THE EXPERIENCES OF CAREGIVERS CARING FOR CHILDREN DIAGNOSED WITH ACUTE LEUKEMIA

BY

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Submitted in partial fulfillment of the requirements for the degree

MSW HEALTH CARE

in the

Department of Social Work and Criminology

FACULTY OF HUMANITIES UNIVERSITY OF PRETORIA

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Month of submission June 2011

Declaration of originality

I, Makopano Sara Mothiba, student number 23085411, declare that this research report titled: 'The experiences of caregivers caring for children diagnosed with acute leukemia' is my own work and the report has not been previously submitted by me at any institution for the degree purposes. All the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

M.S. Mothiba — June 2011

……. ……..

Signature — Date

Acknowledgements

Thank you, Lord Jesus for providing me with the strength to complete this piece of work.

I would also like to thank the following people for their contribution:

- Dr J. Sekudu: Thank you for your patience and guidance
- My parents: I appreciate your intense support.
- The management and staff at the Steve Biko Academic Hospital: Thank you for permitting me to conduct this study.
- All the caregivers: I appreciate your willingness to share your experiences. Without you this study could not be successful.
- Professor Karen Batley: Thank you for editing this document.

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SUMMARY

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Being informed that your child has a form of childhood cancer such as acute leukemia can be devastating for any primary caregiver. The sudden changes that occur affect the receiver of this bad news to the extent that their world becomes focused on the sick child at the expense of the other family members.

This study originated from the researcher's need to gain insight into the experiences of caregivers looking after children diagnosed with acute leukemia. The caregiver could be the legal guardian of the child, the biological mother or the child's grandmother. The aim of the study was to explore the caregivers' daily experiences while they look after these sick children. The objectives also involved providing a broad overview of literature on acute leukemia as a childhood condition, exploring the experiences of caregivers for children diagnosed with acute leukemia and drawing conclusions and recommendations for improved social work intervention specifically for these caregivers.

To explore the experiences of caregivers, the researcher conducted a phenomenological study as part of the qualitative research approach. The participants in the study were recruited by means of availability sampling when they brought their children for treatment. The data was collected by means of in-depth interviews in which ten (10) caregivers shared their experiences. The researcher was able to gain insight into the experiences of the caregivers while they were caring for the patients diagnosed with acute leukemia.

The findings revealed that, while some of the participants had a good support system, others had far less support. Consequently they yearned for the support and physical presence of their family. The researcher found that the participants lived far away from the hospital, which hindered the family from making regular visits to the hospital. This disrupted the family system, because the focus fell mostly on the sick child. There were also major financial implications in caring for a sick child, and the participants' children are all recipients of a welfare social relief grant.

KEY CONCEPTS

- Leukemia
- Acute
- Experiences
- Acute lymphocytic leukemia
- Acute Myeloid Leukemia
- Treatment
- Social worker
- Caregiver
- Hospital
- Family

ABBREVIATIONS

AML – Acute Myeloid Leukemia
ALL – Acute Lymphocytic Leukemia
CANSA – Cancer Association of South Africa
CHOC – Childhood Cancer Foundation
SAPA - South African Press Association
WHO – World Health Organization

CHAPTER 1
GENERAL ORIENTATION TO THE STUDY

1.1 INTRODUCTION

The diagnosis of cancer can be a traumatic experience for the family as a system, especially the patient and the caregiver. Every family and patient reacts differently to the diagnosis of cancer or any chronic condition.

Cancer is the growth of abnormal cells in the body, which results in a breakdown of the process which controls normal cell growth (American Cancer Society, 2007). The process causes a single cell to multiply abnormally. The American Cancer Society (2007) further indicates that acute leukemia is a cancer of the early blood-forming cells. Acute leukemia is a cancer of the white blood cells, but it can involve other blood cell types as well (American Cancer Society, 2007). According to Molete (1999), about 1 500 children are diagnosed with cancer annually in South Africa. Molete (1999) further states that amongst children 0-14 years old, acute leukemia is the most common cancer.

The National Cancer Institute (2003) states that the cause of childhood leukemia is not known. There are two main types of acute leukemia, acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML). Acute lymphocytic leukemia accounts for about three out of four cases of childhood leukemia and AML accounts for most of the remaining cases (American Cancer Society, 2007). There are other types of leukemia, but these are not included in this study. The types of leukemia not discussed here include Chronic Lymphocytic Leukemia and Juvenile Myelomonocytic Leukemia. According to The American Cancer Society (2007), chronic lymphocytic leukemia is extremely rare in children, which is why it was not considered in this study.

According to the World Health Organization (2005), cancer is one of the chronic diseases which are on the increase. The Medical Research Council (2000) reports leukemia as one of the leading cancers in terms of death and causes approximately 1 465 deaths per year in South Africa. The American Cancer Society (2007) reported that about 44 270 new cases of leukemia would be diagnosed in the United States of America during 2008 and, of these, 5 430 would be acute lymphocytic leukemia. About 1 460 people were expected to die of acute lymphocytic leukemia in the United States in 2008 (American Cancer Society, 2007). Molete (1999) reported that over 700 South African children were diagnosed with cancer each year. She further stated that the lack of early detection meant that this figure could reach more than 1500. According to Molete (1999), leukemia comprised 24.7% of all childhood cancers, making it the most common childhood cancer in South Africa (this data was recorded for 1998 and 1999 by the National Cancer Registry).

This study focuses on the experiences of caregivers looking after children diagnosed with acute leukemia. This study emerged from the researcher's involvement in intervention with individuals as a requirement for her practical work in the Master's program. The researcher focused on patients at Kalafong Hospital who had been diagnosed with cervical cancer. The emphasis was on educating the patients about their condition and determining their feelings about cervical cancer. The researcher realized that the patients did not fully understand their diagnosis, which induced feelings of anxiety about their illness. It was only when they comprehended their diagnosis that they were able to explain what they had been going through since being admitted to the hospital. This challenged the researcher to think about children who are diagnosed with cancer and what their caregivers might be experiencing while they take care of them on a daily basis.

The term 'experiences' in this study refers to how the caregivers go through the situation of knowing the diagnosis of acute leukemia and its implications for caring for a child on a daily basis. This entails establishing both the effect that the diagnosis has on the family and what their support structure consists of. The researcher uses the term

'experiences' to explore in depth the caregivers' understanding of the acute leukemia diagnosis and how they make sense of the experiences and the meanings the experience hold. The term refers also to the emotions evoked by the diagnosis. Marlow (1993:6) defines the term 'experiences' as firsthand, personal participation in events that provide a basis for knowledge.

The term 'caregiver' in this study refers to the mother or the grandmother of the child concerned who takes care of the patient on a daily basis. It is imperative to be aware of the caregivers' experiences in order to help them adjust to the challenges of caring for a child suffering from this condition. The social worker's task of determining their experiences will also equip caregivers with a better understanding of how to deal with a sick child. The social worker could thereby develop a procedure for supporting caregivers, which would add value to service delivery in the social work profession.

There is a gap in the field when it comes to focusing on caregivers in terms of what they experience when they have a child diagnosed with acute leukemia. The gap was identified by the former paediatric social worker at Kalafong Hospital, Mr Phuti Kgadima, who told the researcher that the caregiver was addressed only when there was a document to be signed that involved the patient. However, their experiences are overlooked, which means that the challenges they might be experiencing are also overlooked. This study fills that gap by redirecting the focus to the caregivers' experiences.

The children in the paediatric oncology unit at the Steve Biko Academic Hospital often remain in Ward 1.1 for weeks, even months. Dr Rendeys (2010), the doctor in charge of the ward, confirmed that the majority of the children remain in the ward for a long period and that their mothers/caregivers are admitted to the hospital as lodgers. This motivated the researcher to conduct this study so that the caregivers' experiences could be investigated with a view to informing service delivery to them.

The importance of this study is that it aims to determine the caregivers' experience after learning of the diagnosis of cancer in their children. The Cancer Association of South Africa (2008:6) reports that uncertainties and concerns about the illness may cause instability. This implies that normal family relations can be disrupted. According to Fabiola (2009), finding out that a person has leukemia is always a shock to the family. The psychological and social aspects of childhood leukemia are such that family members may fear the new responsibilities they have to face. "Fathers will suddenly find themselves preparing dinner and this threatens the family unit" (Cancer Association of South Africa, 2008). This correlates with this study, as it was reported by the social worker and the doctor in charge of the ward at Steve Biko Academic Hospital that the caregivers remain at the hospital for many months, without prior planning, which could disrupt their family life. The above information confirmed the need for this study, so that the findings could be used to address these aspects in the patients' families.

1.2 PROBLEM FORMULATION

Problem formulation is the first and most important step in the research process (Kumar, 2005:20). In other words, the problem statement provides an overview of the study. Kumar (2005:20) further states that a research problem identifies the researcher's destination. The first step for the researcher in the research process is therefore to formulate a problem and to determine what s/he wants to find out. Research begins with the formulation of the problem, which includes recognizing difficulties and defining and specifying problem areas (Rubin & Babbie, 2004:109). The problem addressed by this study was the lack of information regarding the experiences of caregivers caring for children diagnosed with childhood leukemia.

The National Cancer Institute (2003) emphasizes that cancer research is now focusing on supportive care for patients with leukemia. The researcher is of the opinion that the patients definitely require this support from their families, in this instance, the caregivers.

The Cancer Association of South Africa (2008) points out that the impact of cancer is that family and friends may stay away because they are afraid. On the other hand, they withdraw to protect themselves. The problem is that family members, particularly caregivers, may have negative feelings when they are not able to do what they want to do (Cancer Association of South Africa, 2008). The role of the social worker is to alleviate any identifiable negative feelings. This relates to the fact that some of the caregivers who bring the child to Steve Biko Academic Hospital were admitted as lodgers. Doctors do not always have the time to sit with the caregivers to listen to their concerns about the illness. The caregivers are as a result emotionally affected by the children's condition, which might in turn affect their care-giving role.

The caregivers who bring children to the Steve Biko Academic Hospital Paediatric Oncology Unit include the mothers and grandmothers of the children. Petersen (2010), the social worker for the Oncology Department at the Steve Biko Academic Hospital, indicates that some of the caregivers are admitted to the hospital as lodgers because the children spend a long time there. The caregivers come from different provinces, such as Gauteng, Mpumalanga and Limpopo, which might mean that their other responsibilities are neglected while they are away caring for the patient at the hospital. It became very important to investigate their experiences so that they could be assisted appropriately.

1.3 GOAL AND OBJECTIVES OF THE STUDY

The researcher is of the opinion that a goal gives direction to a study and it is something which one strives to achieve. Alston and Bowles (2003:202) state that the goal of research is to find answers to research questions and to develop theory.

1.3.1 Goal

The goal of this study was, to explore the experiences of caregivers caring for children diagnosed with acute leukemia.

1.3.2 Objectives of the study

According to Kumar (2005:50), objectives are the goals the researcher sets out to reach in a study. Kumar further states that objectives inform the reader about what the researcher wants to achieve. Saunders, Lewis and Thornhill (2000:30) also point out that "objectives leave the reader in no doubt as to precisely what it is that your research seeks to achieve".

The objectives for this study were as follows:

- To provide a broad literature overview on acute leukemia as a childhood condition;
- To explore the experiences of caregivers caring for children diagnosed with acute leukemia.
- To formulate conclusions and recommendations for improved social work intervention for caregivers caring for children suffering from acute leukemia.

1.4 RESEARCH QUESTION

The research question emphasizes the nature of the situation (De Vos, 1998:116). The author maintains that research questions are concerned with single variables, further stating that a good research question is one that is answered by collecting data and whose answer cannot be seen prior to data collection. According to Alston and Bowles (2003:63), qualitative research questions should be understood at the beginning of the research process. The researcher used a research question as it was suitable for this study. Alston and Bowles (2003:52) state that qualitative researchers use research questions that they allowed to emerge from their discussions or observations in the field.

The research question for this study was as follows:

What are the experiences of caregivers caring for children diagnosed with acute leukemia?

1.5 FEASIBILITY OF THE STUDY

The term feasibility implies "recognizing that the reality of undertaking a research project may be to consider where to gain access and to develop a topic to fit the nature of that access" (Saunders *et al.,* 2000:114). The feasibility of the study included the costs involved, for instance, administrative equipment like printing material, a tape recorder and batteries. The above statement illustrates important factors to consider before conducting the study. Considering these factors helped the researcher to estimate the expenses in advance.

In terms of determining the feasibility of this study, the researcher obtained permission from the Steve Biko Academic Hospital. Ethical clearance for conducting the study was obtained from the Faculty of Health Sciences Ethics Committee-University of Pretoria, and from the Postgraduate and Ethics Committee of the Faculty of Humanities at the University of Pretoria. The letter of permission and the letters giving ethical clearance are attached as appendices to this research report. The doctor and nursing sister in charge of the ward were aware that the researcher would be conducting the study using the children's mothers or grandmothers as participants. For instance, the nursing sister informed the researcher of the appropriate time to come to the ward to interview the mothers. (The afternoon was more convenient as the doctor/s and nurses would have finished their ward rounds.)

The availability of participants did not pose any problems as there is an increasing number of children diagnosed with acute leukemia and their parents who come to the hospital, as indicated above. Caregivers who were admitted as lodgers during their children's hospitalization were requested to participate in the study. This study was feasible, as all the financial costs were covered by the researcher and the budget

necessary for covering the costs had already been determined during the planning phase of the study.

1.6 ETHICAL ASPECTS

The term 'Ethics' refers to a code of behaviour appropriate to conduct research (Saunders *et al.,* 2000:131). Several authors (Saunders *et al.,* 2000:132; Alston & Bowles, 2003:21; Banks & Barnes, 2005:246) agree that ethical aspects include avoidance of harm, informed consent, right to privacy, right to withdraw, competence of researchers, debriefing, release of findings and deception of participants. These ethical aspects were applied to this study as follows.

- **Avoidance of harm**

Participants were protected from harm, in this instance, emotional harm. According to Strydom (2002:64), participants should be informed beforehand about the potential impact of the investigation. Alston and Bowles (2003:22) maintain that, contrary to researchers harming participants, they should act to their benefit. For instance, in this study the risks involved included the fact that the participants experienced feelings of sadness when talking about their sick children.

Avoidance of harm during the study included practicing cultural sensitivity towards the participants. The researcher avoided harm by informing them of its possibility so as to alert them not to be disturbed when it happens. The researcher adhered to the ethical aspects by also applying the values, skills and principles of the social work profession.

- **Informed consent**

The researcher concurs that it is imperative to obtain consent from the participants before conducting the study. Kumar (2005:212) reports that it is unethical to collect information without the participants being aware of this. This implies that the participants

must have the psychological ability to be involved in the investigation. Banks and Barnes (2005:247) state that asking for consent offers the respondents the right to participate. Banks and Barnes go on to state that asking for consent also offers the researcher protection from later complaints. Rubin and Babbie (2004:73) state that participants should sign a consent form before they participate in the study. Banks and Barnes (2005:243) define the term 'informed' as disclosing all aspects of what is to occur and what might occur to the respondents. Consent is defined as the competency of the participants to make a rational judgment.

In terms of this study the researcher obtained informed consent from all the participants by means of a written consent form. The participants were able to read what the study was all about and also to see the harm that could possibly occur during the study. When it came to illiterate participants, the researcher read the consent form to them in the language they could understand, as the informed consent letter had been translated into Sepedi. Only when they understood what the study was all about and their role in it, and they had agreed to participate, did the participants sign the consent form. The researcher further requested permission to use the tape recorder to capture information during the interviews. The participants were also informed that during the interviews they are not limited to respond in only English and Sepedi, they may also respond in isiZulu.

- **Right to privacy/anonymity/confidentiality**

Privacy, anonymity and confidentiality are other ethical aspects that were considered in this study. Privacy is the element of personal privacy, while confidentiality is the handling of information in a professional manner (Strydom, 2002:67). This implies that the information obtained from the study should be kept confidential by not sharing it with anybody. Saunders *et al.* (2000:137) state that once promises about confidentiality and anonymity have been given to participants, it is important to ensure that this is maintained. According to Alston and Bowles (2003:21), privacy includes the right to withdraw from the process at any stage. Banks and Barnes (2005:249) define

confidentiality as the process of maintaining secrecy in relation to private information gained during the course of the study.

