

**THE BIO-PSYCHOSOCIAL EXPERIENCES OF BLACK MEN  
LIVING WITH PROSTATE CANCER**

**BY**

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## DECLARATION

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I hereby declare that this research report (mini-dissertation) is my original work. All secondary material used has been appropriately referenced and acknowledged in accordance with the regulations of the University of Pretoria.

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Signature

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Date

## DEDICATION

This dissertation is dedicated to all men living with prostate cancer and their partners worldwide, who are still going strong through the thick and thin of this illness.

God bless you!

## ACKNOWLEDGEMENTS

Firstly special thanks to my God, my Alpha and Omega, the One who knows and understands my destiny.

I would like to thank my supervisor, Mrs Bila. You went above and beyond by providing me with support and guidance. Words cannot express my gratitude to you. I am more appreciative than you will ever know, Thank you!

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Finally, I humbly acknowledge and appreciate the support I received from my family, friends, hospital team, colleagues and participants for the successful completion of this project.

*Ke le lebogathata!* Thank you so much.

## **ABSTRACT**

### **THE BIO-PSYCHOSOCIAL EXPERIENCES OF BLACK MEN LIVING WITH PROSTATE CANCER**

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Studies have shown that men tend to neglect matters relating to their health. Men also suffer from health related conditions like cancer and yet men are generally more likely than women to ignore health related matters, or are reluctant to visit health care facilities like clinics and hospitals to seek medical assistance until symptoms become very pronounced. Cancer is one of the major killers both in developed and developing countries, including South Africa. Recent statistics indicate that black men are at increased risk of prostate cancer and often develop an aggressive type of prostate cancer (CANSAs, n.d.:14).

Living with prostate cancer is a huge challenge for black men, because it is a health condition that is accompanied by life-threatening experiences which include psychological, physical, social and biological challenges. The perception that prostate cancer is relatively rare among black men is incorrect, as the condition means a dramatic change of a man's life and puts a huge burden on their partners. It continues to present with several enduring challenges that continue to defy solution despite extensive research.

Several studies of prostate cancer have been conducted worldwide, so literature on men with prostate cancer is extensive. Despite this there are still gaps, such as

experiences of black men with prostate cancer in South Africa. It is therefore the researcher's conviction that specific research on black men living with prostate cancer in the South African context is scarce.

The goal of this study was to explore and describe the bio-psychosocial experiences of black men living with prostate cancer. The researcher conducted the study using a qualitative approach, with face-to-face, semi-structured interviews with 10 black men from the Pretoria Urology Hospital. The researcher used purposive sampling to select the participants.

The study findings revealed that experiences of black men with prostate cancer are more serious than expected. The aftermath of this condition is characterised by various elements such as fear, stigma, shame, loneliness, status, loss, pain, embarrassment, non-disclosure, cultural barriers, patriarchy, as well as communication barriers with significant others about their real feelings. The issue of communication with their partners about the impact of the condition on their sexual life appeared to be a serious concern with most of the participants. Furthermore, prostate cancer is still perceived as a very personal matter that is kept secret among black men. In addition, lack of support groups as well as failure to utilise the resources because of non-disclosure and a feeling of embarrassment among black men is still a huge problem. The study concludes that living with prostate cancer as a black man is characterised by a complex combination of social, cultural, psychological, biological and physical challenges, which continue to have an impact in the lives of black men.

Recommendations from the study include encouraging black men to participate in voluntary screening, and intensifying the campaigns to deal with the issue of cultural beliefs and lifestyles, as well as the value of early diagnosis. Comprehensive prostate cancer education to address the lack of knowledge and emphasise the resources available for the survivors is also recommended. Furthermore, future research on the following issues is recommended: firstly challenges encountered by partners of black men living with prostate cancer and, secondly, how the cultural practices of the current era impact the health decisions of black men.



## **KEY WORDS**

Cancer

Prostate

Prostate cancer

Black men

Diagnosis

Experiences

Survivors

Bio-psycho social

Support system

Needs

## ACRONOYMS

AAM	African-American Men
BPS	Bio-psycho Social
CAM	Caucasian American Men
CANSA	Cancer Association of South Africa
DRE	Digital Rectal Examination
GP	General Practitioner
IARC	International Agency for Research in Cancer
NCI	National Cancer Institute
PC	Prostate cancer
PSA	Prostate specific-antigen
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TNM	Tumor, Nodes and Metasis
UK	United Kingdom
USA	United States of America
WHO	World Health Organization



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# CHAPTER ONE:

## GENERAL INTRODUCTION AND ORIENTATION OF THE STUDY

### 1.1 INTRODUCTION

Cancer has been considered to be a problem primarily in westernised, developed countries, but today in fact the incidence of cancer is the highest in low and medium income countries, including South Africa. Identifying the causes of many cancers is complex and the prevention and treatment of these cancers is even more difficult (Ross & Deverell, 2010:134). Cancer is one of the most common diseases that affect both adults and children. Prostate cancer is one of the most age-dependent cancers; rare before the age of 50, it increases at a rate thereafter (Foulkes & Cooney, 2010:8). Prostate cancer, like all other cancers, is a disease that brings uncertainty to the patients and their families. Different pieces of literature have identified prostate cancer as one of the cancers that is prevalent in black men.

However, few studies have examined the range of psycho-social factors associated with prostate cancer, such as patients' appraisal of the illness, their resources to manage the illness, the risk for developing long-term emotional distress, and diminished quality of life (American Society of Clinical Oncology, 2015). Although prostate cancer is traditionally known as the "killer" disease, if early diagnosis and symptoms can be given swift attention, chances of survival are high. In Galbriath, Frink and Wilkins (2011:303), prostate cancer is regarded as the most common non-skin cancer diagnosis for men. One in six South African men will get cancer during their lives. In order of prevalence the cancers affecting all South African men are prostate, lung, oesophagus, colon and rectum (CANSAs, n.d.:14). The modern technologies and the types of treatment, as well as early diagnoses are assisting many men to survive prostate cancer and lead a normal life during and after treatment. However, these men might experience a variety of medical and physical effects as well as psychological effects. Since the man is part of a system, the diagnosis and living with cancer will not only affect the man but it will also affect his significant other and immediate family.

The widespread incidence and prevalence of cancer globally is increasing. It is essential that health care practitioners have an understanding of the disease, as well as its psychosocial implications (Ross & Deverell, 2010:134). Worldwide incidence of prostate cancer is 25.3 per 1000,000. It is the second most common cancer in men, with large differences between countries (Ramon & Denis, 2007:1). There are currently more than 1.9 million men living with prostate cancer in the United States of America (USA) (Ramsey, Zeliadt, Hall, Ekwueme & Penson, 2007:92).

Prostate cancer occurs in all social strata and in the USA, but its incidence is almost twice as high in black men as in white men. In 2008 alone there were 12.4 million cancer cases and 7.6 million cancer deaths worldwide. In men, prostate cancer is now the most common form of cancer diagnosed in the more developed regions (WHO, 2008:42). Cancer is one of the major killers throughout both the developed and developing world, including South Africa. Prostate cancer is most prevalent amongst white South Africans, however the recent statistics indicate that black men are at increased risk of prostate cancer and often develop an aggressive type of prostate cancer (CANSAN, n.d.:14). However, these men might experience variety of medical and physical effects, as well as psychological effects. Cancer is a family affair and not an isolated experience of the affected man alone; social work services are crucial to assist the whole family to adjust and cope with the disease and to improve their quality of life during and after the treatment. It is thus imperative for the social worker to have an understanding of the bio-psychosocial experiences of men living with cancer. The proposed study focused on the bio-psychosocial experiences of black men with prostate cancer, to help them cope with their stress levels, involve them in counselling programmes, and allow them to gain more knowledge on living with prostate cancer with regards to their specific socio-cultural context.

### **1.1.1 Definitions of Key Concepts**

The key concepts for this study are:

- **Cancer**

According to Cooper (1993:3), cancer is a disease fundamentally characterised by uncontrolled cell growth. Cancer results from abnormal

growth of otherwise healthy cells. Cancer cells continue to grow and divide without restraint, eventually spreading throughout the body and interfering with the function of normal tissues and organs, eventually leading to death. The term cancer covers well over 100 different medical conditions. Different cancers have unique characteristics requiring different treatments. It is frequently a chronic disease that is sometimes called a “malignant disease”.

- **Prostate**

Kirby, Christmas and Brawer (2001:5) explain prostate as the term that was originally derived from the Greek word ‘*prohistani*’ meaning ‘to stand in front’, and has been attributed to Herophilus of Alexandria who used the term in 335 B.C. It is described as the organ located in front of the urinary bladder and it is further defined as the gland in men that surrounds the neck of the bladder and the urethra and produces a secretion that liquefies coagulated semen (*Mosby’s Medical Dictionary*, 1994).

- **Prostate Cancer**

Prostate cancer is a slowly progressive adenocarcinoma of the prostate that affects an increasing proportion of males mainly after the age of 50 (*Mosby’s Medical Dictionary*, 1994). It is the most common non-cutaneous cancer in men, with increasing incidence in older age groups and rarely diagnosed clinically in men under 40 years of age (American Joint Committee on Cancer, 2010:459).

- **Black men**

The word black refers to the member of a race of people who have dark skin. For the sake of this study it refers to black men living with prostate cancer in South Africa. In other countries like the USA, black people are referred to as African American (Hornby, 2010:138).

- **Diagnosis**

This medical term refers to the discovery of a disease on a person (*Compact Oxford Thesaurus*, 2007:205). The diagnosis of clinically suspicious areas of

the prostate cancer can be confirmed histologically by needle biopsy and also by inspection of the resected tissue from a transurethral resection of the prostate for obstructive voiding symptoms (American Joint Committee on Cancer, 2010:460).

- **Experiences**

The term refers to undergo or come into contact with a particular situation (*Compact Oxford Thesaurus*, 2007:277). In this study it refers to black men who are faced with prostate cancer.

- **Survivors**

This term refers to the people who continue to live, especially despite being nearly killed or experiencing great danger or difficulty. In this study it refers to survivors of prostate cancer and those who are able to deal with the difficult situation of living with prostate cancer (Hornby, 2010:1506).

- **Bio-Psychosocial theory**

Bio-psycho-social theory refers to a combination of biological, psychological and social factors (*Mosby's Medical Dictionary*, 1994) and the bio-psycho-social theory is sometimes referred to as a holistic view, because it focuses on the whole picture of a person; the body and mind as a whole, as well as the external environmental and social factors of the person (Cowles, 2000:12). In this study it refers to the experiences of the black men with prostate cancer in relation to their biological, social and psychological factors.

- **Support system**

The definition of the term refers to provide for, maintain, sustain, keep, take care of, or look after. In this study it means the support that participants receive from significant others including churches, families, workplaces and other organisations relevant to their lives (Hornby, 2010:804).



- **Needs**

It means to require something, because it is essential or very important, not just because you would like to have it. In this study it refers to the needs of black men living with prostate cancer, including support, food and medication (Hornby, 2010:986).

## **1.2 THEORETICAL FRAMEWORK**

The bio-psychosocial model is sometimes referred to as a holistic view, because it focuses on the whole picture of a person; the body and mind as a whole, as well as the external environmental and social factors of the person (Cowles, 2000:12). Furthermore, Ross and Deverell (2010:14) state that “the biomedical model essentially keeps health in the biological context, while the bio-psychosocial model places it in the social context.” In order to understand the psychosocial experiences of black men with prostate cancer, a social worker must attend simultaneously to all three levels of the person to treat the person holistically. In a nutshell, the researcher sees the bio-psychosocial model as an expansion of the biomedical model. Since the model entails biological, psychological and social factors, the researcher believes that it is relevant to the nature of the study which aims to study the bio-psychological experiences of black men with prostate cancer.

A detailed description of the theoretical framework is provided in Chapter Two of the study.

## **1.3 RATIONALE AND PROBLEM STATEMENT**

Prostate cancer presents several enduring challenges that continue to defy solution, despite extensive research. It has long been known that prostate tumours become increasingly prevalent with age, so much so that their occurrence could be viewed as part of the normal ageing process, as the vast majority of men will develop them if they live long enough (Foulkes & Cooney, 2010:3). Most studies regarding prostate cancer amongst black men were conducted in the USA. Black men have the highest incidence of prostate cancer, the highest mortality rates, and they are more likely to have an advanced stage and grade of prostate cancer at initial presentation. There is

no clear indication of the reason for the greater risk and more aggressive quality of prostate cancer among black men. Of possible relevance are biological, economic, nutritional and socio-cultural factors (Gray, Fergus & Fitch, 2005:71). In Africa cases of cancer are estimated at 0.7% and deaths related to cancer at 0.5% (WHO, 2008:42). Prostate cancer occurs in all social strata and in the USA its incidence is almost twice as high in black men as in white men (Ramsey et al., 2007:1993). The National Cancer Institute (NCI) (Tanner, Galbraith & Huys, 2011:65) states that men with prostate cancer make up about 20% of all cancer survivors. Furthermore, all survivor groups the number of prostate cancer survivors is increasing at the most rapid rate (Ramsey et al., 2007:348).

In order of cancer prevalence in South Africa, prostate cancer is ranked number one in men. In black South African men prostate cancer is the second most common histologically diagnosed malignancy (Heyns, 2007:348). The International Agency for Research in Cancer (IARC, n.d.:13) reported that approximately 681 000 new cancer cases and 512 400 cancer deaths were reported in Africa in 2008, including South Africa. These numbers are projected to nearly double to 1.28 million new cancer cases and 970 000 cancer deaths by 2030, due to aging and growth in the population (IARC, 2013). Studies done in North America found that black men with prostate cancer have diverse experiences and are influenced by a wide array of personal and societal factors (Gray et al., 2005:71).

Several studies on prostate cancer have been conducted, so literature on men with prostate cancer is extensive. Apart from this, there is still a gap such as the experiences of black men living with prostate cancer in South Africa. It is therefore the researcher's conviction that specific research on black men with prostate cancer in the South African context is scarce. The researcher has chosen to focus on the black men diagnosed with prostate cancer and on treatment. The researcher saw an opportunity to explore men's health issues more, particularly amongst black (men). The study enabled the researcher to put to rest the myths that cancer is only for certain groups of people, which is supported by studies conducted by Heyns (2007:348). The perception that prostate cancer is relatively rare among black men is incorrect, as the studies conducted found that the incidence of prostate cancer among black men is high as compared to white men. On top of this, cancer

incidence data in Africa are likely to underestimate the true rates because of under-diagnosis and underreporting. There have been no sound prevalence studies done in Africa.

Therefore, the researcher found it relevant to undertake this study on the bio-psycho-social experiences of black men with prostate cancer. In the study the researcher gained a better understanding of the psychosocial experiences of prostate cancer patients regarding the challenges that they face in their daily activities. Furthermore, the research might contribute to the knowledge base of health care workers to enable them to support and guide prostate cancer patients, as well as improving the necessary intervention.

The study's research question was:

**What are the bio-psycho-social experiences of black men living with prostate cancer?**

## **1.4 GOAL AND OBJECTIVES OF THE STUDY**

### **1.4.1 Research Goal**

The **goal** of the study was to explore and describe the bio-psycho-social experiences of black men living with prostate cancer.

### **1.4.2 Research objectives**

- To contextualise prostate cancer as a phenomenon amongst men from different cultures.
- To explore and describe the psychosocial experiences of black men living with prostate cancer.
- To describe the experiences of black men with prostate cancer from different cultural groups.
- To improve social work intervention for black men living with prostate cancer.

## **1.5 RESEARCH METHODOLOGY**

The qualitative research approach was applied in the study, because of the nature of the study which is exploratory. The researcher used the case study design which was aimed at gaining insight into and an understanding of black men with prostate cancer. The population of the study was black men with prostate cancer from the case load of one doctor at the Pretoria Urology Hospital. The data was collected through the use of a semi-structured interview schedule.

A more detailed description of research methodology is in Chapter Three of this report.

## **1.6 LIMITATIONS OF THE STUDY**

The objectives of the research were achieved, however there were few limitations encountered during the study. Since the aim of the study was to focus only on black men living with prostate cancer, the recruitment process of the list provided was a challenge, so it was time-consuming for the researcher to finally get the participants' consensus. The researcher had to recruit them on the phone and as well as give them more time to consult with their families before travelling to their different homes to collect data.

The first challenge was to recruit the black men to participate in the study. It proved challenging due to the nature of the topic, which is very personal, and the fact that sexuality in black men is a serious issue which is not easy to share with others, particularly with a young woman (the researcher). The issue of cultural barriers in black men was a challenge and as a result the researcher spent time to build relationships with the men and gain their trust before the information was gathered.

As a result the researcher spent more time on data collection during the study. Some men from the list that the hospital provided refused to participate in the study. However, in the end 10 participants agreed and through the semi-structured interview schedule the men were able to open up and shared their experiences without any fear. Furthermore, the researcher only used a small sample in the study,

which might not represent the views of all black men with prostate cancer in South Africa.

## 1.7 DIVISION OF THE RESEARCH REPORT

The research report is divided into four chapters.

**Chapter One** is an introduction and description of the orientation of the study. This chapter also contains the study's key terms which are defined, followed by a brief description of the theoretical framework, the rationale and problem statement, the goal and objectives of the study, the research methodology, and limitations of the study.

**Chapter Two** is a review of literature on the experiences of black men with prostate cancer. This is discussed within the bio-psychosocial approach.

**Chapter Three** is a detailed discussion of the research methodology and research findings are provided.

**Chapter Four** includes a summary of the research findings, the conclusion and recommendations.

The next chapter focuses on the detailed experiences of black men living with prostate cancer.

## **CHAPTER TWO: THE BIO-PSYCHOSOCIAL EXPERIENCES OF BLACK MEN LIVING PROSTATE CANCER**

### **2.1 INTRODUCTION**

Prostate cancer, like all other cancers, is a disease that brings uncertainty to the patients and their families. Different pieces of literature have identified prostate cancer as one of the cancers that is prevalent in black men. It is also important to note that the issue of black men living with prostate cancer is a global challenge that needs swift attention. Therefore, this chapter provides a summary on the prevalence of prostate cancer globally and a detailed discussion of the bio-psycho social model, which was selected to inform the study's theoretical framework. Furthermore, a detailed discussion on the psycho-social experiences of black men is included.

The chapter also contains a detailed description of the bio-psychosocial model, the impact of prostate cancer on different aspects; the prevalence of prostate cancer globally, in Africa and South Africa; the etiology, presenting symptoms, and risk factors associated with the development of prostate cancer; as well as the stages of prostate cancer. Furthermore the clinical diagnosis of the condition and treatment of prostate cancer is discussed, followed by the experiences of men with prostate cancer and finally the role of social workers dealing with prostate cancer patients are discussed in this chapter.

The following discussion centres around the bio-psychological model as theoretical framework of the study.

