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EXPERIENCES OF PATIENTS REGARDING ONCOLOGY TREATMENT AND CARE AT HOSPITALS IN VHEMBE DISTRICT OF LIMPOPO PROVINCE

by

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Department of Advanced Nursing Science

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30 August 2016

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DECLARATION

I, **Neo Jacqueline Ramutumbu**, declare that the thesis **"Experiences of Patients Regarding Oncology Treatment and Care at Hospitals in Vhembe District of Limpopo Province"** is my original work. It is submitted in fulfilment of the requirement for a MCur degree in the Department of Advanced Nursing Science at the University of Venda. The sources in this document have been acknowledged accordingly by means of complete references. This work has not been submitted previously for any other degree or purpose at another university.

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Date Signed : 30/08/2016

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DEDICATION

I dedicate this thesis to the participants of this study.

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ACKNOWLEDGEMENTS

- I thank God the Almighty who through his grace gave me the strength and guided me throughout this study.

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ABSTRACT

Cancer is an emerging public health problem in Africa. The numbers are projected to nearly double (1.28 million new cancer cases and 970,000 cancer deaths) by 2030 simply due to the aging and growth of the population. This study explored and described the experiences of patients regarding treatment and care at the hospitals in Vhembe District, Limpopo Province.

A qualitative approach explorative, descriptive and phenomenological was used. The target population were patients undergoing cancer treatment in the five hospitals in Vhembe District. A purposive sampling of the hospitals that have oncology clinics for cancer patients under their care were selected and convenience sampling of participants. Ustructured, in-depth individual interviews were used to collect data. Trustworthiness and ethical considerations were followed to protect the study participants.

The following findings emerged: Participants' feelings of uncertainty about their cancer and treatment, lack of communication, lack of communication and fear of death, experiences of distress due to treatment side effects and lack of communication of cancer diagnosis to family members, social support and the burden of care giving, diverse experiences of support by health care institutions and poor coordination of treatment, positive feelings of self, participants benefiting from treatment and care expressed their trust in the supernatural, fate and belief system as their coping mechanisms. Recommendations were made to assist in the improvement of cancer services in the Vhembe District of Limpopo Province.

Keywords: oncology, cancer risk factors, diagnosis, care, treatment, symptomatic experiences

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LIST OF ACRONYMS

ACA	American Cancer Association
ACS	American Cancer Society
CANSA	Cancer Association of South Africa
HPCSA	Health Professions Council of South Africa
IARC	International Agency for Research on Cancer
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NIH	National Institutes of Health
SABC	South African Broadcasting Corporation
WHO	World Health Organization

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 Introduction

Cancer is rapidly becoming a public health crisis in low-income and middle-income countries (Kingham, Alatise, Casper, Abantanga, Kamara, Olopade, Haabeebu, Abdulkareem&Denny 2013:156). In sub-Saharan Africa, patients often present with advanced disease. Cancer is amongst the three leading causes of death in the low-income countries and the highest increase with regard to incidence is reported in the very same countries (Masika, Wettergen, Kohi & Essen, and 2012:133). Little health care infrastructure exists, and few personnel are available for the care of patients (Masika et al., 2012:133).

Poor access to surgical care and chemotherapy is a major impediment to cancer management in most parts of the world, including sub-Saharan Africa. Additional obstacles include the cost of oncological care, poor infrastructure, and the scarcity of medical oncologists, pathologists, radiation oncologists, and other health care workers who are critical for cancer care (Kingham et al., 2013:156).

According to the International Agency for Research on Cancer (IARC, 2014), about 715,000 new cancer cases and 542,000 cancer deaths occurred in 2008 in Africa. These numbers are projected to nearly double (1.28 million new cancer cases and 970,000 cancer deaths) by 2030 simply due to aging and population growth, with the potential to be even higher because of the adoption of behaviours and lifestyles associated with economic development, such as smoking, unhealthy diet, and physical inactivity (Montazeri, Tavoli, Mohagheghi, Rosha &Tavoli, 2009:1471).

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Cancer incidences are increasing—the World Health Organization (WHO, 2012) predicts that by the year 2020, 15 million new cases will be diagnosed of which 70% will be in the developing world of which some will be at a more advanced stage and not curable at diagnosis (Spence, Grath, Hibbert, Phillip-Jackson, Barrilas, Castaggenier, Ghul, Stemerof & Webley, 2010:10).

Cancer is a term for diseases in which abnormal cells divide without control and can invade surrounding tissues. Cancer cells can also spread to other parts of the body through the blood and lymphatic systems. Below is a brief discussion of different types of cancers which are common: *Carcinoma* is a cancer that begins in the skin or in tissues that line or cover internal organs. *Sarcoma* is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. *Leukaemia* is a cancer that starts in blood-forming tissue, such as the bone marrow, and causes large numbers of abnormal white blood cells to be produced and enter the blood. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system. *Central nervous system cancers* are cancers that originate in the tissues of the brain and spinal cord (NCI: 2013).

The demand for cancer prevention, screening and treatment services is growing rapidly. By 2030, the number of new cancer cases in the United States will increase by 45%, and cancer will become the nation's leading cause of death, largely as a result of the aging of the nation's population. At the same time, the number of cancer survivors, now reported to be at 13.7 million, will continue to grow (Montazeri et al., 2009:1471). In Scotland, Murray, Grant & Grant (2013:17) revealed that patients living in developed and developing countries have differences in resources available to them. Oncology patients in Scotland experienced emotional pain of facing death, and patients in Kenya were concerned with physical pain and financial worries on how to access oncology treatment and care (Murray et al., 2013:17).The researcher has observed that patients in South Africa are also experiencing difficulty in accessing treatment and care, the centres that offer oncology treatment are limited and

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sometimes inaccessible; patients often travel long distances to these centres as outpatients. Access to quality cancer care remains uneven. People with cancer lack access to quality medical care, and rates of access to care are disproportionately lower for African Americans and Latinos (Jacobsen & Jim, 2008:59). One quarter of uninsured individuals forego care because of cost and those without a regular source of care are less likely to receive cancer screening (WHO, 2012). It has been a common a trend that, once people are diagnosed with cancer, they often experience acute stress with undesirable consequences. In most cases, individuals often feel like they are on the verge of losing their independence due to ill health, they also experience pain due to the illness, suffer due to uncertainty about the way forward, prognosis and fear of death and financial difficulties which may arise if unemployment is looming (Jacobsen & Jim, 2008:59).

Cancer affects patients' emotional health. Most patients, families, and caregivers face some degree of depression, anxiety, and fear when cancer becomes part of their lives. These feelings are normal responses to this life-changing experience (Jacobsen &Jim, 2008:59). According Oksel, Ertem & Donmez (2010:10), cancer is the most feared disease among the critical diseases, and described it as death, pain or disorder. Total pain involves the interplay of physical, psychological, social and spiritual factors that construct pain experience (Brant, 2010:7).

1.2 Cancer Care in Limpopo Province

Generally, lack of adequate resources to deal with cancer continues to be a problem in different provinces in South Africa. To mention just a few, the patients in Limpopo Province experience similar challenges of poor infrastructure, scarcity of oncologists and other health care workers specific for oncology patients. When these patients are diagnosed with cancer they need oncology treatment and care. The treatment that they may require varies depending on the stage of cancer the patient is in. The treatment that is available is chemotherapy,

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surgery, radiation and other modes (Chow, Dong & Devesa, 2010:246).

Communicating the news about the diagnosis to the patient and family is a something that the cancer patients are worried about. Cancer patients are anxious about the negative attitude of the general public, so it is in this light that disclosure to the family is difficult. Patients with cancer require care and that their illness needs to be explained to them.

In the district where the research was undertaken, the researcher has observed that there were fewer oncology nurses that can carry out the roles expected of the oncology nurses. It is for this reason that the researcher developed an interest to examine how prevalent and how extreme the experiences are to cancer patients. Cancer management in Limpopo Province is compromised by disparities in specialised care, as the patients who are uninsured receive inefficient medical care due to shortages of resources, infrastructure and skilled oncology specialists. Oncology patients are referred to a tertiary hospital for more advanced care as outpatients with transfer staff that know little about the patients and their illness, stage of cancer diagnosis and treatment. The hospitals in Vhembe are not having specialized oncology services and specialists.

According to Brant (2010:8), health care practitioners focus on the physical pain while underestimating the psychological pain which can be dreadful and reminds the patient of the cancer and uncertainty of the future. Spiritual pain can also affect individual perception and intensity about pain, the significance about pain and the acceptance of the treatment (Brant, 2010:8).

1.3 Problem Statement

A problem statement is an expression of a dilemma or disturbing situation that requires investigation (Polit & Beck, 2008:77; Creswell, 2009:36; Brink, 2012:61). The researcher works at a ward that is adjacent and in the same wing of the wards to the oncology care ward

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and here the researcher has observed and has heared reports of patients going in and out the hospital and some being transferred to tertiary hospital for treatment. Furthermore, as observed in the hospital, some patients return from the tertiary hospitals without any treatment offered due to lack of blood test results or because proper investigations required by the tertiary institutions were not done due to lack of consumables and broken diagnostic equipment.

Patients are travelling daily for the uninterrupted processes of chemotherapy for six months, even though some experience side effects. The treatment centres do not admit them and in the hospitals they stay as lodgers. Oncology patients still lack specialised oncology nurses needed to navigate the oncology treatment process; patients are not fully included in their medical plan as doctors discuss patients in referral letters without considering the patients' needs, fears and uncertainties that need to be addressed by the multidisciplinary team.

The inefficiency of oncology services was reflected upon in the media, the South African Broadcast Cooperation (SABC 2), Zwamaramani on the 18/03/2014, a patient from Ha-Makhuvha Village in Vhembe District, diagnosed with osteosarcoma of the face, was not informed of his condition in time, only offered dosages of analgesia (morphine) every time he went for follow-up at Polokwane Oncology Centre. He was taken X-rays and came back with the X-rays and no one could interpret the X-rays. When the patient was referred back to Polokwane, the response from the spokesperson of the Limpopo Province Department of Health was that there are no specialists in the province and the patient will be referred to CANSA for support services.

1.4 Purpose of the Study

A research purpose contains the central phenomenon to be explored in the study (Creswell, 2009:112). Brink (2012:54) indicated that the purpose of a study is generated by the identification of a specific goal of the study. Therefore, this study sought to explore and

understand the experiences of cancer patients regarding care and oncology treatment at hospitals in the Vhembe District of Limpopo Province.

1.5 Research Question

A research question is a concise interrogative statement that is worded in the present tense and also includes one or more variables (Brink, 2008:80; Brink 2012:55). A central question in qualitative research is a broad question that will be posed by the researcher that asks for an exploration of the concept under study (Creswell, 2009:227).

The research question for this study was:

> *What are the experiences of patients regarding oncology treatment and care in the hospital?*

To probe more of the experiences regarding the treatment and care received at the hospitals, the researcher asked the following central question to each participant:

> *"How do you experience oncology treatment and care at the hospital?"*

1.6 Objectives of the Study

The research objective is a declarative statement that is expressed in the present tense and focuses on one or more variables (Brink, 2012:55; de Vos, Strydom, Fouchè & Delport, 2013:94). The objectives denote the more concrete measurable and more speedily attainable conceptions of such a plan to do or achieve (de Vos et al., 2013:94).

The objectives of this study were to:

- Explore the experiences of cancer patients regarding oncology treatment and care;

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- Describe the experiences of the patients regarding oncology treatment and care.

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1.7 Significance of the Study

The significance of a study conveys the importance of the problem for different audiences that may profit from reading and using the findings (Creswell, 2009:234). This study, based on the findings on the experiences of the cancer patients regarding their care and oncology treatment, may influence policy formulation, education and improvement of care as necessary. The research findings may assist nursing practice to better plan for the oncology patients and assist them in receiving improved treatment and care, based on their individual needs and will be based on informed decisions.

The research findings may contribute to nursing education, so that more specialist oncology nurses are trained. As people diagnosed with cancer are on the rise and palliative nursing is increasingly envisaged, trained nurses for this task would be able to provide cancer care in communities as well. The study may also inform policy makers to increase access to palliative (community- or home-based) care services through its integration into health-care systems. Increased attention to the generation of research evidence is essential to achieve quality and coverage of appropriate evidence-based palliative care for patients with advanced cancer in Limpopo Province.

1.8 Paradigmatic Perspective

A paradigm is a "worldview" or a set of assumptions about how things work. Paradigms refer to established research traditions in a particular discipline (Machet & Maepa, 2004:42). According to Machet & Maepa (2004:42), a paradigm is primarily a model on the basis of which research in a particular discipline is carried out. It includes the accepted theories, models, and body of research and methodologies in a tradition (Machet & Maepa, 2004:42).

1.8.1 Meta-Theoretical Assumptions

Patients diagnosed with cancer depend on a multidisciplinary team for their treatment and

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care. Their dependence on the care start as early as after screening and diagnosis, to be assisted in the comprehension of the nature of their diagnosis, treatment and care that they are expected to undergo and the knowledge on how to deal with their life circumstances. Patients who require oncology treatment need readiness and information about cancer and need to be assisted in making the best decision possible for their treatment and care. The researcher believes that it may be possible to support these oncology patients' care and treatment without adding to their uncertainty about the future and success of their treatment.

Patients with cancer have needs that should be met, that is, needs that all human beings have regardless of illness or not. The researcher believes that the cancer patients can be assisted in finding comfort in the hands of the health care professionals and health care institutions. The researcher believes that patients with cancer should be treated equally regardless of age, culture and race. Believing that the patients with cancer can be assisted to access all the care possible and other health services that comes along with the diagnosis of cancer.

1.8.2 Theoretical Assumptions

Watson's theory of human caring was used as a point of departure (George, 2011:457). Watson's caring theory allows nurses to return to their deep professional roots and values; it represents the archetype of an ideal nurse. Caring endorses the nursing professional identity within a context where humanistic values are constantly questioned and challenged (George, 2011:457). Upholding these caring values in the daily practice of nursing, helps transcend the nurse from a state where nursing is perceived as just a job, to that of a gratifying profession.

Upholding Watson's caring theory not only allows the oncology team to practise the art of caring, but to provide as well compassion to ease patients and families suffering, and to promote their healing and dignity, but it can also contribute to expand the oncology multidisciplinary team's own actualisation. This theory will address the care given to cancer patients in order to find solace and comfort from the care provided by the nurses.

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Promoting and applying these caring values in oncology practice is not only essential to the oncology teams own health, but its significance is also fundamentally tributary to finding meaning in their work. Patients with cancer are in the care of the oncology health care team for a lengthy time and as such the oncologists become more attached to these patients, they also become affected by the stages the patients go through and some die in their hands—as such the care of the service providers would enhance the way they care for these patients.

Caring is grounded on a set of universal humanistic-altruistic values, including kindness, empathy, concern, and love for self and others (Watson, 2007:131). They bring meaning to one's life through one's belief and relationships with other people. Humanistic-altruistic feelings and acts provide the basis of human caring and promote best professional care and best oncology practices.

Oncology patients' beliefs are encouraged, honoured and respected as significant influences in promoting and maintaining health (Watson, 2007:131). Regardless of the scientific regimen required for medical care of a person, the multidisciplinary team should nurture faith and hope, and the deep belief system of oncology patients by encouraging them to adhere to a medical regimen, provide counselling and support (Watson, 2007:131). Nurses, doctors, surgeons and oncologists who are sensitive to others learn better about another's view of the world which, subsequently, increases concern for others' comfort, recovery, and wellness, thus creating a supportive oncology nursing and caring environment.

1.9 Definitions of Concepts

Theoretical definitions give meaning of words in terms of the theories of a specific discipline, is the relationship between a given concept and related concepts within a conceptual framework that are highlighted and made clear (Mouton, 1996:17). An operational definition is a result of the process of operationalisation and is used to define something in terms of a process needed to determine its existence, duration and quantity.

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Operational definitions are done to enable us to measure a constructs that apply to a research (du Plooy, 2001:66).

1.9.1 Care

Care is the provisioning of what is necessary for the health and maintenance and protection, to willingly provide for the needs of others (South African Concise Oxford Dictionary, 2005:172). In this study, care shall mean hospital activities that will be directed to alleviate the deviance of health services on the patient receiving oncology treatment.

1.9.2 Experiences

Practical contact with an observation of facts or an event leaves an impression on one, an event that will arouse an emotion (South African Concise Oxford Dictionary, 2005:407). Experiences refer to the skills and knowledge attained from life events (Hawker & Soane, 2008:349). In this study, lived experience refers to the physical, psychological, social and spiritual or other changes felt by the oncology patients due to the disease treatment and care narrated in an interview.

1.9.3 Oncology Treatment

It is the line of medicine that treats cancers (South African Concise Oxford Dictionary, 2005:812). In this study, oncology treatment shall mean all activities of care meant to alleviate the health care problems of the patient, including counselling, support, medicinal and chemotherapy of the patient.

1.10 Research Design and Method

Brink (2012:217) defined research design as the overall plan to gather data in a research. Research method involves the form of data collection, data analysis and interpretation that the researcher proposes for the study (Creswell, 2009:233). The research design for this study

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was qualitative, explorative, descriptive and phenomenological in order to get an in-depth understanding of the experiences of patients regarding oncology treatment and care in the hospitals that are of the researcher's interest. The hospitals in the Vhembe District that the researcher was interested in were three out of the five hospitals in the Vhembe district, excluding those that have oncology services with the exclusion of the sixth which is mainly a psychiatric hospital.