Anonymity could not be maintained in this study owing to the method of data collection used, but the participants were assured that their names would not be revealed in the research report. Instead of using their names, the researcher referred to the participants as Participant One, Two, and so on. The researcher informed the participants about the supervisor, who had access to the information. However, the supervisor would not know the names of the participants. The participants were also informed that the data in the study would be stored for a period of 15 years in the Department of Social Work and Criminology, University of Pretoria, before it could be destroyed.

- **Deception of respondents**

Strydom (2005:60) describes the deception of respondents as misrepresenting research purposes. This means not telling the participants the truth about the study. Rubin and Babbie (2004:79) emphasize that the subjects/participants must be informed that the information they provide is for research purposes and the reasons for this should be provided. Rubin and Babbie further suggest that one way to avoid deception is to tell the participants that the study is being conducted as part of a university research program.

The researcher did not deceive participants, but provided them with all the information pertaining to the study so that they would know what they were about to get involved in. This helped the participants to be aware that the information they were going to divulge was for a study as part of a university research program. Moreover, on the consent form which the participants signed the researcher clearly described the goal for this study and declared that an audio-tape would be used for collecting the data.

- **Release or publication of the findings**

"The findings of the study should be introduced to the reading public in written form" (Strydom, 2005:65). Strydom further states that the information must be formulated and conveyed clearly to avoid misappropriation. Rubin and Babbie (2004:80) add that negative findings should be reported if they are related to the analysis. Strydom (2002:72) also maintains that the respondents must be informed about the findings of the study.

The researcher openly invited the participants to request the findings after the whole research process had been completed. To facilitate this, the researcher provided the participants with a contact number should they require access and said that arrangements for this would be made. The researcher informed them about all the people who would have access to the findings. For instance, they were notified that the findings would be compiled into a dissertation to be made available to the public in the library of the University of Pretoria. The researcher also informed the participants about her intention to write a manuscript for possible publication in a professional journal.

- **Actions and competence of the researcher**

Another ethical aspect applicable to this study was the actions and competence of researchers. Saunders *et al.* (2000:13) state that capability means that the researchers are feeling comfortable that they have developed the skills that will be required to research the topic, or will do so. The researcher indicated her ability by adhering to all the ethical aspects mentioned earlier. The researcher indicated her ability by informing the participants that she is a social worker registered with the South African Council for Social Services Professions. The researcher has also acquired knowledge on the research methodology by successfully completing the requisite module on this at the Master's level. The researcher therefore has the skills required to conduct a study of

this nature. The study was also conducted under the guidance of a supervisor. The participants were apprised of all these facts.

- **Debriefing of respondents**

Another important ethical aspect is debriefing the respondents. Debriefing means reducing any negative emotions which emerged during the course of the study (Strydom, 2002: 72). For instance, discussing the participants' experiences with them was very sensitive, so debriefing was done immediately after the data collection process had been completed.

The researcher then referred those who needed therapy to the paediatric social worker at the Steve Biko Academic Hospital, as arrangements to this effect had already been made.

1.7 DEFINITION OF KEY CONCEPTS

The next section focuses on definitions of the important concepts to facilitate understanding of the report:

1.7.1 Experiences

An experience entails "what a person learns from doing or seeing things" (Hawkins, Delahunty & Mc Donald, 1998:225).

Experiences can be defined as "firsthand, personal participation in events that provide a basis of knowledge" (Marlow, 1993:6).

For the purposes of this study, the concept 'experience' was defined as something that happens to individuals and affects their lives.

1.7.2 Acute leukemia

According to the American Cancer Society (2007), acute leukemia "is a cancer that invades the blood very quickly".

"Acute leukemia is a disease whereby there are too many white corpuscles in the blood" (Hawkins, Delahunty & McDonald, 1998:360).

In the context of this study the researcher defined acute leukemia as a type of cancer whereby the blood cells cannot perform their normal functions.

1.7.3 Caregiver

The Children's Act 2005 (Act No. 38 of 2005) states that a parent/caregiver includes any person who has parental responsibilities and rights in respect of a child.

"Caregivers are defined as family group members who carry out their caregiving role in the best interest of the child" (Adherence and Networking Group, 2006:36).

In the context of this study the term caregiver means someone who is in charge of attending to a child's daily needs and ensuring the child's safety.

1.8 DIVISION OF THE RESEARCH REPORT

Chapter 1: General introduction to the study, including the goal and objectives of the study, its feasibility, and the ethical aspects observed during the study process.

Chapter 2: Literature review on the following:

Leukemia as a childhood cancer, with special reference to acute leukemia. The role of the social worker in this field has also been addressed in this chapter.

Chapter 3 The chapter contains a detailed description of the research methodology used in the study.

Chapter 4:

The chapter contains the empirical findings of the study.

Chapter 5: Conclusions and recommendations drawn from both the literature and the empirical findings are presented in this chapter.

1.9 Limitations of the study

The limitations and problems which emerged during the study were as follows:

- The use of a tape recorder may have intimidated the participants during the interviews, as the researcher observed that after the interviews some of the participants asked whether the tape would be heard by anyone else. The researcher reassured them again, referring to the confidentiality clause in the consent form.
- The results cannot be generalized from a qualitative study to a larger population. The sample selected to participate in the study was small.
- Some of the responses may have been influenced by the participants who were interviewed first, as they may have shared the contents of the interview with the participants interviewed at a later stage.
- The study was limited to a specific hospital. Experiences could differ in other hospitals with different social environments.
- Some of the impediments encountered were that the participants were not always willing to leave the ward for the interview. Some of them could not differentiate between the role of the researcher and their hospital/ward social worker, and they sometimes wanted to discuss other psychosocial difficulties and obtain resolutions after the interviews.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

The human body constantly makes new cells to grow and replace worn-out or damaged cells (Anti-Cancer Council of Victoria, 2003). Some cells behave abnormally and multiply in an uncontrolled way (The Anti-Cancer Council, 2003). The Anti-Cancer Council (2003) points out that the abnormal cells grow into a lump, which is called a tumour. This is associated with the lack of some of the functions of the normal differentiated tissue (Souhami & Tobias, 2005:32). Bain (2003:1) explains that leukemia results from a mutation in a single stem cell. This implies that acute leukemias are characterized by a defect in maturation, leading to an imbalance between proliferation and maturation as cells of the leukemia clone continue to multiply without maturing to end cells (Bain, 2003:1). On the other hand, Seipelt and Hoelzer (2004: 249) indicate that leukemias occur when the malignant (cancerous) cells lose their ability to mature. As a result, they multiply uncontrollably, replacing normal bone-marrow cells. Several authors (Kruger 2010:320; Hutch, 2009; American Cancer Society, 2008) simply describe leukemia as a form of cancer that occurs when the body produces too many white blood cells to such an extent that normal blood cells are unable to develop. As leukemia disrupts the normal process by introducing a large number of abnormal white blood cells, this eventually decreases the body's ability to fight off diseases (Hutch, 2009).

According to the researcher, it seems that, although there are different opinions about leukemia, it is reasonable to say that authors in this field agree that leukemia occurs when a single white blood cell multiplies uncontrollably.

Leukemias are divided into acute and chronic leukemias (Hutch, 2009; Neal & Hoskin, 2003:213; Bain, 2003:1). CHOC-Childhood Cancer Foundation of South Africa (2008) argues that cancers that occur in childhood (acute) are generally different from those that occur in adulthood (chronic) and occur in developing cells like bone marrow. An acute condition develops quickly, while a chronic disorder develops more slowly over time (Hutch, 2009). Chronic leukemia will not be addressed in this chapter as it does not form part of the focus of this study. If untreated, acute leukemias lead to death in weeks or months (Bain, 2003:1). Souhami and Tobias (2005: 482), however, state that childhood leukemias have a better prognosis if diagnosed early. Over 800 South African children are diagnosed with childhood cancer each year, but owing to the lack of early detection this figure could be over 1 600 (CANSA-Cancer Association of South Africa, 2008). It is estimated that at least 600 children in South Africa die of cancer each year who would survive if they were diagnosed early enough (CHOC, 2008). It is further estimated that, in South Africa, only half of the children are diagnosed and reach a treatment centre in time (CHOC, 2008). It is therefore important that caregivers are made aware of the signs and symptoms in order to respond quickly. However, this may be a challenge in some South African communities who may not have adequate knowledge about leukemia and who also live in rural areas, far from all the resources.

This chapter contains a detailed discussion on acute leukemia. The researcher will describe the causes, staging, symptoms, treatment and psychosocial implications of acute leukemia, specifically for the caregivers. Social work intervention will also be discussed in this chapter. It is important to note that there are two types of acute leukemia, which will be the main focus of this chapter. The treatment options will therefore be discussed by describing the two types, namely acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML). From now on, Acute Lymphocytic/Lymphoblastic Leukemia will be referred to as ALL and Acute Myelogenous /Myeloid Leukemia as AML.

2.2 Definition of medical concepts

The following medical concepts are defined to facilitate understanding of the chapter.

- *Biopsy* is a procedure in which a sample of cells is removed from the body to be examined (Fayed, 2009).
- *Cytoplasm* is a jelly-like substance that surrounds the nucleus of a cell (*Oxford Medical Dictionary, 2000:165).*
- *Eosinophils* are a variety of white blood cells distinguished by their presence in the cytoplasm (*Oxford Medical Dictionary*, *2000:220).*
- *Intrathecal* is a procedure whereby chemotherapy drugs are injected directly into the cerebrospinal fluid (American Cancer Society, [sa]).
- *Lumbar puncture* is a procedure in which cerebrospinal fluid is withdrawn by means of a hollow needle inserted into the space in the region of the lower back (*Oxford Medical Dictionary*, *2000:379).*
- *Lymphocyte* is a type of white blood cell (Marrow, 2010).
- *Prognosis* means chances of survival after a disease is diagnosed based on the stage, type and response to treatment (National Cancer Institute, 2010).
- *Red blood cell* is a blood cell containing the red pigment haemoglobin, which transports oxygen (*Oxford Medical Dictionary*, *2000:227*).
- *Remission* is a reduction in the size of a cancer and its symptoms *(Oxford Medical Dictionary, 2000:563).*

2.3. TYPES OF LEUKEMIA

Neal and Hoskin (2003:213) state that leukemias are divided into lymphoid or myeloid. This implies that acute leukemia is sub-classified by its cell of origin into the lymphoblastic and myeloblastic groups (Neal & Hoskin, 2003:213). These types of leukemia will be discussed in detail, as they form the focus of this study.

It is imperative to know the type of the presented acute leukemia, as this assists doctors in selecting the appropriate treatment. Leukemia is firstly classified as acute or chronic, after which it is then classified by the type of cells in which the leukemia started, either ALL or AML (Fayed, 2009). In children, approximately 98% of leukemias are acute (Miller, 2007). A detailed description of the two types of acute leukemia that form the focus of this study follows.

2.3.1. ALL - Epidemiology and Incidence

ALL is a fast-growing cancer in which the body produces a large number of immature white blood cells (Hutch, 2009; American Cancer Society, 2008). Lymphocytic leukemia develops from cells called lymphoblasts or lymphocytes in the bone marrow (Fayed, 2009). ALL is a progressive bone marrow and blood cancer caused by a high concentration of lymphocytes (Marrow, 2010).

ALL is the most common childhood cancer (Kruger, 2010:320; WHO, 2008:474). Wartenberg, Groves and Adelman (2008:78) agree that ALL is the most common malignancy except in Africa and the Middle East. Leukemia lymphoblasts have uncontrolled growth and cause a drop in production of normal bone marrow cells (Wartenberg *et al.,* 2008:77). This leads to a deficiency in the circulation of red cells, platelets and white cells. Wartenberg *et al.* (2008:77) say that ALL affects white more than black people, and it is also more prevalent in western countries than in the developing countries. According to Deschler and Lubbert (2008:47), ALL is about five times more common in children younger than 15 years. Miller (2007) adds that about 60% of children with leukemia have ALL. In contrast, Kruger (2010:320) reports that ALL comprises nearly 23.5% of all cancers in the age group 0 -14 years.

When it comes to the incidence of leukemia, about 1 500 children are diagnosed with cancer in South Africa (Molete, 1999). That is approximately 3-4 children per 100 000 (Kruger, 2010: 320). In children of 0 -14 years, leukemia is the most common cancer,

comprising a quarter of all cancers in males and females (Molete, 1999; Mqoqi, Kellett, Sitas & Jula, 2004:14). Boys are more commonly affected than girls, with a ratio of 1.2 for 0 -14 years and 2.2 for 15-19 years (Kruger, 2010: 320). Leukemia is the most common cancer of the five childhood cancers (Norman, Bradshaw, Schneider, Pieterse & Groenewald, 2008). Norman *et al*. (2008) report that in 2000 there were 1 418 deaths in South Africa from leukemia. With the increased westernization of the black African society, there is a corresponding increase in childhood ALL. The peak age incidence among black children is in the 3-4 year old age group (Cohn, 1995). The disease often presents at the age of 4-5, or earlier (Souhami & Tobias, 2005: 486). According to a study conducted by Cohn (1995), remission rates and disease-free survival for black children with ALL were lower than for white children. The researcher is of the opinion that the reason for this could be the lower socio-economic status of black people in South Africa as well as their inadequate access to health facilities.

Based on the above information, it is reasonable to say that ALL is a fast-developing childhood cancer, as well as being the most common. Approximately a quarter of children with leukemia have ALL. The researcher observed that there is contrasting information in the literature regarding the incidence of ALL in South Africa. Although the literature agrees that ALL is the most common cancer (epidemiology), writers seem to disagree on the number of new episodes (incidence).

2.3.1.1 ALL Classification

ALL consists of subtypes, which are classified according to the French American-British system (FAB). Bain (2003: 42) notes that the FAB group classifies the subtypes as L1, L2 and L3. The conclusion on the subtype is reached after a biopsy has been carried out, which helps determine the appropriate treatment.

- ALL of L1 subtype

  At this stage the cell is small (Kruger, 2010: 321; Lanzkowsky, 2000:365). Bain (2003:49) adds that this category includes more childhood cases with good

prognoses. The incidence of L1 increases with age and it is the most common subtype in children (Kruger, 2010: 321).

- ALL of L2 subtype

Compared to L1- ALL, L2 incidence does not vary much with age. According to Bain (2003:49), L2 subtype patients have a worse prognosis, and Kruger (2010: 321) argues that at this stage the cells are large.

- ALL of L3 subtype

Bain (2003:118) asserts that this subtype was initially thought to have a poor prognosis, but with more intensive treatment ALL may improve. Kruger (2010:321), on the other hand, maintains that ALL- L3 has a poor prognosis and accounts for only 5% of ALL.

It would seem that the later the diagnosis is made the worse the prognosis becomes. Seeing that ALL affects children, it becomes important to ensure that early detection is emphasized through community education, to avoid late diagnosis. This would go a long way in assisting the caregivers to detect the symptoms early and approach the health facilities while the patient can still be helped.

2.3.2. AML: Epidemiology

AMLs are characterized by an increase in the number of myeloid cells in the bone marrow and blood (WHO, 2008:476). According to the WHO (2008:476), patients with AML present with bruising and have an increased risk of infection. AML can affect children of any age, girls and boys being affected equally (Children's Cancer and Leukemia Group, 2008:1). According to the Children's Cancer and Leukemia Group (2008:1), AML is an overproduction of immature myeloid white blood cells. Approximately 38% of children with leukemia have AML (Miller, 2007). The incidence for AML in South Africa is about 5-7 children per 1000 000 people per year and it comprises about 15% of childhood leukemias in white children (Kruger, 2010: 321). Kruger also states that the incidence of AML has increased among black children. AML

consists of subtypes. It is always important to establish the subtype of AML with which the patient is presenting, to enable the medical team to decide on the appropriate treatment regime, as this would improve the prognosis.

