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Are men generally unable to take care of their health? An inquiry into men's perceptions on reporting and subsequently seeking treatment for prostate cancer

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Chapter One

1.1 Background of study

Men in South Africa as in the rest of the world are disproportionately affected by adverse health outcomes. Often, they do not seek primary health care and therefore do not benefit from the preventative care services provided there. For various reasons, men opt instead to use emergency departments, delay treatment until their condition worsens, or to avoid care completely (Shavers, Shankar, & Alberg, 2002; Whetten et al., 2006).Under these conditions, continuity of care, risk reduction, and adequate illness management do not occur. On average, Black men's life expectancy is 6 years less than White men, 7 years less than Black women, and 11 years less than White women (Minino, Heron, & Smith, 2006). According to Cheatham, Baksdale and Rodgers, (2008), based on life expectancy data, it is not surprising that these men have higher incidence and mortality rates from both chronic and infectious diseases. For example, Black men in America are infected with AIDS at a rate eight times that of White men and are less likely to be alive 9 years after diagnosis (Centers for Disease Control and Prevention, 2005). In South Africa, one in six men will get cancer during their lives (Powell, 2007).

Most astonishingly, for this study, is the fact that the death rate among Black men for prostate cancers is higher than that of any other group in the world, particularly in the United States (National Centre for Health Statistics, 2005). In South Africa, research indicates that Black men are more at risk as compared to men from other race groups (Mfecane, 2010; Ratele, 2008). They are diagnosed at later stages of these cancers and have lower 5-year survival rates. Many explanations have been proposed for the disparities faced by Black men. A health disparities report identified three major barriers to health that affect people's access to healthcare, including (a) lack

of health insurance, (b) lack of a usual source of care, and (c) perception of need, that is, perceived difficulties or delays in obtaining care once care is wanted (National Healthcare Disparities Report, 2005). However these factors cannot explain gender differences of Black people in health and life expectancy. For instance, while lack of adequate health insurance, lack of a usual source of care and perception of need all contribute to the health problems of Black communities, they cannot account for death rates that are almost 2 times higher among Black men than among Black women (Powell, 2007)..

Statistics show that men in South Africa are at an increased risk for prostate cancer with 1 in 23 men being diagnosed with prostate cancer (SA Statistics as per National Cancer Registry, 2004). Testicular cancer is liable for close to 1% of all cancers in men and is one of the most common in males between the ages of 15 and 39. Studies on health behaviours have confirmed the prevalence of higher death rates among men compared to women. Since 2010, Van Rijswijck (2012) has observed that in South Africa the estimated life expectancy at birth is 54.9 years for males and 59.1 years for females. Some studies have examined the frequency in which men seek help for medical, mental health and substance abuse problems; men of different ages (Husaini, 1994), nationalities (D'Arcy & Schmitz, 1979) and ethnic and racial backgrounds (Neighbors & Howard, 1987). The findings have shown that as a group, men seek professional help less frequently than women. An analysis of newspaper articles on unemployment and hypertension conducted by Khunou (2013) has also shown that men less frequently visit primary health care physicians and other medical health specialists. An interesting point on the study of men with hypertension is how ideas of what it means to be a man are directly linked to work, and therefore where unemployment increases hypertension might increase. This is an important point since it indicates the significance of salaried work in how hegemonic masculinities are conceived (Khunou, 2013). Because, "work

and producing income, are key requisites for being a man in most cultures" (Barker, 2005 as quoted in Ratele, 2008, p. 529), where work is unavailable and men's positions are being negatively influenced by the economy, men's health is impacted negatively. Therefore, the social meaning that men get from work does not only provide them with money and the power that comes with it but it also seems to provide a sense of well-being which is significant to their general health (Khunou & Munatswa, unpublished).

A variety of reasons have been suggested as to the causes of premature death of men, (Laveist 1993, Pappas et al., 1993). The reasons include a variety of factors including socio-economic status, ethnicity and access to care (Doyal, 1995). Socio-cultural factors have also been associated with health related behaviour, gender being one of the most important of these factors. Several authors contend that women engage in far more health-promoting behaviours than men (Courtenay, 2000, Marcus, Rakowski & Rossi, 1992.). The implication from these studies is that men are responsible for their early death. The health risks associated with men's gender or particular masculinities have remained largely unproblematised and taken for granted. The consistent underlying presumption in medical literature is such that, what it means to be a man, has no bearing on how men work, drink, drive, fight or take risks (Ratele, 2008). Left unquestioned, men's shorter lifespan is often presumed to be natural and inevitable. For instance, the Sowetan, (2011) quotes Dr Mhinga of the Men's Health Forum saying 'South African men don't take care of their health and as a result die much earlier than they should'. "The article referring to Dr Mhinga is useful in understanding men, however, the problem with the article is that it tends to reduce men's health-seeking behaviour to a general idea of men as irresponsible, uncaring and with lack of interest in their health" (Khunou, forthcoming). In other writings, (Addis & Cohane, 2005) particularly on primary health care, visitation studies have often compared men's and

women's usage of health facilities. For example asking such questions like 'How do men and women differ in their rates of depression?' subtly frame questions of gender as questions of difference. By following this logic, the study of men's health becomes the study of how men and women differ in some psychological trait or behaviour or some underlying biologic mechanism. Relatively little attention, however, has been paid to men's perceptions of their bodies, or their changing sense of masculinity, when disease affects their genital organs.

Given the limitations in research on men and health, and the reasons why Black men delay asking reporting and subsequently seeking treatment for chronic diseases, the study investigated the masculine norms operative among men that impede men from seeking help. The study also investigated subjective experiences of men who have been diagnosed with prostate cancer to elicit notions of masculine identity and reporting and the subsequent seeking of early treatment for such ailments. Because of the difficulty in finding participants, White and Indian men were included in the research. This was done to reach a desired sample and their inclusion was significant in outlining the complexities investigated. This study therefore was an attempt to understand whether men are responsible for this short life span.

Findings from the study point out other things that have somewhat been ignored in literature. For instance, the type of disease or condition influences whether it is to be reported or not. In this case diseases of a sexual nature carry a lot of stigma, compounded by the attitude of nursing staff in public health facilities, thus men choose to only seek help when they have no other choice. Another interesting finding from the research is that prostate cancer emasculates men, as the pathogenesis, the treatment options and the side effects all work to the detriment of men retaining normal sexual functioning. Men in this research therefore, had they known all this, maybe their decisions would have been different.

It is quite important for social work in health settings to understand why some men under some circumstances are able and willing to ask for help so as to integrate understanding masculine norms and stereotypes into an analysis of men's use of health services. In essence this knowledge would thus guide practice with clients as well as mediate between clients and service providers to adjust their services to suit the clientele as well as lobbying the government to consider the needs of men as health policies are designed, reviewed and implemented. In doing research on men, this study contributes to the literature that is available on men in general and also specific to the South African context. This gives perspective of how men behave, interact and utilise health services. From this analysis, it can then be argued whether men are responsible for their ill-health or not.

1.2 Research questions

i. Why are some men, under some circumstances, able and willing to ask for help for some problems and not for others?
ii. How are masculine norms and stereotypes related to difficulty in asking for help?
iii. How can social work professionals integrate understanding masculine norms and stereotypes into an analysis of men's use of health services?

1.3 Aim of the study

The aim of the study is to explore the perceptions that men have on reporting and subsequently seeking treatment for prostate cancer.

1.4 Objectives of the study

i. To elicit participants views on reporting and seeking treatment for prostate cancer.

ii. To investigate masculine norms and stereotypes associated with health help-seeking.

iii. To explore challenges that men face in reporting and seeking treatment for prostate cancer

iv. To explore suggestions on how men can overcome these masculine norms and stereotypes to report and seek treatment.

1.5 Brief chapter synopsis

1.5.1 Chapter two: Literature Review

This chapter outlines the debates in masculinities and health help-seeking practices. It encapsulates the ideas of authors whose opinions are that masculinity viewed as a homogeny, subject men to a harmony and therefore cannot be used to analyse the behaviour of men. Rather men are a heterogeneous group hence the plurality in mascunlinities. The understanding is that men perform different masculinities depending on the place, position to authority, dominant norms and personal preferences. However, an analysis of these different positions broadens the scope in understanding health-seeking practices among men. Furthermore, in the context of prostate cancer, it is important to understand whether men amalgamate into a homogeneous existence, threatened by a common body slayer or that they perform rightly within their life scripts.

1.5.2 Chapter three: Methodology

This chapter explains the research strategy and objectives. It explains what was done, how it was done and provides justification why it was done. It also discusses the ethical dilemmas encountered and how these were managed.

1.5.3 Chapter four: Findings, Pathogenesis of Prostate Cancer

This chapter discusses the pathogenesis of prostate cancer, explaining what it is, what are the causes, symptoms, stages of development, treatment options and possible side effects. This chapter is set to engage the reader to understand the disease so as to prepare for the findings and why some things are emphasised

1.5.4 Chapter five: Findings, Prostate Cancer Related issues, diagnosis, treatment, side effects, policy

This chapter puts prostate cancer into perspective, it explains what research has been done, what treatment is allowed and why, men's experience with diagnosis and the policy surrounding prostate cancer. This chapter also problematises two scenarios in prostate cancer, one; if prostate cancer is considered as a non-aggressive cancer, wouldn't that affect the research, policy and treatment available negatively and two, if men do die of prostate cancer, or related conditions shouldn't it be prioritised in terms of screening and management.

1.5.5 Chapter six: Findings, Men's experiences with prostate cancer

This chapter explains how men live daily with prostate cancer, how their lives have changed basically. It explains how men are emasculated by incontinence and erectile dysfunction, how sex is an important function in life and how men negotiate their identity after treatment. It explores the emotions that come with living with prostate cancer.

1.5.6 Chapter seven: Insights gleaned from the study and conclusions

This chapter attempts to answer the research questions, giving the discussion of findings a solid conclusion. It ties down arguments developed in the discussion of findings and the research report

entirely. At the end it attempts to give recommendations on policy advocacy as well as disease management.

Chapter 2: Literature review

2.1 Introduction

Modern societies are riddled with complexities as they continuously develop. Among the complexities, is the constant change of definitive norms that propel society forward. Issues of health have increasingly been in the spotlight in recent years, primarily focusing on ill-health, infectious diseases, women's reproductive health and most recently men's health. Interestingly over the years, health issues have been considered mostly as the preserve of the medical faculties and somehow little attention has been paid to the social construction and experience of diseases. To note, the attitudes that drive men and women to access health facilities have for some unclear reasons been ignored. Women's reproductive health has also over the years been popularised through the work of feminists and governments to address the disparities in gender. However, with all these advances men's health has significantly been untouched. Different men have for many years seen the masculine influences of men's access to health facilities as homogenous. This assumption of a homogeny among men has been tantamount to a fallacy that men utilise health services in the same way. The literature points out the differences in men's utilisation of health and also the differences in masculine identities operative over time. This chapter attempts to show the differences in attitude that drive men to consume health services, particularly when they have prostate cancer. Whilst there is recognition that prostate cancer research is still new, there is growing evidence that prostate cancer is fast becoming the most common cancer in men and has become the second most cancer killer in men after lung cancer.

2.2 Masculinity and Health

There is disagreement in society about what are considered to be typically feminine and masculine characteristics. These stereotypes provide collective and organised meanings of gender and often become widely shared beliefs about who women and men innately are. People are encouraged to conform to stereotypic beliefs and behaviours and commonly conform to and adopt dominant norms of femininity and masculinity. Masculinity is defined by Connell, (1995) as a set of qualities, characteristics or roles generally considered typical of, or appropriate to, a man. It can have degrees of comparison: 'more masculine', 'most masculine'. Masculine norms stress values such as courage, inner direction, certain forms of aggression, autonomy, mastery, technological skill, group solidarity, adventure and considerable amounts of toughness in mind and body" (Connell, 1995, p. 4) The opposite can be expressed by terms such as 'unmanly'. This emanates from the standpoint that gender is not a fixed set of social norms that are passively internalised and enacted, but it is constantly produced and reproduced in social practice.

Kimmel, (2000) argues that masculine norms affect the way in which men interact with the world. In some instances with positive outcomes, whereas in others, negative. The dominant masculine norms consequently affect the way in which men experience health. Connell, (1995) and Kimmel, (2000), further argue that norms such as courage, inner direction, certain forms of aggression, autonomy, mastery, technological skill, group solidarity, adventure and considerable amounts of toughness in mind and body allow men to rely on self-defined parameters to experience health depending on the norms that appeal most to their lifestyles.

Health related beliefs and behaviours that men display can thus be understood as a means of constructing or demonstrating gender. In this way, Kimmel, (2000) suggest the health behaviours

and beliefs that people adopt simultaneously define and enact representations of gender. Therefore popular masculine norms require, for example, that men suppress their needs and refuse to admit or acknowledge their pain. Health related beliefs and behaviours that can be used in the demonstration of hegemonic masculinity include the denial of weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, dismissal of any need for help, a ceaseless interest in sex, and the display of aggressive behaviour and physical dominance (Mankowski & Maton, 2010). In such exhibition of hegemonic ideals with health behaviours, men reinforce strongly held cultural beliefs that men are more powerful and less vulnerable than women; that men's bodies are structurally more efficient than and superior to women's bodies, that asking for help and caring for one's health is feminine and that the most powerful men are those for whom health and safety are irrelevant (Levant, 2008, Krahé & Fenske, 2002).

Recent research demonstrates that men's gender contributes to their high-risk sexual behaviour (Anderson, 2005; Barker & Ricardo, 2005, Marsiglio & Pleck, 2005). Underlying social problems are social expectations and norms, supported by social and organisational systems and practices that expect boys and men to reject or avoid anything stereotypically feminine, to be tough and aggressive, suppress emotions (other than anger), distance themselves emotionally and physically from other men, and strive toward competition, success and power (Brannon, 1976). Accordingly, men and boys often reject healthy beliefs and behaviours in order to demonstrate and achieve manhood (Charmaz, 1995). By dismissing their health care needs, men construct, deconstruct and reconstruct gender. Similarly men demonstrate dominant norms of masculinity when they hide illness and thus do not seek sick leave from work, insisting that they need little sleep (Khunou,

2013). The result is that when a man does experience an illness or disability, the gender ramifications are often great.