### **2.2 DESCRIPTION OF THE BIO-PSYCHOSOCIAL MODEL**

The bio-psychosocial model is derived from the general systems theory and it views people as being influenced by many factors, such as environmental, psychological and social considerations (Ross & Deverell, 2010:13). The term bio-psychological model was coined by Roy Grinker in 1954 when he used the term in psychiatry to

emphasise the biological against the psychoanalytical orthodoxy (Alvarez, Pagani & Meucci, 2012:173). In 1977 George Engel developed this into a model to be applied to the whole discipline of medicine and not just psychiatry (Alvarez et al., 2012:174).

Furthermore Ross and Deverell (2010:14) state that “the biomedical model essentially keeps health in the biological context, while the bio-psychosocial model places it in the social context.” In order to understand the psychosocial experiences of black men with prostate cancer a social worker must attend simultaneously to all three levels of the person to treat the person holistically.

The bio-psychosocial model is sometimes referred to as a holistic view, because it focuses on the whole picture of a person; the body and mind as whole, as well as the external environmental and social factors of the person (Cowles, 2000:12).

Ogden (1996:5) also describes the bio-psychosocial model as an attempt to integrate the psychological (the psycho) and the environmental (the social) into the traditional biomedical (the bio) of health as follows: the bio contributing factors include genetics, viruses, bacteria and structural defects; the psycho aspects of health and illness are described in terms of cognitions (expectations of health), emotions (fear of treatment), and behaviours (smoking, diet, exercise); and the social aspects of health are described in terms of social norms of behaviour (e.g. the social norm of smoking or not smoking).

In a nutshell, the researcher sees the bio-psychosocial model as an expansion of the biomedical model. Since the model entails biological, psychological and social factors, the researcher thinks that the bio-psychosocial model is the most applicable one for this study as the researcher is hoping that it will contribute to understanding the experiences of black men living with prostate cancer, which will influence the appropriate intervention that can be used to empower them, their families and their medical teams, including medical social workers who deliver services in this context. The researcher is of the opinion that the chosen model was relevant to the study as prostate cancer does not only affect the patient, but also his surroundings. Therefore, health is best understood in terms of a combination of biological, psychological and social factors, rather than the biological factors only. This model

assisted the researcher to develop a better understanding of the bio-psychosocial experiences of black men living with prostate cancer. In this study the researcher also explored all the factors of the model to determine the real experiences of the black patients living with prostate cancer.

## **2.3 IMPACT OF PROSTATE CANCER ON DIFFERENT ASPECTS OF MEN**

Men experience a complex journey living with prostate cancer. A study done in the USA found that men with localised prostate cancer continue to experience treatment related problems that have detrimental effects on their quality of life long after treatment ends, and that patients with rising prostate-specific antigen (PSA) had significantly more bothersome problems related to sexual and hormonal function as compared to men without rising PSA. Studies of men with advanced prostate cancer indicate that treatment can cause complications (reduced libido, fatigue) that can interfere with quality of life and they also report poorer physical and functional well-being (American Society of Clinical Oncology, 2015). Furthermore, in England a study was done by a national survey of cancer patients in 2000 which showed that experiences of patients with prostate cancer were often worse than those with other cancers (Sinfield, Baker, Agarwal & Tarrant, 2008:91), in the sense that the prostate cancer patients experience more challenges and its impact on their lifestyle is very severe. The challenges of men living with prostate cancer and how it affects the aspects of their lives will be discussed in detail. The following aspects are included in the discussion: psychological, physical, emotional, social, culture and gender, sexual life, financial, and marital life.

### **2.3.1 Psychological Aspect**

A study done has shown that men's psychological adaptation is poor and men seem to fare worse than women in adapting psychologically (Nicholas, 2000:30). At the psychological level the cancer diagnosis in itself, even if associated with a prognosis and an absence of aggressive therapy, may be perceived as synonymous with death, pain and suffering and can cause significant psychological distress (WHO, 2008:83). The above-mentioned authors are correct in a sense that since the cause of cancer is unknown and for a long time people associated cancer with death, at



times without listening and understanding the medical team during diagnosis, patients might misunderstand the doctor and misinterpret him/her, thus causing more stress for patients adjusting to this life-threatening situation. The psychological impact of prostate cancer may bring confusion and despair to the patient and the family if they are not properly informed about the extent of the disease and the side effects of treatment.

### 2.3.2 Emotional Aspect

Once the diagnosis of cancer has been confirmed, the family typically progresses through the emotional stages described by Kubler-Ross such as shock, disbelief, anger, guilt and readjustment (Barraclough, 1994:2). The first stage is *shock and disbelief*. The family can become numb on first learning the truth. The bad news seems to be too much to take in. This may be called the stage of denial. Ball and Bindler (2003:271) indicate that the stage of shock and disbelief begins in the first few moments after diagnosis and can last for days. During this period couples need more answers and explanations about the illness. The shock helps to postpone the full impact of the crisis. This is followed by the stage of *anger and guilt*. Anger and guilt surface as the family becomes more aware of the illness. The man's anger may not be directed towards anyone in particular. Men may also react to their own illness with some degree of guilt. The fact that the guilt usually has no basis in real events does not lessen the feeling. At this stage they will need their families for support, particularly their wives. The next stage is *deprivation and loss*. During this stage, the men enter a stage of deprivation and loss related to their father/husband role. The fact that they have suddenly changed from a familiar role of being a provider to their families, to the unexpected role of being a sick father or husband might make them feel helpless and worthless. The last stage is *gradual readjustment and acceptance*. As the father/husband's condition improves the family may readjust their life to normal, but if the father/husband's condition deteriorates, the family may re-enter the cycle of emotions characterised by fear and grief. The above-mentioned emotional reactions are not rigid, but will differ from one individual to the other depending on their circumstances. The role of the social worker is to support the man and the family while they go through these emotions. Dealing with these emotions will

eventually assist the family to cooperate in order to transform to these emotions into positive behaviour.

### **2.3.3 Physical Aspect**

There are numerous physical conditions that may arise as a result of prostate cancer and its various treatments. The treatment of prostate cancer has different effects, depending on the methods applied and the aggressiveness of treatment. At the physical functioning level the principal means of treating cancer, namely surgery, chemotherapy and radiation, are powerful but often associated with significant sequel. Decreased performance status and physical functioning may lead to problems in carrying out daily activities. The treatment may involve physical mutilation and hair loss, as well as symptoms like pain and vomiting (WHO, 2008:83). In a study conducted in the USA amongst African-American men a lack of energy appeared to be a prominent contributor to the worsening of well-being, and problems with urinating were limiting the men's activities (Chhatre, Wein, Malkowicz & Jayadevappa, 2011:186).

### **2.3.4 Social Aspect**

At the social level, concerns with regard to relationships with a partner, family members, or with social networks may be raised. Cancer patients may experience feelings of loneliness, abandonment and lack of support (WHO, 2008:83). This was confirmed in a study done in Norway which found that prostate cancer is the most common cancer amongst men and that side effects influenced their daily activities and relationships (Ervik & Asplund, 2012:103).

In conclusion, since prostate cancer mainly affects older age groups it might be difficult to cope as the partner of the patient, as it is during the later stage of life that the couple needs each other more for support. When one is no longer capable of taking care of the other, it may become too much to bear as a partner. These men belong to various social structures which form part of their support system. Therefore an external support system of friends, relatives, church members and colleagues is important for the patients during this time.

### **2.3.5 Culture and Gender**

Gender has a significant impact on how men understand and experiences sickness and illness. In a study done by Cameron and Bernades in Britain (in White, 2002:149) where in-depth interviews and questionnaires were used, it was found that men tend not to discuss their physical symptoms and 6% of the respondents reported that they were not even telling their spouses of their painful and intrusive condition. It became evident in this study that culture and gender might be an obstacle in communicating feelings amongst black men living with prostate cancer.

Another study conducted in the USA found that a socio-cultural practices in black African-American and black Caribbean society groups is a contributing factor. In screening for prostate cancer, the black men sampled tended to perceive the test as a threat to their masculine identity and an undignified procedure. A lack of tradition in black communities concerning regular check-ups or preventative care was prevalent (Pedersen, Armes & Ream, 2011:465).

### **2.3.6 Sexual Life**

Normal erectile function may be disturbed in prostate cancer patients by a number of factors. The erectile nerves may be damaged during surgery, following external beam radiotherapy, or late after brachytherapy, and the resultant erectile dysfunction may be irreversible (Kirby et al., 2001:201). Sexual dysfunction can entail disturbance of libido, erectile function, ejaculation and fertility, or a combination of these. These perturbations can have a major impact on the quality of life, not only of the patient but also of his partner (Kirby et al., 2001:199). There are several studies done with regard to the issue of the sexual life of men with prostate cancer, including black men.

A study 289 men in the USA undergoing external beam radiotherapy for prostate cancer has shown that 62% of those who were potent before treatment remained potent at 12 months. At 24 months this figure reduced further to 41%. Only 62% of

men have been shown to have a return of normal erectile function after this treatment (Kirby et al., 2001:203).

In another study done with 15 sexually active men who underwent cryotherapy for clinically localised prostate cancer, 60% had erectile dysfunction for 6 months after treatment. Another study of 90 non-radiated men treated by cryosurgery for prostate cancer revealed erectile dysfunction at 18 months in 88% of the 74 men who had normal erections before treatment (Kirby et al., 2001:204).

A study conducted in the USA on sexual relations reported that sexual concerns remained high and most men were concerned about sexual issues and reported low satisfaction with their sexual functioning, but relatively few sought treatment (Galbriath et al., 2011:38). Another study done in the USA regarding sexuality is that sexual changes are common, especially after treatment, with 33% to 98% of patients reporting some degree of sexual dysfunction regardless of treatment modality cited (Tanner et al., 2011:154).

It was further mentioned in Pedersen et al. (2011:465) that amongst black men, fear of erectile dysfunction, sterility and decreased sex drive associated with treatment were also identified as factors potentially deterring men from being tested for prostate cancer. Other studies done amongst African-American men indicated that the ability to have and maintain an erection was of highest concern. It was also found that in African-American men problems with urinating were limiting their activities. In conclusion, it appears that injuries occur during treatment and lead to a high risk of impotence. Sex can be a challenging aspect to communicate about, as the patients might feel embarrassed and as a result of their inability, they might find it hard to put on a brave face for their partners or to consult a specialist.

### **2.3.7 Financial Aspect**

A study done in the USA found that the partners of the men living with prostate cancer need to deal with other life stressors, such as being forced to learn new household skills ranging from managing the family finances to dealing with household repairs (Tanner et al., 2011:155). Finally, apart from managing the

household needs, there are financial burdens related to medical treatment and travelling from home to the hospital for check-ups.

### **2.3.8 Marital Life**

The diagnosis of cancer also tends to cause the integrity of the family system to suffer severe assault. In some instances the husband, who had previously been the dominant family figure and business manager, has to face the fact that a role reversal has occurred and his wife is now fulfilling these roles. It was also found that previously strained marriages may collapse under the stresses of financial changes and medical costs, impaired communication, and changes in family roles and lifestyle (Ross & Deverell, 2010:147).

## **2.4 PREVALENCE OF BLACK MEN LIVING WITH PROSTATE CANCER GLOBALLY, IN AFRICA AND SOUTH AFRICA**

### **2.4.1 Globally**

It is difficult to estimate the worldwide prevalence of clinical prostate cancer due to insufficient data from developing countries. The most complete epidemiological data are derived from the USA where the incidence of clinical prostate cancer has been fairly accurately documented (Kirby et al., 2001:25). In Miocinovic (2013:1), prostate cancer is the second leading cause of cancer related deaths after lung cancer in the USA. There are currently more than two million men in the USA living with prostate cancer. It is further stated that 17.6% (1 in 6 men) of Caucasians men and 20.6% (1 in 5 men) of African-American men are being diagnosed with prostate cancer. The lowest rates are observed in Asian countries, specifically China and Japan, and the highest rates are observed in North America and Scandinavia (Miocinovic, 2013:1).

### **2.4.2 In Africa**

The reported global differences in the prostate cancer burden among African countries and third world nations are highly influenced by the quality of data from cancer registries in those countries, which may be subjected to underreporting due

to limited resources for data collection, access to care and differences in infrastructure (Miocinovic, 2013:4). In Africa, while black men have been noted to have the highest incidence of prostate cancer, the World Health Organization (WHO,2008) reports a low incidence of prostate cancer in sub-Saharan African countries.

(WHO,2008) estimates for the 2002- age standardised incidence rates for Africa were 13.8/100.000 for Eastern Africa, 24.5 for middle Africa, 5.8 for Northern Africa, 40.5 for Southern Africa, and 19.3/100.000 for Western Africa. It is also suggested that the lower incidence observed among African men may be due to underreporting, lack of appropriate diagnosis, limited access to care, differences in technical manpower and infrastructure, and quality of cancer system. Therefore, cancer incidence data in Africa are likely to underestimate the true rates because of under-diagnosis and underreporting. There have been no sound prevalence studies in Africa.

### **2.4.3 In South Africa**

In black South African men, prostate cancer is the second most common histologically diagnosed malignancy (Heyns, 2007:348). Prostate cancer is the number one cancer diagnosed amongst South African men followed by lung, oesophagus, colon/rectum, and bladder. In South African context, one in six South African men will get cancer during their lives. In order of prevalence the cancers affecting South African men are prostate cancer, lung cancer, oesophagus, colon, and rectum (CANSA, n.d.:2014)

## **2.5 RISK FACTORS ASSOCIATED WITH THE DEVELOPMENT OF PROSTATE CANCER**

With prostate cancer, like any other cancer, the exact cause of this disease is unknown. However there are possible risk factors associated with prostate cancer (Gray et al., 2005:71). Black men have the highest incidence of prostate cancer and the highest mortality rates, and they are more likely to have an advanced stage and grade of prostate cancer at initial presentation. There is no clear explanation of the greater risks and more aggressive quality of prostate cancer for black men. Of

possible relevance are biological, economic, nutritional and socio-cultural factors. The possible risk factors are discussed below.

### **2.5.1 Genetics and Family History**

In recent years much evidence linking prostate cancer and a strong genetic component has emerged due to findings of elevated risk in men with a family history of disease (Miocinovic, 2013:5). This is also confirmed by Foulkes and Cooney (2010:34), who state that after advanced age the strongest established risk factor for prostate cancer is having a family history of the disease. In a study done it was found that between 10% and 15% of men with prostate cancer has at least one affected first degree relative. Another study done in the United Kingdom (UK) in Foulkes and Cooney (2010:35) found that there is a greater than expected incidence of prostate cancer in the male relatives of men who have died from the disease. This was confirmed by a study of 228 men dying of prostate cancer that revealed a relative risk of prostate cancer in fathers and siblings that was nearly three times higher than that of a control group. Kunkel, Bakker, Myers, Oyesanmi and Gomella (2000:89) reported that generally men with heredity prostate cancer 1 (HPC 1) have a 90% risk of developing prostate cancer in their 90s.

In general, the above-mentioned findings confirm that men with relatives of prostate cancer are more susceptible to be diagnosed with prostate cancer in their lifetime.

### **2.5.2 Age Factor**

Several pieces of literature have confirmed that prostate cancer is age dependant. According to Kirby et al. (2001:29) the strongest predetermining factor for the development of prostate cancer is age. Prostate cancer is rarely found in men under the age of 50, but it is increasingly common in men above 50. In Foulkes and Cooney (2010:8) prostate cancer is also regarded as one of the most age-dependent cancers; rare before the age of 50, it increases at an exponential rate thereafter. This confirms the statement that the older the men get, the greater the possibility of them developing cancer.



### **2.5.3 Diet**

Foulkes and Cooney (2010:12) mentioned that factors possibly associated with prostate cancer have been dietary. A significant number of research studies have supported the western diet as one of the main influences in the risk of developing prostate cancer (Miocinovic, 2013:7). The same excess of intake of total dietary fat, particularly from animal sources, consumption of red meat and dairy. Red meat and dairy are products that are considered to be the main dietary offenders in prostate cancer development. Different studies also showed that heterocyclic amines, which are found in grilled and high temperature cooked meats, and high linolenic acid also appear to be associated with an increased risk of developing prostate cancer. This is also supported by the follow-up study done in the USA which has evaluated over 4700 men with respect to, among other things, diet and the risk of the development of cancer. During the course of this study, 300 men had a diagnosis of prostate cancer (Kirby et al., 2001:30).

For black men, total red meat intake (processed plus unprocessed red meat) was associated with a higher risk of prostate cancer. The possible influence of meat cooking methods on the risk of prostate cancer is based on limited evidence and is currently an active area of research (Foulkes & Cooney, 2010:16).

### **2.5.4 Infection / Inflammation**

Foulkes and Cooney (2010:32) indicated that the role of infection and inflammation in carcinogenesis has long been established for specific cancer types, and interest is growing in this regard for prostate cancer. An increased risk of prostate cancer in men with a prior history of prostatitis, chronic inflammation, and sexually transmitted diseases (STDs) has been documented by several studies. The association of prostate cancer with STDs was previously described in patients with history of syphilis, gonorrhoea and trichomoniasis (Miocinovic, 2013:8).

Kirby et al. (2001:32) differ with the above-mentioned author with regard to infection as a possible risk factor in prostate cancer development, as it states that it is difficult to prove that viruses are certainly a potential environmental trigger for prostate



cancer since many viruses are ubiquitous and others are impossible to isolate from tumour cells.

### **2.5.5 Environmental Factor (Agent Orange / Radiation / Tobacco)**

Kirby et al. (2001:32) mentioned that other environmental factors which have been described in literature to be associated with an increased risk of prostate cancer include exposure to Agent Orange, radiation and tobacco. The extensive exposure of veterans to Agent Orange during the Vietnam War prompted a few studies to evaluate and measure the relative risk of prostate cancer in this population. In a large review of 13 000 veterans an approximate twofold increase in the development of prostate cancer was indicated, as well as higher Gleason scores in the exposed group. Furthermore, in studies done with rectal cancer patients in Sweden, it was found that patients who were exposed to radiation therapy due to rectal cancer showed an increased risk of secondary cancers, including a twofold increase in prostate cancer. Kirby et al. (2001:32) mentioned that prostate cancer incidence appears to correlate with latitude; the disease is more common in the Northern States of the USA and Europe than in more southerly locations.

Inconsistencies also exist in the association of cigarette smoke as prostate cancer carcinogen, but the risk of increasing circulating androgen levels and oxidative stress caused by smoking is believed to contribute to the development of prostate cancer (Miocinovic, 2013:9). However, Kirby et al. (2001:32) mention that tobacco smoking has been implicated as an aetiological factor in malignant tumours of the lung and bladder and many other neoplasms, but no such association has yet been found in prostate cancer. Furthermore, the following authors agree that men with a history of smoking are at risk of developing prostate cancer, and they have indicated that for fatal prostate cancer a recent smoking history was associated with a statistically significant increased risk (Foulkes & Cooney, 2010:35).