Population is the entire set of individual or objects, having some common characteristics which are relevant to the problem under study (de Vos et al., 2013:223). The population in this study, were the patients receiving oncology treatment and care at the selected hospitals in the Vhembe District in Limpopo Province. The selected hospitals were Donald Frazer, Malamulele and Tshilidzini.

Non-probability purposive sampling was used in this study, to select the hospitals and the participants. Purposive sampling was based on the judgement of the researcher regarding participation of the subjects based on the representativeness of the study population of the cancer patients. In-depth individual interviews were used during data collection in this study, because they promoted systematic collection of subjective and phenomenological information on the experiences of the cancer as was narrated by the study participants. It provided an understanding of and the insight into the study participants (de Vos et al., 2012:298). Data were analysed using the phenomenological research method (Kleinman, 2004:14). The researcher undertook to uphold the rights of the participants without violating the participant's rights. Chapter 3 will give a detailed description of the research design and method.

1.11 Ethical Measures

A code of ethics in qualitative research that involves moral decision was taken and considered by the researcher throughout the process of the study (de Vos, 2013:115). In this

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study, the researcher undertook at all times to do what is right and good without violating the rights of the participants. The following ethical measures were considered: permission to conduct the study, obtaining informed consent, respect for human subjects, freedom from exploitation, maintenance of confidentiality and anonymity.

1.12 Measures to Ensure Trustworthiness

Measures were taken to ensure that the research findings were worth paying attention to and well considered. It was ensured that the findings of this study reflected the true experiences of the oncology patients regarding oncology treatment and care. The researcher used the four criteria for establishing trustworthiness, namely: truth value, applicability, consistency and neutrality (Brink, 2012:172). A dense description of how the researcher ensured credibility is given in Chapter 3.

1.13 Arrangement of the Study Chapters

Chapter 1: Overview of the Study

Chapter 2: Literature Review

Chapter 3: Research Design and Methods

Chapter 4: Findings, Discussion and Literature Control

Chapter 5: Recommendations, Limitations and Conclusions

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1.14 Summary

In the overview of this study, the need to explore the experiences of patients regarding the oncology treatment and care at the hospitals in Vhembe District was significant for the researcher as cancer incidences are on the rise globally as described by literature. The description of these experiences was deemed necessary for their understanding to document and advise the institutions on the actual needs of the cancer patient receiving care and oncology treatment. The overview of this study was described in Chapter 1 and included the following: Introduction, background to the research problem, research question, purpose research design and methods, data analysis, ethical consideration, measures to ensure

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trustworthiness and the arrangement of chapters. Chapter 2 embodies the literature review.

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CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

A literature review is an account of what has been established on a topic by researchers and published in accredited scholarly journals. The purpose of a literature review is to convey the knowledge and ideas of what has established on a topic their strength and weakness are. A literature review is defined by a guiding concept like objectives and the problem statement

2.2 Purpose of the Literature Review

Literature is reviewed to conduct a critical analytical appraisal of the recent scholarly work on the topic by determining what is already known about the topic. In the process, the researcher can obtain a comprehensive picture of the state of knowledge, identify the research problem and refine the research questions (Brink, van der Walt & van Rensburg, 2014:71). This allows the researcher to place the study in the context of the general body of knowledge, which minimises the possibility of unintentional duplication and increase the probability that the new study may add valuable contribution, obtain clues of the methodologies and instruments and to compare findings of existing studies and those of the study at hand (Brink et al., 2014:71)The information was selected from literature published in nursing journals, on cancer support and care provided by the family, informal and formal caregivers. This study is aimed at exploring and describing the experiences of patients regarding oncology treatment and care at the selected hospitals in the Vhembe District in Limpopo Province., The overall literature review in this chapter is to appraise literature regarding cancer risk factors, oncology treatment modalities and the symptomatic experiences of oncology patients.

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2.3 Cancer Causes and Risk Factors

The major risk factors for cancer are: tobacco, alcohol, diet, sexual and reproductive behaviour, infectious agents, family history (genetic predisposition), occupation, environment, and pollution. According to the estimates of the American Cancer Society (ACS, 2013), approximately 40% of the cancer deaths in 2003 were due to tobacco and excessive alcohol use. An additional one-third of the deaths were related to poor diet and malnutrition. Many of the one million skin cancer cases were due to overexposure to ultraviolet light from the sun's rays. It should be noted that medical science has not been able to pinpoint many of the exact causes of cancer, but has been able to estimate risk factors and occurrence associated with various agents.

2.3.1 Tobacco

Eighty to ninety percent of lung cancer cases occur in smokers (ACS, 2013). Smoking has also been shown to be a contributory factor in cancers of the upper respiratory tract, oesophagus, larynx, bladder, pancreas, and probably liver, stomach, breast, and kidney, as well. Recently, scientists have also shown that second-hand smoke inhalation (or passive smoking) can increase one's risk of developing cancer.

2.3.2 Alcohol

Excessive consumption of alcohol is a risk factor in certain cancers, such as liver cancer. Alcohol, in combination with tobacco, significantly increases the chances for an individual to develop mouth, pharynx, larynx, and oesophageal cancers (ACS, 2013). Metabolisation of ethanol in alcoholic drinks to acetalhyde which is a toxic chemical and a probable human carcinogen. Acetaldehyde can damage both DNA and protein. Also, reactive oxygen species can damage DNA, proteins and lipids through a process called oxidation. Impairing the body's ability to break down and absorb a variety and nutrients may be associated with cancer risk, including vitamin A. Nutrients in vitamin B complex include folate, vitamins D and E, and carotenoids. Increased blood levels of oestrogen, a sex hormone, is linked to the

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risk of breast cancer.

2.3.3 Diet

Thirty five percent of all cancers are estimated to be due to dietary causes. Excessive intake of fat leading to obesity has been associated with cancers of the breast, colon, rectum, pancreas, prostate, gall bladder, ovaries, and uterus (ACS, 2013). Increased salt in the diet has been linked with a higher risk of stomach cancer by damaging the stomach lining to become more sensitive to carcinogens. It can also interact with *Helicobacteria pylori* that is linked with both stomach ulcers and stomach cancer. Red processed meat contains a red pigment called haem which could irritate the bowel and trigger the production of harmful chemicals by bacteria in the gut leading to higher risk of cancer (NCI, 2015).

2.3.4 Sexual and Reproductive Behaviour

The human papillomavirus (HPV) which is sexually transmitted, has been implicated to cause cancer of the cervix. In addition, it has also been shown that women who have not had children or have children late in life have an increased risk for both ovarian and breast cancer (ACS, 2013). Cooper, Hoffman, Carra et al. (2007) indicated that lower socioeconomic status, alcohol intake and being single or black appear to be the determinants of increased sexual activity in South African women—cervical cancer risk is associated with increased sexual activity and the number of sexual partners.

2.3.5 Infectious Agents

Certain infectious agents, including viruses, bacteria and parasites can cause cancer in infected people or increased the risks of cancer development. Some viruses can disrupt normal controls of cell growth and proliferation. They may also increase the chance that a person will be affected by other cancer causing agents such as tobacco, ultraviolet radiation and the bacteria and parasites that can cause chronic inflammation which lead to cancer

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(NCI, 2015).

2.3.6 Family History

Certain cancers like breast, colon, ovarian, and uterine cancer do recur from generation to generation in some families. A few cancers, such as eye cancer—retinoblastoma, colon cancer, and a type of breast cancer known as early-onset breast cancer, have been shown to be linked to certain genes that can be tracked within a family. It is therefore possible that inheriting particular genes makes a person susceptible to certain type of cancers (ACS, 2013).

2.3.7 Occupational Hazards

There is evidence to estimate that certain occupational hazards account for 4% of all cancer deaths (ACS, 2013). For example, asbestos workers have an increased incidence of lung cancer. Similarly, a higher likelihood of getting bladder cancer is associated with dye, rubber, and gas workers; skin and lung cancer with smelters, gold miners, and arsenic workers; leukaemia with glue and varnish workers; liver cancer with polyvinyl chloride (PVC) manufacturers; and lung, bone, and bone marrow cancer with radiologists and uranium miners (ACS, 2013).

2.3.8 Environmental Radiation

Exposure is believed to cause 1–2% of all cancer deaths (ACS, 2013). Ultraviolet radiation from the sun accounts for the majority of melanoma deaths. Other sources of radiation are X-rays, radon gas and ionizing radiation from nuclear material.

2.3.9 Pollution

There is a well-established link between asbestos and cancer. Chlorination of water may account for a small rise in cancer risk. The main danger occurs when hazardous chemicals from industries escape into the surrounding environment. It has been estimated that 1% of

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cancer deaths are due to air, land and water pollution (ACS, 2013).'The living conditions as well as physical, biological social and cultural responses to these conditions environmental exposure that involve activities that subject people to agents that individuals cannot control such as pesticites, passive tobacco smoke and ionizing radiation, some of these agents may be present in air, food,water and soil,these can occur in the homes , schools ,in health facilities, work places and other settings in daily lives" (International Summit on Breast Cancer and Environments, 2002).

2.4 Types of Oncology Treatment Modalities

2.4.1 Surgery

Surgery can be used to diagnose, treat or even help in the prevention of cancer in some cases. Most people with cancer will have some type of surgery. It often provides greater chances of cure if the cancer has not invaded nearby tissues and other parts of the body.

2.4.2 Chemotherapy

Chemotherapy is the use of medicines and drugs to treat cancer. The thought of having chemotherapy frightens many people. Knowing what chemotherapy is, how it works and what to expect, can often help calm the patients fear and ultimately give the patient a better sense of control over their own cancer control treatment strategy.

2.4.3 Radiation Therapy

Radiation therapy is the use of high energy particles or waves to destroy or damage the cancer cells. It is a common cancer treatment used along (in combination) with other forms of cancer cures and at times alone. Targeted therapy is a newer form of cancer treatment to more precisely identified cancer cell to be attacked with little damage to the adjacent normal tissues. It is a growing part of the existing arsenal of cancer treatment modalities.

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2.4.4 Other Therapeutic Rationales

Stem cell transplantation, photodynamic therapy, laser cancer treatment, blood product donations and transfusions are some cancer treatments that are not common in South Africa. The researcher is interested in determining the patient's experiences of the cancer therapies they are undergoing and the experiences of the care they receive as they receive the treatments from the entire multidisciplinary team geared for cancer care.

2.5 Symptomatic Experiences of Cancer Treatment

Cancer treatment produces side effects (adverse events) that need to be attended to in order to alleviate the suffering of affected patients.

2.5.1 Pain

Patients with cancer may experience pain due to the information of the diagnosis of cancer; they experience emotional pain and need proper counselling for their emotional pain. Survivors may experience continuous pain after cancer treatment and the pain may be mild or severe and may require analgesia (e.g., morphine) for their pain. Pain may result from cancer treatment or that the cancer may have spread to other parts of the body; bone metastasis; peripheral neuropathy due to injury on the nerve resulting from chemotherapy. Radiation and surgery can also lead to varying pain (NCCN: 2014).

The National Comprehensive Cancer Network (NCCN) is an alliance of 25 of the world's leading cancer centres, working together to develop treatment guidelines for most cancers, and dedicated to research that improves the quality, effectiveness and efficiency of cancer care. NCCN offers a number of programmes to give clinicians access to tools and knowledge that can help guide decision-making in the management of cancer.

Guidelines are developed and updated by 47 individual panels, comprising over 950 clinicians and oncology researchers from the 25 NCCN member institutions. These panel members are multidisciplinary, disease-specific sub-specialists who are both clinicians and

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researchers. In addition, each guideline undergoes annual institutional review where it is circulated for comment among the multidisciplinary faculty at each NCCN member institution.

The NCCN Guidelines are composed of several critical components, as follows:

- These programmes and resources provide clinicians with access to tools and knowledge that can help guide decision-making in the management of cancer.
- Listing of panel members providing institutional affiliations and specialties.
- Algorithms or decision pathways outlining the step-by-step clinical decision-making process for patient management.
- Discussion or text summarising the data the recommendations are based upon and the important issues considered in interpreting the data and developing the algorithms.
- Listing of references providing the evidence on which recommendations are based.
- Disclosure of potential conflicts of interest of panel members and NCCN headquarters staff.

2.5.2 Nausea

Nausea and vomiting in cancer patients may be triggered by the administration of emetogenic chemotherapy drugs. Not all patients experience nausea and vomiting; patients who had severity of nausea and vomiting during the past cycle of chemotherapy, would have poor control of nausea and vomiting in subsequent cycles (Higgins, Montgomery & Bovbjerg, 2007:171). Nausea and vomiting are among the most feared side effects of cancer treatment. While many people treated for cancer have bouts of nausea and vomiting, there are medicines that work well to control these side effects (ACA, 2009).

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2.5.3 Fatigue

Patients with cancer experience and report fatigue during their illness and treatment. In a study conducted in Sweden by Ahlberg, Ekman, Gaskon-Johanssons & Mock (2003:14) an assessment of the cancer-related fatigue indicated that the cause of fatigue is not known and there are gaps in the knowledge of the mechanism thereof and the management therefore is focused on the treatment of anaemia and behaviour interventions like exercise that are able to relive fatigue.In addition, the patient is assessed for the presence of seven treatable factors known to contribute to fatigue: pain, emotional distress, sleep disturbance, anaemia, and alterations in nutrition, deconditioning and comorbidities Ahlberg,et al (2003:14). If any of these conditions are present, they should be treated according to practice guidelines, with referral to other health care professionals as appropriate, and the patient's fatigue should be re-evaluated regularly. The National Cancer Institute (NCI:2013) asserts that fatigue is a common feature to cancer patients and that fatigue has a serious impact on the day-to-day activities of cancer patients and that patients complain that they lose their self-control and become dependent (Meeneghan & Dowling, 2010:52).

2.5.4 Depression

Patients with cancer are mostly reported to be having depressive episodes following the diagnosis of cancer and during treatment of cancer. It is not always possible to measure the depression of the patients, especially those who do not want to talk about their feelings.

2.5.5 Anxiety

Anxiety occurs in cancer patients and the anxiety may increase as the disease progresses. It may be part of the adaptation of the patients to cancer. The level of anxiety may differ from person to person. Patients' anxiety states abate as they learn more about their cancer. Vera(2009:4) in the study on the relationship between uncertainity in illnesss and anxiety in patients with cancer indicated that anxiety is a threat to homeostasis, a presence of impending

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change, a sense of loss, uneasiness or increased apprehension.

2.5.6 Drowsiness

Patients who require more analgesia and opioids because of the intensity of their pain will experience drowsiness that can interfere with their day-to-day activities, the assessment and treatment of conditions like anaemia and tolerable exercises can assist in the reduction of drowsiness in these patients.

2.5.7 Dyspnoea

It is a problem experienced by patients with cancer of the respiratory tract or a feature in advanced cancer causing distress. Dyspnoea can be multifactorial and the identified cause of the dyspnoea can be managed to alleviate breathlessness.

2.5.8 Insomnia

Insomnia is common in cancer patients that could be caused by the general anxiety following the diagnosis and the uncertainties of the future. Caffeine, steroids and other cancer treatments can cause insomnia in cancer patients. The underlying causes of insomnia should be treated to alleviate sleep disturbances. Some patients with cancer are said to take more than three consecutive days with sleep deprivation. The NCI conducted a study to understand sleep disorders in cancer patients and concluded that the general population of people with cancer experience sleep disturbances, physical pain and illness, hospitalisation, drugs and other forms of treatment may disrupt sleeping patterns of cancer patients (Ancoli & Moore, 2008:245).

2.6 Experiences of Cancer Patients

2.6.1 Cancer Care

Care is defined as an abstract and concrete phenomenon related to assisting supporting or enabling experiences or behaviour towards others with evident anticipated needs to improve

a human condition of life (Oxford English Dictionary, 2005). It is the aim of the National Cancer Screening Service to ensure that its services are both accessible and culturally appropriate for all eligible individuals in the population. Barriers for some patients include poor health motivation and counselling, fear, embarrassment and mistrust of cancer treatments. It has been well documented that the social conditions in which people live and work can have a negative impact on health. Lack of income, inappropriate housing, unsafe workplaces, and lack of access to health care systems are some of the social determinants of health leading to inequalities (WHO, 2004).

In treating patients with cancer there are different guidelines that are to be followed so that all the treatment protocols are correctly followed for the benefit of the patients. The American Society of Clinical Oncology has developed a process for adapting other organizations' clinical guidelines such as The Pan Canadian Guidelines on screening .In South Africa, there are practice guidelines that have been adapted from the NCA and those laid down by the WHO (2004). Patients with cancer are required to receive treatment for a long time as per these guidelines.

Doumit, Huijer & Kelly (2007:3004) in a phenomenological study conducted in Lebanon, on the lived experiences of Lebanese oncology patients receiving palliative care highlighted that patients expressed problems with their dependency in the health care systems such as their dislike for pity, their worry for the family and their families concerns about their illness, their reliance on God and divinity, their dislike of the hospital stay, their need to be productive, their fear of pain and need to communicate. These experiences are very important to be revealed by the patients as the patients' inner feelings are not known. The need for these phenomenological interviews may assist in the planning of care as required by individual patients.

