

***PREPARATION AND SUPPORT BY NURSES TO
CAREGIVERS OF CHILDREN DIAGNOSED
WITH CANCER IN THE NORTHWEST
REGIONS OF NAMIBIA***

BY

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Declaration

I declare that the “Preparation and Support by Nurses to Caregivers of Children Diagnosed with Cancer in Northwest Regions” is my own work and it has not been submitted for any degree or examination to any other university. Furthermore, all the sources that I have used, and quoted have been indicated and acknowledged by means of complete references.

I further declare that the content and/or the cover of this thesis may not be reproduced in any form without a written consent of the author or the University of Namibia.

Signed: Eva Ndahalako Amakali

Date: August 2006

Place: Windhoek

Dedication

I would like to dedicate this thesis and express special thanks to my husband Amram and my daughters Ndapandula, Namalwa and Iyaloo who have provided love and a supportive atmosphere during my period of study and also throughout my career.

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I wish to express my sincere gratitude to my parents Eila and Paulus Hangula who created an educational environment and promoted an interest in learning and made a great sacrifice for me to pursue my career in nursing.

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- The Regional Council, Ohangwena, Omusati, Oshana and Oshikoto Regions for granting me permission to do my research on the caregivers of children diagnosed with cancer in the four regions.
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Abstract

There have been several complaints that children diagnosed with cancer in the Northwest regions are discharged from the hospital while they are still sick, and that their caregivers are not taught how to take care of these children at home and told what to expect during the disease process. This has brought about a situation where caregivers are not returning their children for follow-up as scheduled and are, in some cases, taking their children to traditional healers. The prevailing situation regarding children with cancer, coupled with the absence of studies on caregivers of children diagnosed with cancer in the Northwest regions, provide support for the study.

The study which is descriptive in nature, aimed at describing and exploring the preparation and support which nurses provide to the caregivers of children diagnosed with cancer in Northwest Regions. The study used both a quantitative as well as a qualitative approach. The quantitative approach was used to obtain the biographic data of the participants while the qualitative approach was used to explore the preparation and support that nurses provide to the caregivers of children diagnosed with cancer.

The study population consisted of caregivers of children diagnosed with cancer in the Northwest regions, the nurses in Oshakati State Hospital units where the children diagnosed with cancer are admitted, and Windhoek Central Hospital Pediatric Oncology Department. Short questionnaires were developed to obtain the biographic data of the

participants prior to the interview and the focus group discussion. Guidelines for face to face interviews and focus group discussion were developed and used to help the researcher to be focus. Two focus group discussions and one interview were held with the nurses as well as thirteen face to face interviews with caregivers of the children diagnosed with cancer. The focus group discussions were held in the patients' dining room in the selected wards, as it was felt that this would create the minimum of disturbances. The interviews took place within the caregivers' homes.

The findings of the study reveal that caregivers in this study mostly live in the rural areas far from the health facilities. Even where the facilities exist they do not provide the specialised services for the children diagnosed with cancer. The findings of the study also showed that nurses undertook a number of care activities in relation to the care of the children diagnosed with cancer. It was also felt that nurses have insufficient levels of competence to prepare and support the caregivers of children diagnosed with cancer. They need training to enable them to prepare and effectively support caregivers of children diagnosed with cancer. The study concluded that there is a need for continuing education on cancer nursing topics so that nurses working with children diagnosed with cancer can contribute to the improvement in the quality of care delivered to these and their caregivers.

TABLE OF CONTENTS

| | PAGE |
|------------------|-------------|
| Declaration | i |
| Dedication | ii |
| Acknowledgements | iii |
| Abstract | v |

CHAPTER 1: INTRODUCTION AND BACKGROUND OF THE PROBLEM

| | | |
|-----|---------------------------|----|
| 1.1 | Introduction | 1 |
| 1.2 | Statement of the problem | 7 |
| 1.3 | The purpose of the study | 9 |
| 1.4 | Objectives of the study | 9 |
| 1.5 | Definition of terms | 10 |
| 1.6 | Paradigm of the study | 13 |
| 1.7 | Significance of the study | 16 |
| 1.8 | Summary | 17 |

CHAPTER 2: THE RESEARCH DESIGN AND METHODOLOGY

| | | |
|-----|----------------------------|----|
| 2.1 | Introduction | 18 |
| 2.2 | Research design and method | 18 |
| 2.3 | Hypothesis | 20 |
| 2.4 | The study population | 21 |

| | | |
|------|--|----|
| 2.5 | Sampling | 22 |
| 2.6 | Pre-testing instrument | 23 |
| 2.7 | Data collection | 24 |
| 2.8 | Strategies to ensure trustworthiness of the data | 31 |
| 2.9 | Data analysis | 33 |
| 2.10 | Ethical considerations | 35 |
| 2.11 | Summary | 36 |

CHAPTER 3: ANALYSIS OF DATA AND LITERATURE CONTROL

| | | |
|---------|---|----|
| 3.1 | Introduction | 37 |
| 3.2 | Quantitative analysis | 37 |
| 3.3 | Qualitative analysis | 52 |
| 3.3.1 | Theme 1: Experience of caregivers and nurses in the preparation of caring for the children diagnosed with cancer. | 53 |
| 3.3.1.1 | Different viewpoints on caregivers' preparation | 54 |
| 3.3.2 | Theme 2: Support by developing a helping, trusting and caring relationship between caregivers and nurses | 57 |
| 3.3.2.1 | Factors influencing a caring and trusting relationship | 60 |
| 3.3.3 | Theme 3: Problems experienced in applying a holistic approach to caring for the child diagnosed with cancer | 67 |
| 3.3.3.1 | Stumbling blocks in achieving holistic care | 68 |
| 3.3.3.2 | Lack of effective communication and information | 82 |

| | | |
|-----|---------|----|
| 3.4 | Summary | 86 |
|-----|---------|----|

CHAPTER 4 CONCEPTUAL FRAMEWORK

| | | |
|-----|---------------------------------|----|
| 4.1 | Introduction | 87 |
| 4.2 | Elements of the practice theory | 87 |
| 4.3 | Summary | 95 |

CHAPTER 5: CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

| | | |
|-----|--------------------------|-----|
| 5.1 | Introduction | 96 |
| 5.2 | Purpose | 96 |
| 5.3 | Conclusions | 97 |
| 5.4 | Recommendations | 98 |
| 5.5 | Limitations of the study | 105 |
| 5.5 | Summary | 107 |

| | | |
|-------------------|--|-----|
| REFERENCES | | 108 |
|-------------------|--|-----|

LIST OF TABLES

| | | |
|-----------|--|----|
| TABLE 1.1 | Data from Windhoek Paediatric Oncology Department 2003 | 2 |
| TABLE 3.1 | Gender of the respondents | 38 |
| TABLE 3.2 | Age of caregivers | 39 |
| TABLE 3.3 | Region where caregivers reside | 40 |

| | | |
|------------|---|----|
| TABLE 3.4 | Religion of the caregivers | 41 |
| TABLE 3.5 | Relationship of the caregivers to children diagnosed with cancer | 44 |
| TABLE 3.6 | Duration of cancer | 45 |
| TABLE 3.7 | Distances from health facilities in kilometres | 46 |
| TABLE 3.8 | Age of the nurses | 47 |
| TABLE 3.9 | Qualifications of the nurses | 48 |
| TALBE 3.10 | Duration in the cancer department / the ward where children diagnosed with cancer are admitted | 49 |

LIST OF FIGURES

| | | |
|------------|--|----|
| FIGURE 3.1 | Educational levels of caregivers | 42 |
| FIGURE 3.2 | Employment status of the caregivers | 43 |
| FIGURE 3.3 | Post basic courses that nurses undergo | 50 |

LIST OF ANNEXURES

| | | |
|-------------|---|-----|
| ANNEXURE A: | Guidelines for face to face interview for caregivers | 125 |
| ANNEXURE B: | Guidelines for focus group discussion for nurses | 129 |
| ANNEXURE C: | Caregivers interview sample | 133 |
| ANNEXURE D: | Nurses focus group discussion sample | 141 |
| ANNEXURE E: | Letter of permission from the Governor – Ohangwena Region | 156 |
| ANNEXURE F: | Letter of permission from the Governor – Omusati Region | 157 |

| | |
|--|-----|
| ANNEXURE G: Letter of permission from the Governor – Oshana Region | 158 |
| ANNEXURE H: Letter of permission from the Governor – Oshikoto Region | 159 |
| ANNEXURE I: Letter of permission from Senior Medical Superintended of Oshakati State Hospital | 160 |
| ANNEXURE J: Letter of permission from the Senior Medical Superintended of – Windhoek Central Hospital | 161 |
| ANNEXURE K: Letter of permission from Permanent Secretary of MoHSS | 162 |

CHAPTER 1

INTRODUCTION AND BACKGROUND TO THE PROBLEM

1.1 Introduction

Cancer is a disease process that begins when an abnormal cell is transformed by a genetic mutation of the cellular deoxyribonucleic acid (DNA). Cancer cells are described as malignant neoplasmas. They demonstrate uncontrolled growth that follows no physiological demand (Smeltzer & Bare 1999:265).

Cancer is a worldwide disease which affects one or more body sites, and occurs in patients of all ages, as well as children. It is also proved that cancer contributes to morbidity and mortality in all populations.

During the year 2000 in the United Kingdom 400 new cancer cases were diagnosed among children (National Statistics 2003:1). Currently in the United States 12 400 children and teens under the age of 20 years are diagnosed with cancer (Trust for American Health 2005:1). According to Candlelighters Childhood Cancer Foundation (2005: 1) currently, one in every 330 Americans develops cancer before the age of 20 years. Cutland (year not indicated: 1) indicated that, in the Republic of South Africa 800 children are diagnosed with some form of cancer every year. According to Katjire (1995:9) in a study that was conducted during 1991-1994 in Namibia, various childhood cancers were recorded.

Although childhood cancers are considered to be rare, the above information indicated that cancer among children is becoming a problem even in Namibia.

There are various cancers, which were diagnosed in the children of Namibia. The information indicated below in Table 1.1, was obtained from the Pediatric Oncology Department in Windhoek Central Hospital during 2003. The information include cancer cases admitted to the Windhoek Pediatric Oncology Department from 1994-2002.

TABLE 1.1 Data from Windhoek Pediatric Oncology Department 2003

| TYPE OF CANCER | NUMBER OF PATIENTS | NUMBER OF DEATHS |
|-------------------------------|---------------------------|-------------------------|
| Leukemia | 31 | 18 |
| Neuroblastoma | 11 | 3 |
| Retinoblastoma | 30 | 6 |
| Wilm's/tumour/ Nephroblastoma | 38 | 13 |
| Brain tumour | 17 | 12 |
| Rhabdomyosarcoma | 2 | 2 |
| Hepatopblastoma | 2 | 0 |

Table 1.1 shows the distribution of various types of cancer among the children in Namibia as well as the deaths, which occurred as a result of cancer. Wilm's tumour ranked the highest followed by retinoblastoma and leukemia. Although Wilm's tumour ranked the highest, Leukaemia is the most common type of cancer that causes deaths among children in Namibia.

According to the Ministry of Health and Social Services (MoHSS) in the Namibia Demographic and Health Survey 2000 (2003:2), Namibia has a total population of 1,826,854 people. Forty-three percent (43, 0%), which is 785 547, are under 15 years old. Considering the total cancer admissions and the total under 15 years old, this is a large number.

Acute lymphoblastic leukemia is the most common type of childhood malignancy accounting for almost 25% of all cancer diagnoses worldwide (Hay, Hayward, Levin & Sondheimer 2003:892). Wilm's tumour/Nephroblastoma ranked the highest of all childhood cancers recorded in Namibia during 1994-2002 respectively. Other childhood malignancies recorded worldwide that correspond to the Namibia cancer incidence are Neuroblastoma, Retinoblastoma and Rhabdomyosarcoma (Hay et al 2003:907,913).

It is the worldwide trend that the majority of children diagnosed with cancer are treated in hospitals for a certain period of time and then discharged. When they are in the hospital they are treated and cared for by the professional multidisciplinary health team. The nurses spend a great deal of time with them because they provide bedside care (anonymous 1 2005:1). Furthermore, most of the nurses are specially trained and educated to care for patients with cancer.

When the condition of the child is stabilized, after a period of time, they are discharged from the hospital and sent home. At home it is usually the family,

guardian, or caregiver that must care for the child during this period. It is during this stage of home care that the support to caregivers is of utmost importance.

When a child is diagnosed and treated with cancer the patient (child), family and the caregivers enter a complex and often frightening world of a modern medicine. Furthermore, it is widely accepted that caring for patient who is diagnosed with cancer can be a demanding and difficult task (Papadatou, Papazoglou, Bellali & Petraki 2002:1).

It is therefore important that special attention be given to assist the caregivers to be able to cope with the sick child at home. However, what would also be of assistance would be if there is a proper system of home visits were in place where members of the multidisciplinary health team could visit these households on a regular basis to support the caregivers.

Caregivers should be informed and be taught how to deal with conditions such as bleeding, skin problems, hair loss, nutritional concerns (anorexia and malabsorption), pain management, fatigue, psychosocial status, body image, stomatitis, and maintenance of tissues integrity, infections, and other relevant complications (Smeltzer & Bare 1999:296-303).

In Namibia, according to Windhoek Pediatric Oncology 2003, among the one hundred seventy nine (179) cancer cases indicated in Table 1.1 page 2, forty-eight percent (48%) of the cases were referrals from Oshakati State Hospital (a referral

hospital for Northwest regions). Therefore the study focused on the preparation and support by nurses to caregivers of children diagnosed with cancer in the Northwest regions.

In Namibia, there is no system in the delivery of health care of regular home visits by health professionals in place, especially in the Northwest regions. By implication, it means that people have to come to the hospital for assistance.

There are many challenges facing the caregivers. One is to travel to the health facilities, since the majority of the people live in the rural areas. Financial constraints are also a problem for the rural community in the Northwest regions of Namibia. Most of the people depend only on agricultural products. Even if they produce some surpluses it is unlikely that they will sell their products to earn money for survival due to the fact that markets are far away, and transport is not readily available. This affects their ability to afford hospital and transport fees.

Furthermore in the rural areas people have strong beliefs in tradition and culture. Common cultural beliefs in the four regions are: Incurable diseases are seen either as a result of witchcraft or as a sin and these diseases if occur, there is no need to go the hospital. It is also believed that if the disease cannot be cured with the western medicine, the traditional men will be able to cure it (Munodawafa 2002:8).

Malnutrition among the children diagnosed with cancer is also another problem. According to the registered nurses in the Oncology unit in the main referral hospital, sick children who are readmitted for cancer treatment are mostly severely malnourished. Another problem is that some caregivers are also illiterate, which makes it difficult to provide guidance that will assist them, in this regard.

It is against this background that caregivers in the Northwest regions of Namibia should be prepared to care properly for the children diagnosed with cancer when they go home. In a study that was done by Moore and Beckwitt (2004:16) on children with cancer and their parents, it was found that there was a need for supportive educative aspects in certain areas of care. Because nurses spend most of the time with these patients they, together with the rest of the multidisciplinary team, should educate and train the caregivers on how to cope at home with the children diagnosed with cancer.

It was also evident in other studies that there is a need to adopt a family centered approach from the beginning of the treatment and care of the children with cancer (Holm, Patterson, Gurney 2003: 312, Friedman, Hilden & Powaski 2004:436; Caguni, Liston & Dupas 2004:59).

It is thus clear, that good communication between the patient (child), family (caregivers) and the health care team especially the nurses, is essential for the quality of care that the child is going to receive at home. Nurses should plan, coordinate and evaluate the health education session for the caregivers.

In Namibia, all the children diagnosed with cancer are treated only at a Pediatric Oncology Department of which there is only one in Windhoek. The children diagnosed with cancer in the Northwest regions are taken care of in their homes after discharge from the Pediatric Oncology Department. Therefore there is a need for the caregivers to be given proper information in order to cope with the disease. This was also emphasized by Reeve (2003:2) who indicated that it was high time for the family to be recognized as an essential part of the health care system that the nursing staff is to support.

It is important for caregivers to receive the necessary training and support to ensure that they are equipped psychologically as well as with the appropriate skills to meet the needs of the children diagnosed with cancer. This preparation of caregivers should focus on emotional preparation and support, direct physical intervention, including (personal care), nutritional management and management of community resources. Caregivers should be trained to assess the children and observe the changes in their condition that would require contact with health team members.

1.2 Statement of the problem

There have been several complaints in the media that the children diagnosed with cancer are being discharged from the hospital, even when they are very sick. These children are to be cared for by their caregivers (parents and guardians) in their homes where there is no health equipment and no health facilities nearby.

Furthermore there are complaints in communities that caregivers of children diagnosed with cancer are not taught how to take care of their children at home. Therefore some parents/caregivers are taking their children to traditional healers after cancer diagnosis. Other caregivers do not come for follow up sessions due to several reasons, such as incurable diseases being seen as the punishment from God and that no one can do anything about them.

Taking all the circumstances into consideration, it is not clear what preparation and support nurses provide to caregivers, specifically when sick children are discharged from the hospital. The question that can also be asked is: How well are the caregivers prepared to care for the children diagnosed with cancer at home?

From the above discussion, the following research questions need to be investigated:

- To what extent do the nurses prepare and support the caregivers of the children diagnosed with cancer in Northwest regions during hospitalization and discharge?
- Which support systems are available for the children diagnosed with cancer and their caregivers?
- What problems do the caregivers of children diagnosed with cancer experience when caring their children at home?

1.3 The purpose of the study

The purpose of the study was to explore and describe the preparation and support which nurses are providing to the caregivers of the children diagnosed with cancer in the Northwest regions of Namibia, namely Ohangwena, Omusati, Oshana and Oshikoto Region.

1.4 Objective of the study

The objectives of the research are to:

- describe the demographic profile of the participants,
- determine the preparation and support which nurses are providing to the caregivers of children diagnosed with cancer,
- identify the support systems which are available in the community for children diagnosed with cancer as well as their caregivers, and
- describe problems experienced by the caregivers of children diagnosed with cancer in the Northwest regions.