### **2.5.6 Sexual Activity**

A study done in the UK has shown that prostate cancer mortality in 1 400 reputedly celibate Catholic priests was comparable to that within the general male population.

According to the results, the influence of sexual activity on the development of prostate cancer should be considered uncertain (Miocinovic, 2013:9). However, the above studies differ with Foulkes and Cooney (2010:26) with regard to sexual behaviour; they indicated that apart from the history of sexual transmitted infections, the most consistent report is that married men are at an increased risk as compared to the unmarried. The significance of this observation is unclear. It may be that men who never marry differ from married men with respect to testosterone levels, sex drives and risk of STIs. In conclusion on risk factors associated with the development of prostate cancer it is clear that there are only a few established risks, which are advanced age and having a family history of prostate cancer. Men with a family history of prostate cancer are at higher risk than the men with family history of prostate cancer. It is better to prevent prostate cancer than to treat it.

## **2.6 THE ETIOLOGY OF PROSTATE CANCER**

The term “prostate” was originally derived from the Greek word “*prohistaní*” meaning “to stand in front of” and has been attributed to Herophilus of Alexandria who used the term in 335 B.C. to describe the organ located in front of the urinary bladder; detailed anatomical depictions did not appear until the Renaissance. However, while the existence of the prostate has been recognised for over 2 300 years, accurate descriptions of the gland’s internal structure, physiology and pathology have occurred only relatively recently (Kirby, Christmas & Brawer, 2001:5).

There are probably three steps in the natural history of prostate cancer. Firstly, the development of micro foci of incidental prostate cancer. Secondly, the progression from occult to clinically significant localised prostate cancer and, thirdly, metastasis often cancer of lymph nodes, bones or other organs (Kirby et al., 2001:34).

## **2.7 DIAGNOSIS AND STAGING OF PROSTATE CANCER**

Many patients with prostate cancer are asymptomatic at diagnosis, others report dysuria, a change in urinary frequency, haematuria, dribbling, decreased force of the urine stream, and incomplete bladder emptying. Metastatic disease may present with

pain in the back, hips or perineal area, bowel or ureteral obstruction, or weight loss and fatigue (Kunkel et al., 2000:86).

Different authors have emphasised the importance of staging in prostate cancer and the following authors have explained the staging in detail. The extent or stage of cancer at the time of diagnosis is a key factor that defines prognosis and is a critical element in determining appropriate treatment, and accurate staging is necessary to evaluate the results of treatment and clinical trials (American Joint Committee on Cancer, 2010:1).

Staging is used to determine the extent of the patient's cancer to give a prognosis and to evaluate and select the appropriate treatment options (Ramon & Denis, 2007:109). Clinical staging of prostate cancer is most often based on the Tumour, Nodes and Metastasis (TNM) system using biopsy specimen and digital rectal exams (DRE) (Foulkes & Cooney, 2010:291). Stage T1 is based on the differentiation of the cells in the primary tumour (T), Stage T2 is based on the findings from the digital rectal examination (DRE), and Stage T3 is assigned when cells extend into areas surrounding the prostate gland. Stage T4, N, and M are based on the extent of cell spread (Foulkes & Cooney, 2010:291).

Below follows detailed descriptions of two staging processes of prostate cancer, namely clinical and pathological staging.

### **2.7.1 Clinical Staging**

Clinical staging includes any information obtained about the extent of cancer before initiation of defining treatment. It is divided into T1 to T4. In T1, clinically in apparent tumour not palpable or visible by imaging. This stage is characterised by less of tissue resected, tumour is identified by needle biopsy. T2 staging tumour is confined within the prostate and it involves one or two lobes. In T3 staging the tumour extends through the prostate capsules, there is unilateral extra capsular extension and bilateral extra capsular extension and the tumour invades the seminal vesicle. T4 staging of the tumour invades the bladder neck, external sphincter or rectum, as well as the levator muscles or the pelvic wall (Kirby et al., 2010:92).

## **2.7.2 Pathological Staging**

Pathologic staging includes any information obtained about the extent of cancer through completion of definitive surgery as part of the first course treatment or identified within 4 months after the date of diagnosis, whichever is longer, as long as there is no systemic or radiation therapy initiated or the cancer has not clearly progressed during that time frame (American Joint Committee on Cancer, 2010: 4). It is divided into pathology tumour (PT2 to PT4). In PT2 the organ is confined, unilateral and bilateral. In PT3 there is extra prostatic extension with seminal vesicle invasion. In PT4 it is invasion of the bladder, rectum and tissue (Kirby et al., 2010:92).

In conclusion, the researcher views the information of staging during the diagnosis as important to the family, but particularly the patient, because the extent of prostate cancer at the time of diagnosis is a key factor that defines prognosis and is a critical element in determining appropriate treatment. It is also imperative for patients and their families to have a full knowledge on the staging of prostate cancer during diagnosis, so that the patient can have a better understanding of treatment options available based on the staging of prostate cancer. A better understanding of the staging during diagnosis gives the patient an opportunity to make the best decision regarding his treatment. After diagnosis, the next practical step for discussion is treatment options. Patients need to have information about the available treatment options for prostate cancer and possible side effects of such treatment. Below are possible treatment options that can be discussed with the patient and his family.

## **2.8 TREATMENT OF PROSTATE CANCER**

The treatment of prostate cancer depends on the patient's age, health, DRE, tumour stage, PSA level, prostate biopsies, Gleason scores, and response to prior treatment for prostate cancer (Kunkel et al., 2000:88). Diagnosis and treatment of prostate cancer have long-term effects on men, physically, psychologically and emotionally. It has been long understood that prostate cancer and treatment affect both members of the couple, especially in the area of sexual functioning, intimacy and

communication (Galbriath et al., 2011:303). The Department of Health (2001) also maintains that there are number of factors that influence the choice of treatment. These include the age of the patient, the location and extent of the cancer, and risks and benefits associated with the treatment options available to the patient.

In a study done in the USA it was found that men with localised prostate cancer continue to experience treatment related problems that have detrimental effects on quality of life long after treatment ends and that patients with rising PSA had significantly more bothersome problems related to sexual and hormonal function as compared to men without rising PSA. Studies of men with advanced prostate cancer indicate that treatment can cause complications (reduced libido, fatigue) that can interfere with quality of life and they also report poorer physical and functional well-being (American Society of Clinical Oncology, 2015). All available prostate cancer treatment options (surgery, external beam radiation therapy, etc.) have patient side effects related to urinary, bowel and sexual dysfunction while active surveillance also carries the cost of additional follow-up and prostate biopsies (American Society of Clinical Oncology, 2015).

Each therapy has significant advantages and disadvantages which the patient and doctor need to explore before a proper treatment can be recommended for the patient. The following are treatment options for prostate cancer patients which are available worldwide, including in South Africa:

- **Chemoprevention**

The term “chemoprevention” means to reverse the process of cancer formation. Rather than focusing on the identification and treatment of a clinically evident cancer, chemoprevention focuses on the identifying targets in the process of carcinogenesis and using a drug or nutrient to prevent the development of cancer (Neppe, Kibel & Andriole, 2013:143). The strategies for chemoprevention are further subdivided into primary, secondary and tertiary. **Primary prevention** is preventing the development of disease in an unaffected healthy person. **Secondary prevention** is treatment in individuals with a premalignant condition with the goal of preventing progression to frank malignancy. **Tertiary prevention** involves prevention of recurrence or

progression of disease in an individual with known or previously treated malignancy. Chemoprevention has the potential to reduce mortality from the disease, over-treatment, morbidity from treatment, and costs (Neppel et al., 2013:144).

- **External Beam Radiation Therapy (EBRT)**

This type of treatment has a long standing history in the treatment of prostate cancer, however the technique of therapy has evolved dramatically. The management of patients with prostate cancer has also changed over time, with decreased utilisation of EBRT, and an increased use of brachytherapy during the 1990s. EBRT has seen tremendous advances in technology in recent years. No randomised trials comparing EBRT to radical prostatectomy or to brachytherapy have been successfully conducted. Side effects of radiation therapy are typically divided into acute effects and late effects. Acute effects occur during the first course of radiotherapy and within the immediate 3-6 month period following radiation treatment, while late effects generally develop a year or more after treatment (Karnes & Blute, 2013:271).

- **Radical Prostatectomy (RP)**

This type of treatment has been recommended by some for almost all stages of prostate cancer. Radical prostatectomy is widely used today only in men in whom it is likely to afford a cure in effect. This treatment option applies to those men with a stage T1 or T2 disease with low-to-moderate grade pathology and a life expectancy of more than 10 years (Kirby et al, 2010:117). RP has been associated with a lower risk of cancer recurrence and cancer related death, as well as with improved survival compared with watchful waiting (Karnes & Blute, 2013:271).

- **Radiation therapy (RT)**

Radiation therapy provides an alternative, definitive treatment approach to clinically localise prostatic carcinoma. The criteria for patients considered for RT is histological evidence of prostate cancer, clinically localised disease, sufficient life expectancy to render the cure worthwhile, and absence of lower

urinary tract disorders, among others. Since each therapy has its own pros and cons the following are advantages of RT: potential cure and also avoidance of surgery. However, there are several disadvantages including prolonged treatment and potential morbidity, rectal injury, bladder damage, incontinence, impotence, haematuria (Kirby et al, 2010:129).

Kunkel et al. (2000:88) slightly differ with the above authors with regard to the benefits and risks of RT. These authors stated more advantages of RT compared to other treatment options like RP. In applying RT the benefits include pain control in metastatic disease and less urinary leakages, and it can be successfully used in localised tumours. The risks are that gastrointestinal problems are more likely to be seen after RT, as well as impotence and incontinence.

- **Hormonal therapy**

As the Department of Health (2001) simply puts it, hormone therapy is used to prevent cancer cells from getting the hormones they need to grow. In prostate cancer hormonal therapy is preferred in symptomatic patients. Hormonal therapies include orchiectomy, oestrogen use, or chemical castration. Bilateral orchiectomy removes 95% of serum testosterone and is a minor, low-cost procedure that eliminates the need for daily medication. Metastatic pain may also be relieved within hours or days. However, the side effects of this therapy include the loss of libido and impotence (Kunkel et al., 2000:88).

- **Surgery**

Surgery is a method that still plays a major role in the treatment of prostate cancer. Surgery is an option in locally advanced cancer. Opponents of surgery in patients with a high risk cancer have argued a lack of benefit if the prostate cancer is not completely excised, that is if there are micro metastasis (Karnes & Blute, 2013:276). The men diagnosed with a final stage of prostate cancer or those presenting with an aggressive type of cancer are likely to go for surgery.



In conclusion making decisions on treatment and the methods is also essential. All treatment options should be carefully and clearly discussed with patients and their families. It is also essential that the patient and doctor work together in making these decisions, because they are life changing. Furthermore it is important to ensure that patients are well informed of all treatments and their advantages and disadvantages. The patient must also be given counselling before any treatment and be prepared to make an informed decision for his future.

## **2.9 PROGRAMMES AVAILABLE FOR PROSTATE CANCER**

In South Africa the treatment of prostate cancer differs with services from private and public hospitals. There are selected hospitals in South Africa, both in the private and public sectors, with oncology sections and specialising in treating cancer patients. There is also CANSA-NGO which relies on donors/funders and also receives a subsidy from the government to offer prevention services for all types of cancers, including prostate cancer, and support services. This non-profit organisation (NGO) operates in all nine provinces of South Africa in the form of satellite offices (CANSA).

The following programmes are available in South Africa, including services for prostate cancer:

- The CANSA presents awareness and education campaigns to local communities. Campaigns include men's health issues.
- Screening services and self-examination. It is important to conduct self-examination, as well as knowing the symptoms to be aware of, the recommended age to commence self-examination, how often to conduct the exams, and what the recommended medical checks are. In terms of prostate cancer, PSA finger-prick blood is conducted.
- Online support resources in the form of a Facebook group, I survivor online support programmes.
- Individual counselling and support groups. The pressure of dealing with cancer can be too much and individual counselling is an effective way of unloading some of the stress in a safe and supportive environment. Support groups give survivors an opportunity to share their insight with, as well as



provide emotional support, understanding, hope and inspiration to fellow group members. The numbers of support groups offered in different centres are: hoping is coping groups, Sharing and Caring groups, cancer-specific groups, day care group and the Tough Living with Cancer (TLC) group.

- The CANSA's mobile clinics. The clinics travel to the remote areas of South Africa.
- The CANSA's toll free call centre (CANSA,).

The CANSA does not provide treatment, so if any abnormalities are detected during screening, the person screened will be referred to appropriate specialists. Based on the list of the programmes mentioned above there are still uncertainties whether the programmes are well-known and accessible to all men in South Africa. For example, based on the fact that prostate cancer affects men mostly above the age of 65 the question is whether programmes such as online support are effective in educating and supporting ordinary men living with prostate cancer and whether these men are able to access the internet.

## **2.10 ROLE OF A SOCIAL WORKER**

No single profession can fulfil all the requirements needed to look after a prostate cancer patient, hence a multidisciplinary approach is essential. Ross and Deverell (2010:162) emphasise that a team approach is important not only in the hospital, but also after the patient has been discharged. According to Van Schalkwyk (1995:651), medical social workers are in the best position to provide the patient and the family with counselling because of their intensive social work training in counselling of groups, individuals and families, and their extensive experience with rehabilitation services.

The researcher is in agreement with Van Schalkwyk (1995:643), who is of the opinion that medical social workers should have knowledge of psychology, communication, basic anatomy, and medical terminology, together with the ability to relate well to the patient and their family, offer warmth, and create a non-judgemental and acceptable emotional environment for the patient. The social worker is a vital

member in the oncology department and should be regarded as such. The oncology social worker is able to give social and emotional support to patients, families, employers, and staff in the department (Van Schalkwyk, 1995:651).

The social worker also has to provide support services to the family and enters the role of facilitator. The social worker can facilitate a couple and family support groups where members are able to support and learn from each other (Van Schalkwyk, 1995:652). In these support groups the social worker will be able to address the family's fears and their emotions. The groups will also help in teaching the couples some coping skills. One-on-one sessions with the patients can also be helpful in this regard (Van Schalkwyk, 1995:652). It is also confirmed by Cowles (2000:74) that in the health field the social work services may be for an individual patient (one-on-one), all or part of patient's family, any other small groups of people, or another large sector of the community or society.

To summarise this chapter, it is evident that prostate cancer is one of the leading cancers amongst men of different cultures and that black men are mostly diagnosed with an aggressive type of prostate cancer. It is also evident that various factors contribute to the high number of black men with prostate cancer. Prostate cancer is a condition that is accompanied by life-threatening experiences which include the psychological, emotional, physical, social and sexual aspects of a man. Prostate cancer means a dramatic change for a man and a huge burden on the family members, particularly partners; hence a holistic approach using a multidisciplinary team which includes a social worker is necessary to meet the needs of a prostate cancer patient and his family. All stakeholders need to work together to ensure that the quality life for prostate cancer patients is improved.

## CHAPTER THREE: RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS OF THE STUDY

### 3.1 INTRODUCTION

The focus of this chapter is on the research methodology, as well as the research findings. The goal of the study was to investigate the bio-psychosocial experiences of black men living with prostate cancer. The chapter starts with a description of the research question, research approach, type of research, research design, research methods, as well as the ethical considerations of the study. The chapter continues with the research findings, including the biographical details of the participants, then a discussion of the themes and sub-themes. The chapter ends with a summary of the findings of the study.

### 3.2 RESEARCH QUESTION

The research question for the study is:

- *What are the bio-psychosocial experiences of black men living with prostate cancer?*

Hofstee (2011:85) observes that a research question is used to name as precisely as possible what the study will attempt to find out. In this regard the research sought to explore the bio-psychosocial experiences of black men living with prostate cancer.

Furthermore, the above-mentioned question focuses on the research topic and particularly on “black men living with prostate cancer” – not all men.

The research question is also open-ended as it starts with the word “what”, thus allowing the black men to share their various experiences of living with prostate cancer.

In answering the question, the researcher used the objectives of the study to establish the following sub questions:

- What is the level of knowledge of men with regard to prostate cancer?
- What are the challenges of living with prostate cancer?
- What are the experiences of living with prostate cancer as a black man?
- What services are available for men living with prostate cancer?

Due to the nature of the study, there are situations where better information about sensitive issues can be obtained by interviewing the participants (Kumar, 2011:148). The researcher did interviews to obtain answers from the research questions.

### **3.3 RESEARCH APPROACH**

Due to the exploratory nature of the study, as well as the desire to understand a complex phenomenon such as prostate cancer, a qualitative approach was most applicable for the purpose of the study. The exploration, depth and complexity of the topic fitted well within the qualitative approach. Qualitative research as a research methodology is concerned with understanding the process of social and cultural contexts which underlie various behavioural patterns and is mostly concerned with exploring the “why” questions of research. The emphasis is on the quality and depth of the information, not on the scope or breadth of the information provided as in quantitative research (Maree’, 2007:51). Qualitative research studies are characterised by an emphasis on describing, understanding and exploring a phenomenon using categorical and subjective measurement procedures. Construction of hypotheses is neither advocated nor practised (Kumar, 2011:88).

The aim of the study was for the researcher to gain a first-hand, holistic understanding of people’s feelings, perceptions and interpretations of a particular phenomenon, which in this study is prostate cancer (Fouché & Delpont, 2011:63). In this specific study a qualitative research approach was more applicable in the sense that the researcher explored the bio-psychosocial experiences of black men living with prostate cancer. The ultimate goal of qualitative research is to explore and understand the central phenomenon. The researcher furthermore has selected a

qualitative research approach, because the purpose of the study was to understand the bio-psychosocial experiences of black men living with prostate cancer, as well as the meaning that they attach to their everyday lives. Furthermore, the qualitative approach allowed the researcher to explore prostate cancer within the context of the daily lives of black men.

### **3.4 TYPE OF RESEARCH**

The researcher used applied research. In applied research the aim is to collect information about the various aspects of a situation, issues, problem or phenomenon, so that the information intended to be gathered by the researcher can be used in other ways, such as improved intervention, administration and the enhancement of understanding a phenomenon (Kumar, 2011:10). In this study the focus is on understanding the experiences of black men living with prostate cancer. Applied research is the scientific planning of induced change in a troublesome situation (Fouché & De Vos, 2011:94). Furthermore, the research was exploratory in nature as the topic looked for insight (Fouché & De Vos, 2011:95) into the phenomenon of black men living with prostate cancer.

### **3.5 RESEARCH DESIGN**

The design was the case study design and the sub-type was collective case study.