Despite the awareness of masculine norms affecting men's health attitudes, men appear to be missing from much gender and development policy. Cleaver, (2002) notes with dismay that despite the change in approaches from Women in Development to gender and development with a need to recognise social relations between men and women, there is little recognition of the need to analyse and understand the lives of men. In this instance men are rarely explicitly mentioned in gender policy documents, and when they are mentioned, they are generally seen as obstacles to women's development. While recognising that women in general may face greater social and economic disadvantages than most men, evidence from research suggests that men are not always the 'winners' and that ignoring their situation risks overlooking gender-specific inequities, (Cleaver, 2002, p. 3). Examples of gendered vulnerabilities which disadvantage men are particularly in the area of health. For instance in many societies linking notions of masculinity to virility render men more at risk from HIV infection.

The obvious absence of health programmes accommodating men contribute to a growing ignorance among men about their health practices. For instance in the sexual reproductive health arena men who have sex with women are not receiving adequate levels of sexual and reproductive health care, and the care they receive is neither comprehensive nor integrated (Mosher, Chandra, & Jones, 2005). The need for more accessible sexual and reproductive health services for men is demonstrated by the fact that although condom use has increased during the past two decades, levels of unprotected sex and other sexual risk behaviours among men remain high. For example, data from the 2002 National Survey of Family Growth (NSFG) in the USA indicate that more than one-third of sexually active men who were neither married nor cohabiting, had not used a condom

during sex at any time in the past four weeks (Martinez, 2002). The prevalence of condom nonuse increased with age, from 26% among 15-19 year-olds to 55% among 25-29 year-olds and 73% among 40-44 year-olds (Martinez, 2002). Moreover, nearly one-fourth of men aged 15-44 reported having had 15 or more female partners during their lifetime, and the proportion was even higher (one-third) among Black men in this age-group (Martinez, 2002). Given these high levels of risky behaviour, it is unfortunate that the health care system fails to meet the sexual and reproductive health care needs of men.

An additional factor that limits knowledge about men's utilisation of sexual and reproductive health care is that the research has focused primarily on teenagers. It is important to examine men's receipt of such care beyond the teenage years because levels of HIV and other STDs are highest among men in their 20s (Centers for Disease Control and Prevention, 2005). In addition, older males are less likely than adolescents to encounter sexual and reproductive health information in their daily lives. Although the content of school-based sex education is often limited, these programs provide a formal context for discussion that is absent for older men. Research is needed to examine access to and patterns of sexual and reproductive health care utilisation among men aged 20 and older (Centers for Disease Control and Prevention, 2005). Furthermore, data on women's receipt of sexual and reproductive health services raise questions about care for men that have not been addressed. For example, women are more likely to receive clinical gynecologic services (Pap and pelvic exams) than any other sexual or reproductive health service. What kinds of sexual and reproductive health services are men most likely to receive?

The sexual and reproductive health of men in their own right is a topic that has garnered increased attention in recent years, as has the subject of how men can contribute to women's reproductive health (African Gender Institute, 2002). Several efforts have been made to define the services that

men need and how best to provide them (Sonenstein, 2000). Although men's clinical care needs are not as broad as women's, men clearly need access to many of the same services, such as testing and treatment for sexually transmitted diseases (STDs) and reproductive tract disorders. Indeed, some researchers have suggested that increases in STD rates in the United States have motivated family planning clinics to expand their services to include men (Schulte & Sonenstein, 1995). Moreover, it can be argued that societal responsibility for contraception falls too heavily on women and that men should play a greater role in using methods, participating in contraceptive decisions and supporting women's use of contraceptives.

2.3 Masculinity and health help-seeking behaviour

Social psychologists have treated help-seeking as a complex and dynamic process involving help seekers, help providers, types of help requested and the situations in which the help is sought (Wills & DePaulo, 1991). Accordingly all potential help-seeking contexts create on-going conflicts between the intra- and interpersonal benefits and costs to requesting help. For instance, empirical work on invisible support suggests that the emotional costs to receiving help often result in recipients being unaware of or unwilling to report help received. According to Bolger, Zuckerman and Kessler (2000) both the effects of gender socialisation and the process of constructing masculinity in particular help-seeking contexts are moderated by basic social psychological processes.

Mahalik (2000) and Real (1997) posited that men are influenced by normative masculinity messages communicated through the use of descriptive, injunctive and cohesive masculine norms. According to Real (1997) normative masculinity operate when a male observer sees what most men are doing in a situation. For example norms such as the idea of men being strong and

independent suggest that men should not have problems and may foster perceptions of non-normativeness when problems do occur. Men may experience barriers to seeking help from health professionals when they perceive other men in their social networks as disparaging the process. According to Morris and Miller, (1975) this is especially so if other men are perceived as unanimous in their attitudes. A large number of men express similar attitudes; as such men see themselves as quite similar to members of their reference group. The interactions among variations in each of these groups' characteristics make it clear how men's help-seeking can be both influenced by common masculinity norms and highly variable in different contexts (Morris & Miller, 1975).

In another spectrum of thought, feminist and social constructionist theorists have emphasised how the masculinity norms of self-reliance and the avoidance of dependence help maintain men's access to power and control. According to Brehm (1966) by complying with a request to get professional help, a man may experience a loss of control over the decision-making process. Efforts to retain control by avoiding professional help thus establish masculinity as the preservation of autonomy at considerable cost. Experimental studies done by Wills and DePaulo (1991) concluded that men are least likely to seek help when a problem is perceived as ego central. Ego central problems are those that are perceived to reflect an important quality about oneself. What individual men perceive as central to the self is a function of both dominant masculinity norms and the way masculinity is constructed in specific help-seeking contexts. For example men who generally conform to the norm of emotional stoicism are likely to feel that seeking help for depression is a threat to his self-esteem.

Naslindh-Ylispangar, (2008) also argued that health-seeking behaviour is also enhanced by the perceived threat that predicts the likelihood of a person taking recommended preventative health

action. If the person does not see a health care behaviour as risky or threatening, there is no stimulus to act. For example, a healthy 50 year old man might not think that he is at risk of suffering prostate cancer. According to Naslindh-Ylispangar, (2008) there are two types of perceived threats: perceived susceptibility and perceived severity. Susceptibility refers to how much risk a person perceives he or she has; severity refers to how serious the consequences might be. To effectively change health behaviours, the individual must usually believe in both susceptibility and severity.

Hochbaum, Kegels and Rosenstock (1974) suggested that a person's behaviour is determined by his/her intention to perform the behaviour and that this intention is, in turn, a function of his/her attitude toward the behaviour and his/her subjective norm (Croyle, 2005). Accordingly, the best predictor of behaviour is intention. Intention therefore, is the cognitive representation of a person's readiness to perform a given behaviour, and it is considered to be the immediate antecedent of behaviour (Croyle, 2005). This intention is determined by three things: their attitude toward the specific behaviour; their subjective norms; and their perceived behavioural control. Hochbaum et al. (1974) argue that only specific attitudes toward the behaviour in question can be expected to predict that behaviour. In addition to measuring attitudes toward the behaviour, there is also a need to measure people's subjective norms – their beliefs about how people they care about will view the behaviour in question. To predict someone's intentions, knowing these beliefs can be as important as knowing the person's attitudes.

The above discussions seem to explain health help-seeking behaviour. However, questions of whether health behaviours are indeed rational go unanswered. For instance Potter and Perry, (2010) question the rationality in health behaviour, they thus point out that health behaviour expands beyond the individual's rationality. Alternative factors may predict health behaviour, such

as outcome expectancy (whether the person feels they will be healthier as a result of their behaviour) and self-efficacy (the person's belief in their ability to carry out preventative behaviour). Black, Hawks and Keene (2006), Polit & Beck (2007) allude to the fact that in health behaviour there is a huge role for emotional factors such as fear and denial. These emotional factors contribute immensely to the individual's decision of whether to seek health-help or not. Thus the readiness of an individual to confront emotional factors plays a decisive role in health help-seeking behaviour.

2.4 The genesis of men's health practices in Africa

The health practices of men in Africa have always been a subject of much dispute among scholars. Some scholars argue that men's health practices can be viewed in the context of acceptable norms in their society. These scholars argue therefore that health-seeking practices entail responsibility of care of others more than the self. Being an adult male therefore marks the onus of responsibility over others. According to Lindsay and Miescher (2003), in African societies men achieved adult masculinity by taking the role of provider and protector of families. The provider role 'assumed' therefore that *men looked at the well-being of their wives and children.* Theirs was a responsibility to ensure that their families were healthy and not necessarily looking at themselves.

The provider role came as a result of men being in the work place. The workplace was a site of masculine work culture which emphasised skill and physical strength. Because of the dire economic conditions, indignity and humiliation, conceived through racism, African men intended to prepare their families for future opportunities, whilst sacrificing themselves for the benefit of the communities where they came from (Ouzgane & Morrell, 2005). Thus masculinity in the workplace surrounding the provider role became an equivalent to activism. The workplace offered

a continuous need for men to earn to afford their responsibilities until they were worn out. This is an important indicator of men's health practices in that masculine identities for African men denied these men space for emotion and weakness, even illness. As a result the ability to save and build a home was to secure a home when sickness dominated hence the idea that the 'rural home was a place to retire and die' became practise among African men (Ouzgane & Morrell, 2005).

The workplace had no room for illness. The contest between how men in Africa perceived modern medicine of hospitalisation and traditional methods often left many confused. Most men thus chose what appealed to them culturally. Instead of seeking treatment for illness in the modern medical centres, where they paid a lot of money, men found alternatives, including traditional medicine and sometimes self-medication to a point when they were bedridden. This inability to access medical facilities allowed men to propose and find reason to blame, sometimes enough to fuel allegations of witchcraft when illness struck (Lindsay & Miescher 2003; Ouzgane & Morrell, 2005,). Inherent in these men's interpretation of their health was a flawed perception of invincibility. Their bodies had been supposed be full of skill and physical strength due to the demanding working conditions and mostly by the dominant masculine norms. Illness therefore challenged this masculine perception that got reinforced each day as demands to produce more were made daily.

The workplace demanded the physical presence of every worker since production was dependent on the aggregate contribution of all (Lindsay & Miescher, 2003; Ouzgane & Morrell, 2005). Being absent because of illness therefore created problems for the production process and considering the limited number of people that could do such tasks meant that production suffered. The capitalist orientation in modern economies was too rigid and inflexible to allow room to get better. Men with no choice, found themselves in the workplace despite illness (Lindsay & Miescher, 2003; Ouzgane

& Morrell, 2005). This occurrence is important in understanding men's health practices. On the one hand, the demands of the rigid and inflexible workplace did not allow room to seek health promoting behaviour, particularly where it involved physical strength. On the other hand, notions of being manly, refusing to accept illness, regarding it as a weakness allowed men to ignore their health concerns. In other words, men's health-seeking practices were affected by both the capitalist methods of production and the resultant masculinity identities that ensued. It can therefore be argued that the workplace created a 'mechanical man', whose conceptions of health despised, what Lindsay & Miescher (2003) stated as 'thin and weak, always crying' type of men. So between being bedridden and being ferried to the rural areas to die, men relied on traditional medicine and sometimes self-medication.

It is important to notice that the conceptions of men's health practise from this point of view suggest that men waited until their illness was noticeable by others. This carries the implication that for the 'mechanical men' seeking treatment was a delayed and prolonged practice, one that came when the illness was advanced (Kimmel & Aronson, 2004). Success of treating illness in advanced stages was thus dependent on the type of illness it was. Consequently, most men passed on and therefore it became pertinent and synonymous that men would leave their work places to die in the villages.

Encompassed in the discussion above are several assumptions and generalisations that might not have been true for all men. Firstly, there is the distinction between men, those that were involved in the capitalist mode of production that consequently assumed the title 'mechanical men' and practised hegemonic masculinities. This is quite a difficult position to take because no-one can be certain that men behaved the same, bearing in mind what kind of work they did, what positions

they held and what luxuries they enjoyed. Accordingly, the generalisations are fallacious and difficult to confirm.

Secondly, there is an assumption that men that practised traditional forms of accumulation and wealth procurement did not practise hegemonic masculinities and their approach to health was different. However, Gough, & Robertson, (2010) argue that in all male dominated societies, men portayed the defender image. "They showed strength and courage, repressing feelings of vulnerability, fears, sensitiveness in order to be ready for necessary violence. Sexuality was therefore used as an instrument for aggression and the penis as a weapon. The result was to deny all pain till death was inevitable, and even when dying, fight until there was no strength left" (p. 66). This on the contrary indicates that men's health practices, despite location seemed to be similar. Their response to seeking medical attention was delayed till illness rendered the body weak.

Lastly, acceptance of a health service provider was culturally dependent, and continues to be so, even to this day. Men as rational beings chose, at the time what appealed to them culturally, and therefore sought traditional medicine/self-medication depending on their preferences. Consequently, the position of every man concerned towards the dominant masculine norms shaped his response. Where masculine norms emphasised medical facilities, men would follow suit, likewise where dominant masculine norms emphasised traditional medicine, the case might have been the same. The generalisation that men canvass a congruent homogenous mass is disturbing, considering the different class situations that existed and still continue to this day.

2.5 Defining men's health

‘Men’s health’ is a term used in general parlance by the media, academics, health practitioners and the public. According to the World Health Organisation (WHO, 2007), a healthy man is one who is empowered to experience optimum physical, mental and social well-being and experiences health as a resource for everyday living. It is important to therefore recognise that men’s health is more than the result of biological, physiological or genetic functioning but that it is also affected by wider social, cultural and environmental factors. These definitions have contributed to conceptualisations that suggest that men’s health is akin to a disease or condition unique to men for which risk factors are different for men or for which different interventions are required for men.