The Children's Cancer and Leukemia Group (2008:2) mention the following AML subtypes as classified by the FAB group. Lanzkowsky (2000: 366) and Bain (2003:7) also use the FAB classification to describe the subtypes. Swierzewski (2007) states that FAB is the most popular method of classifying acute leukemia. The subtypes are as follows:

- **M0- AML** with minimal evidence of myeloid differentiation. Myeloid refers to the blood-forming cells found in the bone marrow, while differentiation refers to how developed/mature the cancer cells are in a tumour (National Cancer Institute, 2010). This subtype is said to have a poorer prognosis (Kruger, 2010: 322).

- **M1- AML without maturation** implies that the development of the cancer cells is not maturing at this stage. Bain (2003: 8) states that M1 category accounts for 15-20% of AML.
- **M2- AML with maturation**. Kruger (2010:322) asserts that the prognosis for this subtype is favourable.
- **M3- Acute Pro-myelocytic leukemia**. In this subtype most cells are abnormal, accounting for 5-10% of childhood AML. However, M3 has the best prognosis (Kruger, 2010:322).
- **M4- Acute myelo-monocytic leukemia**. Lanzkowsky (2000:366) describes this subtype as being associated with a major increase of eosinophils.
- **M5- Monocytic leukemia** containing poorly differentiated monocytoid (Lanzkowsky, 2000:366).

According to Lanzkowsky (2000:366) classification M4 and M5 subtypes are common in children under two years of age. Classification M2 and M3 have a good prognosis, M4

has a fair prognosis but M5's prognosis is poor (Kruger, 2010:322; Souhami & Tobias, 2005:486).

As noted, AML is the most common leukemia. Once the type of leukemia has been classified, the medical team can determine the stage/risk factor and initiate treatment. It is imperative for the caregiver to be involved in the child's treatment, starting with the diagnosis phase, so that s/he can understand the whole process. This will encourage the active participation needed for the benefit of the patient.

2.4. SYMPTOMS OF ACUTE LEUKEMIA – ALL and AML

Some of the symptoms of acute leukemia include chronic fatigue, fever, weight loss, frequent bacterial and viral infections, headaches, skin rash, bone pain, easy bruising, bleeding from the gums or nose, blood in the urine or stools, enlarged lymph nodes and/or spleen and abdominal fullness (Kruger, 2010:320; CANSA, 2009; Hutch, 2009; Seipelt & Hoelzer, 2004:251). Fayed (2009) cites abnormal bleeding as one of the symptoms of acute leukemia. Compared to AML, patients with ALL experience more bone and joint pain at the clinical presentation of ALL (Larson & Anastasi, 2008:110). Marrow (2010) says that small red spots beneath the skin and testicle swelling are not uncommon symptoms of ALL in children. Another symptom which often occurs in children is difficulty in walking, especially in children who have extreme swelling of the large joints (Swierzewski, 2007).

The South African Children's Cancer Study Group/SACCSG (2009) reports that many children in South Africa are diagnosed with leukemia at an advanced stage. To improve this situation SACCSG (2009) have distributed posters in Zulu, Xhosa and South Sotho to primary health care clinics across the country indicating the symptoms/warning signs of childhood cancers, including leukemia.

It seems that most authors agree about the symptoms of acute leukemia, which facilitates the understanding of the condition. It becomes very important to have

caregivers educated on these symptoms so they can act immediately when they observe them in their children. They have to be motivated to take all the symptoms seriously to avoid delay in the diagnosis and treatment induction.

2.5. THE DIAGNOSIS OF ALL AND AML

Before treatment or any medical intervention can begin, it is essential to make a specific diagnosis. In the pages to follow, the researcher will discuss how acute leukemia is diagnosed by using the staging process. According to the Children's Cancer and Leukemia Group (2008:3), a lumbar puncture is performed to see if the spinal fluid contains any leukemia cells. ALL is often diagnosed after a patient has experienced a 4-6 week period of illness and the symptoms are present (Swierzewski, 2007). The National Cancer Institute (2004) states that various tests are carried out to determine the stage of the cancer. These include physical examinations, imaging studies, laboratory tests, pathology reports and surgical reports. The abovementioned tests will be elaborated on below.

- **Physical examinations**

During a physical examination, the doctor examines the body by looking, feeling and listening for anything unusual. Physical examinations may indicate the size of the tumour/s and the spread of the cancer (National Cancer Institute, 2004). During the physical examination, the doctor looks for lumps, other abnormalities or symptoms of leukemia (Fayed, 2009). Schoenstadt (2006) says that the healthcare providers also take and review the history of the patient's past illnesses and treatment. In this study, the caregivers are the people who provide the collateral information because the patients are still too young to provide it.

- **Imaging Studies**

Imaging studies may be used to determine whether leukemia has invaded other organs in the body. These indicate pictures of areas inside the body. Imaging studies are important in determining the stage of the cancer. Imaging studies include computerized tomography (CT scans), magnetic resonance imaging (MRI) scans and positron emission tomography (PET) scans (American Joint Committee on Cancer, 2002:214). All the scans indicated above can show the size of the tumour and indicate whether the cancer has spread. However, Swierzewski (2007) maintains that CT scans are not usually used for leukemia patients unless the doctor thinks that the disease has spread. In such cases, a CT scan can detect changes in the lymph nodes. MRI may be used if the doctor suspects that leukemia involves the brain or lungs (Swierzewski, 2007).

- **Laboratory tests**

These tests include testing the blood, urine and other fluids and tissues taken from the body. According to Fayed (2009), a complete blood count can detect leukemia. A complete blood count determines the number of red blood cells, white blood cells and platelets (Fayed, 2009; Swierzewski, 2007). Other blood tests used to diagnose acute leukemia include the peripheral blood smear, cytogenic analysis and bloods to see how organs are functioning and if they are being affected by leukemia (Lanzkowsky, 2000:363). Schoenstadt (2006) explains the reasons that necessitate blood tests by reporting that leukemia causes a very high level of white blood cells, low levels of platelets and low levels of haemoglobin, which is found inside red blood cells.

- **Pathology reports**

These include information on the size of the tumour and its growth into other tissues and organs. A biopsy may also be performed. This is a procedure in which a sample of cells is removed from the body to be examined (Fayed, 2009). The American Joint Committee on Cancer (2002:214) states that a biopsy of the tumour completes the

staging process. Bone marrow biopsy is used to diagnose leukemia (Fayed, 2009; Schoenstadt, 2006). The diagnosis is then made from blood and marrow samples (Souhami & Tobias, 2005:484).

From the above discussion on how acute leukemia is diagnosed, it is evident that a single examination cannot be relied on, so a number of tests need to be performed for more reliable results. Diagnosing acute leukemia requires several tests to decide on the type and risk group of the disease. In turn, the subtypes as described in point 2.1 and 2.2 classifications of both AML and ALL help determine the diagnosis of the disease. These tests assist in determining the exact condition, so that the patient can receive the appropriate treatment.

2.5.1 STAGING

Before treatment can be initiated, it is essential to know the stage of the disease. Staging describes the extent or severity of an individual cancer (National Cancer Institute, 2004). The National Cancer Institute (2004) emphasizes that staging depends on the location of the primary tumour, its size, the number of tumours, the spread of cancer into the lymph nodes and the presence or absence of metastasis. The Children's Cancer Group, as indicated by Neal and Hoskin (2003:235), classifies treatment according to the stages of the disease. The stages according to Neal and Hoskin (2003:235) are presented as follows:

- **Stage 0**- This stage refers to the early cancer that is present only in the layer of cells in which it began, or the site of origin.

- **Stage I, II, III** – The higher numbers indicate more extensive disease, greater tumour size and/or the spread of the cancer to nearby lymph nodes or organs. For instance, the Children's Cancer Group (in Neal & Hoskin, 2003:235) states that in stage 2 the tumour extends beyond the site of origin.

- **Stage IV** – This stage refers to the cancer which has spread to other organs or has metastasized.

In contrast, Swierzewski (2007) and Schoenstadt (2006) point out that there is no standard staging system for ALL and AML. Both authors state that, for childhood ALL and AML, risk groups are used instead of stages to describe cases of the disease. According to Schoenstadt (2006), the subtype of AML and whether the leukemia has spread outside the blood and bone marrow, rather than the staging system, will determine treatment. Schoenstadt (2006) describes the risk groups as being low, high or recurrent. Marrow (2010) also prefers to refer to risk groups, though the author states that risk groups are similar to stages. The low risk group includes children between 1-9 years old with a white blood cell count of less than 50,000/µL at diagnosis. High risk includes children younger than one year or older than nine. 'Recurrent' refers to the leukemia that has recurred after it was treated (Marrow, 2010). Swierzewski (2007) takes the discussion further by reasoning that leukemia begins in the bone marrow and has often spread to other organs by the time it is detected, so there is no need for traditional staging. The traditional staging that Swierzewski is referring to is the one the researcher mentioned, as indicated by Neal and Hoskin.

The researcher believes that it is imperative to detect the leukemia cells as soon as possible, as this may lead to a good prognosis. The doctor can evaluate the risk group of each patient and thus determine the type of treatment which will be used. It is essential for the caregiver to be informed about the patient's state, so as to facilitate cooperation, in the best interest of the patient. This can be achieved after the child has been classified as low or high risk.

2.6. PREDISPOSING FACTORS OF ACUTE LEUKEMIA: ALL AND AML

Many authors in this field refer to predisposing factors, which means that it is not possible to point to one thing as the cause of this condition. As with any medical condition, it is essential to know the causes in order to effectively treat the condition.

Knowing the causes or predisposing factors can also be used to prevent the condition. Wartenberg *et al.* (2008:82) indicate various factors that are associated with the development of acute leukemia. These include genetic disorders and radiation (Wartenberg *et al*., 2008:82).On the other hand, the WHO (2008:483) maintains that little is known about the causes of acute leukemia. As a result, the researcher is of the opinion that more research needs to be conducted to establish the causal factors of acute leukemia.

A discussion on the predisposing factors of acute leukemia follows.

2.6.1 Genetic factors

Genetic factors are associated with AML in children (Deschler & Lubbert, 2008:47). Children with Down syndrome have an increased likelihood of developing acute leukemia (Deschler & Lubbert, 2008:47; Neal & Hoskin, 2003:213). Souhami and Tobias (2005: 483) assert that in Down syndrome there is an increased risk of ALL. According to Seipelt and Hoelzer (2004:399), children with Down syndrome have a 10-20% increased risk of developing leukemia. The reason is a defective DNA repair mechanism (Souhami & Tobias, 2005: 483). Wartenberg *et al*. (2008:82) state that acute leukemia is associated with chromosomal abnormalities. Moreover, chromosomal abnormalities occur in up to 15% of patients with ALL (Albitar, Giles & Kantarjian, 2008:127). In addition, Wartenberg *et al. (*2008:82) state that the molecular anomalies may be inherited during pregnancy and may develop during injury or early childhood.

2.6.2 Infectious causation

Another important possible cause of ALL and AML is associated with the decrease of the immune function (Wartenberg *et al.,* 2008:83). Children of mothers who reported infections during pregnancy have increased rates of childhood malignancies (Wartenberg *et al.,* 2008:84). The WHO (2008:484) reports that immune-suppression caused by malaria or Human Immuno-deficiency Virus (HIV) may cause childhood

leukemia. According to the WHO (2008:484), infection is suspected of playing a role in the causes of leukemia, but this is not conclusive. Fayed (2009) cites another aspect of the risk factor in acute leukemia. She states that leukemia may occur in people infected with the T-cell leukemia virus. The T-cell leukemia virus can be passed from mother to child during pregnancy or through breastfeeding.

2.6.3 Other etiologies

Ionizing, radiation, maternal smoking, alcohol consumption, diet and paternal occupation such as exposure to various chemicals may cause childhood leukemias (Wartenberg *et al.,* 2008:87). Chemicals referred to include DDT, which is prominent in some industries (Souhami & Tobias, 2005: 482). It is essential to understand that DDT is a powerful chemical that was widely used as a pesticide by farmers in South Africa until it was outlawed in 1974 (Wells & Leonard, 2006:6). However, the Malaria Control Programme continued to use DDT (Wells & Leonard, 2006:6). DDT usage has now been extended into other areas, such as the Limpopo and Mpumalanga Provinces (Wells & Leonard, 2006:7). Wells and Leonard (2006: 12) further report that DDT may potentially lead to cancers, but this is not conclusive.

According to Miller (2007), to limit the risk of prenatal radiation exposure as a trigger for leukemia, pregnant women should inform their doctors of their condition before medical procedures such as X-rays are carried out. Miller (2007) emphasizes that such procedures can be predisposing factors for acute leukemias, as the mother would be exposed to radiation. Souhami and Tobias (2005: 482) also agree that ionizing irradiation exposure in pregnancy doubles the risk of childhood leukemia. In terms of maternal smoking, the risk of acute leukemia is increased in children whose mothers smoked marijuana (Souhami & Tobias, 2005:483).

It is important for pregnant mothers to be educated on these predisposing factors to leukemia, so that they take the necessary precautions in trying to prevent them. This could be done at the prenatal clinics, to minimize the occurrence of this condition as far

as possible. For women who are not motivated to attend prenatal clinics because of lack of access, there should be an effort to reach out to them, specifically in rural areas. The emphasis should be on strengthening primary health care efforts, to empower the communities through community health education.

2.7 TREATMENT OPTIONS FOR ACUTE LEUKEMIA PATIENTS

There are various treatment options available for acute leukemia. According to CHOC (2008), if leukemia is diagnosed early and treated correctly, the majority of children (about 70%) can be cured. Unfortunately, in South Africa, many children are diagnosed at an advanced stage of cancer due to ignorance on the part of their caregivers as well as lack of access to the health care facilities, leading to poor prognosis.

The aim of treatment is to destroy the leukemia cells. The American Cancer Society (2009) describes prognostic factors which will influence treatment. These include the patient's age, white blood cell count and response to chemotherapy. The researcher will describe treatment options by discussing ALL and AML separately. According to Neal and Hoskin (2003:233), treatment for ALL consists of combinations of drugs that are different from those used in the treatment of AML. Age as an important prognostic factor, and the types of treatments are specified below:

2.7.1. The role of age in the treatment of leukemia

The American Cancer Society (2009) argues that the younger patients tend to have a better prognosis if diagnosed at an early stage of leukemia. Leukemia incidence increases from birth to age three, and ALL incidence rates are higher amongst younger children (Wartenberg *et al.,* 2008:80). The authors go on to mention that the peak incidence period is from age two to five, and this rate continues to increase at a rate of about 1% per year. Wartenberg *et al.* (2008:80) state that ALL is higher among males than females and is more pronounced among whites than blacks. ALL make up 24 % of diagnosed cases of childhood leukemia (CANSA, 2008). Miller (2007) states that

although all children with ALL and AML are treated with chemotherapy, the dosages and drug combinations differ. The age of the child will therefore determine the dosage given. This is done by conducting the white blood cell count, as the higher the white blood cells the more intense the treatment will be (Miller, 2007). Overall, what is important to note is that each patient's general health is evaluated, taking into consideration the patient's age, before the doctor can initiate treatment.

2.7.2 TREATMENT FOR CHILDREN WITH AML

Chemotherapy drugs are used to treat cancer by destroying cancer cells before they divide and spread throughout the body. It is stated that chemotherapy is usually used to eradicate the abnormal leukemic clone in the bone marrow (Kruger, 2010:322). Chemotherapy is also used to slow down the spread of cancer that has already spread throughout the body. Feuerstein and Findley (2006) report that chemotherapy treatment can cause memory and cognitive problems as side effects. The American Cancer Society (2009) reports that AML treatment using chemotherapy is divided into two phases namely induction and consolidation.