The researcher used the collective case study design. The design was chosen as research in the qualitative approach mainly entails the selection of people from whom the information, through an open frame of enquiry, is gathered (Kumar, 2011:104). In this study information was gathered from black men with prostate cancer. This design in the study was aimed at gaining greater insight and understanding of the dynamics of a specific situation (Maree', 2007:76).

The benefit of using a collective case study is that it gives the researcher the opportunity to spend more time with the individuals when collecting data. This gives the researcher an opportunity to ask participants to elaborate on certain issues and get complete information regarding the topic (Leedy & Ormrod, 2013:141). This type

of design enabled the researcher to meet with the black men in person and also build a rapport with them, and as a result their experiences surrounding prostate cancer were gathered.

### **3.6 RESEARCH METHODS**

#### **3.6.1 Introduction**

The research methods include the following: research population and sampling, data collection method, data analysis, and the pilot study.

#### **3.6.2 Study Population**

A population is the full set of cases from which a sample is taken (Welman, Kruger & Mitchell, 2005:53). The study was conducted with the participants from Pretoria Urology Hospital at the venues chosen by them. Eight participants were interviewed at their respective homes and two at the hospital on the day of their check-ups. In this study, the population were all black men diagnosed with prostate cancer who were patients of a private urologist at Pretoria Urology Hospital, utilising private sector medical care. The Pretoria Urology Hospital was chosen specifically for its experiences and expertise (Nieuwenhuis, 2007:79) in rendering health care services to the men in general and prostate cancer patients in particular.

#### **3.6.3 Sampling**

The primary purpose of sampling is to collect specific cases and events that can clarify and deepen understanding (Neuman, 2003:211). In non-probability sampling each unit in a sampling frame does not have an equal chance of being selected (Strydom & Delpont, 2011:391). The selection of patients was done primarily through purposive sampling. Purposive sampling is a deliberate non-random method of sampling, which aims to sample a group of people or setting with particular characteristics (Bowling, 2002:380).

The primary consideration in purposive sampling was the researcher's judgment as to who can provide the best information to achieve the objectives of the study and whether those participants that are likely to have the required information are willing to share with the researcher. In the study the selected black men living with prostate cancer were able to provide the required information on their experiences.

The following criteria were considered by the researcher to select the participants:

- Black men of all ages diagnosed with prostate cancer.
- Black men residing in Pretoria (Gauteng Province).
- Male patients of an identified private urologist at the Pretoria Urology Hospital.
- Male patients treated for prostate cancer in 2014/2015.
- Patients who voluntarily provide informed consent.
- Patients who speak and understand English.

The participants were selected with the assistance of the urologist and his clerks from the files they keep at the hospital, which have recent updates of the patients, to avoid contacting patients who are terminally ill or have passed away. The clerk of the identified urologist requested the patients to indicate their names and contact details if they are interested in participating in the study when they come for their routine treatment. The researcher then contacted the patients that left their names and an appointment was made with them. A letter of informed consent was first on the discussion agenda, followed by the purpose of the study before the interview commenced. The researcher managed to get permission from 10 participants for the study.

#### **3.6.4 Data Collection**

The aim of qualitative interviews is to see the world through the eyes of the participants, as they can be a valuable source of information (Maree', 2007:87). In this study, the focus was on black men living with prostate cancer and they were a valuable source of information as they have managed to provide the researcher with rich data regarding prostate cancer. The researcher used semi-structured interviews

to collect data. The semi-structured interviews were considered, because the topic of prostate cancer was of a very sensitive nature (Welman et al., 2005:167).

The researcher used a semi-structured one-on-one interview with an interview schedule to explore the physical, emotional, sexual, financial and social aspects to obtain information regarding prostate cancer from participants. A set of predetermined questions on prostate cancer on an interview schedule was used as a guide to obtain answers from participants not as a dictation by the schedule (Greef, 2011:352).

The researcher had one interview session with each participant. The longest interview lasted for one and half hour and the shortest about 45 minutes. Recording permission was sought verbally and through signed consent forms. Only two participants out of 10 agreed to be recorded. The other eight preferred the use of notes during the interviews. The researcher respected their decision in this regard and mainly utilised note taking to collect data.

A semi-structured interview has its own advantages and disadvantages. The advantage of using this method was that it allowed the researcher an opportunity for probing and clarifying of answers regarding living with prostate cancer (Maree', 2007:87). Since the researcher had an opportunity to build a rapport with the participants before the interview took place, rich and complete data was obtained as participants were open and honest with their experiences.

However, one of disadvantages of using semi structured interviews to collect data is that it generally lasts for a considerable amount of time and can become intense and involved, depending on the particular topic (Greef, 2011:353). This was experienced in this study during the interviews with the participants, as it took time to recruit, build a trust, and also set a date for a meeting. It was evident during this study that prostate cancer is a private matter to most black men as some that were also selected by the doctor to participate in the study refused without giving a reason.



### **3.7 DATA ANALYSIS**

The goal of analysing qualitative data is to summarise what the researcher has seen and heard in terms of common words, phrases, themes, or patterns that would aid the understanding and interpretation of that which is emerging. The aim is never to measure, but to interpret and make sense of what is in the data (Maree', 2007:100).

In qualitative studies the aim of analysis is to transform data into findings. In this study, the researcher used the eight steps of Creswell's data analysis process.

#### **3.7.1 Planning for the Recording of Data**

Data was recorded directly from the interviews with the participants, by means of a voice recorder. The researcher used field notes and also obtained permission from the participants to use the voice recorder to collect information. The researcher should practice and build habits for labelling audiotapes, carrying extra batteries for the recorder, and finding quiet places for taking notes (Schurink et al., 2011:404). The researcher ensured that all the necessary documents and support systems are ready and available for the analysis. The researcher took notes during data collection and made an audio recording. A cell phone was used to record data and the consent of the participants in this regard was sought. The recorded data was later transferred onto a disc for safekeeping.

#### **3.7.2 Data Collection and Preliminary Analysis**

Data analysis frequently necessitates revisions in data collection procedures and strategies. These revisions yield new data that are then subjected to new analysis (Schurink et al., 2011:405). The reason to repeatedly revise the data is to follow up any idea and to eventually produce rich data. The researcher followed up any idea from the data and as well as reading the interview notes. The field notes which were collected during the study were grouped together, especially those with similar views.

### **3.7.3 Data Management**

This is the first step in data analysis away from the site (Schurink et al., 2011:408). The researcher believes that this is a very critical phase in analysing data, as all information collected must be ready and for safe analysis. The data needs to be managed in a way that if clarification is needed, it must be available and easy to access by the researcher. The collected data was organised into files and folders on the computer and have back-up storage on a CD for safekeeping. The researcher also ensured that the results of patients are safely managed by saving them in the system, and colour coding the field notes. The collected data was organised into files, clearly marked with different colours to differentiate participants. The researcher ensured that all information gathered was well documented to ensure that it is safe if clarification should be needed on something.

### **3.7.4 Reading and writing memos**

The researcher read the transcripts several times in their entirety to get immersed in the details, trying to get a sense of the interview as a whole before breaking it into parts (Schurink et al., 2011:409).

### **3.7.5 Generating categories, themes and patterns and coding data**

The researcher used the different colours in the coding process for the themes and categories for clear interpretation of data and themes emerged during the study. Similar topics were regrouped into themes and sub-themes.

### **3.7.6 Testing emergent understanding and searching for alternative explanations**

In this phase the researcher looked at the patterns that are similar and found a way of explaining the phenomenon.

### **3.7.7 Interpreting and developing typologies**

This process involves making sense of the data collected. The researcher made conceptual linkages between seemingly different phenomena. The researcher explained the findings in terms of the bio-psychosocial model as theoretical framework of the study.

### **3.7.8 Presenting data**

This is a final step whereby the researcher presents the information gathered in the form of a report, as well as making recommendations.

## **3.8 TRUSTWORTHINESS OF QUALITATIVE DATA**

In qualitative research the researcher is the data gathering instrument, thus it seems that when qualitative researchers speak of research validity and reliability, they are usually referring to a research that is credible and trustworthy (Maree', 2007:80). In this study the researcher has taken into consideration the four constructs of trustworthiness.

### ➤ **Credibility/Authenticity**

Trochim and Donnelly (in Kumar, 2011:185) describe credibility as establishing that the results of qualitative research are credible or believable from the perspective of the participants in the research. Schurink et al. (2011:420) also state that credibility in a qualitative study is whereby the researcher ensures that the subjects have been accurately identified and described. In addition, the researcher asks if there is a match between participants' views and the researcher's reconstruction and representation of them.

In the study, the following strategies were applied with the purpose of increasing the credibility of the study. Firstly, member checking, the researcher managed to do member checking with the view to verify the accuracy of data collected (Schurink et al., 2011:420). Secondly, peer debriefing was also employed in the study, whereby a detailed report including

how the data gathering was managed and analysed, as well as information on the research design was shared with fellow researchers in qualitative research.

Furthermore the employed strategies added great value to the study and trustworthiness was also strengthened through the process of engaging in dialogue with other researchers within the qualitative approach. Another strategy, namely triangulation, was applied by combining data from the interview with each participant by using the available literature on the topic.

➤ **Dependability**

Dependability involves whether the research is well-documented or audited (Schurink et al., 2011:420). In this study the data collected was well-documented and recorded in the same way the black men shared their experiences of living with prostate cancer to ensure the accountability of the study. The ultimate goal of the study was to present the findings that reflect the experiences of the black men living with prostate cancer and through well-documented data this was achieved.

➤ **Conformability**

Conformability refers to the degree to which the results could be confirmed (Trochim & Donnelly, in Kumar, 2011:185). This is also referred to as objectivity, in which the findings of the study could be confirmed by others (Schurink et al., 2011:420). The researcher ensured the conformability of the study by reflecting on the data collected. In this study, conformability has been obtained because findings of the study are as a result of the bio-psychosocial experiences of participants, rather than because of the personal ideas of the researcher.

### 3.9 PILOT STUDY

In Greef (2011:349), a pilot study is a process whereby the researcher comes to grips with some of the practical aspects, namely establishing access, making contact, and conducting the interview, as well as becoming alert to her own level of

interviewing skills. In this study, the researcher conducted a pilot study before the main study with one participant, with the purpose of testing if the chosen method is effective and will produce rich data. This was confirmed during the pilot study as the researcher got an opportunity to identify and edit some errors before the main study.

### **3.10 ETHICAL CONSIDERATIONS**

Ethics are defined by Strydom (2011:114) as a set of moral principles that are suggested by an individual or group and subsequently widely accepted, which offer rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students. In the study, the researcher applied the ethical considerations discussed below. Before embarking on the study, the researcher considered the fact that the topic is a personal affair and it is a serious issue amongst black men to talk about something relating to their sexuality, therefore the researcher ensured that ethical considerations were maintained from the beginning to the end of the study.

The following aspects were considered in the study.

#### **3.10.1 Voluntarily participation**

Participation in the research study should at all times be voluntarily and no one should be forced to participate in a project (Rubin & Babbie, 2008:71). In this respect the researcher emphasised their right to withdraw from the study, as the sensitivity of the topic was highly considered. Participants were told what the study entails and what is expected from them. Written consent was sought from the participants prior to the study.

#### **3.10.2 Informed consent**

Taking into consideration the nature of the patients' illness, the researcher ensured that the participants in the study were psychologically and legally competent to give consent and were aware that they are allowed to withdraw from the investigation at

any time (Strydom, 2011:117). In the study the researcher ensured that each participant signed a consent form before the study commenced. Detailed and adequate information regarding the study was clearly provided to the participants before they signed the consent forms. Furthermore, the researcher checked with the participants that they understood what was outlined in the form. The participants were also informed about the use of a voice recorder and that the data will be stored at the University of Pretoria, Department of Social work and Criminology, for 15 years. The researcher sought participants' verbal permission to use a digital recorder and take notes during the interviews.

### **3.10.3 Confidentiality, anonymity and privacy**

The more sensitive the information or the more concealed the manner in which the information is gathered, the greater the responsibility of the researcher and all concerned to treat the information as extremely confidential (Strydom, 2011:120). In this study the researcher handled the participants in a more sensitive manner due to the nature of the condition. The researcher reminded the participants that the information collected will be kept in a safe place where people will not have access to it and also that their real names will not be used in the report, to protect their identities. Participants were also ensured prior to data collection that any information such as names and addresses that might identify them would not be included in the research report, bearing in mind that prostate cancer is a very personal and sensitive matter.

### **3.10.4 Debriefing of the participants**

Debriefing involves the subjects' opportunity to work through their experiences and the aftermath, and is one way in which the researcher can assist subjects in minimising possible harm which may have been done in spite of all precautions taken against it (Strydom, 2011:122). Due to the nature of the topic, the researcher double checked the emotional level of each participant and clarified with each participant whether there were issues that needed attention. None of the participants were referred to the psychologist that was made available to provide counselling.

### **3.10.5 Avoidance of harm**

Strydom (2011:115) states that emotional harm to subjects is often more difficult to predict and determine. Since the study involved a very sensitive health issue amongst black men the participants may have experienced concrete harm, with regard to their family life and relationships. In this study all the participants sought permission from their partners and children to participate in the study. To avoid any harm during the interviews with participants, the researcher made a private clinical psychologist available to provide counselling in case any harm was done. In this study there was no incidence of emotional harm done the participants.

### **3.10.6 Publication of the findings**

Report writing includes doing all one can to make sure one's report is as clear as possible and contains all the information necessary for readers to understand what is being written (Strydom, 2011:26). In this report the researcher will ensure that the findings of the study are presented as clearly and objectively as possible.

## **3.11 EMPIRICAL FINDINGS OF THE STUDY**

The empirical findings of the study are presented in detail in this section. It starts with the biographic profile of the participants. It is followed by a discussion of the themes and sub-themes that emerged during the interviews with the participants.

The themes and sub-themes are presented in the form of tables, charts and graphs, followed by a detailed discussion of these themes and sub-themes, supported by direct quotations from the participants.

### **3.11.1 Biographic details of the participants**

Ten black men living with prostate cancer participated in the study. Important biographic information of the participants included age, educational level, gender, marital status, language, income, area of residency, educational level, and number of years on treatment. The participant's profiles are summarised in Table 3.1.



**Table 3.1: Biographical profile of participants**

Participant	Age	Gender	Race	Marital status	Language	Employed/income	Educational level	Area of residency	Number of years diagnosed	Knowledge of treatment
Participant A	76	M	B	Married	Tswana	Pensioner	Tertiary qualification	Pretoria north	More than 3	Yes
Participant B	80	M	B	Married	Tswana	Pensioner	Secondary level	Pretoria north	More than 3 years	Yes
Participant C	76	M	B	Married	Tswana	Pensioner	Secondary level	Pretoria west	Less than 3 years	Yes
Participant D	55	M	B	Married	Tsonga	Employed	Tertiary level	Pretoria north	Less than 3 years	Yes
Participant E	74	M	B	Married	Tswana	Pensioner	Secondary level	Pretoria central	Less than 3 years	Yes
Participant F	76	M	B	Married	Zulu	Pensioner	Secondary level	Pretoria north	Less than 3 years	Yes
Participant G	70	M	B	Widower	Pedi	Pensioner	Primary level	Pretoria west	More than 3 years	Yes
Participant H	47	M	B	Married	Tswana	Employed	Tertiary level	Pretoria west	Less than 3 years	Yes
Participant I	57	M	B	Married	Pedi	Employed	Secondary level	Pretoria north	Less than 3 years	Yes
Participant J	54	M	B	Married	Tswana	Employed	Secondary level	Pretoria central	Less than 3 years	Yes



The following charts and histograms explain the participants' biographic profiles mentioned in the table above.

### 3.11.1.1 *Race of participants*

All participants were black African males, as the focus of the study were only on the biopsychosocial experiences of black men.

### 3.11.1.2 *Age of participants*

Participants' age as indicated in Table 3.1 indicates that there was only one participant below 50 years, and only three below 60 years. Six participants were above 60. None of the participants were below 40 years. This attest to the fact that prostate cancer is common amongst men above 50 years and rare below the age of 40.

The chart below shows the age of the participants.

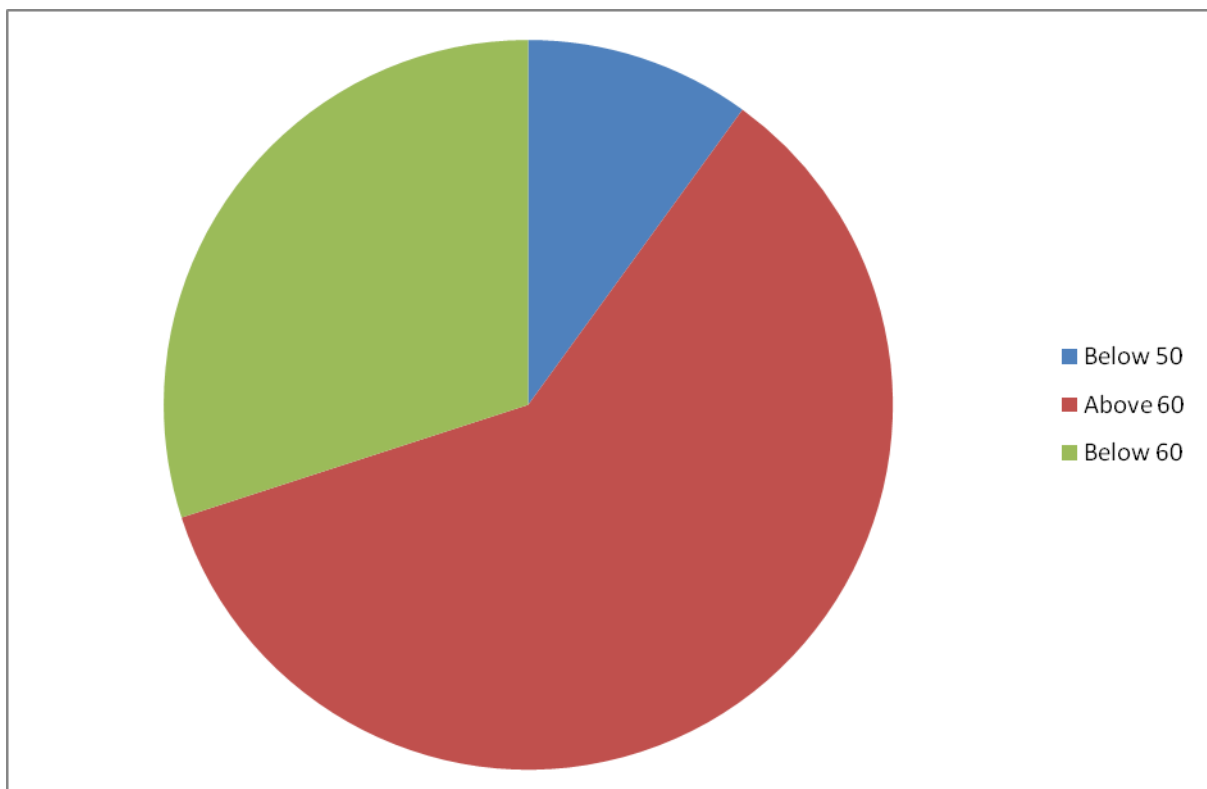
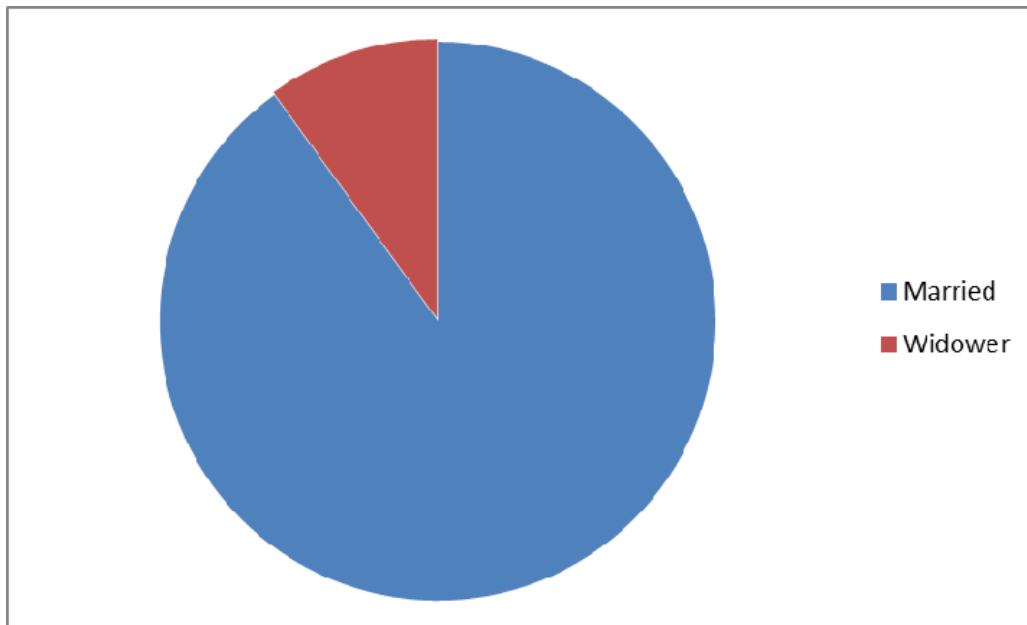