Cancer care today often provides medicinal and surgical treatment, but fails to address the psychological and social problems associated with the illness, this failure can compromise

the effectiveness of health care and thereby adversely affect the health of cancer patients. Epstein and Street (2007:66) in their study on patient centred communication in cancer care indicated that psychological and social problems created or exacerbated by cancer, including depression and other emotional problems, lack of information or skills needed to manage the illness, lack of transportation or other resources, and disruptions in work, school, and family life cause additional suffering, weaken adherence to prescribed treatments, and threaten patients' return to health.

Care rendered to the oncology patients should be patient-centred; the caregivers are expected to provide such care as needed by the cancer patients with dignity and respect. Patients value professionals who are aware of their individuality and their unique way of experiences of their cancers and its impact on their lives.

In a study conducted in South Western Turkey on the life experiences of women living with breast cancer, Cebeci, Yangin & Cebeci (2012:406) discussed three themes that emerged from the study, which were, the patient's need of family and spousal support, need to worship and need to receive and share information, living with loss of one's breast and self-image, changes in the perception in health care and a greater appreciation of life. The results of the study challenged the health care providers and educators to be more aware of the difficulties that the women face when living with breast cancer.

Patients with lung cancer were assessed on their experiences while hospitalised in several United State Regions about their cancer care outcomes. The survey was undertaken to assess the rating of the overall quality of cancer care and experiences with three domains of interpersonal care (physician communication, nursing care, coordination of and responsiveness of care). The results indicated that the rating of care differed significantly by race, language and health status (Ayanian, Zaslasky, Arora, Kahn, Malin, Ganz et al., 2010:5154).

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According to the Health Professions Council of South Africa (HPCSA: 2012) Policy document, in any health care delivery system, the emphasis should always be to provide quality care to patients in the most cost-effective way possible. Quality based on best practice may not be sacrificed in the interest of cost. However, quality must be seen in the context of affordability. The need to use available opportunities to educate communities and the at risk groups is important for early screening and diagnosis. In South Africa, there are screening programmes offered at the primary health care available without financial implications on the part of the patients. However, the implementation of these programmes are haphazard or not implemented in most rural clinics, only minimal sensitisation is done according to the departmental health calendar.

2.6.2 Communication in Cancer Care

Patient-centred communication has been defined as the skills and processes that foster eliciting, understanding and validating patients' perspectives, understanding the patients within the patient's own psychological and social context, reaching a shared understanding of the patient diagnosis and treatment options and helping the patient to share the decision-making powers by offering them meaningful involvement in choices relating to their health (Perochia, Hodoroski, Williams, Kornfeld, Davis, Monroe & Bright, 2010:3). Good communication among patients with cancer, family caregivers, and the health care team helps improve patients' well-being and quality of life. Communicating about concerns and decision-making is important during all phases of treatment and supportive care for cancer.

Communication between clinicians and patients is the most important process towards cancer care where the complexities of medical treatment, the uncertainties regarding the disease and the treatments outcomes are discussed (Schofield, Butow, Thompson, Tattersall, Beeney & Dune, and 2003:48). Patients' preferences for communication during diagnostic consultation were not always consistent with published guidelines. According to Schofield et al. (2003:48), recommendations on how to break bad news is primarily based on expert opinion

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and that patients' satisfaction with communication and psychological morbidity was found to be associated with particular communication practices. Psychological adjustment was related to patient ratings of the quality of doctor discussion about treatment options Schofield et al. (2003:48). Patients who wanted more emotional support at the time of diagnosis subsequently experienced poorer psychological adjustment.

The differences in patient preferences show that a list of prescriptions for how to disclose a cancer diagnosis is too simplistic (Schofield et al., 2003:48). Guidelines for clinicians should be derived from patient-based data rather than be limited only to clinical opinion. Guidelines concerning communication at the time of diagnosis also need to address discussions concerning the implications of the diagnosis and making treatment decisions. The health care personnel should have a way of communicating the results.

Communication within oncology is a core clinical skill, but one in which few oncologists or specialist cancer nurses have received much formal training on (Schofield et al., 2003:64). Inadequate communication may cause much distress for patients and their families, who often want considerably more information than is usually provided. A study conducted in Sydney on the psychological response of patients receiving a cancer diagnosis (Schofield. et al., 2003:64) indicated that the patient's experiences are that one is never ready to hear of the cancer diagnosis, but it's necessary for them to hear about it.

Many patients leave consultations unsure about the diagnosis and prognosis, confused about the meaning of and need for further diagnostic tests, unclear about the management plan and uncertain about the true therapeutic intent of treatment. A successful relationship between patients and health care providers depends on the establishment of trust, which is strongly connected with truthful communication (Surbone & Zwitter, 1997:66).

Good communication facilitates early diagnosis, self-management, reduces undue stress and a state of patients not knowing about their diagnosis and what to do next (Thorne, Hislop,

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Armstrong & Oglov, 2008:34). Patients who have experienced good communication about their cancers are better able to communicate their feelings and are in a better position to make informed choices. According to Thorne et al. (2008:34), many cancer patients hold the belief that communication with their health care providers has a meaningful part to play in shaping the outcome of cancer control and management.

Patients require to be informed about their diagnosis or the aim of the investigations that lead to the diagnosis of cancer. In a study undertaken in Belgium on socio-economic status of the patient and doctor patient communication. Willems, De Maesschaik, Devuengele, Derese & Maeseneer (2005:139) reported that patients from a lower social class receive less positive socio-emotional utterances and a more directive and less participatory consulting style, characterised by significant less information giving.

Willems et al. (2005:139) pointed out that a doctor's communication style is influenced by the way the patients communicate and that patients from higher social classes who communicate more effectively and express the need to be told more by the health care team tend to benefit from the proceedings. A more effective communication could be established by both the doctor and the patients through doctor's awareness of the contextual communicative differences and empowering the patients to express concerns and preferences.

2.6.3 Acquiring Information Regarding Cancer Care and Support

Patients who lack support of the health care team or do not have information about their cancers may seek unreliable information from unreliable sources (Simonelli, 2010:98). With information patients can reveal the innermost feeling that will guide the therapist on the emotional support the patient requires. Supportive care is a multi-dimensional field which covers all aspects of cancer patients, except for the specific aspects of antineoplastics, with the goal to preserve as much as possible the overall well-being (Simonelli, 2010:98).

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According to Klastersky & Lossignol (2011:55), it is difficult to define best supportive care as it would imply that the best have been reached yet there are still patients whose support needs are not met, the study further indicates that supportive care in oncology allows consideration to any new developments that could contribute to the quality care of patients with cancer whether specific anti-cancer treatment is administered or not (Klastersky & Lossignol (2011:55).

While disclosing a cancer diagnosis to a patient is common practice, how it is disclosed and the impact it has on the patient are poorly understood. Physicians should disclose a cancer diagnosis in a personal setting, discussing the diagnosis and treatment options for a substantial period of time whenever possible (Figg, Smith, Price, English, Thurman, Steinberg, & Emanuel, 2010:77). Patients with cancer do not want relatives to be there when information about their cancers are revealed because of the stereotypes the community have towards cancer patients and the stigma attached to cancer by the communities, some patients with cancer prefer to be alone when receiving the diagnosis.

2.6.4 Emotional and psychological Support

The diagnosis of cancer is an emotionally-laden one, known to generate the psychological distress in the affected individuals. According to the NCI (2014), dealing with different different side effects and life changes of cancer treatment can be hard on you emotionally as well as physically. Cancer can bring up a wide range of feelings you are not used to dealing with. Receiving such a diagnosis has been associated with uncertainty outcome and despite the outcomes and the advances in modern medicine patients often fear the worst upon hearing that they have cancer. Patients diagnosed with cancer experience levels of anxieties and depression severe enough to affect the quality of their lives. The issues that cloud them are psychological need and fear of treatment and recurrence after treatment. Adults who are diagnosed with cancer, have previously encountered or heard of individuals who have been diagnosed with cancer, have a tendency of remembering and focusing on all of the negative

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aspects of living with cancer.

A study conducted in Denmark by Kristiansen, Tjornhoj-Thompson & Krasnik, 2010:244). on the experiences with emotional support by nurses amongst Danish-born and migrant patients has shown that emotional support in informal relationship may be difficult to access because of fear or lack of knowledge, both perceived the support delivered by health care professionals as available, empathetic and valuable and that formal relationship with health care professionals are of great importance (Kristiansen et al., 2010:244). The study indicated that the supportive care was not influenced by the cultural difference; patients in the study indicated a need to talk to someone about their disease and treatment (Kristiansen et al., 2010:244). In this case the nurses were viewed as being capable of and willing to listen to patient worries and fears. Regular assessments of the patients' needs should always include psychological assessment to assess the psychological response of patients receiving a diagnosis of cancer (Schofield, Butow, Thomson, Tattersal, Beeny & Dunn, 2003:48).

For cancer patients, cancer is a death sentence, some develop guilt from own poor health habits, fear of pain suffering, death and stigmatisation. The levels of psychological aspects such as depression, anxiety and hopelessness prevailed in most cancer patients. The physical and emotional effects of cancer and its treatment may be very different from person to person (Levit, Balogh, Nass, & Ganz, 2013). The differences in age, cultural background or support systems may result in very different care needs (Levit et al., 2013:17). Today, it is not possible to deliver good-quality cancer care without addressing patients' psychosocial health needs. All patients with cancer and their families should expect and receive cancer care that ensures the provision of appropriate psychosocial health services (Levit et al., 2013:17). Comprehensive care will take the following issues into account for each patient:

2.7.1 Physical symptoms of cancer

Common physical symptoms include pain, fatigue, loss of appetite, nausea, vomiting,

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shortness of breath, and insomnia. The patients that experience severe physical symptoms in cancer should be admitted in the hospitals where they can be given treatment to gain the strength. When patients are undergoing treatments for cancer, tumour cells die and release potassium and purines, an increase in potassium levels in the body may cause cardiac arrhythmias, muscle weakness, twitching and cramps, purines convert to uric acid that may result in renal failure causing flank pains, gout when uric acid is very high. A case of elevated phosphates with secondary lowered calcium may cause heart block (ACA, 2013).

According to the guidelines of the ACA (2013), patients on chemotherapy need supervision and specialised care before and after chemotherapy. They need fluid intake that is regulated, and may also need intravenous therapy and supervised diuretics to increase urine flow and may need treatments of increase the excretion of the uric acid produced by the dying tumour cells and may also need dialysis. The differences in the patients that are receiving chemotherapy in United States is that patients are monitored and followed up after chemotherapy and observed for complications while in hospital if their condition warrants that. Conversely, patients with cancer in Vhembe are treated on an outpatient basis and travel 220 km for treatment; the distance coupled with the effects of treatment can be detrimental to experiencing a good quality of life. Patients' anxiety states are exacerbated by these circumstances and are said to have a negative experience in the care provided. Anxiety associated with cancer may increase feelings of pain, interfere with one's ability to sleep, cause nausea and vomiting and interfere with the patient's quality of life, and may be life threatening.

A study conducted in South Western Turkey concerning women's perception of their care and various needs during breast cancer treatment revealed that health care providers and educators need to be more aware of the difficulties that women face when living with breast cancer (Cebeci et al., 2012:407). The challenges revealed by this study included the loss of a body part and perception of own feminity, changes in everyday life and changes in self-

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perception. According to the study conducted by Cebeci et al. (2012:408), the cancer patients experienced episodes of sadness and crying due to the losses they experienced like the loss of hair, the disfigurement of their bodies after the mastectomy and other surgical treatments. The patients in their study attached importance to support given by the family during their illness.

2.7.2 Spiritual Support

Spiritual care is an act of supporting the faith needs of a patient, providing devotional opportunities, encouraging denominational connectedness and cooperation in pastoral care Hence, Hegarty (2007:77) reflected on it as important to assist patients who may be religious or not seeking answers for their question about the meaning and purpose for their illness through their own experiences. Cebeci et al. (2012:408) indicated that the participants reported that an increase in worship needs occurred after receiving the diagnosis of cancer. The belief that the disease was something coming from God and that it was their fate to develop cancer. Some patients believed that they could get rid of the disease by worshiping (Hegarty, 2007:77). With a cancer diagnosis, patients and families often look more deeply for meaning in their lives. Some found that the disease brought them more faith, whereas others questioned their faith as they struggle to understand why cancer happened to them. van der Lee, van der Born, Swarte, Heintz, Graeff and van den Bout (2005:6607) indicated that there is an association between depression and the incidences of explicit request for euthanasia in terminally ill patients. This is an indication that the cancer patients require intensive care and support such as palliative care and the need to be made comfortable. An expert in palliative care can help people explore their beliefs and values so that they can find a sense of peace or reach a point of acceptance that is appropriate for their situation.

2.7.3 Palliative care in cancer

Palliative care is comfort care given to a patient who has a serious or life-threatening disease, such as cancer, from the time of diagnosis and throughout the course of illness. The World

Health Organisation (WHO,2012) recommended that all countries implement comprehensive palliative care programmes. Palliative care is an approach which improves the quality of life and families facing the problems associated with life threatening illnesses, through the prevention and treatment by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual (WHO, 2012). Hospitals, cancer centres, and long-term care facilities provide palliative care. Patients may also receive it at home. Palliative care addresses the emotional, physical, practical, and spiritual issues of cancer. Palliative care improves the quality of life of patients and family members, as well as the physical and emotional symptoms of cancer and its treatment.

O'Brien, Rose, Campbell, Weller, Neal,Wilkinson, McIntosh & Watson (2011:200) conducted a qualitative study in the United Kingdom to gain insight into the experiences of follow-up care after treatment for prostate cancer and identified the psychosexual needs, and uncovered that men were rarely invited to discuss the side effects of treatments and care within the follow-up appointments and lack of rapport with the health care professionals and made them to raise the concerns themselves; older patients were embarrassed to raise the psychosexual concerns as they felt they would be considered too old to worry about the loss of sexual function (O'Brien, 2011:200).

Treating a patient's emotional and social needs, including symptoms such anxiety or helping with family is important. However, it is usually provided by a specialist who works with a team of other health care professionals (health care team) such as doctors, nurses, registered dieticians, pharmacists and social workers (Fröjd, Lampic, Larsson, Birgegard & van Essen, 2007:524). According to Fröjd et al. (2007:423), the team should consider the patients' verbal and non- verbal communications together with the questions that the patients ask to evaluate the extent of the patients' worries or concerns.

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2.7.4 Coordination of Cancer Treatment and Care

Cancer patients and their relatives experience inadequate information about and psychosocial support in relation to diagnosis, treatment, symptom management, aftercare, prognosis and rehabilitation (Wulff, Thygesen, Søndergaard & Vedsted, and 2008:227). Patients experience continuity breaks of which one type is inadequate information transfer, especially when care involves providers in different settings (Wulff et al., 2008:228). According to Wulff et al. (2008:228), patients also express uncertainty about where to go and who to address in case of questions or problems. Cancer care and treatment needs to be well-coordinated so that the patients' uncertainties are addressed and the physical, psychological, social and spiritual needs are not ignored and questions answered, however, cancer treatment and care is fragmented and poorly coordinated (Wulff et al., 2008:228). The need for structured support and guidance is dire in areas of care where there are insufficient clinical nurse specialists who can improve patient safety and support and coordinate the patient management. Cancer care can be extended by involving the community members that can liaise with the nurse about their patients in the community with a service that is not yet established and there are patients that are cared for at the hospitals. The number of patients seen at the hospitals is big and trained staff are few that can really give oncology care.

In the hospital, the use of oncology nurses could be very effective in the navigation of the patients so that the patients cannot be lost in the process and to assist in co-ordination of the patient treatment and care. The treatment of cancer may cause side effects. An important part of cancer care is relieving the symptoms and side effects. The approach called palliative care is aimed at reducing the symptoms and treatment.

Palliative care specialists can provide resources to help patients and families deal with the emotions that come with a cancer diagnosis and cancer treatment. The health care team that is expected to take steps in the journey of the patients with cancer comprises the oncologist, the nurse, social workers, the chaplain, dietician, physical and occupational therapists. Each

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one of them has a significant role in the care and treatment of these patients; however, the researcher would point out the clear role of the nurse in this relationship. The nurse who provides care helps in the management of pain and other symptoms like allaying the patient's anxiety. The nurse acts as the main contact person with the rest of the team. The nurse has this relationship and role of being first contact of the patients. According to Griffiths, Simon, Richardson & Conner (2013:39), cancer can place a burden in both physical and psychological well-being of the patient.

In South Africa, the concept patient navigation can be aligned with the scarce availability of the trained oncology nurse specialists, who are the ones following up the cancer patients at the centres of care. These type of nurses are scarce and with lack of resources to follow-up all the patients that need such care. The doctors that are seeing these patients are not the same doctors every time and with little knowledge about cancer care. Griffiths et al. (2013:39) alleged that in a hospital where there are more specialists, patients report better care at the hospital. All cancer patients require some kind of treatment for cure or the relief of pain and other symptoms, including palliative care when a curative option no longer exists. According to Masika et al. (2012:133), in their study in Tanzania on health-related quality of life and needs of care, both men and women reported low quality of life, especially with regard to physical role, social function and a high level of symptoms and problems, especially those of finance and pain.