2.7.2.1 Induction

The purpose of AML induction therapy is to eradicate the abnormal clone (Kruger, 2010:323). This phase is also known as the standard therapy with the purpose of prolonging survival (Estey, 2008:2). The commonly used drugs are daunorubicin and cytarabine, which are given for several days in a row. The schedule of treatment may be repeated in 10 days or two weeks (American Cancer Society, 2009). The American Cancer Society further states that a shorter interval between treatment phases causes more severe side effects but may be more effective in killing the leukemia cells. Neal and Hoskin (2003:233) report that chemotherapy may cause nausea and vomiting.

Cohen (2010) indicates that induction therapy for children with AML starts with two or three drugs. If doctors think that the AML may not respond to two drugs alone, they may

add etoposide (American Cancer Society, 2009). This is usually done for children with very high numbers of white blood cells or whose leukemia has certain chromosome abnormalities. It is said that treatment with these drugs is repeated until the bone marrow shows no more AML. However, Souhami and Tobias (2005:487) state that there is a risk of death in the first few weeks during induction therapy.

The researcher is of the opinion that this may be a difficult time for the caregivers. The reason for this is that the caregivers have to endure seeing their child undergo the treatment and side effects mentioned above. Fabiola (2009) urges families to know and find out as much as they can about the disease in order to understand and to play an active role.

In most cases, chemotherapy given directly into the cerebrospinal fluid also helps prevent AML from spreading to the brain or spinal cord (American Cancer Society, 2009). According to the American Cancer Society (2009), radiation therapy to the brain is not used very often and the risk of recurrence in the brain or spinal cord is lower in children with AML than in children with ALL.

2.7.2.2 Consolidation

This procedure begins after the induction phase, when the bone marrow has no more visible leukemia cells. American Cancer Society (2009) states that stem cell transplant is often recommended. Sameul (2009) reports that stem cell transplantation may be used to enable treatment with high doses of chemotherapy and radiation. However, for children without a suitable stem cell donor, consolidation consists of giving the chemotherapy drug cytarabine in high doses (American Cancer Society, 2009). Thereafter, intrathecal chemotherapy (chemotherapy given directly into the cerebrospinal fluid) is given every one to two months for as long as consolidation continues.

CHOC (2008) reports that many children with acute leukemia are treated at the specialist centers, and that as a result families may have to travel long distances from home for treatment. This correlates with what the researcher has observed, as some children being treated at the Steve Biko Hospital in Pretoria are from the Limpopo and Mpumalanga Provinces. The caregivers are requested to remain in the hospital as lodgers until treatment has been completed. After a thorough analysis of the treatment options for children diagnosed with AML, the researcher holds the view that the treatment for leukemia is long-term and requires a specialized hospital, as the local community hospitals are not equipped to administer this treatment.

2.7.3 TREATMENT FOR ALL

For children with ALL, chemotherapy is recommended for the first round of treatment, as the child has to be hospitalized for three to six weeks (Dugdale & Zieve, 2009). The authors further state that children with a low white blood cell count have to be placed in isolation to avoid infections. Additional treatments for ALL include transfusion of blood products such as platelets or red blood cells. Kruger (2010: 321) states that treatment for ALL has improved over the years from 0% to 80%.

The main treatment for children with ALL is chemotherapy, which is divided into phases, namely induction, consolidation and maintenance (Seipelt & Hoelzer, 2004:259). These phases are discussed below.

2.7.3.1 Induction

The goal of induction chemotherapy is to achieve remission (Dugdale & Zieve, 2009). According to the American Cancer Society (2009), more than 90% of children with ALL enter remission after one month of treatment. Children with standard risk ALL often receive three drugs for the first month of treatment (American Cancer Society, 2009). All children need spinal taps as well to inject chemotherapy into the cerebrospinal fluid to kill the leukemia cells that may have spread to the brain and spinal cord. In contrast with

AML, children with ALL are given intrathecal chemotherapy twice during the first month and four to six times during the next one or two months (American Cancer Society, 2009). It is stated that doctors try not to use radiation therapy, as it may cause problems in the child's intellectual development and growth, specifically when it comes to children younger than two years of age.

2.7.3.2. Consolidation

The next intensive phase of chemotherapy is consolidation (Kruger, 2010:321). Kantarjian (2007) explains that consolidation chemotherapy interferes with the production of blood cells by the bone marrow resulting in a low white blood cell count. The phase lasts for about four to eight weeks (American Cancer Society, 2009). The consolidation phase reduces the number of ALL cells still in the body. According to the American Cancer Society (2009), several drugs are used in combination to prevent the remaining ALL cells from developing resistance. Intrathecal therapy (injecting chemotherapy directly into the cerebrospinal fluid) is then applied (American Cancer Society, 2009). This means that a child is given a spinal tap to inject the chemotherapy into the cerebrospinal fluid. This process is usually given twice during the first month and from four to six times during the next one or two months (American Cancer Society, 2009). This is similar to the process in the induction phase discussed earlier. Children with high risk leukemia generally receive a more intensive regimen of chemotherapy (American Cancer Society, 2009). Generally the more intensive the consolidation, the higher the cure rate (Kantarjian, 2007).

2.7.3.3 Maintenance

This phase begins if the leukemia remains in remission after induction and consolidation (American Cancer Society, 2009). The treatment plans use methotrexate and 6-mercaptopurine given as pills along with vincristine, which is given intravenously (Souhami & Tobias, 2005:488; American Cancer Society, 2009). Kruger (2010:321) says that maintenance treatment is administered with central nervous system

prophylaxis. The researcher views this as a preventative method to block the metastasis to the brain. Lanzkowsky (2000:380) states that maintenance therapy is given for a period of from eight to twelve weeks. During the first few months of maintenance, treatment includes one or two repeats of intensified treatments similar to the induction (American Cancer Society, 2009). On the other hand, Souhami and Tobias (2005: 488) state that, with intensive induction and consolidation regimens, prolonged maintenance therapy will be less necessary. The authors mention further that at the end of childhood ALL treatment a testicular biopsy is sometimes performed.

The total duration of therapy, induction, consolidation and maintenance for most ALL treatment plans is two to three years (American Cancer Society, 2009). This is to keep the cancer from recurring, as acute leukemia will almost always recur if this additional chemotherapy is not given (Miller, 2007). This concurs with what has been stated by Souhami and Tobias (2005:488), that relapse at any site is unusual beyond one year after treatment has stopped. The researcher holds the view that it is imperative for the caregivers to be knowledgeable about the duration of chemotherapy. As indicated, the treatment may occur over a period of two to three years. The caregivers must therefore continue to bring their child for treatment, as this could minimize the chances of relapse and result in complete remission.

The treatment plans may change if the ALL does not go into remission. The doctors usually check the child's bone marrow soon after treatment starts to see if the ALL cells are responding (American Cancer Society, 2009; Souhami & Tobias, 2005:488). If they do not respond, chemotherapy is prolonged.

In conclusion, it is important to remember that if a child relapses during initial or maintenance treatment or after one year following the cessation of therapy, a bone marrow transplant is considered (Souhami & Tobias, 2005:488). It is clear that leukemia treatment takes a long time. The caregiver must therefore be open to the changes which are likely to occur specifically in their own life and the life of the child/patient. Such changes include adjusting to the reality that the child will be at the hospital to

receive treatment, which may have side effects. Induction, consolidation and maintenance therapy are essential to killing the leukemia cells. The aim of therapy for both ALL and AML is to ultimately diminish the leukemia at its original site and to prevent the cancerous cells from spreading to the surrounding cells/organs, particularly the brain.

2.8 PSYCHOSOCIAL IMPLICATIONS OF ACUTE LEUKEMIA

It is essential to provide supportive care to the family/caregiver and the patients. The following discussion focuses on the psychosocial implications of acute leukemia for the patient, caregivers and on the role of the social worker.

2.8.1 Implications for the patient

The researcher is of the opinion that the person who is diagnosed with the disease is the most affected. For purposes of this study, the 'patient' refers to a child who has acute leukemia. When the patient is first admitted to the hospital, s/he has to establish new relationships with the nursing staff, doctors and other patients in the ward. The patient also has to adapt to the new environment. The Adherence Networking Group (2006: 3) maintains that in comparison with adults, children are more dependent on others for their well-being and care. This implies that the way in which their caregivers deal with them and their illness strongly affects their ability to cope with their illness (Adherence Networking Group, 2006:3).

As the child spends a long period hospitalized s/he is likely to be absent from school or pre-school. Acute leukemia means that the child's schooling is disrupted. When a child is out of school for a long period of time, s/he may experience reactions such as depression, apathy and poor self-concept (McDougal, 1997). It is imperative to note that even after the child has been discharged from the hospital s/he will have to continue the treatment as an out-patient on a weekly and/or monthly basis. As indicated above, leukemia treatment like chemotherapy may continue for a prolonged period. The child's school curriculum will thus be disrupted in the long term. McDougal (1997) adds

that repeated absence from school and peers may have a negative impact on social and psychological adjustment.

There are also psychological issues relating to physical appearance (McDougal, 1997). These include growth delay, decreased growth, problems with sexual maturation, reproductive problems and cataract development (American Cancer Society, [sa]). Science-Daily (2008: 2) lists several other health conditions that can occur as a result of cancer treatments, including musculoskeletal activity limitations, and cardiac and neurological conditions. These effects usually display within two to five years after treatment (McDougal, 1997). They are more common in children who were under the age of five at the time of treatment. The American Cancer Society [sa] reports that there are long-term implications as the child grows, depending on the type of treatment s/he had undergone. Chemotherapy may contribute to a slow-down in growth (American Cancer Society, [sa]). Kadan-Lottick (in *Science Daily*, 2009) adds that chemotherapy and radiation exposure are associated with short stature and cognitive problems. The researcher is of the opinion that as the child matures s/he may experience emotional problems due to the abovementioned physical problems caused by cancer treatment.

2.8.2 Implications for the caregivers

A family is an emotional relationship system which consists of eight interlocking concepts: differentiation of self, triangles, family emotional system, family protection process, emotional cutoff, multigenerational transmission process, sibling position and societal regression (Goldenberg & Goldenberg, 2008: 179). Goldenberg and Goldenberg further indicate that when any of these concepts becomes dysfunctional it may cause anxiety within the family system. The caregiver is affected when a child is hospitalized. Cancer places considerable psychological stress on patients and their families (Cherny & Catane, 2004: 399). Cherny and Catane (2004:399) indicate that managing psychological complications in any form of cancer, such as depression and difficult psychosocial issues like bereavement and family dysfunction, are challenging for even the most skilled oncologist.

The caregiver sometimes has to spend a great deal of time in the hospital with a sick child. As a result, she may have to leave the rest of the family at home. The researcher is of the opinion that being absent from home may disturb the caregiver psychologically, as she has to be away from her family and/or children. The Adherence Networking Group (2006:149) reports that depression is common amongst the caregivers. As a result, other family members may have to assume the caregiver's role during her absence. The Adherence Networking Group (2006: 148) emphasizes that, if the caregiver is ill and has few supports, this may add to the stresses of caring for the child. The WHO (2008:82) reports that families may have to face increased medical costs occasioned by longer hospital stays or higher rates for the use of primary care medical services. This is also applicable in this study, as caregivers of children diagnosed with acute leukemia usually remain at the Steve Biko Academic Hospital for weeks or months while the patient is undergoing treatment. The WHO (2008:82) states that family members are confronted with a number of distressing emotions and experiences. These include the fear of death and uncertainty about the nature and prognosis of the disease (WHO, 2008:82).

It is evident that the caregiver is affected by caring for a child who has leukemia. This necessitates the social worker's playing an active role by ensuring that the caregivers are able to cope with their children's illness.

2.8.3 The role of the social worker

The role of the social worker is to identify the needs and concerns of the caregivers. Ell and Morrison (in Cowles, 2000:118) emphasize that the social worker's primary responsibility is to promote their clients' well-being. The researcher is of the view that promoting the clients' well-being can be done only after the social worker has identified their needs. Ell and Morrison (in Cowles, 2000:118) indicate that social workers in health care have the responsibilities of decision-making, differential diagnosis, counseling the resistant patient, team building, consultation and education. For the

purpose of this study the social worker can assist the patient and caregiver in the following manner:

- *Decision making* – The social worker's role will be to explain to the caregivers why the type of treatment was initiated for the child.
- *Differential diagnosis* - The social worker can facilitate this role by educating the caregiver and patient on the different diagnoses and explain in-depth the patient's diagnosis to the caregivers.
- *Counseling the resistant patient* – The role of the social worker is to provide counseling to the caregivers, who may be reluctant (owing to cultural beliefs) or unsure about the treatment chosen for the child.
- *Team building* – The role of the social worker will be to include the patient and caregiver as team members who play an active role in providing input to enhance the treatment process.
- *Consultation* – The social worker's role is to check on the caregivers daily to ensure that they are not displaying symptoms of depression.
- *Education* – The health care social worker's role is to teach the caregivers about leukemia as a childhood condition. The reason for this is that if the caregivers are knowledgeable about the disease they will be able to understand the type of treatment chosen for their child, its side effects and duration.

According to Fabiola (2009), finding out that a child has acute leukemia is always a shock to the family. The family is often overwhelmed and finds it difficult to ask the proper questions and to remember everything the doctor advises (Fabiola, 2009). This implies that counseling should be initiated to support the caregivers. The researcher is of the opinion that the role of the social worker is to alleviate the fears of the caregivers by explaining in detail what acute leukemia entails. Cowles (2000:134) states that the social worker's responsibility is to assess both the emotional and social environmental problems experienced by the patients. During therapeutic intervention with the caregivers, it is therefore vital for the social worker to give the family an opportunity to determine how to cope during and after the disease. CHOC (2008) states that

psychosocial support for the children and families is important in helping them cope with the stresses they may encounter when their children are diagnosed with cancer. The diagnosis of cancer for the child can mean several years of coping with treatment and long hospitalization (CHOC, 2008). Social workers can thus play a role in providing support. The Cleveland Clinic Foundation (2007) concurs that individual counselling is important, as patients are able to express their fears more readily. In the context of this study, individual counselling is identified as a need for the caregivers to enable them to provide constructive support for the patients. This would also be applicable to other family members particularly the caregivers.

The aim of counselling is to improve the quality of life for the patients and their families. The social worker can apply the child-centered approach when working with children. The Adherence Networking Group (2006:2) emphasizes that a child-centered approach involves children as far as possible as active participants in their own treatment and tries to promote the child's development in a holistic way. Older children, who have the mental capacity to understand what is going on, can benefit from counselling. The younger child may be confused about being in the hospital. If a child is medically fit, play therapy techniques may be used to enhance adjustment and coping. The Adherence Networking Group (2006:3) maintains that children's capacity to understand and cope with the challenges they face is still developing throughout childhood. The social worker therefore has to have the skill and knowledge about the stages of development to enable her/him to render an adequate service to the child.

Like Cowles, Dhooper (1997: 214) adds to the roles of social workers in public health. These include the social work role of creating and mobilizing financial resources, program planning, program implementation and service provision, illness prevention and health promotion. For purposes of this study, the social worker in health care may facilitate these roles in the following approach:

- Creating and mobilizing financial resources

The social worker's role is to assess the caregiver's home circumstances and if the caregiver and the patient have a low socio-economic status the social worker has to liaise with community resources. This will assist the caregivers with the services available in their communities. For instance, caregivers with low socio-economic status may be referred for welfare assistance or a self-development program.

- Program planning

The social worker's role as planner is to plan health promotion activities, which can be directed at the caregivers and their families. This will include the family in educational activities focusing on childhood cancers. The researcher is of the opinion that inclusion may enhance a supportive structure between the caregiver, family and patient.

- Service provision

The social worker's role is to render an effective service to the patient and the caregivers in order to enhance their potential and functionality once they have been discharged from the hospital. This may be achieved by referring the caregivers to community resources.

According to Riba (2002), families are usually concerned about the future. Stevens (2000:13) maintains that most fathers or husbands cannot deal with the problem. It is therefore the social worker's responsibility to help the family and caregiver adjust to the changes.

