

**EXPERIENCES OF MEN DIAGNOSED WITH PROSTATE  
CANCER IN THE FOUR NORTHERN REGIONS OF NAMIBIA**

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**ABSTRACT**

Men diagnosed with prostate cancer have different experiences and express different emotions regarding their diagnosis. In daily conversations, some patients revealed that they were totally surprised by the diagnosis, others expressed that they were in denial, while some anticipated their diagnosis. As a result, a qualitative study aimed at exploring and describing the experiences of men diagnosed with prostate cancer was carried out in the four northern regions: Oshana, Ohangwena, Omusati and Oshikoto.

A phenomenological, explorative and descriptive design was followed as the basis for conducting the study. The data was collected through in-depth interviews conducted at an intermediate hospital in the northern part of the country. A sample of ten (10) men diagnosed and living with prostate cancer was selected using a purposive sampling technique. The sample size was determined by saturation of data as reflected in repeating themes.

Rich data on participants' experiences with prostate cancer after being diagnosed was obtained through individual interviews. During these interviews, participants were asked only one central question: "What is your experience with prostate cancer after being diagnosed?" Interviews were tape recorded and field notes were taken during the interview to ensure that all experiences of the participants were captured. Communication skills were employed to encourage participants to verbalize their experiences regarding prostate cancer. Interview data was transcribed verbatim.

The data was analysed according to Tesch's eight steps of coding. The steps entail a process of breaking down, examining, comparing and categorizing the raw data. The researcher and an independent qualitative research expert carried out the coding. Four (4) themes emerged and form the study's results. Measures to ensure trustworthiness, as proposed by Polit & Beck (2012), were used to ensure reliable and valid findings.

It became evident that men diagnosed and living with prostate cancer had different experiences after their diagnoses, some experienced physical discomfort and physiological changes in their bodies. It was recommended that more emphasis should be put on supportive care towards men diagnosed with prostate cancer to reduce the burden of various experiences after being diagnosed with the disease. Community-based health education programmes on prostate cancer are needed to create awareness and knowledge on the disease. Individual approaches to assist men with their thoughts and feelings after being diagnosed with prostate cancer should be considered, as well as the incorporation of strategies to be more effective at obtaining social support. Existing misconceptions about prostate cancer that are likely to influence how men prioritize to cope with the diagnosis needs to be addressed. It is also recommended that a model to facilitate effective communication should be developed with the aim of improving interaction between nurses and doctors with men diagnosed and living with prostate cancers and their families.

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**List of abbreviations**

BPH	:	Benign Prostate Hyperplasia
CDC	:	Communicable Disease Clinic
CSSD	:	Central Sterilization Supply Department
DRE	:	Digital Rectal Examination
ICU	:	Intensive Care Unit
MoHSS	:	Ministry of Health and Social Services
OPD	:	Outpatients Department
OOPD	:	Oncology Outpatients Department
PMO	:	Principal Medical Officer
PSA	:	Prostate Specific Antigen test
UK	:	United Kingdom
UOPD	:	Urology Outpatients Department



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**DEDICATION**

***“Dorteia”***

*this is for you*

**DECLARATION**

I, Salomo Salomo, hereby declare that the “Experiences of men diagnosed with prostate cancer in the four northern regions”, is a true reflection of my own work, and that all of the sources used have been acknowledged in the text and bibliography. This version is an original work, and has not previously been submitted in full or in part for a degree at any other university.

This thesis may not be produced, stored in any retrieval system or transmitted in any form or by any means, whether mechanical, electronic, photocopied, recorded, or otherwise without the express permission from the author or the University of Namibia on his behalf.

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## **CHAPTER 1**

### **INTRODUCTION AND BACKGROUND OF THE STUDY**

#### **1.1. INTRODUCTION**

Cancer is a growing health problem in many countries, especially in the developing world where it is estimated that more than half the global burden of cancer exists. It has been estimated that the global burden of cancer doubled in the last 30 years, and is expected to double again by 2020 (MoHSS, 2011). Reproductive cancers, especially breast, cervical and prostate are among the top causes of cancer morbidity and mortality worldwide. The most common forms of the disease in women (in developed countries) are cervical, breast and stomach cancer. In the year 2005, Namibia had 179 cases of breast cancer and 129 cases of cervical cancer (MoHSS, 2008). On the other hand, the top five types of cancer that affect men in Namibia include skin cancer; Kaposi sarcoma; prostate cancer; ear, nose, and throat cancer; and colorectal cancer (MoHSS, 2011).

Prostate cancer is the second most common cancer in men, the sixth most common cause of cancer deaths in men, and the tenth most common cause of cancer deaths worldwide. In 2007, there was an estimated 254 000 deaths worldwide from prostate cancer, making it the sixth leading cause of cancer deaths among men. Approximately one in seven men in the United States will be diagnosed with prostate cancer during their lifetimes. According to global estimates for 2002, prostate cancer is the most common type of cancer diagnosed among men in high-resource nations (Holland et al., 2010).

Prostate cancer is now the most common male cancer in Europe and the US, with more than 30,000 new cases per annum in the UK. Eighty-five percent of men are diagnosed at the age of 65 and older. To date, more than two million men in the United States have lived with prostate cancer (American Cancer Society, 2012). Prostate cancer is the leading cause of cancer deaths among American men, and is the most common carcinoma in men over the age of 65. Prostate cancer is the second most common cancer for men in the Western world. The latest incidence figure suggests that in the UK, 35 000 men were diagnosed as having prostate cancer, and there were over 10 000 deaths as a result of the disease (Bower & Waxman, 2010).

Prostate cancer occurs when a malignant tumour forms in the prostate tissue, a gland in the male reproductive system. The prostate is a small exocrine gland of about 20 - 25 g located deep in the pelvis, interposed between the bladder and external urinary sphincter, surrounding the urethra. Its main function is to make fluid for semen, a white substance that carries sperm (Kampel, 2007). Some prostate cancers can grow and spread quickly, but most of the time prostate cancer grows slowly. Many men die at an old age without ever knowing they had prostate cancer, and it is only when an autopsy is performed that doctors know it was there. Several studies have indicated that perhaps about 80% of all men in their eighties had prostate cancer when they died, but neither they nor their doctor knew (MNT Knowledge Center, 2013).

Haidula (2014) reports that statistics from the Cancer Association of Namibia indicated that prostate cancer is increasing, with 126 and 311 cases reported in 2006

and 2012, respectively. While these numbers may seem low, Magadza (2014) reports that with respect to prostate cancer, health experts say that every man is at risk of developing it, with the lifetime risk estimated at almost 100%. The risk is particularly high if there is a family history of prostate cancer. Experts have therefore recommended that every man above the age of 35 should go for regular check-ups, ideally once a year.

Generally, the incidence of prostate cancer rises markedly after the age of 50, and more than 66% of men diagnosed are older than 65. Genetic mutations in certain genes may contribute to the risk of prostate cancer in susceptible men (Lewis, Dirksen, Heitkemper, Bucher & Camera, 2011). Kampel (2007) pointed out that men who are at high risk by virtue of family history, known genetic predisposition, and African ancestry should be offered screening at younger ages, perhaps beginning at the age of 40.

The symptoms of prostate cancer include frequent urination, blood in the urine, painful urination, painful ejaculation, and difficulty achieving or maintaining erections. If the prostate cancer is advanced, the following symptoms are also possible: bone pain especially in the spine, pelvis or ribs, weakness of the legs, and urinary and/or faecal incontinence. Risk factors include increasing age, family history, and an unhealthy diet (Cancer Association of Namibia, 2009). The disease can spread by local extension, through the lymph system, or by way of the bloodstream. The etiology of prostate cancer is unknown, but there is an increased risk for people with a family history of the disease (Nettina, 2014).



Being told of a cancer diagnosis brings the future into question, as men ponder their chance of survival. At times, the information men receive from healthcare workers about prostate cancer seems to conflict with what they hear from other men in the community. Unanswered questions can be bewildering to patients, promoting distrust in the health care system and causing men to live in the unknown. Patients usually look for answers as a way to alleviate their anxieties and achieve a sense of comfort and stability (Krumwiede & Krumwiede, 2012).

Among men diagnosed with prostate cancer, 98% survive at least five years, 84% survive at least 10 years, and 56% survive 15 years. Most cancers are detected when a man seeks medical attention for group symptoms of urinary obstruction (Smeltzer, Bare, Hinkle & Cheever, 2010). On the other hand, a routine repeated Digital Rectal Examination (DRE) is important in early detection of prostate cancer. A Prostate Specific Antigen test (PSA) is another procedure used to diagnose prostate cancer (Nettina, 2014). The rationale for screening men for prostate cancer is the potential to reduce the risk of death through early detection (American Society of Clinical Oncology, 2014).

However, frustrating delays are often experienced in getting back laboratory test results, as most of these results for tissue histology take more than two weeks. Only 20% of health facilities conduct digital rectal examinations for prostate cancer screening, and only 37% provide the PSA test (MoHSS, 2011).

Men are usually physically and psychologically affected by the diagnosis of prostate cancer and treatment they endure. The diagnostic confirmation of prostate cancer

takes a few days after the submission of the specimen to the laboratory. This lapse in time causes many men to become anxious about the diagnosis. In addition, the potential for death causes emotional distress. The cause of the disease usually puts them under multiple stress-provoking situations.

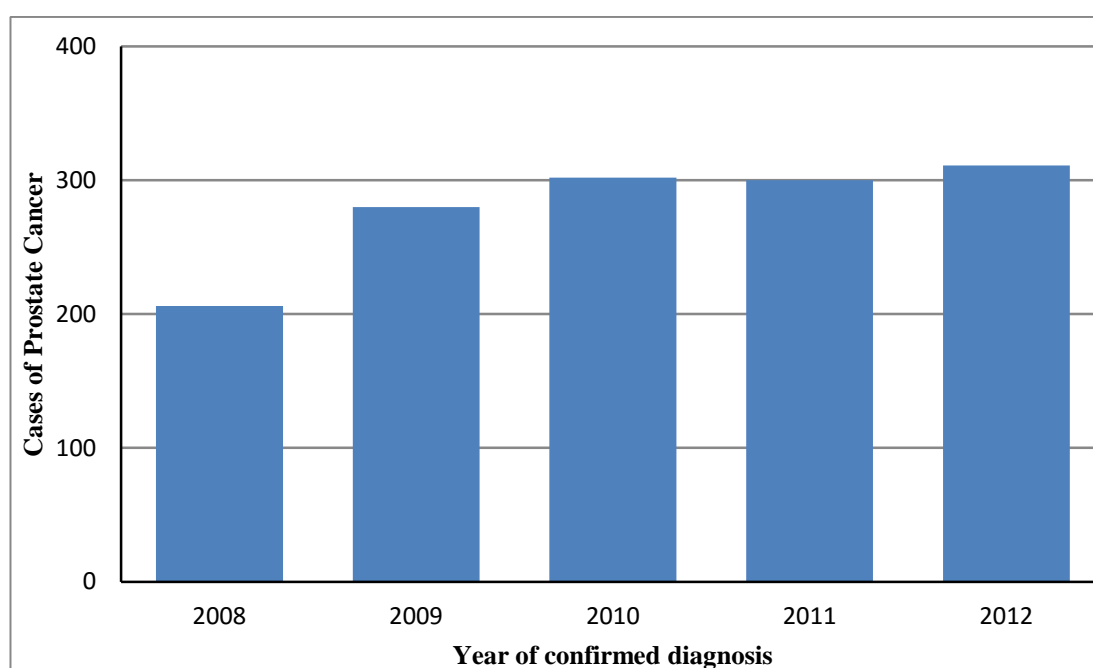


Figure 1.1: Cases of Prostate Cancer diagnosed in Intermediate Hospital Oshakati from 2008–2012.

In an Intermediate Hospital Oshakati in the northern part of Namibia, specifically the male surgical ward, a total of twenty-six (26) patients have been admitted after being diagnosed with prostate cancer in the year 2011. Statistics have also revealed that four patients have died of prostate cancer in the same year (MoHSS, 2011). This number increased in the year 2012 when a total of thirty-five (35) patients aged 39 to 95 years were admitted in the same ward with prostate cancer. Out of these thirty-five (35) patients, ten (10) reportedly died of prostate cancer in the same year. These

revelations indicated the number of patients admitted or killed by prostate cancer in the year 2012 compared to the previous year.

The management of prostate cancer depends on the stage of the disease. Early diagnosis and treatment in most cases will increase the survival rate. It is believed that certain health behaviours significantly reduce the risk of prostate cancer. These include eating a diet rich in fruits and vegetables, regular physical activity and regular prostate screening (Clarke, 2014).

Most men treated for prostate cancer experience complex side effects such as hot flashes, diaphoresis, fatigue, depression and erectile dysfunction. Individuals who were afflicted by radiation, experienced burnt skin, fatigue, diarrhoea and occasional nausea had higher rates of skin cancer. On the other hand, men who underwent prostatectomies usually experienced brief or prolonged episodes of incontinence, impotence, erectile dysfunction, and/or loss of libido. The two most significant negative outcomes of surgery included incontinence and erectile dysfunction. Incontinence and sexual dysfunction are usually difficult for men, causing humiliation and shame (Krumwiede & Krumwiede, 2012).

Having a trusted relationship with one's healthcare provider has a significant impact on men's comfort level during their experience. Open communication and receiving all of the facts from physicians and nurses facilitates trust. However, inconsistent nursing care places a strain on the nurse-patient relationship. Usually, men feel devalued when inconsistent nursing care and lapses in communication occurs. However, men usually speak of feeling comfort through the development of trusted

connections and the unwavering support they receive throughout their experience with prostate cancer (Krumwiede & Krumwiede, 2012). For many men with this diagnosis, the optimum management is uncertain, with a spectrum of treatment options ranging from no treatment at all to complex surgery or radiation therapy (Tadman & Roberts, 2007).

The Cancer Association of Namibia has been involved in cancer awareness activities and the provision of screening services in Namibia as indicated in figure 1. In 2012, a total of 311 patients were diagnosed (histology proven) with prostate cancer, 300 patients were diagnosed with prostate cancer in the year 2011, 302 in 2010, 280 in 2009, and 206 in 2008 (Cancer Association of Namibia, 2009).

## **1.2. BACKGROUND TO THE PROBLEM**

Cancer is an experience that affects all aspects of a person's life in ways that people without cancer cannot imagine. As a clinical instructor based in the Intermediate Hospital Oshakati in the northern part of Namibia, the researcher has daily contact with cancer patients, including men diagnosed with prostate cancer. During those clinical encounters, the researcher has observed that men diagnosed with prostate cancer have different experiences and express different emotions on their diagnosis. In daily conversations, some patients revealed that they were totally surprised by the diagnosis, others expressed that they were in denial, while some anticipated their diagnosis. On the other hand, the long waiting period for the test results causes a shared experience of restlessness and impatience that tends to threaten men's

psychological integrity. Most men described the prostate cancer diagnosis as a traumatic event.

Some patients characterised prostate cancer and treatment as painful and as causing urinary incontinence, sexual dysfunction and emotional suffering. Almost every patient described the post-operative catheter treatment as the worst part of the experience. According to the prostate cancer patients, the urinary leakage around the catheter tubing caused embarrassment and resulted in social withdrawal.

### **1.3. PROBLEM STATEMENT**

Having observed men with different emotions regarding their prostate cancer diagnosis and management, the researcher became concerned as to whether health workers know enough about men's experiences with prostate cancer, and whether they do enough to support men receiving the diagnosis. Another concern was also whether men are sensitised towards preventing this type of cancer. Therefore, the researcher was interested in exploring and describing the experiences of men diagnosed with prostate cancer in the four northern regions: Oshana, Oshana, Oshana, Oshana, Oshikoto and Omusati.

### **1.4. PURPOSE OF THE STUDY**

The purpose of the study was to explore and describe the experiences of men diagnosed with prostate cancer to have an understanding of what they go through in order to make recommendations for health workers to strengthen the support rendered to the patient.

### **1.5. OBJECTIVES OF THE STUDY**

The following objectives have been formulated to guide the research:

- Explore the experiences of men diagnosed with prostate cancer in the four northern regions of Namibia.
- Describe the experiences of men diagnosed with prostate cancer in the four northern regions of Namibia.

### **1.6. SIGNIFICANCE OF THE STUDY**

Sharing this study's findings will enable healthcare workers to have a clear understanding of the challenges experienced by men diagnosed with prostate cancer in Namibia's four northern regions, which will then assist them in rendering support to these patients. This study's findings will also enable the researcher to make recommendations to the Ministry of Health and Social Services in terms of how health workers can support cancer patients who have gone through the prostate diagnostic process, especially those with a prostate cancer outcome.

### **1.7. LIMITATIONS OF THE STUDY**

This study was conducted with men already diagnosed with prostate cancer in Oshakati Intermediate Hospital. It was conducted among a small number of men diagnosed with prostate cancer. Therefore, the study's results will not be generalised to the broader population because the participants' geographical and cultural orientation may not be the same as that of men in other regions. However, the

researcher envisages that the study's findings might be of use to other healthcare workers dealing with patients diagnosed with prostate cancer.

### **1.8. PARADIGMATIC PERSPECTIVES**

A paradigm is a collection of logically linked concepts and propositions that provide a theoretical perspective or orientation that tends to guide the research approach to a specific topic. The importance of a paradigm in this study is that it influences the identification of a researchable problem, the most appropriate methods, and the relevant techniques by which the data was collected, analysed and interpreted (Rew, 2005). It is a discipline's specific method of structuring reality and the nature of knowledge (Brink, Van der Walt & Van Rensburg, 2013; Boeije, 2012). In this study, the paradigm framed the way in which a discipline's concerns were viewed, and the direction that a research project took (Brink et al., 2013). It served as the window through which the researcher viewed the context (Shuttleworth, 2008; Holloway & Wheeler, 2010). Therefore, the paradigm assisted in structuring the question that needed to be posed in this study: "What is your experience after being diagnosed with prostate cancer?"

On the other hand, assumptions are the basic principles that we accept on faith, take for granted, or assume to be true without proof or verification (Brink et al., 2013; Repko, 2012). In this research, assumptions were important because they influenced the logic followed in the study (Grove, Burns & Gray, 2013; May & Holmes, 2012; Scotland, 2012). The paradigm for this study consisted of ontological,

epistemological, axiological, methodological and rhetorical assumptions that are described in the following sections.

### **1.8.1. Ontological assumptions**

Ontology is a philosophical belief system about the nature of the social reality that can be known and how it can be known. A researcher's ontological assumptions impact his topic selection, the formulation of research questions, and strategies for conducting the research. The ontological assumption in research entails an indication of the researcher's preference by specifying what are considered truths about knowledge, information, and the world (Wangombe, 2013). The conscious and unconscious questions, assumptions and beliefs that the researcher brings to the research project serve as the initial basis for an ontological position.

Ontology is considered the study of being (Scotland, 2012). It is a patterned set of assumptions about the nature of reality. Ontological assumptions are concerned with what constitutes reality. According to Botma, Greeff, Mulaudzi and Wright (2010), qualitative researchers believe that people construct their own reality through their lived experiences (ontological perspective) and support the theory that knowledge is developed by interacting with people, and that we construct our own interpretation and meaning of the experience (epistemology) within a phenomenological methodology. This is done by using methods such as interviewing and observation. In this view, the research question is not about the reality of the world, but about people's interpretation of that reality.