1.5 Definition of terms

Caregivers: are usually non-professionals, who provide for social and health needs of others (Stanhope & Lancaster 1996:1085). The American Society on Aging (ASA) (2003:1) describes caregivers as those persons who provide assistance to someone else who needs it, in order for that person to maintain an optimal level of independence.

In this study the caregivers are parents/guardians who are taking care of children diagnosed with cancer and are always available to take care of children diagnosed with cancer. The caregivers are there to provide all types of care, including administration of medicines, performance of basic and special procedures as required by the children's condition while at home.

Cancer: The term cancer is a collective term describing a large group of diseases characterized by uncontrolled growth and spread of abnormal cells.

This group of diseases:

- arises from different tissues and organs,
- differs greatly from one another in appearance and growth,
- may follow different courses of development in their hosts, and
- responds to a variety of therapies applied to them (Polaski & Tatro, 1996:118).

Child diagnosed with Cancer: The child who, according to the histological investigation, is proved to have cancer.

Nurse: In this study nurses mean a registered nurse and an enrolled nurse.

Registered Nurse: A graduate trained nurse who has satisfactorily completed the period of theoretical and practical training so prescribed by the (Nursing Act No.8 of 2004) and has met all the requirements prescribed in respect of a registered nurse training programme and has been licensed to practice as such (Nursing Act, 2004 Act No.8 of 2004).

Enrolled nurse: A graduate trained nurse who has satisfactorily completed the period of theoretical and practical training so prescribed by the (Nursing Act No.8 of 2004) and has met all the requirements prescribed in respect of enrolled nurse training programme and has been licensed to practice as such (Nursing Act, 2004 Act No.8 of 2004).

Home-based Care: refers to care of the patient at the patient's place of residence, whereupon too community resources are used to render effective care. The focus of home care is on the patient and the primary caregiver can be the parents, relatives and significant others (Young, Van Niekerk & Mogotlane 2003:199, Stanhope & Lancaster 1996:1094).

Support: It is what comes to an individual through the action of others. It is a fundamental component of any notion of life and is important for the maintenance of psychological well being (Anonymous 2 2005:1). According to the Macmillan English Dictionary for Advanced Learners, International Student Edition by Rundell and Fox (2002:1443) support means to help someone and be kind to them when they are experiencing difficult times.

In this study support means regular interaction with the caregivers of the children diagnosed with cancer in order to assist them with therapeutic sessions, reassurance, and problem solving.

Preparation: According to the Macmillan English Dictionary for Advanced Learners International Student Edition by Rundell and Fox (2002:1110) as well as Marckwardt, Cassidy and McMillan (2000:996) preparation means to prepare someone for something.

For the purpose of this study preparation of someone means caregivers, the something means caring for the child diagnosed with cancer. In this study, it means that health education sessions on how to fulfill the basic human needs of the child would be important such as nutrition, hygiene, pain management, wound care, and the treatment of side effects such as nausea, stomatitis and skin damage.

Support groups: These are groups in which the people with common experiences join together for emotional support, technical expertise, education, and information,

refuge from discrimination and to lobby for better support (Kibel & Wagstaff 1997:212).

1.6 Paradigm of the study

The phenomenon of interest in this study is the experience of caregivers and nurses in the process of preparing the caregivers for home care of children diagnosed with cancer. According to Polit and Hungler (1999:13) research in the naturalistic tradition emphasise the inherent complexity of humans and their ability to create their own experiences. Therefore a heavy emphasis is placed on the understanding of human experiences. A paradigm according to Babbie and Mouton (2001:645) is the fundamental model or frame of reference we use to organise our observations and reasoning.

Basford and Slevin (2003:1521) describe a paradigm as a particular perspective, or worldview, or a theoretical framework that establishes how we view and understand the world. In this study the following set of assumptions guided the investigation Ontology, Axiology, Epistemology and Methodology assumptions.

Ontological assumption (Nature of reality)

Cancer is a universal disease that affects people without regard to race, sex, socioeconomic status or culture. Cancer evokes deep fears of pain, suffering, dependence, disfigurement and death. Variables that have been identified as shaping attitudes towards cancer are life experience, especially those related to the disease,

parental and cultural values, an attitude towards illness, society's emphasis on youth, health and beauty, social pressures and portrayals of people with cancer in the mass media (Thompson, McFarland, Hirsch & Tucker 2002:1182-1183).

On the other hand, positive experiences and hopeful presentations of cancer and its treatment will give the individuals, group or community a clear perspective on treatment and care of the patients.

However, patients will experience the reality and the process of the disease differently and so will the caregivers. Therefore, it is important that health care workers, and especially nurses, understand these experiences, because the dynamic, holistic, and individual aspects of these experiences should be captured in their entirety and within the context of those experiencing them (Polit, Beck & Hungler 2001:15). This enables nurses to support and prepare both the children and their caregivers.

Axiological Assumption (role of values in the inquiry)

The researcher went in the field with no biased ideas concerning the phenomena, the experience of the participants concerning the preparation process of home care and the support provided during the diseases process. To be able to understand the participants' experiences, the researcher convinced them to participate during the conversations and to speak candidly.

During this process of interaction the researcher valued the aspect of objectivity as opposed to subjectivity as being of great importance. It is sometimes difficult for any researcher to remain an outsider because involvement in the process enhances acceptance by participants.

According to Polit and Hungler (1999:12) voices of those being studied are crucial to understanding the phenomenon of interest, and subjective interactions are the primary way to access these interests. However, the researcher also valued the principle of objectivity, and tried to gather rich information.

Epistemological Assumption (How is the researcher related to those being researched)

The researcher is a nurse tutor and cancer nursing is one of the subjects taught by her. Therefore the way the nurses prepare caregivers is of the utmost importance to ensure quality patient care. Although the whole multidisciplinary team is involved, it is the nurse who spends the most time with the caregiver in the hospital. On the other hand, the caregivers are human beings and it is often lay persons who depend on the knowledge and skills from the health worker to care for the patient at home. It is of the utmost importance that this aspect be considered and that they are given the necessary training and support they need.

Methodological assumption (how is the knowledge obtained)

The information in this study was obtained through a qualitative approach and inductive process. It is a flexible design, context bound and the emerging interpretation is based on participant's experience. The emphasis is on narrative information and the information was classified into themes and categories. The collection of data and the analysis were done concurrently. As the researcher sifted through information, insights were gained, and new questions emerged. Through the inductive process the information was integrated to develop a description that helps to explain the phenomena under observation (Polit, Beck & Hungler 2001:11; Polit & Hungler 1999:9).

1.7 Significance of the study

The purpose of the study was to explore and describe the preparation and support that nurses are providing to the caregivers of children diagnosed with cancer. The results of the study could be used to raise awareness and improve the preparation and support that is provided to the caregivers of children diagnosed with cancer in the Northwest regions of Namibia. It is hoped that this knowledge will eventually be used by other regions in the country.

1.8 Summary

Cancer is a disease that is responsible for morbidity and mortality in all populations worldwide. It is also known that it affects anyone from childhood to old age. Cancer requires treatment, monitoring and management for many years and as a result much of the care of the patient diagnosed with cancer is given at home by the caregivers. Unfortunately all the drugs used in the treatment of cancer are not selective cytotoxic to cancer cells only. Useful cells can also be affected resulting in serious complication, thus making cancer care more complicated. In this chapter the background to the problem was given. Furthermore, the purpose and objective of the study was indicated as well as the paradigmatic perspective of the study and the significance of the study. In the next chapter the research design and methodology will be discussed.

CHAPTER 2

THE RESEARCH DESIGN AND METHOD

2.1 Introduction

In this chapter the research design and the methods are described. The research design and methods include the descriptions of aspects such as the study population, the sampling technique, and data collection methods used in this study.

2.2 Research design and method

The research design is a plan or blueprint of how you intend to conduct the research study (Babbie and Mouton 2001:74). Furthermore, the research design guides the researcher in planning and implementing the study in a way that is most likely to achieve the intended goal (Burns & Grove 2001:223). The study is, descriptive, explorative, and contextual. The study is qualitative in nature in that the researcher wanted to explore and describe the preparation which nurses are providing to the caregivers of children diagnosed with cancer.

The quantitative approach was only used to gather and analyse biographic data to get a broader picture of the participants. The biographic profile can have an influence on specific actions or behaviours of the participants.

The qualitative approach for this study was used on two of the groups namely caregivers and nurses. This approach is appropriate because this is the proper way to determine nurse's experience regarding the training and support of caregivers of children diagnosed with cancer in the Northwest regions throughout the diseases process. It also intended to find out from the caregivers, how they experience the preparation and support.

Furthermore, selection of the qualitative design is based on the notion that it involves human beings and their environment. The experience of when/how training and support of caregivers and the experience can only be explained by themselves (nurses and caregivers) (Babbie & Mouton 2001:28, Polit & Hungler 1999:644).

Explorative design

The purpose of the explorative design is to obtain a richer familiarity where little is known about the area of study (Babbie & Mouton 2001:79). This design was used to gain insight and knowledge into the experiences of nurses and caregivers in their preparation to care for children diagnosed with cancer at home.

Descriptive design

Descriptive research attempts to observe, count, describe and classify in order to provide a precise report of a characteristic of a population or phenomena under study (Babbie & Mouton 2001:105, Polit & Hungler 1999:19). This provides a truthful account of a phenomenon and experience in the world around us (Mouton 1996:102).

The study described the complexities and the influences of many factors in a situation that included vivid materials, like quotations from the interviews and focus group discussions from different participants. In this study rich, complete descriptions of caregivers and nurses experience on their preparation to care for the children who are diagnosed with cancer at home, were given (Merriam 1998:978).

Contextual

The study is contextual in nature because it focused only on caregivers and nurses, for the children diagnosed with cancer in the Northwest regions and on the preparation needed to care for them (children diagnosed with cancer).

2.3 Hypothesis

No hypothesis is formulated for this study. The descriptive study was aimed at exposing the nature of the situation concerning the preparation and support which nurses are providing to caregivers of children diagnosed with cancer.

Therefore the research problem and purpose were used to direct the study (Burns & Grove 2001:182).

2.4 The study population

Babbie and Mouton (2001: 100) describe a population as the group (usually of people) about whom one wants to make conclusions. It is the elements that the research focuses upon and to which result obtained can be generalized (Bless & Higson- Smith 2000:85).

The study population for this study comprises two different populations namely; the caregivers of children diagnosed with cancer in the Northwest regions and the nurses in the Central Region (Khomas) and Northwest Region (Oshana).

The study sample for nurses in the Central Region included nurses from the Pediatric Oncology Department in Windhoek Central Hospital since these are the people who admit the children diagnosed with cancer. The nurses in the Northwest regions included the nurses in the Oshakati State Hospital, those from the wards where children diagnosed with cancer are admitted before being referred to Windhoek and after their return from Windhoek. The Oshakati State Hospital was selected to represent other hospitals in the Northwest regions as it serves as the referral hospital for all other district hospitals in the Northwest regions.

In this study, caregivers are those whose children (diagnosed with cancer) were admitted in Oshakati State Hospital during 1994-2002, (including those who died.)

2.5 Sampling

Sampling refers to the process of selecting a portion of the population to represent the entire targeted population (Bless & Higson-Smith 1995:85-87). According to Babbie and Mouton (2001:288) sampling in phenomenological tradition is often purposeful and directed at certain inclusive criteria. Therefore the researcher considered purposeful sampling as appropriate for this study.

Sampling (Caregivers)

Intensity sampling was used in selecting the caregivers for the study. Intensity sampling is a subcategory of purposeful sampling and it refers to selecting information rich cases that manifest the phenomena of interest intensely. Therefore the caregivers of children diagnosed with cancers (who were admitted in Oshakati State Hospital from 1994-2002) and who were still being on treatment and those who died during 1994-2002 in the Northwest regions were included.

The caregivers were identified through checking the records in Oshakati State Hospital. First the children diagnosed with cancer were identified in the admission books in the two wards where children diagnosed with cancer are admitted. Secondly the registration numbers indicated in the admission books were used to trace the file from the hospital admission office.

The files were then consulted and used to trace the addresses of the caregivers. The totals of 33 childhood cancer admissions were recorded in the Oshakati State Hospital during 1994-2002. Among the 33 admissions only 22 files could be traced from the Oshakati State Hospital admission office. Twenty-two files were used to locate (find addresses of the caregivers) and bring the total number of caregivers to 22. Only 13 caregivers interviewed because nine caregivers could not be traced.

Sampling (Nurses)

The study units for the nurses were selected by using accidental sampling. Accidental sampling entails the use of the most readily available persons or subjects for the use in a study (Babbie & Mouton 2001:202).

All nurses who found working in the Oshakati State Hospital units where children diagnosed with cancer are admitted as well as Windhoek Central Hospital Pediatric Oncology Department during the time of the study were consulted and a total of twelve (12) nurses were included.

2.6 Pre-testing instrument

Pilot face-to-face interviews and pilot focus group discussions were conducted. The purpose of the pilot study was to rule out the possibility of ambiguously worded questions. According to Huysamen cited in De Vos (2000:179) the purpose of a pilot study is to investigate the feasibility of the planned project and to bring possible

deficiencies in the measurement procedure to the fore. The validity of oral data was ensured by giving the short questionnaire to the supervisors for discussion. Reliability was ensured during the pilot study.

The population for the pilot study includes two nurses from Oshakati State Hospital (the supervisors of the target wards) and a caregiver from Ohangwena region. Appointments were made one week in advance. A debriefing session was done. The short questionnaires were first handed out to be completed and then the question on their experiences concerning preparation for caring for the sick child was posed. During the pilot study a tape recorder and notes were used to collect data. The use of the tape recorder was explained to the participants. A chance to ask questions was given to those who needed clarification. All the participants understood the leading question and elaborated on their experiences. The data collected was analyzed to enable the researcher to improve on the questions and techniques used in the study.

2.7. Data collection

Data collection is the process of collecting data from the chosen participants. In this study the data was collected from the nurses and the caregivers. Personal data was gathered by a short questionnaire (quantitative), while data of the experiences of the participants was gathered through focus group discussion and interviews (qualitative).

Preparation of the field

Caregivers

The researcher first made contact with the schools that are in the same area as the caregiver's homes. The researcher then found out from the teachers and the school children whether they knew the caregivers and also in order to get their addresses and telephone numbers. If the answer was positive then the researcher made contact with the caregivers by cell phone to make an appointment for an interview. This procedure was followed for all 13 participants. This was done one week before each interview was conducted.

Nurses

Intermediate Hospital Oshakati: Selected participants were contacted one week before the date of the focus group discussion to make arrangement and to confirm a date for the focus group discussions.

Windhoek Central Hospital (Oncology department): Selected participants were contacted, by phone, one week before focus group discussion to make arrangements and to confirm a date for the focus group discussions.

Interviews

Interviews with caregivers were conducted as planned. A silent room/space was used to conduct the interviews. The participants were put at ease, informed, and had the use of the tape recorder explained to them.

Then the demographic data of the participants was recorded in short questionnaires.

The interviews were tape-recorded and field notes taken.

The following introduction was used by the researcher to obtain information on the preparation and support which nurses are providing to the caregivers of children diagnosed with cancer in the Northwest regions

“Firstly I would like to thank you for allowing me to discuss with you your experience on how you were prepared and supported by the nurses during the disease process of your child.

Secondly I would also like to inform you that: The aim of the interview is to collect information concerning your experience when caring for your child who is diagnosed with cancer. The information that you provide will assist in improving the care of the children with cancer and their caregivers. Please share your honest feelings and ask for clarification if the question is not clear to you.

The information that you are going to provide will be treated confidential. To maintain anonymity no name will be used during the discussion instead you will be identified as “Mbushe” or according to the clan if prefer so.”

Participants were also reminded that participation in the study was voluntary, no money would be offered.

The interview started by asking the central question.

“Please tell me your experiences on how you were prepared and supported by the nurses throughout the disease process to care for the child who is diagnosed with cancer.”

Focus group discussion

The focus group discussion with nurses was conducted, as planned, in Oshakati State Hospital. In Windhoek Central Hospital the face to face interview was done instead, because of the staff shortage nurses could not be gathered for a focus group discussion. A patient dining room was selected for the focus group discussion since it was regarded as being the place where the least disturbance would occur. Two focus group discussions were conducted one for each of two different units in Oshakati State Hospital; one consisted of four nurses and the other seven nurses. Participants were put at ease and had the use of the tape recorder explained to them. Then the short questionnaires for collecting the demographic data were distributed for completion and handed to the researcher. As indicated earlier, the focus group discussion in the Windhoek Oncology Department could not materialize as proposed, due to the staff shortage. Therefore face to face interviews were conducted using the guidelines for focus group discussions.

Participants were all informed that the purpose of the discussion was to obtain information on how they prepared and supported the caregivers of children diagnosed with cancer to enable them to care for their children at home.

After the purpose of the discussion was stated the researcher set out the rules for the session as follows:

- The focus group discussion will be tape-recorded, so that all the information is captured.
- Everybody is expected to contribute to the discussion.
- Participation in the study is voluntary. Everyone has the right to withdraw any time he/she wishes.
- Everyone has the right to ask for clarification if the question is not clear to and no one is forced to answer any question that they do not feel like answering.

The following introduction was used by the researcher to obtain information on the preparation and support which nurses are providing to the caregivers of children diagnosed with cancer in the Northwest regions

“First of all I would like to thank everybody here for availing yourself to come and attend this discussion in which we will discuss matters related to the preparation and support which nurses are providing to caregivers of children diagnosed with cancer. This session was chosen because of increased incidence of childhood cancer. You were also specifically selected due to the fact that you are working with children diagnosed with cancer to give information that can also assist the researcher in answering the research question.

I would like to inform you that: The aim of the focus group discussion is to collect information concerning the preparation and support which nurses are providing to the caregivers of children diagnosed with cancer. The information will be used to improve in the areas concerning the care of children diagnosed with cancer. No report will be prepared which identifies the views of any of the participants. All information will be kept confidential.”

After the introduction the following central question was posed to the participant.

“Tell me your experiences on the preparation and support you give to the caregivers of children diagnosed with a cancer throughout the disease process.”

Interview

The individual nurse was requested to make an appointment for the individual interview and the same question was posed to the nurse before the interview started.