In light of the above psychosocial implications the researcher infers that leukemia has some form of effect on the caregivers and the patient. It is the social worker's task to reassure the parties concerned by helping them to realise their potential and reach the point of accepting the leukemia diagnosis and the treatment plan.

2.9 SUMMARY

Overall, it is important to remember that acute leukemia is a condition that mainly affects children before the age of 18. Even though the real causes of the disease have not yet been established, it is important to be aware of the signs and symptoms. The symptoms include fatigue, easy bruising, excessive bleeding and aches in the joints and bones.

As highlighted in this chapter, the early detection of acute leukemia is best, as this leads to an improved prognosis. Knowledge of the symptoms will help the caregivers to seek medical assistance as soon as they observe any change in the child. This may entail taking the child for several tests to determine the exact diagnosis so that there can be appropriate treatment. Chemotherapy treatment may last for several months or years depending on the malignancy of the cancer in the body. Prolonged treatment for the child necessitates long hospitalization. This may disrupt the family system financially and psychologically. It is therefore essential to help caregivers through this traumatic and often exhausting period. The way to give this assistance is to understand their experiences.

Therapeutic interventions can be facilitated by the social workers. This can only be done once it is known how the caregiver/family is experiencing this new challenge. Thorough assessment is essential so that appropriate intervention could be implemented.

CHAPTER 3
RESEARCH METHODOLOGY

3.1. Introduction

This chapter presents the research methodology followed in conducting this study. The process in research methodology includes clarifying the research question and deciding on the research design. This involves data-collection design and sampling, the recruiting plan, debriefing of participants, insight development and interpretation of data and research reporting (Cooper & Schindler, 2006:201). According to Saunders, Lewis and Thornhill (2009: 107), embarking on research is a way of developing knowledge in a particular field. The purpose is to answer a specific problem in a particular organization as a way of developing new knowledge (Saunders *et al*. 2009:107). The following aspects are discussed in detail in this chapter: research approach, the type of research, research design, the data-collection method and analysis, population and sampling.

3.1.1 RESEARCH APPROACH

The qualitative approach is concerned with understanding rather than explaining why things happen (Fouché & Delport, 2002:29). The *Free Dictionary* (2001) states that qualitative research involves an in-depth understanding of human behaviour. According to Alston and Bowles (2003: 54), qualitative research is about finding the meanings that people ascribe to their experiences. Alston and Bowles' definition of the qualitative approach correlates with the approach of this study, which was aimed at exploring the participants' experiences. Several authors (Alvesson & Deetz, 2000:60; Marlow, 1993:66) agree that the qualitative approach to research constructs broader descriptions of and meanings for the individuals' concerns. The approach uses interviews for collecting data.

This study was qualitative in nature, as it focused on the experiences that caregivers had to deal with on a daily basis. The research approach was found to be appropriate, as the focus was on the meaning the participants attached to their experiences.

3.1.2 TYPE OF RESEARCH

Applied research means that the findings of the study can be applied to matters in practice (Banks & Barnes, 2005: 239). Kumar (2005:9) says applied research is used in a great deal of research in the social sciences.

This study used applied research, the rationale being that it focused on addressing practical issues. This implies that applied research is conducted for the findings to be used in addressing a problem in practice. Such research is suitable for exploring and addressing a problem, as was the case in this study, where the researcher formulated recommendations aimed at improving social work service delivery for caregivers of children diagnosed with acute leukemia.

3.1.3 RESEARCH DESIGN AND METHODOLOGY

The researcher used a phenomenological research design. Phenomenology emphasizes a focus on people's subjective experiences and interpretations of the world (Trochim, 2006; Babbie & Mouton, 2001: 271). The researcher here focused on the caregivers' experiences. The phenomenological design was used, as the researcher wanted to determine these experiences. The caregivers described in detail what they had gone through in the course of caring for a child who had been diagnosed with acute leukemia.

3.1.3.1 Method of data collection

The method of data collection used in this study was in-depth interviews. The interviews were recorded on an audio tape, with permission from the participants. The researcher

interviewed the participants one at a time in a private room. The participants' consent was required before they could be interviewed. Written consent forms were provided, which they had to read and understand before giving consent. For those who could not read English, there were consent forms written in Sepedi, which were read to them. The researcher asked for their consent if they were prepared to participate. The participants were also informed that during the interview they could respond in their preferred language.

According to Saunders *et al.* (2000:242), the use of interviews helps the researcher to gather data that is valid, reliable and relevant to the research question and objectives. Interviews are a more flexible way of collecting data (Alston & Bowles, 2003:111).

Saunders *et al.* (2000:244) maintain that unstructured interviews, also known as in-depth interviews, are used when the researcher wants to explore a general area more closely. This applied to this study, as the researcher wanted to do an in-depth exploration of the experiences of caregivers looking after children who had been diagnosed with acute leukemia. In this approach, participants are given the opportunity to talk freely about events in relation to the topic (Saunders *et al.,* 2000:244). Marlow (1993:70) states that during unstructured interviews the researcher guides the interview process while the participants talk.

3.1.3.2 Data Analysis

Analyzing the data collected demands that the researcher uses certain tools that ensure the reliability of the study (De Vos, 2002:341). According to Saunders *et.al.* (2000:381), qualitative data analysis is based on meanings expressed through words, and collection requires classification of data into categories. The following aspects were addressed in the process of data analysis:

- **Categorization of data**

The first activity of data analysis involves classifying data into meaningful categories (Saunders *et al.,* 2000:383), for instance, by using coloured labels to re-arrange data. Alston and Bowles (2003:207) describe this as data reduction, meaning that the data is coded and categorized in order to identify important aspects. As far as this study was concerned, the data was categorized according to the themes emerging from the interviews (Byrne, 2001). Bradley and Devers (2007) maintain that data usually originates from interview transcripts or observation notes, and must be amalgamated to represent major themes or categories that describe the phenomenon. Byrne (2001) describes this method of data analysis as thematic analysis.

For this study, the data was categorized according to the themes emerging from the interviews. The researcher transcribed each interview from the audio recorder by using a verbatim format; thereafter the researcher read the notes on each interview in order to identify the themes and patterns in each participant's experience. The researcher then highlighted similarities and differences in each interview. In doing this, categories in the interviews were identified.

- **Analytical Aids**

Another aspect in qualitative data analysis involves the use of aids. According to Saunders *et al.* (2000:388), in addition to writing up the recordings of a research session and assigning units of data to appropriate categories, a record of additional information is made. This activity is said to help the researcher recall the context and content of the interview (Saunders *et al*., 2000:388). Summarizing the key points that emerged from the interview is imperative. In this study, the researcher analyzed the data by transcribing from the tape recorder what each participant said and summarizing the key points. The analytical aid in this study was therefore an audio tape, as all the information was analyzed from the recordings.

- **Interpretation**

Qualitative data analysis also includes interpretation. According to Alston and Bowles (2003:207), interpretation involves identifying patterns, trends and explanations, the conclusions from which can be tested through more data collection. The researcher analyzed the data by interpreting what the participants said during the interviews. Some of the responses were presented verbatim to emphasize the participants' opinions. Finally the research report is presented in text format.

3.1.4 DESCRIPTION OF THE POPULATION, SAMPLE AND SAMPLING METHOD

3.1.4.1 Population

The population refers to all the potential subjects whom the researcher would like to include in the study (Strydom & Venter, 2002:198). Sternberg (2001:607) defines a population as "the entire set of individuals to which a generalization is to be made".

The researcher's population comprised of caregivers for children diagnosed with acute leukemia and receiving treatment at the Steve Biko Academic Hospital. A caregiver could be the child's mother or grandmother.

3.1.4.2 Sample

According to Trochim (2006), sampling is the process of selecting units for examining people from a population of interest. Therefore, by studying the sample, results are generalized back to the population from which the study was conducted. For this study the sample contained ten participants.

3.1.4.3 Sampling method

Kumar (2005:165) states that sampling in qualitative research is flexible in the sense that the researcher can continue with the interviews until saturation point has been reached. Kumar (2005:165) defines 'saturation point' as the point when new information can no longer be obtained.

The researcher used availability sampling. According to Strydom (2005:202), availability sampling or accidental sampling entails any case that crosses the researcher's path and has anything to do with the phenomenon to be studied. Alston and Bowles (2003:88) further argue that availability samples are drawn from a convenient group and the sample reflects the problem being investigated. Saunders *et al.* (2000:176) add that convenience/availability sampling involves selecting those cases that are easiest to obtain from the sample. Availability sampling was suitable for this study as the caregivers were available in the ward, seeing that they had brought the children to the hospital and some had been admitted as lodgers there. According to Alston and Bowles (2003:88), the number of participants is determined by their access and availability. The researcher selected ten participants to form the sample.

CHAPTER 4
EMPIRICAL FINDINGS

4.1 INTRODUCTION

The purpose of this chapter is to present the empirical findings of the study. Because the study is qualitative, the findings are presented in words and some of the participants' responses are presented verbatim, to emphasize their opinions.

4.2 RESEARCH FINDINGS

The researcher maintains that it is important to understand the profile of the participants before the research findings can be discussed. This will guide the reader in appreciating the full impact of the participants' experiences. It is essential to bear in mind that the participants spend a long time in the hospital as lodger-mothers or bringing the child to the hospital for follow-up treatment. According to the researcher's observation, a lodger-mother is someone who is admitted to the hospital, not for medical reasons, but in order to stay with the patient and assist with the caring activities (in this case to assist the child).

As the names of the participants have been withheld, the researcher will refer to them by numbers 1, 2, 3 and onwards.

4.2.1 Profile of the participants

The profiles of the participants are discussed briefly as follows:

- **Participant one**

This participant was caring for a two year-old child, who was a patient at the time of this study. The participant also has two other children aged four and eleven. Her relationship with the father of the patient has been terminated. They reside in the Free State Province. The participant had been admitted as a lodger-mother and had been in the hospital for a month. At the time of the interview she was going home and was expected to return to the hospital again within a week, as her child was receiving chemotherapy treatment. This participant had been employed but had left her job to take care of her child. All her children receive child support grants.

- **Participant two**

This participant has an eight (8) year-old son, who had been diagnosed with ALL for the first time in 2008. He relapsed and had been re-diagnosed in September 2010. At the time of the interview, the mother had been in the hospital for two months. She stays in Tembisa situated in Gauteng Province, with her only son, the patient. The participant has a small family, as both her parents are deceased and her brother lives in Hammanskraal. This participant is not married and tries to generate income by selling vegetables and ice cubes from home. She receives a child support grant for the patient.

- **Participant three**

This participant has a seven year-old child who is a patient at the hospital. She also has a fourteen year-old son. She is a single parent who lives with her children, sister and mother in Mpumalanga Province. At the time of the interview the participant had been a lodger-mother for almost one (1) year. Previously she was a lodger at another hospital, from November 2009, but the ward was moved to the Steve Biko Academic Hospital in January 2010, when the patient was transferred. The participant is a recipient of child support grants for both her children, as she is unemployed.

- **Participant four**

The participant has a four year-old child who has leukemia. She also has a 12 year-old daughter. The participant is separated from the patient's father and she stays in Mpumalanga Province with her children and her two sisters. At the time of the interview, the participant had been staying in the hospital for seven (7) months. Prior to the child's hospitalization, the participant was employed, but now receives child support grants for her two children.

- **Participant five**

The participant's child, who is the patient, is two years old. The participant has two other children aged 11 and 20. She stays in Tembisa with her 11 year-old child. The participant's 20 year-old daughter lives in Rustenburg with her aunt. At the time of the interview, this participant had been in the hospital with her child for four (4) months. The participant is a single parent, as the father of her children is deceased. She is unemployed and receives child support grants for her two young children.

- **Participant six**

The participant and her five (5) year-old child had been in the hospital for three (3) months at the time the interview was conducted. The participant is a single mother of two other children aged three (3) and seven (7). The three year-old stays with the participant's sister and aunt while the seven year-old stays with her paternal grandmother during the participant's absence. The family is from Mpumalanga Province. The participant had been employed, but resigned in June 2010 to take care of the patient. She receives child support grants for all three children.

- **Participant seven**

At the time of the interview, the participant had been in the hospital as a lodger-mother for a period of two (2) months with her two (2) year-old child. The participant has another child aged 12. She is from Kimberly, where her mother takes care of the 12 year-old child. The participant is unemployed and receives child support grants for her two children.

- **Participant eight**

This participant first came to the hospital in January 2010 and remained in the hospital with her child for three months. She and her seven (7) year-old child were discharged from the hospital and she continues to bring the child for follow-up treatment fortnightly. At the time of the interview the participant had been bringing the child to the Steve Biko Academic Hospital for six months, that is, since April 2010. The participant has two (2) other children aged seven (7) and 23. She stays in Bronkhortspruit with her children and husband. The participant is unemployed and receives a child support grant for her seven (7) year-old child.

- **Participant nine**

This participant stays in Olievenhoutbosch-Gauteng Province with her partner and her four (4) year-old child, who is the patient. At the time of the interview the participant and her child had been in and out of hospital for a year. This is mainly because of the treatment the child was receiving. At the time of the interview the participant was unemployed, although she said she could obtain a job but could not sustain it. Her child receives a child support grant as the biological father of her child is not supportive.

- **Participant ten**

This participant has a five (5) year-old son who is the patient, and an eight (8) year-old son. They stay in Witbank, in Mpumalanga Province with four other family members. The patient was first diagnosed in 2007, was on chemotherapy and then relapsed in 2010. At the time of the interview the mother had been in the hospital for two months. She was employed before the child's illness but had to abandon her job to take care of her child. This participant receives child support grants for her two children.

4.2.2 Discussion of the research findings

The themes were designed to answer the research question: 'What are the experiences of caregivers caring for children diagnosed with acute leukemia?" The responses given in Sepedi and isiZulu have been translated, to facilitate understanding. It is important for the reader to note that some of the participants and patients who were previously in another hospital in Pretoria during 2009 had been transferred to the Steve Biko Academic Hospital owing to the relocation of the paediatric ward. The themes which emerged during the interviews are as follows:

- **Reasons for bringing the child to Steve Biko Academic Hospital**

All the participants said that their child seemed tired all the time. They had all taken their child to the local hospital before being transferred to the Steve Biko Hospital. Some of the responses given by the participants are as follows:

"*I took my son to hospital several times, I was surprised to see my son swelling and getting worse."*

"*Ke ile sepetleng sa gae gantši mafelelong sepetlele se ntlišitše mo Steve Biko ka ge ngwana waka a be a sa hlole a kgona go sepela (I went to my local hospital numerous times before being transferred to the Steve Biko Hospital because my son couldn't walk any more)".*

"Mangimuletha la esibhedlela babecabanga ukuthi ubehlukunyezwa, ubaba wakhe wangisola ngokumhlukumeza. Ngiqede amaviki ngiphuma ngingena esibhedlela kusukela ngonyaka wa 2009, ngaphambi kokuthi si ze la. (When I took her to the hospital they thought she was being abused, her father accused me of abusing her. I have spent weeks in and out of another hospital since October 2009, before we came here)."

"Ngwana o be a phela a lwala, ke mo kitimiša le dipetlele ba tšea dix-ray eupša ba sa bone gore bothata ke eng. (My child was always sick and I took him to hospital where x-rays were taken, but it was not clear what he was suffering from)."

"He used to vomit a lot and stopped walking, so I decided to take him to the hospital."

"O be a lla ka hlogo ebile mmele wa gagwe wa thoma go kokomoga. (He was complaining about having a headache and his body started swelling)."

All the participants said their child stopped walking and was crying more frequently. This correlates with the symptoms of acute leukemia as identified by Kruger (2010: 320) being fatigue, weight-loss, joint and bone pain, which are some of the symptoms of acute leukemia.