In this study, reality is contained in various lived experiences of the participants, namely men diagnosed with prostate cancer in the four northern regions, as well as the realities of the researcher. It is assumed that every man diagnosed with prostate cancer in the four northern regions had different experiences. The central question to be answered by the participants was, “What is your experience after being diagnosed with prostate cancer?” The leading assumption was that men diagnosed with prostate cancer in the four northern regions had different experiences after being diagnosed. The question attempted to explain how the phenomenon is subjectively explained or viewed by the researcher and participants as well to investigate the extent of the truth about the particular phenomenon (Wangombe, 2013).

The researcher used direct quotations from the in-depth interviews, and they are included in chapter 3. On the other hand, themes and sub-themes were developed that gave clear meanings to the experiences and the reality of men diagnosed with prostate cancer (Burns & Grove, 2009).

### **1.8.2. Epistemological assumptions**

Epistemology concerns the acquisition of knowledge and how the relationship between the researcher and the researched is understood (Wangombe, 2013). It is a philosophical belief system about who can be a knower (Repko, 2012). On the other hand, epistemology addresses the origins, nature, methods, and limits of human knowledge while focusing on questions relating to the nature of knowledge. The researcher’s epistemological and ontological positions form the philosophical basis of a research project. Scotland (2012) described epistemology as concerned with the nature, forms and theory of knowledge as it pertains to the ways in which human

beings know the world (Holloway & Wheeler, 2010). Epistemological assumptions are furthermore concerned with how knowledge can be created, acquired and communicated, or in other words, what it means to “know”. Therefore, epistemology can assist in an attempt to answer the question, “What is the relationship between the researcher and what is being researched (the phenomenon)?” A logical question following the above would be, “How is the researcher related to those being researched?”

The researcher interacted with specific participants on a specific topic whereby the findings were obtained through in-depth interviews. Thereby, the researcher attempted to address the above question by collaborating and investing his time in data collection activities that facilitated an in-depth understanding of the experiences of men diagnosed with prostate cancer (Polit & Beck, 2012). Simultaneously, the researcher also gained an in-depth understanding of the phenomenon as well as specific views, perceptions, cultural background and experiences from the participants (Brink et al., 2013).

In this study, it is assumed that data collected through in-depth interviews with men diagnosed with prostate cancer in Namibia’s four northern regions enabled the researcher to gain knowledge regarding the experience of men diagnosed with prostate cancer.

### **1.8.3. Axiological assumptions.**

Axiology refers to the role of values and the inquiry in general (Polit & Beck, 2012). Values and biases are to be held in check, and objectivity should be sought.

According to Hays and Singh (2011), axiological assumptions try to address what is considered ethical and moral behaviour by the researcher, and how his values influence the research question and design. Axiology also includes how people view themselves in relationship to others with more emphasis on the role of values and ethics in research. Values shape the interpretations made by the researcher as well as those of the participants. It can be assumed that regarding this study, participants with prostate cancer, as well as the researcher, brought their own values.

#### **1.8.4. Methodological assumptions.**

Methodological assumptions explain what the researcher believes is good scientific practice (Botma et al., 2010). It is about how the best evidence can be obtained (Polit & Beck, 2012). Qualitative research is concerned with the in-depth descriptions of people or events as the researcher attempts to obtain rich, real, deep and valid data. It focuses on gaining insight and understanding about an individual's perception of events (Nieswiadomy, 2014).

In a study, the quality of research findings depends on the methodological procedures followed. Polit and Beck (2012) stated that in a qualitative study, data collection is an intense experience, especially if the phenomenon being studied concerns an illness. It required the researcher to become intensively involved in the participant's real world. This interaction between the researcher and the participant leads to an understanding of the experience and thus generates concepts (Holloway & Wheeler, 2010).

In this study, the researcher served as a research instrument by utilising in-depth interviews as the primary method of collecting data; afterward, the data were analysed qualitatively. The study's conclusions reveal the need to support men diagnosed with prostate cancer to help them cope with the diagnosis (Polit & Beck, 2012).

#### **1.8.5. Rhetorical assumptions**

Rhetoric is described as the art of persuasion (Firestone, 2013). The rhetorical structure of research paper pertains to how the researcher goes about persuading the reader of the paper's worth. The overall rhetorical assumption in qualitative research is not truth seeking as such, but instead reporting on reality through the eyes of the research participants. This applied to all studies, as it reports on what was seen and heard in the most objective way possible. The research paper's rhetorical style is therefore referred to as a humanistic interpretation and a description of the research results (Firestone, 2013).

Qualitative methods express the assumptions of a positivistic paradigm, which holds that behaviour can be explained through objective facts. Design and instrumentation indicates how bias and errors are eliminated. Rich descriptions show that the researcher was immersed in the setting, whereby the reader is given enough detail to make sense of the situation (Polit & Beck, 2012).

In this study, the researcher reported on what he saw through his observations and heard during the interviews, enabling the researcher to engage participants in a discussion with participants about their experience with prostate cancer. Purposive

sampling was employed to enable the researcher to identify the participants who possess such experiences with prostate cancer. Detailed descriptions were obtained from the participants during the interviews.

## **1.9. DEFINITIONS OF KEY CONCEPTS**

The concepts to be defined in this study are obtained from the title of this dissertation: “Experiences of men diagnosed with prostate cancer in the four northern regions.” The concepts are defined as follows:

### **1.9.1. Experience**

An experience is practical contact with and observation of facts or events. Experience can also be defined as an event or activity that leaves a lasting impression. In this study, experience refers to those practical contacts and observations that leave a lasting impression on men diagnosed with prostate cancer in Namibia’s Oshana, Oshikoto, Omusati and Ohangwena regions.

### **1.9.2. Diagnosis**

A diagnosis is the identification of a disease or condition through a scientific evaluation of physical signs, symptoms, history, laboratory test results and procedures. Diagnoses determine the type and cause of a health condition on the basis of patient signs and symptoms as well as data obtained from laboratory analyses of fluid, tissue specimens, and other tests. For this study's purpose, the prostate cancer diagnosis has been confirmed by a medical officer through laboratory analysis of fluid or tissue specimens and other tests.

### **1.9.3. Cancer**

Cancer refers to a neoplasm characterised by the uncontrolled growth of cells that tend to invade surrounding tissue and metastasise to distant bodily sites. Each cancer is distinguished by the nature, site, or clinical course of the lesion (Holland et al., 2010).

Prostate cancer therefore refers to a malignant tumour (carcinoma) of the prostate gland, a common form of cancer in men. The prostate gland in men surrounds the neck of the bladder and the proximal part of the urethra, and it produces a fluid that becomes the semen. The cause of cancer of the prostate is unknown, but it is believed to be hormone-related. The disease may cause no direct symptoms, but can be detected in the course of diagnosing bladder obstruction, or urethral obstruction, haematuria, or pyuria. It is commonly detected by prostate-antigen testing and digital rectal examinations with confirmation by co-needle biopsy. Treatment is through surgery, radiation therapy, or hormones depending on the age of the patient, extent of the disease, and other individual factors.

### **1.10. OUTLINE OF CHAPTERS**

This thesis is presented in the following chapters.

Chapter 1: This chapter consists of the introduction and background of the study and thereby sets the scene for the research. The motivations for the researcher to conduct the study as well as the study's objectives are found in this chapter.

Chapter 2: The research design and methods that the researcher adhered to during the study are described as well as ethical considerations, data collection methods and process followed. It also contains the measures employed to ensure trustworthiness during the study.

Chapter 3: This chapter analyses the data and the literature is described. Themes and sub-themes that emerged are outlined in this chapter, as well as the literature that supports the study's findings. Direct and verbatim quotes from interviews and field notes are incorporated and aligned with the discussions.

Chapter 4: This chapter includes discussion of the study's findings. Various similar findings obtained by other researchers are reflected on in this chapter, and the literature is integrated into the discussions to serve as additional evidence of the study's findings.

Chapter 5: As the study's last chapter, this chapter outlines the conclusion and the summary of the findings in context. In addition, it includes information on limitations and recommendations with regard to the experiences of men diagnosed with prostate cancer in Namibia's four northern regions: Oshana, Oshikoto, Omusati and Ohangwena. The conclusions were used to determine whether the study's objectives were achieved. Therefore, the conclusion was based on the study's findings, which addressed the research question: "What is your experience after being diagnosed with prostate cancer?"

### **1.11. SUMMARY**

Prostate cancer is the most common male cancer in Namibia other than skin cancer (Cancer Association of Namibia, 2009). Men diagnosed with prostate cancer have varied experiences: some express surprise, some denial and others anticipate their diagnosis. The Intermediate Hospital in the northern part of Namibia serves as a referral hospital for most patients diagnosed with prostate cancer, and it also serves as the context for this study. The researcher identified a need to explore and describe the experience of men diagnosed with prostate cancer in the four northern regions, as it is evident through statistics and observation that men's experiences with prostate cancer go unnoticed and unheard.



## **CHAPTER 2**

### **RESEARCH DESIGN AND METHODS**

#### **2.1. INTRODUCTION**

In this chapter, the design and methods employed in conducting research on prostate cancer are discussed. Thus, it includes the study's research design, population, sample, research instruments and procedure (Holloway & Wheeler, 2010). A research design is a plan or blueprint of how the researcher intends to conduct the research. It also refers to a set of logical arrangements from which prospective researchers can select one suitable for their specific research goals. A research design focuses on the end product, formulates a research problem as a point of departure, and focuses on the logic pertaining to the research (De Vos, Strydom, Fouche & Delport, 2011). Research methodologies are the principles and ideas on which researchers base their procedures and strategies. The researcher briefly describes the methodology adopted and the reasons and justification for it (Holloway & Wheeler, 2010).

#### **2.2. RESEARCH DESIGN AND METHODS**

The researcher adopted a qualitative, phenomenological, explorative and descriptive design to gain insight and discover meaning regarding the experiences of men diagnosed and living with prostate cancer in Namibia's four northern regions: Oshana, Oshana, Oshikoto and Omusati (Burns & Grove, 2009; Holloway & Wheeler, 2010).

### **2.2.1. Qualitative design**

A qualitative research approach was systematically employed to describe the experiences of men diagnosed with prostate cancer in Namibia's four northern regions: Oshikoto, Oshana, Omusati and Ohangwena (Burns & Grove, 2009; LoBiondo-Wood & Haber, 2010).

Qualitative research enables the researcher to interpret the data. This allows the researcher to develop a description of an individual or setting, analyse data for themes and sub-themes, interpret or draw conclusions about meaning personally and theoretically, state lessons learned, and offer further questions to be asked (Tappen, 2011). In this study, themes and sub-themes were formulated during data analysis.

### **2.2.2. Phenomenological design**

LoBiondo-Wood and Haber (2010, p. 102) define phenomenological study as “a process of learning and constructing the meaning of human experience through intensive dialogue with persons who are living the experience.” Phenomenological study generates a description of a phenomenon of everyday experience, allowing participants to have a direct experience with the phenomenon being studied (Leedy & Ormrod, 2010; Holloway & Wheeler, 2010; Edmonds & Kennedy, 2013). In this study, the researcher's goal was to understand the meaning of the experience of men diagnosed and living with prostate cancer.

### **2.2.3. Exploratory design**

Exploratory research is conducted to gain insight into a specific situation, which in this study refers to the lived experiences of men diagnosed with prostate cancer in

Namibia's four northern regions: Oshana, Oshana, Oshikoto and Omusati (De Vos, Strydom, Fouche & Delport, 2011).

#### **2.2.4. Descriptive design**

In qualitative studies, description is more likely to refer to an intensive examination of phenomena and their deeper meaning, thus leading to a more detailed description. Therefore, this study's descriptive section entails the description of men's experiences living with prostate cancer after it was explored as described in 2.2.2 (De Vos et al, 2011).

#### **2.2.5. Contextual design**

The study's context refers to the environment and the conditions in which the study takes place as well as the participants 'culture and location (Holloway & Wheeler, 2010). According to Pequegnat, Strover and Boyce (2010), contextual study is any study wherein the phenomenon of interest is studied in terms of its immediate context. Context refers to a particular setting in which a study is taking place, which can include the environment, people, and so forth. If the researcher understands the context, he can locate the actions and perceptions of individuals and grasp the meanings that they communicate, because in qualitative research the events and actions are studied as they occur in an everyday, real life setting. It is therefore important for the researcher to be sensitive to the context of the research and immerse himself in the setting and situation because both personal and social context is important.

This study is contextual in nature because it was carried out in the surgical wards, nuclear medicine, and oncology departments of the intermediate hospital in Namibia's four northern regions. These departments were selected because the researcher is familiar with the intermediate hospital's setting; he (the researcher) uses it to monitor students in clinical performance as a clinical instructor, consequently interacting with men diagnosed with prostate cancer. The aim of selecting a contextual design for this study was to maintain focus on the experiences of men diagnosed with prostate cancer in Namibia's four northern regions: Oshana, Omusati, Oshana and Oshikoto.

### **2.3. RESEARCH SETTING**

The study setting is the physical location of the research, for instance award in a hospital, a clinic or the community (Holloway & Wheeler, 2010). This study was conducted in Intermediate Hospital Oshakati, a public hospital in the Oshana region. The hospital was established in 1964 and started operating on 28 June 1966. It served as a referral hospital catering to the four northern regions of Namibia: Oshana, Oshikoto, Omusati and Oshana. According to the staff establishment of 2015, the hospital employs about 28 medical officers, 226 registered nurses, 240 enrolled nurses, 12 administrative officers, 191 cleaners and 20 drivers. Other employees include but are not limited to cooks, human resources professionals, mortuary assistants, occupational therapists, radiographers and work hands.

The hospital consists of various departments including the outpatient department (OPD), the casualty department, the laboratory services department, the operating

theatre, the central sterilisation supply department (CSSD), the intensive care unit (ICU), the dental clinic, the physiotherapy department, the communicable diseases clinic (CDC), the eye clinic, the nuclear medicine department, the plastic surgery department, the x-ray department and the male circumcision department. This study was conducted through in-depth interviews with men diagnosed with prostate cancer in the following departments/wards: the oncology outpatient department (OOPD), the nuclear medicine department, the male surgical ward (Ward 3A), the male urology department, and the male oncology department (Ward 3B).

#### **2.4. POPULATION**

Brink (2010, p.123) defines population as “the entire group of persons or objects that meets the criteria which the researcher is interested in studying.” The population for this study is comprised of men between the ages of 39 to 95 years old already diagnosed with prostate cancer. There are no statistics available concerning men in this age group to indicate the size of the population. The reason why the investigator opted to study this age group as the population for this study is that, according to the records obtained from the Intermediate Hospital in the northern part of Namibia, the incidence of prostate cancer in this age group is high.

#### **2.5. SAMPLE AND SAMPLING**

A sample is a part or fraction of a whole, or a subset of a larger set, selected by the researcher to participate in a research study. It consists of a selected group of the elements or units of analysis from a defined population, provided that it has the same characteristics as the population (Brink, 2010). Polit and Beck (2012) define

sampling as “the process of selecting cases to represent an entire population so that inferences about the population can be made”(p.275). In this study, a non-probability purposive sampling technique was used. Purposive sampling enables the researcher to search for a particular participant who can illuminate the phenomenon under study, therefore allowing the researcher to include those who are especially knowledgeable regarding the question at hand, which in this study refers to prostate cancer (LoBiondo-Wood & Haber, 2010; Brink, 2010). Purposive sampling maximises the range of specific information obtained from a particular context, in this case prostate cancer (Brink, Van der Walt & Van Rensburg, 2013; Du Plooy-Cilliers, Davis & Bezuidenhout, 2014).

Purposive sampling enables the researcher to purposefully choose elements that he or she wants to include in the sample, and thereby exclude those that do not (Du Plooy-Cilliers, Davis & Bezuidenhout, 2014). The following inclusion criteria were applied during sampling:

- Participants should be between the ages of 39 and 95 years old.
- Their diagnosis should have been confirmed through Prostate Specific Antigen (PSA) testing or a Digital Rectal Examination (DRE) followed by a core-needle biopsy (Smeltzer et al., 2010).

## **2.6. PREPARATION OF THE RESEARCH FIELD**

Field preparation was completed according to specifications set by DeVos et al., (2011); in order for the data collection to be appropriately executed, crucial information should be obtained. Such information will provide direction to the

researcher on how to approach the participants and how to handle the situation that he or she will find in the field during the data collection.

The researcher started consultations three weeks in advance with the regional health director of the Oshana region where the Oshakati Intermediate hospital resides. Other health professionals consulted included the following: the medical superintendent, the nurse manager and the unit managers for the departments where data collection was going to take place. The researcher informed them of the study's objectives and explained to them the importance of providing a suitable room in each unit in which the study was conducted. This is in line with Botma et al. (2010), who stressed that during the preparation for the study, it is important to obtain permission and consultation from all relevant stakeholders, gatekeepers and people on the ground. Through these consultations, the researcher secured the venue (room) in each department where the research interviews were conducted. This was facilitated by the fact that the researcher was employed in the intermediate hospital at the time. Factors such as privacy and noise levels were looked at during the selection of such rooms.

All of the unit managers for the departments were issued a schedule well in advance regarding the envisaged dates and times at which the researcher planned to collect data. Prior to each interview, the rooms were cleaned and seating arrangements were set up consisting of two chairs facing each other in a non-confrontational manner. All men diagnosed with prostate cancer from the same department were interviewed

in the same room for consistency. A tape recorder was obtained to record the interviews.

## **2.7. DATA COLLECTION**

Data collection methods refer to the process of selecting subjects and gathering data from these subjects (Grove, Burns & Gray, 2013). The actual steps of collecting data are specific to each study and depend on the research design and measurement methods. In this study, the data collection entailed the collection, analysis and interpretation of the results with regard to the experiences of men diagnosed with prostate cancer in Namibia's four northern regions which are Omusati, Oshana, Oshikoto and Ohangwena.

The tape recorder and field notes were also used during the interview to ensure that all of the participant's expressions were captured. This follows specifications set by Brink et al. (2013), who caution researchers that without high-quality data-collection techniques, the accuracy of the research conclusions can easily be challenged. It is therefore essential that the researcher is familiar with the various data-collection techniques, including their advantages and disadvantages, so that he or she can select the most suitable technique for the study purpose, setting and population.

Concurring with the above statements, Holloway and Wheeler (2010) pointed out that the best way to record the exact words during the interview is through tape recording. Pilot testing of the interview questions was conducted before the actual interview in order to ensure validity.



### **2.7.1. Individual interviews**

In this study, individual interviews were conducted in order to obtain rich data on participants' experiences with prostate cancer after being diagnosed. An individual interview is an interaction between the participant and the researcher where a data collector (researcher) questions a participant verbally (Grove, Burns & Gray, 2013; LoBiondo-Wood & Haber, 2010). It has the potential to generate in-depth information. The researcher was actively involved in the process of collecting the data in order to obtain authentic insight into the participants' experiences.

Data credibility is strong because the participants' meanings and interpretation are studied during the interview. In an individual interview, insights can be developed into other people's experiences, emotions and feelings (May & Holmes, 2012). In an interview, the researcher is considered the instrument because he or she primarily employs him or herself as an observer, interviewer and participant. The researcher was interested in obtaining rich data by asking men about their experience in being diagnosed with prostate cancer, interviews were considered the most appropriate way to obtain rich information on those experiences. Therefore, in this study, the participants were all engaged in in-depth (face-to-face) interviews that allowed dynamic interaction between the researcher and the participants. The researcher personally interviewed the hospitalised prostate cancer patients from January 2014 to March 2014 in the male surgical ward of the northern Intermediate Hospital. Prostate cancer patients who came for their follow-ups were also interviewed in the Urology Outpatients Department (UOPD). The researcher was able to interview patients with

prostate cancer from the four northern regions of Namibia because the Intermediate Hospital serves as a referral hospital for cancer patients from all of those regions.