The role of the researcher

The researcher was a primary data collector assisted by a research assistant who took notes while the researcher was facilitating the session. According to Hammel, Carpenter and Dyk (2000:31) data collection in qualitative research requires minimum researcher-imposed structure and maximum participant-free involvement. This principle was maintained throughout the interviews and the focus group discussion. Furthermore, the researcher maintained a close social interaction in order to enhance access to the information.

Communication Techniques

In this study the following communication techniques were utilized in face to face interviews and focus group discussions to obtain information.

Probing: This is the technique employed in interviewing to obtain a more complete answer to a question. It is a non-directive phrase or question used to encourage the respondent to elaborate on an answer (Babbie & Mouton 2001:646). In this study the questions were skillfully asked to probe the participant, to explain their experiences in detail, without affecting the nature of the subsequent responses.

Paraphrasing According to the Macmillan English Dictionary for Advanced Learners International Student Edition by Rundell and Fox (2002:1028-1029) paraphrasing is the expression of what someone else has said or written using different words, especially in order to make it shorter or clearer. It is done to confirm the understanding of the interviewees in regard to what they have said. Whenever necessary, the researcher in this study restated what the participants said during the interview in order to confirm the information provided.

Clarifying: This involves questioning statements that are not understood by the interviewer or a participant with the purpose of gaining the exact understanding (Shifiona 1998:20). In this study the questions were asked to clarify unclear statements. The respondents were also informed of their right to ask for clarification in case the questions were not clear to them.

Minimum Response: This is the ability of the interviewer to do more listening than responding to avoid biasing the participants. After the interview and focus group discussion begun and the interviewer encouraged the participants to continue talking by nodding her /his head (Burns & Grove 2001: 420-421). In this study the participant's perspective was obtained through attentive listening.

Field notes

Field notes are observations written manually into a notebook by the researcher. They contain detailed descriptions of the social situation and interactions in the research field (Tarling & Croft 1998:5.). Field notes were taken during the interviews and utilized afterwards, during data analysis.

Language

All the interviews for the caregivers were conducted in Oshiwambo and translated into English. The reason for that was that the participants could not understand or speak English. The focus group discussions for nurses were conducted in English.

2.8 Strategies to ensure trustworthiness of the data

Credibility refers to the confidence in the truth of the data (Polit, Beck & Hungler 2001:312). In this study credibility was demonstrated through data source triangulation, whereby nurses and the caregivers were participants in the same study.

Dependability refers to the stability of the data over time and over condition (Polit, Beck & Hungler 2001:315). In this study dependability was ensured through inquiry audit. According to Babbie and Mouton (2001:278) the inquiry auditor examines the documentation of critical incidents and keeps a running account of the process of inquiry. The inquiry auditor also examines the product such as data, findings, interpretation and recommendation and attests that it is supported by data and is internally coherent, so that the “bottom line” may be accepted. The researcher sent the preliminary research report, together with interview notes, cassettes recorded during the interviews and focus group discussions, interpretation and the recommendation made to the study supervisors for evaluation.

Confirmability refers to the objectivity and neutrality of the research data. Confirmability in this study was ensured through what Lincoln and Guba (1984) cited in Babbie and Mouton (2001:278) calls a confirmability audit trail. A Confirmability audit trail means that an adequate trail is left to enable the auditor to determine if the conclusions, interpretation, and recommendation can be traced to their sources and if they are supported by the enquiry. The recorded tape cassettes, field notes, data analysis process (including themes developed), findings, methodological notes were sent to the study leaders to establish whether the findings were a product of the study.

Transferability refers to the extent to which the findings can be applied in another context Babbie and Mouton (2001:277). It is also labeled as “fittingness” (Streubert & Carpenter 1999:29). Purposeful sampling and detailed descriptions of the research

setting are two strategies used to ensure transferability. The researcher provided the detailed descriptive data concerning the focus of the inquiry including target population and research methods. The detailed description enables the consumer to evaluate the applicability of the findings to another context.

2.9 Data analysis

Quantitative analysis: This was done through statistical procedures for the purpose of describing the biographic information of the caregivers and the nurses (Babbie & Mouton 2001:646, Polit, Beck & Hungler 2001:469).

Qualitative analysis: The collected data was transcribed. After each session the researcher read through the script and listened to the tape recorder and made notes. To facilitate data analysis, data was classified in themes based on the pattern and structure of the thematic categories. The data was then encoded and the codes were used to sort and organise the data. This is the same as Polit, Beck and Hungler (2001:382) calls editing analysis style. The researcher using an editing analysis style acts as an interpreter, who reads through data in search of the meaningful segments. Once segments are identified and reviewed the researcher develops categorisation themes and corresponding codes that can be used to sort and organize the data.

Data Management and reduction

Because of the volume of the data acquired in a qualitative study the initial effort at analysis was focused on immersion with the data and data reduction to facilitate examination (Burns & Grove 2001:596).

Immersion in the data (Dwelling with the data): This process involves reading and rereading the script and notes, recalling observation and experiences, listening to the tapes until become immersed in the data (Burns & Grove 2001:596). The researcher spent a lot of time reading field notes, listening to the tapes and trying to learn about the experience of the caregivers and nurses concerning the preparation and support which nurses are providing to the caregivers of children diagnosed with cancer.

Data reduction: This refers to a technique for analyzing qualitative data that focuses on decreasing the volume of data to facilitate examination (Burns & Grove 2001:794). During this phase the researcher started attaching meaning to elements in the data in order to discover common ground regarding the preparation and support of the caregivers of children diagnosed with cancer.

Developing themes and Categories

A good starting point in analyzing of qualitative data is to look for themes and categories that have emerged and to use these to structure the results section of the research report (Hancock 2002:34). A theme is an abstract entity that brings meaning and identity to a current experience and its variant manifestation, such a

theme captures and unifies the nature or basis of the experience into a meaningful whole (De Santis & Ugarriza 2000:362).

The process started by coding every item of information so that the differences and similarities can be recognized. This was done when the researcher read through the scripts. Whenever the researchers find a meaningful segment in a script, a code is assigned to signify that particular segment. This process continued until all the data had been segmented.

The researcher then read through the segmented data and categorised each data in a way that described what it was about. The identified categories were re-examined again and those linked in some way were categorized again in major categories/themes. Because the study was primarily descriptive in nature, the categories were fairly concrete in that they focused on differentiating various types of events and actions about the phenomena preparation and support of caregivers of the children diagnosed with cancer. Three themes with various categories were developed from the data and used to structure one portion of the result section of the research report (see page 52).

2.10 Ethical consideration

The Permanent Secretary of the MoHSS approved the study. Permission to get access to the selected hospitals was given by the Senior Medical Superintendent of

the Windhoek Central Hospital and Oshakati State Hospital. Permission to get access to the caregivers in the regions was given by the Governors of the regions concerned. Informed, verbal consent was obtained from both the caregivers and nurses. Confidentiality was ensured, as no information provided by the informants will ever be identified with them. Anonymity was ensured. No participant was asked to provide his or her name. Participation in the study was voluntary and clarification provided that participants could withdraw at any time.

2.11 Summary

Research design and method, the topic of this chapter provided a general understanding of how the study (on the preparation and support by nurses to caregivers of cancer diagnosed children) was conducted.

Details on the steps involved were given as well as the strategies used in the population selection and sampling. Data collection methods and analysis were also highlighted and discussed.

CHAPTER 3

ANALYSIS OF DATA AND LITERATURE CONTROL

3.1 Introduction

Data analysis is an interpretation of the collected data for the purpose of drawing conclusions that reflect on the interest and ideas that initiated the enquiry (Babbie & Mouton 2001:10). Data analysis in any research includes summarizing the mass of information/data collected (Hancock 2002:20). The summary communicates the most important feature about the phenomena under investigation.

This chapter first presents analysis of the biographic data for both nurses and caregivers using a quantitative approach. The analysis of the qualitative data concerning the preparation and support which, nurses are providing to caregivers of children diagnosed with cancer will then be presented.

3.2 Quantitative analysis

A short questionnaires used for gaining biographic information about both participants (caregivers and nurses) was analysed, first for the caregivers and then for nurses. Statistics were rounded off to the nearest full number.

BIOGRAPHIC INFORMATION OF CAREGIVERS

Item 1: Gender of the respondents

Table 3.1 Gender of the respondents

| Gender | Frequency | Percentage |
|---------------|------------------|-------------------|
| Male | 2 | 15,0% |
| Female | 11 | 85,0% |
| Total | 13 | 100% |

Table 3.1 indicates that two 2 (15, 0%) of the caregivers are males while 11 (85, 0%) are females. This might be due to the fact that culturally care-giving is regarded as women's responsibility and this is especially dominant in the Northwest region of Namibia where the study took place.

The findings of this study concur with the study that was done on the Profile of Informal and Family Caregiver by American Society on Aging (ASA) (2003:3) in which seventy five percent (75, 0%) of the caregivers were found to be females. Both studies show that care giving is a women's responsibility.

Item 2: Age of the caregivers**Table: 3. 2 Age of caregivers**

| Age | Frequency | Percentage |
|--------------|------------------|-------------------|
| 25-45 | 7 | 54,0% |
| 46-65 | 2 | 15,0% |
| 66-85 | 4 | 31,0% |
| Total | 13 | 100% |

The caregivers who participated in the study were in the age range from 25 – 85years. Seven (54, 0%) of the caregivers are between 25-45 years, two (15, 0%) are between 46-65 years and four (31, 0%) are between 66-85 years.

Table 3.1 shows that the majority of the caregivers are represented by fifty-four percent (54, 0%) and thirty-one (31, 0%) respectively. The fifty- four percent (54, 0%) is an indication of a sample of caregivers in the productive age, overwhelmed with many responsibilities such as employment, household activities, as well active participation in social events. The thirty one percent (31, 0%) are elderly, who are in need of care and are now have the care-giving responsibility.

Elderly people who are mostly grandparents as well as caregivers were found. Grandparents are concerned not only with the sick child, but also for their own child (parent), their own needs and their wellbeing with specific reference to their health (Hodder & Keene 2001:5).

Item 3: Location of the caregivers

This results indicated that 13 (100, 0%) of the caregivers live in the rural areas. These statistics appear to be influenced by the fact that many people in the Northwest region of Namibia are living in the rural area. Considering the consequences and the situation in the rural area, this is an indication that caregivers need thorough preparation and support to be able to care for the sick child.

Item 4: Region where the caregivers reside

Table 3.3 Region where the caregivers reside

| Region | Frequency | Percentage |
|---------------|------------------|-------------------|
| Ohangwena | 7 | 54,0% |
| Omusati | 2 | 15,0% |
| Oshana | 3 | 23,0% |
| Oshikoto | 1 | 8,0% |
| Total | 13 | 100% |

Table 3.3 indicates that seven (54, 0 %) of the caregivers are from the Ohangwena Region, two (15, 0%) from Omusati Region, three (23, 0%) from the Oshana Region and one (8, 0%) from the Oshikoto Region. The unequal regional representations was not considered, since caregivers were all referred through the Oshakati State Hospital and the equal representation would not have had an effect on the result.

Item 5: Religion of the caregivers

Table 3.4 Religion of the caregivers

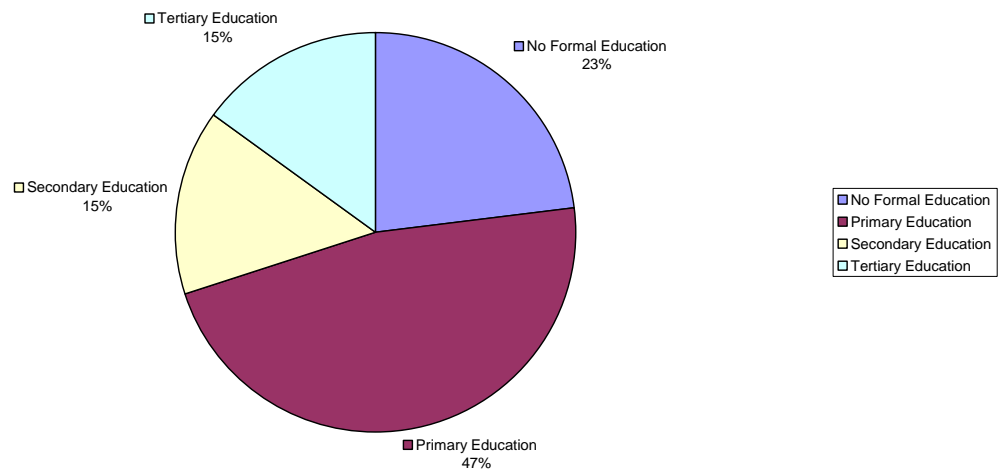
| Religion | Frequency | Percentage |
|-----------------|------------------|-------------------|
| Lutheran | 10 | 77,0 % |
| Anglican | 3 | 23,0 % |
| Total | 13 | 100,0 % |

Thirteen (100%) of the caregivers are believers, with 10 (77, 0%) being Lutherans and three (23, 0%) are Anglicans. All caregivers in this study are Christians. Christians always value and appreciate any assistance from their church leaders (pastors) or a prayer from the group of church members while in difficult situations like cancer diagnosis. Any help from church members serves as an emotional support for the caregivers who then improve their coping abilities and, thus the child's quality care.

Religion is also regarded as a source of strength for believers (Fryer 1994: 46). It is through religion that caregivers find the meaning of their children's suffering. Religion is also a source of emotional support and it should always remain part of cancer care. By implication, the caregivers in this study seem to have a source of emotional support.

Item 6: Educational levels of the caregivers

Figure 3.1: Educational levels of caregivers



The findings reveals that the levels of formal education ranged from 6 (47, 0%) with primary education, 2 (15, 0%) with secondary education, 2 (15, 0 %) tertiary education/post secondary education and 3 (23, 0%) with no formal education. Educational level has an impact on the caregivers' ability to understand the care instructions. The majority of the caregivers are literate. This is a sample of persons who have the ability to understand the care instructions.

Item 7: Employment status of the caregivers

Figure 3.2: Employment status of the caregivers

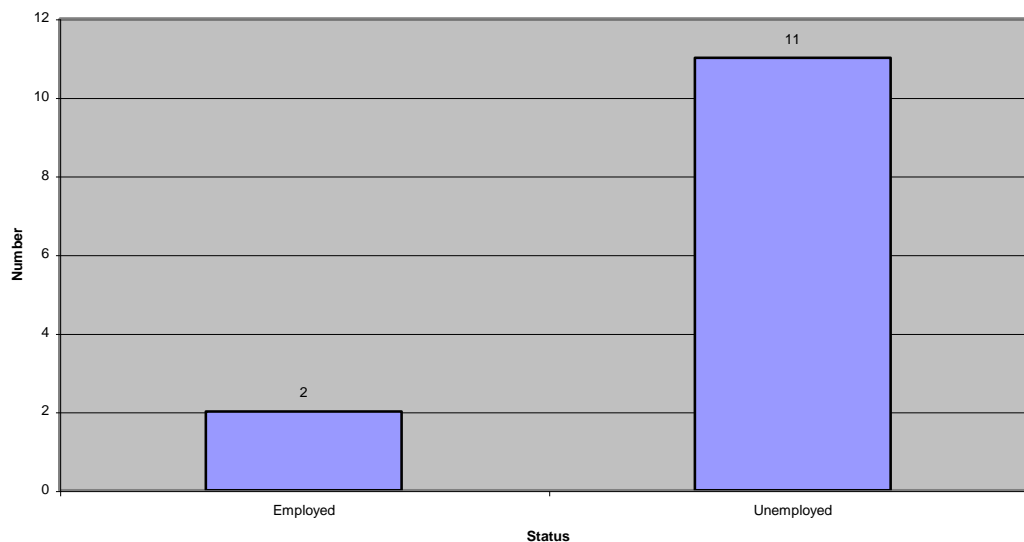


Figure 3.2 shows that 11 (85, 0%) of the caregivers are unemployed while (15, 0%) are employed. Care-giving poses considerable financial risks for caregivers (Stubbs 2000:3). Thus, cancer diagnosis could have an impact on the already financially disadvantaged individuals (caregivers).

Item 8: Number of people living with caregivers

All the caregivers live with more than two children, ranging from three up to 20 children. Two (15,0%) of the caregivers live with three children, six (47,0%) of the caregivers live with four children, two (15,0%) with six children, two (15,0%) live with seven children , and one (8,0%) with about 20 children.

Among the caregivers, three (23, 0%) of caregivers live also with one of their parents. Other family members who live with caregivers ranged from one to 10

people. Family members could be regarded as a source of support, but they could also be a source of stress for the caregivers.

Item 9: Relationship of the caregiver to the children diagnosed with cancer

Table 3.5 Relationship of the caregivers to the children.

| Relation | Frequency | Percentage |
|-------------------|------------------|-------------------|
| Biological parent | 7 | 54,0% |
| Grandparent | 2 | 15,0% |
| Brother/Sister | 1 | 8,0% |
| Aunt/Uncle | 2 | 15,0% |
| Cousin | 1 | 8,0% |
| Total | 13 | 100,0% |

Thirteen (100, 0%) of caregivers are related to the (children diagnosed with cancer) recipient of care. Seven (54, 0%) of the caregivers are biological parents of the children diagnosed with cancer and six (46, 0%) guardians (aunt/uncles, cousin, brother/sister, grandparents).

Childhood cancer is a disease that affects the whole family. When the child is diagnosed with cancer the entire family is affected. Furthermore parents as caregivers must add the physical, emotional and social demands of siblings to their own response to illness in addition to economic burden of care (Bandman & Bandman 2002:124).

Whatever the caregivers relationship has been with the child prior to the child's diagnosis and the child's current needs, this new dimension may stimulate changes both positive and negative (Anonymous 4:2001).

Item 10: Duration of cancer

Table 3.6 Duration of cancer

| Duration | Frequency | Percentage |
|-----------------|------------------|-------------------|
| 0-1year | 3 | 23,0% |
| 1-5years | 7 | 54,0% |
| 5-10years | 3 | 23,0% |
| Total | 13 | 100,0% |

Table 3.6, indicates that three (23, 0%) children have had cancer for less than one year, Seven (54, 0%) have had cancer for 1-5 years while three (23, 0%) have had cancer for 5-10 years. Most of the children in this study have been on cancer treatment for more than two years. This long period of treatment indicates long interaction between the nurses and the family of the child with cancer. By implication, the caregivers should have been ably supported and exposed to all involved.