Figure 3.1: Age of the participants

### 3.11.1.3 *Marital status*

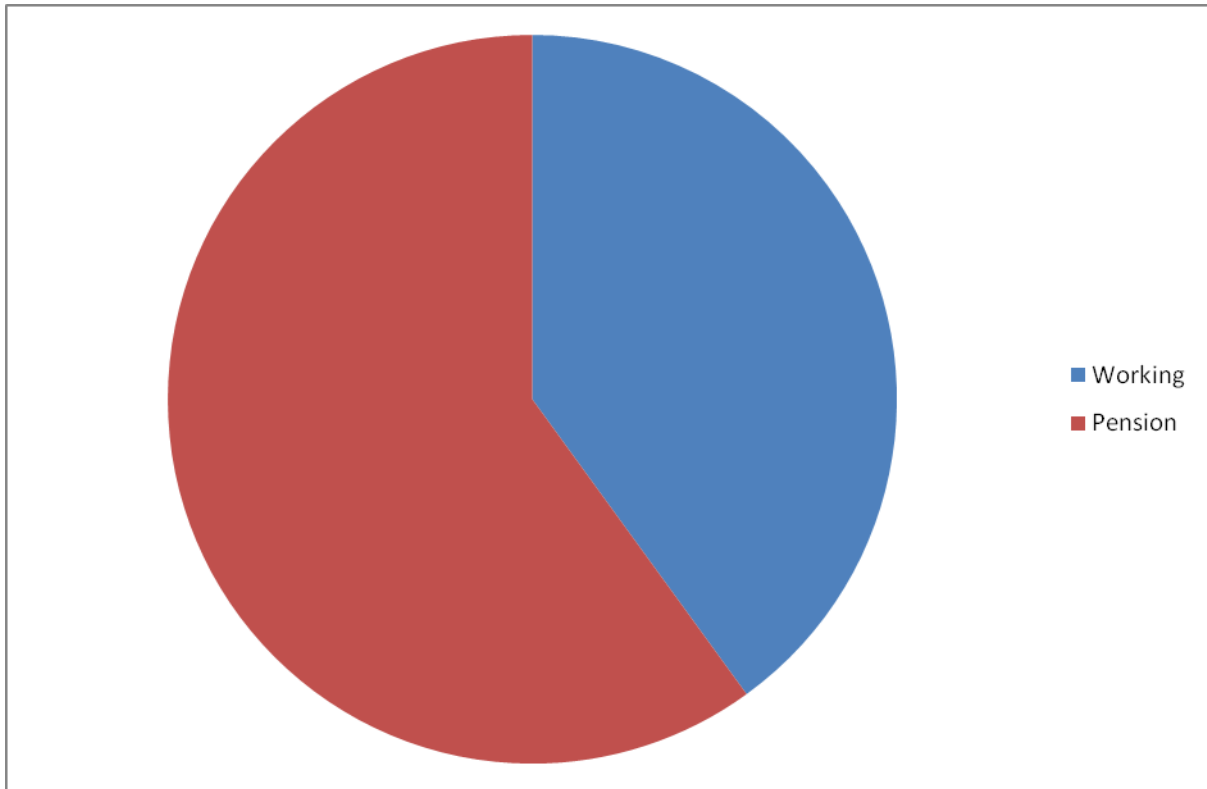
Of the 10 men that participated in the study, nine were married and living with their wives of many years and only one participant was a widower, who lost his wife before he was diagnosed with prostate cancer. The pie chart below summarises the information. Only one participant was in his second marriage.

**Figure 3.2: Marital status of the participants**



#### **3.11.1.4 Employment / income status of the participants**

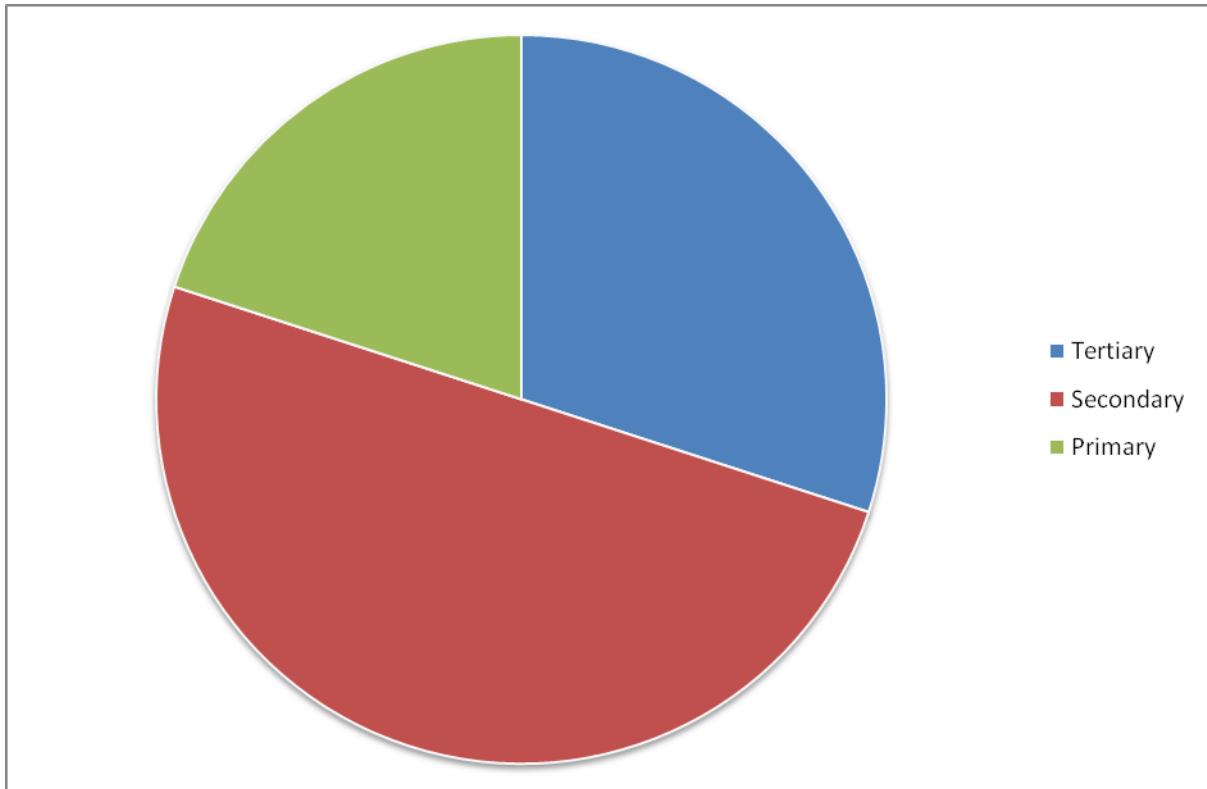
The findings show that most of the participants were pensioners. One participant took early retirement after his operation, because he could not cope at work. Four participants were working and six were on pension.



**Figure 3.3: Employment status of participants**

#### **3.11.1.5 Educational level**

All participants attended school, however only few attained tertiary qualifications. Most of them were employed in government departments and private companies, and occupied average positions, thus the reason all of them could afford the services of a private hospital. Those on pension also occupied average positions before they retired and they continue to utilise their medical aid schemes. Others are on their children's medical aid schemes.



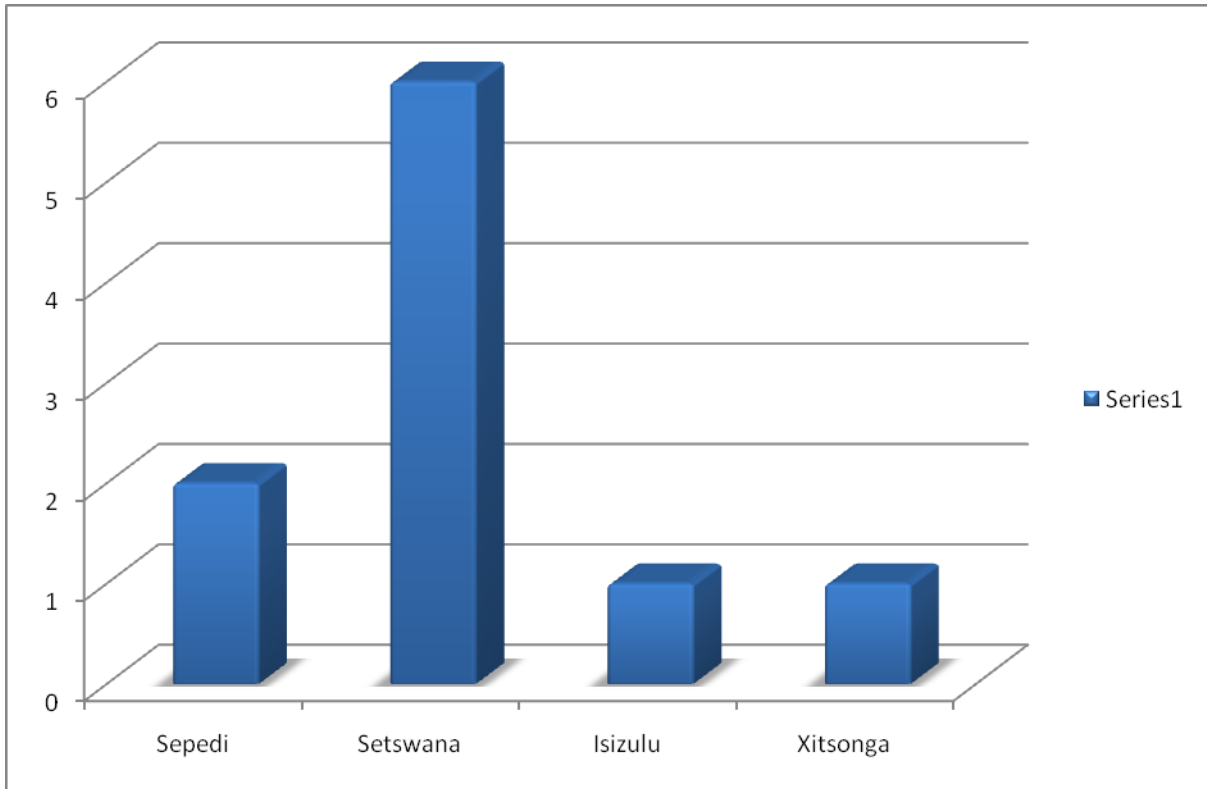
**Figure 3.4: Educational level of participants**

#### **3.11.1.6 Age of dependants**

The findings revealed that most participants were living with their partners only. In some cases they had only one child and grandchildren. The majority of their children were adults, married and living in their own houses. None of the participants had children under the age of 15. Only one participant had a child under 21 years.

#### **3.11.1.7 Language of participants**

Since the focus of the study was on black men, of the 10 participants in the study two speak Sepedi, one speaks Xitsonga, one IsiZulu and six Setswana. The majority of the participants were Setswana speaking because Pretoria is dominantly a Setswana and Sepedi region, and the focus of the study was on participants residing around Pretoria.

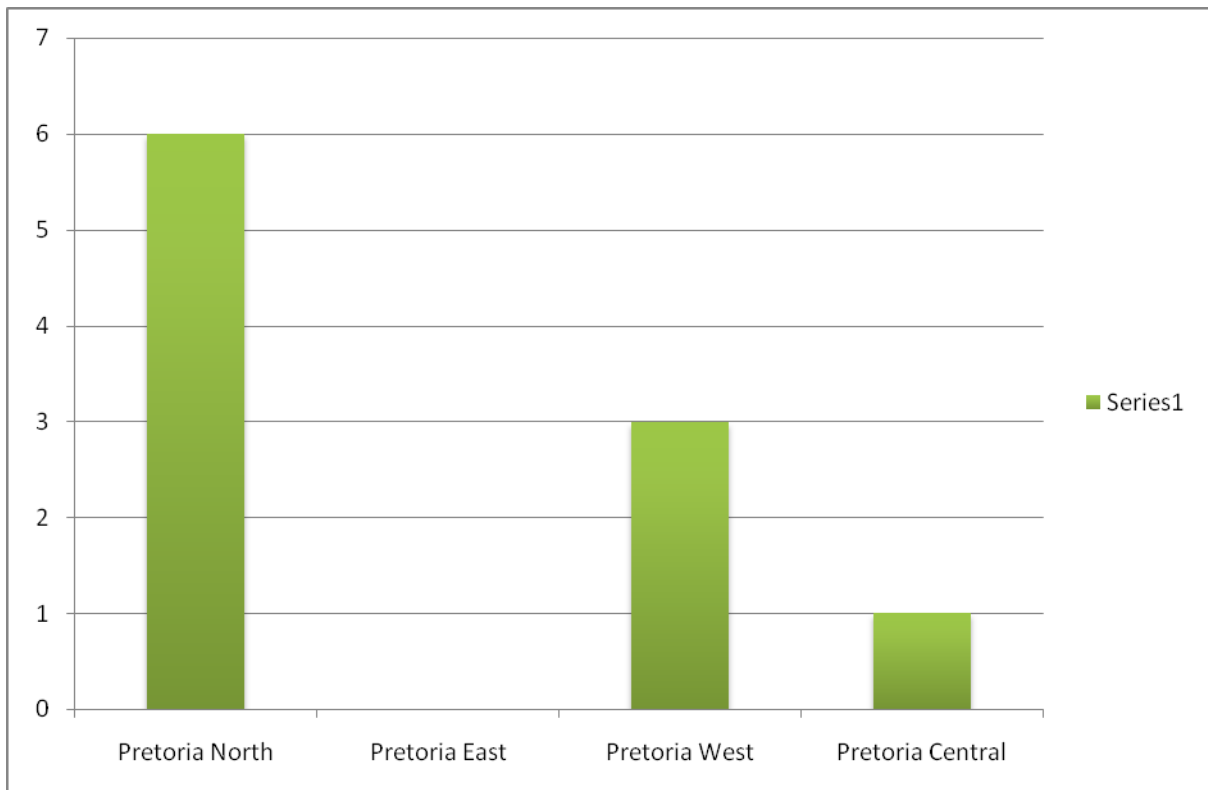


**Figure 3.5: Language of participants**

### **3.11.1.8 Area of residency**

All participants were residing in Pretoria, as per the selection criteria. Six participants resided in Pretoria North, three in Pretoria West and one in Pretoria Central. None of the participants were from Pretoria East.

The histogram below represents the area of residency.



**Figure 3.6: Area of residency**

### **3.12 THEMES AND SUB-THEMES**

Recurrent themes and sub-themes emerged during data collection and analysis. They are presented in table format and supported by direct quotations from participants. Data from each participant was processed and organised separately. The themes and sub-themes that emerged from each participant are merged and discussed together. The differences and similarities were highlighted through direct quotations from the participants. The discussion of themes and sub-themes is simultaneously integrated with literature where necessary.

**Table 3.2: Themes and sub-themes**

<b>Themes</b>	<b>Sub-themes</b>
1. Knowledge of prostate cancer	1.1 History of prostate cancer 1.2 Understanding of prostate cancer 1.3 Reaction after the diagnosis
2. Treatment of prostate cancer	2.1 Understanding the stages of prostate cancer 2.2 Understanding of treatment provided 2.3 The impact of treatment on the lifestyle of participants 2.4 Experiences of hospital services 2.5 Alternative treatments
3. Challenges experiences by participants	3.1 Bio-psychosocial impact of living with prostate cancer 3.2 Emotional aspect 3.3 Financial impact 3.4 Sexual impact 3.5 Marital impact 3.6 Physical impact 3.7 Poor communication with family 3.8 Impact of living with prostate cancer on the workplace
4. Needs of black men living with prostate cancer	4.1 Resources
5. Available support systems	5.1 Family support for participants 5.2 Community support for participants 5.3 Medical support for participants
6. Strategies to improve services provided to black men living with prostate cancer	6.1 More education about prostate cancer 6.2 Counselling services for survivors and families

### **3.13 DISCUSSION OF FINDINGS**

As indicated above, the findings will be discussed and simultaneously integrated with literature in this section.

#### **3.13.1 Theme 1: Knowledge of prostate cancer**

The discussion of prostate cancer with the participants revealed that the majority of participants had little knowledge about prostate cancer. The following factors were

discussed to determine the level of knowledge amongst participants: history of prostate cancer, understanding of prostate cancer and reactions after the diagnosis.