In preparation for the interview, a quiet location with few distractions was located (Creswell, 2013). Bordens and Abbott (2014) point out that face-to-face interview could be conducted in any suitable environment. The researcher was in agreement with Leary (2012) who pointed out that when interviewing, the researcher must structure the interview setting in a way that promotes respondent comfort. Interview procedures often involve a need for the researcher to establish rapport with and gain the cooperation of the interviewee by making him or her feel comfortable and competent enough during the interaction (Silverman, 2011).

Being a full-time government employee, interviews were conducted over three months after working hours from 17:00 to 19:00. Special arrangements were made with registered nurses who work in the outpatient department to call the researcher anytime that they come across a man diagnosed and living with prostate cancer in order for the researcher to interview such patients. This process continued until the researcher conducted 10 interviews. Saturation of data occurs when additional participants provide no new information, and when themes that emerged become repetitive. At this point, the sample is considered adequate and the data is taken as being rich and thick (Brink et al., 2013).

Before the interview, the researcher welcomed the participant in the interview room, offering a chair and assuring him of confidentiality regarding the information shared. Thereafter, the researcher requested verbal consent from the participants after

explaining the study's objectives and asking for consent for the tape recorder. The researcher requested that participants be as honest as possible when answering the questions, and informed them to seek clarification if a question was not understood. All participants were informed of their right to opt out of the study if they wished to do so. The data obtained in this study is rich, thick and descriptive. The data's authenticity was ensured by the tape recordings and field notes (Tappen, 2011).

An interview guide was used as a data collection tool to enable the researcher to maintain the consistency of the questions during the interviews and not to miss out on any questions that could assist in the gathering of rich data (Ridenour & Newman, 2008). Creswell (2014) states that the purpose of the interview guide is to help the interviewer remember the points to cover, especially with probing questions.

The interview started in earnest with a single, broad, planned question reviewed beforehand with experts in the field in order to test appropriateness and applicability (Botma et al., 2010). The question was open ended in nature and focused on the experience of the phenomenon. In this study, a central question was, "What is your experience with prostate cancer after being diagnosed with it?" Marshall and Rossman (2011) stated that an interviewer should have superb listening skills and be skilful at personal interaction, question framing, and gentle probing for elaboration. Probing refers to stimulating a respondent to produce more information, to clarify and expand responses, and to explicate meaning (Bernard, 2013; Brink et al., 2013). In this study, the researcher employed both verbal and non-verbal communication

skills to encourage participants to verbalise their experience regarding prostate cancer.

A total of ten (10) face-to-face interviews were conducted before data saturation was reached. According to Burns and Grove (2011) the number of participants in a qualitative study is adequate when saturation and verification of information is achieved in the study area. Saturation of data refers to the point when the information being shared with the researcher from subjects becomes repetitive; in other words, the ideas shared by the participants have been shared by other subjects and no new ideas emerge (Lo-Biondo-Wood & Haber, 2010; May & Holmes, 2012).

Soon after the interview was over, the researcher and the participants listened to the tape-recorded interview to check for audibility and completeness (Botma et al., 2010). Verbatim transcription of each interview was done as soon as possible to maintain rich descriptions and therefore promote the study's credibility.

### **2.7.2. Field notes**

Field notes are a written account of the things the researcher hears, sees, feels, experiences and thinks about in the course of the interview (Botma et al., 2010; De Vos et al., 2011). Holloway and Wheeler (2010) describe field notes as a record of observation in the field that reflects the participants' words as accurately as possible. The notes help the researcher remember and explore the process of the interview, and thereby ensure that rich data does not go unrecorded. The notes can be taken by hand or recorded with a tape recorder. Observations are translated into written records that researchers take while observing or immediately afterwards. When

writing field notes, researchers should collect a series of direct quotes representing the participants' thoughts and the phenomena under study. This should be done as soon as possible after the interview while the memory is fresh and the details are not lost in order to capture the behaviour and words of the participants, therefore enabling the researcher to reflect on and engage with the data (Holloway & Wheeler, 2010).

If an interview is taped, it is recommended that researchers take notes in the event that the recording equipment fails (Creswell, 2014). Audio recording is acceptable to many people, but their permission to be recorded must be obtained (Matthews & Ross, 2010). Mouton (2013) stressed that as a form of keeping quality assurance in qualitative research, the researcher should keep track of his or her fieldwork as a form of quality control. Therefore, by keeping a record of what transpired during the fieldwork process, the researcher constructs an historical record of the whole process to which he or she can refer later if necessary.

In this study, field notes were taken by the researcher during and immediately after the in-depth interviews with the participants while the memory was still fresh. No interview was conducted without consent from the participants.

## **2.8. DATA ANALYSIS**

Data analysis in a qualitative study proceeds hand-in-hand with data collection. It consists of preparing and organising data such as text data in transcripts for analysis, then reducing the data into themes through a process of coding and condensing the codes, and finally representing the data in a discussion (Creswell, 2014). In this

study, the researcher used qualitative techniques that are used to analyse words rather than numbers (Ulin, Robinson, Tolley & McNell, 2002), namely through reading, coding, displaying, reducing and interpreting. The technique was applied as follows:

- *Reading:* This is the first step that provides the general sense of the information and an opportunity to reflect on its overall meaning (Creswell, 2014). During this step, the researcher reads and re-read the text and wrote notes in the margins of the field notes. This enabled the researcher to come up with the study's themes and sub-themes (Amukugo, 2009).
- *Coding:* While reading, the researcher started attaching codes to the chunks of the text representing the already-identified themes and sub-themes.
- *Displaying:* The researcher started exploring the themes and sub-themes after the coding was complete.
- *Reducing:* After exploring the themes and sub-themes in detail, the data was reduced to essential points.
- *Interpretation:* This means making sense out of the data (Creswell, 2014). At this point, the researcher came up with the overall and final interpretation of the study's findings (Amukugo, 2009).

The data analysis was done in line with Tesch's eight steps in the coding process (Creswell, 2014). These steps entail a process of breaking down, examining, comparing and categorising the raw data. The researcher opted for these steps

because of its systematic approach and clear descriptions. The eight steps are as follows:

Table 2.1: Tesch's steps of data analysis and its application to the study

Tesch's steps of data analysis	Application to the study
1. Make sense of the whole. Read all of the transcriptions carefully and jot down some ideas as they come to mind. This step necessitates careful and repeated reading of the transcripts obtained to identify significant words and phrases.	The researcher read the entire transcript several times and immersed himself in the details to try to get a sense of the interview as a whole by breaking it into parts. By looking over the field notes from the interview transcript, the researcher disregarded predetermined answers and saw what the respondents have to say.
2. Pick one of the shortest and most interesting interviews, go through it and find the underlying meaning.	The main activity for the researcher was to search for relevant parts of the data and analyse them by comparing them with other data and classifying them.
3. Arrange those topics into columns of major topics, unique topics and leftovers.	The researcher wrote notes in the margins of the transcripts in order to explore the database. This task was completed with several participants, and similar topics were clustered together in a column as themes and sub-themes.
4. Assign each topic a code and write the codes next to the appropriate segment of the text to see whether new categories and codes emerge.	After arranging topics into columns in this study, the researcher went back to the data by abbreviating the topics as codes and wrote codes next to the appropriate segments of the text. In the coding, the emphasis was on trustworthiness and credibility. Similar items were given the same code.
5. Find the most descriptive wording for your topics and turn them into categories. Seek ways of reducing your total list of categories by grouping topics that relate to each other.	The researcher used the coding process to generate descriptions. All topics that were grouped together were checked for coherence. Therefore, coding generated a number of themes that appeared as major findings of this study that have been used as headings in the findings section.
6. Make a final decision on the abbreviation of each category and alphabetise these codes. To arrive at the final set of categories and codes, the researcher must go through the materials many times.	A final column with themes and sub-themes was created.



Tesch's steps of data analysis	Application to the study
7. Group the data belonging to each category in one place and perform a preliminary analysis. Data reduction is a form of analysis that sharpens, sorts, focuses, discards and organises data in such a way that final conclusions can be drawn and verified.	The act of giving the same codes to the descriptions was in essence a way to reduce the data.
8. Recode your data, if necessary.	Data were re-coded after an initial coding.
Source: Creswell (2014); Flick (2008); May & Holmes (2012); Schreier (2013); Silverman (2011)	

The process of data analysis involves making sense of the text. In qualitative research, data analysis is almost always conducted concurrently with gathering data, and through the process of data analysis, the researcher makes sense of the text (Botma et al., 2010). Therefore, the researcher attempted to simultaneously gather, manage and interpret a growing bulk of data.

Once the researcher had all of the data, it was reconstructed into a manageable format that makes reporting possible, which could include a description of the development of themes, interpreted with the existing literature in mind, and the integration of concepts. In support of this method, Brink et al. (2013) pointed out that qualitative analysis involves the integration and synthesis of narrative non-numeric data that is reduced to themes and categories with the aid of a coding procedure.

According to Polit and Beck (2012) the analysis of qualitative material typically begins with a search for broad categories or themes. A theme refers to an abstract entity that brings meaning and identity to a current experience and its variant



manifestations, and it captures and unifies the nature or basis of the experience into a meaningful whole.

The researcher analysed the data as a whole and identified the main statements as the core experience of men diagnosed with prostate cancer in Namibia's four northern regions. In other words, the units of text in this study's transcription were reduced to a series of core sentences or ideas. Themes and sub-themes were identified as indicated in chapter three (3) of this study. The themes refer to major findings and usually link a group of categories that have identifiable interrelationships into conjectures. They display multiple perspectives from individuals and are supported by diverse quotations (Botma et al., 2010). In this study, various quotations from participants in support of themes are reflected in chapter three. Study supervisors assisted by verifying the study's accuracy of the data analysis.

## **2.9. ETHICAL CONSIDERATIONS**

Research ethics are central to all research involving human participants (May & Holmes, 2012). Leary (2012) outlined six issues dominating the discussion of ethics in research that involves human participants: lack of adequate human consent, invasion of privacy, coercion to participate, potential physical or mental harm, deception and violation of confidentiality. Because there are some risks involved in every study, especially where human subjects are involved, the researcher considered the following ethical measures in this study:

Approval to conduct the study was sought from the School of Post Graduate studies at the University of Namibia, the Ministry of Health and Social Services (MoHSS),

and the Regional Health Directors of Namibia's Ohangwena, Oshana, Oshikoto and Omusati regions.

The participants were informed about the study in a comprehensive way (Latimer, 2003). The researcher allocated ample time to explain to participants individually what the study was about and what was required from them in terms of participation in order to obtain verbal informed consent. The tape recorder was used to collect data from the subjects, so their permission to be recorded was requested by the researcher. The participants were also informed that the tape recordings would be kept in a lockable cabinet for a period of five years after the study's completion. No language barrier was experienced by the researcher; therefore no translator was used during this study. Three fundamental ethical principles guided the researcher in the study as described in the following sections.

#### **2.9.1. Respect for persons**

The principle of respect for persons indicated that people should be treated as autonomous agents with the right to self-determination and the freedom to participate or not participate in the research (Burns & Grove, 2011). On the other hand, the right to self-determination is based on the ethical principle of respect for persons and indicates that humans are capable of controlling their own destiny. In this study, the principle of self-determination was adhered to because the researcher treated the subjects as autonomous agents.

A basic rule of research is that the participants cannot be forced, coerced or unduly induced to participate. In other words, participants must voluntarily agree to

participate (MacLean & Wilson, 2011; Leedy & Ormrod, 2010). In this study, voluntary participation was ensured by explaining to the subjects that they were free to withdraw without the risk of penalty or prejudicial treatment. This ensured the subjects that they could withdraw at anytime without being required to offer an explanation.

In this study, the subjects had full freedom to decide whether they wanted to participate in the study without external controls, observing their right to protection and freedom of choice (Locke, Spirduso & Silverman, 2007; LoBiondo-Wood & Haber, 2010). Therefore, the researcher refrained from any form of coercion, covert data collection or deception (Burns & Grove, 2011). Voluntary participation was therefore ensured.

### **2.9.2. Beneficence**

With regard to the principle of beneficence, people must take an active role in promoting good and preventing harm in the world around them, as well as in research studies (LoBiondo-Wood & Haber, 2010). Beneficence implies that a decision results in the greatest good or produces the least harm to the client (Arnold & Boggs, 2007). In this study, the researcher at all times protected the participants from discomfort and harm by ensuring that the benefits of the study outweighed the risks (Brink, 2010). Therefore, in this study the researcher did not conduct any medical or other physical experiments on participants (Matthews & Ross, 2010).

### **2.9.3. Anonymity and confidentiality**

Burns and Gove (2009) refer to confidentiality as the management of private data in the research in order for the subjects' identities not to be linked to their responses. Furthermore, anonymity implies that subjects' identities cannot be linked even by the researcher with his or her individual response. In this study, the subjects were all assured of anonymity regarding presentations, reports, and publications. May and Holmes (2012) stated that in qualitative research, anonymity is preserved by coding the data in a way that participants cannot be identified in any presentation of the findings. The subjects' worth and dignity was protected at all times during the study. Instruments and methods to be used during the interviews were disclosed to the subjects. Their responses were anonymous, and the information was treated with high confidentiality. Participants could not be identified, as their names were not mentioned during the interview. All information concerning the study was kept in a place only accessible by the researcher, and this enabled unauthorised people not to have contact with the study's information.

An invasion of privacy occurs when private information is shared without a person's knowledge or against his or her will (Burns & Grove, 2011). In this study, the principle of privacy was observed because information obtained from the subjects was never shared with unauthorised individuals except for the study's supervisors. Neither alteration, addition nor any form of forging data took place after the data collection. No personal identification data was collected throughout the study.

With regard to tape recording, participants were all made aware that the voice recordings will only be made available to the researcher and the study supervisors,

meaning no one had access to the tape recorder throughout the study except the researcher and the study supervisors.

#### **2.9.4. Fair treatment/justice**

The fundamental ethical principal in fair treatment is based on the ethical principle of justice, which implies being fair and impartial (Arnold & Boggs, 2007; Burns & Grove, 2011). This principle was ensured in the study because the study subjects were all selected for reasons directly related to the research, and not because they were readily available or could be easily manipulated (Brink, 2010). All subjects who met the eligibility criteria were interviewed. On the other hand, all research subjects were asked similar questions in order to ensure the principle of justice.

Other important principles that the researcher used throughout the study included honesty and integrity in conducting the research, sharing and utilising data responsibly, truthful reporting of results and assigning authorship in scientific publications describing the research (Brink, 2010).

#### **2.10. MEASURES FOR ENSURING TRUSTWORTHINESS OF THE DATA**

Trustworthiness is the degree of confidence that qualitative researchers have in their data, assessed using the criteria of credibility, transferability, dependability, confirmability and authenticity (Polit & Beck, 2012). Trustworthiness in qualitative research means methodological soundness and adequacy (Holloway & Wheeler, 2010). According to Holloway and Wheeler (2010) the qualitative research should be evaluated by criteria that have been specially developed for it. In this study, four

criteria for establishing the trustworthiness of qualitative data were used: credibility, dependability, confirmability and transferability (Polit & Beck, 2012). There are also a number of ways in which qualitative researchers can check and demonstrate to the reader whether the research is trustworthy: member checking, peer debriefing, triangulation, audit trail, thick description and reflexivity (Holloway & Wheeler, 2010). In this study, the application of different criteria is tabulated after the discussions to follow.

#### **2.10.1. Credibility**

Credibility was maintained during the study. Credibility refers to the confidence in the accuracy of the data and the relevant interpretations (Polit & Beck, 2012). It also refers to steps in qualitative research to ensure accuracy, validity, or soundness of data (LoBiondo-Wood & Haber, 2010). Creswell (2013) pointed out validation strategies that are frequently used by qualitative researchers: prolonged engagement and persistent observation, peer review or debriefing, member checking and external audits (Cohen, Manion & Morrison, (2007). On the other hand, May and Holmes (2012) added some other techniques for enhancing credibility in qualitative research: saturation, member checks, audit trail and peer debriefing.

Prolonged engagement and persistent observations in the field include building trust with participants, learning the culture, and checking for misinformation that stems from distortions introduced by the researcher or informants (Creswell, 2013). Credibility is enhanced when the researcher spends long periods of time with the participants in order to understand them better and gain insight into their lives (Du Plooy-Cilliers et al., 2014). Morgan (2014) stated that the common benefit from

preliminary qualitative work is the researcher's ability to build relationships with people who will respond to his or her research questions. This does not only help the researcher learn more about the people but it also gives him or her chance to get to know the research participants.

Creswell (2014) pointed out that spending prolonged periods of time in the field enables the researcher to develop an in-depth understanding of the phenomenon under study, and can convey detail about the people that leads to greater credibility for a narrative account. Therefore, the more experience a researcher has with participants in the setting, the more accurate or valid the findings. Prolonged engagement is the precondition for building trust and rapport with participants, implying that the researcher stays in the field until data saturation occurs (Jooste, 2013).

Peer review or debriefing provides an external check of the research process. The role of the peer debriefer is to keep the researcher honest and to ask hard questions about methods, meanings, and interpretations. Member check is the most critical technique for establishing credibility (Creswell, 2013). It involves asking participants in the study to check whether they agree with the researcher's interpretations of the findings (May & Holmes, 2012).

External audits allow an external consultant or auditor to examine both the process and the product of the account by assessing its accuracy. In addition, an external auditor can provide an objective assessment of the project throughout the process of research or at the study's conclusion (Creswell, 2014). In order to maintain the

study's credibility, this study's report contains information about the researcher, including his credentials (Polit & Beck, 2012). The researcher is a registered nurse by profession and a clinical instructor at Oshakati Regional Health Training Center in the Ministry of Health and Social Services. He has thirteen years of nursing experience. Table 2.1 depicts how the credibility criteria were applied in the study.

Table 2.2: Criteria of credibility

Credibility	Method of application
Prolonged engagement	<p>The researcher is the clinical instructor, who most of the time has contact with prostate cancer patients admitted to the Intermediate Hospital where the interviews took place. This enabled him to gain trust from such patients by establishing rapport with them. Close rapport with participants provided access to richer information.</p> <p>The researcher spent three months (January 2014-March 2014) personally interviewing participants diagnosed with prostate cancer. The data was collected until saturated.</p>
Member checking	The researcher solicited participants' views on the credibility of the findings and interpretations by replaying the tape.
External audits	The research findings in this study were audited by an external auditor in South Africa who examined whether or not the findings, interpretations, and conclusions are supported by the data.
Peer review or debriefing	The credibility of this study was ensured through peer review (colleague and a doctoral graduate student) who went through the data collected.

### 2.10.2. Transferability

Transferability refers to the extent to which qualitative findings can be transferred to other settings, as an aspect of a study's trustworthiness (Polit & Beck, 2012; Du Plooy-Cilliers et al., 2014). One mechanism for promoting transferability is the amount of information qualitative researchers provide about study contexts. LoBiondo-Wood and Haber (2010) pointed out that, with regard to transferability, there should be enough details for one to evaluate the data's relevance and importance.



In qualitative research, it is often not possible to work with a large and representative sample, thus the focus is on the quality of information obtained from the participants rather than the size of the sample. The depth and the richness of the information provided allows for inductive generalisations from the sample to the target population. Therefore, transferability refers to the data's generalisability (Jooste, 2013).

Creswell (2014) stated that a rich, thick description allows readers to make decisions regarding transferability because the reader describes in detail the participants in the study. With such a detailed description, the researcher enables readers to transfer information to other settings and determine whether the findings can be transferred because of the shared characteristics.