2.7.5 Health Care Disparities

Jea-Pierre, Hendren, Loader, Rousseau, Schwartzbauer, Sanders, Carroll, Fiscel & Epstein (2011:111) asserted that health care disparities based on race, ethnicity and income remain a public health challenge in the United States. Despite the significant advances in the prevention, early detection and cancer management, individuals from racial/ethnic minorities and lower socio-economic groups continue to have a higher cancer mortality rates than their counterparts. According to of the cancer alliance, cancer patients require a full continuous

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cycle of chemotherapy and radiation within a protocolled timeframe which, if interrupted, puts the patient's life in danger and it has a poor outcome.

Lack of access to medication, broken machines and rescheduling has made life-saving cancer treatment very difficult to access for many patients.

2.8 Summary

The literature review has covered many aspects of oncological treatment experiences by cancer patients around the world and in South Africa. The study is aimed at providing researched evidence on the in-depth exploration and description of the experiences of patients regarding oncology treatment and care at hospitals in Vhembe District of Limpopo Province and contribute to the body of knowledge on improved caring of cancer patients.

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CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 Introduction

Methodology is the approach used by the researcher to guide the conduct of the study, the paradigm that influences how a researcher presents a research question and decides on the methods and data analysis to employ in a study (Giddings & Grant, 2007:52).The purpose of research methodology is to inform the reader of how the investigation was carried out, what the researcher did to solve the research question and respond to the research questions (Brink, van der Walt & van Rensburg, 2014:199).

3.2 Research Design and Methods

The research design and method of this study was focused on the research strategy and approach, population and sampling, method of data collection, data analysis and interpretation. Research methods involved the forms of data collection, analysis and interpretation that researchers proposed for the study (Creswell, 2009:233). In this study, a qualitative, explorative, descriptive and phenomenological design was used in order to get an in-depth understanding of the experiences of patients regarding oncology treatment and care.

3.2.1 Qualitative Research

Qualitative research is a means for exploring and understanding the meaning that individuals or groups ascribe to a social or human problem. (Brink et al., 2014:232). The researcher has chosen this type of method in this study as there was a need to explore the oncology patients' experiences with an attempt to understand the phenomenon in its entirety stressing the importantce of people's interpretation to events and circumstances.

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The researcher elicited verbal and visual data and described the data in the field notes; data were recorded with an audiotape. The participants were studied in their own setting in order to discover their social world of receiving oncology care. The study was qualitative, its purpose was to explore the depth and richness and the complexity in the patients' views and perception of the care and oncology treatment they are receiving.

The following characteristics of qualitative research were important in this researchconcepts may be interpreted in a number of ways; concepts and contracts are meaningful words that can be analysed to gain greater depth of understanding. The observations were subjective; the researcher observed and experienced them personally. It occurred in non-structured manner. It was possible to record unexpected events which added to the richness of the data, the context was taken into account and was observed as forms of behaviour as they occurred. In this study, the researcher attempted to understand the experiences of patients regarding oncology treatment and care in the selected hospitals. A distinctive aspect of qualitative research is that the researcher attempts to understand people in terms of their own definition or self-description and concepts of the world (Creswell, 2009:12).

3.2.2 Exploratory Research

Exploratory research is conducted to gain insight into a phenomenon, community or individual (Brink, 2012). Exploratory research strives to explore the dimension of the phenomenon so that it provides more insight about its nature and the manner in which it manifests itself. The main purpose of exploration was asking questions to understand the nature or extent of a complex problem; the researcher explored the experiences of patients regarding oncology treatment and care at the hospitals. The researcher chose the explorative design as it would provide an opportunity to ask questions to explore the phenomenon in full by actively communicating with the research participants to understand their experiences. The researcher described the explored experiences as narrated by the participants.

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3.2.3. Descriptive Research

In descriptive research, phenomena are described or the relationship between variables are examined and there is no attempt made to determine cause and effect of a relationship (Brink et al., 2014:11). The main purpose of descriptive research is to paint a picture using words and to present a profile (Neumann, 2006:35). In this study, the researcher described the experiences as explored and narrated by the patients regarding cancer treatment and care.

3.2.4 Phenomenological Research

Phenomenology is the thorough, systematic study of human experience that aims to produce insightful descriptions of the way people experience their world (Creswell, 2009). Phenomenologists believe that knowledge and understanding are embedded in everyday life, and that truth and understanding can emerge from life experiences, which comprise thoughts feelings, values, emotions, purposes and actions (Burns & Grove, 2003).

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The hermeneutic phenomenological structure of van Manen (1990) provides the following six fundamental human science research steps:

1. Turning to a phenomenon which seriously interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualise it.
3. Reflecting on the essential themes that characterise the phenomenon.
4. Investigating experience as we live it rather than as we conceptualise it.
5. Maintaining a strong and orientated caring relation to the phenomenon.
6. Balancing the research context by considering the parts and the whole.

Brink et al. (2014:122) indicated that there are actions that should be taken in a phenomenological study during an enquiry process which are:

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3.2.4.1 Bracketing

Bracketing, where the researcher should be able to identify own preconceived ideas, beliefs and opinion about the phenomenon under investigation so that the researcher can consider every available perspective. The researcher had her own perception on how patients are treated, own perception on how the cancer patient might feel, thus bracketing of own perception was applied to avoid the researcher bias during data collection.

3.2.4.2 Intuition

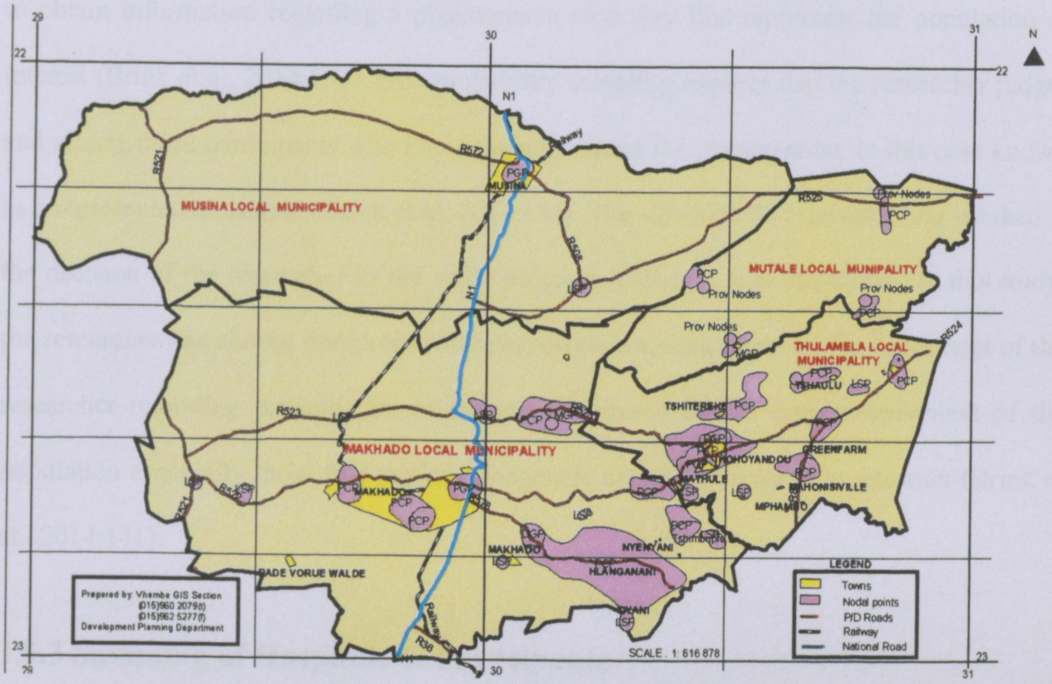
Intuition occurs when the researcher tries to develop an awareness of the lived experience. The process requires that the researcher be open to the phenomenon and becomes totally immersed in that phenomenon aided by the participants' description. The interviews were non- directional.

3.3 Research Setting

Research setting is a specific place where the data were collected, that is, the real life situation and environment (Brink, 2014:59). The Limpopo Province is located in the north eastern part of South Arica, most people live in rural areas, and it is at the curve of the Limpopo River sharing borders with Botswana to the west, Zimbabwe to the north and Mozambique to the east. It consists of the Bapedis, Tsongas and Vhavenda ethnic groups. Limpopo Province has five districts: Mopani, Sekhukhune, Capricorn, Warterberg and Vhembe. Vhembe District is at the border of Zimbabwe. Vhembe District has four sub-districts/municipalities: Musina, Mutale, Makhado and Thulamela (Figure 3.1). The inhabitants in the Vhenbe district are of the lowest socio economic quintile (Baron, Day Monticelli, Vermaak, Okarafor, Moodley & Doherty (2006:150). The hospitals in the Vhembe District that have patients who are treated and referred to Polokwane cancer treatment centre are six namely: Siloam, Louis Trichardt, Donald Frazer, Elim, Malamulele & Tshilidzini. The hospitals have no oncology facilities and programme, patients are treated

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in the general wards by general practitioners like any other patients. The oncology nurses are just processing the transfers and ensuring that the patients are booked in for their next consultations and follow-ups



Source: Limpopo Province Freight Data Bank, Vhembe, 2007).

Figure 3.1: Map of the Vhembe District study site and its four sub-districts

3.4. Population of the Study

According to Polit & Beck (2008:761), a population is the entire set of individual or objects that share common characteristics which are relevant to the problem under study. The population in this research encompassed patients receiving cancer treatment and care at the purposively selected hospitals in the Vhembe District of Limpopo Province.

3.5 Sample and Sampling Method

3.5.1 Sample

A sample is a subset of a population that will be selected from a study population to

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participate in the study (Polit & Beck, 2008:765).

3.5.2 Sampling Method

Sampling refers to the researcher's process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest (Brink et al, 2014:132). Non-probability sampling requires that the researcher judges and selects those participants who know the most about the phenomenon, in this case known as a representative sample (Brink et al, 2014:133). The direction that the sampling is taken is the decision of the researcher as the study progresses (Brink, et al 2014:139). In this study, the researcher has chosen non-probability purposive sampling based on the judgement of the researcher regarding participation of the subjects based on the representativeness of the population especially those that are knowledgeable about the research in question (Brink et al., 2014:141).

3.5.3 Sampling of Hospitals & Participants

Hospitals

A purposeful sampling method was used to sample hospitals in the district that have an active oncology programme. The hospitals that were purposefully sampled were Tshilidzini which is a referral hospital as well as Malamulele and Donald Fraser, the community hospitals in the Vhembe District. The relevant authorities had given permission to access the hospitals, see annexure 8, 9 and 10.

Participants

Access to the participants was gained through the oncology nurses working in the selected hospitals. Participants were chosen because they illustrated some feature that was of interest to the researcher (de Vos et al Strydom, Fouche &, Delport, 2006:328). Inclusion criteria are used in a study to clearly show association of participants following their characteristic of

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interest (Neumann, 2011:230). Sampling criteria list the characteristics that are essential for membership in the target population (Burns & Grove, 2003:255).The elements that were considered for selection in the sample were, in this case, as indicated below:

- The researcher selected participants who were willing to participate voluntarily.
- The participants who were under the care at the selected hospital for their cancers, all cancers included.
- The participants were at least treated for a year or more for cancer at a selected hospital.

Data saturation was reached when 13 participants have been interviewed and there was no new information gathered from the participants (de Vos et al., 2012:234). Accessing the participants in this study formed part of the purposeful sample accessed through colleagues who were working in the oncology care units of the different hospitals. The researcher introduced the study at the oncology clinics on the days the patients came for follow up and requested if any of the patients would like to participate. Copies of the information sheet (Annexure 11) were left with those that wanted to participate extra copies were left with the nurses to assist in giving information, the nurses assisted with the contacts that wanted to participate,the researcher contacted the research participants to set up the dates,time and venue for the interview.

3.6 Data Collection

The researcher used in-depth individual interviews with the research participants to gather information on their experiences regarding the care and oncology treatment they received at the hospitals (Burns & Groove, 2011:594). Phenomenological research allowed achievement of rigorous quality as in natural scientific research, and articulated methodology in such a

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manner that data collection and data analysis were both seen as part of a single, unified process with the same underlying theory of science.

3.6.1 In-depth Individual Interview

An interview is the most commonly used technique in social research suitable in exploratory designs in which questions cannot be narrowly defined. The participants were free to elaborate on the topic as they saw fit, focusing on specific aspects and related the topic to their experiences.

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An unstructured in-depth interview using one broad statement: "what is your experience regarding oncology treatment and care at the hospital" was used to gather data from the participants (de Vos et al., 2012:298). The researcher is conversant with different languages spoken in the district as she was the sole instrument collecting the data. The interviews were free flowing with its structure limited to the focus of the research. Interviews were particularly useful in exploring, probing and searching what was significant to what the participants perceived. The broad question enabled the researcher to gain a better understanding of the experiences of these oncology patients regarding their care and oncology treatment. Other probing questions included aspects like physical, psychological, spiritual, financial and social to get the detailed information of the experiences of these patients regarding cancer treatment and care.

The researcher guarded against being directional during the interviews by not directing the interview towards her own bias. An audiotape recorder was used to record the interviews that were later transcribed verbatim for analysis purposes (Brink et al., 2014:34). The research participants were informed about the use of audiotape recorder in the *Partipant Information Sheet* (Annexure 11) and *Informed Consent Declaration* (Annexure 12) before using it in the interviews and participants could request to stop the tape record if they so wished.

3.6.2 Communication Strategies

The following communication strategies were used in this study:

3.6.2.1 Scene Setting

The place for interviewing was determined by the researcher and the participants. The researcher started by introducing the research topic to the oncology patients and their role in the study (Henning, Van Rensburg & Smit, 2004:75). Times were set by both the researcher and participant; the comfort of all participants was observed. The researcher adhered to the times set by the participants and provided a more private place without noise that could

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disturb the interview and made sure the participants were supported and free from harm. A plan was arranged with the different hospital social services to assist in the counselling of the participants if a need arose after reliving their unfortunate experiences during the exploration. The researcher also asked probing questions in a sensitive way not to provoke emotions and did not divert from the aim of the exploration.

3.6.2.2 Clarifying

During the interview the researcher clarified information and concepts that the participants informed the researcher about and the researcher captured the real thoughts of the participants (Brink et al., 2014:159). The statements such as 'tell me more about what you have just told me' were used to allow the researcher to clarify the shared information.

3.6.2.3 Reflecting

Reflecting is a process of summarising part of the conversation during the interview process to check whether the interviewer's perception corresponds with that of the participants (Brink et al., 2014:158). Depending on the interview and participants' ability to express their experiences, the questions and the probes were changed slightly to capture the true meaning of the interview responses so that they could give a meaning to what the participants meant.

3.6.2.4 Minimal Responding

The researcher encouraged the participants to express their experiences regarding oncology treatment, care and support at the hospitals by listening without interrupting them in their responses to the interview questions. The researcher used non-verbal responses like nodding to encourage the participants to narrate more.

3.6.2.5 Probing

Probes are prompting questions that encourage the respondents to elaborate on the topic

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(Brink et al., 2014:158) the researcher used probing questions to encourage the cancer patients to relate their experiences regarding treatment, care and support in the hospitals. This also entailed asking the participants to explain more of the narrated experiences regarding the care and oncology treatment.

3.6.2.6 Field Notes

Field notes and logs are the record keeping devices for interviews (Brink et al., 2014:159). Field notes were written when the researcher described what was observed during interviews. They are descriptive accounts in which the researcher objectively records what is happening in the setting (Neuman, 2006:364). Field notes are an important data collection technique. Non-verbal responses and gestures that the participants made were written down to augment pertinent information relevant to the research. The researcher kept notes to remind her of the happenings during the interviews. It is a system for remembering, retrieving and analysing observations (Neuman, 2006:364). The researcher needed field notes on the observations that were not picked up by the audiotape recording. Observational notes are similar to field notes in that they are also descriptions of events experienced through watching and listening to the participants where no interpretations were provided.

3.7 Data Analysis and Literature Control

Phenomenological data analysis involves coding, categorising and making sense of the essential meanings of the phenomenon (Kleiman, 2004:14). The researcher worked with the rich descriptive data, the common themes began to emerge. Analysis basically involved total immersion for as long as it was needed in order to ensure both a pure and thorough description of the phenomenon. The structure of phenomena is the major finding of a descriptive phenomenological inquiry. This structure was based upon the essential meanings that were present in the descriptions of the participants and was determined by analysing phenomenological research (Kleiman, 2004:14). Thus, the researcher:

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1. Read the interview transcripts in their entirety in order to get a global sense of the whole.

2. Thoroughly read the interview transcripts a second time and divided the data into meaningful sections or units.

3. Integrated those sections or units that were identified as having a similar focus or content and made sense of them.

4. Subjected and integrated meaningful sections to a process that was known as free imaginative variation. The free imaginative variation process determined the researcher's integrated meaningful units essential for compilng a fixed identity for the phenomena studied (Kleinman, 2004:14).

5. Elaborated findings that included descriptions of the essential meanings that were discovered through the process of free imaginative variation.

6. Revisited the raw data descriptions again in order to justify her interpretations of both the essential meanings and the general structure.

7. Proved and substantiated the accuracy of all the findings by reference to the raw data.

8. On completion of the analysis of the data, followed a critical analysis of the work within the study.

This critical analysis included verification that:

1. Concrete, detailed descriptions were obtained from the participants.

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2. The phenomenological reduction has been maintained throughout the analysis.