Men’s health has also been defined as any issue, condition or determinant that affects the quality of life of men and/ or for which different responses are required in order for men (and boys) to experience optimal social, emotional and physical health (NSW, 1999). As such men’s health should be concerned with a broader range of issues than specific diseases of the male reproductive organs. Khunou, (2013) further argues that while rubbishing the disease focused approach to men’s health, prostate problems, testicular concerns and erectile dysfunction concerns have remained prominent features of the international discourse on men’s health. Yet even this definition has its limitations (Khunou, 2013). These stem from not taking into account multiple masculinities in defining men’s health. Men are thus not a heterogeneous group.

There hasn’t been a political will to investigate objective facts about masculinities and men’s health, even though attention to men’s health is increasing (Luck, Bamford & Williamson, 2000). The danger in attracting political spotlight is that it leads to expectations of quick solutions and absence of such in the short term will be followed by a sudden loss of interest and the topic of men’s health will recede into shadows. Men’s health as health in general has several dimensions

that need consideration. These dimensions include physical health, mental health and emotional health. Perceptions of health amongst men become the most decisive factor in determining their health-seeking practices. Kirby, Kirby and Farah (1999) posits that as rational beings men consider their perceptions of health as follows: feeling healthy or not and therefore giving reasons for being or not being healthy. These reasons fashion the next step of action that is, visiting the doctor. Visiting the doctor also depends on the reason given and most importantly the frequency. The doctor's visit shapes the directions for medication at the present moment and in future, that is, either to go to the doctor again or to self-medicate depending on the illness (Kirby, Kirby & Farah 1999).

The set of actions that men take considering their health practices emanate from their definition of health. According to O'Dowd and Jewell (1998), men define health in three ways, '*a) state of well-being, b) being healthy and c) body working well, feeling good, alert and able to cope'* (p.126). These definitions of health inform men's perceptions of health. For instance, prevention is perceived by men to mean, taking care, avoiding doctors, not abusing /misusing drugs as well as avoiding premature death. A state of well-being is perceived as absence or lack of illness/diseases/disability, pain, worries, and stress. Being healthy is perceived as the lack of restrictions and having access to medication. Body working well is explained that as a mechanical body, it should function in all aspects, that is, feeling good, alert and the ability to cope (O'Dowd & Jewell, 1998).

These perceptions on health allow men to categorise health into dimensions such as physical and mental health. Consequently, men's reaction to these different dimensions differs greatly. The dimension of physical health is marred with notions of social capital, including suicide, risk taking and accidents whereas mental health is configured to mean mental distress, deviance and

alcoholism. The result has been such that men's response to physical health concerns often leads to severe effects of hospitalisation and death, whilst the response to mental distress often lead men into the criminal justice system (Luck, Bamford & Williamson, 2000).

Given the premise outlined above, men's reaction to illness therefore becomes easy to predict. According to Luck, Bamford and Williamson (2000) men's reaction to especially, prostate and testicular cancer often leads to psychosis and neurosis, resulting in deviant sexual behaviour. The threat to manhood often carries severe masculine ramifications that go beyond physical health. This threat to manliness affects men's definitions or rather expectations of health outcomes. For instance Luck, Bamford & Williamson, (2000) posit that in the male dictionary of health certain words carry certain meanings. In this case, prevention is synonymous with avoiding doctors and premature death, absence is synonymous with no medication, presence is synonymous with control and ability is synonymous with recovery and responsibility .

2.5 Masculinities and prostate cancer

Prostate cancer is a form of cancer that develops in the prostate, a gland in the male reproductive system. Most prostate cancers are slow growing; (Baade, Youlden & Krnjacki, 2009). However, there are cases of aggressive prostate cancers. The cancer cells may metastasise (spread) from the prostate to other parts of the body, particularly the bones and lymph nodes. Prostate cancer may cause pain, difficulty in urinating, problems during sexual intercourse, or erectile dysfunction. Other symptoms can potentially develop during later stages of the disease.

Rates of detection of prostate cancers vary widely across the world, with South and East Asia detecting less frequently than in Europe, and especially the United States. Prostate cancer tends to develop in men over the age of fifty (Siegel, 2011). Globally it is the sixth leading cause of cancer-

related death in men (Baade, Youlden & Krnjacki, 2009) and in the United States it is the second (Siegel, 2011). Prostate cancer is most common in the developed world with increasing rates in the developing world (Baade, Youlden & Krnjacki, 2009). However, many men with prostate cancer never have symptoms, undergo no therapy, and eventually die of other unrelated causes. Many factors, including genetics and diet, have been implicated in the development of prostate cancer. The presence of prostate cancer may be indicated by symptoms, physical examination, prostate-specific antigen (PSA), or biopsy. Prostate-specific antigen testing increases cancer detection but does not decrease mortality (Baade, Youlden & Krnjacki, 2009).

The age and underlying health of the man, the extent of metastasis, appearance under the microscope and response of the cancer to initial treatment are important in determining the outcome of the disease. The decision whether or not to treat localised prostate cancer (a tumor that is contained within the prostate) with curative intent is a patient trade-off between the expected beneficial and harmful effects in terms of patient survival and quality of life. Management strategies for prostate cancer should be guided by the severity of the disease. Several studies suggest that masturbation reduces the risk of prostate cancer (Yeh, E. T. & Bickford,2009; Mwangi-Powell, 2007). However, many low-risk tumours can be safely followed with active surveillance. Curative treatment generally involves surgery, various forms of radiation therapy, or, less commonly, cryosurgery; hormonal therapy and chemotherapy are generally reserved for cases of advanced disease (although hormonal therapy may be given with radiation in some cases) (Mwangi-Powell, 2007).

People with prostate cancer generally encounter significant disparities in awareness, funding, media coverage, and research—and therefore, inferior treatment and poorer outcomes—compared to other cancers of equal prevalence (Farrell and Sterba, 2008). In 2001, The Guardian noted that

Britain had 3,000 nurses specialising in breast cancer, compared to only one for prostate cancer. It also discovered that the waiting time between referral and diagnosis was two weeks for breast cancer but three months for prostate cancer (Farrell and Sterba, 2008). A 2007 report by the U.S.-based National Prostate Cancer Coalition stated that for every prostate cancer drug on the market, there were seven used to treat breast cancer (Arnst, 2007). The Times also noted an 'anti-male bias in cancer funding' with a four to one discrepancy in the United Kingdom by both the government and by cancer charities such as Cancer Research UK (Arnst, 2007). Equality campaigners such as authors Farrell and Sterba, (2008) cite such stark spending inequalities as a clear example of governments unfairly favouring women's health over men's health. Disparities also extend into areas such as detection, with governments failing to fund or mandate prostate cancer screening while fully supporting breast cancer programs. For example, a 2007 report found 49 U.S. states mandate insurance coverage for routine breast cancer screening, compared to 28 for prostate cancer (Arnst, 2007). Prostate cancer also experiences significantly less media coverage than other, equally prevalent cancers, with a study by Prostate Coalition showing 2.6 breast cancer stories for each one covering cancer of the prostate (Browne, 2001).

2.6 The status of men's sexual health

Many studies have examined the frequency in which men and women seek help for medical, mental health and substance abuse problems. The findings have shown that, as a group, men of different ages (Husaini, 1994), nationalities (D'Arcy & Schmitz, 1979) and ethnic and racial backgrounds (Neighbors & Howard, 1987) seek professional help less frequently than women. In these studies it has been shown that men less frequently visit primary health care physicians and other medical health specialists. This is a tendency that is predominantly associated with what is considered men's powerful internalised notions of masculinity and masculine identities (Addis &

Mahalik, 2004). As such there is a need to approach understanding men's help-seeking as a product of masculine gender role socialisation.

Role socialisation paradigms assume that many of the tasks associated with help-seeking such as relying on others, admitting a need for help, recognising and labelling an emotional problem, conflict with messages men receive about the importance of self-reliance, physical toughness and emotional control (Real, 1997). Addis and Mahalik (2004) propose that masculine gender role socialisation identifies the negative consequence for men's well-being for adopting particular masculine ideologies. For example, internalising the ideological position that men should be tough, competitive and emotionally inexpressive can have detrimental effects on men's physical and mental health. Pleck (1995) posits that masculine gender roles are socially constructed from stereotypes and norms that create problems for individual men. These are then translated into beliefs that men carry around to their detriment. Research done by Seedat et al. (2009) shows that when looking at non-natural deaths, 7.1 males die for every female. This is because women deal with other health issues better than men, due to their more health conscious lifestyles particularly after falling pregnant.

Statistics on life expectancy tend to mask differences between individuals from various socio-economic backgrounds when it shows men's premature mortality being higher than that of women. This assumes universality in the behaviour of men therefore generalising the concept of gender. However, analysis of masculinities echoes the point that not all men experience the world in similar ways (Connell, 1995, Khunou, 2013, Morrell, 2001). It is therefore quite imperative to recognise that men's health status is more than a consequence of biological, physiological and genetic function; it is also affected by wider social, economic, cultural and environmental factors (Khunou, 2013). Segregatory health inequalities thus influence the health practices of men from different

class backgrounds, for example where western medical practices have been positioned as scientific and trustworthy, traditional African healing practices have been ridiculed as backward and deadly (Khunou, 2013), hence a different cultural response among men.

Prostate cancer is now the most common male cancer (Bach, Schrag, Brawley, Galaznik, Yakren, & Begg, 2002). It usually affects men over the age of 50, and is sometimes difficult to diagnose because the symptoms of prostate enlargement are common both to benign prostatic hyperplasia and to prostate cancer. Once diagnosed, some men decide to opt for 'watchful waiting' rather than rush into any form of active treatment. This is because no one has demonstrated that treatments for prostate cancer improve overall survival (European Society for Medical Oncology, 2007). All the treatments for prostate cancer have some unwanted side effects (European Society for Medical Oncology, 2007). Men with prostate cancer sometimes become aware of the problem because of incontinence; this is, however, also among the side effects of treatment. During radiotherapy and prostatectomy nerves may be damaged, leading to incontinence or impotence, and radiotherapy may cause damage to other tissues, such as the bowel or bladder. Hormone treatment and orchiectomy lead to loss of libido and potency. These side effects may occur immediately, though sometimes after a period of time. Hormone treatment and orchiectomy also lead to other side effects such as hot flushes, breast enlargement and a reduction in physical and mental energy (Doll, & Petro, 1982). The changes that are experienced by men who have had active treatments for prostate cancer provide a unique perspective on the 'taken-for-granted' nature of the masculine body.

Easthope (1992) highlighted that illness that affected sexual organs and caused sexual problems has been considered women's problems. In his book 'What a Man's Gotta Do' Easthope (1992) acknowledged that if the problem resulted in an inability to have children, men often times were

allowed to marry another woman, instead of checking what the cause of the problem was. In a way, men's sexual health, particularly when the men were healthy looking and industrious, was relegated as the wife's fault. This view suggests that polygamous relationships were allowed and accepted whilst men's health status was never questioned. The result was that contracting a sexual disease was therefore tantamount to dying so it became taboo to talk about, since men's sexual health was never in question. As such, resilient men found ways to survive through illness, some found medication to self-cure whilst others resorted to traditional healers. Most importantly, the perception of men's sexual health illness held by men, implicated women as being faulty whenever illness affected sexual organs. Consequently such men could not view sexual illness as pertinent to their health as every other disease.

While traditional/ hegemonic masculinity required men to be physically strong, instrumental and goal oriented, focusing on achievement, lacking emotional and interpersonal skills and relating to women in a dominant manner, enlightened African men began reversing these notions, (Ouzgane & Morrell, 2005). The changing version among middle class men places more emphasis on intellectual than physical strength, more on interpersonal skills and companionship style relationships with women. This challenges hegemonic masculinity and therefore the status of men's health. The multiplicity of men's attitudes indicates the multiplicity of health interventions they would undertake. That is, while it might be fashionable for 'traditional' men that perform hegemonic masculinity to avoid showing weakness and illness, those that challenge such notions are likely to become, in the words of Lindsay & Miescher, (2003,p. 26) "thin and weak, always crying" men, watchful of their health practices.

Regardless of having traced the change in the health-seeking practices based on the class of men in question, one fundamental aspect warrants special attention. Sex and sexuality play a large part

in the discussion of men and masculinity. Men are goal oriented in sex, and it is therefore the orgasm that counts. As such men bring to the sex act numerous concerns about their technical performance asking questions like 'did I do well?', 'did I satisfy my partner?' Men, irrespective of their position to hegemonic masculinity, believe they must be in charge, they feel responsible for orchestrating the lovemaking and subsequently its success. Thus images of normal male sexual functioning are synonymous with the thought of being a 'real man'. Consequently, men believe that all intimate physical contact should lead to genital sex and that they should always be ready for it. Genitalisation of sex means that sexual organs are highly important to male self-images. Impotence therefore acts as an enormous threat to a man's sense of well-being.

Sex and sexuality plays a large part in discussions of men's health and masculinity. Gough, & Robertson, (2010) argue that in the narrow sexual arena, men are typically ignorant about the prevention and early detection of diseases like prostate and testicular cancer, yet these are among the leading cancer threats for men. In defending this line of thought, Gough, & Robertson, (2010) argue that pressures toward masculinity appear to keep men away from counsellors, psychotherapists and physicians, but when men finally submit to serious illness they are hospitalized 15% longer than women diagnosed with the same condition. As such being a man in the patterns of hegemonic masculinity can be so dangerous not only to men's health but also to the health of others.