Item 11: Distance from the health facilities

Table 3.7 Distances in km

| Distance in km | Number | Percentage |
|-----------------------|---------------|-------------------|
| Less than 1 km | 1 | 8,0% |
| 1 – 10 km | 6 | 46,0% |
| 10 km – 30 km | 2 | 15,0% |
| Above 30 km | 4 | 31,0% |
| Total | 13 | 100,0% |

Table 3.7, shows that one (8, 0%) of the caregivers lives within one kilometer from the health facilities. Six (46, 0%) of the caregivers live within 10 km – 30 km, while two (15, 0%) live more than 30 km from the health facilities.

Caregivers in this study mostly live in rural areas far from the health facilities. It was also found that, even where the facilities exist, they do not provide specialized services for children diagnosed with cancer. Jackson and Vessey (1996:8) also pointed out that living in the rural area where few appropriate services are available requires the families to travel a great distance for cancer treatment and results in many barriers to obtaining adequate health care.

BIOGRAPHIC DATA OF NURSES

Item 1: Age of the nurses

Table 3.8 Age of the nurses

| Age | Frequency | Percentage |
|------------------|-----------|------------|
| 30-40 | 6 | 50 |
| 41-50 | 4 | 33 |
| 51-59 | 1 | 8 |
| Age not revealed | 1 | 8 |
| Total | 12 | 100 |

Table 3.8 shows that the age range of nurse varies from 30-59 years. Six (50%) are between 30-40 years, four (33%) are between 41-50years, while one (8%) are between 51-59years. One of the nurses did not reveal her age with the reason that it is her private information. The ages of nurses are an indication of a group of nurses that are expected to be psychologically and professionally mature. These are the nurses who are expected to be responsible for preparing and supporting the caregivers of children diagnosed with cancer during the disease process.

Item 2: Gender of the nurses

Twelve (100%) of the nurses are females according to the findings. This might have been influenced by the fact that there are not many male nurses, as nursing was regarded as a women's profession.

Item 3: Qualification of the nurses**Table 3.9 Qualification of the nurses**

| Qualification | Frequency | Percentage |
|---|------------------|-------------------|
| Degree in Nursing Science | 3 | 25,0% |
| Diploma in Nursing science/Midwifery | 5 | 42,0% |
| Certificate in Enrolled Nursing/Midwifery | 4 | 33,0% |
| Total | 12 | 100,0% |

The figures in Table 3.9 show that nurses are qualified as general nurses. Three (25, 0%) have a Degree in Nursing Science, five (42, 0%) have a Diploma in Nursing Science while four (33, 0%) have a certificate in Enrolled Nursing and Midwifery.

By implication it means that not all the nurses are registered nurses. So it is also expected that enrolled nurses prepare and support caregivers.

Item 4: Duration of experience in the cancer department / the ward where children diagnosed with cancer are admitted

Table 3.10 Duration in the cancer department/ the ward where children diagnosed with cancer are admitted

| Duration | Frequency | Percentage |
|-----------------|------------------|-------------------|
| 0-1yrs | 2 | 17,0% |
| 1-2yrs | 2 | 17,0% |
| 3-4yrs | 1 | 8,0% |
| 5yrs and above | 7 | 58,0% |
| Total | 12 | 100,0% |

The table above reflected that most of the nurses had been working in the cancer department/the wards with children who have cancer for longer than one year. This period had exposed them to the children diagnosed with cancer and their caregivers, thus enabling them to prepare and support the caregivers during the course of the disease.

Item 5: Basic Nursing courses that nurses undergo that prepare them to care for children diagnosed with cancer

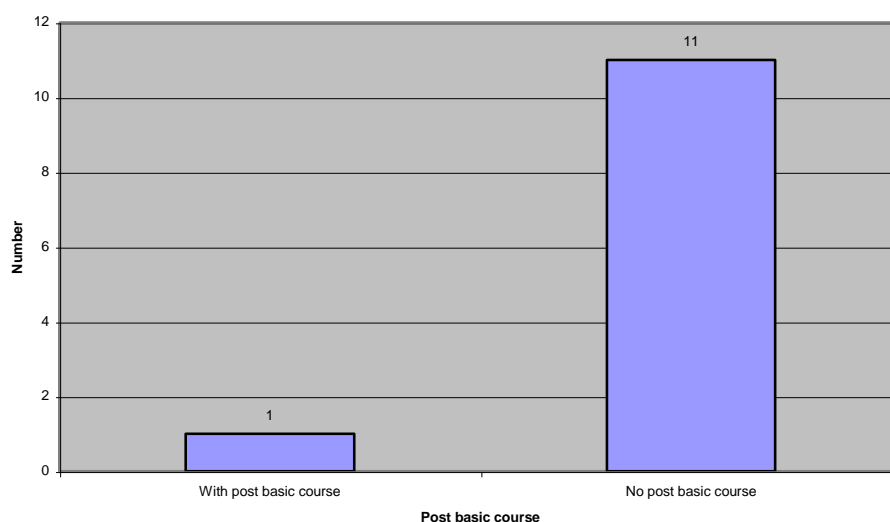
Two (25, 0%) of the registered nurses indicated that they had received training on the care of the children diagnosed with cancer during their basic training (Diploma in Nursing and Midwifery course). The other six (75, 0%) registered nurse indicated that they did not receive training during their basic training.

All the four (100,0%) of the enrolled nurses indicated that they had not received any training on the care of the children diagnosed with cancer during their basic training (Enrolled Nursing and Midwifery Training course). Nurses had undergone the training at different times and in the curriculum there is no specific focus on oncology nursing for children.

Item 6: Post Basic Nursing courses that nurse undergo that prepares them to care for children diagnosed with cancer.

Figure 3 Post Basic Nursing courses that nurse undergo that prepares them to care for children diagnosed with cancer.

Figure 3.3 Post basic courses that nurses undergo



It was found that One (8, 0%) of the nurses had undergone a post basic course on oncology nursing. Eleven (92, 0%) indicated that they had not undergone any post basic course that prepared them to care for the children diagnosed with cancer.

Nurses indicated that they had undergone any training on childhood cancer. On the open ended question on how they updated themselves, the participants respond as follows: through reading newsletters and books on oncology nursing, through attending medical seminars and workshops and through caring for the children diagnosed with cancer.

3.3 Qualitative analysis

The following themes and categories were arrived at.

Themes, categories and sub-categories

| Themes | Categories and sub-categories |
|--|---|
| Experiences of caregivers and nurses in caring for children diagnosed with cancer | Different view points on caring for children with cancer <ul style="list-style-type: none"> • Negative and Positive aspects |
| Support by developing a trusting and caring relationship between caregivers and nurses | Factors influencing a caring and trusting relationship. <ul style="list-style-type: none"> • Emotions experienced by participants. • Follow-up care of children diagnosed with cancer. |
| Problems in applying a holistic approach to care for the child diagnosed with cancer | Stumbling blocks in achieving holistic care <ul style="list-style-type: none"> • Basic needs and the fulfillment thereof <ul style="list-style-type: none"> -Physical needs -Psychological needs -Spiritual needs • Lack of effective communication and information |

3.3.1 Theme 1: Experience of caregivers and nurses in caring for children diagnosed with cancer

Children diagnosed with cancer are not always hospitalized for the whole period of their illness. Once they are stabilized they are discharged to go home. At home someone must take care of them (children diagnosed with cancer) and this person is usually called the caregiver. Because the child is still ill, it is important that the caregiver be properly prepared to care for the child at home (Doyle, Hanks, Cherny & Calman 2005: 988). The preparation programme should include all the aspects involved in cancer care namely the basic, spiritual, psychological and medical needs of the caregivers and the sick child (American Cancer Society 2005: 2; Kasper, Brawnwald, Fauci, Hauser, Longo & Jameson 2005: 437).

Childhood cancer, like adult cancer, is treated aggressively, often with a combination of chemotherapy, radiation and surgery at a time when the child is growing and developing (Lamb 1999:1). The treatment has a long term impact on the child's physical and psychological health, thus the need for a proper preparation programme for caregivers. Usually the main aim of a cancer care programme is to ensure and maintain the physical health and appropriate development of the child diagnosed with cancer (Jackson & Vessey 1996:219).

Categories

3.3.1.1 Different viewpoints on caregivers' preparation

Negative and positive aspects of the preparation

Caring for the child diagnosed with cancer is a demanding and difficult task for the caregivers. Thus, the caregivers need to have knowledge, skills, confidence, and be self empowered to take up the caring role. It is only through a properly planned caregivers' preparation programme that the nurses are able to empower the caregivers. The nurses are in a key position to consult with other health team members and serve as a source for the development of such a programme.

The preparation programme should include training that is individualised, practical, and should be offered in various formats like lectures, discussions and demonstrations (Mooney, Wolfe & Sommer year not indicated:1). An individualised preparation programme takes into consideration the weaknesses and strengths of the caregivers as well as the available resources. Practical and supportive preparation refers to the possibility of implementing the learned nursing care activities as well as encouraging the caregivers to be active participant in their children's' care programme.

Negative and positive remarks were made by the participants in this regard. It was found that there is no preparation programme for the caregiver of the children

diagnosed with the cancer in Northwest regions. These were the verbatim remarks of the participants.

“I was just called to go to Windhoek to collect my child... When I go to the hospital, the nurse just informed me that they could not continue with the child anymore, but I was not asked if I would be able to take care of my child at home.”

Another caregiver also explained:

“I was not included in the discharge planning but I was just called and told that the child’s life is to end, take the child home and take care of the child... I was not asked if I would be able to take care.”

On the other hand the nurses stated that sometimes the parents are not around during the time of hospitalisation, therefore they cannot be prepared to care for the child. However it is clear from the literature that nurses are in a key position to consult with caregivers beforehand and other members of the health team on a preparation programme (Stanhope & Lancaster 1996:540). This was also the opinion of Nettina (2006:1610, 1642-1643) that caregivers should be encouraged to take an active role in caring for their children even during hospitalisation, to enable them to be prepared when the child is discharged.

To complicate the issue of preparation, it was also indicated in many cases caregivers are not allowed to accompany the children to Windhoek where the main treatment unit is situated. After completion of specialised treatment the children are referred to the specific referral hospital.

Only then are the caregivers told to meet the children either at Oshakati State Hospital, which is a referral hospital or at the district hospitals. Even though the caregivers are responsible for the total care of their children diagnosed with cancer at home none of them indicated that they had received any preparation on how to take care of the child diagnosed with cancer at home apart from the follow-up date given. This is the statement of one of the caregivers.

“I was told to meet the child at the hospital of my district which I did and they just gave me the date for the next visit”

Although it was found that there is no formal preparation programme, nurses indicated that they use their own initiative to prepare the caregivers where possible. This is evident from the following statements.

“There is no programme but if the child has a wound I show the caregiver how to take care of the wound a week before the child is discharged.”

“I explained to the mother how to administer the medication of the child at home.”

“There was a child who developed facial disfigurement when she/he was referred back from Windhoek after the treatment (nose completely absent). I talk to the caregiver and advised her to cover the area for some time to protect the area and also to avoid public reaction that may affect the child psychologically.”

Another positive remark was that although there is no preparation programme some of the caregivers also indicated having received information on important aspects of child care such as diet and the safety of their children who are diagnosed with cancer. This is evidenced in the following statements from the caregivers:

“I was informed on the type of the food the child should eat and also what type activities the child should avoid.”

“I was told that the child should avoid fatty food and must not swim or climb trees to avoid accident.”

Caregivers’ education on basic nursing care is very important in any home care setting. It is also highlighted by that caregivers should be able to demonstrate basic skills on care techniques such as changing wound dressings, feeding as well as administering medication before the child is discharged (Nettina 2006:1642-1643).

3.3.2 Theme 2: Support by developing a helping trusting and caring relationship between caregivers and nurses

Childhood cancer is considered one of the major challenges a family can face (Williams 1992:1). Learning that your child has cancer is a very difficult experience. Caregivers, themselves, are at risk of developing illnesses like depression if they do not receive support from the health team members, family or friends.

As a caregiver, one may feel anxious, afraid and unsure about the future of the child and wonder how one will cope with the cancer.

Nurses working with caregivers of the children diagnosed with cancer have a significant supportive role in helping the caregivers understand the various therapies, preventing and managing expected side effects or toxicities, and observing for late effects of cancer treatment (Wong, Perry & Hockenberry 2002: 1373).

Playing a supportive role is about providing help or encouragement to the caregivers of the child diagnosed with cancer. It is through a trusting, caring and helping relationship that nurses are able to provide support to the caregivers of children diagnosed with cancer.

Caring is essentially ethical and moral in nature. It is based on knowledge, experience, and value (Van der Wal & Phil 2002:16). A caring and trusting relationship in the care of a child diagnosed with cancer is manifested through appreciating the caregivers and the child as human beings, showing respect, talking and to listening to, being honest to the child with cancer and caregivers as well as encouraging the caregivers to call if the need arises (Anonymous 3 2005:1).

Developing a caring and trusting relationship is about doing what is right within the confines of existing socio-religion and cultural norms, values and a like (Van der Wal & Phil 2002: 16).

Caregivers of children diagnosed with cancer, therefore need to be supported, taking into consideration their cultural, education and spiritual as well as socio-economic needs.

Cancer diagnoses and its treatment therefore require support of other team members to help the caregivers address the social, emotional, educational and spiritual issues that are part of the childhood cancer experience (American Cancer Society 2005:2).

Caring, counseling and offering educational activities are ways through which nurses can offer support to the caregivers of children diagnosed with cancer. Through education, nurses play an instrumental role in providing support and reassurance as well as accurate information regarding diagnosis, procedure and treatment plans. Education plays a role in giving the caregivers skills that make coping with cancer as a disease easier. Educating the caregivers about the possible side effects of cancer treatment as well as management helps caregivers to manage the child at home. It is important that the caregivers are given the opportunity to demonstrate the caring strategies before discharge (Nettina 2006: 1373 – 1374).

While caregivers' education promotes knowledge and skills on childcare, counseling on other hand helps the caregiver to cope. Gilbert (2004:50-51) described counseling as the activities of groups whose performance is based upon establishing a therapeutic relationship with a client.

Counseling of the caregivers therefore includes further explanations to the caregiver about the diagnosis (information), and explaining to the caregiver about the available treatment, including effects (support). Caregivers can also be linked to the available services within the community (Link to care) (MoHSS 2004: 11 – 16).

Counseling also includes, firstly identifying accurately the key concerns of the caregivers and the child with cancer (whether they be physical, social, psychological or spiritual in nature). Secondly counseling may help the caregiver to find strategies to resolve those concerns that can be resolved (Doyle et al 2005: 1176)

Categories

3.3.2.1 Factors that promote a caring and trusting relationship

Cancer is very complex and to care for the child diagnosed with cancer is thus extremely difficult. There are various factors that contribute to the success of a caring relationship that is developed between the caregiver, child with cancer, and the health team. Factors include emotions associated with cancer diagnoses as well as the care provided from the diagnoses, initiation of the treatment and throughout the follow up visits. Since there are many issues surrounding cancer diagnosis and treatment, trusting relationship can only be developed if the caregivers are made aware of everything involved.

Emotions experienced by the participants when the child was diagnosed with cancer

The life of the child is so precious and is hard to give that up (Dr. Joanne Wolfe) as quoted by McConnaughey (2000:1). Childhood is the time of happiness and everyone is a happy observing a child growing well. Any disruption in the child's health is likely to have the caregivers experience difficult emotions particularly fear, helplessness, and negativity.

Caregivers in this study experience different emotions that are similar to those identified by (Vlok 2004:342-348). The following statements from the caregivers evidenced this:

"I felt helpless because cancer is incurable disease only putting hope in God. I didn't hear of any person recovered from cancer."

"I felt bad because cancer is chronic and incurable disease."

"I was having fear. What I was afraid of is that if the person is diagnosed with cancer, it may take up to ten year under the treatment."

"I was just putting myself in the hand of God because I did not know what the future holds for me but I was not having any hope."

“I was really afraid because I don’t know whether me myself or any of my family member has got cancer.”

For most of the caregivers in this study, a cancer diagnosis carries a connotation of fear, hopelessness and thoughts of death. This appears to be influenced by the belief that cancer is fatal and once given a diagnosis, the child will live with the disease until death. This lends support to the view of Ash, McCockle and Ferguson (2004:65) that cancer is believed to be fatal despite the advances in diagnosis; treatment and that individuals are living longer, and in better health, with their disease. To assist the caregivers to cope with these emotions, the management of the child and the caregivers is best undertaken as a multidisciplinary collaboration among the various health team members working closely with the child diagnosed with cancer as well as the caregivers (Kasper et al 2005:435).

However these emotions were also found in the study that was done by Soliday & Smith (year not indicated: 1-8) on Psychological Aspects of Carcinoid Disease on a study of Carcinoid Patient and Caregivers. Soliday and Smith concluded that a significant proportion of individuals both patients and caregivers reported elevated depressive and anxious symptoms as a result of cancer diagnosis. On the other hand nurses also experience negative emotions when nursing the children diagnosed with cancer especially if the prognosis is not good.

This is evident in the following statements:

“I am comfortable in caring the children with cancer, but it is difficult, because sometimes you spent a long time with a child and you develop a relationship that the child looks as if is your own child. When you come to the time it is very difficult.”

“It is very difficult experience because we as nurses we also need counseling in order for us to be prepared for this task. I am not really comfortable in preparing and supporting the caregivers to care for their children, putting yourself in the shoes of those children suffering from pain...it is really painful. Sometimes you spent sleepless nights thinking about those children whose pain is not always responding to the treatment... It is not easy but as nurses we have to accept.”

It is evident from the literature (Papadatou et al 2002:1) that professionals who care for the children, who are dying or suffering from chronic diseases like cancer, suffer intense fear and increased helplessness.

While some of the nurses reported experiencing difficult emotions in preparing and supporting the caregivers, it was apparent that this was not the case with one of the nurses. The following statement evidenced this

“I had oncology training and it is my pleasure to receive children with cancer and sent them back home cancer free. In case of incurability as long as I keep them pain free it is really good.”

