participants communicated that their level of spirituality and relationship with God is stronger now. Thus it can be concluded that religion affects the person's ability to cope in a difficult situation and is therefore a protective measure. This links up with the psychosocial approach which takes into considerations people's cultural backgrounds and the meaning people attach to events in their lives. The meaning that the participants attached to religion and the support they received from their faith was seen as their main form of support.

4.3.1.2 *Sub-theme 2: Support structures*

Support structures enabled the parent of the child diagnosed with cancer to either become the primary caregiver, or to continue working in order to provide for the family. Without the support structures in place the parent would have to continue to support both the ill child as well as the healthy child(ren). The same can be said in the case of employment, support structures enable the parent to either continue working while another family member becomes the primary caregiver, or for the parent to become the primary caregiver and the support structure assists the parent financially. Thus it can be concluded that support structures enable to parents of a child diagnosed with cancer to cope with the situation and is therefore a protective measure. This links up with the psychosocial approach which sees a person as an active participant in his/her life and situation. The participants who had the necessary support were able to actively support their ill child, and fewer role changes were experienced in the family system as a result.

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4.3.1.3 *Sub-theme 3: Personality traits*

Personality traits entail the parents' personality type and characteristics, and how these influence him/her to cope with a child being diagnosed with cancer. The researcher identified a pattern within the participants' answers. The participants who were extroverts were also the optimistic ones, while those who were introverts were more pessimistic. It was the researcher's observation that those participants who were more optimistic, coped better with the diagnosis of cancer in their child, than those who are generally more pessimistic. It corresponded to the "glass half full VS glass half empty" approach. The participants who were generally extroverted type of people, coped better with the diagnosis of cancer in their child and this could be because extroverts generally express their emotions better to other people, and can thus receive the necessary support, while introverts tend to keep to themselves and process inwardly, which may cause them to isolate themselves from their support structures. Five participants were extroverts and optimistic while four participants were introverts and pessimistic. Thus it can be concluded that personality traits of the parents of a child diagnosed with cancer enabled them to utilize their personality traits in order to obtain sufficient support and is therefore a protective measure. This links up with the psychosocial approach which takes into account people's individual personalities and coping strategies. This reinforces the importance of social workers working from a person-centred approach and working from where the client is in order to appropriately address their needs.

4.3.2 Theme 2: Restrictive measures

The research showed that there were certain factors that restricted a family from coping efficiently with the diagnosis of cancer in their child and thus served as restrictive measures for them. The participants, who experienced one or more of these restrictive measures, found it more difficult to cope and had more disruptions in the family system.

4.3.2.1 *Sub-theme 1: Role changes*

The participants experienced role changes after the diagnosis of cancer in their child. The parent who was working full-time had to stop working and become the primary caregiver of the ill child.

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The parent who used to balance work and the children, had to give the responsibility of primary caregiver to a family member in order to be able to continue working. Older children took over tasks such as cooking and cleaning from the parent who became the primary caregiver. Older children also had to take more responsibility for their school work and extra-curricular activities. Therefore it can be concluded that a child diagnosed with cancer affects the family system and the roles they had, and it can thus be seen as a restrictive measure. This links up with the psychosocial approach seeing that the family system actively changes their roles in order to adapt to the situation and continue in a forward and positive direction. Social workers in the health fields should provide families with the necessary resources in order to enable them to actively promote well-being in the family system of a child diagnosed with cancer.

4.3.2.2 *Sub-theme 2: Single parents*

The participants who were single parents experienced the most adjustment difficulties due to a child diagnosed with cancer. Their employment was affected, their financial status was affected more severely and they had to either care for the ill child or the healthy child(ren). Their support was more limited than the participants who were married and had the support of a spouse. Therefore it can be concluded that being a single parent with a child diagnosed with cancer is more difficult than for a parent who is married, and it is thus a restrictive measure. This links up with the psychosocial approach in the sense that single parents need more support than parents who share the responsibility when a child is diagnosed with cancer. The single parents need to be enabled and empowered to cope with the situation and need more resources in order to actively promote the well-being of their family system.

4.3.2.3 *Sub-theme 3: Multiple children*

The participants who only had the child diagnosed with cancer were able to focus all their attention on the child's health and medical treatment. The participants who had the child diagnosed with cancer as well as other healthy children had to divide their attention and put in extra effort to attend to their needs equally.

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The younger children experienced feelings of jealousy towards the ill child who was receiving more attention and gifts. The older children experienced feelings of sadness and discomfort for their sibling who was ill and the severity of the situation. Thus it can be concluded that parents who only had one child (the child diagnosed with cancer) experienced less feelings of guilt and of being torn between different situations and needs and is therefore a restrictive measure. This links up with the psychosocial approach because people experience situations differently and the meanings they attach to a situation also differ from person to person. Social workers in the health field need to recognise this aspect in order to provide appropriate supportive services to each member of the family system.