A man's sexual activities are profoundly infused by gender. Masculine gender socialisation defines and sets the standard for sexual performance, and the quality of this performance in turn, bears the authority to confirm (or shatter) one's identification as a man. Therefore a man experiencing sexual difficulties often feels that his masculinity and not merely his sexuality has been threatened. When the culturally prescribed standard for sexual performance is not met, this loss "extends to the entire

male-body, disabling him, de-sexing him, and submitting him to powerlessness — to 'impotency'" (Fergus, Gray and Fitch 2002). Studies done by Fergus, Gray and Fitch (2002) highlight that sexual dysfunction was experienced as a focal disruption for participants owing to the centrality of sexuality in each man's life and person. Regardless of how stereotypically 'macho', or sexually active the man was, or how invested in sexual performance he professed to be, each was fundamentally shaken by the sometimes dramatic change in his sexual capacity. Literature on erectile dysfunction point to the fact that diminished sexual functioning is the most significant source of distress, a finding that held across varying treatment modalities (Fergus, Gray and Fitch, 2002)).

2.7 Theoretical framework: Person-in-situation

The 'person-in-environment' perspective views the client as part of an environmental system. It encompasses reciprocal relationships and other influences between an individual, relevant others, and the physical and social environment. This perspective is based on the notion that an individual and his or her behaviour cannot be understood adequately without consideration of the various aspects of that individual's environment (social, political, familial, temporal, spiritual, economic, and physical) (Mizrahi, & Davis, 2008). Person-in-environment is a system for identifying and recording problems that people experience in the social functioning in relationships with others and in relation to community institutions that generally serve to help social functioning. A person-in-environment perspective provides a more adequate framework for assessing an individual and his or her presenting problem and strengths than an approach that focuses solely on changing an individual's behaviour or psyche, or one that focuses solely on environmental conditions (Mizrahi, & Davis, 2008).

The person-in-environment offers a platform for wider investigation into a person's well-being taking into consideration the environmental interaction. In this case, it provides a framework to investigate the person and environmental interaction of men with prostate cancer. The person-in-environment perspective thus allows for investigations into the person's well-being, in particular the men whose reality change once they are diagnosed. Important considerations from this point of view thus include accepting that the person will experience changes in their daily life, so does the environment where they are situated. Therefore, it is quite important to understand the person-in-environment, bearing in mind the stance adopted by the framework, that, 'the whole is greater than sum of its parts' (Gitterman & Germain, 2008). The person-in-environment therefore allows for an attempt to understand the person-environment interaction without separating the two. For example, the framework enables the social worker to look at the men with prostate cancer and assessing their social functioning in the context of their immediate environment.

The person-in situation approach to viewing an individual's problems is so informative so as to provide a holistic interpretation of the individual's needs. While taking into consideration the person and the environment, the approach adds a third dimension, being the 'situation' (Gitterman & Germain, 2008). This component is important in that while the person and the environment might not necessarily change, the changes in the 'situation' come with a complete set of dynamics. In light of this assertion, changes in the situation would thus initiate changes in the person-environment interaction. The change in 'situation' and the new dynamics of interaction affect the individual both positively and negatively. The positive dynamics are an important tool to build resilience. However, the negative dynamics in the interaction are likely to lead to maladaptive behaviour.

Following negative effects of person-environment interaction, a changing situation might trigger what would otherwise be unbelievable behaviour from a person. For instance, the loss of reproductive control in men is tantamount to a loss of manhood. This has grave consequences on how men live, interact, socialise and even work. The constant reminder that a man has become inadequate often triggers multiple reactions. These range from frustration, wanton behaviour, decline in self-esteem, social withdrawal and sometimes an urgent need to prove their manhood in other spheres like domestic violence.

Chapter 3: Research Design and Methodology

3.1 Introduction

This chapter provides a detailed explanation of the research design, sampling procedures, research instrumentation, pre-test of the research tool and methods of data collection. The primary aim and objectives, data analysis as well as ethical considerations taken into account in carrying out the research are also discussed in this chapter.

3.2 Research Design

The research was embedded in the qualitative approach and explored the lives of 20 men with prostate cancer. Of the 20 men, 7 were one on one interviews, 5 were email stories, and the other 8 were from a focus group. A qualitative research design is defined by de Vos, Strydom, Fouche and Delport (2005) as a naturalistic interpretive approach concerned with understanding the meanings which people attach to phenomena in their social worlds. Babbie (1992) defines exploration as the attempt to develop an initial understanding of some phenomenon and description as the precise measurement and reporting of the characteristics of some population or phenomenon under study. The researcher aimed to obtain in depth understanding of situations and meanings of those involved. The method of inquiry involved multiple cases of men with prostate cancer who lived different experiences. Creswell (2003) argues for the existence of multiple cases in a study whereby it involves the intensive analyses and description of multiple units or systems bound by space and time.

According to de Vos, Strydom, Fouche and Delport (2005) qualitative methods are used to gain first hand holistic understanding of phenomena of interest by means of a flexible strategy of problem formulation and data collection as the investigation proceeds. The benefits of a qualitative

research design are that it is flexible and unique and evolves throughout the research process. Qualitative research also utilises interviewing as the predominant method of data collection which allows the researcher to generate in-depth responses from participants' accounts as well as to probe for more information and clarity during data collection.

3.3 Population and Sampling Procedures

3.3.1 Population

A research population refers to the people or units from which a sample is drawn. This includes every other unit that fits the description even if it would not be selected. In eccentric terms the research was on men with prostate cancer. Therefore every man with prostate cancer was eligible for the research. The dynamics in the participants in this research range from age, class, location, level of education, occupation, and interest in life. These dynamics constantly shape the different men's perceptions of self and manliness. This consequently impacts on the dominant views they have to perceive the world and influence their position towards positive health-seeking practices.

Age has been an important consideration and determinant for participants in this research. The participants were aged 40 and above. The reason for selecting men between the age of 40 and over is that among Black people prostate cancer has been diagnosed at such an early age and also that the chances to be affected by prostate cancer increase with age. The older one gets the higher the chances of being infected. Age also was an important consideration in terms of the norms operative among the different age categories particularly concerning attitude towards health help-seeking. Even though there isn't uniformity in the narratives, the particular age periods inform one's perception and consequent use of health service.

Significant to age is class. Class is defined by Andrew, (2001) as social stratification in which people are grouped into a set of hierarchical social categories, the most common being the upper, middle, and lower classes. Men from different classes have different perceptions of health. In this research, men from the three classes were represented. Reasons why men from all classes were represented include location and preparedness to talk, and also strong values that cancer wasn't a concern that needed to be dealt with. Those that participated were mostly working men, those who either had a job or worked for themselves and others that had retired. Their perception of health centred on maintenance of their lifestyles. Those who worked for themselves emphasised that they constantly need to be healthy because the success of their business is dependent on their well-being. Consequently they had to consult regularly. Those that were working also expressed concerns that their income was dependent on their well-being particularly in a world of meritocracy. The constant need to be promoted compels them to seek to be healthy.

Another consideration was level of education. Educational attainment influences health throughout the life span. People with higher levels of education have better access to healthy social and physical environments, more job and income security, and a greater sense of control over life circumstances (Winkleby, Jatulis, Frank, & Fortmann, 1992). Education is also associated with health literacy, health awareness and self-care – all of which can contribute to improved health and wellbeing. Most of the participants had a high regard for education with most, if not all in possession of a university or college degree/diploma. Their awareness in life expanded generally from beliefs to facts and followed a calculated risk benefit analysis. Reason, is one fundamental attribute to their decision-making. It is however questionable/debatable whether logic applies to issues of emotion and wellness.

Participants were divided in terms of occupation between entrepreneurs and working class men (employed by organisations). According to the WHO, employment and working conditions greatly affect health equity (Kivimaki et al., 2003 as cited in CSDH, 2008). This occurs because poor employment conditions expose individuals to health hazards, which are more likely for low-status jobs. Evidence confirms that high job demand, low control, and low rewards for effort in these low status jobs are risk factors for mental and physical health problems, such as a 50% excess risk of heart disease (Stansfeld & Candy, 2006 as cited in CSDH, 2008).). Impoverished workers are more likely to hold part-time jobs, move in and out of work, be migrant workers, or experience stress associated with being unemployed and searching unsuccessfully for unemployment, which all in turn affects health outcomes.

3.3.2 Sampling

This sample was purposively selected. Purposive sampling refers to deliberately including participants with set experience and or knowledge needed by the researcher de Vos, et al., (2005) According to de Vos, et al., (2005) purposive sampling refers to a deliberate process of selecting respondents in a sample composed of elements that contain the most characteristic, representative or typical attributes of the population. According to Babbie and Mouton (2001) purposive sampling is used to obtain a fairly representative portrayal of the phenomenon being studied and the method relies on selecting participants based on the researcher's judgement. The reason of using purposive sampling is that qualitative research is less often interested in asking about a central tendency in a larger group but more interested in why particular people (or groups) feel a particular way, the processes by which these attitudes are constructed and the role they play in dynamic processes within the organisation or group. Embedded in this is the idea that who a person is and where that person is located within a group is important. Therefore purposive sampling

recognises that research participants are not always created equal thus selecting only those individuals that will best enhance the research.

A total of 20 men were interviewed. Out of the 20, only seven were face to face individual interviews, the other were through the focus group, the support group and the narrative stories. It was difficult to get men who were survivors of prostate cancer to interview. Initially I had proposed to interview Black men who were suffering from prostate cancer, however, I struggled to get such men to participate. Even though the statistics indicate a growing number of cases of prostate cancer among Black men, these statistics do not specify where these men are located. As such I included White and Indian men. The reason for including Indian and White men is that, they were more accessible than Black men. For instance I found a support group for cancer survivors and even though this group was for any cancer survivor, none of the members were Black. So to find a place where I could find Black men to interview was difficult. Hence White and Indian were included.

Given the difficulties experienced by others who have studied men (Khunou, 2013) I volunteered at Sonke Gender Justice Network (Sonke), CanSurvive and Cancer Association of South Africa (CANSA) as a way to gain a better understanding of men and to allow for better access to men as participants. Sonke was strategic in that I could understand the work that they do with men as well as get referrals for key informants of men's utilisation of health services. Through CanSurvive I was able to access men to participate in my focus groups. CanSurvive offers support groups and cancer buddies for survivors of any type of cancer, hence I was able to invite men with prostate cancer to join my focus group. I volunteered at CANSA, because as the biggest association for cancer in research and support, I was going to receive the necessary tools to conduct research in prostate cancer as well as finding participants.

Realising that I still hadn't found Black men to participate I established a support group in Soweto for prostate cancer support and sent out adverts in Soweto to invite men to participate. In the printed adverts, some men managed to contact me and with the help of volunteers managed to establish a support group in Orlando East. This support group was targeted at Black men and being in Soweto it increased the chances of getting Black men to participate. The support group started slowly but numbers keep increasing atn each meeting. The meetings are twice a month.

3.4 Pretesting the interview

Babbie and Mouton (2001) suggest that regardless of taking extra care in formulating a data collection instrument, there still is a chance of making mistakes. Pre-testing a data collection instrument is regarded as being crucial to the research process as it enhances content validity of the research tool. A pre-test of the interview schedule was conducted by the researcher prior to data collection. The purpose of the pre-test was to uncover problems in the research instrument, gaps, shortcomings and inconsistencies and establish any difficulties that the participants would be likely to encounter in responding to the questions posed. Consequently, the order of the questions had to be changed to allow a better flow of the interview and related issues on the schedule were grouped together.

3.5 Research site

The interviews were not conducted on one site. Each interview was conducted where it was most convenient for the participant. So for the individual interviews I travelled to their homes around Johannesburg. Some were in Sandton, Randburg and the bulk came from Soweto. The focus groups were held at Sans Souci Hotel in Milpark. This was the venue where CanSurvive hosts its meetings, therefore it was a convenient place for me to conduct the focus groups just after the

CanSurvive meeting. I would thus quickly rush into interviewing the men before they left. The support group is held in Soweto, Orlando East. This is a convenient place for men who would otherwise feel embarrassed to travel to town for a support group, because of the incontinence they suffer from.

3.6 Data Collection

i) Interviews

Interviews are one way in which data is collected to answer research questions. A semi-structured interview schedule with open ended questions was used as the main research instrument. Padgett (2008) explain that in semi-structured interviews, the researcher has a list of themes and questions to be covered and these may vary from one interview to the next. The semi-structured interview schedule also allowed the researcher's flexibility to follow up on interesting leads that were raised by participants.

Open ended questions were used. Open-ended questions allow the participant to provide his or her own answers to the questions. The advantage of open-ended questions is that the participant is given room to elaborate on a response and the researcher can probe for more information and request clarity. In this research face to face interviews were one of the ways in which data were collected. A total of seven face to face interviews were conducted with men from different racial backgrounds. Out of these seven, Blacks, Indians and White people were represented. In these interviews, a similar interview schedule was used. However, each individual interviewed had a different profile which made some of the questions in the schedule irrelevant.

These interviews took place between July and September. There is a difference also in the early interviews and the later interviews. In the earlier interviews, the questions asked were rather basic, they lacked depth but gave way to probing. These interviews were less focused and more generalist even though they were centred on the individual. The later interviews were more focused on specific things. These had depth and instead of knowing about everything they concentrated on specific experiences.

Reasons why there are differences between the earlier interviews and the later interviews can be summed up as follows: firstly, the earlier interviews were informed by my zeal on the subject. I was thus more interested in knowing how people were affected and what prostate cancer was all about. In the end these interviews were generalist. Secondly, the later interviews were informed by the knowledge I had acquired on prostate cancer, so they asked on the pathogenesis of cancer, how it began, how participants noticed it, what were the changes in their lives, how did they respond to these changes, what were their fears and experiences, what were their options, what was the result of the treatment options, what side effects did they experience, and how did they deal with such side effects. Lastly, my probes were also informed by my knowledge of prostate cancer. I had taken an interest in knowing the pathogenesis of cancer so I understood staging in cancer and the possible effects on the bodily functions. So instead of waiting for a cue from a participant, I instead probed accordingly.