There were a number of issues raised by the nurses relating to how they experience and cope with both the children diagnosed with cancer as well as their caregivers. Nurses often described having to deal with difficult emotions (particularly depression). However one of the nurses indicated her/his appreciation in working with children diagnosed with cancer and their caregivers.

It was apparent that educational preparation of the nurses played a role in this regard. It is also evident from the literature (Vlok 2004:340) that specialised training for nurses caring for patients with chronic diseases like cancers helped the nurses to cope and enabled them to deliver quality nursing care.

Follow-up care of the children diagnosed with cancer

It has been shown that survivors of childhood cancer are at risk of developing secondary cancer and of experiencing organ dysfunction and reduced growth and development (Kasper et al 2005: 438). This is of a concern for any child who has completed cancer treatment. After the completion of the treatment children are followed up.

Follow-up care involves regular medical check ups that include a review of the medical history and a child's physical examination. Follow-up care of the child is important because it helps to identify changes in the health of the child, development of secondary cancer as well as unusual treatment side effects and the late effects of cancer treatment (Hammond, Levitan & Williams 2002:1).

To ensure compliance with treatment, follow-up care is important. It is also important for the nurse to talk with the caregivers about any questions or concerns about the care that the child should get or the follow up schedule. Failure to comply with the follow up schedule was found to be the problem among the caregivers and influenced the caring, helping and trusting relationship. The following remarks were made by the nurses:

” Some of the caregivers do not turn up for follow up dates as required.”

“Compliance with the follow up is a problem among the caregivers”

According to the nurses, caregivers indicated that the reason why they cannot comply with the follow-up schedule as required are because they have no money for transport, or no one to accompany the child to the hospital. The other reason given for non-compliance was of a cultural nature, the belief that the child is bewitched. This is evidenced by the following statement from the nurses:

“Some caregivers bring only the children to the hospital when they realized that the traditional healer is no longer of help or if they no longer coping at home with the child but not according to the follow up schedule...but when they come to the hospital their excuses is always money problem or no one to take the child to the hospital.”

“More often caregivers indicated that there is a need for them to be ‘examined’ by traditional healer to see what really went wrong, so that when they are treated in the hospital they know. Therefore sometimes the time is spent with the traditional healer.”

Culturally, if the person is bewitched, then modern medicine alone will not do. Therefore, the child may be taken to traditional healers and this may cause a disruption in the child’s treatment (follow-up) schedule, which in turn results in the cancer progressing and a delay in identifying any recurrences. This was also the conclusion of a study by (Munodawafa 2002:9) on Cultural Consideration when Measuring Family Functioning in Childhood Cancer, that quite a lot Africans will go to consult Western medical, church and traditional practitioners either concurrently, or alternatively, when faced with abnormal illnesses like cancers. They believe in the power of the spirit elders for support and in coping with such dilemmas.

During the interview with the caregivers, it was also apparent that they mostly live in the rural area far from the clinics and hospitals. Caregivers pointed out that with every follow-up they have to pay a hospital admission fee as well as the transport fee to either the district hospital or to the referral hospital. The following statement confirms this:

“The problem was the hospital fee and transport fee because with every admission you have to pay N\$ 22.00.”

“The problem is money because you have to pay transport and hospital fee.”

The literature evidenced that cancer imposes a heavy economic burden on the family of children diagnosed with cancer (Stubbs, Pearson & Pittsburgh 2000:3). Thus patients diagnosed with cancer and their family have financial concerns related to the strain of medical expenses and the cost of daily living as a result of cancer (University of Minnesota Cancer Center 2001:2). For a caring trusting relationship, it is firstly important that the negative emotions be worked through and secondly that there is continuous interaction through follow-up visit.

3.3.3 Theme 3: Problems experienced in applying a holistic approach to caring for the child diagnosed with cancer

Caring involves more than carrying out nursing procedures, such as bed making, feeding or giving treatment (Lindberg, Hunter & Kruszewski 1994: 5). It is about caring for the patient and taking into consideration the physical, psychological and spiritual needs of the client / patient. Attempting to attend to physical needs without addressing the patient non-physical concerns is likely to cause frustration and failure (WHO 1996: v), thus the need for a holistic approach to patient care. In order to promote a holistic approach to care / treatment, one must encourage and provide multidisciplinary team approach (Cutland Year not indicated: 1).

Families of children with chronic illness like cancer are often subjected to many challenges as a result of the consequences of cancer consequences (Neff & Spray 1996:448). If the impact of the cancer is to be minimised and the children are allowed to develop to their maximum, a holistic approach and co-coordinated care must be provided (Jackson & Vessey 1996: 6). There are many factors that need to be considered in order to provide holistic care to children suffering from cancer.

Categories

3.3.3.1 Stumbling block in achieving holistic care

Holistic care is a more interventionist approach, with the goal of working with the patient or client to specifically address issues which compromise quality of life. A holistic approach requires the allocation of greater attention to the individual's internal world (feelings, emotions and nutritional status and external environment (relationships, physical and economic situation (Twinn, Robertson & Andrews 2002:89). All this can only be achieved through proper individual assessment.

Basic needs and assessment there of

Basic needs are essential requirements for living. These are physiological processes as well as physical activities and adaptation processes, all of which enable an individual to function with optimum efficiency and respond appropriately to the environment. Basic needs can be classified into physical needs, psychological and spiritual needs (Young, Van Niekerk & Mogotlane 2003: 96,102).

Cancer has an impact on the fulfillment of the individual basic needs, and the children with cancer are dependent on their caregivers for the fulfillment of these basic needs. Physical needs comprise of the following:

- oxygen,
- circulation,
- fluids and electrolytes,
- nutrition, elimination,
- skin integrity,
- mobility and exercise,
- hygiene,
- comfort and rest,
- safety, sensation and
- perception and sexuality (Young, Van Niekerk & Mogotlane 2003: 96,102). The experiences of the caregivers to fulfill the physical basic needs were indicated under the categories of nutrition, hygiene, comfort and rest and safety.

Nutritional needs

Proper nutrition is important in children with cancer because the nutritional requirements increase during illness due to the change in the metabolic process, therefore the need for adequate nutrition to aid recovery of the damaged tissue. This damage is as a result of illness (Itano & Taoka 1998:223; Abeloff, Armitage, Lichter & Niederhuber 1995:1907).

Nutrition is another important component of infection prevention. An adequate protein-caloric intake provides the child with better host defenses against infection and increases tolerance to chemotherapy and irradiation (Wong, Perry & Hockenberry 2002:1374).

Concerning nutrition, caregivers in this study experienced difficulties in obtaining the required food for their children who were diagnosed with cancer. However these caregivers showed interest in ensuring that they procured food required for their children's condition.

For example one participant stated:

"If I happen to get money, I always use it to buy "good" food for her."

Another participant indicated that:

"My brothers and sisters who are working often send us money, and used that money to buy food for the child."

Although the caregivers indicated their willingness to provide their children with a special diet as instructed, none of them (caregivers) could relate the special feeding to the cancer and its treatment.

Furthermore the caregivers mostly referred to special food that is only available in the market place although there are some of the local foods that have the same nutritional constituents as those in the market place.

This could be an indication of lack of individualised preparation of caregivers in relation to satisfaction of children's basic needs. This was also found in the study by Hannele, Erikson, Abonen and Salantera (2004: 330) that in most cases the information provided to children diagnosed with cancer and their caregivers is irrelevant to their situation.

The nurses' experiences were also an indication of the stumbling blocks that occur when caring for the child suffering from cancer. The following statements are evidence of this:

“Children who are admitted to the cancer unit are sometimes severely malnourished.”

Nurses in the Windhoek Central hospital on the other hand indicated that since the children in the ward for a long time they encourage the family (those available) to bring them family food.

Hygienic needs

The word hygiene refers to the science of health and its preservation, in particular the word refers to cleanliness, both of the individual and the environment (Young, Van Niekerk & Mogotlane 2003:98).

Cancer treatment (chemotherapy) has a negative influence on the child's immune system, thus putting the child at risk of infections (Cutland, year not indicated: 1). Therefore maintenance of personal and environmental hygiene is important in the care of the child diagnosed with cancer.

The caregivers indicated that they were told to keep the children and the environment clean. However it was sometimes difficult because they did not have the means to do so. The following statement is evidence of this

“When the child discharged from the hospital she was just confined to bed. Later child developed sores. It was difficult for me because I did not have medical items to use (e.g. linen save).”

On the other hand nurses indicated that they show the caregivers how to clean their children so that they do not get infections.

However caregivers indicated some of knowledge concerning the safety of the children with cancer at home. The Following safety measures were taken: children were prohibited from swimming, climbing trees and doing heavy duty. This concurs with the view of Jackson and Vessey (1996:220) that swimming in dirty water and climbing trees must be avoided in children with cancer in order to avoid infection and injury in the already immunocompromised children.

Comfort and rest

Physical comfort means not only the absence of pain, but includes factors such as position of the body. Rest is closely allied to comfort and refers to a state of physical inactivity, response and relaxation (Young, Van Niekerk & Mogotlane 2003:99).

One of the stumbling blocks to ensuring comfort and rest is pain. Pain is often found in (children) suffering from cancer. Cancer pain control requires analgesics that are

administered around the clock as well as continuous monitoring of the child's response to prescribed analgesics (Wong, Perry & Hockenbery 2002:1374). A pain-free, stable condition allows the child the time to devote her /his energies to things that are important to him/her like playing, talking to friends and siblings (quality time).

A patient (child diagnosed with cancer), whose pain is not responding to the prescribed analgesics dosage, should always have their prescribed dosage or drug modified. The nurses thus have the responsibility to assess the pain response of the patient as well as teaching the caregivers and the client in this regard.

It was found that caregivers experience problems in controlling the pain in their children diagnosed with cancer. The following statements evidenced this.

"Sometimes when pain starts it won't improve even with administration of painkiller (medicine)..."

"My child was having severe pain especially in her last days but I could not do anything."

Some nurses who participated in the study also fear their inability to control the pain of the children admitted in their wards. This is evidenced in the following statements:

“Children with cancer have severe pain; even if you give medicine pain still continue.”

“Pain in cancer is unpredictable; it is really difficult to control.”

In this study it was apparent that nurses were dealing with difficulties in managing the pain of the children under their care. Uncontrolled cancer pain can be severe and may interfere with the child's food intake and contribute to infection.

In a study of acute oral pain and mucositis in bone marrow transplant and leukemia patients, pain in individuals diagnosed with cancer was found to be a significant and challenging clinical problem that required an interdisciplinary approach as well as multimodal interventions (McGuire, Yeager, Dudley, Peterson, Owen, Lin & Wingard 1998:385).

Safety and security

Safety and security as non-physical basic needs are essential for the care of the children with cancer. Safety and security refers to the need for structure and freedom from fear and anxiety (Marker 2003: 1). In this context the need for structure refers to the need for home environment and materials that are conducive to the child's home care. The need for freedom from fear and anxiety is fulfilled through the caregivers' ability to attend to the needs of the children diagnosed with cancer.

In this study caregivers indicated a certain degree of insecurity. The following statement evidenced this.

“I did not know what to do with my child...she was swollen on the mouth. I only end up feeding him with “Oshikundu” because there was nothing I can give.”

“You know in our houses things are scarce, being given your sick child to take him/her home is very difficult.”

This has an impact on the child’s need for safety and security during the disease process.

Psychological needs

Psychological needs usually comprise of cognition, adaptation, self esteem, support, security, autonomy, relaxedness and stimulation (Young, Van Niekerk & Mogotlane 2003:100-101)

Childhood cancer has an impact on all aspects of life, and causes considerable distress in the family. Concerns about this cancer and the desire to promote normal growth and development of the child has, led to an approach to care that gives attention to all parts of the child’s life and also that of the caregivers. Growing interest concerning the impact of suffering caused by cancer on the child and the caregivers necessitates the need for continuous psychological support for the child and the caregivers (Rustøen, Wiklund, Hanestand & Moum 1998: 235).

It was found, in this study that the caregiver's psychological needs specifically were not properly attended to. When caregivers were asked to explain how the nurses assisted them with their psychosocial needs, in many instances respondents (caregivers) indicated that nothing was done in that respect. This is also confirmed by the following case.

A caregiver whose child was diagnosed both with cancer and HIV did not come back for follow-up. The reason was that the caregivers had other commitments. This affected the child negatively; because the child is reported to have developed health problems during the time when the interview was conducted. The non-compliance of this particular caregiver might have been caused by many psychological factors.

The first factor is that the caregiver may have been in denial. Secondly the caregiver might have misunderstood the information provided. Thirdly, the caregiver / parent might have chosen to ignore the information provided to him /her. By implication, the psychological unpreparedness of the caregiver complicated the physical illness of the child with cancer. This lends support to the view that psychological unpreparedness for the disease or any stressful situation frequently complicates physical illness (Abiodun 1991:1).

One of the caregivers has a child who developed a physical defect due to illness, but she /he considers the defect not to be a problem. This can also be a form of denial. Caregivers or parents sometimes can express denial by pretending that nothing serious has happened.

Denial is normal, but if it persists for too long, it may have an impact on the care of the child. For instance, this child requires rehabilitation services but because the caregiver does not see the need and regards the child as normal, he/she ends up neglecting the needs of the child.

Contrary to the above, nurses indicated having used various strategies to support the caregivers of the children diagnosed with cancer. The basic psychosocial strategies included establishing relationships through information provision, referring caregivers of newly diagnosed children to others in the same position and referring the caregivers to other health team members e.g. social worker, and doctors. This was evident from the following statements.

“Sometimes parents with newly diagnosed children are referred to those whose children have been diagnosed for a long to serve as others counselors.”

“During admission the Sister in charge of our department always calls one of the nurse and a caregiver if available for them to discuss caregiver’s concerns.”

There were also positive remarks made by the caregivers regarding the satisfaction of their psychological needs.

“The nurses told me that it is difficult having a child with cancer. Take care of your child, if you need help we are ready to help.”

All the caregivers who participated in the study indicated that there are no childhood cancer-specific support groups available in their communities. Support groups reported to be available are those dealing with people infected and affected by HIV/AIDS. These groups are said to comprise of people of different age groups mostly church members.

On the other hand, nurses indicated that there are no support groups that they (nurses) liaise with concerning the caregivers of children diagnosed with cancer. It is also assumed that since the support groups for HIV infected are mostly doing home based care, they might also be assisting caregivers of children diagnosed with cancer. A nurse in Windhoek Central Hospital indicated that there are no clues of what is going on the communities especially for those coming from a distance

Making use of support groups can make a valuable contribution. Lowe (2003:1) highlighted the importance of support groups as follows: “Any caregivers will find comfort and assurance in a disease-specific support group where the problems and solutions are discussed. You can intimately involve in a situation like your own.”

Overall, the psychological needs of the caregivers and the children suffering from cancer were not met. This appeared to be influenced by lack of information, lack of support, lack of a patient-centered approach, delay in disclosing the diagnosis and test results as well as distance to the oncology treatment centre, and having to make a quick decision for the children referral to the treatment centre.

This is evidenced by the following remarks from both the nurses and the caregivers:

“It is difficult because sometimes the doctor knows the diagnosis and prognosis but is not telling the caregivers are just treating the child, in that case I will not have anything to start on. This really puts us in difficult position to prepare the caregivers but what we can do is just to encourage the caregiver to be strong and pray God.

“My child was treated for quite a long time almost eleven to twelve months, but no improvement the tumour is just growing until the body bent on side. She was even having problems when walking. I was wondering what was wrong with the child. The child was also discharged from the hospital in such a sick condition after she was operated three times. I remember that she was operated three times in Windhoek and Cape Town respectively. We were just given a follow up date on discharge nothing else.”

It is also evident from the literature (Daugherty 2005:1) that sometimes doctors are reluctant to disclose the diagnosis and are also not willing to discuss the prognosis.

Spiritual Needs

Spirituality is a critical part of cancer childcare (Lubkin & Larsen 1998: 215). Spirituality is a core dimension and critical determinant of a health related quality of life. A child cancer diagnosis often engenders spiritual needs, as the child and a caregiver struggle to find meaning and hope in the suffering that they experience.

The child and a caregiver experience cancer in their own different ways but all share the need to maintain a sense of spirit (Woodgate 2002:1).

Burton and Watson (2000: 98) maintain that religious faith can provide support, solace and personal meaning during a crisis and some patients and families turn to their spiritual roots during life-threatening illness. Religious faith is a system of spiritual belief. It is believed to have the potential to reduce the psychological and physical distress that often accompanies cancer diagnosis (Gallup & Lindsa: 1999) as quoted by Dann and Mertens (2004: 1). Thus spiritual dissatisfaction may affect other need of the children and the caregivers.

Taylor et al (1995), Millison and Dudley (1992), Carson (1989) as quoted by (Lubkin & Larsen 1998:220) identified numerous nursing interventions to promote spiritual well being to the patient and the family suffering from cancer. These include referring the patient and family to a pastor, facilitating religious rituals, prayers, providing spiritual music, active listening, dialogue about spiritual matters, recommending spiritual reading materials and being therapeutically present (trusting, loving empathetic and humble).

Caregivers in this study indicated that there are various groups of people that used to visit the wards preaching and singing. Caregivers felt that their spiritual needs were recognized by religious leaders (Doyle et al 2005: 954; Woodgate 2002: 1). This is evident in the following statements:

“There was always a church service in the ward...is only that language I do not understand but sometimes we were also asked to sing.”

“It was good that pastors are coming to the hospital wards pray and do blessing service to the sick.”

Nurses rarely indicated having addressed religious issues with the client except referring (telling) them to see their religious leader (representative or chaplains). This is evidenced by the following statements from the nurses.

“I used to inform the caregivers about the available spiritual services.”

“I encouraged the caregivers to see their religious leader if needed especially concerning their children’s baptism.”

On the basis of these results, the nurses in both hospitals where the study took place only talked with the caregivers about religious exercise, more specifically about the spiritual service available in the hospital. This concurs with the study conducted by Kuupelomaki (2002: 216) whereby nurses view the role of chaplain as particularly important in the provision of spiritual support.