4.3.2.4 *Sub-theme 4: Date of diagnosis*

The participants, whose child was diagnosed with cancer in 2013, thus six or more months prior to the research, were more at ease with the situation and had reached the stage of acceptance. The participants' whose child was diagnosed with cancer in 2014, thus six or less months ago at the time of completion of the study, were still in the process of acceptance and experienced greater feelings of emotional distress and anxiety regarding the future and prognosis of their child. The researcher noted that the participants, who had a new diagnosis, were in a different phase of grieving than the participants who had an older diagnosis. In terms of Kubler-Ross's phases of grieving, the participants who had a new diagnosis would either be in the Anger phase, the Denial phase or Depression phase. The participants who had an older diagnosis were more likely to be in the Acceptance phase. Thus it can be concluded that those who have more time to adjust to the news of the diagnosis of cancer in their child, were less anxious and distressed and therefore time of diagnosis can be seen as a restrictive measure. This links up with the psychosocial approach and the meaning that the participants attached to their situations and how they were coping with the diagnosis of cancer in their child. People's personality should also be taken into account when you determine whether or not a family system is coping with the diagnosis.

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4.3.3 Theme 3: Financial related aspects

The research showed that financially related aspects had a major influence in the family system's ability to cope with the diagnosis of cancer in their child. Employment vs unemployment was the major factor, affecting the family system's ability to sustain themselves during this time of crisis due to the high costs of medical expenses. This also affected their ability to be able to afford medical aid and transport.

4.3.3.1 *Sub-theme 1: Employment/Unemployment*

Being employed improves the ability to provide for the family and to pay for the medical expenses when a child is diagnosed with cancer. Being unemployed forces you to make use of government grants, loans or assistance from family members to be able to provide for the family and to pay for the medical expenses when a child is diagnosed with cancer. If you are a minimum wage employee, you will attend to basic needs such as food, clothing and shelter first and medical aid and luxuries will be attended to last. However an unemployed parent has the same risk of having a child diagnosed with cancer as an employed parent. Therefore it can be concluded that financial stability is affected by employment or unemployment. The psychosocial approach takes into consideration what social and psychological impact a life changing event has on the family system. The financial impact on the family system of a child diagnosed with cancer is a major cause for concern and these families need to be linked with the correct resources in order to maintain their financial independence and still be able to provide their ill child with the necessary health care services.

4.3.3.2 *Sub-theme 2: Supportive employer*

In the case of a parent of a child diagnosed with cancer who is employed, a supportive employer plays an important role in the parent's ability to support his/her spouse and ill child. If the child is admitted or receives treatment and the parent needs to be there, or transport the child to appointments, and the parent is unable to take time off from work, he/she will feel torn between his/her responsibilities to his/her child and the employer. It may also cause the parent to lose his/her job in the long run, if the employer can no longer accommodate the parent.

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Therefore it can be concluded that a supportive employer assists the parent in attending to his/her family's emotional needs and to remain employed and thus also attend to the family's financial needs. This links up with the psychosocial approach where a person utilizes his/her support structures to cope with the life changing situation, and this was easier for the participants who had the support from their employers.

4.3.3.3 *Sub-theme 3: Transport*

All the parents of a child diagnosed with cancer in this particular study did not stay close to the place of treatment and therefore needed to travel great distances for medical assistance. It also prevented them from returning home to their family members on a regular basis and this affected their relationships negatively. Due to high transport costs, families also experienced higher levels of debt or financial strain. Thus it can be concluded that transport and funding of transport has a great impact on the family and their ability to cope with a child diagnosed with cancer. This links up with the psychosocial approach, because the participants want to actively participate in maintaining the well-being of their family system, but transport was a hindering factor for most. Social workers in the health care setting should be aware of aspects such as the above mentioned in order to assist the clients and finding workable solutions.

4.3.3.4 *Sub-theme 4: Medical aid*

Very few people who receive minimum wages were able to fund a medical aid. Those who were unemployed were not able to fund a medical aid either. Those who had a medical aid soon realized that it only covers certain aspects and that there are still services that need to be paid privately. Those who either did not have a medical aid or those whose medical aid was depleted, had to make use of government facilities to attend to the needs of the child diagnosed with cancer. This caused them to have to wait for these services to become available and they were still left with outstanding accounts for admission and treatment. Thus it can be concluded that having a child diagnosed with cancer and not having the benefit of a medical aid, places enormous amounts of financial strain on the parents.

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This links up with the psychosocial approach and falls into the same category as transport difficulties. If the participants had better access to resources such as financial aids, they would be able to cope better and remain financially independent.

4.4 Recommendations

4.4.1 Recommendations for practice

The researcher is of the opinion that medical personnel working with families in crisis, such as the diagnosis of cancer in a child, should understand the psychosocial effect it has on the family in order to be able to support them appropriately during the process. It is important for social workers working with families of a child diagnosed with cancer to understand that they may experience different emotions, as discussed in Kubler-Ross and that one family may react differently to another family. The participants indicated that the staff at Nicus Lodge played an important role in the process of dealing with the diagnosis and treatment, and this needs to continue. In order for the staff to appropriately assist the families in this situation, they need to be properly trained and equipped with the necessary skills and tools. These tools can include training in stress management, being able to empathetically convey difficult news to families and to teach supportive skills to the families. Some of the participants indicated that they were not always sure about prognoses and diagnoses, and therefore it is important to work together in a multi-disciplinary team to address the shortcomings in communication. When this is done, families will receive the same information and the multi-disciplinary team will be able to address the issues as they arise.