There were challenges in conducting these interviews. One of the challenges was language especially with participants of Black origin. Since I am Black, they assumed I could understand vernacular languages. I however do not understand, even though I have a marginal understanding of Zulu. So the interviews were slow and frustrating. However, they progressed well. All the men could speak some form of English which made the interviews possible. Another challenge was to

reach participants. I struggled to get to the well-to-do participants from Sandton and Randburg, who wanted me to interview them in the comfort of their homes. Either I had a transport problem since taxis don't arrive or I would get lost in the suburbs regardless of having directions on a map. For the others, it did not differ as I had never been to Soweto and so going there I needed some sort of guide. I could not find any link to get there and what made it worse were people on the taxi's attitude. Since I was Black, they assumed I could speak the vernacular and so asking directions in English put off some people who would just walk away or in some instance, show hostility towards me. However, all the men I interviewed were quite helpful; they tried to guide me to their homes as much as they could. The interviews were smooth and the participants willingly participated. The interviews were then audio recorded.

ii) Focus groups

I used focus groups as a way to collect data as well. These focus groups were conducted with men who refused to be interviewed individually but were willing to contribute to this research. So between July and September, I conducted two focus groups that were about an hour and half long. These focus groups were held at Sans Souci hotel in Milpark. In the two sessions that were held, the participants were White and Indian men.

The focus groups focused on issues like the pathogenesis of prostate cancer, how it began, how participants noticed it, what were the changes in their lives, how did they respond to these changes, what were their fears and experiences, what were their options, what was the result of the treatment options, what side effects did they experience, and how did they deal with such side effects. The participants in these support groups were eager to share their experiences and so each men present had some sort of contribution to make on almost each of the questions that I asked.

The focus groups were beset with challenges. One of the challenges that I encountered was that before the participants agreed to be interviewed, they had to do a profile check on me. This was because they said they didn't want to speak to a journalist who would disregard their confidentiality and print a story in the following day's newspapers. After assuring them of who I was and showing proof, they contacted someone who had referred me to cross check whether I was legitimate or not. This created a problem with me in that they had assumptions which some participants came to confirm in the focus group. So instead of focusing on the issues at hand, they questioned my person, i.e, who I was, where I was from, if I was capable of conducting a focus group, suffice to say that some interpretations of some participants reactions were tantamount to racism. However, the focus group still carried on. The other challenge I faced was my age. I was a grandson to most of the men in the focus group, so they referred to me as such. They indicated that had I been much older it wouldn't be as difficult to speak openly. However, since it was for a school project they were willing to help.

The advantage of having these focus groups was that I could get a lot of input on one aspect from the different men at the same time. I could get dissenting opinions and experiences which increased my awareness of the disease. Another advantage was that through these discussions, I was able to invite men to speak freely without being vindicated as in one on one interviews. One person could speak and another could relate and so it went along much easier. The disadvantage that I could see at the time was that putting all the data into memory was going to be a challenge. Since I did not record the focus groups, because the participants refused, neither did I have an assistant to record important information, I struggled between facilitating and making field notes. So by the middle of the first support group I had stopped taking notes. Instead I wrote process reports afterwards. My ability to write detailed process notes come from my social work training.

iii) Key informant interviews

Key informants were a significant component of data collection. Key informants in this research are people who have worked with cancer patients. These refer to one oncologist, one oncological nurse, a psychotherapist and the head of prostate cancer research at the National Health Laboratory Service (NHLS). It was important that I interviewed these people for the reasons that follow:

To understand the pathogenesis of prostate cancer I interviewed an oncologist. This interview was significant to increase my knowledge of the disease. From this I got to know how the cancer developed and possible causes and symptoms. But most importantly I learnt about the stages that the cancer takes in the course of its development and consequent treatment available for each stage. The stage and treatment had direct effects on the side effects that developed. I thus learnt also of the different side effects and how these could be managed. My interview with an oncology nurse was similar to that of the oncologist. However it differed quite significantly in that the nurse attended to the patients daily. The nurse saw how the patient changed and how the patient experienced treatment. The nurse was able to talk to me about the feelings the patient goes through, the pain and the suffering. The interview with the psychotherapist was to understand the attitudes of men concerning seeking for health help. This interview was to establish if there was something significantly manly, that encouraged or discouraged health help-seeking, and if there was, was it embedded in being a man or was it external and how that could be dealt with. Lastly the interview with the head of research on prostate cancer was to understand whether there was legislation that encouraged men to access widespread screening, or whether there were clinical drugs that would improve treatment or reduce the cost in treatment as well as broadening the treatment choices.

iv) Narrative stories from prostate cancer survivors

I invited survivors to share their experiences of prostate cancer. I asked these people to share what they thought was an important challenge in their life in relation to prostate cancer, diagnosis and treatment. I soon found out that sex was a major concern with prostate cancer treatment. Four men shared their stories with me. These men wrote their own stories about their experiences and emailed them to me. The stories talk about how their sex life has changed and how the loss of having an erection has emasculated them.

The advantage of narratives is that the story tellers concentrate on what's important to them. They thus give a lot of detail on or many things they have experienced. In this research the stories dwelt mostly on the side effects of treatment on erectile dysfunction. The men that wrote to me had undergone radical prostatectomies and talked about how sex was different afterwards, with some indicating that sex was non-existent since then. The limitation of these narratives is that each writer writes about the things that are important to him, there is no uniformity in the sequence of the data. They do not answer the research questions per se, but rather can be used to back up some claims that I make in interpretation and write up.

Other data collection methods

i) Support groups: linking research and practice

Doing interviews and focus groups alerted me to the danger or precarious state that the men who participated in the interviews faced. To address such I established a support group to urgently deal with issues of negation and also as a data collection method. I established the support group in Orlando East, Soweto, primarily because I could not refer the men to Emthonjeni Centre for further counselling since it was too far for them and also an embarrassing journey to commit to. Most of the men in the support group suffer from incontinence hence travelling in public transport would

be embarrassing since they randomly wet their pants. So the support group was established to cater for men who wanted continued emotional support and who couldn't travel in public transport.

The support group concentrated on fears that men had, for instance prostate cancer presented a two-fold fear, one the fear of not being 'man enough' vs the fear of the 'inevitable but protracted death'. The support group thus focused on the experiences that these men faced. So topics of discussion included living with prostate cancer, social pressure, dealing with self in reflection, building confidence to face the world, what makes a real man, dealing with pain facing death, and prostate cancer as a challenge to well-being among others. These topics provided a lot of information relating to how the men felt, how they interacted with the world, how their lives were changed, in some ways for the good and in some ways for the worse, how their sexual beings had come to a standstill and for others, non-existent.

As a social worker I realised that interviewing men and then referring them to someone else for help was essential. However, dealing with men one needs to understand that men need to trust you sufficiently to open up. Referring them to someone else would break that trust and discourage them from taking it up. So I established an open group where survivors of prostate cancer would invite others to receive consistent support from someone they trusted. I chose to run the support group because of my awareness of the disease, the pathogenesis as well as the social manifestations. And as a social worker I was thus able to manage issues of confidentiality, among other ethical considerations.

The main reason why I used this practice as a research method was that there was a lot of useful information being shared regularly as far as prostate cancer was concerned. This information covered such topics such as dominant norms, manliness, fear and loss, and vulnerability. These

themes are usually not captured in mainstream research. Knowing that I was qualified to explore such themes, I realised that these were significant data that needed to be consolidated.

Running the support group had it challenges. One of the challenges with the support group as a research method was that there was too much fluidity between objectivity and subjectivity. The support group is very subjective, participants dwell on issues that are affecting them at the time rather than the things I would consider objective. So to address this challenge I ensured that each meeting's topic was related to the things I wanted to know about. For instance, vulnerability was a topic, so was living with prostate cancer. These specific topics gave details to my quest in that participants dwelt on their experiences, thereby enriching the data I collected. The other challenge was ethical considerations. Questions like was I deceitful or was confidentiality considered arose. So to address these, at each session I would remind the participants that the reason for establishing the support group was for me to understand the phenomenon of prostate cancer as well as providing support to the participants. Whosoever was not content or couldn't give consent was free to leave. The support group has kept growing even to this day. Even when I have finished collecting data, I still carried on with the support group.

ii) Training in Cancer support and advocacy

I went to cancer support and advocacy training. These trainings were meant to capacitate health workers in cancer care on the nuances in cancer. The one training was on anatomy to understand the pathogenesis of cancer. This training was conducted at the University of Pretoria in conjunction with the Cancer Association of South Africa in June 2013. There was another training on cancer buddies provided by CanSurvive, an organisation that deals with cancer support for survivors. This training was aimed at caregivers to cope with survivors or cancer patients.

These trainings were important to aid my understanding of prostate cancer treatment and care for the patients. It provided knowledge on the stages and treatment options as well as side effects. It also taught me how to handle and manage the patients as well as how to cope as a caregiver. This was important especially to avoid burn out and to constantly offer support to the patient from diagnosis to remission or sometimes even death. The training also focused on the different screening tests and gave detail on the different tests. The Prostate Specific Antigen test (PSA) which is widely recommended does not say much in relation to the prostate cancer itself. Unless observed for a period of time the trends show an alarming difference in the results, thus the PSA test doesn't say much. The finger test is preferred since the oncologist is able to feel whether the prostate has enlarged or not. However, in as much as this was as informative, it also is knowledge that I have gained. The tests remain a preserve of qualified medical practitioners.

iii) Social media

Social media also provided a way to gather data. By social media, I am referring to the use of Facebook and Twitter. Facebook and Twitter were used strategically to post different bouts of information seeking responses. For instance, educative videos on the different tests were put on Facebook for people to see. As a page manager I was able to see how many people it would have reached. Questions were asked to elicit people's responses on different subject matters. The responses were then used to predict or confirm people's attitudes. Even though it is difficult to prove, some things can be said. For sensationalised topics, people would gladly share the posts on Facebook with their friends and comment but on matters of concern that were educative, the number of people that shared the status or commented or viewed the post decreased shockingly even when the posts preceded each other. This confirmed that people have observable patterns, for things they are not prepared to face, they would rather not engage thus they ignore educative posts.

3.7 Data analysis

Data were analysed using thematic content analysis. Babbie and Mouton (2001) define thematic content analysis as a process where emerging themes are categorised and interconnected and the write up of the research findings is guided by these emerging themes. According to Weber (1990) thematic content analysis entails classifying of textual material and reducing it to relevant and manageable data. Data analysis followed the following steps:

a) Step one: familiarisation and immersion, where the researcher immersed himself in the data and familiarised with the data, developing ideas about phenomena being studied, making notes and brainstorming;
b) Step two involved inducing themes whereby information was organised based on the principles that underpinned the material. The researcher tried to identify contradictions, tensions and processes evident in the data.
c) Step three involved coding the information whereby the researcher grouped certain information in order to compare responses from participants.
d) Step four entailed identifying sub issues and themes that come up as result of coding and comparing the information.
e) The fifth and last step entailed interpreting the information and meaning was attached to the data (Weber, 1990).

Braun and Clarke (2006) highlights the advantage of using thematic content analysis noting that it summarises key features of a larger body of data, provides flexibility, makes it easier to analyse larger amounts of data and can generate unanticipated insights. Disadvantages of using thematic

content analysis are that it is time consuming and there might be one or two persons who articulate certain themes hence making it difficult to record the data.

3.8 Ethical Consideration: Experiences from the field

Some of the ethical considerations in this research include informed consent and voluntary participation, confidentiality and doing no harm to participants. Informed consent and voluntary participation were observed through the following: I took time to explain my research to the participants-to-be and gave them an information sheet that also explained what I had just said. Upon perusal of the information sheet I would then invite people to participate in the study. Upon granting consent to participate I would give them consent forms to sign. The consent forms were two fold, the one to participate and the other to be audio recorded. Once they signed, I would have obtained their consent.

Confidentiality may not be guaranteed in this research for some participants. For instance the key informants will be mentioned by name so as to protect myself from being accused of falsely quoting anyone. Also because these key informants are strategic people in their fields they are willing to be publicised as having said something. However, for other participants confidentiality is ensured because pseudonyms were used in the write up of this research. To avoid revealing the actual identity of the participants, pseudonyms were used in quotations. However, some of the participants have indicated that they would want to be heard, so instead of using pseudonyms on specific quotes, they would want to be mentioned. A case in point is in the interview with Peter Roberts, he mentions that he wants people to know what he said and doesn't mind if I were to use his actual name in the research. So whenever necessary, confidentiality would not be observed depending on the interview and point being made.

In all research, researchers are encouraged to do no harm to the participants. So in this research to observe doing no harm to participants, counselling services were provided on a referral basis to Emthonjeni Centre for those participants that required counselling further than the scope of the interview. More interestingly, a therapeutic support group was established in Soweto to try and mediate the consequences of interviewing men.

There are several things that need to be mentioned about doing no harm to participants. In as much as it is necessary to observe the principle of doing no harm to participants, it is necessary for ethics committees to consider the harm on the researcher. Literature on research emphasise almost as a rule that a researcher should not in any way harm the participants, but rarely if not ever mention that the researcher may be harmed by the research. I would like to use my experience in this research to argue that researchers should also safeguard themselves from potential harm for their research. In my case when I established a support group and had interviewed some men prior to starting the support group, two men scheduled for the support group's second session passed away. These men were among the first I had contacted in my preparation to establish the support group and they had become my reference points. Their death had a knock-on effect on me. This was compounded by the fact that the content of the interviews I conducted was quite emotional and the men expressed vulnerability. As a man interviewing men I suffered vicarious trauma.

I could not continue with the interviews when the deaths happened. In prostate cancer research a lot of publications imply that men die with prostate cancer and not of prostate cancer. So both my supervisor and I had not prepared for such to happen. Neither did the Wits Ethics Committee for Non-Medical research. My argument therefore is that when considering or observing the principle of doing no harm, it shouldn't be limited to participants only, but rather consider the researcher as well so as to establish coping mechanisms. In my case, the School of Human and Community

development, under which I am doing my research could not help. The University's Career, Counseling and Development Unit (CCDU) gave me an appointment in about a month's time when I wanted an urgent intervention. I found it very slow and not responsive to my situation. I then contacted Lifeline and got an immediate appointment. Without making a case against the University's support structure, I think it is necessary to consider the potential harm to the researcher so as to prepare the coping strategies and mechanisms.