It is important for the researcher to ensure transferability by providing sufficient (thick) descriptive data in the research report for readers to evaluate the applicability of the data to other contexts. A thick description means that the researcher provides detail when describing a case or when writing about a theme (Creswell, 2014). Therefore, a thick description is necessary to enable someone interested in making a transfer to reach a conclusion about whether that transfer can be contemplated as a possibility (Polit & Beck, 2012). Table 2.2 below depicts the application of transferability in this study.

Table 2.3: Criteria of transferability

Transferability	Method of application
Dense description	The researcher ensured transferability by providing sufficient (thick) descriptive data in the research report for consumers to evaluate the applicability of the data to other contexts.
Purposive sampling	A purposive sampling method was employed in order to deliberately select the participants who will be able to give rich information about their experiences of living with prostate cancer.

### 2.10.3. Confirmability

Confirmability refers to objectivity; that is, the potential for congruence between two or more independent people about the data's accuracy, relevance or meaning (Polit & Beck, 2012). It guarantees that the findings, conclusions and recommendations are supported by the data and that there is internal agreement between the investigator's interpretation and the actual evidence (Brink, 2010). Others who look at the data must derive a similar conclusion as the researcher (Du Plooy-Cilliers et al., 2014). For this criterion (confirmability) to be achieved, findings must be transcribed verbatim without the researcher's biases, motivations, or perspectives (Polit & Beck, 2012). The application of confirmability in this study is reflected in table 2.3.

Table 2.4: Criteria of confirmability

Confirmability	Method of application
Confirmability audit	<p>The researcher attended the thesis workshop at the University of Namibia at the beginning of the course, which equipped him with the necessary knowledge to pursue a study.</p> <p>A literature review was conducted during the study.</p> <p>An independent expert researcher in South Africa did the trail audit of the study data for relevance in order to ensure the study's confirmability (Polit &amp; Beck, 2012).</p>

#### 2.10.4. Dependability

With regard to dependability, the research methodology used in this study as well as the questions contained in the interview guide were first checked by the study supervisors for relevance before the actual data collection started. Dependability refers to the stability (reliability) of data over time and the conditions (Polit & Beck, 2012; Weiten, 2014).

Both dependability and confirmability are established through an auditing of the research process (Creswell, 2014). Brink (2010) stated that dependability requires an audit whereby the enquiry auditor follows the process and procedures used by the researcher in the study and determines whether they are acceptable. Table 2.4 reflects the application of dependability in the study. Furthermore, triangulation is a criterion of dependability achieved by means of using more than one method of data collection (Holloway & Wheeler, 2010). In this study, triangulation was applied as discussed under table 2.4.

Table 2.5: Criteria of dependability

Dependability	Method of application
Dependability audit	<p>Research methodology and questions contained in the interview guide were checked by the study supervisors for relevance before the actual data collection.</p> <p>The researcher was guided by the study supervisors to ensure compliance with the institution's protocols.</p> <p>The study's methodology was described in detail.</p> <p>A literature review was conducted during the study.</p>
Triangulation	<p>Individual interviews, field notes and a voice recorder were used as methods of data collection. The researcher compared the notes with the recordings.</p> <p>Qualitative, explorative and descriptive designs were used.</p>
Peer examination	Research experts were involved to give opinions on the study.



<b>Dependability</b>	<b>Method of application</b>
Dense description	Sample and sampling procedures, data collection and analysis were described in the study. Complete comprehensive transcriptions of the interviews were created.
Coding	The researcher analysed the data after which themes and sub-themes for the study were identified. An external auditor followed the process and procedures used by the researcher in the study to determine whether they are acceptable.

#### **2.10.5. Authenticity**

Authenticity refers to the extent to which the researcher fairly and faithfully shows a range of different realities (Botma et al., 2010; Polit & Beck, 2012; Holloway & Wheeler, 2010). Authenticity emerges in a report when it conveys the tone of the participants' lives as they lived it. A text has authenticity if it invites readers into a vicarious experience of the lives described and enables readers to develop a heightened sensitivity to the issues depicted. When a text achieves authenticity, readers are better able to understand the lives being portrayed, with some sense of the mood, feeling, experience, language, and context of those lives (Polit & Beck, 2012). Table 2.6 outlines the study's application of authenticity.

Table 2.6: Criteria for authenticity

<b>Authenticity</b>	<b>Method of application</b>
Authenticity	Participants' expressions and feelings regarding their experiences with prostate cancer are reflected in chapter 3 of this study. The researcher used direct quotations in the study reflecting the lived experiences as expressed by participants during the study.  The researcher tape-recorded the interviews to capture the participants' experiences during the interview. Field notes were also used for verification via transcription.

## **2.11. SUMMARY**

This chapter outlined the qualitative, phenomenological, explorative and descriptive design used in the study. It identified the study population, the sampling method, the research instrument, and the procedure followed during data collection. Steps of data analysis were explained and measures to ensure trustworthiness and its applicability to the study were described. In the following chapter, the researcher will discuss the identified themes and sub-themes he arrived at during data analysis with applied literature control.

## **CHAPTER 3**

### **DATA ANALYSIS AND DISCUSSION OF FINDINGS**

#### **3.1. INTRODUCTION**

The previous chapter discussed research design, data collection, method of analysis and ethical considerations. This chapter will concentrate on the analysis of the data and the discussion of the results that emerged from the data analysis using a narrative writing style. The segments that contain similar central meanings for each participant were grouped together during data analysis as supported by LoBiondo-Wood and Haber (2010), and literature control was incorporated. The purpose of literature control is to expand the researcher's understanding of the phenomenon from multiple perspectives, and this may include an examination of sources in which the phenomenon is described (Polit & Beck, 2012). In reviewing the literature, phenomenological researchers look for experiential descriptions of the phenomenon. In this study, a more thorough literature review was done during data analysis and interpretation, and this study's findings were compared with findings from previous studies (Polit & Beck, 2012).

This study's objective was to explore and describe the experience of men diagnosed with prostate cancer in Namibia's four northern regions namely; Omusati, Oshana, Oshikoto and Ohangwena, and thereby enabled the researcher to have a broader understanding of the experiences of men living with prostate cancer. Participants were selected by means of a purposive sampling and non-probability sampling techniques based on inclusion criteria that have been set. One central question was posed to each participant:

**“What is your experience with prostate cancer after being diagnosed with it?”**

Communication skills were employed by the researcher to establish rapport and encourage participants to verbalise their experiences with prostate cancer.

Data collection was conducted by means of face-to-face, in-depth interviews in which 10 participants were interviewed during a period of three months (January 2014-March 2014). The researcher began the data collection by interviewing the hospitalised prostate cancer patients in the male surgical ward of the northern Intermediate Hospital, and later the prostate cancer patients who came for their treatment follow-up at the Urology Outpatients Department (UOPD) of the same hospital. An interview guide was used to assist the researcher during the interview, listing probing questions. The responses from the participants were documented verbatim.

With the consent of the participants, the researcher also made use of the voice recorder to record the data. Matthews and Ross (2010) pointed out that if the researcher wants to work with full verbatim data recorded in the interview, each interview's data should be transcribed into written form. In this study, all of the recorded data for each interview was transcribed verbatim in order to capture all of the responses during the interviews. Data collection ceased when the researcher reached data saturation regarding the experiences of men diagnosed with prostate cancer in Namibia's four northern regions (Brink et al., 2013; Van Rensburg, 2013).

Qualitative data analysis occurs concurrently with data collection. Therefore, the researcher attempted simultaneously to gather data, manage a growing bulk of collected data, and interpret the data's meaning. Data collection occurs concurrently with data analysis, so the process is complex (Burns & Grove, 2009). Thus, careful skills in analytic reasoning are needed.

In this study, the researcher has used content analysis whereby the data analysis was recorded manually. Content analysis is a set of methods for systematically coding and analysing qualitative data (Bernard & Ryan, 2010). Content analysis is designed to classify the words in a text into a few categories chosen because of their theoretical importance (Burns & Grove, 2009). This involved reading and rereading notes and transcripts, recalling observations and experiences, and listening to the recordings until the researcher becomes immersed in the data (this is also known as the hands-on process). In this study, the researcher spent hours reflecting on the possible meanings and relationships of the data (Brink et al., 2013).

The data was transcribed into themes and sub-themes that were established after data analysis (Burns & Grove, 2009). Qualitative data is non-numerical, and is therefore presented in the form of written words and audiotapes. The names of the participants were thus not revealed. A coding system was used whereby each and every study participant was given a code. The process of coding involves aggregating the text data into small categories of information, seeking evidence for the code from different databases being used in a study, and then assigning a label to the code whereby words and phrases are classified (Creswell, 2014).



### **3.2. DESCRIPTION OF RESEARCH FINDINGS**

The results described in this chapter are based on transcriptions of the interviews (Burns & Grove, 2011), giving the researcher authentic insight into the participant's experiences. In qualitative data analysis, there is a search for themes that are the dominant features or characteristics of a phenomenon under study (Tashakkori & Teddlie, 2009). One of the researcher's most fundamental tasks after data analysis was the identification of the themes for this study. Themes allowed the researcher to present large quantities of data in a condensed format (LoBiondo-Wood & Haber, 2010).

A theme can also be defined as a set of ideals that permeate written work to prove a point or highlight a common issue (Rodriguez, 2014). In this study, themes are derived from codes that are linked to data from participants. The researcher took the responsibility to illustrate the richness of the data by conveying to the readers the relationship between the themes identified and the quotes shared, reflecting the phenomenon as experienced. This is essential to ensure the study's trustworthiness (Polit & Beck, 2012).

A sub-theme is just like any other theme with only one difference: it inherits the parent theme's resources (Govida, 2014). Therefore, a sub-theme can be a child of another sub-theme, and it can be branched and organised by the researcher the way that he or she deems fit. In this study, six themes were identified. Table 3.1 (below) forms the basis for discussing the themes and sub-themes of the lived experience of men diagnosed with prostate cancer revealed through data analysis. Each theme will

be discussed, verified with the necessary direct quotations from the interviews, and supported by relevant and appropriate literature.

Table 3.1: Study themes and sub-themes

Themes	Sub-themes
3.3.1 Theme 1: Participants expressed different experiences with regard to family and community.	3.3.1.1 Families render unwavering physical and psychological support. 3.3.1.2 Some feelings of rejection in terms of family and community were expressed. 3.3.1.3 Wives fear contraction of disease.
3.3.2 Theme 2: Participants experience inconsistent care from nurses.	3.3.2.1 Lack of nursing care for physical needs of patients. 3.3.2.2 Lack of psychological support from nurses.
3.3.3 Theme 3: Different experiences regarding lack of knowledge as well as misconceptions were expressed.	3.3.3.1 Participants verbalise their lack of knowledge on prostate cancer. 3.3.3.2 Misconceptions exist about prostate cancer that were verbalised by participants.
3.3.4 Theme 4: Participants experience physical discomfort and physiological changes in the body.	3.3.4.1 Participants experience severe pain and discomfort. 3.3.4.2 Concerns about changed sexual feelings and sexual dysfunction.

This chapter outlines the discussions of the themes and sub-themes in detail regarding the experiences of men diagnosed with prostate cancer in Namibia's four northern regions: Omusati, Oshana, Oshikoto and Ohangwena.

### **3.3. DISCUSSION OF THEMES**

#### **3.3.1. Theme 1: Participants expressed different experiences with regard to family and community.**

This theme describes the essence of how the study's participants viewed their relationship with their family and community members after being diagnosed with prostate cancer. Participants gained strength and confidence through the support of

others. Most participants expressed that they would not have been able to be successful in spite of their illness without the support of family members. This agrees with Weiten (2007) who stated that adherence is improved when patients have family members or friends who help them comply with treatment requirements.

A study conducted by Krumwiede and Krumwiede (2012) on the lived experiences of men diagnosed with prostate cancer revealed that men gained strength and confidence through the support of others. Support and encouragement from family members brings comfort to men diagnosed with prostate cancer. Most participants acknowledged that it would have been very difficult to deal with their illness without family support.

The above sentiments agree with the results of a study by Halbert, Wrenn, Weathers, Delmoor, Have and Coyne (2011) on the sociocultural determinants of men's reactions to a prostate cancer diagnosis; they revealed that men who have greater constraints in their relationships with family members and friends were most likely to avoid thoughts and feelings concerning prostate cancer. Spouses are an important source of support for men diagnosed with prostate cancer, and they may play an important role during diagnosis by asking questions during consultations and obtaining other medical information. The study results underscore the importance of having family and friends who allow men to express their concerns freely.

Meanwhile, the study conducted by Gray, Fitch, Phillips, Labrecque and Fergus (2000) about the experiences of men with prostate cancer and their spouses revealed that social support is one of the factors that appears to be relevant in how prostate

cancer patients and their spouses come to deal with the illness. Most of the couples in the study were explicit about confronting the challenges of illness together as a team. On the other hand, most men in the study looked primarily to their spouse for support; others expressed their gratitude for assistance in the practical matters like catheter management and dealing with incontinence. The study concluded that both patients and spouses cited social support as the primary factor facilitating coping.

In this study, it was found that most men received immense support from their family members after being diagnosed with prostate cancer. The following sub-themes were identified after the participants were asked to describe the assistance that they received from their family members after being diagnosed with prostate cancer.

#### *3.3.1.1. Sub-theme 1: Families render unwavering physical and psychological support.*

Support refers to helping people and being kind to them when they are having a difficult time. Furthermore, the term “unwavering” refers to strong and steady support despite opposition or other problems. Support is the perceived comfort, caring, esteem, or help a person receives from other people or groups (Sarafino, 2008); it is one of the many factors that appear to be relevant in how prostate cancer patients and their spouses come to deal with the illness (Gray et al., 2000). Support can come from the person’s spouse, lover, family, friends, physicians or community organisations. People with support believe they are loved, valued, and part of a social network including family and community organisations that can help in times of need or danger.

The support that should be given to men diagnosed with prostate cancer by their family members included supporting the treatment decision made by men, accompanying them to the hospital for treatment follow-up, assisting with transporting money, encouraging them to adhere to their treatment as prescribed, and reminding them about the next treatment follow-up date (Krumwiede & Krumwiede, 2012). The results from this study revealed that most participants experienced effective social support from their family members after being diagnosed with prostate cancer. However, it was also found that nurses do not provide support to men diagnosed with prostate cancer. With regard to effective social support, this is what one of the participants had to say:

*“My wife supported me and informed me that I should never miss my follow-ups. They have accepted my disease and told me to accept it, too. That is all. My wife was even the one who wakes me up today [sic] to come to the hospital.” [P9]*

When participants were asked to describe their experiences about the support they received from their family members after being diagnosed with prostate cancer, their responses indicated immense support. The findings correspond to a study conducted by Krumwiede and Krumwiede (2012) regarding the experiences of men diagnosed with prostate cancer, which reveals that most participants expressed immense support from their family members after being diagnosed with the ailment, giving them a sense of relief and comfort as patients, and enabling them to make appropriate decisions about their treatment. All men indicated that support from their

family was important because it allowed them to deal with the difficult circumstances of prostate cancer. Most participants acknowledged that it could be very difficult to go through the diagnosis of prostate cancer on their own. Participants concluded that family is probably the most major support entity that one needs during a time of illness. The findings by Krumwiede and Krumwiede (2012) support this study's findings because participants expressed that family members usually took them to the hospital when they could not walk on their own. In this study, the same response was garnered by a participant:

*“Family members help me well such [sic] as taking me to the hospital when I could not able [sic] to walk. I really thank them because they understand my disease.” [P8]*

Participants stated that their spouses and children accepted the disease after it was disclosed to them. This is supported by the results of a recent study conducted by Halbert et al. (2011) that found that spouses are an important source of support for men who are diagnosed with prostate cancer. Some participants stated that their wives and married children are their supporters, especially those with houses closer to their parents' home. This is what one of the participants had to say when asked to describe the support he received from his family members after being diagnosed with prostate cancer:

*“Ok, you are correct ... [adjusting himself well on the chair] I am having a wife and children and I have told them that the doctor diagnosed me of [sic] prostate cancer.” [P9]*

In agreement with the above, Mogotlane, Mokoena and Chauke (2015) pointed out that family members should assist men diagnosed with prostate cancer with care, compliance with treatment and emotional support. A study by Gray et al., (2000) on the experiences of men with prostate cancer and their spouses revealed that most men told their family members about their diagnosis because they have the right to know; most men in the study looked primarily to their spouse for support. Men who have strong relationships with their family members and friends are most likely to avoid their thoughts and feelings about prostate cancer (Halbert et al., 2011). A study conducted by King, Evans and Moore (2015) examined men's experiences of supportive care for prostate cancer; the researchers cited one-to-one peer support from family and friends as highly valued by men diagnosed with prostate cancer. Peer support reduced men's sense of isolation and enabled sharing and exchange of experience, information, and tips.

Torrey (2006) pointed out that for a man who is married or living with a partner in a long-term relationship, the other person will be affected by the prostate cancer almost as much as the cancer patient. It is therefore imperative to include the partner from the beginning of the discussions about cancer. Men who initially hide the news from their partner invariably find that they have made a mistake. Wives and partners can be extremely supportive and helpful in such situations. As another participant responded:

*“The support from the family is very good because the children and my wife have all accepted the disease. For now, I am not that seriously sick, therefore I am just doing my work as usual. With regards to the family*

*members' behaviours, they are still behaving well as usual. The support at home is really going on very well."* [P7]

The comments from the above participants were in accordance with the writings of Tadman and Roberts (2007): "family members as carers have a significant role in providing physical and emotional care during the cancer journey" (p. 100). The experience of cancer is shared by the family in a number of ways, as stated by the following participant:

*"My wife use [sic] to bring me to the hospital all along until last month when I became better. At least I am better now. Previously, I could not walk at all."* [P4]

*"Oh, yes. They really use [sic] to help me for example by taking me to the toilet, etc. Especially, my wife use [sic] to help me a lot."* [P4]

The carer is often the patient's partner, but may also be a relative or a friend or neighbour (Tadman & Roberts, 2007). The following verbal expressions are indicative:

*"The family feeds me well. Most of the times [sic] they bring me to the hospital and take me back home. They also assist me with some money to buy things, for example N\$200.00 or even N\$300.00. Most of the time they visit me in the hospital. My wife supported me all along since I was diagnosed, but she is now getting tired because she ever supporting [sic] me."* [P1]



Another participant who expressed his satisfaction with the support he received from family after being diagnosed with prostate cancer had this to say:

*“They never rejected me at all, but did a lot of good things towards [sic] me. You know that patients can be difficult people. Sometimes, they may think that they are not being taken care of, such as proper feeding, etc. But, with regards to my family, they never mistreat me but help me well.” [P8]*

In support of these statements, Tadman and Roberts (2007) pointed out that social support is composed of the following elements: emotional support, informational support, instrumental support and social work support. Emotional support involves the expression of the positive feeling that one is cared for, loved, or esteemed. Mostly, patients get this type of support from their families and friends.

Frank (2009) advised that if a cancer patient must rely on a small group of close friends or family members, at least one should be available to accompany that patient to treatment. The following quotation is evident:

*“I am having my child [pointing at his daughter who was sitting in a waiting area] who always brings me to the hospital if I am sick. She is the only one who uses [sic] to bring me to the hospital, because I am only staying with the boys in the house and she is having her own house nearby that of ours.” [P2]*

Another participant responded:

*“The children also accepted the disease. I have told you that it was my son who took me to a doctor in Windhoek.” [5]*

Being newly diagnosed with cancer is one of the most difficult circumstances in which a patient and his or her loved ones can find themselves. The emotional or psychological issues generated by cancer are numerous. When initially diagnosed with cancer, one must deal with fear and in some cases shock and disbelief (Frank, 2009). Distress and anxiety is universal; feelings of isolation and depression are common. The solution involves people. Family, friends, and loved ones sustain cancer patients. Furthermore, many cancer patients and their loved ones can benefit from individual or family counselling.