The skills set and training of social work within this field contributes to a more holistic approach in assisting the families and preventing long-term trauma due to their understanding of personal and family functioning. Social workers within the health care field can identify factors that influence functioning and they have the ability to focus their interventions on enabling the families to adjust to the changes in their family system.

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Services that social workers can assist with in the health care field, specifically the oncology field, include supportive communication between spouses, marital adjustment, familial adjustment, adjustment to role changes, expressing of emotions, education regarding diagnosis, prognosis and treatment options, and connecting families to resources such as support groups and financial aids. Support groups are a valuable resource for support, solidarity and information.

4.4.2 Recommendations for research

Future research can focus on a larger sample in order to test results, as well as to include all racial groups in order for it to be more applicable and generally accepted in the health care field. Further research can be done based on this research and can explore how it affects families in different socio-economic situations and the long-term effects of a child diagnosed with cancer on the family. Support was the main reason participants indicated that they were coping – future research can focus on adequate support systems and programs that assist families during this process. Financial strain was the most prominent aspect mentioned by participants that affected their lives once a child is diagnosed with cancer. Future research can focus on supportive measures and resources that will assist the families in coping with the diagnosis of cancer in their children on a financial level. The researcher therefore recommends that future studies should target both private and government hospitals in rural areas where resources might be less obtainable. The researcher recommends that qualitative data collection methods be retained in follow up studies because they allow the participants to provide rich and descriptive data with regard to their perceptions and experiences of families with a child diagnosed with cancer and the psychosocial effect thereof.

4.4.3 Recommendations according to themes

4.4.3.1 *Theme 1: Protective measures*

Social workers in the oncology field should be advised that there are certain aspects that enable a family to cope better with the diagnosis of cancer in a child. These aspects, such as religion and support, should be enhanced and made part of the treatment plan and supportive counselling that a social worker provides.

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Personality should be taken into account when dealing with families of a child diagnosed with cancer, in order to effectively support them and provide in their emotional needs.

4.4.3.2 *Theme 2: Restrictive measures*

Social workers in the oncology field should be advised that there are also aspects that hinder a family from coping with the diagnosis of cancer in a child. The focus of social work intervention in the health care setting should be on the role changes that can occur and how to address them effectively, how to cope as a single parent and to provide the single parents with the necessary support and providing family counselling in order for siblings to understand the situation and the effect it has on them as a family. The date of diagnosis is also important when providing supportive counselling to families – the date of the diagnosis affects where they are with coping with the news and how much it has affected their family.

4.4.3.3 *Theme 3: Financial related aspects*

Social workers in the oncology field should be advised on the impact the diagnosis of cancer in a child has on the parent's financial independence, their employment and the emotional impact it has on the parents due to stress of medical bills, transport costs and being able to provide efficiently for their family. The social workers need to connect the families to the necessary resources such as government subsidies and grants, to lessen the financial burden on the family of a child diagnosed with cancer.

4.5 Closing statement

The diagnosis of cancer affects the family system as a whole, not only the child diagnosed with cancer. Families experience emotional fatigue trying to cope with the diagnosis, as well as the changes it brings in the family and the effect it has on the ill child and trying to balance everything. This is supported by Bregje, et al. ([Sa]:135) who states, as mentioned in Chapter One, that the consequences of a chronic illness or life-threatening illness extends to the family members and does not only affect the patient. Cancer in a child has an effect on the parents' marriage due to the focus being on the ill child and not on them as husband and wife.

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As mentioned in Chapter One, Franik, et al. (2010:151) states that parents can feel anxiety and distress, as well as limitations in their daily routines when a child is diagnosed with cancer. Cancer in a child has an effect on the family's financial independence, due to high costs of medical treatment and specialist services, as well as regular hospitalization and travelling costs. Williams, et al. (2009:95) supports this by stating that families experience strain in physical, emotional and financial areas in their lives. Some parents need to stop working as a result of taking care of the ill child and thus their income is lower than prior to the diagnosis, which places financial strain on the family system.

Families of a child diagnosed with cancer cope better when they have adequate support systems, people who they can rely on and who rely on their faith to keep them going, as opposed to families who do not have these supportive measures to rely on. Siblings of a child diagnosed with cancer are also affected – older siblings need to adapt and often role changes are experienced, while younger siblings are unable to understand the situation and experience loss and rejection. Williams, et al. (2009:97) supports this statement by mentioning that siblings of a child diagnosed with cancer can experience feelings of loneliness, isolation, anxiety, depression, anger, withdrawal, low self-esteem and behaviour problems. If a family is treated in a holistic manner and all of these psychosocial aspects are addressed effectively, less long term trauma will be experienced by the family system and they will be able to continue to contribute to society in a positive manner.