### **3.13.1.1 Sub-theme 1.1: History of prostate cancer**

Some participants agreed that they know nothing about the history of prostate cancer and the majority of participants mentioned that they only know that there is no cure for prostate cancer and none of the participants gave full information regarding the history of prostate cancer. A few participants indicated that they did self-research after being diagnosed with prostate cancer. The response from the participants indicated that the only knowledge that they have is that as one gets older and if there is a history of cancer in the family, the possibility of prostate cancer increases. The participants mentioned that they learnt factors associated with prostate cancer after being diagnosed. The following quotes from the participants support the statement.

- *“I used to hear about it on the radio and never thought one day it will be me, but I can’t tell where it comes from, but it is a dangerous condition.”*
- *“I never read more about the prostate cancer, until I was diagnosed.”*
- *“I’m telling you that prostate cancer was there before, men used to die in silent and the families will not tell exactly the cause of death. It is only now that some men like me became open and survived it, but there are still those who are dying alone without knowledge that the treatment is available.”*

Though participants mentioned that they did not have all the information regarding the history of prostate cancer the literature confirmed their response that for prostate cancer, like other cancers, the exact cause is unknown. However, there are possible risk factors associated with prostate cancer (Gray et al., 2005:71) and ageing is the main cause of prostate cancer. It has long been known that prostate tumours become increasingly prevalent with age, so much that their occurrence could be viewed as part of the normal ageing process, as the vast majority of men will develop them if they live long enough (Foulkes & Cooney, 2010:3). There are other risk factors associated with prostate cancer, however in the study the participants managed to provide only two factors, namely age and history of prostate cancer in the family.



This finding can relate to the bio-psycho-social model in that it views people as being influenced by many factors, such as environmental, psychological and social considerations (Ross & Devereil, 2010:13). The fact that all participants failed to give a full explanation regarding the history of prostate cancer and only managed to give two risk factors associated with prostate cancer is an indication that both internal and external factors contribute to their level of knowledge. It is internal in a sense that it is embarrassing to talk about it as an individual or external in that society is ignorant about the issue of sexuality. The themes and sub-themes that follow in the study will determine if the social factors play a role in the lives of participants as survivors of prostate cancer.

#### **1.13.1.2 Sub-theme 1.2: Understanding of prostate cancer**

Of the 10 participants interviewed, two waited for more than three months after the referral from their general practitioners to the specialist and eight went to the urologist immediately. Of the 10 participants interviewed in this study, the majority of them learned about the condition from the media (radios, TVs, books), but with little understanding and also without undergoing voluntary screening. One participant mentioned that he heard about the condition from the men's talk show by a team of doctors from the local hospital at his church. He then took the step to do voluntary tests for prostate cancer and the results came back positive.

The following statements from participants confirm this:

- *"I noticed some difficulties when passing urine and thought of consulting a GP, but I had work commitments to be in Venda for two weeks. When I was still in Venda, I struggle to pass urine, and pains becomes worse and the following morning when I wake up I find myself in a pool of blood and I had to throw away the underwear I was wearing that night. It was terrible and immediately the transport was arranged for me to return to Pretoria and went to GP and immediately referred to Urologist."*
- *"I consulted two GPs about the pain I feel when passing urine, the first GP thought I had a kidney's problem and when the pain becomes worse. I*

*consulted the second GP who suspected that I have prostate cancer after presenting with symptoms and he referred me to Urologist. I kept the referral letter with me for more than three months, and I don't know exactly what I was thinking..."*

The above statements by participants is substantiated by Nicholas (2000:28) that the clinical course of cancer typically begins with the initial recognition of symptoms and a decision to seek medical care, something that men do not do as routinely or as readily as most women, and that men are less knowledgeable than women about health in general and about specific diseases such as cancer. Furthermore men perceive themselves as less vulnerable to disease than women, although men know less about health, and as a result men are probably unfamiliar with specific screening recommendations and common symptoms of cancer (Nicholas, 2000:29). This is evident that health decisions is still a serious challenge to most black men, particular on conditions relating to sexuality, including prostate cancer. The little understanding men have of prostate cancer can lead to a delay in diagnosis and proper treatment. The element of delay came up several times in this study during the interviews with the participants. The above views of the participants are confirmed by Barraclough (1994:6) that delay in a diagnosis means less successful treatment. Some men seek medical advice immediately if they notice symptoms which might signify cancer, while others wait a few days hoping that in the meantime the symptoms may go away or deliberately put off taking any action until "go for vacation" or something else. The findings from this study revealed that there was an element of delay to seeking medical attention after the first diagnosis in a few participants, which might be as a result of participants going through various emotional stages. The following participants confirm that some patients put off taking any action to attend to other matters, as mentioned by the authors above.

The experience of the above participants confirms Barraclough's (1994:6) findings that patients' delay may be linked to the following factors:

*Ignorance:* some men believe that cancer is always fatal, so there is no point in seeking treatment.

The second factor is *anxiety*. It involves a situation in which some patients are so terrified of cancer they dare not go to the doctor. Another factor that contributes to the delay in seeking treatment is *denial*. The patients are assumed to be terrified of cancer on one level, but are able to block out this anxiety from conscious awareness. “They sometimes claim they did not notice any symptoms.” The last factor that also leads to treatment delay is *embarrassment*. The cancers related to sexual organs like the prostate give rise to symptoms which some patients are reluctant to discuss.

The bio-psychosocial model regards a person as influenced not only by biological factors, but by other social factors. In the findings the decision of two participants were influenced by external factors, the workplace being one of them. Furthermore this concurs with Ross and Deverell (2010:14) that the bio-psychosocial model keeps health in social context, not in biological context only. On a positive note, eight participants interviewed went to seek help immediately.

Sub-theme 1.3 is the reaction of patients after the first diagnosis.

#### **1.13.1.3 Sub-theme 1.3: Reaction after the diagnosis**

A total 10 participants revealed various forms of reactions after diagnosis. However, not all of them have adjusted to the condition. Those who are coping better acknowledged the support they received from family members and the medical team. Participants mentioned the following:

- *“When the doctor revealed that I have a prostate cancer it was not something new to hear, but I asked myself why me but am surviving...”*
- *“I felt a pain and it was terrible even to share it and what came to my mind was death.”*
- *“Doctor assured me that I will be fine with proper treatment and is true am surviving.”*
- *“It was a shock and was the first one in the family to be diagnosed of prostate cancer.”*

The study findings provide concrete evidence that being diagnosed with cancer often involves a progression through various emotional stages. Barraclough (1994:8) explains the various emotional stages that patients often experience after the diagnosis. The first stage is *shock/disbelief*; it involves initially learning about the truth, and in this study it is confirmation that the patient has prostate cancer. This is also a stage in which the person is in denial and usually lasts no more than a few days. The second stage is acute distress as the full reality dawns. *Anxiety, anger, bargaining and protest* follow, often lasting several weeks. The third stage is of *depression and despair* and lasts several weeks. The last stage is of gradual *adjustment and acceptance*, often taking several months.

All participants interviewed went through the emotional stages. Under the bio-psychosocial model, one of the core elements is significant others and it is evident that placing health in the social context of the patient is very important. The man is not an island; the presence of significant others in the lives of these participants helped them to cope with the condition. The sub-themes in this section highlighted that the focus of health is not only about the biological aspect; other aspects like social and psychological aspects are important in the lives of the participants and they influence the participants' perceptions of their health.

The next theme is the treatment of prostate cancer.

### **1.13.2 Theme 2: Treatment of prostate cancer**

A total of 10 participants mentioned that they are still on treatment, though different types of treatment according to their stages of prostate cancer. The majority of participants were advanced stage of prostate cancer, therefore surgery was required as one of the treatment options. The following sub-themes are included in the section: understanding the stages of prostate cancer, understanding of treatment provided, the impact of treatment on the lifestyle of participants, the importance getting treatment, experiences of hospital services, and alternative treatment for prostate cancer. The following discussion contains the responses of the participants about understanding the stages of prostate cancer.

### **1.13.2.1 Sub-theme 2.1: Understanding the stages of prostate cancer**

Of the 10 interviewed, three were diagnosed more than three years ago, and seven less than three years ago. The majority of participants were diagnosed with an advanced type of prostate cancer and one with the last stage of prostate cancer. Participants mentioned the following:

- *“I was diagnosed with the advanced type of prostate cancer and doctor told me dad am in the last stage of prostate cancer.”*
- *“I did not know the stage I was and after the doctor explained to me, I have better understanding.”*

The study findings in this sub-theme provide concrete evidence that literature has mentioned regarding the importance of staging of prostate cancer, and that the extent or stage of cancer at the time of diagnosis is a key factor that defines prognosis and is a critical element in determining the appropriate treatment. Accurate staging is necessary to evaluate the results of treatment and clinical trials (American Joint Cancer Committee, 2010:1). The participants' responses show that they have a better understanding about the stages of prostate cancer. Under the bio-psycho social model the idea that all the three levels, namely biological, psychological and social processes, must be taken into account in every health care task is true, because they are all integral to and interactively involved in physical health and illness (Alvarez et al., 2012:174).

### **1.13.2.2 Sub-theme 2.2: Understanding of treatment provided**

All participants mentioned that they had an opportunity to discuss their treatment options with their doctor. The study revealed the participants' commitment to the treatment, as none of them have ever thought of stopping the treatment. However, some patients indicated that they were anxious not knowing what to expect from the treatment.

The participants shared the following views regarding the understanding of treatment:

- *“I did my own research after the doctor explained the best possible treatment for me, and it helped me to have a better understanding.”*
- *“I had a better understand of what entails my surgery after discussion with my doctor.”*
- *“I did not have a choice as my situation was serious and have to go for surgery, which was the longest and risky as I was in the advance stage of prostate cancer, I did not have any other choice.”*

The above-mentioned quotes of the participants are supported by Barraclough (1994:9) whose research shows that most cancer patients are prepared to tolerate very severe unwanted effects as the price of curing their disease. It is exactly the same tolerance that the participants have experienced with regard to treatment. Starting a new treatment usually brings a mixture of hope and anxiety. The great majority of patients appreciate receiving all the information beforehand. The findings of this study confirm research done in the USA regarding the fact that black men were more concerned about regaining erectile capacity during their recovery process than other aspects.

This highlights another important element of the bio-psychosocial model that is considered in dealing with people in health care. The psychological aspect of the participants was considered in agreeing with the treatment provided and without an understanding was going to be difficult to accept the treatment.

The model helped the researcher to have an understanding of what the participants went through as without a knowledge and empowerment from the doctor with information of what entails the treatment provided to them. Therefore the bio-psychosocial model empowered the researcher to understand that a holistic approach is essential in providing proper health care services to the survivors of prostate cancer,

### **1.13.2.3 Sub-theme 2.3: The impact of treatment on the lifestyle of participants**

During the interviews with the participants the issue of incontinence and impotence were the primary concerns for most of the men. All participants have confirmed that the treatment of their cancer had a serious impact on their lifestyle. For example the participants said the following:

- *“I don’t know what happened, but after the surgery I was unable to control my urine, and still having a urine leakage and live with the diapers, the surgery of this condition had changed my life.”*
- *“I have been using the diapers for two years now after the surgery, six months and still experiencing problems...”*
- *“After the operation I started isolating from public...”*

The following authors agree with what the participants have mentioned regarding the side effects of prostate cancer. Kunkel et al. (2000: 90) cited that men suffering from prostate cancer report impotence, fatigue and incontinence as their primary concerns and the cost of treatment-related side effects, such as impotence, incontinence and damage to the rectum and bladder neck, have to be weighed against the limited evidence of benefits (Foulkes & Cooney, 2010:7). Research has established that other men are left with very little control over urine flow and as a result social isolation and embarrassment are understandable consequences (Wall & Kristjanson, 2005:88).

Thus as stated in the bio-psychosocial model, health care is not only placed in biological context as the bio-medical model states but in social context as well. The response from the participants highlighted the importance of taking into consideration how the condition affected the lifestyle of the participants. The issue of isolation and living with diapers full-time makes their condition even more uncomfortable.

#### **1.13.2.4 Sub-theme 2.4: Experiences of hospital services**

All the participants were using private hospital services. None of them experienced problems with hospital care before, during or after operation. Two participants said the following:

- *“I had a good relationship with hospital staff starting with my doctor to the nurses, even now the relationship is still going strong.”*
- *“I only had a contact with the doctor and nurses, no other professionals, but the care was great.”*

#### **1.13.2.5 Sub-theme 2.5: Alternative treatments**

It was observed during the interviews with participants that the question was too difficult to answer. Most of the men confirmed that they were on medication to boost their erectile capacity. Only one participant revealed that he consulted a traditional doctor. The participants said the following:

- *“I have been using the medication to boost my erection, prescription from the doctor.”*
- *“My daughter am using a booster and it is really helping a lot as am so desperate to satisfy my wife.”*
- *“I never used anything, my focus was on my recovery with hospital treatment only.”*
- *“I was taken to the traditional healer and thereafter went to hospital, I did not believe that I have cancer.”*

As indicated in this sub-theme the participants were uncomfortable to deliberate on the issue of alternative treatment. However, only a few confirmed that they are using alternative treatments mainly for erectile capacity.

Under the bio-psychosocial model the issue of external factors are considered, and it was confirmed with the participants that their lifestyle is also influenced by their beliefs and traditional practices.



In conclusion of this theme, treatment is the essential aspect of any disease. In this regard the treatment of prostate cancer is important in the lives of the patients and their significant others. Ball and Bindler (2003:541) state that the goal of treatment may be curative, supportive or palliative. Curative is aimed at getting rid of the man's cancerous cells. Supportive treatment includes pain management and other interventions to assist the body's defences and to make the patient comfortable. Palliative care is designed to make the patient as comfortable as possible when no curative treatment is possible.

The theme and sub-themes of this section highlighted that all elements of a bio-psychosocial model are applicable in treating participants. Thus the literature confirms that the bio-psychosocial model is sometimes referred to as a holistic view, because it focuses on the whole picture of a person; the body and mind as well as the external environmental and social factors of the person (Cowles, 2000:12).

The next theme focuses on the challenges experiences by the participants.

### **1.13.3 Theme: 3: Challenges experiences by participants**

The study focused on the bio-psychosocial experiences of black men living with prostate cancer. The study revealed that black men living with prostate cancer have issues in all aspects of their lives. This will be discussed under the sub-themes.

#### **1.13.3.1 Sub-the 3.1: Bio-psychosocial impact of living with prostate cancer**

The main issue that was found challenging to black men living with prostate cancer is their social life. Social life was a dominant subject during the interviews regarding their experiences of living with prostate cancer. The participants confirmed that their social life prior to prostate cancer was different as compared to their present one. The participants said the following regarding their social life:

- *"After the operation I started isolating from public..."*
- *"I do hang out with men, but for a short period"*
- *"My social life is worse now..."*

- *“As much as I would like to spend some time with friends after work, I can’t because I must contain my urine until I reach home as it is going to embarrass me...”*

The above quotes confirmed that their social life has limitations and it is not the way the participants wish to spend time with the people. It is true that men living with prostate cancer’s social life suffer and this results in feelings of loneliness and sadness. The following literature studies done on the social life of men with prostate cancer concur with the participants that cancer patients may experience feelings of loneliness, abandonment and lack of support. (WHO,2008:83).Another study done in Norway regarding the impact of prostate cancer found that prostate cancer is the most common cancer amongst men and that side effects influenced their daily activities and relationships (Ervik & Asplund, 2012:103). The different phases of prostate cancer are likely to present different psycho-social issues, leading to a need to understand how patients are affected during the various phases of illness to provide comprehensive phase specific care (American Society of Clinical Oncology, 2015). Much of the participants have the full support of their wives, however they are also aged which might put a double burden on their wives as they have their own chronic conditions to deal with as well. It is therefore important to realise that other support systems for prostate cancer survivors are important. The participants confirmed that their social life prior to prostate cancer was different as compared to the present one of living with prostate cancer. This also confirms the core element of the bio-psychosocial model that the social aspect is important in understanding the experiences of the participants. It is also evident that not only the biological aspect suffers, but their relationship with their significant others suffers as a result of the limitations to their social life.

### **1.13.3.2 Sub-theme 3.2: The emotional aspect**

The impact of prostate cancer on the emotional well-being of the participants was revealed during the discussion. All participants acknowledged that it causes emotional pain to live with prostate cancer.

Participants shared the following:

- *“It is not easy as a man to show your feelings to your families, wife and children.”*
- *“I know how I feel and when am alone it hurts, even if am crying, I make sure that my wife doesn’t see me.”*

The findings of the study concur with what literature has said that the diagnosis and treatment of prostate cancer can have long-term effects on men, physically, psychologically and emotionally. It has been long understood that prostate cancer and its treatment affect both members of a couple, especially in the area of sexual functioning, intimacy and communication (Galbriath et al., 2011:303).

It is also evident from this study that the participants are human beings and they agreed that living with prostate cancer brings pain to their lives. However, they refused to show their real feelings to their wives.

Under the bio-psychosocial model the behaviour of the person is also influenced by environmental factors. The fact that the participants did not want to show their emotions was a confirmation that, culturally speaking, it is unusual to see a man crying. It is true that when dealing with health issues all aspects, including culture, have to be considered to have a better understanding of what it is like to be a black man living with prostate cancer. Thus the bio-psychosocial model provided a better understanding of black men in the study.

#### **1.13.3.3 Sub-theme 3.3: Financial impact**

Most participants emphasised the issue of financial burden during the interviews. Of the 10 participants interviewed, only one took early retirement, four were still working and five are pensioners. Looking at this result is evident that the other needs of participants are affected, apart from having medical aid schemes to cover major treatment costs. Several voices came out regarding the impact of prostate cancer on finances. The following expenses were mentioned by participants during the

interviews, which include the issue of diapers, adequate care, medications and travelling expenses:

- *“It is hard for us, me and my wife we are pensioners am using diapers fulltime is hard at times...”*
- *“I do pay cash for other medications every month as medical aid scheme doesn’t cover all my medications.”*
- *“It is very expensive living with prostate cancer, everything is money...”*
- *“After the operation, I could not contain urine and since am using diapers till today.”*

All participants interviewed were from the Pretoria Urology Hospital and under different medical aid schemes. However, it was revealed that some medication is not covered, which basically means that the participants have to pay cash for it. Other needs mentioned during the interview are adequate diet, diapers for those with incontinence, and travel costs to and from the hospital. It was uncovered in this research that two participants are on diapers full-time and one is a pensioner who mentioned that things become too much for him, as they have to pay other monthly bills like food, water and lights. Another participant is still working, so though his needs are expensive it is less stressful for him compared to the pensioner. It was further uncovered in the study that the participants’ wives are also pensioners and this put a double burden on the family. It was also found that the working partners of some participants had to take other financial responsibilities that were meant for their partners before diagnosis.

It is evident from the participants interviewed that prostate cancer has an impact on their needs, which is also confirmed by a study done in the USA which found that partners of the men living with prostate cancer need to deal with other life stressors, such as being forced to learn new household skills ranging from managing the family finances to dealing with household repairs (Tanner et al., 2011:155). This highlights that prostate cancer has a serious impact on the lives of the participants significant others, especially the children, as both parents are pensioners and have other needs

to take care of. There are new responsibilities as far as financial responsibilities and changes are concerned.