Frank (2009) stressed that the more united the loved ones are behind a patient, the stronger that patient will be throughout his or her ordeal with cancer. A cancer patient needs the sturdy support of good friends and loved ones to cope with cancer. It is therefore important for one to surround him or herself with people who truly care and know how to communicate.

This study's findings reflect research study conducted by Krumwiede and Krumwiede (2012); they found that most of the men diagnosed with prostate cancer expressed gratitude for the support they received from their family members and friends. Their study also revealed that all of the married men indicated that the most significant emotional and physical support was received from their spouse.

According to the participants that support provided a sense of comfort and reassurance in their time of uncertainty. According to Krumwiede and Krumwiede (2012), men diagnosed with prostate cancer expressed a feeling of comfort through the development of trusted connections and the unwavering support they received throughout their experience with prostate cancer. Most men diagnosed with prostate cancer gained strength and confidence through the support of family members. Therefore, most men did not feel that they would have been able to make it through the experience without that support.

#### *3.3.1.2. Sub-theme 2: Some feelings of rejection by the family and community*

Rejection refers to a refusal to show someone the love or kindness that they need or expect. An experience of rejection by a loved one has the power to compromise the quality of a person's life, and results in a feeling of being abandoned or unloved (Van Vuuren, 2013). Cancer patients are usually feared in their community, as people believe that they may transmit the disease to them. That misconception of cancer as a disease for homosexuals has resulted in the rejection of men diagnosed with prostate cancer in their communities. Other contributing factors to rejection include lack of knowledge about prostate cancer, stereotyping and fear of the unknown.

In this study, one of the experiences expressed by men diagnosed with prostate cancer was rejection by family and community members. Some participants said that following their diagnosis of prostate cancer, some family and members of the community developed a fear of being infected with the disease and opted to keep their distance. The following quotations are evident:

*“When people hear that you are having cancer they will be far from you and they will not come closer to you. People are saying it is a disease for gay people, therefore they should have fear because of that ... [laughing].”*  
[P6]

*“They do not want to come into contact with you because they think you will spread the disease among them.”* [P8]

When one participant was asked to describe how the community perceives men diagnosed with prostate cancer, this is what he had to say:

*“I have seen one man who was recently rejected by his own family after being diagnosed with prostate cancer. They are not even visiting him, but because I am a counsellor I went to his house and encourage him [sic] that I am also having cancer therefore he should not lose hope in life.”* [P7]

A participant (a man diagnosed with prostate cancer) who witnessed the rejection of men diagnosed with prostate cancer had this to say:

*“Some people stay away from him and do not want to associate with him because they regard him as a dangerous person who can kill people. They regard that person as a person with a dangerous disease, therefore should [sic] not be in contact with other people.”* [P8]

The participants' experiences are in agreement with Sarafino and Smith (2012), who pointed out that many cancer patients experience psychological problems that stem

from changes in their relationships with family members and friends. People may begin to avoid the patient, for instance because they may feel personally vulnerable in his presence.

#### *3.3.1.3. Sub-theme 3: Wives fear disease contraction*

Fear is something bad or unpleasant that you are afraid might happen. It is a response to a perceived threat that is consciously recognised as a danger. Walsh and Crumbie (2007) define fear as an unpleasant feeling caused by a threat in the environment. The defining characteristics of fear include a report of apprehension, increased tension, decreased self-assurance, being scared, feeling alarm, terror or panic. The diagnosis of prostate cancer alters most relationships in one way or another, especially if other people are aware of the diagnosis. This may result in men being rejected, even by their own partners. Some men worry that they will become unattractive and unlovable. In this case, couples therapy can address these issues and help the couple gain some perspective on how their relationship has been changed by cancer (Holland et al., 2010).

In this study, some men expressed that upon hearing the diagnosis of prostate cancer, their wives developed fear of acquiring the disease from them. Men also said that their wives were reluctant to have sex with them due to the fear of contracting prostate cancer. This is evident in the following quote:

*“[Laughing] Yes, sometimes when I want to have sex she just say [sic] noo, noo, noo ... [waving his right index finger in the air while shaking his head]. She is scared of the disease that I am having [sic].” [P4]*

In support of the participants' statements, the literature indicated that sexual compromise after a cancer diagnosis and treatment can lead to a number of fears and concerns. Attitudes and behaviours can be shaped by other fears. Some women may become concerned that their husband may transmit cancer to them through sexual contact. In addition, some men may worry that their wives will not want to stay with them after a prostatectomy because of the change in their bodies. This could be because of the myths that cancer can be transmitted during sex via bodily fluids such as semen. It further revealed that some healthy spouses who fear the consequences of cancer and do not want to cope with it may flee relationships. Therefore, couples counselling can be helpful in expanding communication skills, dispelling unfounded fears and myths, and supporting patients and partners during the cancer experience (Holland et al., 2010).

### **3.3.2. Theme 2: Experiences of inconsistent care from nurses**

In this study, inconsistent means not staying the same throughout. Generally, nurses provide supportive care to cancer patients in order to help them meet the physical, psychological, emotional and spiritual challenges of prostate cancer. The care that nurses should render to prostate cancer patients included supporting the patients to gain some feeling of control over the disease and decisions, turning patients (especially those with advanced prostate cancer and pain), conveying a sense of caring during physical care, comforting the patient when in pain, and helping the patient and family to set achievable goals (Nettina, 2014). In this study, most participants revealed having experienced inconsistent physical and psychological care from nurses after being diagnosed with prostate cancer. Participants felt

devalued when inconsistent nursing care and lapses in communication occurred. In support of these findings, Krumwiede and Krumwiede (2012) found that the nurse-patient relationship for men diagnosed with prostate cancer includes nurses not responding to needs in a timely manner, not appearing competent in the treatment process and not communicating in a caring manner. Similar findings were found in this study, whereby participants expressed inconsistent care from the nurses. These findings are supported by King et al. (2015), who found that men with prostate cancer perceived a lack of understanding of proper support among healthcare professionals. According to the study's participants, these needs included support to deal with treatment side effects, particularly erectile dysfunction and urinary incontinence. This is reflected in the following sub-themes.

#### *3.3.2.1. Sub-theme 1: Lack of nursing care for patient's physical needs*

Lack of nursing care for physical needs refers to the unavailability of physical assistance to the individual in need. Men diagnosed with prostate cancer usually require physical assistance, especially in the advanced stage of the condition. This includes turning the patient while in bed and assisting with walking, feeding and bathing.

This is contrary to Walsh and Crumbie (2007), who pointed out that continuing help and support for men diagnosed with prostate cancer should be readily available from the nurse, doctor, social worker, hospital chaplain, friends and relatives. The type of physical care by nurses for men diagnosed with prostate cancer should convey a sense of caring and reassurance (Nettina, 2014). The following quotations are clear

indications of what participants have experienced as far as nursing care for physical needs:

*“You do not just see any nurse for help. After they give you medicines, then they are gone ... [pointing his right hand to the room door]. When you ask them to help you by putting you on the bed pan they might come, but after they put you on the bed pan they just go and never come back to remove you from it. One nurse will tell you that he/she is coming but will only turn up very late. The other nurse will tell you that he/she is coming but will never turn up at all. If you ask nurses to come and cover you they only take a blanket and throw it to your legs ... [pointing to his legs]. You never see nurses after dinner, but you only see them tomorrow morning when they come to ask you how you slept.” [P1]*

One participant who seemed to be very disappointed with the lack of nursing care for physical needs had this to say:

*“The difficulties that we have experienced as men are that ... [pause], health workers use [sic] to tell us that cancer usually affect [sic] men at the age of 50 or 55, therefore informed us to visit the doctor, but most of the time we find yourself [sic] not knowing where to go because when you go to the hospital to be screened of cancer sometimes they use [sic] to ask us that who told us that we are having cancer, or they simply tell us that they are too busy. When you come to the hospital they never give you assistance as they use to talk at the radio [sic], therefore sometimes you just feel like*



*going in the hospital and look for that person who was talking at the radio because what they talking [sic] is not what they are practicing. That is why we are saying, even if you go to the hospital, you will never get assisted.”*  
[P7]

The above expressions from the participant are contrary to Mogotlane, Manaka-Mkwanazi, Mokoena, Chauke, Matlakala and Randa’s (2015) findings; they stressed that patients should be provided with health information in order to be able to make informed decisions and choices about their health. This is supported by Searle (2000), who pointed out that the nurses are responsible for informing cancer patients about the care required after the diagnosis. When asked to describe the support that they receive from the nurses after being diagnosed with prostate cancer, this is what one participant said:

*“There was no support. After I was told that I am having prostate cancer, they only gave me this paper ... [raising his histology result in the air] and told me to come to Oshakati. There was no discussion on that regard.”* [P2]

The above quotation is a clear indication of lack of nursing care in meeting the physical needs of men diagnosed with prostate cancer. This accords with Krumwiede and Krumwiede’s (2012) findings which revealed that inconsistent nursing care exists through not responding to the patients’ needs in a timely manner, not appearing competent in the treatment process and not communicating in a caring manner, all of which strained the nurse-patient relationship.

A study by Shikongo (2000) on the nursing care given by registered nurses to cancer patients admitted to the hospitals of the North-West Health Directorate found that 57.1% of patients diagnosed with cancer rated the nursing care by registered nurses as good, 23.8% of the respondents rated it as fair and just 14.3% rated it very good. Only one patient (4.8%) rated the nursing care by registered nurses as poor.

#### *3.3.2.2. Sub-theme 2: Lack of psychological support from nurses*

Psychological support refers to any activity that improves a person's ability to function under the extraordinary level of stress observed in the context of a critical event (Nettina, 2014). Young, Van Niekerk and Mogotlane (2003) stated that psychological needs comprise cognition, adaptation, self-esteem, support, security, autonomy, relaxation and stimulation. The psychological support that can be given to men diagnosed with prostate cancer in a hospital includes relieving emotional suffering and reducing long-term negative psychological effects suffered by men diagnosed with prostate cancer. The benefit of psychological support for men diagnosed with prostate cancer includes reduced depression, lower anxiety, less pain, and improved self-management and coping skills, helping patients feel more in control and improving their quality of life (Nettina, 2014). Psychological support also enables men to cope more successfully with the hardships that they face after being diagnosed with prostate cancer. Coping involves dealing with the illness in order to regain a state of equilibrium (Gross & Kinnison, 2007).

The other support that should be given to men diagnosed with prostate cancer is counselling. In this study, counselling refers to the facilitative process in which the counsellor working within the framework of a special helping relationship uses

specific skills to assist clients to develop self-knowledge, emotional acceptance, emotional growth and personal resources (Van Vuuren, 2013). The participants in this study expressed lack of psychological support from the nurses after being diagnosed with prostate cancer. The following quote from one of the study participants is evident:

*“I never saw anybody giving me counselling after being diagnosed. Not at all! I was even taken blood [sic] several times here in the hospital ... [showing to his veins on both arms], but was never told any results of those blood tests. I was also taken some x-rays [sic] but they did not even show me those x-rays, but only told me that I am going to be operated [sic]. That is all.” [P1]*

The above sentiments from the participants are being supported by the findings of a study conducted by Gray et al. (2000) on the experiences of men with prostate cancer and their spouses; it reveals that men were more concerned with information regarding prostate cancer. A study conducted by King et al. (2015) found that men reported receiving information about prostate cancer and its treatment from various sources including healthcare workers; however, the content and timing of information delivery from healthcare professionals did not always meet their needs. Information was always perceived to be inadequate and difficult to understand.

In support of the participant’s statements, the literature indicated that counselling should not be confused with dispensing information (Corey, 2013). Counselling programmes will suffer in effectiveness and credibility unless the healthcare workers

exhibit understanding, warmth, humaneness, and positive attitudes toward humankind (Gibson & Mitchell, 2008). It is therefore worth noting that there is a person who either have no one to talk to about personal issues or who prefer to deal with their issues by talking to a counsellor rather than someone who knows them well (Geldard & Geldard, 2005).

A recent study conducted on men diagnosed with prostate cancer in Uganda reveals poor knowledge about prostate cancer and a low uptake of prostate cancer screening among Ugandan men, whereby the majority of them (85.7%) reported that they had never been counselled by any physician to undergo screening for prostate cancer; 50.2% did not know that they had any risk factor of prostate cancer, while 50.1% did not know that they had any symptoms of prostate cancer (Nakandi, Kirabo, Semugabo, Kittengo, Kitayimbwa, Kalungi & Maena, 2013). A study conducted by King et al. (2015) on men's experiences of support for their prostate cancer diagnosis found that lack of continuity of care and empathy among healthcare professionals prevented men diagnosed with prostate cancer from discussing sensitive issues. Men reported having a difficult time talking to healthcare providers about intimate issues such as sexual function, and many reported not being asked by their general practitioners about it at an appropriate time and context. Another participant had this to say:

*"No, I was not counselled and I did not search for it also. Not even one who gave [sic] me counselling. Counselling is different from what they told me because they were supposed to tell me that I should not be fearful." [P6]*

The above sentiments are in line with a study by Neukrug, Britton and Crews (2013) about the common health-related concerns of men; the study revealed that men are considerably less likely to seek counselling services compared to women. The study also revealed that today's counsellors continue to have limited training regarding men's issues, and feel uncomfortable discussing some prevalent male-related healthcare concerns such as erectile dysfunction, benign hypertrophy of the prostate, prostate cancer and penile cancer. The following quotes serve as evidence of the lack of counselling by nurses towards men diagnosed with prostate cancer at hospitals:

*“No, I was never approached by a person to give me information regarding this disease and how to live with it. I have really never seen a counsellor who talks to me regarding this disease.” [P8]*

*“No. I was never given counselling. The doctor who diagnosed me is a German national, therefore our communication was not that good because I could only hear few [sic] words”. No ... [shaking the head] I was never counselled.” [P9]*

According to the literature, where there is a language barrier translators should be used (Mogotlane, Chauke, Matlakala, Mokoena & Young, 2013). Furthermore, medical practitioners are expected to tell the patient what is wrong and not the other way around. A study conducted by Shikongo (2000) about the nursing care given by registered nurses to cancer patients who are admitted to the hospitals of the North-West Health Directorate found that 61% of participants (registered nurses) never had counselling sessions with their patients. Mogotlane, Mokoena and Chauke (2009)

stated that where possible, written information should be provided to men with more emphasis on health promotion; they also found that all males from 40 years onwards should be encouraged to undergo annual digital rectal examinations for early detection of prostate cancer, and should undergo testing for prostatic-specific antigen.

In agreement with the above sentiments from the participants, a study conducted by Evans, Duffey and Englar-Carlson (2013) about men in counselling revealed a lack of engaging men in the counselling process. The study recommended that healthcare workers and counsellors become informed about the issues affecting men so that they can better serve their mental health needs.

A study conducted by Michel, Hall, Hays and Runyan (2013) about male recruitment into the counselling profession concluded that there are fewer men entering the counselling profession, therefore a gender gap in the counselling profession has created a female-dominated environment that contributes to male marginalisation and privilege. The findings suggested that men may not feel as if they have a voice or place within the counselling services. Male counsellors are therefore a valued constituency for men seeking help regarding the sexual issues and challenges of fatherhood that are usually linked to the diagnosis of prostate cancer.

Another participant had this to say:

*“No. I was never counselled. Nobody came to me. I never saw anyone counselling me and if I could have seen him/her I could have listened to him/her. If he/she could have told me how I should live with prostate cancer, I should have listened. I was even asking myself about the types of food that I should eat, but I was not told anything else such as what to eat or how to live. I was not told anything.” [P5]*

In support of the above participant’s expressions, the literature pointed out that a diet high in animal fat and low in vegetable fat can increase the risk of aggressive prostate cancer, possibly by affecting hormone levels (Insel & Roth, 2008). Therefore, soy foods, tomatoes, and cruciferous vegetables are advisable for cancer patients due to their possible protective effects. Poor nutritional habits have been linked to cancer among others (Weiten, 2014). Individuals diagnosed with cancer should be advised to eat and drink healthily (Walsh & Crumbie, 2007). A nutrient-dense diet should be a high priority for older people because nutrient deficiencies in older adults can exacerbate physiological deterioration (Swartz, De la Rey, Duncan & Townsend, 2010).

The above quotes agree with the findings from a recent study conducted by Avery et al. (2014). The researchers interviewed men diagnosed with prostate cancer, their partners, and healthcare professionals on the importance of dietary change for men diagnosed with and at risk of prostate cancer; most men diagnosed with prostate cancer said that they were rarely given dietary advice by their healthcare

professionals after their diagnosis. Few men expressed confusion and dissatisfaction with unreliable and contradictory dietary information from healthcare workers. This is in agreement with Weiten (2014), who stated that a large portion of patients leave their doctor's offices not understanding what they have been told and what they are supposed to do. Similarly, healthcare professionals also indicated uncertainty about what information to provide patients, with most reporting that they did not routinely initiate discussions on dietary change with prostate cancer patients. However, most men and their partners reported that they would welcome and consider acting on dietary advice should it become available. On the other hand, providing dietary information to both men diagnosed with prostate cancer and their partners may encourage shared responsibility and strengthen men's rationale to make positive dietary changes (Avery et al., 2014).

The literature emphasised that patients who had undergone a prostatectomy should be counselled to maintain a high fibre diet in order to avoid straining due to constipation (Pudner, 2010). Ideally, the patients' home situation regarding diet should be discussed prior to and after admission.

The literature emphasises that psychological support is an important part of treatment and recovery for cancer patients; therefore individuals undergoing a cancer-related check-up should be given health counselling (Insel & Roth, 2008). Approaches for helping individuals cope with their cancer should begin during the diagnostic interview with the doctor (Sarafino & Smith, 2012).



This study's findings gave a clear picture to the researcher that men diagnosed with prostate cancer are rarely counselled in order to cope with their diagnoses. The next discussion will regard the experiences of rejection by family and community members.

### **3.3.3. Theme 3: Different levels of knowledge and misconceptions were expressed**

Knowledge has to do with all of the facts that someone knows about a particular subject. Lack of knowledge is the condition of being without sufficient knowledge. In this study, lack of knowledge on prostate cancer meant that men diagnosed with prostate cancer did not have any nor had insufficient knowledge regarding prostate cancer. The contributing factors to lacking knowledge on prostate cancer among men include the following: lack of awareness and lack of sensitisation programmes regarding prostate cancer from healthcare workers for the community, ignorance and lack community participation in health-related activities (Nettina, 2014).

A misconception is an incorrect fact that is widespread. It is a belief, view or opinion, usually widely held, that is incorrect, usually resulting from incorrect thinking or flawed understanding. The Oxford South African Concise Dictionary (2010) defines a misconception as a false or mistaken view or opinion.

When asked about what they know about prostate cancer, study participants could not provide correct answers about the disease. Walsh and Crumbie (2007) emphasised that the timing and manner of information given to patients are important factors in developing a therapeutic relationship between the nurse and the

patient. Individuals should be given appropriate information should a cancer diagnosis be confirmed. The patient has the right to know and to be informed about the diagnosis and prognosis of his or her illness (Potter, Perry, Stockert & Hall, 2011). Providing health information to patients is a legal, moral and professional responsibility for all nurses (Mogotlane et al., 2015). Patients should receive information in order to be able to make informed decisions and choices about their health. The literature stressed that nurses should play a vital role in educating clients about health screening, with specific emphasis on annual prostate examinations to facilitate the early detection of malignancy (Mogotlane, Mokoena & Chauke, 2009).