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List of References:

Accurate and reliable dictionary. http://ardictionary.com/Family/562(Accessed on 2014/09/20).

Addoption.com. http://jewish.adoption.com/faith-based/what-is-a-family.html(Accessed on 2014/09/20).

Bauman, L.J.; Drotar, D.; Leventhal, J.M.; Perrin, E.C. and Pless, I.B. 1997. A review of psychosocial interventions for children with chronic health conditions. *Paediatrics, 100(2):244-252*.

Barber, J.G. 2002. *Social work with addictions*. 2nd ed. New York: Palgrave Macmillan.

Barker, R.L. 2003. *The Social Work Dictionary*. 5th Ed. Washington DC, USA: NASW Press.

Bless, C., Higson-Smith, C. & Kagee, A. 2006. *Fundamentals of social research Methods*. 4th Edition. Cape Town, South Africa: Juta & Co Ltd.

Bregje, A., Houtzager, F., Oort, J., Josette, E., Hoekstra-Weebers, M., Huib, N., Caron, C., Grootenhuis, M. & Last, B.F. [Sa]. Coping and family functioning predict longitudinal psychological adaptation of siblings of childhood cancer patients. *Journal of Paediatric Psychology, 3:130-159*.

Brink, H. 2011. *Fundamentals of research methodology for health care professionals*. 2nd ed. Cape Town: Juta & Co. (Pty) Ltd.

Caldwell, R.M.; Silverman, J.; Lefforge, N. and Silver, C. 2004. *The American Journal of Family Therapy, 32:55-60*.

© University of Pretoria

Children's Act 38 of 2005. (Published in the *Government Gazette*, (28944) Pretoria: Government Printer).

Chui, W.C.C. and Chan, S.W.C. 2005. Stress and coping of Hong Kong Chinese family members during a critical illness. *Journal of Clinical Nursing, 16:372-381*.

Coping with family life. 2014. http://www.cancer.net/coping-and-emotions/communicating-loved-ones/family-life (Accessed on 2014/09/21).

Darity, W.A. 2003. Employment discrimination, segregation and health. *American Journal of Public Health, 93(2):226-231*.

Da Silva, F.M.; Jacob, E. and Nascimento, L.C. 2010. Impact of childhood cancer on parents' relationships: An integrative review. *Journal of Nursing Scholarship, 42(3):250-261*.

Davies, N.J.; Kinman, G.; Thomas, R.J. and Baile, T. 2008. Information satisfaction in breast and prostate cancer patients: implications for quality of life. *Psycho-oncology, 17:1048-1052*.

Dictionary.com. http://dictionary.reference.com/browse/psychosocial(Accessed on 2014/09/20).

Dolgin, M.J.; Phipps, S.; Fairclough, D.L.; Sahler, O.J.Z.; Askins, M.; Noll, R.B.; Butler, R.W.; Varni, J.W. and Katz, E.R. 2007. Trajectories of adjustment in mothers of children with newly diagnosed cancer: a natural history investigation. *Journal of Paediatric Psychology, 37(2):771-782*.

Dorfman, R.A. 1996. *Clinical Social Work: Definition, practice and vision*. New York: Brunner/Mazel Publishers.

Eckard, M. M. & Hutchings, S. 2006. *Department of Jurisprudence: Social welfare law*. Pretoria: University of South Africa.

© University of Pretoria

Epstein, N. B., Bishop, D., Ryan, C., Miller, A. & Keitner, G. 1993. *The McMaster model view of healthy family functioning. Normal Family Processes:138-160*. The Guilford Press: New York/London.

Fallowfield, L. 2002. Quality of Life: a new perspective for cancer patients. *Nature reviews: cancer, 2:873-879*.

Farnik, M., Brozek, G., Pierzchala, W., Zejda, J.E., Skrzypek, M. & Walczak, L. 2010. Development, evaluation and validation of new instrument for measurement quality of life in the parents of children with chronic disease. *Health and Quality of Life Outcomes, 8:151-159*.

Fouché, C.B and De Vos, A.S. 2005. Problem formulation. In De Vos, A.S (Ed.); Strydom, H.; Fouché, C.B. & Delport, C.S.L. 2005. *Research at Grass Roots: For the social science and human service professions*. Pretoria: Van Schaik Publishers.

Fouché, CB and Schurink, W. 2011. Qualitative research designs. In De Vos, A.S (Ed.); Strydom, H.; Fouché, C.B. & Delport, C.S.L. 2011. *Research at Grass Roots: For the social science and human service professions*. Pretoria: Van Schaik Publishers.

Frank, N.C., Brown, R.T., Blount, R.L. & Bunke, V. 2001. Predictors of affective responses of mothers and fathers of children with cancer. *Psycho-oncology, 10:293-304*.

Free Dictionary. http://www.dictionary.reference.com/browse/emotion (Accessed on 2010/04/09).

Free Dictionary. http://www.dictionary.reference.com/browse/well-being (Accessed on 2010/04/09).