Six (6) of the participants do not reside in the Pretoria area, but come from areas outside the Gauteng Province. Two (2) participants come from Tembisa in Johannesburg, and only two (2) participants live in Pretoria. This is because many of the local and provincial public hospitals are not sufficiently equipped to attend to oncology patients, leading to long-distance traveling for the patients and their caregivers

to obtain appropriate medical treatment. For instance, the PET CT scanner, which is used for detecting cancer, planning treatment and examining the effects of cancer therapy, was only the second to be placed in a South African public hospital (Steve Biko Academic Hospital), the other being at Nkosi Albert Luthuli in KwaZulu-Natal (Ndaba, 2008). The PET CT scanner, which is one of the most powerful tools in diagnostic imaging, is said to be the first of three in Gauteng public hospitals, which will benefit people from neighbouring provinces (Hlongwa, 2008).

From the above information it is clear that the participants had to take their children to the hospital several times before the correct diagnosis could be made. This was bound to evoke anxiety on the part of the participants, as they did not know what was wrong with their children. Having to travel to a distant hospital could also have added to the existing anxiety.

- **Participants' reaction to the diagnosis**

The following responses indicate how the participants reacted after they were informed that their child had acute leukemia.

"Ke kwele bohloko ge ba mpolella gore cancer e boile gape, e thomile ka 2007 ya boa gape ka 2008 bjale ba mpolella gore e boile gape. (I was extremely upset when they informed me that the cancer cells had re-surfaced as he was first diagnosed in 2007, he was in remission until 2008 and now in 2010 it has re-emerged)."

"*Ke kwele bohloko ge doctor a mpotša , ke llile matšatši a mantši le ge ebe ke sa tsebe gore kankere ke eng (I was very upset when the doctor told me, I cried for days, even though I didn't know what leukemia was)".*

"E be ke tšhugile kudu kudu mara manese ba ile ba nkgothatša. Ba mpoditše gore ba tlo dira dinyakišišo tše dingwe gape. (I was extremely scared but the nurses re-assured me. They informed me that more tests would be conducted)".

"I was devastated, I still am." (This participant was sobbing uncontrollably during the interview).

This participant had been in the hospital for a period of two months at the time the interview was conducted. The researcher reassured her by briefly informing her about what the diagnosis meant. The participant was told to speak to the nursing sister in the ward for some clarity.

"E be ke sa kwešiši ka bolwetši bya ngwana (I did not understand my child's diagnosis)."

When the researcher probed her reasons for not asking the staff for an explanation, the participant responded by saying:

"Ke tšhabile go botšiša ka gobane ga ke nyake go tshwenyega kudu (I was scared of asking for fear of worrying too much)."

"Nako ye nngwe ke fela ke nagana gore dingaka di tšhaba go mpotša gore ngwana o lwala bjang. (I sometimes think the doctors are not telling me the truth about my child's prognosis)."

"Ngezwa ubuhlungu kakhulu mabengitshela ukuthi unesifo somdlavuza ngonyaka ka-2008, manje ngitshelwe ukuthi i-ALL ibuyile futhi, manje ngiyasaba. (I was very upset when I was informed about his cancer in 2008, now they've told me the ALL has returned and I am scared)."

"Ngangesaba ngoba angazi nokuthi yini umdlavuza, kuze kube manje angikazi kahle ukuthi umntwana wami uzolunga noma cha (I was scared because I did not even know what cancer was, and even now I am not certain whether my child will get well or not)."

"When they told me that he had leukemia I was confused, mostly because I didn't know what they were talking about."

All the participants reacted in the same way when they were first informed about their child's diagnosis. The participants explained that the first emotions they experienced was hurt and shock. This was possibly because they all had to wait for several days while tests were performed on the child to determine the actual diagnosis. For other participants, the anxiety emerged when they were informed that their child was no longer in remission and the cancer had returned. Sternberg (2001:411) describes fear as an emotion characterized by being afraid of harm focused on a particular experience. All the participants said they were shocked when the doctor broke the news. The other common reaction was crying. It seemed that all the participants, when informed about the diagnosis for their child, also experienced feelings of shock or disbelief. This may have stemmed from the lack of information that they had at that time. According to Chapman (2006), people find it difficult to accept facts, information or reality when they are in a state of shock or denial. This may explain why the participants, when informed about the diagnosis, did not comprehend the information (this aspect will be discussed in detail at a later stage). Sternberg (2001:593) says that the first phase, when people are facing psychological challenges, is shock. During this phase the person is stunned and often feels detached from the situation (Sternberg, 2001:593). The researcher is of the opinion that the participants felt shocked when they were informed that their child had leukemia, so they were not able to recall everything that the doctor said to them.

All the participants said the doctor had informed them about the diagnosis. However, it emerged during the interviews that some of them had not understood the actual meaning of the diagnosis, even after the doctor's explanation. Six (6) of the participants knew that their child had leukemia but confessed that they did not really know what the condition or the treatment meant.

- **Participants' perceptions of acute leukemia**

This section focuses on what and how the participants perceived and understood the term 'leukemia'. The participants' responses to the researcher's question "What do you understand by the concept leukemia?" follow:

" Bangitshelile ngayo kodwa angikayazi kahle hle ukuthi iyini (They told me about it but I am not really sure what it is)."

"Eish ga ke tsebe gabotse gore ke eng (I am not sure what it is)."

"I know it's cancer, but how you get it… I am not sure."

Three of the participants responded by saying:
"Ke kankere ya madi. (It is cancer of the blood)."

"I can't really explain what it is."

" Angazi. (I do not know)."

"*My son has leukemia and he is on chemotherapy".*
When the researcher asked this participant to elaborate on what chemotherapy is the participant responded by saying:
"*There is a drip on my child, they say it is chemotherapy. I don't even know what this chemotherapy is. What is chemotherapy? …but at least he is looking better… and he can play in the ward because he can now manage to walk."*

All the participants acknowledged that they had heard of the term *cancer.* Three (3) of the participants were able to say that leukemia was a cancer of the blood. Four (4) of the participants had sufficient knowledge about leukemia and the chemotherapy treatment their children had to endure. The participants who did not understand the diagnosis admitted that, when the diagnosis and treatment options were discussed with them, they were still in a state of shock. This correlates with Adams (in Holosko & Taylor, 1994:125) who states that most parents are in shock and absorb very little information during the first week or second week after diagnosis. It is therefore essential to clarify the reasons why most of the participants reacted the way they did. Davis

(1993:19) states that being told that a child has a chronic disease such as leukemia will have little meaning for most parents. Davis further points out that people face a state of uncertainty varying from ignorance to some limited knowledge. Hence, the majority of the participants were not able to fully explain what leukemia was about.

Given their limited knowledge about their child's condition, the researcher posed another question to determine how the participants thought their children felt about always being in hospital. The reason for posing this question was to further explore the explanation which the caregivers provide to their children when they ask them for the reason for hospitalization. This was in an effort to find out whether the participants discussed things with their children, as the researcher is of the opinion that being in and out of hospital may be confusing for a child. Here are some of their responses:

"*He always asks me when are we going home."*
When the researcher asked this participant whether her son knew why he was in hospital, she responded by saying:
*"He knows he is sick but doesn't know from what." (*This participant's child is seven (7) years old.)

"He doesn't know what is wrong with him, I also don't know why he is getting side effects, like now he just vomited." (The participant's child is five (5) years old.)

"Indodakazi yami iyazi ukuthi uyagula, kodwa usesemncane ukuthangazwisisa (My daughter knows that she is sick but she is too young to understand)."
This participant's child is 4 years old. The participant understood what the diagnosis entailed. She stated that:
"Umntwana uzolashelwa i-chemotherapy izinyanga eziyisithupha, sizoza kaningana la esibhedlela (The child is going to receive chemotherapy for six months, we will be at the hospital a lot)."

"*Ngwana ga a tsebe gore gobaneng a le mo sepetlele, yena o no nyaka go ya gae. (The child does not know the reason why he is in hospital, he just wants to go home).*"

"Ngamtshela ukuthi icancer ibuyule, wakhala, kodwa ubengazi ukuthi uzongena ephuma kambalwa esibhedlela (I told him the cancer had come back, he cried… but he did not know that he would be in and out of hospital several times)."

The researcher asked only the participants who have slightly older children about what they may be feeling about hospitalization. The participants thought that the children did not realize what was going on, as they were still young. Only half of the participants interviewed had children older than five (5) years of age. The Adherence Networking Group (2006:119) explains that younger children will not be able to understand fully what the illness and its implications are and they may feel confused and afraid. It is evident that most of the participants did not fully understand their child's diagnosis, so were unable to explain it to the patients. The children would most definitely have been confused about their frequent hospitalization.

- **Future prospects of the child**

The participants felt uncertain about their child's future. This in turn added to the stress of caring for the child. Some of the participants who confirmed this said:

"*Ke tshwenyegile ka bophelo bja ngwanake ko crecheng ka gobane dijo tša gagwe di šwanetše go fetoga. (I am concerned about my child's future at the crèche as his diet will have to change).*"

"I am scared that my child can get infections when she is not at the hospital, I am even scared to take her to crèche".

"Ngwanake ga se a kene crèche, o thomile go kula a ne le mengwaga e mebedi… bjale ba re cancer e boile gape o tlo fiwa chemo ya dikgwedi tse selela gape (My child has

never attended crèche as he started getting sick when he was two years old… now they said the cancer has returned, and he has to receive chemotherapy for another six months).”

(This participant feels uncertain about her child’s future, as the cancer cells keep returning. As a result, the child has never been to the crèche with other children and now he has to spend more time in and out of hospital.)

“Ngikuthola kunzima ukumelana nendaba yalo mntwana, futhi kwesinye isikhathi ngiye ngizibuze ukuthi uzoshona noma uzophila na (I find it really difficult to deal with my child’s relapse and I sometimes ask myself whether he is going to die or survive).”

“We will just wait and see what will become of my child, but I believe he is getting better.”

“Ke tla no rapela gore a fole ka gore nako yengwe wa kaonafala (I will pray for her cure as sometimes it seems she is getting better).”

“Indodakazi yami ibangcono futhi nodokotela uthi sesizophuma maduzane la esibhedlela, bese uyoqhubeka nge chemotherapy yakhe izinyanga eziyisithupha njenge sigulane sangaphandle (My daughter is getting better and the doctor informed us that we will be discharged from the hospital soon and she will proceed with chemotherapy for the next six months as an outpatient).”

The participants were pleased with the support they received from the nursing personnel. It became apparent to the researcher that the participants required much more assistance on a therapeutic level. This could be provided by the social worker, who was able to alleviate the participants’ sadness and the stressors. It seemed to the researcher that the participants felt uncertain about the future of their children because they did not know what to expect and were placing all their trust in the doctor for a good prognosis.

The WHO (2008:82) states that family members are confronted with a number of distressing emotions and experiences. These include fear of death and uncertainty about the nature and prognosis of the disease (WHO, 2008:82; Barnes, 1998:83). This reflects what the participants in this study reported.

- **The participants' level of acceptance regarding the diagnosis**

Another aspect which emerged from the interviews was the level at which the participants had accepted their child's leukemia diagnosis. The following responses illustrate the different levels of acceptance of the diagnosis by the participants:

"*Ke amogetše gore ngwanaka o a lwala le gona o tla fola, gape ka nako yela ya mathomo e be ke ke neetše, ke no ke potša gore dingaka di tla mo thuša (I have accepted that my child is sick and he will be cured. When I first found out about the diagnosis I was scared and reassured myself that the doctors would help him).*"

"I am happy because my child is getting better, now he can walk."

"Sengamukele ukuthi uyagula, ekucaleni ngangikhathazekile kodwa manje sengehlise umoya njengoba udokotela engicele ukuthi ngimlethe azothola ukulatshwa. (I have accepted that he is sick. At first I was worried, but now I am feeling more at ease as the doctor requested me to bring him for chemotherapy treatment)."

"Ke amogetše gore o na le leukemia mara ga go bonolo ka gobane ka morago ga sebakanyana o boa a kula gape.(I have accepted that he has leukemia but it is not easy because after a while he starts getting sick again)."

"I have accepted. What can I do?"

"Ngisamukele isimo sakhe njengoba esetshelwa okwesibili (I have made peace with his condition, as this is his second diagnosis)."

Some of the participants said that they had accepted their child's condition. The participants said this was because they could see evidence that their child was improving medically because s/he was receiving the appropriate treatment following the correct diagnosis. This was not the case for one participant who had recently been informed about her child's diagnosis. She was afraid that the child would have to continue treatment over a long period.

This seemed to indicate that some of the participants had adjusted to their situation, as they had been undergoing this process for weeks or months, taking the child home for several days and then returning to the hospital. When people accept their condition, they make whatever adjustments are necessary to live with the reality of the disease (Shotz in Sternberg, 2001:593). This explains why the participants seemed to have made peace with the fact that their children had cancer. The researcher is of the opinion that the participants had accepted their children's diagnosis because they had been in and out of hospital for months. As a result, the participants had acknowledged the diagnosis, but felt helpless about what they could do to improve the child's illness. The researcher also attributes the participants' acceptance of the diagnosis to the fact that they did not fully understand what the disease entailed, so they could more easily adjust and accept the situation.

The researcher could argue that the participants' understanding may be attributable to the nature of their profiles, as indicated earlier on. For instance, the participants had a low socio-economic status, and depended on social welfare grants. Their school qualifications were below the tertiary level. The researcher is of the opinion that there may be a link between the two aspects, the socio-economic status and their level of understanding of the diagnosis. However, this remains to be explored in further studies.

From the above theme and sub-themes the researcher can deduce that the initial reaction of the participants is disbelief and they look to the medical team for re-assurance. Although the participants had been living in the hospital with their children

for several weeks or months, it seems this arrangement still did not provide answers to their question about what leukemia entails. This is in terms of the diagnosis, symptoms, treatment and further management. This calls for social work intervention, where the social worker plays the role of educator and advocate to ensure that the caregivers understand what they are dealing with. For instance, "social workers can serve as context interpreters by providing an explanation of the disease from the medical perspective to the patient (in this instance the caregiver) and interpreting the patient's/caregiver's perspective of the disease to other interdisciplinary team" (Gregg, 2009:112). Gregg (2009:112) states that reaching consensus on understanding the disease contributes to effective treatment, as social workers become the voice of individuals.

- **The participants' experiences as lodger-mothers caring for a child diagnosed with acute leukemia.**

  - **Daily activities**

All the participants have to be in the ward with their children at 7h00 every day. They bath and feed their children, and remain in the ward with them until 22h00.

The researcher asked the participants how they experienced the schedule of being in the ward for the whole day. None of the participants seemed to have any problems with the schedule. At 7h00 they had to be in the ward to bath and feed their child before ward rounds. From there they remained in the ward with the child to feed him/her during meal times, to provide the doctor/nurse with any other information they may require and to sit with the child. The participants said that they were content to be part of the child's recovery and were able to see the child's improvement.

The researcher is of the opinion that the participants would do anything for their child. However, she also thinks that the participants were not getting any mental stimulation by sitting in the ward for the entire day, which could affect their mental health status.

- **Support system/s**

The support systems which emerged were the families and the medical personnel. The following responses illustrate the participants' experiences of family support:

"*No-one has come to visit me and my son. But I console myself because my sister and aunt are looking after my children".* This participant had been lodging at the hospital for four (4) months.

"*My family doesn't visit us, but I have been here for three (3) months and I go home bi-weekly".*
"My child's father came to visit once".

"Ga gona motho o a tlang go re bona mo sepetlele, Kgale re le mo sepetlele ka November 2009, ga ba re founele gomme le nna ga ke na tšhelete ya go ya gae (No one has been to visit us since November 2009. They don't even phone. I cannot afford to go home as I have no money)."

"Usisi wami wayesazi ukuthi ngiletha ingane izothola usizo nemithi, kodwa akazange abuze ngesimo se ngane. (My sister knows that I bring the child for treatment, but she does not ask about the child's progress)."

"His father can't come to the hospital but he phones to check on us."

"Ko gae ba fela ba lekola gore re tsogile bjang. (My family sometimes phones to find out how we are doing)."

As stated by the South African Government Services (2009), "families are faced with challenges and need support to function optimally, thus risk factors within the family situation can leave families vulnerable and unable to fulfill their roles and responsibilities

towards family members". Seven (7) of the participants reported that they had not been visited by their family members while in hospital.