In this study, it became evident that men diagnosed with prostate cancer lack knowledge on the ailment. Similarly, the study's results reveal misconceptions about prostate cancer. The following sub-themes were identified by the researcher under the different experiences regarding a lack of knowledge, as well as misconceptions by men diagnosed with prostate cancer.

#### *3.3.3.1. Sub-theme 1: Participants verbalise their lack of knowledge on prostate cancer*

Lack of knowledge is a state of being uninformed. The knowledge of prostate cancer that men are expected to possess included what prostate cancer is, the causes, the signs and symptoms, and the prevention methods (Nettina, 2014). In this study, lack of knowledge on prostate cancer was revealed by the fact that most men diagnosed with prostate cancer displayed no idea of the nature of the disease. This runs counter to the literature, which emphasises that nurses should provide patients with the necessary knowledge regarding diseases commonly occurring in their communities

(Meyer, Naude, Shangase & Van Niekerk, 2009). Participants in this study pointed out that they never received information from healthcare workers regarding prostate cancer despite their coming for follow-up appointments several times. This study revealed a lack of knowledge among men diagnosed with prostate cancer attributed to insufficient health information from healthcare workers with regard to the disease. The following two participants' expressions are evident:

*"I do not know anything about prostate cancer. I do not know. How can I know unless you tell me?" [P2]*

*"They are saying it is a disease...aah...[taking a deep breath while looking down]. No, I don't know what type of a disease it is. I don't want to lie...[taking a deep breath while shaking his head]." [P2]*

This is what two other participants had to say when asked whether they had any knowledge on prostate cancer:

*"No ... [shaking his head], I never knew about this disease at all. I only used to hear that there is cancer that can kill people." [P8]*

*"I do not know anything about cancer. Is the doctors who knows [sic] about it." [P3]*

In order to equip men with knowledge regarding prostate cancer, the study conducted by Neukrug et al. (2013) on common health-related concerns of men suggested that healthcare workers should provide education on prostate cancer at the

places where men congregate such as barber shops, sports stadiums and the workplace, rather than waiting for men to come to the healthcare facilities. The study also suggested that the active recruitment of men with prostate cancer into healthy activities should be undertaken to attract men to listen.

A study conducted by Winterich, Gizywacz, Quandt, Clark, Miller, Acuna, Dignan and Arcury (2009) about men's knowledge and beliefs about prostate cancer revealed that education and not race is associated with knowledge. In-depth interviews were conducted with African-American men with diverse educational backgrounds. The study stated that understanding men's knowledge and beliefs about prostate cancer is important so that physicians can add to the existing knowledge and correct misinformation. It was concluded that interaction should focus on all men with low education to correct their misinformation about prostate cancer, and to engage them in shared decision-making about screening. Below are the expressions of some participants who were asked to describe what they know about prostate cancer:

*"I don't know what type of a disease it is. I never knew anything about cancer. They only say, "So and so died because of cancer." For me to ask them again that what [sic] cancer is all about it may sound as if I am asking too much. I only know cholera very well because it is common at our side. I know cholera very well. Cancer is only known in hospitals by nurses." [P3]*

*“Not at all. I only use to hear [sic] about it. I never saw a person sick of cancer, but I only use to hear people say cancer ... cancer ... but far from me.” [P10]*

*“I only use to hear [sic] about it. When I was told that I was having prostate cancer, I started asking myself that the cancer that I usually hear people talking about is now in my body ... [looking up].” [P10]*

Walsh and Crumbie (2007) pointed out that in the case of a poor state of knowledge about prostate cancer by men diagnosed with the disease; nurses have a major role to play with medical staff by making sure that men are well-informed about the disease to enable them to make well-informed decisions with regard to treatment options. For additional information and support regarding prostate cancer, men should be referred to the relevant agencies (Nettina, 2014). This does not correspond to this study's findings, as most participants expressed lack of knowledge on prostate cancer. Similarly, the study has also revealed that both nurses and doctors have failed to provide information about prostate cancer to men diagnosed with the disease. In most cases, men diagnosed with prostate cancer have been treated without being given information related to prostate cancer.

In agreement with the above statements from participants, a study conducted by Nakandi et al. (2013) assessed the current knowledge, attitudes and practices of adult Ugandan men regarding prostate cancer; the study revealed the general poor knowledge and several misconceptions regarding prostate cancer and screening. According to the study, the majority of Ugandan men are simply not aware of

prostate cancer. Although much emphasis has been placed on cancer in women in Uganda, especially breast and cervical cancer, little attention has been given to the cancers affecting men. Currently, there is no programme targeting prostate cancer that may explain the lack of awareness about the ailment. Meanwhile, there is no published data on the prevailing knowledge, attitudes and practices regarding prostate cancer in Uganda. Low literacy may be overlooked, but it remains a significant barrier to the diagnosis of early-stage prostate cancer among low-income men.

A recent study conducted by Nakandi et al. (2013) about the knowledge, attitudes and practices of Ugandan men diagnosed with prostate cancer reveals that only 10.3% had strong knowledge of the presenting symptoms of prostate cancer, while 47.9% did not know any ways of screening for prostate cancer.

#### *3.3.3.2. Sub-theme 2: Misconceptions exist about prostate cancer.*

The Concise Oxford English Dictionary (2011) defines misconception as a false or mistaken view or opinion. The Macmillan English Dictionary (2007) defines misconception as a wrong belief or opinion as a result of not understanding something. The findings of this study revealed misconceptions about prostate cancer. Most participants in this study described cancer as a scary and bad disease that only results in death should an individual be diagnosed with it. Furthermore, the study found that men delay seeking a screening for prostate cancer due to a fear of being diagnosed with cancer, a disease perceived by the community as dangerous. Some participants described prostate cancer as a disease for homosexuals. When asked to

describe what their culture thinks about prostate cancer, this is what two of the participants said:

*“Ai .. [scratching his head], we cannot really explain it because we are not really sure, but we can say it is disease [sic] for gay people ... yes, something like that.” [P6]*

*“Oi ... [paused while smiling] apparently, it came from America. It is Americans who explained it that it [sic] is a disease for gay people.” [P7]*

This is what another participant had to say after being asked to describe how a person diagnosed with prostate cancer was perceived culturally in the community:

*“ They say if you get sick of cancer you will die. I never heard of someone say [sic] a certain person was sick of cancer and he/she is still alive, no! They only say: a certain person was sick of cancer and he/she is dead. That is all ... [shaking his head].” [P3]*

In support of the participants' expressions, a study conducted by Gray et al. (2000) about the experiences of men with prostate cancer and their spouses echoed similar sentiments that most couples talked about fear, and that people would be scared off if they knew about cancer because everyone associates cancer with death. The study revealed that the diagnosis of prostate cancer led couples to consider their future deaths. Many took steps to ensure that practical matters would be taken care of should things go badly. Financial matters were handled and funeral plots were purchased in advance.

A study conducted by Halbert et al. (2011) on the socio-cultural determinants of men's reactions to prostate cancer diagnoses found a similar situation by revealing that cultural factors influence men's reactions to being diagnosed with prostate cancer. The literature also has it that an individual behaviour is heavily influenced by culture (Geyer, Mohotlane & Young, 2013; Snyder & Berman, 2014). The following quotation is evident:

*“Culturally, they believe that cancer is a killer disease. They are even saying that AIDS is better than cancer because if you get cancer, you will just go to the grave. That has resulted in people to delay coming to the hospital because most of them will just keep on putting traditional herbs on the wounds and the time they will come [sic] to the hospital, cancer is already advanced.” [P7]*

Another participant stated the following:

*“They say those diseases cannot be treated. So, people are just scared because they know that if they develop cancer, there is no any [sic] other way that they can be assisted ...” [P9]*

A study conducted by Shikongo (2000) about the care given by registered nurses to cancer patients who are admitted to the hospitals of the North-West Health Directorate found that 61% of the registered nurses observed fear in patients diagnosed with cancer. These findings agree with Sarafino and Smith (2012), who stated that cancer is probably the disease people fear most. Among the many



stressors faced by patients with cancer are dependency, disability, and fear of painful death (Holland et al., 2010).

#### **3.3.4. Theme 4: Experiences of physical discomfort and psychological changes in the body**

For men diagnosed with prostate cancer, radiation therapy to the pelvis can cause fibrosis over time and can interfere with the nerves and blood vessels necessary for erections (Holland et al., 2010). During or following prostate treatment, issues of pain and hormonal status can influence sexuality. In this study, participants expressed physical discomfort and psychological changes after being diagnosed with prostate cancer.

Men indicated that they experienced distress, pain and discomfort as well as changed sexual feelings and sexual dysfunction after being diagnosed with prostate cancer. The researcher found this evident in that men diagnosed with prostate cancer have undergone multiple-stress provoking situations. The following sub-themes emanate from the experiences of physical discomfort and psychological changes in the body.

##### *3.3.4.1. Sub-theme 1: Participants experience severe pain and discomfort.*

In this study, pain refers to a strongly unpleasant bodily sensation caused by illness or injury, whereas discomfort refers to a feeling of mental uneasiness or a feeling of slight pain, slight anxiety or embarrassment. Prostate cancer and other debilitating diseases cause men to develop distressing discomfort, disempowerment, emasculation and fear of the future. When diagnosed with prostate cancer, men experienced distressing discomfort and developed fears regarding life-expectancy (Neukrug et al., 2013). Factors that contribute to the experience of distressing

discomfort among men diagnosed with prostate cancer include pain, inability to pass urine, swelling and leaking catheters (Krumwiede & Krumwiede, 2012).

The urinary catheter's impact on men diagnosed with prostate cancer was one of the study's major findings. Similar findings were revealed in the Krumwiede and Krumwiede (2012) study; the urethral catheter was a constant reminder of prostate cancer for men, and it served as a threat to hope. Urinary leakage around the catheter tubing results in stress, embarrassment and social withdrawal among most prostate cancer patients (Stellenberg & Bruce, 2007). In this study, similar experiences were expressed by various participants:

*"I stayed four nights crying after being inserted me [sic] with a urethral catheter. I started releasing blood. I then became better when the blood stopped."* [P3]

*"The urethral catheter might be the one that has caused my penis to be swollen. I am saying this because I have been with it for many months. It only became swollen after I was inserted with a catheter."* [P4]

The course of the prostate cancer disease requires men to hold up under multiple stress-provoking situations. The results of the study conducted by Krumwiede and Krumwiede (2012) revealed that all of the participants were physically and psychologically affected by the diagnosis of prostate cancer and the treatment they endured. A significant finding was the impact that the urinary catheter had on the individuals who elected to have surgery. The stress and embarrassment led to social

withdrawal. Many participants described the urinary catheter as the worst part of the experience. On the question of whether the penis may be swollen due to the urinary catheter, one participant elaborated:

*“Yes my penis is swollen. I am just thinking that it could be because when they tried to remove the catheter maybe it went too far in the body. Look, the penis is just here .... [smiling while pointing to the penis] but when they remove it, it seems it was so deep, maybe around 100 centimetres ... 100 centimetres [shaking his head], not even twenty centimetres, no ... it was too long when it come out [sic]. I think it could be the one that that [sic] caused harm, because until now my penis is still swollen but with no pain. No pain but only the swelling.” [P4]*

The most distressing discomfort experienced by men diagnosed with prostate cancer was having urinary leakage around their catheter tubing (Krumwiede & Krumwiede, 2012). The removal of the urinary catheter was distressing for the participants, as they often experienced urinary incontinence for the first time.

A study by Penson, McLean, Freng, Albertsen, Gilliland and Hamilton (2008) on urinary and sexual outcomes five years after a radical prostatectomy in men revealed that 14% of men reported frequent urinary leakage or no urinary control 60 months after being diagnosed with prostate cancer. In a study by Stanford, Feng, Hamilton, Gilliland, Stephenson, Eley and Albertsen (2000) on urinary and sexual function after a radical prostatectomy for clinically localised prostate cancer, it was found that 18 or more months following radical prostatectomy, 8.4% of men were incontinent.

A similar study was undertaken by Potosky, Davis, Hoffman, Stanford, Stephenson, Penson and Harlan (2004), which found that five years after the diagnosis, men treated with radical prostatectomy for localised prostate cancer continued to experience worse urinary incontinence. Mogotlane, Mokoena and Chauke (2009) support the previous sentiments by pointing out that possible complications of prostatic surgery include haemorrhages, bladder spasms, urinary inconsistency and erectile dysfunction. Urinary incontinence is common in patients with prostate cancer after the removal of a urinary catheter, and it usually gradually subsides (Nettina, 2014). Other literature also indicates that as prostate cancer progresses, lower urinary tract symptoms may develop and men will commonly experience urinary frequency, dysuria, nocturia, and incomplete emptying of the urinary bladder (McLafferty, 2014). The above findings are in agreement with this study's participants, one of whom stated the following:

*“They kept on inserting urethral catheters one after the other. When I say they should remove it they say [sic], no ... [shaking his head while looking down]. Most of the time it leaks leaving the whole bed to be wet.” [P1]*

*“I started with urination problems whereby I was only passing very little urine and sometimes nothing at all. In the night, I use [sic] to have abdominal pain here ... [pointing at the lower abdomen] and when the pain starts I cannot able [sic] to sleep the whole night.” [P8]*

A participant continued by asking:

*“Can this tube [pointing to the urethral catheter] be removed? This tube leaks sometimes. I feel bad because when it leaks it start painning [sic].”*

[P8]

The literature finds that incontinence and impotence are two of the most feared complications of prostate cancer treatment. Incontinence is a problem because the male urethra, which carries urine from the bladder to outside of the body, runs directly through the prostate. Thus, when the prostate is being destroyed by surgery, radiation, or cryotherapy, the urethra is inevitably affected. According to Torrey (2006), the good news about urinary incontinence caused by treatment for prostate cancer is that in most cases, the problem subsides over time. Most studies suggest that incontinence continues to be a long-term, major problem for approximately 5 to 10% of men treated for prostate cancer, but it can be improved. The first step is to control the leakage with absorbent pads of some kind. Wide varieties are available at pharmacies and medical supply stores. The next step in improving continence is to ask an urologist to rule out a urinary tract infection that could make the problem worse. This can be done by checking the urine. Two participants made these statements:

*“Blood ... blood ... blood [with eyes closed]! I was not comfortable with the urethral catheter when I walk [touching his legs] because I always feeling [sic] like falling down when walking. This shoulder [pointing at his left shoulder] seemed as if it was disconnected.” [P3]*

*“I was actually thinking that the catheter should be removed, but they refused. They said they will remove it in November, but when I went home it started leaking so much. It is paining [sic] so much. The pain even goes to the abdomen, back and legs.” [P1]*

The above sentiments agree with Holland et al. (2010), who pointed out that the fear of urine leaking, of smelling of urine, and of having to use diapers feels regressive and humiliating. Urinary incontinence occurs as a complication of surgery and radiation. Loss of urinary continence leads men to shun social engagements. It is therefore important for urologists and their staff to work with patients to identify ideologies of incontinence, to educate patients and families about incontinence, and to offer suggestions to alleviate and reduce symptoms. Interventions for urinary incontinence include pelvic muscle re-education, bladder training, and anticholinergic medications.

Holland et al. (2010) pointed out that urinary continence leads men to shun social engagements because the fear of urinary leaking, smelling of urine, and of having to use diapers is humiliating. The complications of radical prostatectomy for prostate cancer include urinary incontinence and leakage at the anastomotic site of the urethra and bladder (Monahan, Sands, Neighbors, Marek & Green, 2007). Other literature indicates that using a urethral catheter after a prostatectomy increases patient discomfort (Walsh & Crumbie, 2007). Nettina (2014) pointed out that chronic pain in prostate cancer is related to bone metastasis. Cancer pain is a serious problem when the illness is in the advanced stages (Sarafino & Smith, 2012). According to

Holland et al. 2010), pain is among the most prevalent and distressing symptoms encountered in patients with cancer. It is a common problem for cancer patients, with approximately 70% of patients experiencing severe pain at some point in the course of their illness. It is suggested that nearly 75% of patients with advanced cancer have pain.

On the other hand, pain is often a symptom of advanced prostate cancer, which can be difficult to control. Pain syndromes result from local expansion and inflammation of the prostate gland, from local tumour growth, and from distant long bone, vertebral, and skull metastasis. Pain not only impairs mobility but also accompanies neurologic impairments such as cranial nerve deficits, paralysis, incontinence of the bowel and bladder, and impotence. Patients with pain are significantly more depressed or anxious compared with patients without pain (Holland et al., 2010). During the interview, participants expressed experiences of various degrees of pain after being diagnosed with prostate cancer. These are highlighted in the following statements:

*“I started with pain at [sic] this shoulder... [pointing to his right shoulder] especially when I am working. The pain refused to subside and later noticed [sic] pain at this shoulder [pointing to his left shoulder].” [P5]*

*“I use [sic] to experience bone tenderness that is why I was taken to the machine in order for the doctor to determine its severity. Tenderness in the bone use [sic] to be severe in the night when sleeping, but in the morning you are just fine.” [P7]*

Another participant stated:

*“I experienced backache, legs pain and paining [sic] the whole body. The heart also uses [sic] to be tired when I am working.” [P10]*

The International Association of Pain defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (Holland et al., 2010). Pain is regarded as an important symptom, defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage (Dinat, 2009). It is among the most prevalent and distressing symptoms encountered in patients with cancer. It is a common problem with cancer patients, with approximately 70% of patients experiencing severe pain at some time in the course of their illness. It has been suggested that nearly 75% of patients with advanced cancers have pain (Holland et al., 2010).

Pain is complex and unique for each individual whenever it is experienced (Alexander, Fawcett & Runciman, 2006). This means that it is difficult to understand what pain is like for another person. Pain is highly subjective, and only the person experiencing it can describe it. It serves as a major function by alerting us to possible harm or damage.

The pain associated with a progressive, cancerous process may involve several physiological mechanisms that induce pain. The compression of neural tissues produces a continuous, stabbing or sharp, well-localized pain that follows the neural



distribution of the involved nerve. On the other hand, sudden occlusion of a tube such as a ureter may produce a severe, cramping, colicky pain. Tissue damage results in inflammation, and the inflammatory process produces tenderness and sensitivity to touch. The pain associated with necrosis is severe and often excruciating, and tends to be unresponsive to most treatment regimens (Alexander et al., 2006).

Understanding the complex nature of pain and its pathophysiology is necessary to institute appropriate pain management. Some patients may view pain as a punishment; others may see it as having some value for self-testing or personal growth; others may see it as something that must be eradicated. Patients with cancer often fear that pain means that their disease is progressing, or that pain will increase as death approaches. The nurse's responsibility is to make the patient as comfortable as possible, and to observe and report findings that help the physician make a correct diagnosis and prescribe appropriate treatment.

It is not often possible or always desirable for a nurse or doctor to treat emotional, social and spiritual pain, but an appreciation and understanding of total pain will make treating the patient's physical pain more effective. The patient can describe his or her pain; therefore, it is important for the nurse to listen to the patient. The nurse should not assign his or her own value to the patient's pain.

#### *3.3.4.2. Sub-theme 2: Concerns about changed sexual feelings and sexual dysfunction*

Concern is defined as being worried about something. Factors that contribute to the concern regarding changed sexual feelings among men diagnosed with prostate

cancer include loss of libido and erectile dysfunction (Krumwiede & Krumwiede, 2012). Most participants in this study expressed aspects related to their sexuality in the context of sexual function following the diagnosis of prostate cancer. Sexual dysfunction is a psychological disorder involving persistent difficulties in sexual interest, arousal, or response (Nevid, Greene, Johnson & Taylor, 2005).