Friedman, L.C.; Kalidas, M.; Elledge, R.; Chang, J.; Romero, C.; Husain, I.; Dulay, M.F. and Liscum, K.R. 2006. Optimism, social support and psychosocial functioning among women with breast cancer. *Psycho-Oncology, 15:595-603*.

© University of Pretoria

Gil, K.M.; Gibbons, H.E.; Jenison, E.L.; Hopkins, M.P. and Von Greunigen, V.E. 2007. Baseline characteristics influencing quality of life in women undergoing gynaecological oncology surgery. *Health and Quality of Life Outcomes, 5(25):1-7*.

Goldbeck, L. 2006. The impact of newly diagnosed chronic paediatric conditions on parental quality of life. *Quality of Life Research, 15:1121-1131*.

Gray, M. 2003. Developmental Social Work: a 'strengths' praxis for social development. *Social Development Issues, 24(1):4-14*.

Greeff, M. 2005. Information collection: interviewing. In De Vos, A.S (Ed.); Strydom, H.; Fouché, C.B. & Delport, C.S.L. 2005. *Research at Grass Roots: For the social science and human service professions*. Pretoria: Van Schaik Publishers.

Grootenhuis, M.A. and Last, B.F. 1997. Adjustment and coping by parents pf children with cancer: a review of the literature. *Support Care Cancer, 5:466-484*.

Heath, J.A.; Lintuuran, R.M.; Rigguto, G.; Tikotlian, N. and McCarthy, M. 2006. Childhood cancer: Its impact and financial costs for Australian families. *Paediatric Haematology and Oncology, 23:439-448*.

Heaven, P.C.L. and Ciarrochi, J. 2007. Personality and religious values among adolescents: A three-wave longitudinal analysis. *British Journal of Psychology, 98:681-694*.

Hill, J., Kondryn, H., Mackie, E., McNally, R. & Eden, T. 2003. Adult psychosocial functioning following childhood cancer: the different roles of sons' and daughters' relationships with their fathers and mothers. *Journal of Child Psychology and Psychiatry, 44(5):752-762*.

Hodges, S. 2002. Mental health, depression and dimensions of spirituality and religion. *Journal of Adult Development, 9(2):109-115*.

© University of Pretoria

Hovey, J.K. 2005. Fathers parenting chronically ill children: Concerns and coping strategies. *Comprehensive Paediatric Nursing, 28:83-95*.

Iwamitsu, Y.; Shimoda, K.; Abe, H.; Tani, T.; Kodama, M. and Okawa, M. 2003. Differences in emotional distress between breast tumour patients with emotional inhibition and those with emotional expression. *Psychiatry and Clinical Neurosciences, 57:289-294*.

Jacobson, J.C.; Zhang, B.; Block, S.D.; Macjejewski, P.K. and Prierson, H.G. 2010. Distinguishing symptoms of grief and depression in a cohort of advanced cancer patients. *Journal of Death Studies, 3:257-273*.

Jagannathan, A. and Juvva, S. 2009. Life after cancer in India: coping with side effects and cancer pain. *Journal of Psychological Oncology, 27:344-360*.

Jia, H.; Uphold, C.R.; Wu, S.; Chen, G.J. and Duncan, P.W. 2005. Predictors of changes in health-related quality of life among men with HIV infection in the HAART era. *AIDS Patient Care and STD's, 19(6):395-405*.

Johnson, J. Single parent face complex issues. *Single Parent, 38(4):101-102*.

Kalil, A. 2009. Joblessness, family relations and children's development. *Family Matters, 83:15-22.*

Kubler-Ross, E.1969. *On Death and Dying.* [S1]:Scribner.

Kumar, R. 2005. Research Methodology: A step by step guide for beginners. 2nd Ed. [SI]: Sage.

Laubmeier, K.K.; Zakowski, S.G. and Bair, J.P. 2004. The role of spirituality in the psychological adjustment to cancer: A test of the transactional model of stress and coping. *International Journal of Behavioural Medicine, 11(1):48-55*.

© University of Pretoria

Lauria, M.M., Clark, E.J., Hermann, J.F. & Stearns, N.M. 2001. *Social Work in Oncology: supporting survivors, families and caregivers*. California: American Cancer Society.

Leedy, P.D. & Ormrod, J.E. 2010. *Practical Research: planning and design*. 9th ed. New Jersey: Pearson Education, Inc.

Lincoln & Guba (1985) in Lietz, C.A.; Langer, C.L. and Furman, R. 2006. Establishing trustworthiness in qualitative research in social work: implications from a study regarding spirituality. *Qualitative Social Work, 5(4):441-458*.

Long, K.A. and Marsland, A.L. 2011. Family adjustment to childhood cancer: A systematic review. *Clinical Child and Family Psychology Rev, 14:57-88*.

MacDonald, H. & Callery, P. 2007. Parenting children requiring complex care: a journey through time. *Child: care, health and development, 34(2):207-213.*

Maree, K. & Pietersen, J. 2007. Sampling. In Maree, K. (Ed.) *First steps in research*. Pretoria: Van Schaik Publishers.