3. Essential meanings were discovered.

4. A structure was articulated.

5. The raw data verified the results.

Literature control: Previous studies were used to establish similarities and as well as to determine the uniqueness of the present research during analysis.

3.8 Measures to Ensure Trustworthiness

Trustworthiness is a way of ensuring data quality or rigour in qualitative research (Brink, 2014:172). Ensuring trustworthiness entails taking measures to make sure that the research findings are worth paying attention to and taken into consideration. It is very important to note that the researcher was the instrument of data collection and analysis, therefore the truthfulness and accuracy of the data were based on the interpretations of the researcher. The researcher ensured that the data collected were accurate and that she has made the right representation and interpretation. To ensure that the findings of this study were a true reflection of participants' experiences, criteria used for developing trustworthiness of qualitative studies include credibility, dependability confirmability and transferability (Polit & Beck, 2008:539). The researcher used the following criteria to ensure trustworthiness.

3.8.1 Credibility to Ensure Truth Value

Credibility alludes to confidence in the truth of the data and interpretation thereof (Brink et al., 2014:172). Truth value is a criterion that explains how one can establish confidence in the truth of the findings of a particular enquiry. The researcher used the strategy of credibility to ensure that the findings of this study reflected the experiences of cancer patients regarding

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care and support. The researcher re-evaluated the interview outcome with the participants and asked more questions to probe and establish truth in the interview.

3.8.2 Prolonged Engagement

The researcher engaged with the participants longer during recruitment consenting and data collection. The participants were able to express their feelings and experiences freely and without fear (Brink et al., 2014:172). The researcher established a relationship of trust with the participants in order to relate their experiences without fear of intimidation. The researcher engaged with the participants as she introduced herself as a student researcher that required patients to participate in the study. The researcher involved the participants by giving them an information sheet during the signing of the consent form and then discussed the interview time. The researcher believed that with the number of engagements the researcher planned to have with the participants was enough for them to ensure a trusting relationship.

3.8.3 Triangulation

Triangulation in this study was done by asking diverse questions, seeking different sources and using different methods (Brink et al., 2014:172). In-depth interviews of the research participants, direct observation of the participants narrating their experiences regarding oncology treatment and care, using of an audiotape recorder and contact with the research supervisor and co-supervisor enhanced the trustworthiness during the initial stages of data collection and data analysis to ensure the truth value of the data collection and analysis.

3.8.4 Member Checking

Member checking was done by providing feedback to the participants after the interviews to ensure that the researcher has captured the true meaning of the participants' experiences and allowed validation by the participants (Mouton, 2009:277). This strengthened the trusting

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relationship the researcher has built with participants and allowed the researcher to rectify mistakes (Brink et al., 2014:172).

3.8.5 Referential Adequacy

The researcher kept field notes written about everything that happened during interviews and all non-verbal gestures noted. An audiotape recorder was used to capture all information during interviews (Mouton, 2009:277). This allowed the researcher to provide the best description as narrated by the participants.

3.8.6 Peer-Debriefing

Discussion of the findings was done with colleagues of similar educational level at the university's peer review forum. Peer review was done to check information gathered and how the researcher analysed the information. An independent coder was asked to analyse the information. Data and method of analysis were discussed with colleagues who had an interest in the subject matter (Mouton, 2009:277).

3.8.7 Consistency to Ensure Dependability

Dependability refers to the provision of evidence such that, if it was to be repeated in the same setting or similar participants in a similar context, the findings would be similar (Brink et al., 2014:172). How can one be sure that the findings will be similar if the findings were repeated on the similar participants in the same setting (Brink et al., 2014:172; Mouton, 2009:278). Methodology used in this study was described in full by the researcher. The proposal was presented for peer review and methodology had been clearly described.

3.8.8 Neutrality to Ensure Confirmability

Confirmability means answering a question, on how the researcher will ensure that the findings will be reflecting the participants' voices in the interview rather than using the

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researcher's biases (Mouton, 2009:278). This clearly indicated that findings were the product of concern and the focus of the interview was not biased by the researcher. The researcher followed research methods following previous studies on how others conducted their own. The researcher examined and identified herself to avoid being biased. The researcher was the only investigator, asked the supervisor and the co-supervisor to be involved in the research from the initial planning phase until the final report. An independent coder was invited to validate and confirmed the research findings.

3.8.9 Applicability to Ensure Transferability

Applicability refers to the ability to apply the findings in other contexts and settings or to other participants (Brink et al., 2014:172). The strategy for establishing applicability is transferability. This consists of the nominated data, sampling, dense description of the results and direct quotations of the study participants. Transferability was ensured by presenting dense descriptive of data that allowed comparison (Brink et al., 2014:173).

3.9 Ethical Measures

Ethics is a set of moral principles that are suggested by individual persons or a group of people. They offer rules and behavioural expectations about the most correct conduct towards the research subjects, sponsors, other researchers, employers and other research students (de Vos et al., 2013:115). Ethics is doing what is right and good during research. It is the application of all the ethical principles to the research process to ensure that:

- Human, humane, humanistic and moral reasons are upheld.
- Credibility and trustworthiness of the data enhance the research objectives.
- The researcher demonstrates authenticity.

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The researcher maintained the highest possible standards of research and assumed awareness of the possible influences of personal biases and subjectivity (Brink et al., 2014:35)

The following ethical measures were considered:

3.9.1 Permission to Conduct Research

Ethical clearance to conduct research was requested obtained from the University of Venda Higher Degrees and Ethics Committee (Annexures 1-3). After the approval of the proposal, permission was sought from the Department of Health in Limpopo (Annexures 4 and 5), the hospitals where data were collected (Annexures 6-10) and from the research participants (Annexures 11 and 12).

3.9.2 Right to Self-Determination and Justice

The right to self-determination is based on the principle of respect for the subjects. The researcher treated the participants as autonomous beings with freedom to conduct their lives as they wish. The researcher informed the participants about the proposed study and allowed them to choose voluntarily to participate in the research and to withdraw from the research at any time they found it necessary (Brink et al., 2014:37). The researcher did not violate the participant's rights of self-determination by coercing them to participate in the research, covert data collection and deception. (Annexures 11 and 12).

3.9.3 Obtaining Informed Consent

Informed consent refers to the provision of full information about the research process to the participants so that they have more information on the right to voluntary participation or not to participate (Brink et al., 2014:38). An information sheet was prepared for the participants

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to take an informed decision including information about the study, the processes of the participation, the purpose of the study, the benefits of the study and assurance of anonymity and confidentiality. Written informed consent (Annexure 12) was obtained from the participants voluntarily without duress, coercion or bribery (Brink et al., 2014:38).

3.9.4 Respect for Human Rights/Protection from Discomfort

The right to protection from discomfort and harm is based on the ethical principle of beneficence, which holds that one should do good and, above all, no harm to the study participants. The researcher ensured that participants were comfortable by selecting suitable venues, times and days to participate in the research. The researcher guarded against embarrassing the participants during the interviews. Questions and probes were considerate. The researcher ensured that participants did not incur any financial loss by participating in the research by travelling to the settings. During the interview, participants were promptly observed for any type of discomfort; none of them experienced discomfort during the interviews to need referral to avoid further discomfort (Brink et al., 2014:37).

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3.9.5 Freedom from Exploitation/Right to Fair Treatment

The right to fair treatment is based on the ethical principle of justice, which is grounded on the ethical principle of justice, which asserts that each person should be treated fairly. The researcher ensured that the participants were willing to participate as outlined in the sampling criteria. The roles of the researcher and that of the participants were thoroughly explained in the study and on the information sheet (Annexure 11) accompanying the consent form. The researcher avoided inflicting psychological harm to the participants by carefully considering the phrasing of questions (Brink et al., 2014:32).

3.9.6 Confidentiality

Confidentiality is related to the researcher's management of private information shared by

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the participants, i.e., such information must not be shared with others without expressed authorisation of the research participants (Brink et al., 2014:209). The researcher did not allow other health professionals or unauthorised persons access to raw data of the study. In this study, confidentiality was maintained by using numbers instead of names. The data collected were not related to participants' names. The data collected were kept in a safe place and was only revealed to the study supervisor. Permission to share the data with the supervisors was obtained from the study participants (Polit & Beck, 2008:178).

3.9.7 Right to Privacy

Privacy refers to the extent that a participant is prepared to share personal information or withhold it from others. Private information of the participants was not be shared with other participants. The researcher ensured that the participants did not lose their dignity, friendships or employment. The researcher ensured that the self-respect and dignity of the participants were maintained throughout the research (de Vos et al., 2013:110). The researcher conducted the study in a non-judgemental manner. Anonymity was used in the raw data and no names were recorded. Voluntary participation was upheld. Participants were regarded as autonomous, with the right to make choices without intimidation or being forced (de Vos et al., 2013:110). Participants were informed of their right to terminate or withdraw their participation any time in the study despite having provided prior consent to participate, without suffering any negative consequences or victimisation whatsoever (Brink, 2006:33).

3.10 Summary

A qualitative, exploratory, descriptive and phenomenological approach was used to gather the experiences of patients regarding oncology treatment and care. A detailed description of research methods, measures to ensure trustworthiness ethical measures was provided in this chapter. Discussions of the findings of the study and literature control will be the subject of Chapter 4.

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CHAPTER 4

DISCUSSION OF THE FINDINGS AND LITERATURE CONTROL

4.1 Introduction

This chapter addresses the research findings according to themes and sub-themes. Relevant literature was used as to control the findings. The objectives of the study were to:

- Explore the experiences of c patients regarding oncology treatment and care.
- Describe the experiences of the patients regarding oncology treatment and care.

Data saturation was reached after in-depth interviews with 13 participants who have been treated for cancer at the three purposively selected hospitals in the Vhembe District of Limpopo Province. The participants where purposively selected and met the inclusion criteria of this study. The ages of the participants ranged from 45 to 59 years. Of the 13 participants only 2 were males and 11 females. Males were reluctant to participate in the study. The research question to the participants was:

What are your experiences regarding oncology treatment and care.

The question was followed by the probes to encourage the participants to share more of their experiences.

4.2 Themes and Sub-Themes

Table 4.1 outlines the themes and sub-themes that emerged from the qualitative data analysis.

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Table 4.1: Themes and sub-themes that emerged from qualitative data analysis

Themes	Sub-Themes	
1. Feelings of uncertainty	1.1	No proper formal communication
	1.2	Anxiety about prognosis
	1.3	Fear of death
	1.4	Lack of communication regarding updates due to language barriers and cultural issues
	1.5	Fear of disclosure about certain cancers
2 Experiences of distress	2.1	Experiences of pain and treatment side effects
	2.2	Experiencing body changes due to disease and treatment side effects
	2.3	Loss of female identity and masculinity
3. Social support and the burden of care giving	3.1	Positive feelings towards social support
	3.2	Negative feelings towards social support
4. Diverse experiences of support by health care institutions and treatment care coordination	4.1	Delay in diagnosis and treatment
	4.2	Experiences of dissatisfaction with transfer procedures and coordination and lack of proper referral systems andlspecialists
	4.3	No proper overnight accommodation for the transfer of patients
	4.4	Lack of food provision by the institutions
	4.5	Purposive time delay by the transfer staff to accumulate overtime
	4.6	Transferring oncology patients with non-oncological patients and lack of self esteem
	4.7	Fragmentation of services
	4.8	Lack of proper referral system and lack of specialists
5. Positive feelings of self and expression of trust in the supernatural	5.1	Need to complete treatment and be free of cancer
	5.2	Appreciation of the services received
	5.3	Acceptance of diagnosis and its course of treatment
	5.4	Expression of having trust in the supernatural
	5.5	Belief in fate
	5.6	Religious practices
	5.7	Traditional practices

4.2.1 Theme 1: Feelings of Uncertainty

Uncertainty is a source of stress for people affected by a life-threatening illness such as cancer. The participants described uncertainty in all stages of cancer, it prevails in the duration of their suffering, the way it ends and the future concerns. The following sub-

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themese emerged: No proper formal communication, anxiety about prognosis, fear of death, lack of communication of updates due to language barriers and cultural issues and fear of communication about certain cancers.

4.2.1.1 No Proper Formal Communication

Communication in cancer care must help patients to receive the bad news, handle the emotional impact of a life-threatening illness. The participants expressed concern about their uncertainty as the results of lack of or no communication at the time of their diagnosis and during the period they awaited the results to confirm the diagnosis.A participant expressed concern about how the diagnosis was communicated as follows: **"The doctor looked into the results, read them and just looked at me for a very long time before he could say a thing until I concluded that I might be having a cancer and maybe that is at a final stage".**Another participant said: **"The day that I was told of the cancer, I could not ask more as I was shocked, the doctor used a foreign language and the nurse who was trying to interprete was struggling with the language".** These uncertainties lead to anxieties about their prognosis and further complicate managing these anxieties without communication and poor understanding of the processes. Sandeman & Wells (2011:340) reported similar findings with lung cancer patients who experienced uncertainty and unpredictability about what to expect in the future, and it is clear that patients are often ill-prepared for what is ahead.

Males are different in sharing their inner most feelings and now in the event of such stress, when they did not know what to communicate about to the spouse and significant others for support.

4.2.1.2 Anxieties About Prognosis

Anxiety and distress can affect the quality of life of patients with cancer and their families.

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Anxiety is a reaction to stress due to the thought of negative consequences of the illness. One participant expressed her concern in this manner: "**Now that I have a cancer, as a single parent will I be able to continue with my work and how will I explain my absence from work when I have to go for treatment.**" The participant further expressed her rising anxiety by stating that: "**I was unable to tell my employer about my cancer. I was afraid about how they would react.**" A participant expressed her anxiousness about the treatment as follows: **"I did not believe that I will get better, felt like I was going to die before I started the treatment."**The fear of treatment and associating it with dying is supported by the study by Van Oers, & Schlebuch (2013:527) who indicated that anxiety occurs in all treatment modalities, but significantly higher in patients undergoing chemotherapy and highest before the first infusion.

4.2.1.3 Fear of Death

Fear of death is experienced as the patients start to become aware of their prognosis. Such patients include those who have been on treatment and are not getting any better. Patients themselves are able to evaluate their own quality of life; a decline in the health status would make the patient think that it is their end. One participant expressed the fear of death as follows: **"I delayed going for treatment because of the fear of dying as I had seen someone I know who was diagnosed with breast cancer, had breast removal and died soon after that."** The participants in this study were adults who had their preconceived ideas regarding cancer, the experiences they have had of other community members regarding cancer. The diagnosis of cancer to them meant complete loss of hope. This is supported by a study that was conducted by Eustachi, Jibbs & Grossman (2014:498) who explored the experiences of meaning of hope in relation to the healing process of patients living with stage 3 or 4 non-small-cell cancers that indicated that patients described a process where hope was diminished or completely lost, regained and reshaped as they learned to live and grow following their diagnosis.Another participant expressed the following: "**When I had this**

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disease I thought I was never going to be healed, nor find my pain controlled." Gonen, Kaymak, Cankurtaran, Karslioglu, Ozalp & Soygur (2012:350), in their studies on the factors contributing to death anxiety in cancer patients, talked of death anxiety as life-shortening in anxious cancer patients, though death anxiety cannot be regarded as a natural consequence of having cancer, but as a consequence of unresolved psychological and physical distress.

4.2.1.4 Lack of Communication of Updates Due to Language Barriers and Cultural Issues

Communicating important updates to cancer patients on how their treatment will be conducted is a cornerstone of oncology care. Most participants' fears and anxieties were brought about by the lack of understanding and not knowing about the disease sequel. One participant expressed frustration brought about by lack of proper information as follows: **"When I was told to come and book for transport, I did, went to the treatment centre without the necessary letters or results required. I was returned to come back on another date. That increased my anxieties and I was very distresses about it until I went there as arranged and then I had everything necessary, most of the orientation was given to me by some patients who were on the same travelling with me for treatment."** Patient are sharing their ideas and experiences that are good or bad which can affect them starting the cancer journey positively or negatively. In a study conducted by Cheng, Chan, So, Choi & Cheng (2013:792) on social support and quality of life among Chinese breast cancer survivors, participants expressed that doctors only discuss with them medical treatments and seldom say anything about how to adapt to illness. According to Cheng et al. (2013:793), they alleged that in the event of inadequate information, participants chose to turn to fellow survivors for information

4.2.1.5. Fear of Disclosure About Certain Cancers

The diagnosis of cancer would leave the patients very helpless and at the mercy of a process

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that is out of control. Disclosure is very difficult if one has not yet gone through the shock of being diagnosed with cancer. Certain cancers are not easy to share. Patients are given the bad news alone as they go to the hospitals for consultation without their family. The patients would not be in a position to relate to the other person all the details shared by the health worker. One participant made the following statement with shock and dismay at the researcher's question of asking if the participant had informed her children of her cervical cancer stage 3: **"How could I talk to them about it, my children are males."** This was an indication to the researcher how the cultural background affects the communication in cancer. Cancer diagnosis is more distressing to the patients and family, both economically and psychosocially. The backgrounds of the participants in this study are that of the Vha-Vendas and Va-Tsongas who do not speak about their diseases easily and specifically about their intimate parts of the body. The cancers of the cervix and of the breasts are worst of all as it is not easy for the participants with their cultural background to share. According to Thelly (2012:33), regardless of age, sex, race and ethnicity, family members report obstacles of dealing with problems attending to their own health problems and managing care giving responsibility especialy if they are not aware of the condition they are dealing with.