3.9 Strengths & Limitations

Strengths

i) The use of multi-racial men

The idea to involve more than one racial group was because there were not enough men in the desired population to participate in the study. Involving men from multi-racial backgrounds was therefore necessary, particularly where screening for prostate cancer also varies with race. Using a multi-racial population was therefore desirable. Using multi-racial men, contrary to popular belief, enriched the findings in that they gave multi-variate responses. These multi-variate responses would therefore be useful to make a case for or against any racial group.

Limitations

ii) Using social networks where information cannot be guaranteed

Using Twitter and Facebook to get people's reaction is difficult to interpret. One can never be sure why people would respond to one posting more than another. However, it gives perspective into what kinds of information people respond to. These social networks also reach a significantly huge

number of people, which enables information sharing. Even though there is no guarantee that the information reached the intended audience, the responses or no responses give an indication of people's willingness to engage on the said subject. This was important especially during interviews as it shaped my sensitivity to what could be taboo in different cultures. From these social networks it is difficult to ascertain reliability and validity of interpreting the findings. However, even though reliability and validity can't be ascertained, in social networks, the findings can be validated through other methods like interviews. Hence triangulation of methods was an important consideration.

iii) The research topic

The research topic was a good way of exploring social realities. However components of the study were intrusive in the more conservative cultures. For instance talking about how radical prostatectomy affected a man's sexual functioning was met with resistance in Black participants. They showed signs of discomfort talking about personal experiences. In contrary to this perception, the research opened men up in their vulnerability to speak up about it. They were thus able to express their fears and vulnerability in safe spaces. I have established prostate cancer support groups for men that I have interviewed so that they are not exposed to reversal effects of interviewing where they feel like they need to protect their vulnerability. In other words this research has opened an avenue for advocacy.

Chapter 4: Pathogenesis of prostate cancer

4.1 What is Prostate cancer?

Prostate cancer is cancer that occurs in a man's prostate — a small walnut-shaped gland that produces the seminal fluid that nourishes and transports sperm. Prostate cancer is one of the most common types of cancer in men. Prostate cancer usually grows slowly and initially remains confined to the prostate gland, where it may not cause serious harm. While some types of prostate cancer grow slowly and may need minimal or no treatment, other types are aggressive and can spread quickly. Prostate cancer grows locally within the prostate, often for many years. Eventually, prostate cancer extends outside the prostate.

4.2 Signs and symptoms

Prostate cancer has been famous for showing no symptoms until it has advanced. According to Dr Ntshiki of the Wits Medical School, prostate cancer is notorious for showing no visible or easily identifiable symptoms. For the two types, aggressive and passive prostate, there is however a significant differentiation. The aggressive prostate cancer is likely to show symptoms easily as it advances quicker in the body, whereas for the passive prostate cancer, no symptoms might show. Consequently, there are signs and symptoms to look out for and these include the following: Trouble urinating, Decreased force in the stream of urine, Blood in the urine, Blood in the semen, Swelling in the legs, Discomfort in the pelvic area, and Bone pain.

4.2.1 Trouble Urinating & Decreased Force in the Stream of Urine

According to Dr Babb of the National Health Laboratory Service (NHLS) responsible for making the cancer registry, men that have prostate cancer experience trouble urinating, as there is

decreased pressure in the urine. This is a result of an enlarged prostate blocking the pathway of urine in the urethra. Therefore when men urinate, the urine does not come out as a continuous flow, it either cuts in the process or only just a little comes out. However, there is increased strain in trying to get the urine out which in turn induces a burning sensation as the man urinates. Furthermore, there is loss of control of when and how the urine comes out. Its flow is as irregular as the times it comes out. For some men, the urine leaks at random times. This condition has medically been referred to as urinary incontinence[1].

Before being diagnosed with prostate cancer some of the participants attest to experiencing such problems. In an interview with Kgalema, he said,

> *"…but l used to see my brother always when he used to go to the toilet he cried iiiiiiiiiiii iiiiiiiiiiiiii pressing… He asked what is the symptom and l replied l have noticed my brother whenever he goes to the toilet he screams iiiiiiiiiiiiiiiii pushing out the urine and he goes like sssssssssshuuuuuuuuuuu at the end of the peer as a sign of relief. That's when l started to suspect something is wrong"* **(Interview, Orlando East, 13/07/25).**

Confirming the uncontrollability of urine, he claimed that,

> *"You know once you are in this you wear black because sometimes you leak."*
>
> **(Interview, Orlando East, 13/07/25).**

4.2.2 Blood in Urine & Semen

When the cancer is spreading aggressively in some instances it causes blood leaks in urine and semen. According to Dr Ntsiki of the Wits Medical School, instances where there is blood in urine

[1] Urinary incontinence- is any involuntary leakage of urine

and semen are uncommon, however, they indicate a serious threat of the prostate cancer. More often than not, such patients are then rushed off to theatre to save their lives. It thus appears that in blood in urine and semen is an indication of severe/aggressive prostate cancer. However, it is often difficult to locate the source of the blood in urine and or semen to reduce its occurrence to an indication of prostate cancer. Even when it raises significant alarms, it is worth investigating the origins and therefore establish the cause for the blood leaks.

It has however been difficult for men with such indications to receive appropriate treatment. According to Dr McIntosh, a clinical sexologist (2013), these symptoms are synonymous with a lot of sexually transmitted diseases. So when men are presented with such they consistently look out for sexually transmitted diseases to cure. Health care staff that examine or treat these men usually have limited time to do thorough examinations of what is really going on. Therefore, unless the blood leaks continue, there might be no diagnosis.

4.3 Tests to Identify Prostate Cancer Stage

After a prostate cancer diagnosis, tests are done to detect how the cancer has spread, if it has, outside the prostate. Not all men need every test. It depends on the characteristics of a man's prostate cancer seen in a biopsy. Tests to help determine the stage of prostate cancer include a digital rectal exam where a physician puts a finger up the rectum trying to locate the growth of the prostate, a Prostate-specific antigen (blood test), an MRI of the prostate using a rectal probe, a CT scan of the abdomen and pelvis, looking for prostate cancer metastasis to other organs, an MRI of the skeleton, or a nuclear medicine bone scan, to look for metastasis to bones and Surgery to examine the lymph nodes in the pelvis for any prostate cancer spread.

Dr Ntshiki highlighted what the different stages were and what they entailed. She described prostate cancer stages as the following:

Prostate Cancer Stage I

In stage I, prostate cancer is found in the prostate only. Stage I prostate cancer is microscopic; it can't be felt on a digital rectal exam (DRE), and it isn't seen on imaging of the prostate.

Prostate Cancer Stage II

In stage II, the tumor has grown inside the prostate but hasn't extended beyond it.

Prostate Cancer Stage III

Stage III prostate cancer has spread outside the prostate, but only barely. Prostate cancer in stage III may involve nearby tissues, like the seminal vesicles.

Prostate Cancer Stage IV

In stage IV, the cancer has spread (metastasised) outside the prostate to other tissues. Stage IV prostate cancer commonly spreads to lymph nodes, the bones, liver, or lungs.

4.4 Reactions to diagnosis methods

- Patients

Of all the tests done to determine whether one has prostate cancer or not, only one seems to attract reactions from men interviewed. The digital rectal exam, where a physician inserts a finger into the rectum to locate the prostate seems to attract controversy among men who consider themselves heterosexual. These men find it difficult to understand and accept why the test should be done

through the insertion of a finger up their rectum. In an interview with Pule he shows frustration in the test. He exclaimed,

> *"….isn't there a way to diagnose men, that does not involve a finger being stuck in your anus? Very soon, they will be sticking other things… its very disgusting and I'm not homosexual.'* (Interview, Dobsonville, 13/07/19).

It has often been ignored that men are self-conscious of their bodies and such an exercise exist as a violation to the male body ideals. In a book, The Adonis Complex: The Secret Crisis of Male Body Obsession, Pope, Phillips and Olivardia (2000) argued that men of all ages are preoccupied with the appearance of their bodies. "*Men obsess therefore on whether they look big enough, muscular enough, manly enough among other things."* (Pope et al., 2000, p 3). Images displayed across board convey the same message to men that '*if you are a real man, you should look bigger and better than you do'.* In a similar light men then start to question whether by allowing a physician to insert a finger into their rectum, they are being unmanly or homosexual. It seems that even though homosexuality is as widespread as heterosexuality, it still hasn't been accepted as normal by some men. Even Pule's statement confirms that there might be something despised about homosexuality. In essence the digital rectal exam appears to contravene with popular male practices, hence it is despised.

- Doctors

For physicians, the digital rectal exam is a simple procedure that does not require a lot of resources. It is quick and simple and produces results from which they can start work to healing. According to Dr Ntshiki, the digital rectal exam is efficient, easy to administer and cheap. It can be done therefore by every physician, without wasting money going to a specialist. Dr Ntshiki also

acknowledged that treating cancer is quite expensive hence cutting costs wherever possible would represent such a rational decision. Similarly, Dr McIntosh and Dr Babb, argue in favour of the digital rectal exam, indicating that it can always be administered at the receiving local primary health care facility, it is cheap and easy to administer.

4.5 Prostate cancer treatment

a) Cure

Radiation therapy

Radiation therapy uses high-powered energy to kill cancer cells. Prostate cancer radiation therapy can be delivered in two ways:

i. Radiation that comes from outside of your body (external beam radiation).

During external beam radiation therapy, a machine moves around the body, directing high-powered energy beams to the prostate cancer. One typically undergoes external beam radiation treatments five days a week for several weeks. Most external beam radiation uses X-rays to deliver the radiation, but doctors are studying whether using protons may reduce the risk of side effects.

ii. Radiation placed inside your body (brachytherapy).

Brachytherapy involves placing many rice-sized radioactive seeds in the prostate tissue. The radioactive seeds deliver a low dose of radiation over a long period of time. A doctor implants the radioactive seeds in the prostate using a needle guided by ultrasound images. The implanted seeds eventually stop giving off radiation and don't need to be removed.

Side effects of radiation therapy can include painful urination, frequent urination and urgent urination, as well as rectal symptoms, such as loose stools or pain when passing stools. Erectile dysfunction can also occur. There is a small risk of radiation causing another form of cancer, such as bladder cancer or rectal cancer, in the future.

Surgery to remove the prostate

Surgery for prostate cancer involves removing the prostate gland (radical prostatectomy), some surrounding tissue and a few lymph nodes. Ways the radical prostatectomy procedure can be performed include:

i) Making an incision in your abdomen.

During retropubic surgery, the prostate gland is taken out through an incision in the lower abdomen. Compared with other types of prostate surgery, retropubic prostate surgery may carry a lower risk of nerve damage, which can lead to problems with bladder control and erections.

ii) Making an incision between your anus and scrotum.

Perineal surgery involves making an incision between the anus and scrotum in order to access your prostate. The perineal approach to surgery may allow for quicker recovery times, but this technique makes removing the nearby lymph nodes and avoiding nerve damage more difficult.

iii) Laparoscopic prostatectomy.

During a laparoscopic radical prostatectomy, several small incisions are made in the abdomen. The doctor inserts special surgical tools through the incisions, including a long, slender tube with a small camera on the end (laparoscope). The laparoscope sends images to a monitor in the operating

room. The surgeon watches the monitor while guiding the instruments. Laparoscopic surgery may offer a shorter hospital stay and quicker recovery than traditional surgery.

iv) Using a robot to assist with surgery.

During robotic laparoscopic surgery, the instruments are attached to a mechanical device (robot). The surgeon sits at a console and uses hand controls to guide the robot to move the instruments. Using a robot during laparoscopic surgery may allow the surgeon to make more precise movements with surgical tools than is possible with traditional laparoscopic surgery.

Chemotherapy

Chemotherapy uses drugs to kill rapidly growing cells, including cancer cells. Chemotherapy can be administered through a vein in the arm, in pill form or both. Chemotherapy may be a treatment option for men with prostate cancer that has spread to distant areas of their bodies. Chemotherapy may also be an option for cancers that don't respond to hormone therapy.

Whenever possible, surgeons may use 'nerve-sparing technique' to lessen the risk of postoperative long-term impotence. Not all urologic surgeons are trained in this and should be asked about before surgery. When it is not possible to spare nerves in the area of the prostate and still get the cancer out, generally the nerves should be sacrificed to offer the best chance of cure.

b) Manage

Hormone therapy

Hormone therapy is treatment to stop the body from producing the male hormone testosterone. Prostate cancer cells rely on testosterone to help them grow. Cutting off the supply of hormones may cause cancer cells to die or to grow more slowly. Hormone therapy options include:

i) Medications that stop your body from producing testosterone

Medications known as luteinising hormone-releasing hormone (LH-RH) agonists prevent the testicles from receiving messages to make testosterone. Drugs typically used in this type of hormone therapy include leuprolide (Lupron, Eligard), goserelin (Zoladex), triptorelin (Trelstar) and histrelin (Vantas).

ii) Medications that block testosterone from reaching cancer cells.

Medications known as anti-androgens prevent testosterone from reaching your cancer cells. Examples include bicalutamide (Casodex), flutamide and nilutamide (Nilandron). These drugs typically are given along with an LH-RH agonist or given before taking an LH-RH agonist.

iii) Surgery to remove the testicles (orchiectomy).

Removing the testicles reduces testosterone levels in the body. The effectiveness of orchiectomy in lowering testosterone levels is similar to that of hormone therapy medications, but orchiectomy may lower testosterone levels more quickly.

Hormone therapy is used in men with advanced prostate cancer to shrink the cancer and slow the growth of tumours. In men with early-stage prostate cancer, hormone therapy may be used to shrink tumours before radiation therapy. This can make it more likely that radiation therapy will be successful. Hormone therapy is sometimes used after surgery or radiation therapy to slow the growth of any cancer cells left behind.