Matthews, E.E. and Cook, P.F. 2009. Relationships among optimism, well-being, self-transcendence, coping and social support in women during treatment for breast cancer. *Psycho-Oncology, 18:716-726*.

Maurice-Stam, H., Oort, F.J., Last, B.F. & Grootenhuis, M.A. 2008. Emotional functioning of parents of children with cancer, the first five years of continuous remission after the end of treatment. *Psycho-Oncology, 17:448-459*.

Medical Dictionary. http://medical-dictionary.thefreedictionary.com/cancer (Accessed on 2014/10/21).

Medical Dictionary. http://encyclopedia.thefreedictionary.com/family+system (Accessed on 2014/10/21).

© University of Pretoria

Medical Dictionary. http://medical-dictionary.thefreedictionary.com/Pediatric+oncology (Accessed on 2014/10/21).

Medterms. http://www.medterms.com/script/main/art.asp?articlekey=2580 (Accessed on 2014/04/09).

Merriam Webster Web-dictionary and Thesaurus. http://www.merriam-webster.com/dictionary/psychosocial (Accessed on 2014/10/21.)

Monterosso, L.; Kristjanson, L.J.; Aoun, S. and Phillips, M.B. 2007. Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service. *Palliative Medicine, 21:689-696*.

National Cancer Registry. http://www.cansa.org.za/cgi-bin/giga.cgi?=751&limit=10page=0&sort=D&cause_id-1056&cmd=cause_dir_news(Accessed on 2014/10/21).

Nieuwenhuis, J. 2007. Introducing Qualitative Research. In Maree, K. (Ed.) *First steps in research*. Pretoria: Van Schaik Publishers.

Nolan, M.T.; Hodgin, M.B.; Olsen, S.J.; Coleman, J.; Sauter, P.K.; Baker, D.; Stanfield, C.; Emerling, A. and Hruban, R.H. Spiritual issues of family members in a pancreatic cancer chat room. *Oncology Nursing Forum, 33(2):239-244*.

Nolbris, M.; Abrahamsson, J.; Hellström, A.L.; Olofsson, L. and Enskär, K. 2010. The experience of therapeutic support groups by siblings of children with cancer. *Paediatric Nursing, 36(6):298-304*.

Noll, R.B.; Gartstein, M.A.; Vannatta, K.; Correll, J.; Bukowski, W.M. and Davies, W.H. 1999. Social, emotional and behavioural functioning of children with cancer. *Paediatrics, 103:71-80*.

© University of Pretoria

Northfield, S. and Nebauer, M. 2010. The caregiving journey for family members of relatives with cancer: how do they cope? *Clinical Journal of Oncology Nursing, 14(5):567-577*.

Oxford Dictionaries. http://www.oxforddictionaries.com/definition/english/cancer (Accessed on 2014/10/21).

Oxford Dictionaries. http://www.oxforddictionaries.com/definition/english/child (Accessed on 2014/10/21).

Padgett (1998) in Lietz, C.A.; Langer, C.L. and Furman, R. 2006. Establishing trustworthiness in qualitative research in social work: implications from a study regarding spirituality. *Qualitative Social Work, 5(4):441-458*.

Papaikonomou, M. and Nieuwoudt, J. 2004. Exploring parents' stories of coping with their child's cancer: a qualitative study. *South African Journal of Psychology, 34(2):283-300*.

Pappas, S. 2013. *Personality traits and personality types: what is personality*? http://www.livescience.com/41313-personality-traits.html (Accessed on 2014/10/21).

Patel, L. 2005. *Social Welfare and social development in South Africa.* Cape Town: Oxford University Press Southern Africa.

Patenaude, A.F. and Kupst, M.J. 2005. Psychosocial functioning in paediatric cancer. *Journal of Paediatric Psychology, 30(1):9-27*.

Patton, M. Q. 2002. *Qualitative research and evaluation methods*. 3rd ed. London: Sage Publications.

Peterson, R. & Green, S. 2009. *Families first-keys to successful family functioning: Family roles.* Virginia Tech.

© University of Pretoria

Pikler, V.I. and Brown, C. 2010. Cancer patients' and partners' psychological distress and quality of life: influence of gender role. *Journal of Psychological Oncology, 28:43-60*.

Schroevers, M.; Kraaij, V. and Garnefski, N. 2008. How do cancer patients manage unattainable personal goals and regulate their emotions? *British Journal of Health Psychology, 13:551-52*.

Shapiro, J.P.; McCue, M.A.; Heyman, E.N.; Dey, T. and Haller, H.S. 2010. Coping-related variables associated with individual differences in adjustment to cancer. *Journal of Psychological Oncology, 28:1-22*.

Sherman, A.C.; Plante, T.G.; Simonton, S.; Latif, U. and Anaissie, E.J. 2009. Prospective study of religious coping among patients undergoing autologous stem cell transplantation. *Journal of Behavioural Medicine, 32:118-128*.

Sigelman, C.K. and Rider, E.A. 2006. *Life-span: Human development*. 5th ed. Belmont: CA. Thomson Wardsworth.