As a result, individuals representing different religions are allocated to various hospitals. The reason for this is to foster the faith and spirituality of each patient and family (American Cancer Society 2005:6). Overall the spiritual needs of caregivers were attended to.

3.3.3.2 Lack of effective communication and information

Communication is a process whereby information is transmitted between people. The interaction between patient/client and the multidisciplinary health team is the vehicle by which the health information is imparted to the patient/client. For the health personnel to be helpful, they should not only possess specific health-related knowledge and skills but should be able to communicate effectively and function at a high level of empathy and sincerity (Young, Van Niekerk & Mogotlane 2003:284).

Children who are diagnosed with cancer usually have a long period of hospitalisation and treatment with intervals between these periods. This situation requires long-term interaction between the health care team and the caregivers. Thus interpersonal communication is very important.

Interpersonal communication is defined as communication that occurs between people who have known each other for some time. Importantly, these people view each other as unique individuals, not as people who are simply acting out social roles (Borches 1999:1, Sines, Appleby & Raymond 2001:44-25).

In the process of interpersonal communication information, training and education should be given by the nurses to the caregivers. Furthermore the caregivers should be given ample opportunities to ask questions. It is therefore important that correct, clear, honest and direct communication exists between the nurse and the caregivers.

Information needs to be given a little at a time and repeated frequently (Fryer 1994: 11).

It became apparent in this study, that caregivers experienced lack of communication and information. In many instances the information provided is unclear and incomplete, leaving the caregivers with many unanswered questions. This is evidenced by the following statements from caregivers:

“I feel that the government failed its responsibility. The failure is that I have heard that the child is to be sent to Cape Town but later was just operated in Windhoek and sent back home to Oshakati. I don’t know if it was a money problem.”

“The treatment of my child did not end well. The child was given a follow up to Windhoek, but when we went to Oshakati for Windhoek transport arrangement she was turned back home. Now I am worried because she is have one kidney and is approaching puberty. I do not know now if she engages in sexual activities if she will be able to carry the pregnancy.”

The implications of such situations are that the lack of information may create a gap between the service provider and the recipient of care (public). The other point of concern is how the caregivers perceived the information and support provided. Much depends on the cultural background, some caregivers may respond to the instrumental support more than the emotional or and vice versa (Courtens, Stevens, Crebolder & Philipsen 1996:165).

Parents of children diagnosed with cancer need information in order for them to understand the need for active treatment and prolonged follow-up of the child (Cutland year not indicated: 2, Searle 2000: 250). Communication with someone whom you have confidence in and whom you trust and respect, will only be effective if it is clear, direct & honest (American Cancer Society 2005:7).

In this study, lack of information about the child's diagnosis was found to be a problem among the caregivers who participated in this study. This is evidenced by the following statements from the caregivers:

"I do not know if cancer occurs as a result of our actions because after the death of my child, two of the family members also died of cancer."

"I do not know whether the child is born with the disease or not, because when I was expecting her at four month gestation I experience my periods. When she got sick at the age of one month she started urinating blood."

In many instances the caregivers know that the child is suffering from cancer but do not know what it is or what causes it. The same was found by Yin and Twin (2004: 20) in the study conducted among the Hong Kong Chinese families with cancer.

Furthermore, none of the nurses indicated that caregivers are provided with information on the available treatment for their child and the effects of the available treatment on the child's condition.

This might have an impact on the care of a child diagnosed with cancer, since therapy may bring unpleasant symptoms and the child may appear more ill (Wong, Perry & Hockenberry 2002: 1372).

Nurses also highlighted some shortcomings when it comes to information and communication between the caregivers and the health team. Delay in disclosing the diagnosis and test result is said to persist among the medical practitioners who have the overall responsibility to inform the patients. This is evidenced by the following statements from the nurse

“Some times the doctor knows the diagnosis and the prognosis but is not telling the caregiver is just treating the child.”

Nurses also have a responsibility to communicate and give information to the patient pertaining to the required care (Searle 2000: 250). Therefore the blame cannot only laid on the doctors, nurses are responsible.

The following story from one of the caregivers concurs with the above statement from the nurses.

“One day I brought my child to the hospital because of the tumour which was not improving on the treatment. That day I really felt that the hospital staff is tired of us. I was told that the doctor is off. I could not go back home but decided to overnight with my child. Next morning I was first at the consultation room.

The nurses were just avoiding me, I was just told to hang on until I was called in. I was told that the child has got cancer and is not going to cure but I have to take my child home and take care of her.”

3.4 Summary

In this chapter, data obtained was analysed and the findings obtained were discussed, taking into consideration findings by other researchers in the same field. The main problems were the following; lack of a proper preparation programme, several factors influencing a caring and a trusting relationship between caregivers and nurses, difficulties in fulfilling basic needs in caring for children diagnosed with cancer, and the lack of effective communication and information.

CHAPTER 4

CONCEPTUAL FRAMEWORK

4.1 Introduction

The conceptual framework deals with concepts that are relevant to the study topic thus providing a framework of the problem under investigation (Polit, Beck & Hungler 2001:462). The conceptualisation also refers to both clarification and the analysis of key concepts in a study and to the way in which one's research is integrated into the body of a larger existing conceptual framework (Mouton: 1996:110).

The framework within which the study was conducted is discussed within the practice model as described by Dickhoff, James and Wiedenbach (1968:434-435), using elements of practice theory, which are context, recipient, purpose and dynamics (interaction).

4.2 Elements of the practice theory

Context: Hospital and the home

Children diagnosed with cancer are admitted to the Oncology Unit at Windhoek Central Hospital, stay there until they have stabilised then sent back to their district

hospital. From there they are discharged home. Thus, the different hospitals, as well as the home as the context, are a multipurpose environment in which the nurses and the caregivers must interact. During this interaction caregivers should be taught and guided on how to care for the child diagnosed with cancer.

When the child diagnosed with cancer is hospitalised it is a strange environment and the family as well as the child is usually frightened. The role of the nurse in this regard is to assist the child and the caregivers to settle in to this new environment. This will be the beginning of the process of the preparation and support to the caregivers and the child. It is during this stage that the nursing process should be applied in the care of the child. Caregivers, if at all possible should be involved.

Preparation of the caregivers comprises the assessment of the caregiver as well as the child's needs, planning to fulfill the needs for both, implementing the plan, evaluation of the progress or lack of progress and accurate record keeping.

The patient charter of Namibia, which is a national document, stipulates the rights of the patients and clients. It stipulates that citizens who are suffering from any ill health or disease are to be protected and will enjoy the same rights as their healthy compatriots (MoHSS 1998:1-9). Therefore caregivers and the children should be informed about all the aspects concerning diagnosis, treatment and care. This places an ethical obligation on nurses to provide caregivers and patients with relevant health education and information (Young, van Niekerk & Mogotlane 2003:285).

Furthermore, the Nursing Council of Namibia is a statutory body that is accountable for the highest standard of nursing care for all the people of the Republic of Namibia. The Nursing Council of Namibia requires that the nurses practice the highest standard of nursing care. To achieve this, caregivers should be prepared to be able to adopt to change, identify and solve problems concerning the care of the children at home. The creation of an environment conducive for interaction between the nurses and the caregivers is therefore mandatory.

Agent: The Facilitator and the recipient

The facilitator (nurses in the hospital)

Nurses are an important group of health workers. Nurses as health care team members spend lots of time with the caregivers and the children during hospitalization. Therefore they can serve as coordinators of the health care team as regards the treatment. If the family expectations of what support a nurse can provide are greater than nurses can provide, the nurse may need to help the caregiver to find another team member who can provide the time and support needed for the child and caregivers . It is important for the nurses to remember that the success of cancer children's treatment will only be determined by their caregivers' commitment to treatment. This is usually a result of psychological preparedness.

Teaching and guidance of caregivers involves more than merely giving information. It also includes support to the caregivers. Nurses should determine the needs of the sick children as well as those of the caregivers.

Assessment should also concern the ability of the caregivers to satisfy the basic needs of the children diagnosed with cancer at home. The basic needs include physiological needs like nutrition, clean water, elimination of waste products (toilet facilities), mobility and exercise, personal hygiene, comfort and rest, safety and security and self esteem (Young, Van Niekerk & Mogotlane 2003:97-98).

According to Jackson and Vessey (1996:200) radiation has many side effects similar to those of chemotherapy, which include nausea, vomiting, diarrhea, mucositis, cataracts, skin changes, hair loss, and endocrine abnormalities. It is therefore very important that the nurses working with children diagnosed with cancer help the caregivers to understand the various therapies.

Nurses should have the clinical knowledge and the competences, read widely, and keep abreast of developments in order to assist the caregivers during preparation sessions. Furthermore nurses attitudes towards the children diagnosed with cancer and the caregivers should be characterised by respect for the caregivers as human being. Nurses should be aware that each child and each caregiver is a unique being with his or her own biological, psychological, social and spiritual needs.

The problems experienced by the children with cancer differ based on the cancer site, disease progress, and the treatment protocol. Leukemias are, for example, treated with a combination of chemotherapy and radiation (Hay et al 2003: 891-893).

Since chemotherapeutic agents are not selective to malignant cells only, useful cells can also be damaged in the process. This leads to complications that are worse than the disease itself.

Cancer treatment is a long-term therapy and the children are only admitted for treatment on a regular basis in order to keep hospitalisation at a minimum. It is important to realize that long-term home care can put the child and the family at risk of developing family coping problems. The nurse should then be a positive force to encourage the development of positive coping mechanisms that the child's condition demands.

Nursing interventions that are of value to the caregivers of child diagnosed with cancer include:

- assessing and understanding the caregiver's cultural values about cancer and its treatment,
- communicating frequently with the caregivers,
- making the caregivers comfortable by orientating them to the hospital setting and hospital procedures,
- referring the caregivers to others health team members and
- preparing the caregivers for home care (Thompson et al 2002:1184).

The quality of life of the children diagnosed with cancer should be improved through the provision of medical and emotional support for the children diagnosed with cancer and their caregivers.

Support groups, individual counseling, provision of adequate supplies and medications as well as regular respite periods are all the strategies that can be employed in supporting the caregivers. Debriefing sessions are also very important for the emotional refueling of all the caregivers (Young, Van Niekerk & Mogotlane 2003: 209).

Recipient: Caregiver and the child diagnosed with cancer

Caregivers are mostly lay people but they are the backbone in the care of the child diagnosed with cancer at home, although they are not recognized as such and in many instances left without any information regarding their role and function (Reeve 2003:2).

It is expected that the caregivers will perform the health care procedures at home that were previously done by the nurses in the hospital. It is a stressful experience for them, therefore they need information and education. All members of the health team, especially nurses, can assist, guide and teach them how to do specific procedures and give them information that is needed about the diseases and specific aspects of caring, like food intake. The caregivers should be given ample opportunities to ask questions and to discuss their fears and problems.

With more advanced technology most of the children diagnosed with cancer will have a normal life expectancy. This requires the caregivers to have understanding of the child's situation. Very importantly is the understanding about the child's growth

and development as well as the effects of the cancer and its treatment on children's growth and development.

The role of the educational arena should not be overruled. Participation in school promotes independence and opportunity for self-esteem building that is not readily achieved at home Sylva (1994); Weitzman (1984) as cited in (Jackson & Vessey 1996:37). The Namibian Constitution provides equal rights to education for all children irrespective of their health. It is important for the child to continue with his/her schoolwork while in the hospital. Parents should be encouraged by the nurses to collaborate with the schoolteacher and hospital teacher to ensure minimal interruption in the child's schoolwork.

The nurses should have regular liaison sessions with the multidisciplinary health team as well as support groups in the church or community to discuss the child progress and other problem pertaining to the treatment plan and progress. Thus session will also help to foster a good relationship with all concerned and support the caregivers.

Information concerning the situation at home is also important. Data about the home environment (which includes the availability of electricity and presence of the home physical structure that can make it easier to, make use of the medical equipment) is needed. All this information will help to determine how easy or difficult it will be to perform the task in the home.

Factors that also need to be assessed include age of the child diagnosed with cancer, family members and family background (Thompson et al 2002: 1184).

The purpose

The purpose of the preparation and support is to educate the caregiver to care for the child at home in a proper way.

Dynamic Interaction

One of the aspects of preparation and guidance is to facilitate caregiving. Authors stated that by facilitating, the facilitator (nurse) enables the caregivers to move on to the next stage; that is to cope with the aspects of caring. It is important that all stakeholders concerned with the care and the treatment of the child should be involved in all matters affecting care and the treatment.

Thus interpersonal communication is of the utmost importance. The way in which communication takes place in the health care system, in particular communication between the nurse and patient, the nurse and the patient relationship is of importance (Searle 2000:253).

The art of communication is a vital factor that should give warmth and meaning to nursing practice. The way in which the nurses' image and actions are communicated to the caregivers will determine the degree of trust that the caregiver has in the nurse.

Children who are ill and who have moved from the safe, known environment of their home to the impersonal environment of the hospital need tender loving care. Tender loving care is something more than skill and knowledge. It is something that flows from a compassionate human being who has the ability to dispel anxiety and to handle people (Searle 2000:263). This is particularly important for the children diagnosed with cancer and their caregivers. Thus nurse-patient interactions involve a wide range of activities subsumed under the umbrella term communication and these include social conversation, information giving, asking and answering questions, explaining and demonstrating skills (Quinn 2000: 444).

When giving information to the caregivers the nurse should ascertain what the caregivers already know about the issue and then build upon that knowledge. She/he should deal with the most important aspects first and those lesser importance later. Further-more the nurse should avoid overloading the caregiver with information but, proceed in sequence of small steps, checking the understanding of the caregivers at each step and avoiding medical terminology (Quinn 2000:450).

4.3 Summary

In this chapter, the framework in which the study was done was discussed using the practice model and the elements of practice theory. For the purpose of this study, the conceptual framework was not used to develop a model but to indicate the important aspects in which the preparation of caregivers by nurses could be done. However, this framework can also be used as a basis for further research.

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 Introduction

The previous chapter provides a conceptual framework under which the study was conducted. This chapter provides a brief overview of the study with emphasis on the purpose, conclusions and recommendations for the improvement of preparation and support of the caregivers of children diagnosed with cancer. Limitations of the study will also be highlighted in this chapter.

5.2 Purpose

The purpose of the study was to explore and describe the preparation and support, which nurses are providing to the caregivers of the children diagnosed with cancer in the Northwest regions of Namibia namely; Ohangwena, Omusati, Oshana and the Oshikoto Region.

5.3 Conclusions

Based on the data and the findings of the study, the conclusion will be discussed according to the objectives of the study.

Objective 1: To describe the demographic profile of the participants.

The quantitative part of the study did not influence the conclusions. The data was only used to get a broader picture of the population.

Objectives 2: To determine the preparation and support which nurses are providing to the caregivers of children diagnosed with cancer.

It was concluded that there were negative as well as positive remarks in this regard. There is no formal preparation programme for the caregivers to care for the sick children at home. However it was also mentioned that some nurses teach the caregivers about wound care and the administration of medication.

Objective 3: To identify support systems available in the community where the children and the caregivers can get assistance.

It was concluded that there are no formal organised support systems where nurses and caregivers are assisted to develop a trusting helping and caring relationship.

The only support system is the religious services assistance that are available in the hospital and the community. Furthermore the different emotions experienced by both groups make this relationship complicated.

Objective 4: To describe the problems that caregivers of children diagnosed with cancer experience relating to the fulfillment of basic needs.

The majority of caregivers are unemployed and therefore experience difficulties in fulfilling the basic needs of the children they care for.

The basic needs that were mentioned were transport to hospital and treatment fees, nutritional needs, lack of support and lack of proper communication.

5.4 Recommendations

Preparation of nurses and caregivers

This is the first study on childhood cancer to have been conducted in the Northwest regions. Therefore other studies in the field are recommended.

Based on the conclusion and analysis of the study findings, the following recommendations were made:

Continuous education for nurses

It is recommended that continuous in-service education session be offered to nurses who are allocated to cancer units to care for children diagnosed with cancer. The

sessions should be conducted by nurses who have the additional qualification in oncology nursing. Topics on childhood cancers as well as on how to assist caregivers should be covered. A family-centered approach should be followed in the care of the child diagnosed with cancer.

It is also recommended that the principles of the family centered approach be considered in the care of the children diagnosed with cancer. The family-centered approach provides a framework for the nurse to ensure that all the aspects of care are focused (Wong 1995:1240).

Furthermore guidelines should be developed to assist the nurses working with children diagnosed with cancer and their caregivers. This can be done by the hospital concerned in collaboration with the Pediatric Oncology Department. Follow up training is also recommended as the staff may rotate.

Preparation programme for caregivers

It is also recommended that a preparation programme be developed and that caregivers be given an opportunity to attend regular sessions. Dates for sessions should, as far as possible, be decided on in consultation with caregivers who have to travel great distances.

Nurses and caregivers should decide together on a framework for the preparation programme and draw up the complete plan to be followed according to a chosen sequence. According to Quinn (2000:468) this sequence should be carefully planned

and can be built gradually. This implies the use of activities that are not highly threatening in the early phases of the programme. As confidence and trust develops, it will be possible to introduce activities that call for a greater personal investment and disclosure.

The following recommendations refer to the content to be included in the preparation programme to assist the caregivers.

Nutritional needs

Childhood is the period that demands proper feeding. The children's diet should contain all the required nutrients in sufficient quantities and quality. Children undergoing cancer treatment are at risk of malnutrition due to the effects of treatment on the gastro intestinal system as well as poor appetite. Cancer increases nutritional requirements due to increased metabolism.

On the other hand, cancer treatment causes gastro intestinal disturbances, which, in turn, lead to under- nutrition. Excellent nutrition before intensive therapy provides nutrient storage during periods of anorexia, nausea and vomiting that will result from cancer treatment (Wong 1995:1623). It is important that nutritional support should be a part/component of cancer treatment. The caregivers need to be informed of the importance of optimum feeding before the start of intensive therapy as well as the nutritional value of the local available food such as fruits, vegetables and milk.

It is recommended that the available foods in the area be studied for their nutritional value and that an information brochure be compiled with this information in the local language.