Side effects of hormone therapy may include erectile dysfunction, hot flashes, loss of bone mass, reduced sex drive and weight gain. Hormone therapy also increases the risk of heart disease and heart attack.

Freezing prostate tissue

Cryosurgery or cryoablation involves freezing tissue to kill cancer cells. During cryosurgery for prostate cancer, small needles are inserted in the prostate using ultrasound images as guidance. A very cold gas is placed in the needles, which causes the surrounding tissue to freeze. A second gas is then placed in the needles to reheat the tissue. The cycles of freezing and thawing kill the cancer cells and some surrounding healthy tissue. Initial attempts to use cryosurgery for prostate cancer resulted in high complication rates and unacceptable side effects. However, newer technologies have lowered complication rates, improved cancer control and made the procedure easier to tolerate. Cryosurgery may be an option for men who haven't been helped by radiation therapy.

Heating prostate tissue using ultrasound

High-intensity focused ultrasound treatment uses powerful sound waves to heat prostate tissue, causing cancer cells to die. High-intensity focused ultrasound is done by inserting a small probe in your rectum. The probe focuses ultrasound energy at precise points in the prostate. High-intensity focused ultrasound treatments are being studied in clinical trials. More study is needed to understand the benefits and risks of this treatment.

4.6 Major issues in prostate cancer treatment

a) Undesirable side effects

i) Erectile dysfunction & Impotence

One of the most emasculating and uncomfortable side effects of prostate cancer treatment is the inability to have an erection soon after treatment, for some only regain the ability a few months

after whilst others never regain it.. Erectile dysfunction has been defined as a consistent inability to sustain an erection sufficient for sexual intercourse (medicinenet.com, 2013).

ii) Urinary incontinence

Other common complications of radical prostatectomy include urinary incontinence - the involuntary leakage of urine from the bladder - and fecal incontinence, the involuntary leakage of stool from the rectum. These complications may get better over time. They may even completely disappear but some men continue to have problems indefinitely. About 25% of men have urine leakage after surgery and need to use absorbent pads or disposable absorbent underwear for up to six months after surgery. But after two years, less than 10% need absorbent pads. In severe cases, some men may need surgery to support the sphincter muscles that control the release of urine.

b) Toxicity of drugs

It has been argued that drugs to treat cancer are quite toxic to the human body. For instance, regardless of how good chemotherapy drugs treat/cure cancer, they expose the body to massive pain

"He said let me say something to you ,statistically you have very little options you can do radiation we can do chemo those are options, yes they are options but let me explain the down sides for you before l ,.he mumbles on the words, l cannot explain the upsides because in my opinion for you they are no upsides to this type of treatment if l have to do one, he said its better of you in my opinion go for surgery, if l do radiation by the time l finish with the amount of radiation your organ will be smaller than a peanut, so what do you wanna do ?...

we can probably do it as a backup somewhere along the line but l would not recommend you that we do radiation or chemo for you because it's going to kill you, straight out' ***Interview Randburg***

Toxicity of cancer drugs has been a topic among cancer researchers across the world. Professor Lucia Uithagen of the University of Brem in Switzerland, who has been researching on the toxicity of cancer drugs was championing alternative treatment strategies at the AORTIC Conference in 2013. In her conference presentation she pointed out that the chemicals in chemotherapy are quite toxic to other body cells. Instead of just curing the cancer, they expose the body's natural immune system to becoming vulnerable for opportunistic infections. Like HIV which makes the body's immune system weak, cancer treatment has a similar effect.

Current discourse on toxicity of cancer treatment seems inconclusive on the way forward at present. In the absence of alternative approaches to treatment, the current methods seem effective. However, they have side effects. So it is inconclusive whether to completely leave the current methods for yet undeveloped treatment methods that are less toxic. In advocacy terms, it would be ideal to develop treatment that does not cause further harm to the patients, but reality suggests that, it is better to have treatment with side effects administered than none at all, since side effects can be managed.

c) Limited Screening and lack of awareness

South Africa is plagued by the absence of widespread screening, a consequence of a lack of awareness on cancer in general. Other than breast cancer, any other cancer is relatively unknown to the general public. For instance, among the participants in this research, only one in twenty men knew what prostate cancer was before their diagnosis. This is a general indication of what

information is available to the public. Local media tend to speak out on breast cancer, making it seem like the only cancer that affects people, especially women. The result has been that breast cancer informational advertisements have been shown on television at the detriment of other cancers. In as much as it is a good thing to speak out against breast cancer publicly, it leaves other equally important cancers out of the public knowledge domain.

In an article published by the Longevity Magazine, Elvis Munatswa argues that Pharmaceutical statistics suggest and confirm that in comparison for instance, there are seven breast cancer drugs to one prostate cancer drug (Munatswa, 2013). The article makes reference of a report by Caroline May of the Daily Caller (10/05/2010) which indicates that according to estimates from the National Institutes of Health, in the United States in 2010, 207,090 women and 1,970 men will get breast cancer, while 39,840 women and 390 men will likely die from the disease. The estimated new cases of prostate cancer in 2010 (all affecting men) were 217,730, while it was predicted 32,050 will die from the disease. Most disturbing however was that in the fiscal year of 2009, breast cancer research received $872 million worth of federal funding, while prostate cancer received $390 million and the fiscal year 2010 ended similarly, with breast cancer research getting $891 million and prostate cancer research receiving $399 million (Munatswa, 2013).

In South Africa however, figures on how much is spent on each of the cancers are not made public. However, from observing what happens in the country one can be sure to draw conclusions. Prostate cancer has only taken national priority since the inception of the Movember Project run through Cancer Association of South Africa and Movember from Australia. Since 2012, November has been reserved in South Africa as the male cancer month, mostly prostate cancer. However, it is preceded by cervical cancer month, and also breast cancer month. The prostate cancer awareness is however driven by non-governmental organisations, which further conceals

how much the government is spending on awareness and screening as well as research and treatment.

Chapter 5: Complexities pertaining to the diagnosis of prostate cancer.

5.1Introduction

This chapter presents the complexities pertaining to the diagnosis of prostate cancer. It speaks of the effects of prostate cancer on the overall well-being of men as well as the effects of prostate cancer treatment. This chapter presents findings on issues such as early presentation of cancer and the challenges in identifying as well as treating it. The findings point to a general delay in screening leading to late diagnosis. The chapter delves into the complexities in the context of the availability and consequent use of health services for screening and management of prostate cancer and the fear of what could be an inevitable but protracted death.

5.2 Context

In South Africa as in the rest of the African continent, the utilisation of health services by men is significantly low. Researchers point to various reasons why there is such a discrepancy in the utilisation of health services by men. The findings have shown that, as a group, men of different ages (Husaini, 1994), nationalities (D'Arcy & Schmitz, 1979) and ethnic and racial backgrounds (Neighbors & Howard, 1987) seek professional help less frequently than women. In these studies it has been shown that men visit primary health care physicians and other medical health specialists less frequently. The profiles of men in this study reflect a similar pattern, whereby a visit to a doctor unless very sick is very infrequent. In Khunou's (2013) study being sick was defined as serious illness not a headache or something that a visit to the chemist could solve. From a sample of 16 men, only two White men said they regularly went to the hospital for check-ups. Their reasons were that their wives were health-conscious. They would instead rather go to the doctor

than answer to their wives, why they didn't go. The rest of the men indicated that they would go only if it was necessary.

It is important to understand why such a pattern exists. Firstly, there is a significant absence of prostate cancer awareness on national media to inform men of the existence or the probability of any being diagnosed. When asked if they knew of prostate cancer, most men in this research said they had a faint idea or no knowledge of it. For instance the following men are quoted responding to the question: Stan, a married White man and father of two, 63 years old and living with prostate cancer for 8 years said, *"I didn't know until l was diagnosed'.* Stan is an entrepreneur in software engineering, his company has been designing business software since 1993. When he was diagnosed with prostate cancer 8 years ago, it had already metastasised in all his bones, from the chin down to his knees. He has been on hormone therapy ever since and constantly changes drugs every six months as the drugs lose its effectiveness.

In another interview Steve said,

> *"No l don't think l have seen anything about prostate cancer you only see breast cancer, l don't think you it gets the acknowledgement that other cancers have and yet it's a big scare you know…",* **(Inteview, Soweto, 2013/07/12)**

Steve is a 60 year old man from Dobsonville in Soweto. He has been living with prostate cancer for the past 5 years. He is in remission at the moment. However, he hasn't recovered from sexual dysfunction, two years after treatment. He is married with 6 children and 5 grandchildren. He also is a double amputee, he lost his right arm and leg in an accident around the same time he was diagnosed. Even though losing an arm and a leg to an accident isn't related to the cancer, it compounds the suffering he experiences, in mobility. He is unemployed and lives off the disability

grant with which he supports his wife and two children and three grandchildren that live in the house. He has received treatment from Charlotte Maxeke public hospital.

David is a 59 year old man, married with four children. He has lived with prostate cancer for the past three years. He is of middle income, he owns a motor vehicle which he uses to transport primary school children for a fee. He is on Discovery Health medical aid and has received treatment at Oliver Day Hospital. He frequently goes to a Virgin Active Gym to keep fit and he keeps a regular dietary plan. Responding to the same question David said,

> "*No, nothing am aware of to be honest with you l think the entire society has been focused on generally along females in this respect you know… breast cancer is recognised as a worldwide … recognition because l think of the incidence level that are so much higher and its frequency of pumping its head up are so much higher and in fact the males have taken the back seat"***(Interview, Soweto, 13/08/14).**

Current literature on the lack of information on men's health issues confirm the fact that, men's health has been relegated to be of secondary importance. Tom Sackville, Secretary of State for Health in the UK in 1995, once said "… the phrase 'men's health' tended to feel unfamiliar… yet there's no good refusing to concentrate on the particular themes of health that apply to men. We're so used to hearing about women's health, child health, etc., it has tended to be accepted that there were things which we could learn by looking specifically at the diseases, behaviours and attitudes associated with women and children and targeting our approaches accordingly" Luck, Bamford and Williamson, (2000, p. 151). This points out that there is inadequate recognition and no attempt at prioritisation of the relative importance of significant sex differences in health delivery system. Therefore there has been a systematic unusualness on reporting male health needs.

The attitude of policy makers have not differed here in South Africa. In the late 1990s, the then president of South Africa Thabo Mbeki is quoted to have denied the link between HIV and AIDS. In an article titled *'Mbeki Aids denial 'caused 300,000 deaths' South African president's refusal to accept medical evidence of virus was major obstacle to providing medicine, say Harvard researchers'*, Sarah Boseley, (The Guardian, 26/11/2008) argued that the Aids policies of the former South African president Thabo Mbeki's government were directly responsible for the avoidable deaths of more than a third of a million people in the country. Sarah Boseley further argues in the same vein that had Thabo Mbeki accepted that HIV & AIDS were related then maybe the spread and management of the pandemic would have been severely curtailed.

In line with the above references, I would like to suggest that the reluctance of policy makers to take action when required, particularly in the health sector, reduces the chances of those that suffer for a particular ailment from benefitting from the best medical care. The negative consequences of such action include a fervent sabotage of care for the already affected. For instance, on prostate cancer there is very limited information made public for lay people to access, there hasn't been policies made to increase widespread screening for prostate cancer on a national level, and also in the training of surgeons, not all are trained to do nerve sparing surgery, especially when performing surgery to remove the prostate.

This is confirmed by several participants in the research. In an interview with two oncologists, Dr Babb the head of research on prostate cancer at the National Health laboratory Service (NHLS) situated in Braamfontein and Dr Ntsiki, an oncologist working at the Wits Medical School at the Charlotte Maxeke hospital, it was obvious that certain things within the health policy making made their work a little more difficult. In their views, the inaction of responsible authorities with regards to policies makes the doctors patiently wait but in the mean-time do nothing, because of legal

recourse. They thus presented a dialectical situation of early presentation vs late diagnosis, in which case, men that present symptoms early could be diagnosed and those that have no symptoms are diagnosed late. This situation thus creates a situation that where there is no widespread screening, late diagnosis would be common in the absence of aggressive media campaigns that educate men to go get checked. Early presentation, in as much as it is desired, runs the risks of overdiagnosis, where men on the presentation of symptoms are diagnosed where they could have lived off the cancer.

According to Dr Babb (Interview, 2013), this presents a difficult scenario, whereby men are diagnosed with prostate cancer on one Prostate Specific Antigen (PSA) test[2], where it would have been beneficial to monitor the PSA over a period of time to observe the trends. Dr Ntsiki (Interview, 2013) concurred indicating that there are two types of prostate cancer, one that is aggressive and the other passive. The aggressive prostate is likely to lead to death as it spreads quickly whereas the other might not be as dangerous. Therefore the PSA test cannot be a once off test to determine the choice of treatment. However, this isn't standard practice since doctors cannot take such a risk, they would rather act.