In this study, loss of erectile function was significant for most men, although they expressed various responses to it. Erectile dysfunction refers to the inability to achieve or maintain an erection that allows satisfactory sexual performance (Mogotlane, Mokoena & Chauke, 2009; Nevid et al., 2005; Balon, 2008). All of the mentioned symptoms indicate a complication of prostatectomy (Nettina, 2014). Approximately one in 10 men over 40 are affected by this condition (Balon, 2008). A man with erectile dysfunction would experience the recurrent, partial or complete inability to achieve or maintain an erection while engaging in sexual behaviour. It also exists when an individual persistently finds it difficult to function adequately while having sex (Austin, Bezuidenhout, Du Plessis, Jordan, Lake, Nel & Pillay, 2010). If a prostatectomy has resulted in impotence, the patient needs to be supported through his grief over the loss of sexuality (Monahan et al., 2007). With regard to the sexual symptoms of dysfunction, the following was stated:

*“With regards to sex, I stopped having sex for a long time due this illness.*

*My penis cannot even erect now [sic], maybe because of this illness.” [P4]*

*“I have experienced lack of interest in sex.” [P3]*

A study conducted by Stanford et al. (2000) on urinary and sexual function after radical prostatectomy for clinically localised prostate cancer concurs; it found that radical prostatectomy is associated with significant erectile dysfunction. Radical prostatectomy is the surgical removal of the prostate and the seminal vesicles (Mogotlane, Mokoena & Chauke, 2009).

Concerns expressed by the participants in this study are supported by the findings of a study conducted by Potosky et al. (2004) on the five-year outcomes after prostatectomy or radiotherapy for prostate cancer; the study reveals that five years after the diagnosis of prostate cancer, erectile dysfunction was more prevalent among participants. It was further revealed that sexual dysfunction was the greatest concern for men diagnosed with prostate cancer. In men, sexual dysfunction is most frequently associated with the inability to achieve an erection due to erectile dysfunction (Walsh & Crumby, 2007; Balon, 2008). Prostatectomy can result in physiological sexual dysfunction, therefore a man and his spouse or partner should be helped to understand such consequences (Monahan et al., 2007).

Penson et al.'s (2005) findings on five-year urinary and sexual outcomes after radical prostatectomy reveal that 71% of men diagnosed with prostate cancer were unable to achieve erections firm enough for intercourse. At 60 months after the procedure, 55% of participants reported an inability to achieve any erection and only 28% had erections firm enough for intercourse. Another study conducted by Penson et al. (2008) reveals similar results; urinary and sexual dysfunction was common five years after a radical prostatectomy. These findings agree with a study undertaken by

Stanford et al. (2000) on urinary and sexual function after radical prostatectomy for clinically localised prostate cancer; the study found that of the 72.7% of men who were potent at baseline, 72.4% reported that their erections were not firm enough for intercourse after surgery. However, despite significant declines in both urinary and sexual performance levels, most men were satisfied with their treatment choice.

A study conducted by Krumwiede and Krumwiede (2012) on the experiences of men diagnosed with prostate cancer found that men who had a prostatectomy experienced a brief or prolonged episode of incontinence, erectile dysfunction, and/or loss of libido. It further stated that the most significant negative outcomes of surgery included incontinence and erectile dysfunction. Therefore, men described dealing with incontinence and sexual dysfunction as a difficult situation that caused humiliation and shame. Mogotlane, Mokoena and Chauke (2009) emphasised that men with erectile dysfunction need a great deal of emotional support because the problem impacts their manhood and can cause emotional problems with partners. Therefore, the nurse needs to address issues regarding erectile dysfunction and refer the patients to a health team that specialises in counselling the couple and/or family. Another participant had this to say:

*“[Laughing while looking down] it makes me to feel bad because since last year I have never had sex with my wife until now. It makes me to feel [sic] bad because I am having a disease that cannot be cured.” [P4]*

*“Being without testes made me feel bad because I am no more [sic] at the same level as before.” [P5]*

The quotation above serves as a clear indication that the study's participants experienced the most common changes in sexual function after being diagnosed with prostate cancer. These include decreased sexual interest and erectile dysfunction (Holland et al., 2010). Men who face a prostatectomy are at risk of erectile dysfunction. This study's findings accord with the results of a study by Krumwiede and Krumwiede (2012) revealing that participants expressed aspects related to their sexuality in the context of sexual function following the diagnosis of prostate cancer. Loss of erectile function was significant for most men in the study, even though they varied a great deal in response to the experience. All of the participants experienced complex side effects such as erectile dysfunction, depression and fatigue. Men who had a prostatectomy experienced either brief or prolonged episodes of incontinence, impotence, erectile dysfunction or loss of libido, therefore dealing with these episodes was difficult for these men and resulted in humiliation and shame. The study further revealed that few men felt more sympathy towards their spouses, as they felt that their spouses were the ones greatly impacted by sexual dysfunction. The next quotations are evidence:

*"She is feeling very bad about it because if you are having a wife you need to have sex with her because you still love each other."* [P4]

*"She sometimes starts mistreating you because of your reproductive organs that are not functioning well. Yes, I have noticed it because the way we use to be is no more the same way we are now. You can just tell."* [P10]

Couples and intimate relationships are vulnerable in the context of prostate cancer. At a time when couple's communication needs to be at its best, it is often at its worst because of the stress of the situation. Studies have shown that spouses and partners have even more distress than patients. Therefore, couples counselling can improve the ability of spouses and partners to cope with the cancer together (Holland et al., 2010). Another participant had this to say:

*"I did not try anything yet because I am still feeling ill. Until now my penis cannot erect. I know that with pain I cannot able [sic] to erect."* [P5]

Multiple obstacles can influence sexual function during and following chemotherapy treatment. Feelings of anxiety and depression, changes in relationships, concern about the loss of physical well-being, and difficulty in coping with changes in the body secondary to cancer treatment all can have a bearing on sexual function. When a cancer diagnosis directly affects the sexual organs, as in the case of prostate cancer, choices regarding sexuality may be a secondary priority to issues of longevity and survival. Sexual and reproductive changes can cause feelings of shame and embarrassment as well as injury to one's self-esteem and identity. These are not issues that are easy to discuss with others (Holland et al., 2010).

Difficulties with sexual function occur from aging, surgery, the cancer itself, radiation, and hormonal therapy. Hormonal therapy in particular can eliminate libido, which often decreases distress about erectile dysfunction. A decreased desire for any physical intimacy can be harmful to a relationship (Holland et al., 2010). Pudner (2010) defines erectile dysfunction or impotence as the persistent or recurrent

inability to achieve or maintain an erection sufficient for satisfactory sexual activity. Erectile dysfunction is an adverse effect of prostate surgery.

At every stage of the cancer illness, families are faced with challenges that threaten to disrupt the stability of their relationships and their quality of life. Changes in sexual function in men diagnosed with prostate cancer including loss of libido or erectile dysfunction can compromise a man's sense of masculinity and disrupt communication and sexual intimacy for the couple. A study conducted by Holland et al. (2010) revealed that qualitative accounts from an early stage of prostate cancer highlighted the tendency to hold back from expressing concerns or fear, particularly with regard to the loss of sexual function. High-distress levels were evident among the partners of men with prostate cancer, with accompanying changes in the couple's relationship.

Sexuality is an essential part of one's personality, and cannot be separated from it. It is part of one's biological makeup, and it includes one's perception of being male or female. Abnormal sexual behaviour is that which is destructive and harmful to oneself or others. Many men fear not being able to have an erection, particularly as they reach middle age. On the other hand, many medical conditions produce physiological erectile dysfunction. When sexual dysfunction is persistent, it usually causes difficulties within the person and between couples (Stewart, 2013).

### **3.4. SUMMARY**

This chapter outlined the themes and sub-themes obtained from a data analysis of the interviews conducted with men diagnosed with prostate cancer in Namibia's four

northern regions namely; Omusati, Oshana, Oshikoto and Ohangwena. Four main themes and several sub-themes were formulated after the data analysis. It was evident from participants' verbatim quote that living with prostate cancer is not easy, as it affects not only the patient but also his family. Relevant literature was incorporated in the discussion. The next chapter discusses the study's conclusions, guidelines, limitations and recommendations.



## **CHAPTER 4**

### **CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS**

#### **4.1. INTRODUCTION**

The previous chapter dealt with data analysis, discussions of findings and literature control. A content analysis was used whereby the data analysis was done manually. Four themes were identified from the experiences of men diagnosed with prostate cancer whereby both their positive and negative lived experiences were discussed.

This chapter will focus on conclusions, limitations and recommendations based on the study's findings. Conclusions were drawn from the findings, which related to the research question: "What is your experience with prostate cancer after being diagnosed with it?" The conclusions were furthermore made in terms of the study's objectives.

This study's recommendations are based on the findings and emphasise supportive care towards men diagnosed with prostate cancer as a way of reducing the burden of various experiences after their diagnosis.

#### **4.2. CONCLUSIONS**

This study's objective was to explore and describe the experiences of men diagnosed with prostate cancer in order to have an understanding of what they go through. In order to achieve the study's objectives, face-to-face, in-depth interviews were conducted with ten participants that were selected by means of non-probability, purposive sampling set on inclusion criteria. A central question was posed to each

participant: “What is your experience with prostate cancer after being diagnosed with it?” The interviews proved to be a source of rich data on the participants’ experiences with prostate cancer after being diagnosed. Interviews were subsequently transcribed and analysed using Tesch’s steps of data analysis, namely breaking down, examining, comparing and categorising raw data. The conclusions drawn facilitate objectives 1 and 2:

**4.2.1. Objective 1: To explore the experiences of men diagnosed with prostate cancer in Namibia’s four northern regions**

Participants were asked to share their lived experiences with regard to prostate cancer after being diagnosed. The experiences were obtained through face-to-face, in-depth interviews. The interviews were recorded and transcribed verbatim (Creswell, 2014). A total of ten interviews were conducted before data saturation was reached. Field notes were also taken. Rich detailed data was obtained, and is described under objective 2.

**4.2.2. Objective 2: To describe the experiences of men diagnosed with prostate cancer in Namibia’s four northern regions.**

A description of experiences was done by analysing data according to Tesch’s eight steps. The data was categorised in themes and sub-themes. The study revealed clear sentiments from participants, including a lack of nursing care for physical needs after being diagnosed with prostate cancer.

Many participants expressed that it would be difficult to go through the diagnoses of prostate cancer without their family members. Most men expressed gratitude for the immense support they received from their family members after being diagnosed

with prostate cancer. Such support provided a sense of comfort and reassurance in their time of uncertainty. The results also revealed the rejection of men diagnosed with prostate cancer by their family and community members, as people believed that they may transmit the disease. Similarly, the misconception of cancer as a disease for homosexuals has resulted in people rejecting men diagnosed with prostate cancer in their communities. Some participants expressed that after being diagnosed with prostate cancer, their wives developed a fear of acquiring the disease through sexual contact.

Men diagnosed with prostate cancer also expressed a lack of psychological support from nurses after being diagnosed with the disease. These findings gave a clear picture to the researcher that men diagnosed with prostate cancer are rarely being counselled to help them cope with their diagnosis. It became evident that men diagnosed with prostate cancer lack knowledge about prostate cancer aggravated by revealed misconceptions about the disease.

Experiences of physical discomfort and psychological changes among participants were mentioned, causing distress, pain and discomfort as well as changed sexual feelings and sexual dysfunction after being diagnosed with prostate cancer. Most participants described the urinary catheter as the worst part of the experience. Loss of erectile function as a significant experience among men was also a major concern.

#### **4.3. LIMITATIONS**

Several limitations were identified. First, the study was conducted with men diagnosed with prostate cancer. The population and sample of the participants for

this study were selected from Namibia's four northern regions: Oshana, Oshikoto, Omusati and Ohangwena. The study's findings will therefore not be generalised to the entire Namibian population because of the participants' geographical and cultural orientation, which may not be the same as that of men in other regions. However, the study's results will be useful for references and future research.

#### **4.4. RECOMMENDATIONS**

The following recommendations are based on the conclusions drawn from objectives 1 and 2: Recommendations were made based on managerial, education and research-related aspects.

##### **4.4.1. Management**

- An internal policy is needed regarding the management of men diagnosed with prostate cancer in the hospital. All health care workers should be oriented to the policy's content in order to ensure the policy's practical implementation.
- Some staff members should be trained in palliative care, which will include managing patients with prostate cancer. It is important that hospital management be sensitised about cancer and the effects of neglected care in order for them to properly manage the associated medical budget.
- Exit interviews for men diagnosed with prostate cancer upon discharge should be conducted in order to solicit their views regarding the quality of nursing care received during hospitalisation. It is advised that this be done by the supervisor or ward matron.

- An annual award for healthcare workers and units that perform exceptionally well can be introduced. This could serve as additional motivation for healthcare workers.

#### **4.4.2. Education**

- A community-based health education program about prostate cancer can be introduced. Such a program can create awareness and knowledge in the community about the disease as well as how to address the existing misconceptions about prostate cancer that are likely to influence how men prioritise coping with the diagnosis. The researcher can present the findings to the hospital management and make himself part of the program. To incorporate strategies to make the program available to all communities, visual material can be prepared to accommodate those who are illiterate.
- Formal in-service education sessions for health care workers (especially for registered nurses) working at oncology outpatient departments, health centres and clinics needs to be implemented. Such in-service education should include more specific information such as counselling men diagnosed with prostate cancer. It is imperative that those working with cancer patients be trained first. Unit managers and registered nurses should establish and implement individualised approaches in all units to help men address their thoughts and feelings after being diagnosed with prostate cancer, as well as to incorporating strategies that help men to be more effective at obtaining social support.

- Psychological support such as counselling is an important part of care for men with prostate cancer. It is therefore recommended that hospital management be sensitised toward and motivated to let counselling trainings be implemented. Technical support such as financial assistance, transport and materials for all regional and district hospitals to enable them to conduct workshops and in-service trainings with all nursing categories regarding managing men diagnosed with prostate cancer should be provided by the Ministry of Health and Social Services. This will enable more healthcare workers to attend important workshops or sessions on care for cancer patients and especially on care for men with prostate cancer.

#### **4.4.3. Future research**

Research on cancer is conducted regularly, but research within the Namibian context is scarce and therefore evidence-based nursing care remains a challenge. The following are some recommendations for further research:

- An assessment should be conducted on the nursing care rendered to men diagnosed with prostate cancer.
- It is recommended to determine the registered nurses' knowledge, attitudes and practices regarding the management of men diagnosed with prostate cancer.
- A model to facilitate effective care and communication for men diagnosed and living with prostate cancer as well as their families should be developed.

#### **4.4.4. The contribution to the body of knowledge**

This study makes a contribution to the body of knowledge particular to the professional nurse in practice as well as society in general. This information will enrich the quality and experiences of nurses regarding the management and care of patients diagnosed with prostate cancer. It also contributes to knowledge concerning the supportive roles that nurse educators play in the training and education of nursing staff. Accordingly, the outcome of this study will result in better care and improved quality of life for both patients and their families.

#### **4.5. CONCLUSION**

This chapter contained the conclusion, limitations and recommendations for this study, in which the experiences of men diagnosed with prostate cancer were discussed. In summary, the recommendations made by this study are aimed at enabling nursing care that incorporates the meaning and understanding of the experiences of prostate cancer and individualised patient care.

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## Appendix A: Permission letter from University of Namibia postgraduate committee to conduct a research study

### UNIVERSITY OF NAMIBIA

Private Bag 13301, 340 Mandume Ndemufayo Avenue, Pionierspark, Windhoek, Namibia



Enquiries: Dr. H. J. Amukugo  
Private Bag 13301  
Mandume Ndemufayo  
Windhoek

Tel. No.: 061- 2064617  
Fax No.: 061-  
e-mail: hamukugo@unam.na

*All correspondence must be addressed to the Office of the Associate Dean*

#### LETTER OF PERMISSION: POST GRADUATE STUDENTS

Date: 30 September 2013

Student Name: Mr Salomo Salomo  
Student number: 9808507

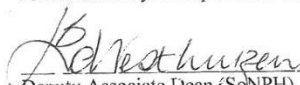
Dear Student

The post graduate studies committee has approved your research proposal.

#### EXPERIENCES OF MEN DIAGNOSED WITH PROSTATE CANCER IN THE FOUR NORTH REGIONS

It may be required that you need to apply for additional permission to utilize your target population. If so, please submit this letter to the relevant organizations involved. It is stressed that you should not proceed with data collection and fieldwork before you have received this letter and got permission from the other institutions to conduct the study. It may also be expected that these organizations may require additional information from you.

Please contact your supervisors on a regular basis.

  
Deputy Associate Dean (SoNPH)



## Appendix B: Request for permission to conduct a research study

Private Bag 15501

Oshakati Regional Health Training Center

Oshakati

08.10.2013

The Permanent Secretary

Ministry of Health and Social Services

Private Bag 13198

Windhoek

Dear Sir

**Re: Request for Permission**

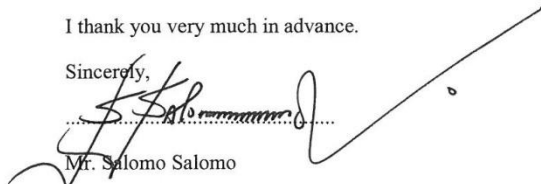
I am writing this letter to your good office seeking for the permission to conduct my study (research) within the Ministry of Health and Social Services (in the four Northern Regions).

The seeking of the permission is necessitated by the fact that, currently I am pursuing my study at the University of Namibia towards a Masters Degree in Nursing Science. The title of the study is: **"Experiences of men diagnosed with Prostate Cancer in the four Northern Regions"**. The population of the study will entail men between the ages of 39-95 years already diagnosed with Prostate Cancer in the four Northern Regions. The study design will be of qualitative in nature.

It is therefore against this background that, I am humbly requesting your good office for a permission to conduct this study within the Ministry of Health and Social Services (in the four Northern Regions). Kindly, find the attached letter of permission from the University of Namibia.

I thank you very much in advance.

Sincerely,



Mr. Salomo Salomo

Senior Health Programme Administrator

Oshakati Regional Health Training Center

**Appendix C: Permission letter from ministry of Health and Social Services to conduct a research study**



**REPUBLIC OF NAMIBIA**

*Ministry of Health and Social Services*

Private Bag 13198  
Windhoek  
Namibia

Ministerial Building  
Harvey Street  
Windhoek

Tel: (061) 203 2560  
Fax: (061) 222558  
E-mail: [tkakili@yahoo.com](mailto:tkakili@yahoo.com)  
Date: 07 November 2013

Enquiries: Ms. T. Kakili

Ref: 17/3/3

**OFFICE OF THE PERMANENT SECRETARY**

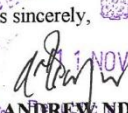
Mr Salomo Salomo  
P.O. Box 15481  
Oshakati

Dear Mr Salomo

**Re: Experiences of men diagnosed with Prostate Cancer in the four Northern regions.**

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
  - 3.1 The data to be collected must only be used for the completion of your Master's degree in Nursing Science;
  - 3.2 No other data should be collected other than the data stated in the proposal;
  - 3.3 A quarterly report to be submitted to the Ministry's Research Unit;
  - 3.4 Preliminary findings to be submitted upon completion of the study;
  - 3.5 Final report to be submitted upon completion of the study;
  - 3.6 Separate permission should be sought from the Ministry for the publication of the findings.