Sjövall, K.; Attner, B.; Lithman, T.; Noreen, D.; Gunnars, B.; Thome, B.; Lidgren, L.; Olsson, H. and Englund, M. 2010. Sick leave of spouses to cancer patients before and after diagnosis. *Acta Oncologica, 49:467-473*.

Skolnik, D. 2013. Living Large. http://www.parenting.com (Accessed on 2014/10/14).

Strydom, H. 2005. Ethical aspects of research in the social sciences and human service professions. In De Vos, A.S (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. 2005. *Research at Grass Roots: For the Social Science and Human Service Professions*. Pretoria: Van Schaik Publishers.

Strydom, H. 2005. Sampling and sampling methods. In De Vos, A.S (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. 2005. *Research at Grass Roots: For the social science and human service professions*. Pretoria: Van Schaik Publishers.

© University of Pretoria

Strydom, H. 2005. The pilot study. In De Vos, A.S (Ed.), Strydom, H., Fouché, C.B. & Delport, C.S.L. 2005. *Research at Grass Roots: For the social science and human service professions*. Pretoria: Van Schaik Publishers.

Svavarsdottir, E.K. 2004. Caring for a child with cancer: a longitudinal perspective. *Journal of Advanced Nursing, 50(2), 153-161*.

The Free Dictionary References. http://www.dictionary.reference.com/browse/cancer(Accessed on 2014/04/09).

The Free Dictionary: Medical Dictionary. http://medical-dictionary.thefreedictionary.com/psychosocial (Accessed on 2014/09/20).

The relationship between the research question, hypotheses, specific aims, and long-term goals of the project. 2003. http://www.theresearchassistant.com/tutorial/2-1.asp (Accessed on 2014/08/17).

Von Essen, L. Sjödén, P.O. and Mattsson, E. 2004. Swedish mothers and fathers of a child diagnosed with cancer: A look at their quality of life. *Acta Oncologica, 43(5):474-479*.

Welman, C., Kruger, F. & Mitchell, B. 2005. *Research Methodology*. 3rd ed. Oxford University Press Southern Africa.

Western Australian Aboriginal child health survey family functioning. http://www.ichr.uwa.edu.au/files/user17/Volume4%20Chapter4.pdf(Accessed on 2014/09/23).

Williams, P.D., Ridder, E.L., Setter, R.K., Liebergen, A., Curry, H., Piamjariyakul, U. & Williams, A.R. 2009. Paediatric chronic illness (cancer, cystic fibrosis) effects on well siblings: Parents' voices. *Comprehensive Paediatric Nursing, 32:94-113*.

© University of Pretoria

Wolf-Christensen, C., Mullins, L.L., Fedele, D.A., Rambo, P., Eddington, A. & Carpentier, M.Y. 2010. The relationship of caregiver demand to adjustment outcomes in children with cancer: The moderating role of parenting stress. *Children's Health Care, 39:108-124*.

Woodgate, R.L. and Degner, LF. 2004. Cancer symptom transition periods of children and families. *Journal of Advanced Nursing, 46(4), 358-368*.

Young, B.; Dixon-Woods, M. and Heney, D. 2002. Identity and role in parenting a child with cancer. *Paediatric Rehabilitation, 5(4):209-214*.

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Annexure A: Ethical clearance from the Research Ethics Committee of the Faculty of Humanities at the University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

16 April 2014

Dear Prof Lombard

Project:	**The psychosocial influences on the family of a child diagnosed with cancer**
Researcher:	**M Marais**
Supervisor:	**Dr CL Carbonaato**
Department:	**Social Work and Criminology**
Reference number:	**27272232**

Thank you for the application that was submitted for review.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 15 April 2014. Data collection 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.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karemn.harris@up.ac.za

Research Ethics Committee Members: **Dr L Blokland**; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris(Acting Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood

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Annexure B: Permission letter requesting to conduct research at a CANSA Centre

CANSA
Cancer Association of South Africa
Research • Educate • Support

Toll-Free 0800 22 66 22
www.cansa.org.za

NORTHERN BUSINESS UNIT
Northern Gauteng Region

+27 12 329 3036 Tel
+27 12 329 2245 Fax
32 Lys Street Address
Rietfontein, 0084
P O Box 275, Postal
Pretoria, 0001

23 May 2013

To whom it may concern,

CANSA Northern Gauteng will assist Monique Marais in obtaining respondents for interviews with parents of children being diagnosed with cancer according to availability. CANSA will first get permission from the parents before their names are released.