Once again, as per the bio-psychosocial model, all aspects of the patient are important. The financial aspect as external factor has an impact on the lives of the participants. Maintaining their health by having transport to the hospital, being retired and needing to use diapers all involves money.

#### **1.13.3.4 Sub-theme 3.4: Sexual impact**

One of the dominant subjects during the discussion regarding the challenges of living with prostate cancer was the participants' sexual life. Sexual life is of great importance to married men and the issue of loss of erection as a result of the condition emerged several times during the interviews with the participants. It is interesting that despite of their age, loss of erection is a serious issue. However, the study revealed that the issue of sexual life is even more serious in participants below 60 which is something understandable considering their age.

The study revealed that eight of the 10 participants were worried about their sexual life, particularly after the operation. They feel incomplete as they were unable to perform their sexual duties as husbands. It is important to note that nine of participants are married, some are still below 60, and their wives are much younger than them. Only one of the 10 participants was a widower. The study also pointed out that even those participants of above 60 are thirsty to regain their erectile capacity. Some men were too shy to go into detail about their private parts or use the common name to refer to their manhood or private parts; instead they used street language to refer to their manhood. Some used non-verbal language and pointed to their manhood, calling it '*moshimanyana*' and '*mothaka*' meaning a 'little boy' and 'buddy'. Fortunately the researcher managed to understand the language they were using in this particular context.

The participants said the following regarding the impact of prostate cancer on their sexual life:

- *“I want to do it as a man with feelings, because I do love my wife and sometimes she will asks me, when u will regain your erectile capacity”.*
- *“I am aware of my condition and recovered well from the operation, I want to have it back, I do try hard with the sexual boosters I have, sometimes it (penis) will surprises me and gets up for few minutes when am excited it goes down.”*
- *“My wife supports me and she is hoping that one day will go back to our normal sexual life.”*
- *“I tried to do it with my wife several times but failed. Look at the age of 76 and my wife is 66 what do I want, as long as my wife does understand and support me.”*
- *“I’m still recovering from operation and I just assume that my wife understands this condition and we never discussed it deeper and I don’t know how she feels about it.”*
- *“I am cut from sexual life, is no longer possible for me and my wife and is of the past.”*
- *“It is boring in the bedroom and with the use of sexual boosters am hoping to have my sexual life again, am telling you my child this condition is terrible, is a thief, it steals from men something that is irreversible.”*

Through observation during the interview, though some men were joking when discussing their sexual lives with their partners, it is evident that this issue has a huge impact in their lives. These jokes, according to the researcher, were an effort to hide the seriousness of this aspect in their lives, because their facial expressions were saying something different than their words.

The response of the participants that normal erectile function may be disturbed in prostate cancer patients by a number of factors is supported by literature. The erectile nerves may be damaged during surgery, following external beam radiotherapy or late after brachytherapy, and the resultant erectile dysfunction may

be irreversible (Kirby et al., 2001:201). Literature also confirms that amongst black men, the fear of erectile dysfunction, sterility and decreased sex drive associated with treatment were also identified as factors potentially deterring men from being tested for prostate cancer. Other studies done amongst African-American men indicated that the ability to have and maintain an erection was of highest concern (Pedersen et al., 2011:465).

The findings on sexual concerns was also revealed in a study conducted in the USA on sexual relations, which found that sexual concerns remained high and most men were concerned about sexual issues and reported low satisfaction with their sexual functioning, but relatively few sought treatment (Galbriath et al., 2011:38). Gray et al. (2005:80) also cited that the loss of erectile capacity proved to be a difficult matter for most men and, despite the fact those participants and their wives had not been sexually active, they hoped that things might change. This the research also revealed that of the nine participants living with their partners, only three participants discussed the issue of sexual challenges with their partners in-depth and sought treatment from a sexologist. Sex can be a challenging aspect to communicate about, as the patients might feel embarrassed. As a result of their inability, they might find it hard to put on a brave face for their partners or to consult a specialist. By the look of things prostate cancer has ended the hopes of most participants of being sexually active as a result of the surgery performed. It was also found that a full discussion on possible loss of sexuality excluded the wives of the participants, prior to and after surgery.

Since the prostate cancer is a sexually-related condition, it is evident in this sub-theme that the issue does not only affect the participants, but their relationships with their wives as well. In a nutshell the bio-psychosocial model provided the researcher with a better understanding that the sexual lives of the participants is not only about them.

#### **1.13.3.5 Sub-theme 3.5: Marital impact**

The diagnosis of cancer also tends to cause the integrity of the family system to suffer severe assault. In some instances the husband, who had previously been the dominant family figure and business manager, has to face the fact that a role

reversal has occurred and his wife is now fulfilling these roles (Ross & Deverell, 2010:147).

This research revealed that of the 10 participants interviewed nine were married and still living with their partners. None of participants divorced after the diagnosis; all of them were still living with their wives. However, the married participants agreed that their marriages have undergone slight changes in their sexual life, communication and financial burdens, among others. They indicated that the areas of concern for their wives are taking on extra household chores and also caring for their husbands' needs.

One participant had this to say regarding the impact of prostate cancer on marital life:

- *“I used to do everything with my wife, before this condition is difficult used to travel a lot and even now being inside most of the time we do things together inside.”*

It is evident with the participants interviewed that prostate cancer did not separate them from their partners; instead it has brought them closer as couples. Gilmore (1997), in Ross and Deverell (2010:147), found that previously strained marriages may collapse under the stresses of financial changes and medical costs, impaired communication, and changes in family roles and lifestyles. In other cases the patience and support of the spouse and family can bring some couples closer together. None of the participants separated from their wives after being diagnosed with prostate cancer.

The issue of jealousy also came out of the interviews with the participants, which affected their marital life though they never communicated this to their partners. The study uncovered that out of the nine participants still living with their wives, four of them expressed the fear that their wives may cheat because of their inability to perform sexually. This issue of sexual dysfunctional had brought insecurity to the lives of the participants.



Some of the black men, for example, had this to say regarding jealousy:

- *“I don’t know what to do, but again I can’t deny my wife an opportunity to visit her relatives, but am always thinking that she will hook up with her old male friends from school or neighbours, it worries me when she is not around.”*
- *“I have known my wife for years, but when she is not around I feel insecure that she might cheat.”*
- *“I don’t want to think too much about it, but I really don’t know what she is thinking, I need her support now.”*

Regardless of the fear that their wives might cheat all participants are still with their wives and they hope that there will be no changes in their relationships.

### **1.13.3.6 Sub-theme 3.6: Physical impact**

The participants expressed the view that the pain before and after the surgery are both very bad. All the participants have confirmed that the pain was too much to handle. All the participants mentioned that the pain before the diagnosis was unbearable and did not share with their spouses until the pain became too much to bear. In addition two participants indicated that they waited for some time after their GP suspected prostate cancer and referred them to the specialist. One participant waited six months and another one a year. They also mentioned that they were afraid of unknown results and the extent of the prostate cancer, even without having the full information about prostate cancer. After extensive self-research they made the decision to consult the specialist.

As some of the participants indicated:

*“After several consultations with my General practitioner and I had severe non-stop pain...”*

*“I don’t know I was afraid, having doubts not knowing what to do, I eventually got courage to go.”*

*“Then the doctor diagnosed me with aggressive type of cancer.”*

*“It was too much to go through the fear, sadness after diagnosis.”*

*“Do you know how they insert the needles and everything before and after the surgery is very painful, the process is not easy...”*

For most of the participants interviewed, more than 12 months had passed after their surgery. The participant with the most recent operation had his operation nine months ago. The issue of pain after the surgery came up several times during data collection.

One participant mentioned the following regarding pain:

- *“I cried alone, and the only way to deal with was to go back to work early, cause I was alone at home, my wife at work and children at school, no one to talk to the whole day and this thing was eating me inside, and was feeling depressed and sad.”*

This finding concurs with the study done by Cameron and Bernades in Britain (in White, 2002:149) where in-depth interviews and questionnaires were used. It was found that men tend not to discuss their physical symptoms, and 6% of the respondents reported that they were not even telling their spouses about their painful and intrusive condition. Literature conducted in the USA also confirms this finding that socio-cultural practices in black African-American society groups are a contributing factor. In screening for prostate cancer, the black men sampled tended to perceive the test as a threat to their masculine identity and an undignified procedure (Pedersen et al., 2011:465).

It is evident from this research that the black men living with prostate cancer are facing this on their own, as most of the participants are afraid to express their feelings and what exactly they are going through to their immediate family members. The significant others of the participants proved to be important and affected by their condition of living with prostate cancer. The surroundings of the participants are also important and this is indicated in the bio-psychological model, as the ability of these participants to cope was influenced by the support of their wives.

### **1.13.3.7 Sub-theme 3.7: Poor communication with family**

All participants shared their status with their wives and some with their children. Of the 10 participants interviewed all have adult children. Two participants mentioned that they did not discuss the condition with their children, despite the fact that they are male adults. Eight participants shared the details of their condition with their children and some extended family members, including friends and colleagues. Three working participants shared their experiences with some of their colleagues.

The following quotations from participants support the above:

- *“I do talk with my wife and most of the time is hard to express to her how I feel.”*
- *“If am seen crying, my family will think am not a man enough and want to them to have confident in me that I will fight this condition...”*
- *“Me and my wife have a good relationship we talk a lot and she comforts me “*
- *“It is between me and wife, my children do know that I was in hospital and operated but did not discuss further with them about my condition...”*
- *“I have spoken to my children and encouraged my sons to be careful when they are over forty years, to check themselves regularly...”*
- *“It is only my wife and her sisters that know about my condition.”*
- *“Apart from my wife and children, only one friend of mine knows about my condition.”*

There are certain issues in society that are treated as individual or family matters and are kept secret forever. It is still happening that men as well-educated as the participants believe that it is embarrassing to talk about something associated with their private parts, especially with other men. Fear of expressing their feelings supports the belief that *“Monnakenku o llela teng”*, which literally means “that a man is a sheep, cries inside”. In addition, to be seen crying and expressing real feelings as a man it means people will judge you as being weak. The researcher observed that it is still happening that amongst black men it is embarrassing for a man to be seen crying, even in the mist of this condition, and thus black men are still suffering alone. The issue of “ego” amongst black men, as it was revealed during the interviews with participants, is still dominating their lifestyles and the important

decisions in their lives. The research revealed that the social life of black men living with prostate cancer is severely affected as a result of non-disclosure or their inability to communicate real feelings with their significant others.

The participants' issue of lack of sharing and their inability to express their feelings with their significant others was uncovered. The study revealed that a lack of communication is a challenge in the lives of black men living with prostate cancer. The fear to open up to their wives has emerged several times during the interviews. The fear of the unknown is applicable to black men living with prostate cancer. The fear that they might be judged is of great concern to the participants. The study revealed that out of all 10 participants interviewed, only two confirmed to have open communication with their significant others.

Talking about the issue of prostate cancer is still challenging, however the participants expressed the view that they felt that it was fine to keep the issue secret. It goes back to the issue of maintaining their status within the community where they live, as well as sustaining the respect that they have from the people. Fear of being judged as a result of the condition and feeling of worthless came out of the interviews with participants. The issue of non-disclosure still dominates the behaviour of the participants living with prostate cancer. To keep things to themselves is seen as the best decision to deal with the condition. It is evident through this study that culture and gender might be an obstacle in communicating feelings amongst black men living with prostate cancer. It is also evident from this study that prostate cancer continues to have a serious impact on the lives of black men, as the study revealed that prostate cancer is still treated as a secret. The findings from these sub-themes proved that all aspects of the participants were affected as a result of living with prostate cancer. Therefore one cannot avoid the fact that under the bio-psychosocial model all the aspects are important and need to be attended as well in supporting survivors, not only the biological being of the participants.

### **1.13.3.8 Sub-theme 3.8: Impact of living with prostate cancer on the workplace**

Of the 10 participants, only two utilised counselling services at work and eight never consulted a therapist before or after the diagnosis. Six participants are not working, therefore they had nothing to share with regard to their workplace experiences. One participant took early retirement.

- *“I also shared my experiences with my colleagues and some of my relatives.”*
- *“I was left with few years to go for pension, but to be back at work with my condition, I was not comfortable, though the management was supportive but using diapers at the same time.”*

Only four working participants indicated that they had support from their senior management at work. One participant mentioned that he utilises the employee assistance programmes at work, and he confirmed that the support he receives in the form of counselling makes his life at work easy. The majority of the participants are no longer at work, since prostate cancer affects older men. One participant took early retirement because he could not cope at the workplace. Since the workplace is another social structure where men spend most of their time, it is very important to those who are still working to have a support system. The study revealed that not all working participants utilised services at work; out of four only two are using workplace employee programmes. This goes back to one of the core elements of the bio-psychosocial model that the external factors of the participants were affected.

### **1.13.4 Theme 4: Needs of black men living with prostate cancer**

Like with any other illness, prostate cancer survivors have their own needs to help them cope with the condition. The following sub-themes explain the needs of the participants in detail.

#### **1.13.4.1 Sub-theme 4.1: Resources**

All 10 participants revealed their concerns regarding resources available for prostate cancer. The following are the views of the participants regarding the issue:

- *“I believe our country is doing better, so wish our health system can put more resources on men’s health like they do in HIV/AIDS, resources be visible and accessible, men start to go for voluntary screening, some of the programmes be dedicated to men and government take initiative to reach more men.”*
- *“Workplace provides more attention on their male employees regarding their health issues.”*

The different phases of prostate cancer are likely to present different psycho-social issues, leading to a need to understand how patients are affected during the various phases of the illness to provide comprehensive phase specific care (American Society of Clinical Oncology, 2015).

### **1.13.5 Theme 5: Available support systems**

Concerns with regard to relationships with a partner, family members, or with social networks may be raised. However, all participants revealed that their wives are their closest support system. Eight participants had the support of their children and two did not disclose the condition to their children, and as a result their children are unable to give them the necessary support.

#### **1.13.5.1 Sub-theme 5.1: Family support for participants**

This research revealed that out of the 10 participants interviewed nine were married and still living with their partners. None of participants divorced after diagnoses, and all of them were still living with their wives. The following quotes confirm this:

- *“I do everything with my wife, before this condition I used to travel a lot and even now being inside most of the time we do things together inside.”*
- *“After operation, I only spoke to my doctor and I decided to deal with it alone, you are the first professional to speak to after the operation.”*
- *“After the operation I started isolating from public...”*
- *“I do talk to my doctor when I go for check- up”*
- *“I do hang out with men, but for a short period.”*
- *“My social life is worse now...”*

- *“As much as I would like to spend some time with friends after work, I can’t because I must contain my urine until I reach home as it is going to embarrass me...”*
- *“I took early retirement as a result of this...”*
- *“Not all my friends know about my condition, only few.”*

It is evident from the participants interviewed that prostate cancer did not separate them from their partners. Instead it has brought them closer as couples. Married participants agreed that their marriages are still on, with slight changes in their sexual lives and financial burdens. They indicated that the areas of concern of the wives are taking on extra household chores and also caring for their husbands’ needs.

As stated in in Ross and Deverell (2010:147), participants’ responses confirm that previously strained marriages may collapse under the stresses of financial changes and medical costs, impaired communication, and changes in family roles and lifestyle. Though the participants mentioned that their lives had changed, other support systems were not aware of what they are going through because they did not disclose the condition to them, such as church members, social clubs, friends, neighbours and other relatives.

They indicated that the areas of concern after diagnosis are when the wives are taking on extra household chores and also caring for their needs. The diagnosis of cancer also tends to cause the integrity of the family system to suffer severe assault. In some instances the husband, who had previously been the dominant family figure and business manager, has to face the fact that a role reversal has occurred and his wife is now fulfilling these roles (Ross & Deverell, 2010:147). The participants interviewed in the study mentioned that they are unable to fulfil other duties as husbands, because of the limitations of prostate cancer on their daily lives. This sub-theme confirms that people belong to systems in life and this is exactly what the bio-psychosocial model means, as it derives from the system theory which views people as being influenced by many factors, such as environmental, psychological and social considerations (Ross & Deverell, 2010:13).



### **1.13.5.2 Sub-theme 5.2: Community support for participants**

The participants said the following:

- *“I kept the issue with my family, wife and children, I think relatives have their own issues and didn’t want them to know and be involved in my own issues. I do know about CANSA but no have much information about their services, never used their service after diagnosis, I only rely on my wife and children.”*
- *“Not all my friends know about my condition, only few.”*

Support systems in the lives of black men remain a critical issue and it remains largely on the family’s shoulders, particularly wives and the doctor. It emerged from the study that the support systems of black men living with prostate cancer are limited because of the various reasons. However the issue of non-disclosure remains the main reason for a lack of support systems. The participants’ responses concur with what the literature says about society’s expectation that men must be tough and independent, and it can lead to the suppression of emotions, a sense of invulnerability, social isolation, withdrawal and a hesitancy or unwillingness to ask for help (Wall & Kristjanson, 2005:91). It is therefore society’s expectations that lead black men to remain silent and deal with the illness with their respective families only. The study also confirms that the environmental factors contributed to the participants’ nondisclosure.

### **1.13.5.3 Sub-theme 5.3 Medical support for participants**

All the participants interviewed confirmed that they have support from their doctor and nurses during and after operation. One participant said this:

- *“After operation, I only spoke to my doctor and I decided to deal with it alone, you are the first professional to speak to after the operation.”*
- *“I do talk to my doctor when I go for check-up for clarity on my condition and it help me to understand my progress.”*

It is evident from the findings that the participants only relied on the doctor; other health professionals were not utilised. Hence there were several challenges that



emerged from the participants during the interviews, including impotence, incontinence, poor communication, and social issues amongst others.

The study has shown that the majority of the participants have a good relationship with the doctor. It is their main medical support. The literature concurs with the participants' responses, however the researchers disagree as there are other professionals under the multidisciplinary team that most participants could have used or referred, but they did not use them and were not made available for them. Therefore none of the participants were referred to psychologists or sexologists. This brings out the issue of lack of communication and openness by participants with other people about their real issues. Medical support is crucial to assist the patient to cope with the condition. Therefore the relationship between a patient and the medical team is important during the process of recovery. A bio-psychosocial model of care provided by a multidisciplinary team that includes professionals with expertise in all important areas affected by prostate cancer is important (Wittmann, Northouse, Foley, Gilbert, Wood, Balon & Montie, 2009:100).

In conclusion of this theme and sub-themes on resources available for black men living with prostate cancer it is true that it is difficult to expect social support as a result of non-disclosure by the participants to other structures. To understand and respond adequately to patients suffering from prostate cancer the health team must attend simultaneously to the biological, psychological and social aspects of the illness.