The participants who received no visits from family members said there were financial problems at home, so they did not expect the family to come to the hospital. This is understandable, given that most of the participants were living far from Pretoria. Traveling can be too expensive, specifically for families living below the poverty line. The Adherence Networking Group (2006: 119) stated that the extent of the burden for children would be heavily dependent on how much support there is from the extended family. The researcher is of the opinion that the participants had been in the hospital as lodger-mothers for such a long time that they had accepted the lack of physical support from friends and family. The majority of the participants had more than one (1) minor child who had been left in the care of their extended families during their absence. The seven (7) participants who had not received visitors said that they yearned for the physical presence of the family. The researcher maintains that receiving emotional support from the family members may contribute to the participants' ability to cope better during this difficult period. The family should therefore be included in the treatment plan for the patient as a way of preparing them for when the patient is continually being admitted and discharged from the hospital. Instead of excluding the family, the social worker ought to ensure that provision is made for them to meet with the nurses and doctors to ask questions and to receive information about the patient's medical progress (Sulman & Verhaeghe, 1994: 53). The researcher infers from the above that psychological and social problems are associated with leukemia as a childhood cancer and that the participants require general emotional support. All the participants said that the medical team was courteous and made their stay at the hospital bearable.

- **Financial implications**

Another consideration that emerged during the interviews was the financial strain experienced by the participants on account of the child's illness. These are the participants' experiences of caring for a sick child:

"*When we go home I sometimes manage to get a job but I can't take the job because after one or two weeks I have to bring the child for chemotherapy. There is no-one to look after her."*

"Ngangi sebenza kodwa manje sekudingeka ukuthi ngimnakekele. (I used to work but now I have to take care of her)."

"Ke na le business e nnyane ko hae jwale ha kea sebetsa koo kgwedi kaofela (I have a small business at home now, I have lost one month of business)."

"Ke be ke šoma ka emiša ka June go hlokomela ngwana (I had a job and stopped in June to take care of my child)."

"Ga ke šome gomme ka dinako dingwe ke hlatswetša batho diaparo gore ba mphe tšheletenyana (I am not working but I sometimes do laundry for people to earn some money)."

"Ngidayisa ama-vegies no-ayisi ekhaya kodwa manje angenzi mali njengoba ngilana. (I sell vegetables and ice cubes at home but now I am not generating any income because I am here)."

"Bengingasebenzi okwesikhashana, nginomndeni wami nama social grants okuyiyona angisiza ukuthola imadlana. (I've been unemployed for a while. I have my family and the social grant as a means of income)."

"E be ke bereka ka emisa ka ge ngwana a kula. (I had a job but I lost it when my child started getting sick)."

As indicated in the participants' statements, it is evident that the majority of the participants had to leave their jobs, which means that when the child was discharged from the hospital there was no additional income per household. Among all the participants, only one (1) is married, and the other nine (9) are single parents. Two (2) of the participants said they had supportive partners.

One (1) participant mentioned that she was uncertain about her employment prospects as she was away from work for one (1) month. Six (6) participants said they had been employed prior to their child's illness. As a result, they had to leave their jobs. Three (3) of the participants had been unemployed prior to lodging at the hospital. Moreover, nine (9) participants had more than one child and they received child support grants for the children below age 14. A child support grant is a form of social relief paid out monthly from the South African Social Services Agency to children whose parents or primary caregivers are unable to support them financially (Blacksash, 2010). At the time the interviews were conducted, the grant was R250 per month. All ten participants were receiving child support grants.

Based on the above information, the researcher can deduce that there are negative financial implications for the caregivers. This in turn contributes to the caregivers' /participants' inability to return home regularly, as the transport cost is high. Owing to the low socio-economic status of the participants, the family members were unable to visit the participant and her child at the hospital. The participants who had to resign from their jobs will now be faced with the challenge of finding employment in a country where there is a significantly high unemployment rate. This means that the participants will have to work harder to obtain a job. CIA World Factbook (2010) reports that 24% of the labour force is without jobs as of February 19, 2010. In a survey released in the first

quarter of 2010, 4.3 million South Africans were unemployed, so the prospect of these participants securing any employment was very limited.

The other major issue relating to the financial implications was that even when the child was discharged from the hospital s/he had to come back for follow-up treatment as an out-patient. This meant that each participant would have to return to the hospital a number of times. Some of the participants would have to make use of public transport to get to the hospital and other participants would use the planned patient transport from their local hospitals. The researcher can therefore deduce that even if the participants were to find another job they would be absent from work frequently, which might jeopardize their successful period of employment.

- **Family implications**

All the participants had to be away from their families in order to be at the hospital with the sick child. Nine (9) participants also indicated that they had to take their other children to live with extended families. This, in turn, places a huge burden on the relatives who take the children into their care. When children are hurt, ill or disabled, they need physical and personal attention and this has consequences for all members of the family (Davis, 1993:11). It explains why the participants had no problem with the relatives not visiting them at the hospital. Some of the participants' responses relating to the help they received from their extended families are cited here:

"My one child is with her aunt and the other child is with my grandmother in Rustenburg".

"My sister is taking care of my son".

"Bana baka ba babedi ba šetše le koko wa bona. (My two children are with their grandmother)."

“Mošemanyana waka o šetše le bomma. (I left my son in my mother’s care”.)

“*Ga go bonolo ka gore ngwanaka o na le mme waka, o nagana gore ga ke mo rate. (It’s not easy because my other child is staying with his grandmother, now he thinks I don’t love him).”*

“I go home whenever I can and my 14 year-old son is at home with my family.”

“O mongwe o šetše le bomma- tatagwe, o mo nnyane o ile ko sesi le rakgadi. (The other child is currently staying with his paternal grandmother and the young child went to stay with my sister and aunt).”

These statements are consistent with literature, as family disintegration may occur due to the illness of one of the family member. Barnes (1998:174) states that therapists have to move beyond the systemic concept to acknowledge that traumatic events can impact on all individuals within the family. What needs to be done when therapists go beyond this acknowledgement is to include the entire family system from the first day the patient is admitted to the hospital. This inclusion can focus on the process the patient will undergo and what the diagnosis means. Goldenberg and Goldenberg (1996: 73) argue that therapists who adopt the systems theory view a symptom developing in one person as meaning that the system such as the family, community or society, has become dysfunctional. Davis (1993:11) emphasizes that problems vary according to the nature, frequency, severity of symptoms and the demands of the necessary treatment. Davis (1993:11) further states that diseases cause stresses such as physical and psychological adaptations and make particular demands upon the resources of the child and family. Adams (in Holosko & Taylor, 1994:127) adds that when children have cancer, siblings are affected by everything that transpires. The author also points out that, at diagnosis, siblings may be sent to stay with relatives or friends and they are often excluded from discussions about the illness, so they often do not understand what is happening.

The findings of this study are consistent with the above statements by Davis and Adams because they indicate that siblings are divided amongst relatives, but the latter cannot always afford to take care of more than one sibling owing to financial constraints. As indicated earlier, one sibling can be taken to an aunt and the other sibling to a grandmother or sister. This accentuates the statement that there will be some form of change within the family as the caregivers are absent from the family environment. The researcher is therefore of the opinion that there may be role changes in the family, as someone else has to assume the responsibility of the mother/caregiver. Barnes (1998: 83) states that role changes occur after the diagnosis of cancer, as parents often focus on the cancer patient and the siblings may begin to assume the role of the emotional caretaker.

In contrast to the positive family implications mentioned above, there seem to be some negative aspects. To emphasize this point, when the researcher inquired about the participants' support structure, half of them gave optimistic responses as they experienced a supportive family, but the other half had had negative experiences, which were expressed as follows:

"*My sister doesn't want to help me with my child, she thinks her illness is due to witchcraft… only if someone could explain to them what is really wrong with my child".*

"My family doesn't come to visit me, they don't even call. Since the child and I were admitted no one has come. I can't afford to go home anytime as I don't have money."

"Yimina omuletha la esibhedlela ukuzothatha amaphilisi ne mithi, kusukela ngenyanga ka- March (I am the one who has brought him to the hospital for treatment, since March."

This participant is married and she alone had been bringing her son for chemotherapy treatment for almost six months at the time of the interview in September 2010. Her husband had never helped with bringing the child for treatment. This participant was

unemployed and used several taxis every time she had to bring the child for chemotherapy.

“ Kua gae gaba kgone gotla go nketela, mara sesi waka wa nfounela ge a kgona. (My family cannot come to visit but my sister phones whenever she can afford to).”
When the researcher asked this participant how she felt about the fact that her family could not come to see her and her child, she responded by saying:
“Ke a kwešiša ka gore ba hlokometše bana baka. (I understand because they are looking after my children).”

“Ubaba wakhe wangempela ungisola ngokuthi angimunakekeli lomntwana, kodwa ubaba lo esihlala naye uyazwisisa futhi uwusizo kakhulu ngokuthi ngize la esibhedlela (Her biological father accuses me of neglecting her, but her step-father is supportive and understands that I have to continually come to hospital).”

The researcher observed that the participants’ concerns related mostly to the family, which seemed to be causing them stress. Although the participants were grateful that their family was taking care of their other children they still yearned for the family to visit, as some felt alone during this difficult period. Powell and Johnston (2007:114) say that children and their parents have to cope with a variety of stressors, such as changes in family interactions, physical discomfort and anxiety caused by strange surroundings and separations from family and friends. The participants said that if only they could get emotional support from the family, they would feel better. The researcher maintains that the participants needed their family to visit them because being with someone that they emotionally related to may have made them feel that they were not so alone. The hospital setting is much different from a home environment.

- **The participants' experience of the role of the social worker**

The researcher asked the participants how they experienced their interaction with the social worker. They gave the following responses:

"Social worker o tlike mara ga a mpotšiša dipotšišo tše wena o mputšišang. (The social worker came but she did not ask me the questions that you are asking)."

When the researcher asked this participant what questions had been asked, she said:
"O no mpotšiša gore ke dula kae, ke na le bana ba bakae… fela. (She asked me where I stay and how many children I have and that's it)."

"I saw the social worker talking to others."

"Social worker wa tla mo mara ga mpotšiša gore ke ikutlwa bjang, o no mpotšiša gore re dula kae le bomang. (The social worker comes to the ward. She didn't ask me how I feel, just where we stay, family composition, and those kinds of questions)."

"Angizange ngithole icounseling. (I did not receive counseling)."

"Social worker o tla go bona fela ge o mo kgopetše. (The social worker will attend to you if you ask to see her)."

"Ngilana esibhedlele, inyanga ezimbili, kodwa angikatholi isikhathi soku khuluma nama social worker. (I have been in and out of the hospital for two months but I have not had the opportunity to talk to the social worker)."

The researcher told this participant to ask to see a social worker if she felt she needed counseling. The social worker was contacted to this effect and she said she would attend to the case.

One participant told the researcher that she had received counseling. She said:
"Social worker o fela a tla a nkgothatsa, go bolela le yena go dira gore ke be bonolo. (The social worker comes to talk and encourage me. Speaking to her makes me feel much better)."
This is the participant whose child who was first diagnosed in 2007 and has now relapsed. This participant reported that discussing her concerns with the social worker made her feel more at ease, so she was benefiting from counseling.

Some of the participants stated that they had only been in contact with the social worker once since their admission to the ward. However, it seems that the participants did not receive any form of counseling. "The primary social work focus is on helping children and families adapt to illness and treatment, increasing their ability to cope, facilitating their learning and personal growth as part of coping and helping them communicate with the health care team" (Adams, 1994: 129). Dimond and Jansen-Santos (1994:509) maintain that one of the major components of the social worker's work in health care is to provide post-hospital planning for patients and families.

One of the most important social work roles is that of educator. In this study it was very clear that the social worker should provide education for the participants, as they needed such a service. This contributed to the fact that the majority of them lacked sufficient knowledge about acute leukemia. Counseling services should include helping children and families by providing information or referral to community resources (Adams, 1994:130). To expand on the importance of education, Campbell, Jackson and Jeglic (1994: 473) maintain that "education of clients, families and other health professionals in order to increase social support of rehabilitation of clients is a major aspect of social work". It seems that the above obligations of the social worker were not fully implemented at the hospital.

The researcher is of the opinion that the participants could benefit from counseling sessions, as this could alleviate their anxiety. In the researcher's opinion, if the

participants were given an opportunity to talk about their feelings, they might also be able to better understand acute leukemia in relation to its diagnosis, treatment and management.

4.2.3 SUMMARY

This chapter addressed the findings of the empirical study. The researcher obtained these findings by using unstructured interviews. The focus was on the caregivers who brought their children to receive treatment at the Steve Biko Academic Hospital. Most of the participants had to remain in the hospital as lodger-mothers. The participants were thus selected according to their availability.

The factors identified included the support systems of the participants, financial implications, family implications and the role that the social worker played during intervention with the participants. These factors formed the themes of the findings, as they highlighted the experiences of the caregivers in-depth.

The findings revealed that some of the participants had unsatisfactory support systems, while others had good support. The support network includes the immediate family members and relatives. The researcher found that the participants were living far away from the hospital, which prevented the family from making regular visits to the hospital. The findings revealed that the participants clearly yearned for the support of their family. However, they said they understood why the family was unable to visit them. The majority of the participants had telephonic contact with their family instead.

Another important factor to consider is the financial implications of caring for a sick child. The majority of the participants had to leave their jobs to care for the ill child. The findings revealed that owing to the children's prolonged chemotherapy treatment the participants often had to often go to the hospital, this made it difficult for them to sustain a job because of regular absenteeism. The findings on this aspect also revealed that all the participants received a child care grant as part of social welfare relief. Owing to the

low socio-economic status of the participants caring for a child who had been diagnosed with leukemia it is evident that the disease had negative financial implications for the participants, as they sometimes had to spend weeks or months at the hospital.

The findings revealed that the participants' families did not understand the diagnosis. This could be explored in further research.

The study revealed that the participants had to leave their other children at home or with relatives, which disrupted the family as a system, because the focus fell mostly on the sick child.

The findings revealed that the role played by the social worker was minimal. During the interviews it emerged that only half of the participants understood what the diagnosis entailed. The researcher therefore maintains that the role of the social worker was not clearly defined to the participants, and as a result it seems that they do not know what the social worker in a paediatric oncology ward should be doing.

CHAPTER 5
SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter will present a summary of the entire research report. A brief discussion of the research methodology will be presented. Conclusions from the literature study and the research findings will also be addressed in this chapter. Lastly, the researcher has provided recommendations for improved social work service delivery and future research.

5.2. SUMMARY

5.2.1 CHAPTER 1

This chapter consists of the general orientation to the study with special reference to problem formulation, the goal and objectives, the research question and ethical aspects of the study. The goal and objectives of the study were formulated as follows:

- Goal: To explore the experiences of caregivers caring for children diagnosed with acute leukemia.

The abovementioned goal was achieved because the participants discussed in detail how they experienced having a child who had been diagnosed with acute leukemia. The participants were able to disclose their feelings and explain the impact that this condition had had on the self, the child and their families.

The objectives of the study that were indicated in Chapter 1 were achieved. They were presented as:

- To provide a broad literature overview on acute leukemia as a childhood condition.

The researcher was able to discuss in detail the condition of acute leukemia. This was achieved in Chapter 2.

- To explore the experiences of caregivers caring for the children diagnosed with acute leukemia.

This objective was accomplished in chapter 4, as all the caregivers willingly shared their story. The caregivers discussed in depth their feelings when they were first informed about the diagnosis and how caring for a child with this childhood condition had impacted on their lives and the lives of their significant others. As a result, the researcher was able to understand their world, through the experiences they shared.

- To draw conclusions and recommendations for improved social work intervention with regard to caregivers caring for children suffering from acute leukemia.

The above objective was accomplished in this chapter, as the researcher was able to identify areas where the social work profession could improve. The research question for the study is as follows:
What are the experiences of caregivers caring for children diagnosed with acute leukemia?