Kind regards,

Dr Annemarie Oberholzer (RN; D Cur)
Community Mobilizer
Tel: +27 (0)12 329 3036
Fax2Email: +27 (0)86 616 5387
Cell: +27 (0)82 562 5912
Cancer Association of South Africa NORTHERN GAUTENG REGION
Address: 32 Lys Street; Rietfontein; 0084

Postal: PO Box 275; Pretoria; 0001

CANCER ASSOCIATION OF SOUTH AFRICA 80 Years 1931 - 2011
ASK AFRIKA TRUST BAROMETER® 2011
Rated as South Africa's 3rd most trusted and admired NGO
Cancer affects us all...
NATIONAL LOTTERY NLDTF
Non-Executive Directors: L Johnstone (Chairperson) | B Pancha (Vice-Chairperson) | Prof. E McIntosh | D Foster | Dr C Masuku | T Mashaba
Executive Directors: S Janse Van Rensburg (CEO) | E Joubert (COO) | R van Jaarsveld (CFO)
Reg. No. 1932/003720/08. NPO No. 000-524

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Annexure C: Informed Consent

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

Department of Social Work & Criminology

Researcher: Monique Marais
Cell: 072 431 6898
Work: (012) 940 9335
Email: monique.swanepoel@yahoo.com

INFORMED CONSENT

1. **Title of the study**: The psychosocial influences on the family of a child diagnosed with cancer.

2. **Purpose of the study**: The purpose of the study is to determine the psychosocial influences on the family of a child diagnosed with cancer. The information gathered will be used to have a better understanding of assisting families who have a child diagnosed with cancer, and the psychosocial influences thereof.

3. **Procedures**: I understand that I will be asked to participate in one interview that will be conducted by the researcher. Should I have any questions during the interview, I can stop the researcher and clarification any uncertainty I have.

4. **Risks and discomforts**: There are no known risks and discomforts associated with this study, although I might experience some emotional distress while answering the questionnaire. If I experience distress, I will inform the researcher. I expect the researcher then to be available to debrief me. If I require further counselling, I will be referred by the researcher for counselling sessions with a suitable qualified counsellor.

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5. **Benefits**: I understand that there are no direct benefits for me participating in this study. The results of the study will, however, assist the researcher to gain a better understanding of the psychosocial influences on the family of a child diagnosed with cancer in order to make recommendations which could assist other families in the same situation.

6. **Participant's rights**: I may withdraw from participating in the study at any time without any consequences.

7. **Financial compensation:** I will receive no financial compensation from the researcher for my participation in the study.

8. **Confidentiality**: I understand that all information which is collected from me will be handled confidentially. However, I give my permission that information collected from me may be used for research and scholarly publications; both in South Africa and other countries, but that my identity will not be revealed unless required by law.

9. **Data storage:** I understand that all raw data will be stored for a period of 15 years in the Department of Social Work and Criminology at the University of Pretoria for archival or further research purposes.

10. **Right of access to researcher:** If I have any questions or concerns, I can call Monique Marais on 072 431 6898 or email on monique.swanepoel@yahoo.com on Mondays to Fridays during working hours (08:00-17:00). The participant will be able to contact the researcher by means of email or phone should he/she seek clarification on any issue or if doubts should arise, whether it is before or after the interview. Should the participant need debriefing after the interview he/she must inform the researcher who will refer the participant to a qualified counsellor. I understand my rights as a research participant and I voluntary consent to participation in this study. I understand what the study is about, how and why it is being done.

_____ _____

Signature of researcher Date

_____ _____

Signature of Participant Date

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Annexure D: Interview Schedule

Interview Schedule

1. Participant's profile

- Age
- Marital status
- Race
- Religion
- Occupation
- Age of child diagnosed with cancer
- Type of cancer diagnosed
- Other children
- Age of other children

2. Emotional impact

- Emotions experienced by parents
- Phase of grieving process
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance
- Anger experienced by parents
- Distress / Anxiety experienced by parents
- Appetite changes experienced by parents
- Sleeping patterns – changes experienced by parents
- Most prominent emotions experienced by parents
- Diagnosis and treatment plan
- Emotions regarding diagnosis and treatment plan experienced by parents
- Emotions of siblings
- Child's emotions' impact on parents

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3. Spousal impact

- Stress caused by diagnosis
- Parental role change
- Time spent with spouse
- Change in marital relationship – positive / negative
- Support system
- Daily routine changes
- Effect on social life / daily functioning

4. Role changes in the family

- Role changes in family
- Role changes amongst siblings
- Full time parent before and / or after diagnosis
- Breadwinner
- Rituals in family
- Grandparents and their roles/involvement

5. Financial impact

- Financial difficulties
- Financial status before diagnosis
- Medical aid
- Cover of medical aid
- Payment of medical bills
- Change in work status of parents
- Effect of diagnosis on finances

6. Impact on siblings

- Parents' relationship with other children
- Time spent with healthy children
- Negative behaviour of siblings
- Effect on healthy children's school performance
- Effect on healthy children's performance in extra-mural activities
- Relationship change between sick child and healthy child

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7. Impact on spirituality and religion

- Spirituality
- Change in spirituality
- Change in religion
- Church attendance – before and after diagnosis

8. Schooling

- Impact
- Support
- Friends
- School work

9. Hobbies / Leisure

- What did the family do in the past
- What did the sick child do in the past
- What do the family do now
- What does the sick child do now

10. Support systems

- Who provides emotional support to the parents
- Who provides financial support to the parents
- Who provides support in terms of care giving to the parents
- Is support provided to the parents from their employers

11. Suggestions

- Do you have any suggestions, recommendations or advice for other families in similar situations as you?

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