4.2.2 Theme 2: Experiences of Distress

Cancer distress is as an unpleasant emotional experience of a psychological, social and spiritual nature which extend on a continuum from normal feelings of vulnerability, sadness and fears to problems that are disabling such as depression, anxiety, social isolation and existential and spiritual crises (Thalen-Lindstrom, 2014:75).

4.2.2.1 Experiences of Pain and Treatment Side Effects

Pain is a major part of cancer diagnosis and if the pain can be adequately managed the patient would not have to choose between fighting cancer and fighting pain. The usual response to pain are anxious feeling. Participants in this research who experienced pain explained it with

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such intensity as if the pain was relived. One participant expressed that: **"The last time I went to the hospital I had taken a decision that they can rather cut off this leg, I was no longer able to tolerate the pain, I had tolerated the pain, the medications they gave me was no longer able to assist me, I was even crying as I spoke to the doctor."**

An attempt by health care providers in relieving pain results in the patient satisfaction. Even if the pain is not completely managed, the patient's anxiety is lessened. Inadequate pain relief increases psychological stress (Burke, Mohn-Brown & Eby, 2011:153).

4.2.2.1 Experiencing Body Changes Due to Disease and Treatment Side Effects

Body image is how one feels about one's own appearance. A participant in this study shared the following: "**My skin turned to be very dark when I started chemotherapy and I was very thin, I was always spitting, I was truly not happy and always isolating myself and not socializing."** Davies (2009), in his studies on cancer survivorship indicated that when the disease is now chronic, no longer a death threat many people are living with the long term physical and psychosocial implication of cancer and its treatment.

4.2.2.2 Loss of Female Identity and Masculinity

Breasts are a focal aspect of a woman's body and play an important role in identifying oneself as a woman and that societal perception connect breasts with being a woman, being feminine and with sexuality. When a woman has been diagnosed with breast cancer her suffering is not only limited to the physical experience, it also affects the psychological being and the fear of losing everything, including societal expectations of a whole woman.A participant in this study, expressed her experiences of breast cancer diagnosis as: "**I did not know how it was going to be when my breast was to be removed, how I was going to look like and how the community was going to say as I will no longer be a whole woman, as I was awaiting for surgery I had thoughts of cancelling."**Another participant

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explained: **"I was devastated when I was informed that I was to go for a mastectomy."** The same participant expressed: "**I could not share the news with my husband."** A participant in this study said: **"My husband left me when I was undergoing treatment after mastectomy."** According to Sadler-Gerhard, Reynolds, Britton & Kruse (2010:265), on their studies on women breast cancer survivors, stories for change and meaning, indicated that when diagnosed with breast cancer a woman realises that her life has a different meaning and that it will never be the same. Societal view is only one true feminine ideal and unsuccessful attainment ultimately results in a loss of social status of womanhood.

A participant in this study, shared the following with sadness in his face about masculinity: **"My problem started a long time ago, I could not share it with my wife, instead I resorted to traditional healers, got better, but the problem started when I could not pass urine at all, went to the hospital and was diagnosed with an enlarged prostate gland, that was when I started to have problems, stayed with an indwelling catheter for at least two months before I went in for surgery. I concluded that my manhood was gone and it distressed me a lot. My wife was very supportive even now, but I always doubted if she was going to stay long because I was no longer man enough for her"** According to a study by Walker & Robinson (2012:463), sexual adjustments amongst men treated with hormone therapy for prostate cancer, indicated that the side effects of androgen deprivation therapy can affect a man's sense of masculinity and sexuality and impact on sexual relationships. A participant complained about loss of hair: **"I started to have hair loss, though I was told that it might happen, I was forced to cut off my hair, liked my hair, never cut my hair at all, I used to plait it."** Cancer treatments such as radiation and chemotherapy attack fast-growing cancer cells. Reed & Conner (2013:358), on definining the illness trajectory of breast cancer, indicated that most women appeared to tolerate uncontrolled pain, and self-medicated, supporting the findings of a survey which found over one-third of women (34%) reporting high levels of pain and other uncontrolled symptoms

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such as hair loss.

4.2.3 Theme 3: Social Support and the Burden of Care Giving

4.2.3.1 Positive Feelings towards Social Support

Social support refers to the feeling of comfort, care and connection that you get from others. Social support is regarded as a complex construct which has long been suggested to have a direct and buffering effect on patients' well-being and emotional adjustment to cancer. One participant expressed the following: **"My sister's children brought me to this hospital because at the hospital where I received treatment they could not make a diagnosis and I was happy that they supported me through out."** Another participant articulated: **"I was not able to cook for myself and my daughter-in-law and son took me in and took care of me, they are still bringing me to hospital and collecting me back from Polokwane, I do not sleep here in the hospital as I travel to and from treatment."** In a study conducted by Mulder (2012:33), participants also emphasised the support from husbands and children was important in encouraging and motivating them, critical in maintaining a positive outlook. A participant in Mulder's (2012:33) study on women lived experience of breast cancer trajectory: the waiting period the impact on feminine identity, reported that the most support she felt was when she communicated with her elder sister as she was also a cancer survivor. The study suggested that there is evidence for the relationship between social support and progression is sufficiently strong and that there is association between social support and psychological adjustment following cancer treatment (Usta, 2012:3570). In this study, the researcher observed that the participants appreciated the availability of the nursing staff that were at times available to assist them in the clarification of certain aspects of their cancer care and the availability of free transport to the treatment institutions.

4.2.3.2 Negative Feelings towards Support

In this study, patients expressed some negative feelings related to support during care.

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Participant expressed lack of communication on factors that led to their greatest distress. This is how one participant responded to a probe about her perceived support and care from the health workers and family: **"I didn't want to speak about my illness, I did not want to hurt them."** The negative feeling the patient felt was supported by a study conducted by Drageset (2012:38), on the psychological distress, coping and social support in the diagnostic and pre-operative phase of breast cancer, namely, that families and patients managed to cope effectively despite often choosing to avoid the discussion of informational and emotional issues related to a patient's cancer despite the claiming to maintain open communication with one another.

4.2.4 Theme 4: Diverse Experiences of Support by Health Care Institutions and Treatment Care Coordination

Health care institutions often provide care for the cancer patients from the time of suspecting cancer through the process of diagnosis and treatment, follow up care and transfer to other institutions for advanced treatment and care.

4.2.4.1 Delay in Diagnosis and Treatment

At times it takes a long time before the patient can receive a diagnosis and be accepted at a tertiary institution for chemotherapy and radiotherapy. The numbers of patients that are referred for treatment are many that are from other districts as Limpopo Province has only one treatment centre. In this study, a participant took a long time before a diagnosis of cancer of the foot was made because she had diabetes and the darkened sore on her leg was treated as emanating from uncontrolled diabetes until it got worse. This is how she explained it: **"I went to the clinic several times to the clinic with an ulcer on my foot and the nurses always told me it's a diabetic sore, some even scolded saying I was not taking care of the sore as it was blackened, they only gave me medicine to wash the sore and the diabetic treatment, until I went for hospital admission when a piece of flesh was taken to the**

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laboratories. It was then that the results revealed that that was a cancer, it delayed me so much to be treated for cancer." Diagnosing cancer takes time, the delay can either be due to lack of expertise knowledge from the heath workers, lack of specialists or a patient related factor of not seeking medical assistance. A study conducted in Britain by Tuteja Khandelwal, Tandon, Bamal, Jain, Srinivas, Kumar & Kumur (2011:9) on patients and provider delays in breast cancer patients attending a tertiary care center: a prospective study, examined the impact of delay in treatment in lung cancer patients awaiting radiotherapy with curative intent showed that 6 out of 29 patients became incurable while they were on the waiting list. That indicated that the delay in treatment is associated with the prognosis and adjustment and causes psychological distress in the patients.

4.2.4.2 Experiences of Dissatisfaction with Transfer, Procedures, Coordination, Lack of Proper Referral Systems and Specialists

For the patients to be transferred to the institutions where the patients were referred from the Vhembe District, transfers should be arranged for the patients according to their appointment dates. Patients bring along appointment cards indicating their treatment dates and the investigations that should be done at the referring hospitals before they come for their next appointment. A participant expressed the following in disappointment: **"I came to be done the blood tests and went home. I failed to collect the results on time on the day of transfer before our nurse went off, the person who gave me the results did not read them and did not explain that there is a problem on the results. I went into the ambulance in the morning and was told that my results were not good and I was returned."** There are protocols to be followed, especially when referring patients for follow-up at the hospitals and the oncology nurses in the hospitals are well conversant with the protocols; some doctors are also informed about these protocols. The oncology trained nurses are very few and are sometimes not available. A participant verbalized the followimg: **"Nurse X would call the patients if the results of the blood were not right so that the**

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patient should come and receive blood before transfer. It was easy some time ago when we used to travel with our nurses because they assisted a lot when there were some issues to be sorted out like following the results that were to be retrieved at Polokwane Hospital."

Having oncology nurses to navigate the process with the patients is very important. McMullen (2013:117) indicate that the role of navigator has the disease-specific knowledge necessary to provide patient-centered care throughout the cancer continuum and promote positive patient outcomes. The role of the oncology nurse navigator has a positive impact on both the patient and the cancer team by providing continuity of care and improved communication.

4.2.4.3 No Proper Overnight Accommodation for the Transfer of Patients

Accomodation is not always available for transfere of patients in all the hospitals. A participant expressed the following in dissatisfaction: **"I stay very far from the hospital. I am forced to sleep on the benches and do not have transport that can bring me to the hospital on time, in winter times it is really very cold in that outpatient hall."** One participant told the researcher: **"I cannot sleep on one side, the side that has a sick breast, I cannot sleep on it and the bench is not ideal for my condition."** The participant further explained her dissatisfaction as follows: **"I sleep on my back, so how can I sleep on my back when we are with the males in one room."** In the other two hospitals that took part in this research, patients are accommodated in the hall where there are cubicles for the males and females, provision for beds and hospital linen is made available for patients travelling. The cost of travelling is covered by the government of Limpopo Province and those that are on disability grant are not paying for the outpatient fees, however, patients are paying for their travel to and from their homes to the local hospitals, some patients are not on any grant, are unemployed and young. The Cancer Association of South Africa (CANSA) provides

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home away from home facilities—in every province in South Africa there are CANSA centres where patients undergoing cancer treatment at oncology clinics from their homes for six weeks at a time. From these CANSA centres patients are transported to hospitals for consultation. The availability of such centres is not always accessible to all the patients, especially those who stay very far in the rural areas and as such they are not fully utilised by these patients. In this study, none of these participants have ever used these centres. A participant from one of the hospitals that provides accommodation to their oncology and other patients that were transferred expressed the following: **"I am happy the way they prepare for our accommodation, we find beds made same as the patient's beds in the hospital."** It was evident to the researcher that disparities in the way the patients who need transfer to tertiary institutions are treated in Vhembe. According to Hegney, Pearce, Rogers-Clark, Martin-Mcdonald & Buikstra (2005:78), the emotional and economic impact of a cancer diagnosis are difficult enough to handle without the added burden of having to travel long distances away from home for cancer care with or without family, friends, neighbours or other social support.

4.2.4.4 Lack of Food Provision by the Institutions

Patients undergoing treatment in most hospitals require food to nourish their bodies as they undergo treatment and travel. Chemotherapy has a side effect of nausea and loss of appetite. In this study, patients brought their own food from home to eat throughout the days they are travelling to and back from the hospitals after treatment which could be three days maximum.A patient shared this with obvious sadness: **"I leave home on the afternoon prior to the appointment date, travel to the local hospital as I stay far from the hospital, with food, sleep at the local hospital, travel to the treatment centre the following day, still eating the same food, travel back in the evening after chemo, then sleep at the hospital as we arrive late when there is no longer transport to go home, same provision until I go home the next day without fresh food, water is better one can easily go to the**

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tap to fetch water."

Participants shed light that on the third day the food they had was no longer edible and the condition they find found hemselves in at the treatment centre were not conducive for them to eat as some vomited and the unpleasantness from the smell of the chemotherapy and watching other patients and sometimes they themselves vomited. According to a study conducted by Elami (2011:514) on dietary and pharmacological management of severe catabolic conditions, nutritional debilitation is amongst the devastating life-threatening complications of cancer and various chronic conditions that arise from the complex interaction between the disease and the host. The study further indicated that patients develop cachexia with progressive muscle tissue wasting with associated worsening of their clinical status. Patients require good nutrition when they are treated with cancer and an encouragement to have good nutrition for the building of their immune systems. Bussink (2012:18) indicated that providing patients with the optimal support during their treatment, nutritional support is recommended as an integral part of anticancer therapy to maintain patient nutritional status and immune function, therapy tolerance and quality of life of the cancer patients.

2.4.4.5 Purposive Time Delay by the Transfer Staff to Accumulate Overtime

The transfer staff in hospitals are only involved with patients as they travel along with them, they are not fully involved in the management of these patients and does not really understand the plight of these patients, theirs is to hand them over to the health workers at their treatment wards and wait for them to finish the business of the day. A participant complained: **"Even if we finish our treatment early, the transfer nurses and drivers delay so that we start travelling back late and that pains because we are forced to sleep on the benches for another day as there would be no transport to go home."** The transfer staff are not only transferring the oncology patients, but every patient in the hospital that

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require accompaniment. Due to the long hours they put on transfer, the transfer staff are remunerated overtime for leaving the hospitals very early in the morning and after hours.The participant further complained: "**The food that I brought to travel with is no longer edible and my body would be tired and I would wish to have fresh food and to sleep well at home.**" After they have received chemotherapy some patients experienced some side effects and require support and care such as the comfort of being in the privacy of one's home. A participant shared the following with the researcher: **"After receiving chemotherapy, I vomit a lot and sometimes I do not vomit because of the chemotherapy, if I see someone vomiting I also start vomiting. I then wish that I could be home without the other patients."** There is not much literature about the time delays of patients on purpose for the sake of overtime, however, there has been an investigation on time delays in the theatres between the delay of the first case and the finish of the last case requiring that the staff should be compensated for the extra time they have worked. People with cancer often develop new and acute problems which require urgent response either due to the disease process or due to the treatment of cancer, as such they require to be returned to the peripheral hospitals or their homes for supportive care. According to the Royal College of Physicians and Royal College of Radiologists (2012: np), cancer patients and their caregivers may not be prepared to deal with emergency situations as they occur. It is evident that the transfer procedures and coordination needs to be monitored closely so that it could not disadvantage the patients and benefit extra hours for the transfer staff.

The WHO (2007) in the report about patient safety and solutions during patient handover requires that there should be policy on handover of patients during transfers of patients and changes of shift, the use of standard procedures in the handover communication and allocate sufficient time for hand over. However, reducing patient delays and improving patient flow accomplish quality care goals by improving access to care and increased life expectancy. Hall et al. (2006), as cited by Afrane & Appah (2014:38) in their studies on quewing theory

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and the management of waiting time in hospital indicated that increasing the length of time spent in undesirable states of waiting for treatment, undergoing treatment or recuperating from treatment and reducing waiting time until the patient is well is beneficial to the health of the patient.

4.2.4.6 Transferring Oncology Patients with Non-Oncological Patients and Lack of Self-Esteen

Patients undergoing oncology treatment at Polokwane Oncology Centre are traveling from the district hospitals with other patients requiring specialised care at Polokwane as well. The nature of these patients' treatments are very different, some cancers produce an offensive aura and patients who do not understand the cancers would not be comfortable travelling with the other patients with an unpleasant smell. A patient complained: **"I used to feel that I was not smelling good. I had a smelling vaginal discharge when I started chemotherapy. I also was not happy to be amongst other people."** Patients who do not have a place to sleep before travelling to treatment do not have a place to bath in the morning before travelling. When they arrive at the hospital they start to collect files and go for consultation before they can get a chance to look for a place to freshen up. After treatment they are to return to their transport to go back to their respective hospitals. Patients with different cancers also need self-respect. It is humiliating for them to know that they are travelling with other patients when they do not smell good.

A participant shared: **"I stand up from the bench I was sleeping on the whole night get into the ambulance without a bath, travel as a woman not having had a bath I feel its uncomfortable, to be seen by the doctor having not had a bath, travel back without a bath arrive late at the hospital still stay overnight and take a taxi the third morning to go and have a bath there I find it humiliating and making my self-esteem very low."**

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Increased risks for infection are attributed to immunosuppression caused by the underlying malignancy and chemotherapy. Furthermore patients with cancer come into frequent contact with healthcare settings and can be exposed to other patients in these settings with transmissible infections. Given their vulnerable condition, great attention to infection prevention is warranted in the care of these patients and ensuring that they are not transported with other patients.

4.2.4.7 Fragmentation of Services

The treatment of patients with cancer or any other patient with a chronic illness is fragmented as patients are seen by different doctors and therapists every time they visit the hospitals. When patients visit after some time the nurse has changed and the doctor is no longer the same. In this study, the participants expressed a lot of dissatisfaction about finding new health care providers who do not know their stories and that they are forced to relate their story to a new therapist, sometimes they find their files missing as the hospital files are kept in one pool. The majority of the patients do not understand some health stories that were written in the bed letter/file and cannot relate adequately to the new therapist if the file is missingThe participant shared this in distress: **"It is not easy to be seen by different therapists, you are forced to relate your history, especially files that are missing, one time you find an old file that was missing and the following visit it's not there."** Missing records of the patients is a problem in all hospital cases as the patients' histories are very important to the total quality of patient care without repeating the investigations that have been done and better understanding of the patients' conditions. A study conducted by Aubin et al. (2012:np) indicated that care is interrupted when patients with cancer come under care of second line and third line health care professionals who may also manage the patients' comorbid conditions. This may lead to fragmented and uncoordinated care and results in an increased likelihood of not receiving recommended preventative or recommended care.