The research question was clearly answered, as indicated in the findings of the study.

5.2.2 CHAPTER 2

This chapter formed the theoretical overview of the topic under study. Acute leukemia as a childhood condition was discussed in detail. The researcher described the two types of acute leukemia, ALL and AML. This was in terms of the diagnosis, symptoms

and treatment of acute leukemia. Chapter 2 established the role of the social worker when s/he is dealing with the caregivers who are experiencing dealing with this challenging condition. The impact of acute leukemia was discussed with the focus on the patient and the caregiver. Overall, Chapter 2 served as a basis for understanding what acute leukemia entails. When one understands the diagnosis, it makes sense to comprehend the emotional and psychological aspects attributed to acute leukemia as a childhood condition.

5.2.3 CHAPTER 3

This chapter provides a detailed description of the research methodology that was used to conduct this study.

5.2.4 CHAPTER 4

This chapter focused on the findings of the research. The information provided by the participants is discussed and analyzed. The findings are also verified by literature.

5.2.5 CHAPTER 5

This chapter presents the conclusions of the study according to the themes and sub-themes identified.

5.3 The profile of the participants

The purpose of identifying the participants' profile was to attempt to realize the full impact of the participants' experiences.

5.3.1 Factors that influenced the participants to bring the child to the Steve Biko Academic Hospital

This theme discussed the reasons why the participants had decided to bring the child to the hospital. The purpose was to determine events which occurred to facilitate this process.

5.3.2 Aspects impacting on the participants' experience after being informed that the child had been diagnosed with acute leukemia

This section focused on the first reaction of the participants after the doctor informed them that their child had a childhood cancer, acute leukemia. The purpose was to understand what feelings occurred and how the news had changed their world.

5.3.3 Perception of acute leukemia

This theme was developed after the researcher transcribed the interviews and came to the realization that some of the participants did not understand the medical condition of their child.

5.3.4 The participants' experiences as lodger-mothers caring for a child diagnosed with acute leukemia

This section covered the broad experience of the participants. Sub-themes were identified to explore in depth how the impact of leukemia had influenced their lives.

- **Financial implications**

This category identified the tough responsibility with which the participants are faced. It also covered the consequences of being in the hospital for a long period of time.

- **Family implications**

This sub-theme exposed the results of the caregiver/participant staying in the hospital for a prolonged period, with specific reference to the family members who remained at home without physical contact with their primary caregiver.

5.3.5 The role of the social worker

This section covered the involvement of the social worker dealing with the participants.

5.4 CONCLUSIONS

An account of the conclusions based on the literature review and the empirical findings follows:

5.4.1 Literature review

- Acute leukemia is a condition that mainly affects children before the age of 18.
- There are two main types of acute leukemia, ALL and AML, with ALL being the most common in children.
- It is not yet clear what the real causes of the disease are.
- The symptoms of acute leukemia include fatigue, easy bruising, excessive bleeding and aches in the joints and bones.
- Early detection of acute leukemia is paramount as this leads to a good prognosis.
- It is imperative for the caregivers to seek medical assistance as soon as the child has been diagnosed with leukemia.
- There is no standard staging system for ALL and AML, as risk factors are used depending on the metastasis of the disease.

- Several tests such as the physical examination, imaging studies and laboratory tests are conducted before a diagnosis can be reached.
- Treatments such as chemotherapy and stem cell transplantation are essential for acute leukemia patients.
- Chemotherapy drugs are used to treat cancer by destroying cancer cells.
- The phases of chemotherapy include induction, consolidation and maintenance.
- Chemotherapy treatment may last for several months or years depending on the malignancy of the cancer in the body.
- The prolonged treatment for the child necessitates lengthy hospitalization. This may disrupt the family system financially and psychologically.

5.4.2 Empirical conclusions

- The majority of participants did not have a clear understanding regarding what leukemia entails.
- Subsequent to the participants being informed about their child's diagnosis, the majority of the participants still did not understand what acute leukemia entailed.
- There are negative financial implications for the caregivers and their families.
- The families of the caregivers were disrupted by their absence and their remaining minor children had to be taken to the extended family for care.
- The majority of the participants were found to be single parents and this affected the care of their other minor children.
- All the participants who were employed prior to being admitted to the hospital as lodger-mothers terminated their contracts, thus making them unemployed single parents.
- All the participants obtained child support grants for the patient and their other minor children.
- Half of the participants had poor support systems and the other half had good ones.

- The participants had to continue treatment for their children as out-patients. This meant that they would attend the hospital weekly or monthly. In turn, the participants' chances of getting and/or sustaining a job were limited.
- The participants' children were between ages of two (2) and seven (7). This means that their scholastic development was being delayed as they were not in a crèche or a pre-school.
- The children were struggling to understand why they had to be in hospital.
- The participants required thorough counseling.
- The family members of the participants should be involved in the entire process of managing the child and the caregiver.
- The role of the social worker working with the participants was not clearly explained to the participants.

5.5 RECOMMENDATIONS

The recommendations discussed below are based on the empirical findings, the social work profession and recommendation for further research study.

5.5.1 Recommendations from the empirical study

- The caregivers need a thorough explanation of their child's diagnosis. This includes the probable predisposing factors, treatment options and further management of the child's treatment. This might help address the caregivers' fears. Discussing the child's diagnosis with the caregiver should be done once the medical team can see that the caregiver is no longer in a state of shock. If it emerges that the caregiver is tearful or emotionally affected, a social worker should be called immediately to provide crisis intervention.

- The researcher recommends that social workers should provide continuous education for the caregivers/parents of the child. As the caregivers are so often at the hospital the social worker should provide continuous counseling.

- The researcher recommends that a fund or sponsor be identified by the hospital board to provide some form of financial relief for the caregivers. This entails purchasing toiletries and assisting with transport for the caregivers. The researcher identified that some of the participants had to use taxis to bring their child to the hospital, weekly or bi-weekly. The participants receive child support grants for their children and they are thus reliant on this form of social welfare relief of R250 in 2010, which is not even sufficient for the basic needs of the patients.

- It is further recommended that a system should be developed whereby a family member is helped to visit the hospital to provide emotional support to the mother and child. In this instance, the researcher proposes that the planned patient transport from various provinces be used to this effect. For instance, when the planned patient transport from Mpumalanga Province or Limpopo Province comes with patients, a family member should be permitted once or twice a month to use the transport system. The researcher established that the majority of the participants yearned for the physical presence of the family, who are not always in a position to afford the transport fees.

- The caregivers/mothers spend most of their time in the ward with their child. The researcher recommends that during their prolonged stay at the hospital, a support group be established for the lodger-mothers. This action will be a beneficial platform where they can share their experiences and talk about any issue they deem necessary. Support groups may be used for educational purposes where the caregivers would be provided with the necessary information pertaining to the diagnosis.

- The community resources should be used. It is therefore recommended that once the caregiver and her child have been discharged from the hospital, they

should be referred to the social worker in their community for continuous counseling or psychotherapy. The paediatric social worker in the hospital should liaise with other social workers to this effect.

5.5.2 Recommendations for the social work profession

- The majority of the participants had only been in contact with the social worker once. It is recommended that as soon as the diagnosis of the child's illness is known, the social worker should provide first phase intervention. The social worker could obtain the history of each lodger-mother during their early stay at the hospital.

- Thereafter, the social worker should establish a support group for the mothers who wish to be included. Support groups can provide both caregivers and children with support from others who face similar challenges.

- Thorough counseling should be provided for all the lodger-mothers, as this would clarify any concerns they may be experiencing.

- The family of each lodger-mother should be consulted to determine whether they require any form of support. Should the social worker identify a family in need, it is further recommended that the area/local social worker be informed to provide supportive services. Moreover, the family members, with the consent of the caregivers, should be called in to the hospital by the social worker, who would explain the child's condition to them. As it is, when the caregivers return home there is no form of support from the family. This may be due to their lack of information, which, when given, may be more effective coming from a professional such as a social worker.

- Once the lodger-mother and child have been discharged from the hospital, the social worker should ensure, by initiating further management that they do not get lost in the system, maybe due to financial problems, as all of the participants in this study were dependent on social security. This is important, as some of the children will have to continue treatment as outpatients for several months to a year. One of the important responsibilities of the health-care social worker is to compile a discharge plan. The social worker could examine issues that may arise when mothers and children leave the hospital, the personal strengths of the individual, their psychosocial needs, personal resources (for example, substitute caregiver, family support) and co-operation of community resources.

- In conclusion, the social workers should play an active role, where they would be visible and available every time they are needed.

5.5.3 Recommendations for future research

Based on the above information, the following recommendations for future research are made:

- The short- and long-term effects of caring for a child diagnosed with a childhood cancer could be explored further.
- The psychological and psycho-social impact on the family members who are faced with a child who has cancer and is undergoing chemotherapy could be explored.
- More research should be conducted comparing the primary caregivers who receive counseling after being informed about their child's diagnosis of leukemia (or any type of childhood cancer) and the primary caregivers who do not receive any form of counseling. The purpose would be to evaluate whether counseling services had any substance.
- Finally, the future requirements of the child should be considered in an attempt to identify precise services in the community in respect of the child.

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UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
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Faculty of Humanities
Research Ethics Committee

30 August 2010

Dear Prof Lombard

Project:	**The experiences of caregivers caring for children diagnosed with acute leukaemia**
Researcher:	**SM Mothiba**
Supervisor:	**Dr J Sekudu**
Department:	**Social Work and Criminology**
Reference no:	**23085411**

Thank you for your response to the Committee's letter of 12 August 2010.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study on 27 August 2010. 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 would 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. John Sharp
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

Faculty of Health Sciences Research Ethics Committee

24/06/2009

Number : **S111/2009**

Title : The experiences of caregivers caring for children diagnosed with acute Leukaemia

Investigator : M S Mothiba, Department of Social Work and Criminology, University of Pretoria (SUPERVISOR: DR J SEKUDU)

Sponsor : **None**

Study Degree: **MSW (Health Care)**

This Student Protocol has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 23/06/2009 and found to be acceptable.

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To
Miss M. S. Mothiba
Department of Social Work and Criminology
University of Pretoria

REQUEST TO CONTNUE RESEARCH STUDY AT STEVE BIKO ACADEMIC HOSPITAL

You request to continue and complete your research study in "The experiences of caregivers caring for children diagnosed with acute leukemia" that was commenced in Kalafong Paediatric Oncology Department, now relocated at Steve Biko Academic Hospital is approved.

Yours Sincerely,

Dr. H.. Tanna
Senior Superintendant
Pretoria Academic Hospital
Dated: 26/4/2012

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YUNIBESITHI YA PRETORIA
Faculty of Humanities
Department of Social Work & Criminology

INFORMED CONSENT FORM

Researcher's Name: Makopano Sara Mothiba

Address : P.O Box 296, Kempton Park, 1620

Name of institution :University of Pretoria

Title of study

The experiences of caregivers caring for children diagnosed with acute leukaemia.

Purpose of the study

To explore the experiences of caregivers caring for children diagnosed with acute leukaemia.

Procedures

The researcher will use an in-depth interview to collect data. I am aware that the audio tape will be used and I give consent to that, to ensure that all the information is captured.

Risks and Discomfort

Due to the nature of this study, specifically that I will be expected to talk about my experiences, it is possible that I could be emotionally affected. The researcher has promised to provide me with a debriefing session immediately after the data collection process has been completed. If I should be found to be in need of further counselling, the researcher has promised to refer me to the social worker at Steve Biko Academic Hospital.

Benefits

The findings of this study will assist in the improvement of the service delivery by professionals in this field, at SBAH and as a result I am confident that I will benefit.

University of Pretoria
Pretoria, 0002
South Africa

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Participant's Rights

I am willing to voluntarily participate in this study after I was informed about the purpose, advantages, disadvantages and risks involved. I have been informed that I may withdraw from the study at any time, should I find it unbearable to continue and this will not be used against me. I am aware of the fact that the data will be stored for 15 years for archiving purposes. Should the data be required for further research purposes, I will be contacted before utilization of the data, for my consent.

Confidentiality and anonymity

My identifying particulars are not going to be used in the research report and only the researcher and her supervisor will have access to the information that I will provide during the interview. Should I decide to withdraw from this study, the information that I would have already provided w ill be destroyed.

Person to contact

Makopano Sara Mothiba : 0727317814

Declaration

I, ..., understand my rights as a research participant, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being conducted.

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Date	Place	Participant's signature
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Date	Place	Researcher's signature
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Date		

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UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities
Department of Social Work & Criminology

TUMELELO YA BATLHOKOMEDI BA BANA

Leina la Monyakišiši : Makopano Sara Mothiba

Lefelo la madulo : P.O Box 296, Kempton Park, 1620

Leina la thutelabogolo : Yunibesithi Ya Pretoria

Hlogo ya nyakišišo :Maitemogelo a bahlokomedi ba bana bao ba tshwerego ke bolwetši ba kankere ya madi.

Lebaka la dinyakišišo

Go nyakišiša maitemogelo a batlhokomedi ba bana bao ba tshwerweng ke bolwetši ba kankere ya madi.

Ditshipidišo

Monyakišiši o tlo butšiša diputšišo tše mmalwa gore a kgone go kgobakantšha dinyakišišo. Nna bjalo ka motlhokomedi wa ngwana ke a tseba gore go tlo šomišwa setšeamantšu go tšea tšeo ke tla be ke di boletšego. Ke fa monyakišiši monyetla wa go šomiša setšeamantšu gore a kgone go boloka mantšu ka moka.

Dikgobalo le go se dudušege botse

Mo dinyakišišong tše, ke loketše go bolela ka maikutlo a ka le gore ke phela bjang le ngwana woo a tshwereng ke bolwetši ba kankere ya madi. Ke a tseba gore go ka direga gore ge ke bolela ka maikutlo, nka tswenyega moyeng. Monyakišiši o tshepiša go nkgothatša ka morago ga nyakišišo. Ge monyakišiši a ka bona gore ke sa nyaka kgothatšo o tlo nkiša go social worker wa sepetlele sa Steve Biko Academic Hospital.

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Monyetla

Dikarolo tša dinyakišišo tše di tlo thuša ge ke kgopela thušo mo bašoming ba sepetlele sa Steve Biko Academic Hospital, kudu kudu social worker. Ke tshepha gore ke monyetla o mogolo go tšea karolo.

Maikarabelo a batlhokomedi ba bana

Ke tshepiša go tšea karolo mo dinyakišišong tše. Lebaka ke gore ke boditšwe ka botlalo gore gobaneng ke swanetše go tšea karolo, le mathata ao a ka diregago le tše botse tšeo di ka tšwang. Ke boditšwe gore ge ke sa tlhwa ke nyaka go tšea karolo nka tlogela ka nako ye nngwe le ye nngwe. Ga go se sebe seo se tlo diregang ge nka tlogela. Ke a tseba gore dinyakišišo tše ditlo dula Yunibesithi Ya Pretoria mengwaga ye lesome-hlano pele di ka lahlwa. Ge go kaba le dinyakišišo tše dingwe gape tše di ka dirwa, ke lokelwa go tsebišwa gore ke fe tumelo yeo.

Khupamarama le boemo ba go se tsebege

Leina la ka le ka se šomišwe mo dinyakišišong tše. Ke a tseba gore ke monyakišiši le morutiši wa gagwe bao ba tlo tsebang ditaba tša ka.Ge nka hwetšwa go le boima go tšwela pele ke dumeletšwe go tlogela go tšea karolo, gomme nkase bonwe molato. Monyakišiši o tshepiša go se šumiše ditaba tšeo ke tla be ke mmoditše tšona.

Ge o na le diputšišo leletša Makopano Sara Mothiba mo 072 7317 814

Boipobolo

Nna.....ke kwešiša ditokelo tša ka bjalo ka motšea karolo mo dinyakišišong. Ke fa monyetla wa go tšea karolo. Ke a kwešiša gore dinyakišišo tše ke tša eng le lebaka leo.

Letšatši	Lefelo	Motšeakaralo

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