Yours sincerely,

  
1 NOV 2013  
**MR. ANDREW NDISHISHI**  
**PERMANENT SECRETARY**

## Appendix D: Request for permission to conduct a research study from the Oshana Regional Health Director

Private Bag 15501

Oshakati Regional Health Training Center

Oshakati

08.10.2013

The Regional Health Director

Private Bag 15501

Oshakati

Oshana Region

Dear Sir

**Re: Request for Permission**

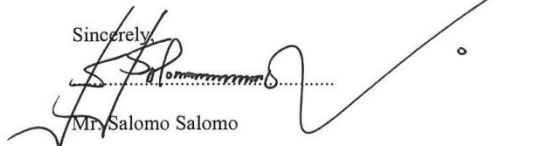
I am writing this letter to your good office seeking for the permission to conduct my study (research) in your respective Region (Oshana).

The seeking of the permission is necessitated by the fact that, currently I am pursuing my study at the University of Namibia towards a Masters Degree in Nursing Science. The title of the study is: **"Experiences of men diagnosed with Prostate Cancer in the four Northern Regions"**. The population of the study will entail men between the ages of 39-95 years already diagnosed with Prostate Cancer in the four Northern Regions. The study design will be of qualitative in nature.

It is therefore against this background that, I am humbly requesting your good office for a permission to conduct this study in Oshana Region. Kindly, find the attached letter of permission from the University of Namibia.

I rely on your usual support and I thank you in advance.

Sincerely,



Mr. Salomo Salomo

Senior Health Programme Administrator

Oshakati Regional Health Training Center

## Appendix E: Permission letter from the director of Oshana region



Republic Of Namibia  
Ministry of Health and Social Services  
Oshana Regional Directorate

Private Bag 5538  
Oshakati  
Namibia

Tel: 09-264-65-223 3119  
Fax: 09-264-65 220 303

Enquiries: Ms Leena Nghukufwa

30 October 2013

Mr Salomo Salomo  
Private Bag 15501  
Oshakati Regional Health Training Center  
Oshakati

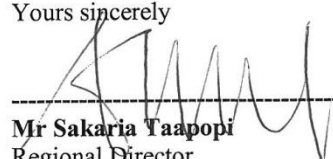
### APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH STUDY

Thanks for your letter dated 08 October 2013.

Permission to conduct a research study on: **Experiences of men diagnosed with Prostate Cancer in the four northern regions**, in Oshana Health Directorate is hereby granted.

Please take this letter with you.

Yours sincerely

  
**Mr Sakaria Taapopi**  
Regional Director



cc. Medical Sup. Intermediate Hospital Oshakati  
Chief Medical Officer-Oshana

**Appendix F: Verbal informed consent**

My name is Salomo Salomo, a student at the University of Namibia conducting a research study to describe the experiences of men diagnosed and living with prostate cancer in the four northern regions. The study will enable the researcher to have a broader understanding of the experiences of men living with prostate cancer. On the other hand, the study findings will be used to make recommendations to the Ministry of Health and Social Services on how to prepare men for such conditions.

The population of this study are men between the ages of 39 and 95 years, already diagnosed and living with prostate cancer in the four Northern Regions. You are therefore being humbly requested to participate in this study. As a participant, you are allowed to withdraw from the study at any time and can refuse to answer questions without negative consequences.

To ensure confidentiality, the names of the participants will not be recorded and that information will not be made public or available to others.

Written permission to conduct the research was obtained from the University of Namibia and the Ministry of Health and Social Services.

Your assistance in this study will be highly appreciated.

Thank you very much.

## **Appendix G: Interviews**

TRANSCRIPTS OF AN INTERVIEW ON THE EXPERIENCE OF MEN  
DIAGNOSED WITH PROSTATE CANCER IN THE FOUR NORTHERN  
REGIONS (OHANGWENA, OMUSATI, OSHANA, OSHIKOTO)

Participant no: 7

Date: 25.09.2014

Time: 10:00–11:05

Language of interview: Oshiwambo (translated to English)

Place: Intermediate Hospital Oshakati (Nuclear Medicine Unit)

Region of the Participant: Oshikoto

Age: : 59

Researcher: Good afternoon sir. My name is Salomo Salomo, a student at the University of Namibia. I am doing a research on the experience of men diagnosed with prostate cancer in Oshana, Ohangwena, Oshikoto and Omusati regions. The study will enable me to have an understanding of the experiences that men diagnosed with prostate cancer. It will also enable me to make recommendations to the Ministry of Health and Social Services in terms of how health workers can support cancer patients who have to go through the prostate diagnostic process.

I would therefore like you to grant me a permission in order to interview you for the purpose of this study, as I have already explained to you earlier. I would like to assure you that, your identity will remain anonymous during the presentations, reports and publications of this study. On the other hand, the results of this study will only be used for the purpose of the study, and your name will not reflect anywhere in the study. Shall you please grant me a permission to interview you?

Participant: Yes, we can proceed.

Researcher: What is your experience with prostate cancer after being diagnosed?

Participant: You know this disease is scary... [while making himself comfortable on a chair], so I am appreciating and thank God because I have accepted the disease. I have accepted it without any fear and I have noticed that the treatment that I got has helped me may be because of my acceptance of the disease. It is difficult for a person with cancer because if you are better today, tomorrow you start feeling ill again. If we came to the cancer clinic the doctors use to help us well and we appreciated that. The difficulties that we have experienced as men are that... [paused], health workers use to tell us that cancer usually affect men around the age of 50 or 55 therefore informed us to visit the doctor but most of the time we find ourselves not knowing where to go because when you go to the state hospital to be screened of cancer sometimes they use to ask us that who told us that we are having cancer, or they simply tell us that they are too busy. I noticed that I have been living with this disease for almost 10 years.....[putting his hands together] and when I went to the private doctors requesting to be examined for prostate cancer they only gave

me various medicines until the disease progressed without being given an appropriate treatment. At the last minute I got one doctor who helped me and I asked that doctor to examine me for prostate cancer. It was at that point when this doctor took the investigations and gave me the results by telling me that I was having prostate cancer and he will send me to the specialist at Oshakati hospital. From there I come to Oshakati and find one good doctor who helped me and later send me to Windhoek. When I went to Windhoek the doctors helped me and put me on one machine that detected that I was having a disease that I have been living with for a very long time, may be because the doctors could not notice it earlier enough. He informed me that my disease has affected the prostate, testes and the bones. The doctor also informed me that it can only be treated with an operation in order for me to live for some years. I decided and signed to be operated and they operated on me. They removed a certain tissue below the testes and from there I started getting much better. They then told me to keep on coming for follow ups at the cancer clinic in order for the doctors to check on my progress. Now the situation is much better even though cancer cannot be cured, at least I am better and a bit confident... [taking a deep breath].

Researcher: Earlier you have stated that sometimes you use to be better but the next day you start getting sick again. Could you specify where and how the sickness uses to be?

Participant: Yes ... [while nodding the head], I can able to tell you. The doctor who diagnosed me is a good one. He informed me that cancer is of different types



because it can be found in the blood, bones, wounds, brains and in the throat. He informed me that mine has extended to the bones. I use to experience bone tenderness that is why I was taken to the machine in order for the doctor to determine its severity. Tenderness in the bone uses to be severe in the night when sleeping but in the morning you are just fine. If you go and talk to a person who is having cancer that is different from that I have, he/she might tell you different experiences because cancers differs...[laughing]. Prostate cancer nowadays seems to be common and aggressive therefore as health care workers you need to screen men. As I have already told you that doctors use to refuse...[shaking the head] screening men for prostate cancer. On the other side some men are very fearful as they usually refuse to seek for cancer screening thinking that doctors might diagnose them of cancer. This delay may result in one to be diagnosed while cancer is already at advanced stage because prevention is better than cure. However there are also some men who are willing to be screened of prostate cancer but they do not know to which doctor they can go. For example when you go to casualty department asking for doctors who can screen you for prostate cancer, health care workers will just tell that they don't know them. That is the main problem.

Researcher: You said the doctor had screened you of prostate cancer after you insisted for it because you had initially visited various doctors but none of them performed it. You have also said that such screening has then resulted in you being diagnosed of prostate cancer. What made you think that you might be having prostate cancer?

Participant: Let me give you the information... [leaning forward]. I experienced a small and hard abscess like a stone at my testes. When I went to a doctor he put on gloves and examined me by touching it. When he gave me medicines I was then thinking that it might burst open or he might operate on it but nothing happen...[shaking the head]. This lasted for many years. One day I listened to the radio and people were talking about prostate cancer telling man that if they have experienced signs on their reproductive organs such as abscess on the testes they should visit their doctors in order for them to be screened of prostate cancer. From there I then decided to tell one doctor to screen me of cancer. However the doctor could not do it but rather asked me to tell him the person who told me that I was having cancer. I finally once again decided to request another doctor to screen me of prostate cancer. When that doctor took some investigation, later he gave me the results saying that I am having prostate cancer. That time the doctor could not waste time therefore he referred me to other doctors in Windhoek who also informed that I was having prostate cancer. Basically I got the information about prostate cancer from the radio and that convinced me that I was having cancer. However, doctors have just kept on giving me pills without screening me of cancer until the sickness became worse.

Researcher: What did you start thinking after being informed that you were having prostate cancer?

Participant: I was told by a doctor in Windhoek. He asked me whether I was ready to be operated and I told him that I was ready at any time. I have also informed him that

I have accepted the disease because all along I wanted to know the type of disease that has been making me sick. I never think of anything else but I just asked God to cement my faith not to fear of this disease but rather carry it just like others who are have been diagnosed with it. I have even surprised the doctor when I told him that I was not afraid to die, therefore he should just tell me straight what I was suffering from and I shall accept it wholeheartedly. I told him that when I am on earth I am waiting to die therefore I do not have any fear but rather wanted to know what I was suffering from. The doctor even asked what type of a person I am because most people use to fear of cancer by believing that once one is diagnosed with it he/she will just die. The doctor encouraged me that I should not fear as I might still have many years to live if God permit.

Researcher: Did you say that upon the diagnosis of prostate cancer the doctor gave you information about prostate cancer:

Participant: Yes ... [adjusting himself on a chair]. He gave me a lot of information; I think about 6 different types of cancers as I have explained at the beginning. He even told me that cancer can be cleared completely should it have been detected its very early stage. He therefore said that if the doctors that I started visiting from the beginning have screened me immediately upon my request, the possibility for it to be cleared could be there. He told me that cancer can be caused by smoking, from infected wound, alcohol etc. Spice can also cause cancer according to him.

Researcher: You said initially when you started visiting the doctors they kept on referring you to one another without any screening of prostate cancer despite your request for it. How did that make you feel?

Participant: Yes, they kept on referring me to one another. That made me to plead ... [putting the hands together] with one doctor to screen me.

Researcher: What is your nearest hospital?

Participant: Onandjokwe hospital.

Researcher: What is the distance between your house and the hospital?

Participant: 20 kilometres.

Researcher: What does your culture say about cancer?

Participant: They believe that cancer is a killer disease. They are even saying that AIDS is better than cancer because if you get cancer you will just go to the grave. That is where people are having the fear because the information about cancer is not availed to them by health care workers. That has resulted in people to delay coming to the hospital because most of them will just keep on putting traditional herbs on the wounds and the time they will come to the hospital, cancer is already advanced. When the doctor asks them if the leg can be amputated, they refuse. Lack of information is the main concern; therefore if people can be given more information then things might change to the better. What I have noticed is that the main problem

lies with the hospital because what the health care workers are telling people at the radio is not what they are practicing. When you came to the hospital they never give you assistance as they were talking at the radio, therefore sometimes you just feel like going in the hospital and look for that same person who was talking because what they are talking is not what they are practicing. That is why we are saying that even if you go to the hospital, you will never get assisted. Male circumcision program is good because if you go to the hospital there is a specific department where you can go for it to be done and people knows about it, but there is nothing similar for the screening of prostate cancer in the hospital. You will never see a specific doctor for prostate cancer screening. If you got to the state hospital there is no doctor with a specific program that today I will do the screening of prostate cancer. It is not there. As you know us black people that we are fearful, you will never see us asking the doctor to do the screening of prostate cancer on us. You will never see that. I want you....[pointing at the interviewer while smiling] to go and fight that there should be routine screening of prostate cancer in our hospitals so that when the person came from home he already know the room at which such service can be offered. That is the only way you can make things better not just to talk on the radio ... [smiling].

Researcher: Can cancer be treated traditionally?

Participant: About treatment they know that it can be treated, but their believe is that if one develops cancer he/she will just die and nothing else.

Researcher: How does the person with cancer perceived culturally in the community?

Participant: Jaa...[paused], people are having different understandings. Some believe that people with cancer will just die. Others especially believers might come to you encouraging you to have hope because cancer is all over the country. Some don't care at all and mistreat you, while others will encourage you to continue with the treatment and wish strength from God. That is how we are being treated in the community. Even at homes, people might be treated in similar way as that of in the community. I have seen one man who was recently rejected by his own family after being diagnosed with prostate cancer. They are not even visiting him, but because I am counsellor I went to his house and encouraged him that I am also having cancer therefore he should not lose hope in life. I told him to be strong in faith. He sometimes even uses to tell people to call me so that I can talk to him. He later died, but with faith and courage. I was also having one neighbour who was diagnosed with prostate cancer and who use to be given injection. When she started losing hair after being given injections she became fearful until she die. Yes, if you keep on thinking about your disease you will die, but if are courageous you will be fine. Just like HIV/AIDS, if you keep on thinking about it you may became mentally ill or you might even commit suicide. That is how it is at the villages.

Researcher: You said you are not afraid to die, and that is what you even told the doctor upon being diagnosed. What type of information regarding prostate cancer were you given after being diagnosed?

Participant: I am a lucky person because I am an HIV/AIDS counsellor and I am working in a church hospital where I am a counsellor, therefore even I have gone to a certain pastor he/she will just tell me to continue doing my counselling work with courage. Therefore even after I was diagnosed I immediately called my family members and informed them about prostate cancer as my diagnosis. I told them to pray for me and behave well.

Researcher: I want to take you back a little bit. You said you have been treated several times until such a time you were diagnosed. You further informed me that you have been referred to Windhoek for further treatment. At what extent have you been counselled after being diagnosed of prostate cancer?

Participant: Hospitals are just like that as you know them...[pointing at the interviewer while smiling], if you find a better nurse to encourage you they are very few. At least at Windhoek I was encouraged by a professor from South Africa who uses to work at Windhoek Central Hospital. He informed me not to be fearful of the disease but to continue taking my medicines. That is the only doctor I have seen at least counselling me. That was also the only doctor you can engage in discussion either by seeking for clarifications or by asking him questions, but he never say he was too busy to talk to me. He was just sitting like you ... [pointing at the interviewer] talking to me and giving me information. The other Zimbabwean doctor also helped me well and encouraged me to take my medicines well.

Researcher: Were you put on cancer treatment after being treated with prostate cancer?

Participant: Aa ... [paused while looking up], with regards treatment I once asked a doctor here whether it is only Panado and Ibuprofen that can be prescribed and they said it depends on how strong one's blood is. They told me that my blood is still strong therefore I should take those medicines. I think the treatment is helping me because if there could be no treatment I might not be looking like this ... [touching his arms]. I like asking, therefore if start becoming weak I will ask them to change medicines for me. For example when I come for follow up on the 22nd September I informed the doctor that I am having tenderness of the bone, and he sent me to this machine, that is the reason why I happen to meet with you now. So, the treatment is really helping me.

Researcher: Did you notice being inserted with the urethral catheter after being diagnosed with prostate cancer?

Participant: No.

Researcher: You earlier said the information that you heard in the radio have prompted you to come to hospital to seek for the screening of prostate cancer, however at the hospital doctors kept on referring you from one doctor to the other without any screening for prostate cancer despite you having been convinced by what you have heard from the radio. Having being treated in such a manner, how did that make you feel?

Participant: Ja ...you always have to feel bad. After such many referrals you will even start searching for a doctor of your choice. The main big concern with doctors



especially the blacks ones is that, even if they examined or make some investigations on you they never tell you of what they found whether negative or positive, never they just look at you. I was even forced to ask one doctor what he detected after examining me and he just said I was fine. I do not like such manners; I do not know may be they use to think that if they tell us the results we may get shocked. This makes me to feel bad. I even told him that I am not a child, just tell me. I said he should tell me what to eat and what to drink. Because if he tells me to drink water, I shall just drink water ... [laughing]. When people are saying our doctors are not working or our hospitals are not working is because of these things ... [paused], people are worried ... [touching his chest].

Researcher: You told me that after being diagnosed of prostate cancer by the doctor you came home and informed your family about it. How can you describe the assistance that you got from your family members after being diagnosed with prostate cancer?

Participant: I thank God because when I informed them they all accepted it because I told them to believe in God. I have also informed them that whether I am having cancer or not I still have to die. The support from the family is very good because the children and my wife have all accepted it. For now I am not yet seriously sick therefore I am just doing my work as usual. With regards to the behaviours, they are still behaving well as usual. The support at home is really going on well.

Researcher: You said you have just been recently diagnosed of prostate cancer after 10 years of enduring the sickness, despite having been visiting various doctors

without any investigations done for prostate cancer. What do you think was the cause of the delay for the diagnosis of prostate cancer?

Participant: Ja ... [taking a deep breath], all I can say is just that I have started getting sick long ago but this cancer was support to be diagnosed early but the doctors who attended to me first did not do their job well. That is also what the professor at Windhoek told me when he said number one, I started getting sick long time ago and I have even requested them to screen me for prostate cancer which they did not do. This was now the 11th year of living with an illness. He informed me that if these doctors could have detected prostate cancer earlier, he could have helped me better. He therefore told me that he is blaming them because they did not manage me well from the beginning.

Researcher: What recommendations can you give to the Ministry of Health and Social Services with regards to the care of patients with prostate cancer?

Participant: Ja ... [taking a deep breath], the only mistake I did was when I could not ask the doctor about the cause of prostate cancer. There I did a mistake. With regards to the Ministry, they should practice what they say in the radio and they should put mechanisms in place whereby hospitals and clinics can have doctors to conduct a routine screening of prostate cancer and that should be known by all the men so that they can go and be screened. Should that happen, I do not think there will a man who will remain unscreened of prostate cancer. Things will just go well as it is currently happening with male circumcision. Male circumcision is now going on well because people have been well informed about it and they understand. If the ministry did not

put up specific clinics for the screening of prostate cancer then, people will not know anything about the screening of prostate cancer. This is just like what I told you from the beginning that, even if you go to Oshakati hospital now and ask health care workers to tell you where you can go for the screening of prostate cancer, they will not tell you anything or they might not even listen to you and you will just go back home. If you go to the clinic where there is a doctor and ask about the screening of prostate cancer they will just tell you that they never heard about such screening before. Only those who are having money can afford such service because if you go to Medipark they will eventually do it for you, unfortunately most of our people do not have such money. The ministry should put in place specialised doctors where we can go straight for such services. They talk well in the radio, but if you go to the hospital you will never be given such information. The ministry can set up a schedule of days on which the screening of prostate cancer can be done, but if we are just waiting for people to get sick before we screen them that will not help anything...[shaking the head while looking down].

Researcher: Anything else you might want to comment before we end our interview?

Participant: Aaa ... [while looking up], Cancers are more less the same, therefore I just want to urge those who are having cancer to accept the disease. The person will just die even if he/she does not cancer. We also want our counsellors to help us well. Especially in Windhoek people with cancer are being helped well, but at our areas here aah ... [shaking the head while smiling], our hospitals are just like the way you know them. I am also urging people like you who are studying ... [pointing at the

interviewer] to help people with dedication upon the completion with your studies. I also want you to go and tell the ministry that people are saying that they do not know where to go for the screening of prostate cancer.

Researcher: Thank you very much.

Participant: Thank you too.