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4.2.4.8 Lack of Proper Referral System and Lack of Specialists

The unavailability of specialists in the province and the district hospitals are a concern. There are no professional sonographers in the district and patients have to book a date first for sonar then a date to be seen by the doctors. Cancer care require a whole lot of specialists, including dieticians and social workers centralised in one place.A participant verbalised her frustration: **"I was returned twice because I did not have sonar results no one had informed me of the sonar, when I went back for the sonar at Mankweng the machine was out of paper to print the sonar results."** A participant shed this light: **"If you do not have an accompanying nurse you find treatment after waiting for a long time, those that have their nurses their treatment issues go well and fast."** There is a growing consensus that poor coordination coupled with fragmented care compromise the quality of care received and increased opportunities for negative outcomes, such as medication errors and avoidable hospitalizations and emengency department visits (Schultz, Pineda, Lonhart, Davies & McDonald, 2013:113).

4.2.5 Theme 5: Positive Feelings of Self and Expression of Trust in the Supernatural

In this study, the patients who were already on treatment and have seen the benefits of the treatment are very positive about the treatment and life in general.

4.2.5.1 Need to Complete Treatment and Be Free of Cancer

A participant verbalised the following: **"I delayed myself a lot because of fear, not liking the hospital and listening to people."** Another participant said: **"After I started treatment my life started to improve. I follow every instruction I am given. I want to find myself free of cancer."** Patients react differently from their diagnosis and usualy this is determined by many factors such as religion, age, and education and belief system. Kleinman (2008:17) on his paper Catastrophe and Caregiving also shared similar sentiments that illness has

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personal, social and cultural meaning.

4.2.5.2 Appreciation of the Services Received

The participants expressed great appreciation for the services rendered, the free transport, and the specialists who are accessed at the government hospitals. The participants were grateful that the province still gives support to the cancer treatment centres. A participant expressed the following: "**Even if there are problems here and there I am thankful that I am receiving treatment without suffering, we are troubled by the travelling in the ambulance.**" Such appreciation was expressed by participants who have reaped the benefits of the treatment, the appreciation was shared with a lot of enthusiasm and good mood.Kleft, de Brouwer, Francke and Delnoij (2014) in their study on how nurses and their work environment affect patient experiences of quality of care:a qualitative study indicated that nursesspend a lot of time with patients and that they have a great impact on the patient experiences and quality of life

4.2.5.3 Acceptance of the Diagnosis and Its Course of Treatment

Cancer is feared by all people in general. The person who has been diagnosed with cancer finds it very difficult to come to terms with the diagnosis, however, with more individualised assessment, intensive counselling and support, the individual finally accepts the diagnosis and slowly gives a positive response to the disease process and the course of cancer management and treatment. **"The hospitals are managing to take us all to treatment without payment for transport and treatment, if we were to pay, some us would have been long dead."** Patient satisfaction is an important aspect of care, especially as aconsequence of respectful treatment, one definition involves whether the care is medically necessary and improves outcome. The second is whether patient and families receive the treatment they wanted, regardless of necessity or effectiveness. The third is only tangentially related to outcomes and involves aspects of care such as communication, respectful treatment

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and convenience, which are consistently a top priority for patients (Budryk, 2015: np).

4.2.5.4 Expression of Having Trust in the Supernatural

Some participants in this study expressed their believe in God; the believe that God is bigger than the diagnosis of cancer and has been a source of hope and healing for some patients who have survived the cancer treatment, but still has hope that the cancer will not return if they trust in the Lord for their complete healing. A participant expressed the following: **"The God I believe in shall not leave me nor forsake me. My cancer will never return and it will be completely healed."** Daugherty, Fitchett, Murphy, Peterman, Banik, Hlubocky and Tartaro, 2005:135 in their studies on trusting God and medicine: spirituality in advanced cancer patients volunteering for clinical trials of experimental agents asserted that patients in their study indicated that they put trust in God and doctors

4.2.5.5 Belief in Fate

Generally, participants expressed their trust in the supernatural, fate and belief system as their coping mechanisms while undergoing cancer treatment. A participant shared: **"For me to have the cancer, it has been predetermined for me by the supernatural, I believe it is out my control."** Some patients believed that the disease was detertmined by God and that it was their fate to develop cancer, while others believed that they could get rid of the disease by worshiping (Hegarty, 2007:77).

4.2.5.6 Religious Practices

Faith healing is based on a belief and is subjective to every individual's faith. The participants believed that if one could confront cancer with faith, they would not be let down. A participant expressed the following: **"I trust in God, there is nothing he cannot do, so says the bible."** Patients with cancer who believe in God has a positive aspect of dealing and coping with the disease. Such patients are mostly compliant to the treatment regimens. When

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the patients are very sick, their belief and trust in God's miracles that escalate. A study by Allen (2010:28) about confronting cancer with faith, indicated that it is one thing to believe in God's promises, but unless you receive and validate them by putting them into your everyday living, without application one is deprived of God revealing himself. According to Allen (2010:33), if one wants a supernatural peace in one's life then one must have a supernatural trust in God.

4.2.5.7 Traditional Practices

People who believe in traditional medicines are not only cancer patients. The traditional societies believe in traditional healers—they are their primary source of health consultation. Moreover, they are accessible amongst the communities that the participants live in. The traditional healers also believe that they are able to cure cancer. A participant shed this light: **"I stayed at a traditional healer's home for two months treated for this ulcer on the leg. I only came to the hospital to be given blood, as I was pale, I lost a lot of blood as they washed the ulcer daily with their medicines, that is, when the doctors diagnosed that the ulcer was cancerous, I wanted to go back to the traditional healer to complete my treatment."** O'Brien et al. (2012:573) indicated that there is little known about the traditional healer's role in cancer management. Therefore, understanding the practices of the traditional healers would enhance literacy about cancer amongst traditional practitioners that would contribute to the earlier diagnosis of cancer and avoid the delays towards early treatment.

4.3 Summary

In this chapter, 5 major themes were established from data analysis of the experiences of the participants who were under the care at the selected hospital for their cancers. Sub-themes were identified from the findings of the study through in-depth individual interviews with the research participants, i.e., information from the cancer patients on their experiences regarding

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the care and oncology treatment they received at the hospitals. Literature controls support the participants' views, where possible. Chapter 5 will cover the recommendations, limitations and the conclusion of the study.

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CHAPTER 5

RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

5.1 Introduction

This is an overview of the study, conclusions drawn from the study, recommendations, limitation of the study and the summary. It presents a discussion of important developments brought about by the findings of the study.

5.2 Overview of the Study

The aim of this study was to explore and describe the experiences of patients regarding oncology treatment and care in the hospitals in the Vhembe District of Limpopo Province. Purposive sampling was done to select the hospitals and the participants

5.3 Conclusions Drawn from the Objectives of Study

The objectives of the study were to:

- Explore the experiences of cancer patients regarding oncology treatment and care.
- Describe the experiences of cancer patients regarding oncology treatment and care.

The following central question was used in this study:

> *What are the experiences of patients regarding oncology treatment and care at the hospitals in the Vhembe District of Limpopo Province?*

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5.4 Conclusions Drawn from the Study

The following categories emerged in the study:

5.4.1 Theme 1: Feeling of Uncertainty

The Feelings of uncertainty and lack of communication pertaining to participants' treatment and care. Participants shared that they expected more from the way they had received the information about them having cancer and how they were going to be treated. There was no sufficient time to synthesise the fact that they have cancer before they could discuss issues of treatment. The rising anxiety about treatment effectiveness and prognosis exacerbated the feelings of uncertainty they had.

The uncertainties led them to think that they might die and started to develop fear of death related to their cancer diagnosis. Lack of proper communication was also seen to be due to the language barriers and cultural issues as the cancer care at treatment centres in Limpopo Province is offered to and accessed by a diverse population with different cultural backgrounds. The fear of disclosure of certain cancers to family and significant other impeded proper support from them

5.4.2 Theme 2: Experiences of Distress

Experiencing distress due to pain and treatment side effects, body changes, and loss of femininity and masculinity. Inadequate communication of cancer diagnosis leads to fear of disclosure of certain cancers. The burden of care giving and social support, diverse experiences of support by health care institutions, treatment coordination, positive feeling of self and the expression of having trust in the supernatural.

5.4.3 Theme 3: Social Support and the Burden of Care Giving

Participants expressed different experiences of social support. Some experienced positive

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social support and others negative interaction. The relationship dynamics of family members and support is a factor that encouraged and motivated the patients to have a positive outlook throughout the cancer journey. Patients who did not have any kind of family support experienced difficulty in having a positive experience of their cancer journey. Some participants expressed that they would not want to hurt their family members or ask them to share the burden of cancer with them. The support they received from the clinical team was not always sufficient for the patients; continuous home-based support is also needed.

5.4.4 Theme 4: Diverse Experiences of Support By Health Care Institutions and Treatment Care Coordination

Participants experienced the support they received from the health care institutions differently. Some experienced delay in getting diagnosed, leading to delay in treatment due to lack of diagnostic equipments and consumables. The delays had led patients being treating late when the aggressive cancers had already taken their toll on the patients' state of health. Participants also indicated that they experienced disparities in the support they received at the institutions. Some institutions offered transport to the treatment centre the patients who participated in this study attended. Some even provide proper night accommodation for patients who had to travel the next day to treatment centres.

In addition, bathing facilities and food provision during travel were offered whereas in some institutions patients had to sleep in the outpatient waiting rooms with no bathing facilities and food provisioning. Participants experienced dissatisfaction in the way the transfer of oncology patients was coordinated. Transfering oncology patients with non-oncology patients, time delays by the transfer staff to push their overtime, delaying patients from going home early, patients transferred by staff who knew nothing or little about them and who could not assist them should a crisis occur. The condition in which other patients were transferred along with cancer patients who had not bathed to treatment centres made the

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cancer patients experience low self-esteem and humiliation. These diverse experiences affected the psychological well-being of the cancer patients.

The fragmentation of services in cancer care was experienced by participants as most disturbing. Participants expressed that each time they saw a therapist is new, they had to explain certain histories about their illnesses every time. At certain times there were barriers in communication due to language and cultural differences. The cultural background of the participants was that of introverts who would not be free to ask questions that they required answers on, resulting in a gap in their knowledge of their condition and care. Participants explained that they did not want to be disrespectful to the therapists by asking a lot of questions. The lack of oncology specialists in the hospitals made the patients dependent on the tertiary hospitals and dependant on the government transportation to seek treatment.

5.4.5 Theme 5: Theme 5: Positive Feelings of Self and Expression of Trust in the Supernatural

Participants expressed that they experienced a great sense of relief when their cancers responded to treatment. They started to accept and believe in the treatment and made sure they were compliant to their treatment and hopeful that they would be cancer free at some stage and started to show appreciation for the services they received. However, this was not the case with those participants whose cancers had not responded to treatment.Patients with terminal illness have spiritual needs and a belief system that framed their perspective towards their illness, death and dying. Religion and beliefs have generally been thought to be helpful in coping with disease and aiding in stress relief. The participants expressed that their traditional practices and believe in fate also helped them in coping with their cancer diagnosis.

5.5 Integration of Results Within the Theoretical Framework

- The researcher believes that cancer patients' health care needs should be met and that

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the patients should find comfort in the hands of the health care institutions and professionals.

- However, there are gaps that have been identified in the exploration of the experiences of the patients regarding oncology treatment and care. The results of this study indicated that the care of patients needs to be improved and provided as in the theory and paradigmatic perspective that directed this study.

- Watson's nursing theory guided this study. This theory allows the return to the deep-rooted values of the profession and allows proper care to be given to oncology patients to find solace and comfort from the care provided.

- The sensitivity towards the needs of the oncology patients should enable health care providers to develop better insight into other views of the world which subsequently increases concern for others wellness, comfort and recovery.

- The use of phenomenology in this study allowed the researcher to experience an in-depth recognition of the lived experiences of the participants.

- Based on this theoretical framework of care and caring the researcher has come up with the following recommendations.

5.6 Recommendations

5.6.1 Organisational/Institutional

- Policies should be formulated with regard to better cancer diagnosis to promote quality oncology care. The policies should address the effectiveness of caring for cancer sufferers

- Training for the oncology nurses should be clearly stated in the policy documents to

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direct and shape the curricula and teaching of cancer care.

- Government policies should include strategies of care for the cancer patients.
- The support programmes for cancer patients should be included in the policies of the government. Psychological support in the form of professional counselling should be outlined in the policy.
- Policies on financial support for the patients with cancer and assistance with food parcels when travelling and when home should be encouraged. Included in the curriculum should be the different treatment modalities and their side effects and how to deal with them.

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5.6.2 Nursing and Patient Education

- The inclusion of cancer care in the basic and post-basic training of nurses should be effected. Nurses in training should be able to care for these patients in the community and in the hospitals as part of their experiential prerequisites.

5.6.3 Nursing Practice, Social/Family Support and Care Giving

- Patients need family and significant others to provide care and support during the cancer treatment. The involvement of the patient's family in all the steps from diagnosis to treatment is significant as is spousal support.
- The family should be equipped with information regarding treatment and knowledge of what treatment side effects could be expected and how these should be managed.
- Family meetings could be established to assess how the family is coping and referring them to the multidisciplinary team.

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- Professional nurses should be able to teach family members on the basics of home-based care and patients' treatment protocols.

- Family members can be assessed individually about their take on caring for cancer patients and counselling given to them to afford them time to air their fears and uncertainties in the absence of the patients so that they can be strengthened to continue such caring.

- Patients who are better cared for and whose cancers are responding to treatment develop a better sense of themselves which indicates that care is accepted and appreciated. They need to complete their treatment if they hope to be free of cancer.

- Patients need to be counselled and supported in all their social experiences, including the support in all their belief systems that assist them in coping with the cancer. It is important that the therapists understand the patients well so that they can be of guidance in some aspects of such belief issues and the use of professional counsellors should be employed in family counselling.

5.6.4 Nursing and Health Care Administration

❖ **Recommendations regarding the fragmentation of services:**

- The increase in the number of patients who require cancer care and treatment should be provisioned for by establishing more treatment centres to accommodate them.

- The availability of a sufficient number of professional oncology nurses is needed to cover the increasing number of patients at the centres. This will alleviate the need for personnel to navigate the patients in terms of proper communication about cancer diagnosis, treatment and its side effects.

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- Patients need to have doctors that can screen them at the peripheral hospitals in time and make a diagnosis in time to avoid delays in treatment.

- The clinical teams that treat the patients should be assigned to see the specific patients at all time to afford patients the same and consistent care if possible.

- The nurses providing cancer care should be the ones who transfer the patients to the treatment centres to avoid transfer of the patients by the staff not known to them.

❖ **Recommendations regarding coordination of treatment and support by the health care institutions:**

- The unavailability of waiting rooms before transfer of patients to treatment centres should be a priority where facilities for proper ablution and food can be provided for.

- The need for supervisory staff at the waiting rooms should be looked into as patients can have health care needs before and after travelling to the treatment centres.

- Transfer of patients should be monitored and the transfer staff should be given proper handover about the patients and their conditions.

- The referral system should be effective with the proper guidelines regarding what investigations should be done on which patients and when before transfer of patients.

- Transporting patients with cancer with the patients who do not have cancer can be separated depending on the number of patients and availability of transport

- The inclusion of cancer care in the home-based care programmes can benefit the patients and their families.

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❖ **Recommendations regarding cancer communication:**

- Cancer care communication is a core skill that the team should be taught to prevent the omission of adequate information about the diagnosis, prognosis and therapeutic options.

- Availability of brochures that inform the patients about their illness and treatment options in different languages can advantage cancer patients.

- The team should be able to recognise the need for the amount and level of communication the patients require to assist in informed decision making about the treatment options.

- Patients' understanding of the communication should be checked adequately and sufficiently to avoid misunderstandings regarding treatment processes.

❖ **Recommendations regarding research:**

- It is important that the topic should be researched in other settings to broaden the view of the experiences of patients regarding oncology treatment and care.

- A study on the evaluation of the care and support given to cancer patients by oncology nurses can be conducted.

- Studies can be done on the experiences of family and patients together regarding caring for a cancer patient in the same settings.

- Studies can be done on a single type of cancer.

5.7 Limitations of the Study

❖ **The study had a number of limitations:**

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- Data were collected from a convenient sample.

- A small sample size limited generalisation to the entire population.

- The use of audiotape records of data collection could have brought about some Hawthorne effects (also referred to as the observer effects) in the responses.

5.8 Conclusion

This study aimed to explore and describe the experiences of patients regarding treatment and care at the hospitals in Vhembe District Limpopo Province. A qualitative, descriptive, explorative, and phenomenological approach was used to obtain data from the participants. Participants who were undergoing oncology treatment for at least a year were purposively sampled and unstructured in-depth individual interviews were used to collect data. Themes and sub-themes that emerged from the data analysis have been dicussed in detail in relation to a literature control in Chapter 4 and again condensed in this chapter. Recommendations were made that may enhance cancer services in the Vhembe District of Limpopo Province.