Hygiene and skin integrity

The risk for infection in the child with cancer is very high due the fact that they are treated with anti metabolites which cause immunosuppression, thus putting the child at risk of infection (Kasper et al 2005:471-476). Therefore, the caregivers should plan bath sessions on a daily basis and hair care on a weekly basis as well as mouth care because of stomatitis that may result in systematic infection in the immunosuppressive (myelosuppressive patient) (McGuire et al 1998:387). Intact skin serves as a first line of the body's defenses against infection. Caregivers should ensure that the child's environment is hazard free. If the skin is damaged the principles of wound care should apply. It is recommended that a brochure be compiled in the local language on the importance of hygiene and follow up visits.

Comfort and rest

Children who are diagnosed with cancer should get enough rest. This can only be obtained if they do not have pain and discomfort. Caregivers should be educated and trained on how to administer medication with specific reference to pain management.

Furthermore, the caregivers also need to attend to their own physical, emotional, and spiritual needs so that they can provide better care to the sick children. Caregivers themselves need to get adequate rest and exercise as well as breaks from care giving

responsibilities (Anonymous 3 2005:1). When possible, the nurses can arrange with the caregivers for the child to either be admitted to hospital for a period of time or arrange with the relatives to relieve the caregivers for a period of time.

Safety and security

Physical safety and security is important for every human being, but emotional safety and security is especially important for children with cancer. Children with cancer can feel insecure because they do not know what is going to happen to them. On the other hand the caregivers can also experience a feeling of insecurity because they may feel they do not know enough about the disease to care for the child and may be anxious. It is recommended that sessions to give emotional support to the caregivers and children be planned when the caregiver with the child goes to the nearest hospital for assistance.

Furthermore, sessions to prepare caregivers for terminal illness as well for death are also important. This is in fact true, as many people, professional or non-professionals, are uncomfortable in the presence of the person with a terminal illness like cancer (Vlok 2004:). These sessions should be done with the assistance of a social worker, if possible.

Support to nurses and caregivers

It is also recommended that the support groups be established by the hospital or the different churches. This could be initiated by the nurses working in the hospital wards where the children are admitted.

Children diagnosed with cancer and their caregivers face many challenges that may leave them feeling overwhelmed, afraid and lonely (National Cancer Institute (NCI) 2002: 1). It is difficult to face these challenges. Often people affected by cancer find and receive comfort and assurance in a disease-specific support group (Lowe 2003:1). This support group will make them (caregivers and patient) feel less alone and improve their ability to deal with the uncertainty and challenges that cancer brings. In the study conducted by (Rustøen et al 1998: 235), it was established that participation of patient and caregivers in support groups has been shown to impact positively on the patients as well as caregivers coping and emotional responses.

The main purpose for participating in the support group is to improve the coping and emotional responses of the children and the caregivers. It is important that the nurse working with cancer children and their caregivers have information about the available support groups within the caregivers' community. It is also important to set up a mechanism or a procedure to be followed regarding referrals of the caregivers and child to these support groups (Burton & Watson 2000: 162-3, Dreyer, Hattingh & Lock 1997:135).

Communication: It is recommended that caregivers be introduced to the health team members responsible for their children's care and offered opportunities to express and share their feelings and to ask questions. This was also emphasised by Fryer (1994:9) who argued that through expressing and sharing feelings, the health team, together with the caregivers and the child, would develop a trusting relationship and build a foundation of mutual understanding to sustain communication throughout the long period of the child's illness.

Nurses should explain to caregivers the treatment, side effects and the care of the child prior to and during the treatment in order to get caregivers co- operation, especially when there is a language problem between the doctor and the caregivers. This was also stated by Searle (2000:250) who was of the opinion that nurses have responsibilities towards the caregivers. The responsibilities include verifying what the doctor has said, explaining things further, if required and providing ongoing information. Use of the interpreter may be necessary to emphasize information.

Caregivers have the right to get information concerning the condition of the child they care for; they will also have a need to get all the information. According to Young, Van Niekerk and Mogotlane (2003:285) the accuracy and effectiveness of the patient (caregivers) education is particularly important in situations where the caregivers will be expected to manage some aspects of treatment independently.

It is recommended that leaflets be prepared and provided to caregivers to guide them in the caring of the child diagnosed with cancer. Special attention should be given to aspect that many caregivers may be illiterate.

Problem in applying a holistic approach

Concerning the financial constraints it is recommended that a committee that consists of caregivers, community leaders as well as hospital personnel be established to determine how caregivers can be assisted in this regard. The nurses in these wards can initiate the committee and this will create a platform where caregivers can be informed about fee structure, transport opportunities, visiting dates to assist the caregivers. It will also give the caregivers the opportunity to explain their problems.

5.5 Limitations of the study

Limitations applicable to this study are related to the study population and the data collection.

Population

In the Oshikoto Region only the Onandjokwe District was included in the study due to the fact that all the files traced from the admission office of the Oshakati State Hospital which is the referral hospital, none of files belongs to the child from the Tsumeb District. Therefore the Oshikoto Region was only to be represented by the caregivers in the Onandjokwe district.

Of the twenty-two files traced in the Oshakati State Hospital only thirteen of the caregivers mentioned were reached and interviewed due to the following:

- **Wrong and inconsistent identification of the patient's files which lead to difficulties in identifying the caregiver's location.** Sometimes the child was brought to the hospital by a visiting family member (visitor). At the hospital the information recorded on the file might only the particulars of the person who brought the child to the hospital.
- In some cases the name indicated in the file was not one known in the village. This was the case especially when traditional clan names such as 'Mukwaanime' are in the village while at the hospital the Christian names are recorded. “

Data collection

Of the three focus group discussions that were proposed only two were conducted, with few people present due to staff allocation. The other focus group discussion was replaced by an individual interview since only two nurses were allocated for a shift on the ward. Therefore one nurse was interviewed while the other one was attending to the patients.

Although it is assumed that participants would answer questions posed to them during the focus group discussion and face to face interview with honesty and integrity it was found that participants at times answered questions in a way that they thought would please the researcher. This is what (Polit, Beck & Hungler 2001: 175) called Hawthorne effect. Although there are strategies used to ensure trustworthiness of the data, there might therefore still a possibility of misinterpretation of the participants' experience.

5.6 Summary

The Government of the Republic of Namibia through the Ministry of Health and Social Services has introduced several programmes that cater to the needs of the children.

However, one of the challenges that has remained throughout the years is childhood cancer nursing, specifically, training for caregivers of children diagnosed with cancer. During this study, questions related to the preparation and support that nurses are providing to the caregivers of children diagnosed with cancer were addressed through focus group discussions with nurses and face to face interviews with caregivers of cancer diagnosed children. Gaps were identified and recommendations were made.

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ANNEXURES

ANNEXURE A

Guidelines for the face to face interview with the caregivers

Introduction

Interviewer: I am Eva Ndahalako Amakali a registered nurse and lecturer at Oshakati Regional Health Training Center in Oshakati hospital. I am also a Masters student at the University of Namibia. Currently I am conducting a study on **The preparation and support by nurses to caregivers of children diagnosed with cancer Northwest Regions (Ohangwena, Omusati, Oshana and Oshikoto).**

Firstly I would like to thank you for allowing me to discuss with you matters related to childhood cancer.

Secondly I would also like to inform you that:

The aim of the interview is to collect information concerning your experience on preparation and support which nurses provided to you during the diseases process of your child. The information that you provide will assist in improving the care of the child with cancer and their caregivers.

I am going to ask your personal information and information related to childhood cancer which will be noted. To maintain anonymity, no name will be used during the discussion instead you will be identified as "Meme." The discussion will be tape-recorded and the reason for tape recording the interview is to assist to capture all the information that you are providing. The information that you are going to provide will be treated confidential. Participation in the study is voluntary. You have the right to express your feelings, ask for clarification if the question is not clear to you. No money will be offered.

First I have to fill in your personal information in this form before we start with the discussion.

A. Biographic data for the caregivers

1. Age:-----
2. Sex: -----
3. Location: Urban --- Rural: ---
4. Region: ---- 5. Religion: -----
6. Educational -----
7. Employment status Employed-- Unemployed-----
8. How many people you live with-----
9. Your relationship to the child diagnosed with cancer-----
10. For how long your child has being diagnosed with cancer? -----
11. Distance from the health facility in km-----.

B. Questions

1. Please tell me your experiences on how you were prepared and supported by the nurses throughout the disease process to care for your child who was diagnosed with cancer.

2. Which support systems are available in your community for the children diagnosed with cancer and their caregivers?

3. What problem do you experience when caring your child at home?

ANNEXURE B

Guideline for Focus group discussion with nurses

Interviewer: I am Eva Ndahalako Amakali a registered nurse and lecturer at Oshakati Regional Health Training Center in Oshakati hospital. I am also a Masters student at the University of Namibia. Currently I am conducting a study on **“The preparation and support by nurses to caregivers of children diagnosed with cancer Northwest Regions (Ohangwena, Omusati, Oshana and Oshikoto)”**.

“First of all I would like to thank everybody here for availing yourself to come and attend this discussion in which we will discuss matters related to the preparation and support which, nurses are providing to caregivers of children diagnosed with cancer. This session was chosen because of increased incidence of childhood cancer. You were also specifically selected due to the fact that you are working with children diagnosed with cancer to give information that can also assist the researcher in answering the research question.

I would like to inform you that: The aim of the focus group discussion is to collect information concerning the preparation and support which, nurses are providing to the caregivers of children diagnosed with cancer. The information will be used to improve in the areas concerning the care of children diagnosed with cancer.

No report will be prepared which identifies the views of any of the participants. Each information will be kept confidential.

Please fill your personal information in the questionnaire provided.

A. Biographic data for the nurse

1. Age ----- 2.Sex-----

3. Qualification -----

4. For how long have you been working in the department?

| 0-1yr | 1yr-2yrs | 2yrs-3yrs | 5yrs and above |
|-------|----------|-----------|----------------|
| | | | |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course-----

6. Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course-----

6.1. If, no how do you keep abreast with new developments regarding cancer nursing care? -----

B. Questions

1. Tell me your experience on the preparation and support you give to the caregivers of the children diagnosed with cancer throughout the disease process.
2. How do you support the caregivers in order for them to cope with them to cope with their children diagnoses?
3. Which support systems/ support groups are available in the community for the children diagnosed with cancer and their caregivers?
4. What mechanism/procedure in the hospital that is followed regarding the care of the children n diagnosed with cancer?
5. What problem do you experience with the caregivers of children diagnosed with cancer?

ANNEXURE C

Caregivers Interview Sample

Introduction

Interviewer: I am Eva Ndahalako Amakali a registered nurse and lecturer at Oshakati Regional Health Training Center in Oshakati hospital. I am also a Masters student at the University of Namibia. Currently I am conducting a study on **The preparation and support by nurses to caregivers of children diagnosed with cancer Northwest Regions (Ohangwena, Omusati, Oshana and Oshikoto).**

Firstly I would like to thank you for allowing me to discuss with you matters related to childhood cancer.

Secondly I would also like to inform you that:

The aim of the interview is to collect information concerning your experience on preparation and support which nurses provided to you during the diseases process of your child. The information that you provide will assist in improving the care of the child with cancer and their caregivers.

I am going to ask your personal information and information related to childhood cancer which will be noted. To maintain anonymity, no name will be used during the discussion instead you will be identified

as “Meme.” The discussion will be tape-recorded and the reason for tape recording the interview is to assist to capture all the information that you are providing. The information that you are going to provide will be treated confidential. Participation in the study is voluntary. You have the right to express your feelings, ask for clarification if the question is not clear to you. No money will be offered.

First I have to fill in your personal information in this form before we start with the discussion.

A. Biographic Data of the Caregiver

1. Age: **45years**
2. Sex: **Female**
3. Location: Urban----- Rural: **X**
4. Region: **Ohangwena**
5. Religion: **Evangelical Lutheran Church**
6. Educational -**Standard five**
7. Employment status: Employed: Unemployed: **X**
8. How many people you live with: **six children**
Four others
9. Your relationship to the child diagnosed with cancer: **She is my daughter.**
10. For how long your child has being diagnosed with cancer? **Eleven to twelve month I can say a year.**
11. Distance from the health facility: **The clinic is nearby but Engela hospital is 25km.**

B. Questions

Interviewer: Please tell me your experiences on how you were prepared and supported by the nurses throughout the disease process to care for your child who was diagnosed with cancer.

Caregiver: It was a very hard and painful experience for me. Let me start with the pregnancy. When I was four month pregnant I experience my periods. I went for a treatment then I was fine. When my child started with the disease she started urinating blood. She was treated at Engela hospital and improved. Now I do not know whether the child was born with the diseases or not, because me myself I do not know whether I have cancer or not.

Interviewer: Can we came back to that later, but for now can we stick with your experiences on how you were prepared and supported by the nurses throughout the diseases process of your child?

Caregiver: Well, what I can say is that those people did not take care of us. I remember that when the child starts I took her to Engela hospital where she was treated for Schistosomiasis. A month after she developed a tumour on the left side at a kidney level and was passing bloody urine still. I took her to Engela hospital and we were referred to Oshakati hospital.

I went with my child, but I was not accommodated in the hospital I was just staying at the place outside the hospital premises were lodgers stay.

I only came to see my child during visiting times. Later I was asked by the nurses to sign forms for my child to go to Windhoek. She went to Windhoek alone with nurses only and also to Cape Town.

Interviewer: Why are you saying that the hospital did not take care of you?

Caregivers: Well, my child was treated for quite a long time almost eleven to twelve months, but no improvement the tumour is just growing until the body bent on side. She was even having problems when walking. I was wondering what was wrong with the child. The child was also discharged from the hospital in such a sick condition after she was operated three times. I remember that she was operated three times in Windhoek and Cape Town respectively. We were just given a follow up date on discharge nothing else.

Interviewer: How did you learn that the child has got cancer?

I was told by the doctor in Oshakati hospital that my child has got cancer. When we were discharged I could not cope with the child at home. I decided to take the child to the hospital before the given date. That day I was given a full responsibility of my child's care.

It was difficult for me because I was also expecting (Pregnant). Huh... That day I felt that the hospital staffs were really tired of us. The doctor who uses to see the child I was told by the nurses that he was off. I could not go home because is far. I decided to overnight in the causality because the Engela bus has already left. The next morning I took my child to consulting room again. Nurses were avoiding us .We were told to hold until I was called in.

The doctor through the nurse interpreter asked me how I related to the child. I told him that is my daughter. He continued asking “if I tell you something concern your child will you be frightened”? My answered was no. Then he proceeded “the child has been treated quite long now. I do not say she is going to die. You take care of the child because she is infected with cancer germs. She was operated and the wound is infected with cancer”.

Then later the nurses told me that I should always remember that God is there to help me and encouraged me to pray. The nurse also told me that I should also try to make the child busy with the toys that she was given in the hospital and to keep the child clean as well as her environment and brackets. I was also told to go and see the social worker at Engela hospital with my child.

Interviewer: What about your experience with the social worker?

Caregiver: When I went to the social worker, she told me that I need to be strong and have hope but nothing was provided that I to can use to help my child...because I was also pregnant the social worker told me to stay nearby hospital. I was very difficult for me because of my child who is sick. At last I decided to arrange with my sisters who come to stay with my child and others in the house while I went for confinement. Unfortunately my child died on the day when I gave birth.

Interviewer: You told me that your child died while you went for confinement. What support did you get from the health team after the death of your child?

Caregiver: Nothing. While I was in labour, I was informed that my child is brought to the hospital; the social worker was also informed because she was the one who accompany my relatives when they come to inform me in the hospital.

Interviewer: What problems do you experience when caring your child who was diagnosed with cancer at home?

Caregiver: I did not experience much problem because the child was not having a wound only a tumour. So keeping her clean was not a problem. The other thing is that her personality is that she was a quite person. When she is not okay she used only turn her back to others.

With that child I was just putting myself in hands of God, because I did not know where it will go but I was no having any hope.

Interviewer: What other information would your like to share with me regarding your experience on preparation and support, which nurses provided to you when caring for your child diagnosed with cancer?

Caregiver: I need information. I come to hear about cancer just during my child illness that it is incurable. The other thing is that those people really do not take care of us. The child was just discharged home sick not even sent to the nearest hospital....Even that social worker at Engela did not do anything.

Interviewer: You provided me a wealth of information that I expect will be valued by health team members. I thank you very much for the information. I hope that the information you gave me is important for us as health workers...because it will help us to improve.

Thank you

ANNEXURE D

Nurses Focus group Sample

Interviewer: I am Eva Ndahalako Amakali a registered nurse and lecturer at Oshakati Regional Health Training Center in Oshakati hospital. I am also a Masters student at the University of Namibia. Currently I am conducting a study on **The preparation and support by nurses to caregivers of children diagnosed with cancer Northwest Regions (Ohangwena, Omusati, Oshana and Oshikoto).**

“First of all I would like to thank everybody here for availing yourself to come and attend this discussion in which we will discuss matters related to the preparation and support which, nurses are providing to caregivers of children diagnosed with cancer. This session was chosen because of increased incidence of childhood cancer. You were also specifically selected due to the fact that you are working with children diagnosed with cancer to give information that can also assist the researcher in answering the research question.

I would like to inform you that: The aim of the focus group discussion is to collect information concerning the preparation and support which, nurses are providing to the caregivers of children diagnosed with cancer. The information will be used to improve in the areas concerning the care of children diagnosed with cancer. No report will

be prepared which identifies the views of any of the participants. Each information will be kept confidential.

Please fill your personal information in the questionnaire provided.

A. Biographic data for the nurse

1. Age: **52yrs** 2. Sex—**F**

3. Qualification: **Diploma in General Nursing and Midwifery B.Cur in Community Nursing Science Nursing Education**

4. For how long have you been working in the department?

| | | | |
|-------|----------|-----------|----------------|
| 0-1yr | 1yr-2yrs | 2yrs-3yrs | 5yrs and above |
| | | | X |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

6. Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

- 6.1. If, no how do you keep abreast with new developments regarding cancer nursing care? **By reading, news and news papers, attending seminars and workshops**

A. Biographic data for the nurse

1. Age: **45yrs** 2.Sex: **F**

3. Qualification

Diploma in nursing and Midwifery, B.Cur in Nursing Science

4. For how long have you been working in the department?

| 0-1yr | 1yr-2yrs | 3yrs-4yrs | 5yrs and above |
|-------|----------|-----------|----------------|
| | | X | |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course.