The next theme and sub-themes are strategies to improve services to black men living with prostate cancer.

#### **1.13.6 Theme 6: Strategies to improve services provided to black men living with prostate cancer**

The participants represented the views of prostate cancer services provided by the private hospital, not public hospitals. Their views on this matter were similar, with more emphasis on prevention programmes dealing with stigma surrounding the issue of prostate cancer.

The following sub-themes present the strategies suggested by the participants.

#### **1.13.6.1 Sub-theme 6.1: More education about prostate cancer**

One participant argued that the South African Government is doing enough and taking care of one's health depends entirely on an individual. The participants mentioned that the services received from the hospital before, during and after the operation was good. However, the following were recommended by the participants as far as services of prostate cancer are concerned:

- The visible awareness on men's health issues to be given more attention in South Africa within black communities.
- Comprehensive education on prostate cancer be given more attention.
- Prevention programmes to be visible at all hospitals and clinics, including private and public facilities.
- Encourage black men to take part in voluntarily screening sessions.

#### **1.13.6.2 Sub-theme 6.2: Counselling services (individually, couples and support groups)**

The participants agreed that counselling is important, however none of them ever attended therapy alone or with the family. Participants mentioned the following:

- *"I was not told about the counselling; me and my wife are dealing with the situation on our own. You are the first professional to share my experiences."*
- *"I receive counselling from work and so far it help me a lot, but it is me alone and never attended a counselling with my wife and I don't know how she feels about certain changes as a result of this illness."*

The above-mentioned statements by participants indicate that counselling sessions should be compulsory, and not only provided if the patient asks for it. It should be available at the hospital for the survivors and their families. The participants' statements are a confirmation that the patient's totality be taken into consideration in the treatment plan as the core element of the bio-psychosocial model.

### 3.14 SUMMARY

The study was carried out with the black men living with prostate cancer from the list of a private doctor at the Pretoria Urology Hospital. The participants were chosen from the Hospital because of its speciality in dealing with men living with prostate cancer.

The researcher used the qualitative approach in the study. The black men living with prostate cancer were selected from the list using purposive sampling with the help of the administration team and a doctor. Ten participants were interviewed using in-depth interviews, guided by interview scheduled questionnaires to collect data. The researcher used Creswell's stages of data analysis in this study, including transcribing and interpreting data, and dividing data into themes and sub-themes. The research achieved its objectives. However, there were challenges that the researcher experienced during the study which included the recruitment process of participants, permission from their spouses/children to participate in the study, and gaining their trust due to the sensitivity of the topic before the interviews.

Apart from these challenges the researcher adhered to the ethical issues which were very important, including voluntarily participation, informed consent and confidentiality. Based on the impact and the seriousness of prostate cancer on the lives of black men on their experiences it was found that through this study, prostate cancer still receives little attention.

The next chapter entails the discussions of the achievement of goals and objectives of the study, key findings, recommendations, and conclusions, as well as further research regarding prostate cancer.

## CHAPTER 4: CONCLUSIONS AND RECOMMENDATIONS

### 4.1 INTRODUCTION

This chapter presents a discussion of how the goal and objectives of the study were achieved. This will be followed by a presentation of the key findings of the study from which a conclusion will be made. The chapter will end with the recommendations.

### 4.2 GOALS AND OBJECTIVES OF THE STUDY

The goal of the study was to explore and describe the bio-psycho social experiences of black men living with prostate cancer.

The goal was achieved through the following objectives;

- **Objective 1: To contextualise prostate cancer as a phenomenon amongst men from different cultures**

This objective was achieved through a literature review which is in Chapter 2 of this report. This objective was also achieved through Theme 8, which is one of the themes that emerged from the interviews with participants. Prostate cancer is described and explored in detail in Chapter 2, including the stages and treatment of prostate cancer, risk factors associated with prostate cancer, and a presentation on the prevalence of the condition worldwide, in Africa and in South Africa. In South Africa the prevalence was explained in detail by interviewing black men from different ethnic groups which are Setswana, Sepedi, Xitsonga and IsiZulu. Theme 1, sub-theme 1.2 explains the knowledge of participants with regard to prostate cancer. The main aim was to check black men's level of knowledge in the context of their own experiences. Their knowledge was shared and it was found that their level of knowledge about prostate cancer prior to the diagnosis was poor. It changed after

diagnosis with self-empowerment, as they did their own research and received information from the doctor.

- **Objective 2: To explore and describe the bio-psychosocial experiences of black men living with prostate cancer.**

This objective was achieved in Chapter 2 whereby the detailed experiences of men living with prostate cancer was explored and described. The areas were social, emotional, financial, psychological, sexual, marital and cultural. It was found that the above-mentioned areas have a serious impact on the lives of the black men living with prostate cancer. The detailed description of bio-psycho social models was also discussed in Chapter 2.

- **Objective 3: To describe the experiences of black men with prostate cancer from different cultural groups.**

Since the focus of the study was on black men living with prostate cancer. This objective was achieved in Chapter 3. Ten black men from different groups were interviewed and shared their experiences of living with prostate cancer. The findings uncovered areas that emerged several times during the interviews, which are listed as all the themes and their sub-themes.

- **Objectives 4: To improve social work intervention of black men living with prostate cancer.**

The objective of the study was achieved through Chapter 2 on the role of the social worker and other health care professionals. Intervention by social workers is much needed based on their experiences, both on an individual and family level. The recommendation and needs of participants under Theme 6 revealed that there is a need for black men to be in a support system, and an improvement in the availability of counselling is needed after the operation. Most participants do not cope and they need a place to share their experiences as part of coping with the condition. The discussion with the participants revealed that life is more challenging outside the

hospital and the black men living with prostate cancer suffer most as a result of non-disclosure, which can only be addressed through a multidisciplinary team whereby all aspects of the men are explored and discussed.

### 4.3 KEY FINDINGS

This section will present the key findings of the study, conclusions and recommendations. The findings, conclusions and recommendations arise from the data collected, as well as the observations made by the researcher. These findings are based on the bio-psychosocial experiences of black men living with prostate cancer.

- The study uncovered that bio-psychosocial experiences of black men are serious in living with prostate cancer. There are areas severely affected by living with prostate cancer, including sexual life. Most participants were more worried about regaining their erectile capacity than their lives, despite their age. The other areas include their financial life, because they have to live with diapers full-time and buy medication cash. It was also uncovered that because of a lack of communication their wives suffer most, and that their social life suffers as a result of non-disclosure.
- Findings have established that men are generally reluctant to make an effort regarding their health issues. In this study all participants were unable to give a comprehensive summary of the stages, types and the extent of their prostate cancer, as well as specific treatment. None of them have had voluntary screening for prostate cancer before.
- The findings uncovered a lack of communication, as most participants in the study did not want their families to know exactly how they are feeling emotionally and psychologically.
- The research findings showed that there is an element of delay among men in seeking help. In this study it was revealed that some participants waited more than three months before they sought help, even when the symptoms became worse.

- The research also discovered that none of the participants belong to any support group which focuses on survivors of prostate cancer and their families; their only support system is their families and doctor.
- The findings indicated strategies to improve services rendered for black men living with prostate cancer, which are visible and accessible awareness on men's health, comprehensive education on prostate cancer both in private and public hospitals and clinics, and voluntary screening for men.

#### 4.4 CONCLUSIONS

- It was concluded that bio-psychosocial issues have an impact on black men, including their social life, relationships, loss of erectile capacity, and loss of relationship with other friends, financial strain, cultural barriers, and so on.
- In conclusion the cultural practices continue to have a serious impact on the health decision of black men in general. The topic is treated as a secret and the cultural perceptions of prostate cancer have an element of shame.
- Conclusion drawn from this study is that treatment options for prostate cancer is generally expensive and painful, particularly for those presenting with an advanced type of prostate cancer, as surgery is needed in most cases.
- It can be concluded that support systems for prostate cancer is so limited as a result of non-disclosure. The only support systems that the participants have are their wives, children, a few friends, colleagues, and other relatives.
- It can be concluded in the study that men are finding it difficult to communicate their feelings to their wives, as participants preferred to hide themselves when in pain and never wanted to be seen crying.
- It is therefore concluded that the issue of prostate cancer is given little attention, though men are out there suffering alone in silence.
- The research concluded that living with prostate cancer as a black man is characterised by various issues that if not attended will continue to cause serious pain and suffering in their lives.

In a nutshell the study managed to explore and reveal the experiences of black men living with prostate cancer and found that men experience a complex journey of living with prostate cancer, which is characterised by the side effects of the

treatment. The recommendations to address the above conclusions are discussed in the next section.

## **4.5 RECOMMENDATIONS**

Based on the above-mentioned findings and conclusions on the bio-psycho social experiences of black men living with prostate cancer, the researcher recommends the following.

### **4.5.1 A Comprehensive Prostate Cancer Education**

This needs to be applied with the aim to address the lack of knowledge amongst black men. Furthermore, the emphasis should be on the resources available for the survivors of prostate cancer and their families. The Government should put more resources into men's health issues in all health facilities, both in private and public facilities, and also in languages spoken by the black men in South Africa, so that information can reach even illiterate men. The Government should improve the management of non-communicable diseases by implementing a long-term model, including men's health.

### **4.5.2 Encourage Voluntary Screening for Black Men**

Prostate cancer screening and tests are to be adopted on a wider scale. More effective promotion will be required so that black men can see the value of early detection and treatment, as well as regular check-ups for men above the age of 40. Encourage black men to participate in voluntarily screening to reduce the incidence of black men presenting with advanced or aggressive types of prostate cancer, and in addition make testing mobile clinics available in all corners of South Africa, both in rural and urban areas.

### **4.5.3 Intensify Awareness Campaigns at all Sectors of Society**

Based on the burden of the condition on black men, prevention is the key to reduce the underlying causes of illness, and improve patients' quality of life and the burden



of dealing with aggressive types of prostate cancer which most black men presented with, including the participants in this research. The shift from treatment to prevention needs to be strongly emphasised in dealing with black men's health care. The awareness campaigns should be intensified to deal with the issue of cultural beliefs and lifestyles, stigma attached to prostate cancer, masculine. Furthermore, the Government should enhance the programmes for the prevention and treatment of non-communicable diseases, including prostate cancer.

#### **4.5.4 Provision of Support Group Services for Survivors of Prostate Cancer**

Based on the sensitivity and seriousness of prostate cancer, support should be made available in the form of individual counselling and support groups for black men living with prostate cancer and their families, particularly for wives at private hospitals prior to and after surgery. The support group sessions can benefit the men by de-stigmatising the condition, suggesting coping strategies, and providing empathy and understanding. The support group could also address the needs of the men. It can also be done with the wives of the men with prostate cancer to supplement individual therapy.

#### **4.5.5 Involvement and Empowerment of Stakeholders**

Oncology is not only about knowledge of the diseases and its treatment, it also includes care of the family whose stability is threatened by the possible changes that they may experience. Therefore a holistic approach using a multidisciplinary team which includes a social worker is necessary to meet the psychosocial needs of both the man and his family. The health team needs to create collaboration between hospitals, including private hospitals, in utilising services that are available from NGOs like the CANSA. All stakeholders including health professionals, wives and NGOs to join hands to ensure that the quality of life for men with prostate cancer is improved. They also need information on how to improve the coping strategies of all affected.

### **4.6 CONDUCTING FURTHER RESEARCH**

There is a need for further research on the following issues:

- challenges encountered by partners of black men living with prostate cancer;
- how cultural practices of the current era impact on the health decisions of black men, and;
- Whether or not cultural barriers are still a challenge in dealing with health care amongst the different cultural groups in South Africa.

In addition, the research should be expanded further in private and public health facilities across the country so that there can be rich information on bio-psychosocial experiences of black men living with prostate cancer and as well as generate several views and recommendations to address the challenges and needs encountered in this area.

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Date: 2014/07/25

The researcher's name: Dikeledi Matlawa

Contact details: 0788746579

Email: Mashienyanem@tshwane.gov.za

#### INFORMED CONSENT FORM

1. **Title of the study:** The Bio -psychosocial experiences of black men living with prostate cancer.
2. **Purpose of the study:** To explore the bio psychosocial experiences of black men living prostate cancer.
3. **Procedures:** The participant will be expected to have a one on one session with the researcher and if need arises a follow up sessions may be requested. Each session will last about 30 minutes and the sessions will involve basically answering the questions the researcher has for the participant. The purpose of these sessions is to find out what are the daily challenges the participant is facing. The interview schedule will guide the sessions.
4. **Risks and Discomfort:** The participant should note that there is possible emotional draining caused by having to share their personal experiences of living with prostate cancer.
5. **Benefits:** The participant should note that there are no financial gains to be expected from this research. However, the participant's involvement with the research will be beneficial to them as an individual and also the society as whole in that sharing their experiences will help someone out there who is in the same situation.
6. **Participant's Rights: the rights of the participant are as follows:**
  - participation is voluntary, no participant will be forced to take part in the research
  - the participant may withdraw from the participation in the study at any time and without negative consequences
  - the participant has a right to speak out if they feel their rights are being violated
7. **Confidentiality:** Confidentiality will be held in highest priority, as follows:
  - The participant is assured that all information is treated as confidential
  - anonymity is assured hence the use of pseudonyms
  - in the event that the participant withdraws from the study, all data would be destroyed.
  - All persons having access to the research data must also be identified.





Date: 2014/08/22

The researcher's Name : Dikeledi Matlawa

Contact Details : 0788746579/012-358-5355

Email: Mashienyanem@tshwane.gov.za

**INFORMATION LETTER REGARDING RESEARCH**

The above mentioned researcher requests you to participate in the study which the title is to explore the bio psycho social experiences of black men living with prostate cancer.

If you are interested in the study kindly provide your address and contact details and leave it with the reception at the Doctor's room.

The researcher will make follow up with you in due course

**Regards**

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

**MRS NJ BILA**

**SUPERVISOR**

Department of Social Work & Criminology    Tel: Number    00 27 12 420 2325/2030    www.up.ac.za  
University of Pretoria    Fax: Number    00 27 12 420 2093  
PRETORIA 0002  
Republic of South Africa

## SEMI-STRUCTURED INTERVIEW SCHEDULE

### Goal of this study

To explore the bio-psychosocial experiences of black men living with prostate cancer.

### SECTION A: BIOGRAPHICAL DETAILS OF THE PARTICIPANTS

#### 1. Age distribution

20-25 yrs		26-31 yrs		32-37 yrs	38-40 yrs		
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#### 2. Gender

Female		Male	
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#### 3. Marital status

Single		Married		Divorced		Widowed		Living with partner	
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#### 4. Language

Sepedi	Tswana	Sotho	Tsonga	Venda	English	Afrikaans	Other, specify
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#### 5. Area of residency

Pretoria Central	Area:	Pretoria East	Area:	Pretoria North	Area:	Pretoria West
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#### 6. Sources of income (mark all those are applicable)

Social grant		Employed		Caregiver		Other, specify	
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#### 7. Education level

Primary education		Secondary education		Tertiary education		Other, specify	
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**8. Number of dependants**

1-2		3-4		5-6		7-8		9+	
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**9. Age distribution of dependants**

< 1 yr		1-4yrs		5-9 yrs		10-14 yrs		15-19 yrs		20 yrs	
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**10. Which other treatment do you take, besides the one in hospital?**

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**11. Number of years on the treatment**

< 1 yr		1 yr		2 yrs		3 yrs		5 yrs		6 yrs+	
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**12. Do you know of any family member that has been diagnosed with this illness before?**

Yes		No		Not sure		Other specify	
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**13. Was it the first time you heard about your diagnosis?**

Yes		No	
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**SECTION B: PROSTATE CANCER**

**PROSTATE CANCER CONDITION**

1. Do you know the history of prostate cancer?
2. Do you know and understand the exact diagnosis of your illness?
3. What was your reaction after diagnosis?

**PROSTATE CANCER TREATMENT**

1. Do you know the stages of your illness? If yes, please explain
2. Do you understand your treatment plan? If yes, please elaborate.

3. Does your treatment plan have an impact on your life-style? If yes, please elaborate.
4. What are your experiences of hospital services?
5. Are you taking any other treatment besides the one in hospital?

### **CHALLENGES OF LIVING WITH PROSTAE CANCER**

1. What are the challenges you are experiencing as a prostate cancer survivor with regard to the following?
  - 1.1 Emotional aspect
  - 1.2 Financial aspect
  - 1.3 Social aspect
  - 1.4 Sexual aspect
  - 1.5 Marital life (if married,)
  - 1.6 Physical aspect
  - 1.7 Communication
  - 1.8 Workplace

### **NEEDS OF LIVING WITH PROSTATE CANCER**

1. Resources needed.

### **AVAILABLE SUPPORT SYSTEM OF THE SURVIVORS**

1. Who is part of your support system, in your family, medical personnel and community?

### **STRATEGIES TO IMPROVE SERVICES PROVIDED TO BLACK MEN LIVING WITH PROSTATE CANCER**

What are your recommendations regarding prostate cancer services at the hospital, with regard to education, treatment and support?

## EDITOR'S STATEMENT

30 March 2016


I hereby declare that I have edited this document entitled **The Bio-Psychosocial Experiences of Black Men Living with Prostate Cancer** by Dikeledi Matlawa, (student number 21315516). The edit entailed correcting spelling and grammar where necessary, and checking for consistencies in style and reference method used. I have not helped to write this document or altered the student's work in any significant way. I will not be held accountable for bad spelling or grammar where the student has rejected my editing.

It was not my responsibility to check for any instances of plagiarism and I will not be held accountable should the student commit plagiarism. I did not check the validity of the student's statements/research/arguments.



Lindi De Beer

**Contact Details:**

 083 456 4358

 [lindi@grammarsmith.co.za](mailto:lindi@grammarsmith.co.za)



GRAMMAR  
SMITH



21 January 2015

Dear Prof Lombard

**Project:** The bio-psychosocial experiences of black men living with prostate cancer  
**Researcher:** D Matlaw  
**Supervisor:** Ms NJ Bila  
**Department:** Social Work and criminology  
**Reference number:** 21315516

Thank you for the response to the Committee's correspondence of 12 November 2014.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 20 January 2015. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

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

We wish you success with the project.

Sincerely

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

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





**Raymond A Campbell**  
Urologist  
MBChB(Pret) | FCS(Urol)(SA) | MMed(Urol)(Pret)  
PR 0295671 | MP 0522112



PELVIC WELLNESS UNIT

19-01-2015

**ATT: University of Pretoria (Ethics Committee)**

To whom it may concern:

This letter is to confirm that Miss M.D Matlawa (Student nr: 21315516) MA Social Health Care Student at your institution have consent from me Dr. R.A. Campbell to recruit patient's / potential participants in her research.

Kind Regards

**Dr R.A Campbell**  
Pr 0295671  
Urology Hospital

Dr. R.A. Campbell

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