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UNIVERSITY OF VENDA LIBRARY

ANNEXURE 1

SUBMISSION OF RESEARCH PROPOSAL TO UNIVERSITY OF VENDA HIGHER DEGREES COMMITTEE

UNIVERSITY OF VENDA

EXPERIENCES OF PATIENTS REGARDING ONCOLOGY TREATMENT AND CARE AT HOSPITALS IN VHEMBE DISTRICT OF LIMPOPO PROVINCE.

BY

Name: Neo Jacqueline Ramutumbu

Student Number : 11565382

Previous Qualification: BA Honours (UNIVEN)

Proposed qualification: Magister Curationis

Research proposal for submission to the higher degree's Committee of the School of Health Sciences at the University of Venda. Department of Advanced Nursing Science

Contact: P.O. Box 7355 Thohoyandou 0950.

082717 8190 (mobile)

ramutumbunj@yahoo.com(e-mail)

nramutumbu@gmail.com

Supervisor: Dr. DU Ramathuba

Co-Supervisor: Mrs D Ndou

Supervisor signature: _____

Co-Supervisors signature: _____

Student signature: _____

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ANNEXURE 2

APPROVAL OF RESEARCH PROPOSAL BY UNIVERSITY OF VENDA HIGHER DEGREES COMMITTEE

UNIVERSITY OF VENDA

OFFICE OF THE DEPUTY VICE-CHANCELLOR: ACADEMIC

TO : MR/MS NJ RAMUTUMBU

SCHOOL OF HEALTH SCIENCE

FROM: PROF J.E. CRAFFORD

DEPUTY VICE-CHANCELLOR: ACADEMIC

DATE : 15 OCTOBER 2015

DECISIONS TAKEN BY UHDC OF 13TH OCTOBER 2015

Application for approval of Master's research proposal in Health Sciences: **NJ Ramutumbu (11565382)**

Topic: "Experiences of patients regarding oncology treatment and care at hospitals in Vhembe District of Limpopo province."

Supervisor:	UNIVEN	Dr. DU Ramathuba
Co-supervisor:	UNIVEN	Mrs. D Ndou

UHDC approved Master's proposal

Prof J.E. CRAFFORD

DEPUTY VICE-CHANCELLOR: ACADEMIC

ANNEXURE 3

ETHICAL CLEARANCE- UNIVERSITY OF VENDA

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Ms NJ Ramutumbu

Student No:
11565382

PROJECT TITLE: **Experiences of patients regarding oncology treatment and care at hospitals in Vhembe district of Limpopo Province.**

PROJECT NO: SHS/15/PDC/02/1903

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr DU Ramathuba	University of Venda	Supervisor
Mrs D Ndou	University of Venda	Co-Supervisor
Ms NJ Ramutumbu	University of Venda	Investigator - Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: March 2015
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: .....
Name of the Chairperson of the Committee: Prof. G.E. Ekosse

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 962 8816/8313 FAX (015) 962 9050
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ANNEXURE 4

REQUEST TO DEPARTMENT OF HEALTH TO CONDUCT THE STUDY

P.O. Box 7355
Thohoyandou
0950

Provincial Department of Health
Research Ethical Committee
Polokwane
0700

Dear Sir/ Madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH.

I am a Magister Curations student at the University of Venda. I am presently conducting a research study entitled "Experiences of patients regarding oncology treatment and care at hospitals in Vhembe District of Limpopo Province. My supervisors are Dr DU Ramathuba and Dr ND Ndou in the Department of Advanced Nursing Sciences.

The objectives of this study are to:

- Explore the experiences of cancer patients regarding oncology treatment and care
- Describe the experiences of the patients regarding oncology treatment and care

1. The participants will be interviewed at their hospitals and the data will be captured in a tape recorder for verification of information.
2. The interview will last for 35-45 minutes. Ethical standards will be observed throughout the process of research: Participants will be asked to sign consent forms.
3. Participation is voluntary; withdrawal is allowed anytime; Information gathered will be kept under lock and key and will be kept for as long as required by the university.
4. A voice recorder will be used to capture information and field notes will be written during the interview and all the recording will be kept with all of the information pertaining to the research.
5. Codes or numbers will be used to avoid names to ensure confidentiality and anonymity. The study will benefit health for the oncology patients, influence policy, students and the Department of Health in the Vhembe District

Thank you
N.J. Ramutumbu

Signature of the researcher: N.J. Ramutumbu .....
Signature of supervisor: Dr D.U. Ramathuba .....
Signature of co-supervisor: Dr N.D. Ndou .....

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ANNEXURE 5

PERMISSION FROM LIMPOPO PROVINCE DEPARTMENT OF HEALTH TO CONDUCT THE STUDY

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Enquiries: Stols M.L.

Ref:4/2/2

Ramutumbu NJ
School of Health Sciences
University of Venda
P.O. Box 7355
Thohoyandou
0950

Greetings,

RE: Experiences of patients regarding oncology treatment and care at hospitals in Vhembe District of Limpopo Province.

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, a copy should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.

Your cooperation will be highly appreciated.

Head of Department

18/05/2015
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http/www.limpopo.gov.za

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ANNEXURE 6

REQUEST TO HOSPITALS IN THE VHEMBE DISTRICT

P.O. Box 7355
Thohoyandou
0950

The Chief Executive Officer
Hospitals in the Vhembe District
Vhembe Limpopo

Application to do research at your institution: .....

I, Neo Jacqueline Ramutumbu, a Magister Curationis student at University of Venda am requesting to conduct research in your hospital as a requirement in my studies.

My research topic is: **Experiences of patients regarding oncology treatment and care at the hospitals in the Vhembe District Limpopo Province**.

The purpose of the study is to determine and describe the experiences of the patients regarding oncology treatment and care at the hospitals.

The findings of the study may assist the hospitals in the provisioning of oncology treatment for cancer patients by the Department of health.

Thanking you in anticipation

N.J. Ramutumbu.

Student number: 11565382

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ANNEXURE 7

PERMISSION FROM VHEMBE DISTRICT DEPARTMENT OF HEALTH TO CONDUCT THE STUDY

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH: VHEMBE DISTRICT

Enquiries: Makhwanya T E

Contact details:084 690 0606 or Makhwanyate@gmail.com

Date: 28th May 2015.

To: CEO

All hospitals

RE: APPROVAL TO CONDUCT THE STUDY: EXPERIENCES OF PPATIENTS REGARDING ONCOLOGY TREATMENT AND CARE AT HOSPITALS IN VHEMBE DISTRICT OF LIMPOPO PROVINCE: MS RAMUTUMBU N J.

1. Please note that the Department of Health has approved the conduction of the above-mentioned study. (See attached copy).
2. The District office has no objection to the conduction of such a study provided it is in line with the methodology as approved by the Ethics Committee of the University.
3. Your hospital is hereby requested to give her the necessary support as the study is likely to benefit profoundly the District in terms of service delivery.

Thanking you in advance for your support.

..... 28/05/2015

ACTING-DISTRICT EXECUTIVE MANAGER DATE

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ANNEXURE 8

PERMISSION FROM MALAMULELE HOSPITAL TO CONDUCT THE STUDY

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
MALAMULELE HOSPITAL

REF : S 4/5

ENQ : Siwela T.S

DATE : 05/ 06/ 2015

TO WHOM IT MAY CONCERN

SUBJECT: PERMISSION TO CONDUCT A RESEARCH STUDY : RAMUTUMBU N.J

1. This serves to confirm that the above mentioned has been granted permission to conduct a research at Malamulele hospital on the basis of conditions outlined in the Provincial department's approval.
2. The research topic is on **"Experiences of patients regarding oncology treatment and care hospitals in Vhembe District, Limpopo province".**
3. Attached hereto is the applicant's letter, research proposal, Training institution's Ethics committee clearance, Provincial and District department's approval and the research study requirements checklist of which the outstanding documents should be submitted on the research date.
4. Hoping for an effective cooperation between the participants of this research.

Thank you

CHIEF EXECUTIVE OFFICER
MALAMULELE HOSPITAL

08 . 06 . 2015
DATE

CONFIDENTIAL

2015 -06- 08

Malamulele Hospital Private Bag X 9245 Malamulele 0982
Tel: (015) 851 0026/7820/7017/7019 Fax: (015) 851 0620

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ANNEXURE 9

PERMISSION FROM DONALD FRASER HOSPITAL TO CONDUCT THE STUDY

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT
DONALD FRASER HOSPITAL

Ref: 4/2/2
Enquiries: Mphephu VF
Cell no. 072 1880 436
Ext. 2106// 2148
08/06/2015

TO: MRS Ramutumbu NJ
School of Health Sciences
University of Venda
P.O Box 7355
Thohoyandou
0950

RE: Permission to do research study at Donald Fraser hospital on experience of patients regarding oncology treatment and care at hospitals in Vhembe District of Limpopo province.

1. The above matter refers.
2. Permission to conduct the above mentioned study is hereby granted.
3. Kindly be informed that:-
   - In the course of your study there should be no action that disrupts the services.
   - To give report to quality assurance manager of Donald Fraser hospital after completion of research study at Donald Fraser hospital.
   - After completion of the study, a copy should be submitted to our institution to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - You are therefore requested to contact nursing audit office number 7, OPD basement for logistic arrangements.

LIMPOPO PROVINCE
DONALD FRASER HOSPITAL
2015 -06- 08
PRIVATE BAG X1172, VHUFULI
DEPARTMENT OF HEALTH

4. Please bring along the following documents:
   - Permission letter granted from department of health.
   - Permission letter granted from educational institution.
   - This letter.

Hoping you will find this in order

SIGNED ..... Date 08/06/2015

CHIEF EXECUTIVE OFFICER

Private bag X1172, Vhufuli 0971
Tel: 015 963 1778/9, 015 1783 1791/2 • Fax: 015 963 1773, 015 963 1796
Cell: 083 248 0184

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ANNEXURE 10

MEMORANDUM OF UNDERSTANDING WITH TSHILIDZLNI HOSPITAL ETHICS COMMITTEE

TSHILIDZINI HOSPITAL ETHICS COMMITTEE

Memorandum of understanding

Tshilidzini Hospital Ethics Committee with N Ramuthi at their meeting resolved to sign a Memorandum of Understanding after the two parties have agreed on the following information:

1. Reasons for making a research at Tshilidzini hospital.

I work at Tshilidzi Matoniom Wing cancer patients are admitted and cared for. Need for Quality care.

2. What will be the benefit of the entire hospital community out of your findings?

The Quality of our cancer patients

3. Who to meet in conducting your research

Cancer patients on treatment

4. What do you do with your findings?

Inform the hospital, district and province and the findings may benefit all the stakeholders

5. We will require the hard copy of your research

Yes that will be provided

6. We do not anticipate any information to be divulged to all types of media without the knowledge of the Ethics Committee and Hospital Board.

7. Memorandum of understanding should be signed by both parties.

Signed by: N Ramuthi

2018/06/02
Date:

N Ramuthi
Researcher

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ANNEXURE 11

PARTICIPANT INFORMATION SHEET

EXPERIENCES OF PATIENTS REGARDING ONCOLOGY TREATMENT AND CARE AT THE HOSPITALS IN THE VHEMBE DISTRICT IN LIMPOPO PROVINCE

INFORMED CONSENT TO PARTICIPATE IN A STUDY

You have been asked to participate in a research study conducted by Mrs N. J. Ramutumbu from the Department of Nursing Science at the University of Venda, Limpopo Province, South Africa. I am doing this study along with Dr D.U. Ramathuba and Mrs N.D. Ndou.

You have been asked to participate in this study, because you are a patient with cancer undergoing treatment and care in the hospitals in the Vhembe District in Limpopo Province. Your participation is voluntary.

Purpose of the Study

The aim of this study is to better understand the experiences of cancer patients regarding oncology treatment and care at the hospitals and how you are coping with these experiences. This information will be used to develop programmes to help cancer patients with the description of these experiences.

Procedures

The study involves conducting in-depth interviews with the researcher at the 5 (five) hospitals in Limpopo Province. The interview will last at least 45 minutes. You are requested to voluntarily partake in this study, as you are a patient receiving cancer treatment in the hospitals.

You will be asked questions about your age ethnicity, marital status, income, family and about your experiences regarding oncology treatment and care. You will also be asked questions about your feelings and how you have been coping since the diagnosis of cancer.You will not incur any costs as the researcher will make arrangement to come for interviews where you deem it fit.

Potential Risks and Discomforts

The study may involve questions that may make you feel somewhat uncomfortable, embarrassed or upset. If you become upset, you may choose to stop the interview. You may refuse to answer any questions in the interview that you do not wish to answer and you can still continue with the interview. You may also choose to withdraw from the study. If you are in need of counselling, you will be referred to the hospital psychologist where you are receiving oncology treatment and care.

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Anticipated Benefits for the Participant

Participants will learn more about their experiences as they relate their feelings and identify their most inner feeling about these experiences; they may gain insight into how they have been coping with their own experiences. They may also be better able to seek out health services.

Anticipated Benefits to Society

This information from this study will be used to develop a programme for better cancer treatment and care.

Alternatives to Participation

The cancer patients who are not willing to participate will still be given treatment as before as participation does not impact on receiving treatment.

Payment for Participation

You will not receive any payment for your participation. You will receive free refreshments at all sessions. The study will involve participants in two interviews; that the first interview and a follow-up interviews if needed to clarify and validate the findings, there are no interventions involved in this study.

Financial Obligation

You will not be made to pay for your participation in this research.

Privacy and Confidentiality

All attempts will be made to ensure your privacy. Codes will be used to identify their tapes to ensure confidentiality. A tape recorder will be used to record the interviews. These cassettes, however, will be used for research purposes only and your identity will not be disclosed in any way.

Participation and Withdrawal

Your participation in this research is **VOLUNTARY**. If you choose not to participate, that will not affect your right to health care or other services. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

Consequences of Withdrawal

If you choose to withdraw voluntarily, this will not affect your relationship with the oncology treatment and care.

Withdrawal of Participation by the Investigator

The investigator may withdraw you from participating in this research if circumstances arise which warrant doing so. If you experience significant psychological distress that prevents you from continuing the discussion, you may be withdrawn from the study even if you would like to continue. The investigator will make the decision and let you know.

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Identification of the Investigator

In the event that you experience an adverse reaction, please immediately contact the investigators listed below. If you have any questions about the research, please feel free to contact:

Dr D.U. Ramathuba@ 0823039656 and Mrs N.D. NDOU@ 0720100571 the supervisor and co-supervisor and the student Mrs N.J. Ramutumbu@0827178190

Rights of Research Subjects

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, you may contact: Department of health research ethical officers.

Department of Advanced Nursing Science
School of Health Sciences
University of Venda

Signature of Research Subject: ..... **Date:** .....

I have read (or someone has read to me) the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this form.

By signing this form, I willingly agree to participate in the research it describes.

I am willing to take part in the interviews as described in this informed consent.

Name of Participant: .....

Signature of Participant: ..... **Date:** .....

Signature Of Investigator: ..... **Date:** .....

I have explained the research to the participant, and answered all of her questions. I believe that s/he understands the information described in this document and freely consents to participate.

Name of Interviewer: .....

Signature of Interviewer: ..... **Date:** .....

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ANNEXURE 12

INFORMED CONSENT DECLARATION

Consent form for the participants

I ..... have been asked to participate in the research study to be conducted by Mrs N.J. Ramutumbu, a student at the University of Venda.

The title of the research is: **Experiences of patients regarding oncology treatment and care at the hospitals in the Vhembe District in Limpopo Province.**

The purpose of the study is to explore and describe the experiences of the patients regarding oncology treatment and care at the hospitals.

The aim of the study is explained to me and also my rights to participate and not to participate is thoroughly explained to me.

I understand that the benefits of this research may benefit me and other cancer patients based on the research findings, the Health Department and the oncology services in the hospitals.

I was assured confidentiality in my participation in the study and that I will be protected from harm of any sort and will be protected from exploitation.

I understand that my refusal to participate will not interfere with my rights to treatment and care. I am allowed to withdraw from the research at any stage of the research.

Participant's Signature: ..... **Date:** .....

Researcher's Signature: ..... **Date:** .....

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ANNEXURE 13

CONFIRMATION BY LANGUAGE EDITOR

UNIVERSITY of the WESTERN CAPE

FACULTY OF NATURAL SCIENCES

DEPARTMENT OF MEDICAL BIOSCIENCES

Donavon C. Hiss | University of the Western Cape | Private Bag X17 | Bellville 7535 | South Africa

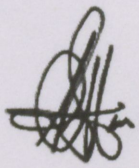
Tel: 021 959 2334 | Cell: 072 200 1086 | Fax: 021 959 3215 | E-mail: dhiss@uwc.ac.za or hiss@gmx.us

11 December 2015

To Whom it May Concern

This serves to confirm that I have edited the language, spelling, grammar and style of the MCur thesis by **Neo Jacqueline Ramutumbu**, titled: "**Experiences of Patients Regarding Oncology Treatment and Care at Hospitals in Vhembe District of Limpopo Province.**" The manuscript was also professionally typeset by me.

Sincerely Yours



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