General nursing and midwifery

6. .Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

6.1. If, no how do you keep abreast with new developments regarding cancer nursing care? **Through attending Medical Seminar and reading pamphlets, magazines and text books related to cancer.**

A. Biographic data for the nurse

1. Age: **40yrs** 2. Sex: **F**

3. Qualification:
Enrolled nurse

4. For how long have you been working in the department?

| 0-1yr | 1yr-2yrs | 3yrs-4yrs | 5yrs and above |
|----------|----------|-----------|----------------|
| X | | | |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course.

No

6. Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

6.1. If, no how do you keep abreast with new developments regarding cancer nursing care? **Through reading newspapers.**

A. Biographic data for the nurse

1. Age: **42yrs** 2. Sex—**F-**

3. Qualification

Enrolled nurse

4. For how long have you been working in the department?

| | | | |
|-------|----------|-----------|----------------|
| 0-1yr | 1yr-2yrs | 3yrs-4yrs | 5yrs and above |
| | | | X |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course

No

6. Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

6.1. If, no how do you keep abreast with new developments regarding cancer nursing care? **Through reading the magazine, watching television and through the radio.**

A. Biographic data for the nurse

1. Age: **34yrs** 2.Sex: **F**

3. Qualification

Diploma in Nursing and Midwifery

4. For how long have you been working in the department?

| | | | |
|-------|----------|-----------|----------------|
| 0-1yr | 1yr-2yrs | 3yrs-4yrs | 5yrs and above |
| | | | X |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course.

No

6. Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

6.1. If, no how do you keep abreast with new developments regarding cancer nursing care?

By reading, news and news papers, attending seminars and workshops

A. Biographic data for the nurse

1. Age: **38yrs** 2.Sex: **F**

3. Qualification

Diploma in Nursing and Midwifery

4. For how long have you been working in the department?

| | | | |
|-------|----------|-----------|----------------|
| 0-1yr | 1yr-2yrs | 2yrs-3yrs | 5yrs and above |
| | | | X |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course.

No

6 .Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

6.1. If, no how do you keep abreast with new developments regarding cancer nursing care? **By reading, news and newspapers, attending seminars and workshops. Through attending Medical Seminar and reading pamphlets and magazines and text books related to cancer.**

A. Biographic data for the nurse

1. Age: **40** 2. Sex: **F**

3. Qualification:

Enrolled nurse

4. For how long have you been working in the department?

| 0-1yr | 1yr-2yrs | 2yrs-3yrs | 4yrs-5yrs | 5yrs and above |
|-------|----------|-----------|-----------|----------------|
| | | | | X |

5. Have you undergone any basic training/course that prepares you to provide nursing to cancer-diagnosed children? Give details of the course.

No

6. Have you undergone any post-basic courses that prepare you to provide nursing to cancer-diagnosed children? Give details of the course. **No**

6.1. If, no how do you keep abreast with new developments regarding cancer nursing care? **By reading, news and news papers, attending seminars and workshops.**

B. Questions

Interviewer: “Tell me your experience on the preparation and support you give to the caregivers of the children diagnosed with cancer throughout the disease process.”

Nurse: It is really difficult and painful experience. Sometimes you know that the child is sick and is in a terminal stage and the prognosis is not good. So, you do not know what to tell the caregiver.

Nurse: I did not attend the oncology training but through experience of working in this department I always try to do what I can to prepare and support the caregivers. For example one child developed facial disfigurement (the nose was completely destroyed). The child comes here referred back from Windhoek. When the caregiver come to pick her/him up I sit with the caregiver and discuss with her/him about his/her concerns. I also advised her to cover the area until such time that the child is used to, in order to protect the area and also to avoid public reaction that may affect the child psychologically. I also encourage the parents to stick to follow up dates as indicated because is important and will help the doctor may be to find a solution to the child problem e.g. plastic surgery.

Nurses: You know that some of children especially those in terminal stage may be discharged from the hospital. I usually teach the caregiver on basic care such as on how to feed the child, perform the wound dressing in case of the wound and also how to bath the child.

Nurses: It is very difficult experience because we as nurses we also need counseling in order for us to be prepared for this task. I am not really comfortable in preparing and supporting the caregivers to care for their children....Putting yourself in the shoes of those children suffering from pain, it is really painful. Sometimes you spent sleepless nights thinking about those children whose pain is not always responding to the treatment.

Nurses: Since many children are not admitted with their parents and the treatment is always done in Windhoek, reaching the caregivers is not possible in many cases, those that we happen to meet. I give health education based on the child's condition like what my colleague has stated.

Nurse: It is difficult because sometimes the doctor knows the diagnosis but is not informing the parents in that case I will not have anything to start on. This really puts us in difficult position to prepare the caregivers but what we can do is just to encourage the caregiver to be strong and pray God.

In these cases the parent may go to search for other help which is always traditional healers.

Interviewer: For those who happened to be informed about their children diagnoses how do they react when the child's diagnoses are revealed to them?

Nurse: They react with fear because of the belief that cancer is incurable.

Nurse: It depends on the coping ability of the caregiver and it also depends on how the parents are prepared to receive the diagnosis such as if they were told on the investigation to be carried out.

Nurses: Even though counseling is done they react with shock and disbelief.

Interviewer: How do you support the caregivers in order for them to cope with them to cope with their children diagnoses?

Nurses: We call them and talk to them and encourage them to share their concerns. Those identified that need assistance of other health team members we do refer them e.g. to social worker and pastors. In many cases they get assistance.

Nurses: We also used to explain the disease, method of spread and also the treatment and how they have to take care of the child.

Nurses: We also used to tell them to go to the people who have their children already diagnosed to serve as the reinforcement for the information provided about cancer treatment. Parents are also referred to support group in the community.

Nurse: The other support that we provide to the caregivers is that since we have spiritual reader here in the hospital we also referred them to spiritual people we also encourage the caregivers who are admitted in the ward to attend the church service and to continue doing so at home.

Nurse: The visiting members of the family we also tell them if possible to continue visiting the child at home.

Interviewer: One of you have indicated that you refer the caregivers to the support groups in the community; are there specific support groups that you liaise with in the community?

Nurse: Not specific but we just to say in case there is. Those that we are aware of are those for HIV/AIDS affected people. In some regions especially in Windhoek there are, like Cancer association... If possible for the cancer Association to expand its branch to our regions so that our children can also benefit.

Interviewer: What type of problems is experienced by the caregivers of children diagnosed with cancer?

Nurse: I think the problem that they are having is mostly financial problems. You may find that the parent did turn up for follow up for that time and gave reasons that there is no money or there was no one to accompany the child to the hospital. Another problem is that they may report to their district hospital on time but because it is not regarded as an emergency they may not be provided with transport this may result in the child missing her/his date of follow up.

Nurse: It also depend on the caregivers understanding problems experienced are failure to comply with the follow up as if there is no hope believes that the child is being witched, that the child is not going to cure and failure as result of other commitment.

Interviewer: What mechanism/Procedure in the hospital that is followed regarding the care of the children n diagnosed with cancer?

Nurses: No, nothing in place the care is only given according to the information and problem that the caregivers and the child have. No guideline especially in this ward and also hospital cancer is new in our region and cases are not many.

Nurse: Now we hear that there is a doctor who uses to see cancer patient in this hospital but only adult patient all our children are still referred to Windhoek.

Interviewer: What challenges do you face when preparing and supporting the caregivers of children diagnose with cancer?

Nurse: Early diagnoses and treatment which is not possible in m any cases. Sometimes children are brought to the hospital earlier but wrongly diagnosed and later refereed with cancer metastasis.

Nurse: The need for nurses trained on oncology nursing and palliative nursing to work with the caregivers and the children with cancer.

Interviewer: You provided me a wealth of information that I expect will be valued by nurses and other health team members involved in the care of the children diagnosed with cancers. Thank you for you time once again.

ANNEXURE E

Letter of permission from the Governor:

Ohangwena Region

220303



REPUBLIC OF NAMIBIA

OHANGWENA REGIONAL COUNCIL
THE DIRECTORATE OF GENERAL SERVICES AND PERSONNEL

TEL. 065 264300
FAX: 065 263033

P. O. Box 13185
Eenhana

21 June 2005

Your Ref:

Our Ref:

Enq: **Mr. P. Uusiku**

Ms. E. N Amakali
P.O Box ~~12196~~ 1296
OSHAKATI

0812837191

Dear Madam,

RE: APPLICATION TO CONDUCT RESEARCH STUDY IN OHANGWENA REGION.

Your letter dated 16 June 2005 has reference.

Approval for your application to carry out your research study in Ohangwena Region in respect of your master's degree course is hereby granted by the Ohangwena Regional Council under the condition that, the data that you will collect should purely be used for your master's degree purpose only.



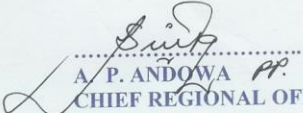
Thanks for your understanding.

Yours truly

.....
Mr. K Ndaitwa
Chief Regional Officer

OHANGWENA REGIONAL COUNCIL
COUNCIL
2005 -06- 2 1
P.O. BOX 13185
EENHANA
TEL: 065-263021/65/66
FAX: 065-263033

ANNEXURE F**Letter of permission from the Governor: Omusati Region**

| | | | |
|--|--|---|---|
|  | REPUBLIC OF NAMIBIA |  | |
| OMUSATI REGIONAL COUNCIL | | | |
| Office of the chief Regional Officer Tel: (065) 251019 Fax: (065) 251078 E-mail: orcouncil@hotmail.com | | Private Bag 523 OUTAPI Omusati Region | |
| 6 February 2004 | | | |
| Ms. Eva Ndahalako Amakali P. O. Box 1296 OSHAKATI | | | |
| Dear Ms. Amakali | | | |
| <u>Re: Application to Conduct a Reserch Study in Omusati Region</u> | | | |
| <ol style="list-style-type: none"> 1. We hereby acknowledge, with thanks, receipt of your letter dated 22 January 2004, addressed to the Hon. Governor of Omusati Region on the above subject matter. 2. This letter serves to inform you that permission has been granted to conduct your research study in Omusati Region. The Council requires you to submit the final report upon completion of your study. 3. We wish you good luck in your studies. | | | |
|  A. P. ANDOWA CHIEF REGIONAL OFFICER | <table border="1" style="margin: auto; border-collapse: collapse;"> <tr> <td style="text-align: center; padding: 2px;"> OMUSATI REGIONAL COUNCIL P/BAG 523, OUTAPI 2004 -02- 0 6 TEL: 065-251019 FAX: 065-251078 </td> </tr> </table> | | OMUSATI REGIONAL COUNCIL P/BAG 523, OUTAPI 2004 -02- 0 6 TEL: 065-251019 FAX: 065-251078 |
| OMUSATI REGIONAL COUNCIL P/BAG 523, OUTAPI 2004 -02- 0 6 TEL: 065-251019 FAX: 065-251078 | | | |
| <hr/> All official correspondence must be addressed to the Regional Officer | | | |
| <small>2004.02.06 EVA RESEARCH PERMISSION</small> | | | |

ANNEXURE G**Letter of permission from the Governor: Oshana Region**

REPUBLIC OF NAMIBIA

OSHANA REGIONAL COUNCIL

Tel. 065 - 220441 / 220363 / 220927 Fax: 065 - 221292

e-mail: onar-cadm@osh.namib.com

e-mail: onarc-govt@osh.namib.com

Our Ref.:..... ONARC/001/002/2004

Your Ref.:.....

Enquiries:..... Mr. J.P. Kandombo.....

Private Bag 5543
Oshakati, Namibia2nd February 2004

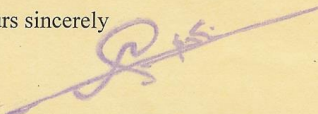
Ms Eva N. Amakali
P.O. Box 1296
OSHAKATI

Dear **Ms Amakali**

**RE: APPLICATION TO CONDUCT THE RESEARCH STUDY IN
OSHANA REGION**

1. Your letter of 22 January 2004, on the matter above, refers.
2. I should take the liberty to sincerely thank you for the efforts made and the initiatives taken by you to conduct the research study in our region.
3. I should however advise you that since the Permanent Secretary: Ministry of Health and Social Services has granted approval for you to conduct the study, it is not within the ambit of this office to hinder the process. That you should liaise with the Regional Directorate of Health of the 4 Regions to work out the modus operandi and the way forward pertaining to your study.
4. I wish to thank you in anticipation of your usual understanding.

Yours sincerely


Hon. Clemens H. Kashiupulwa
GOVERNOR: OSHANA REGION



ANNEXURE H**Letter of permission from the Governor: Oshikoto Region**

OSHIKOTO REGIONAL COUNCIL

TEL: (067) 221435/6 / 221484
 FAX: (067) 220729
 E-mail: oshikoto@iway.com.na

PO BOX 1116, TSUMEB
 NAMIBIA

OUR REF.: RC-TS/ 09/02/04 YOUR REF.:

ENQUIRIES: M. MBOMBO

9 February 2004

E. N. Amakali
 P. O. Box 1296
OSHAKATI

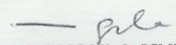
Dear Madam,

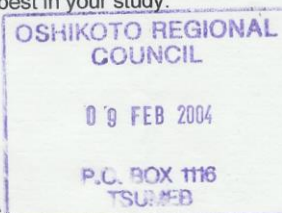
APPLICATION TO CONDUCT A RESEARCH STUDY IN OSHIKOTO REGION

1. Your letter dated 22 January 2004 hereby refers.
2. The Oshikoto Regional Council would like to thank you for including the Region into your research study.
3. It is on this basis that we grant you the opportunity to conduct the said research. Kindly contact the relevant authorities in the Regional Hospitals and selected Health Institutions.

The Council wishes all the best in your study.

Yours Sincerely,


S.S. ANGULA-MUPOIWA
 REGIONAL OFFICER



Cc. The Regional Officer
 Ministry of Health and Social Services

ANNEXURE I

**Letter of permission from the Senior Medical
Superintended: Oshakati State Hospital**



9 - 0 / 0001

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

OSHAKATI STATE HOSPITAL

Tel. No.: (065) 2233143
Fax No.: (065)221390

Intermediate Hospital Oshakati
Private Bag x5501
Oshakati

Enquiries: Dr Korbinian V. Amutenya

27 January 2004

Mrs E. N. Amakali
P.O. Box 12196
Oshakati

Dear Madam

RE: APPLICATION TO CONDUCT THE RESEARCH STUDY AT IHO.

1. Your letter dated 22 January 2004 on the above refers.
2. Permission is hereby granted to carry out the above study at IHO on condition that:
 - You will comply with all the conditions under which approval was approved by the Permanent Secretary.
 - You will give a copy of your findings to the Hospital for improving deficiencies identified.

We wish you success in your study

Yours Sincerely



DR KORBINIAN V. AMUTENYA
SENIOR MEDICAL SUPERINTENDENT



ANNEXURE J

**Letter of permission from the Medical Superintendent:
Windhoek Central Hospital**

9-0/0001



REPUBLIC OF NAMIBIA
Ministry of Health and Social Services

| | | |
|--|---|---|
| Private Bag 13198 Windhoek Namibia | Ministerial Building Harvey Street Windhoek | Tel: (061) 2033004 Fax: (061) 222886 Telefax: International |
| Enquiries: Dr H.N. Nkandi-Shiimi | | Date: 24 June 2005 |

**OFFICE OF THE SENIOR MEDICAL SUPERINTENDENT
WINDHOEK CENTRAL HOSPITAL**

To: Ms E. AMAKALI
P.O. BOX 1296
OSHAKATI
NAMIBIA

RE: **APPLICATION TO CONDUCT A RESEARCH IN WINDHOEK
CENTRAL HOSPITAL**

This is to acknowledged receipt of your letter on the above subject.

We are pleased to inform you that this office has no objection towards your carrying out of your research. Kindly inform my office when exactly you wish to carry out your research for the purpose of planning and preparations. You are also expected to share the outcome of your research with this office.

Yours sincerely,

ACTING
DR. SHALONGO S.K.
Dr H. Nkandi-Shiimi
SENIOR MEDICAL SUPERINTENDENT

**MINISTRY OF HEALTH
AND SOCIAL SERVICES**
Private Bag 13215
2005-06-28
WINDHOEK, NAMIBIA
WINDHOEK CENTRAL HOSPITAL

SENIOR
MEDICAL SUPERINTENDENT
WINDHOEK HOSPITAL
MINISTRY OF HEALTH
AND SOCIAL SERVICES
NAMIBIA

Forward with health for all Namibians by the year 2000 and beyond!

ANNEXURE K

**Letter of permission from Permanent Secretary of the
Ministry of Health and Social Services (MoHSS)**



REPUBLIC OF NAMIBIA

| | | |
|--|---|--|
| Private Bag 13198 Windhoek Namibia | Ministry of Health and Social Services Ministerial Building Harvey Street Windhoek | Tel: (061) 2032507 Fax: (061) 227607 E-mail: sowoses@mhss.gov.na |
| Enquiries: Ms. S. Owoses | Ref.: 17/3/3/AP | Date: 01 December 2003 |

OFFICE OF THE PERMANENT SECRETARY

Ms. E. Amakali
Private Bag 1296
Oshakati

Dear Ms. Amakali,

***THE NATURE OF PREPARATION AND SUPPORT, WHICH NURSES ARE PROVIDING
TO THE CARE GIVERS OF CANCER DIAGNOSED CHILDREN FROM OHANGWENA,
OMUSATI, OSHANA AND OSHIKOTO REGIONS***

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. Kindly be informed that approval has been granted under the following conditions:
 - 3.5.1. The data collected is only to be used for your Masters degree;
 - 3.6. A quarterly progress report is to be submitted to the Ministry's Research Unit;
 - 3.7. Preliminary findings are to be submitted to the Ministry before the final report;
 - 3.8. Final report to be submitted upon completion of the study;
 - 3.9. Separate permission to be sought from the Ministry for the publication of the findings.

Wishing you success with your project.

Yours sincerely,


DR. K. SHANGULA
PERMANENT SECRETARY



Directorate: Policy, Planning and HRD
Subdivision: Management Information and Research