5.3 T*reatment/ management of prostate cancer become very expensive.*

Prostate cancer treatment is very expensive if it is to be effective. The drugs to cure, treat and or manage prostate cancer constantly lose strength after a period of six months or, rather the cancer becomes resistant in a period of six or so months. I interviewed Stan, (a 62 year old man residing

[2] Prostate Specific Antigen (PSA) – is a substance produced by the prostate gland. Elevated PSA levels may indicate prostate cancer. Men with prostate cancer often have PSA levels higher than 4ng/mL, although cancer is a possibility at any PSA level
PSA Test, is used to primarily screen for prostate cancer. A PSA test measures the amount of PSA in the blood.

in Sandton, living with Prostate cancer for 8 years. He is married to a much younger wife and had two children, unfortunately one passed away in a road traffic accident. His cancer has spread throughout his body and he only gets treatment to reduce the pain, since the current treatment options do not work. He is also under hormone therapy to reduce any possible spread, testosterone related.) To this effect in an interview Stan points out two important things. Firstly, he said that there were clinical drugs that were being used in the UK and USA, which were not regulated or prescribed here in South Africa, therefore not available on the market. These pharmaceutical drugs were obtainable at a cost of between US$ 4000.00 and US$ 7 000.00. Secondly, he mentioned that, to obtain these drugs one would require a very good medical aid scheme, since the medical aid only paid up to two thirds of the total cost. In the interview he said,

> *'…afford this American 7 000 dollar a month, because it's not accepted in the country. I am on this discovery health, top of the range medical aid and you got to go to the board and everything and then they will agree to pay half of it. Normally they would just say sorry we not prepared to pay for it because it's not being approved in South Africa that's there rules of their medical aid they are not being funny about it, it's just their standards of rules .There are very few people in South Africa that can afford what is 7 000 dollars a month or 80 000 rands a month after tax, How many people would afford that to pay on a drug? Very few very very few .That would restrict it to certainly less than 10 per of the people that could get cancer, only probably 5 , 4 or 3 per of the people might be able to come up with, you know people would sell their **** to do that and pay for the drug for a year'* ***(Interview, Sandton; 13/07/12)***

In this excerpt the two things that stand out is the cost of drugs and secondly the affordability. The drugs are quite expensive and far above affordable on average incomes for working class people

in the country. Dr Ntsiki confirmed this view saying that the drugs to cure, treat or manage prostate cancer are quite expensive. One of the reasons for these high prices is that there haven't been any development of clinical drugs in South Africa on prostate cancer, rather there is reliance on drugs from the UK and the USA. David's opinion, although it carries a lot of generalisations, is quite context relevant. Incomes are quite suppressed for the average working class men and what compounds the situation is that prostate cancer affect ageing men, in Black circles, those that were victims of the apartheid system. The reality is that most are pensioners, who survive on a monthly grant of R1200 from the government to meet their most basic needs. They neither have large sums of money invested anywhere, to afford these drugs. Theirs is a strong reliance on government services to provide health services. Therefore their access to such treatment and care is greatly reduced. Chances of them surviving the disease also begin to decline in the absence of treatment that is affordable.

The other issue of having a medical aid scheme that contributes to purchasing drugs is dependent on the contributions the client makes to the medical aid scheme. The Discovery Health medical aid has different schemes based on income (discoveryhealth.co.za). For instance the low income earners pay a small contribution and have limited benefits ranging from limited consultation with the doctor to other limited benefits. High income earners contribute more to their schemes and have unlimited benefits depending on the scheme. This creates an unequal distribution of gains where the medical aid favours high income earners. It follows that health is expensive and therefore one needs to earn a high income to afford it. It is not surprising that the medical aid contributes 40% of the total purchase of the drugs. On the other hand in the public health fraternity, drugs are distributed based on availability, and not necessarily need. In public hospitals where these drugs

are free, a patient can only get what is available, regardless of whether it offers better chances of recovery or not (Ndom, 2008).

The pharmaceutical company also contributes 20% whilst the client pays the remaining 40%. In the end, David's contribution to purchasing the drug is about US $ 2800. This is quite a high price for anyone, especially those that work on a government or employee salary. Incomes in South Africa for an average worker range below ZAR 20 000.00 for the high earners, and the majority of workers earn below. Statistics from the Department of Labour on incomes show that incomes for most workers rarely pass the R15000 margin (Dept of Labour, 2006). Likewise trade unions also indicate that wages for general workers are quite paltry, for instance, in the Marikana incident, workers were fighting for ZAR 12.500.00 monthly income (Cosatu, 2012). It is therefore unquestionably too expensive for any of those people to afford these drugs, neither would they be able to make significant contributions to the medical aid.

5.4 *Limited awareness of the disease*

There is a significant lack of information of prostate cancer awareness in the country which is accessible to the public. It is possible that this lack of knowledge of the causes and the absence of visible symptoms of prostate cancer has allowed an information vacuum, particularly for men who do not have access to mainstream research publications. Gathering from the fact that most if not all the men in this research indicate that they only found out about prostate cancer when they were diagnosed, it is possible that they were also clueless about treatment options available for them. Therefore the doctors are left with an arduous task to not only suggest the treatment options but also offer successive counselling for the new patient on the treatment options available. This task to counsel the new patient is then dependent on the workload of the given physician at the time,

given the fact that there are about 7.7 doctors per 10 000 people in the country (Department of Labour, 2006). In any case, the surgeons have a huge workload, particularly in the public hospitals and have limited time to prepare the new patients for the treatment. If this is the case, it is also possible that the treatment side effects are left out of the conversation or rather just said in passing. This would be done to entice the patient into believing that there are no alternatives or that theirs is a choice to either deal with side effects or face death. Therefore men in the situation would choose anything except death.

To support this claim the interviews indicate the following, for instance, when I asked about what treatment options the then prostate cancer patients chose and why, several of them pointed to the fact that, it was what the doctors encouraged, or they didn't know anything else. The following quotes from an interview with Stan are illustrative of these claims:

> "*Well initially …you don't realise what's going to happen but treatment for the cancer is hormone related so everything they are doing they are suppressing your testosterones and your hormones and eventually you do realise that, you know, no doctor has ever said to me that you not going to have sex in the rest of your life you will find out yourself. I think that's quite frustrating to realise what's happening, embarrassing."* **(Interview, Sandton, 13/07/12)**

Other than not having the knowledge of treatment decisions it seems that the treatment options are primarily based on what the physician can do. The doctor is informed by the statistics of the disease and chooses appropriate interventions, mostly in his area of expertise. The patient has little or no discretion on the treatment option. For instance, if what one patient went through is reflective of these doctors, then some things should be done differently. Below is Peter's experience. Peter is a

53 year old Indian man who lives with his wife and two children in Randburg. He owns some businesses in and around Randburg. He was diagnosed with prostate and bladder cancers. He refused surgery as a treatment option, regardless of the many biopsies that confirmed the cancers. He instead chose alternative treatment which has proved costly, more than he could have paid had he chosen surgery or other western treatment. He has a strong belief in the power of options and research. In my interview with him, he alludes to the following:

> "*At that time l had no idea of what my options were but l knew that surgery wasn't my option but l had no clue what other options l had because it was like wooh you just got hit with this thing and you now gonna deal with it."* **(Interview, Randburg, 13/08/16)**

Responding to whether he had ample information to decide on, he said,

> "*Zero the only option l was given was surgery because in between 3-6 months you die… With the type of cancers that l had, prostate and bladder cancers you have very little alternatives and the recommended for most doctors if not all doctors in that situation because they give you a statistics of 70,30 70 against and 30 per for… So when you look statistically what the follow up from that is surgery…"* **(Interview, Randburg, 13/08/16*)***

Without generalising, the reality of this participant was that there was limited information available for him at the time. It is possible that because of the severity of the condition, doctors act to save lives without due consideration of what the patient actually wants. The reasons why doctors would respond with urgency could be primarily to save a life. However, it takes a lot of resistance or initiative from a patient to articulate their needed treatment options. It might be the case that the doctor wanted to perform surgery to make more money. Literature on giving birth point out that some doctors prefer surgery as opposed to natural births, primarily because they make more money

through surgery than what they are concerned with the general health of the woman (Brown, Paranjothy, Dowswell & Thomas, 2013). The same patient argued with his doctor on his preferred treatment option. While the doctor suggested surgery and prepared for it, Peter only agreed to multiple biopsies on the premise that maybe the diagnosis was wrong and also that maybe a different treatment path could be arranged. He argued,

> "*… they wouldn't know but they assume that because they say 70 % of the time it goes through so you will become classified as the 70 % finish. So l turned on and after a while l questioned and said who is the 30 % why can you not classify me as the part of the 30 % that has a chance of survival opposed to what you said to me as the 70 %..."* ***(Interview, Randburg, 13/08/16)***

Significant to this, is also the analysis of class and education background of the patient. It is evident that this man does not only use common sense to question things but has a significantly higher level of processing that allows him to ask questions. Although, it wasn't asked what level of education he had attained, it can be inferred that he has been through rigorous educational training. This occurrence is not isolated but the only one in this research whereby a patient argued with a doctor on possible treatment options. That he was an Indian man points out to the probability that maybe it was within his context that he had learnt to ask objective questions. However, the rest of the men, mostly Black men, did not ask why that treatment was chosen and most importantly what side effects were resultant.

Other men who participated in the study did not ask about the treatment and ended up suffering side effects they were not ready for. In fact, when they chose treatment, it was rather a choice

between dying of cancer and coping with side effects. Most therefore chose to live, however were not ready for the side effects. The following quotations illustrate this fact. Mpho said,

> "*...you know no doctor has ever said to me that you not going to have sex in the rest of your life you will find out yourself. I think that's quite frustrating to realise what's happening."* **(Interview, Sandton, 13/07/12).**

David concurred saying,

> "*the side effects on this is too much sometimes because l had a problem with urinating now, it comes to that thing now when l started like want l said I didn't know like ... you find out like when you want to go to the toilet."* **(Interview, Dobsonville, 13/07/17).**

Another participant, Kgalema, said,

> *"No l was not told , l didn't know about these side effects [of treatment]... ! [like] lt does this to me, how do you feel, how's your stomach, how do you go to the loo... the only thing that l was prepared for was that of the hormones. That l was going to have a problem with them that was all l was told about."* **(Interview, Orlando East, 13/07/25).**

Furthermore, other research on Black men and health suggests a deep mistrust of Western medicine, as reasons why some men would not ask for alternatives. Rather, they would consult traditional healers on the side, as they believe in it more than Western medicine. Therefore even when he was told about the side effects of the treatment he was going to receive, he did not ask for alternatives, or ask why that treatment. David said,

> *"... l was ready to accept that because once somebody a professional tells you that, you must accept"* **(Interview, Dobsonville, 13/07/17).**

5.5 Prostate Cancer Management and Dying

Management of prostate cancer is premised on the view that it does not pose an urgent death threat. Therefore the approaches to contain, cure or manage are chosen particularly at the discretion of the surgeon concerned and the level of the cancer, but most significantly affects funding and research. If this is the case then there are several difficulties that this research envisages. Firstly, in areas where prostate cancer screening is not readily available, it is possible that when diagnosed, the prostate cancer would have been advanced. When the cancer has advanced, it is possible also that the cancer might destroy life. In this scenario also it is possible to assume that the treatment would be unavailable, except in a distant location where resources have been centralised. Secondly, if prostate cancer does not in itself kill, but men do die of related conditions, it is possible to assume that maybe there is a correlation between this cancer and associated illness.

To argue for the two areas above, I would want to refer to the interviews I conducted for this research and also the experiences I have encountered. For the first point that in areas where screening is minimal or privately done, it is possible that the cancer would be diagnosed when it has spread. For instance, interviewing Stan, who was diagnosed when the cancer had metastasised in his bones. Stan is a man, who among other men would like to regard himself as healthy, and has led a healthy lifestyle. When he was diagnosed with prostate cancer, he was shocked that the cancer had spread and so were his family and medical team. He said,

> *"… very advanced it had metastasized into my bones at that stage… prostate cancer starts in your prostate and if it's not treated it will metastasize somewhere in your body and normally it would be in your bones. My bones are affected from my knees up to my neck and up to my shoulders quite severely. I have had considerable radiation already*

but radiation doesn't cure anything it just fixes the pain." **(Interview, Sandton, 13/07/12).**

Stan was diagnosed when he was 55 years of age, which is about 8 years ago and he has lived with prostate cancer for that long.

In a similar encounter, two men, Mampho and Cyril, who were participants in my research who had been diagnosed of prostate cancer passed on, before I could finally interview them. They had been diagnosed with prostate cancer and had lived with it for 3 and 5 years respectively. I cannot confirm for sure if they died of prostate cancer or anything else, but word from the nurse at the hospice where these men lived, confirmed that they died of prostate cancer.

Two other interviews were with Pule and Kgalema, both survivors of prostate cancer. Pule is a 56 year old man who was diagnosed with prostate cancer 10 years ago. He went through surgery to remove the prostate. He is unemployed, lives on a hand-to-mouth basis. He suffered permanent loss of erection and has a wife who is ten years younger than him. In this interview Pule said,

"there are some people which we know like the brother of my friend he died before his time he was supposed to take that treatment he kept on saying, 'Am sugar diabetic' and whatever giving excuses not to do the check-ups for prostate cancer." **(Interview, Dobsonville, 13/07/19).**

Kgalema also is similar to Pule, he too was diagnosed with prostate cancer about 6 years ago. It was an aggressive cancer and he was operated to remove the prostate. He suffered permanent loss of erection. Worse, he now uses a wheelchair for movement. His health has been deteriorating ever since and he stays in a home where he is taken care of. He has family that rarely visits him in the home. In an interview with Kgalema, he said,

"It's nearly 3 years now we discovered it late. But l used to see my brother always when he used to go to the toilet he cried pressing and l would say what's happening and he would say no it's some sugar diabetes. ... I took him to Helen Joseph hospital when we got there l called the nurse privately and l said to the nurse look can you please do me a favour, this guy is my brother l suspect something can you please check him as prostate cancer please. She said it's all right. She called the doctor and told him this man is the brother to this young man so he suspects that his brother might have prostate cancer. He asked what is the symptom and l replied l have noticed my brother whenever he goes to the toilet he screams pushing out the urine and he goes like shuuu at the end of the peer as a sign of relief. That's when l started to suspect something is wrong with this guy. So they take a blood test and send it to the lab urgent. We stood there and the doctor came and said yes your brother indeed has prostate cancer. And they said now we have to admit him and l said l knew there was something wrong with him. He stayed in the hospital for 2-3 weeks then he was discharged am sure about 1 week after coming from the hospital he started again. I took him to Baragwanath hospital that was the last, he only stayed there for three days then he died." **(Interview, Orlando East, 13/07/25).**

These men spoke of their relatives who were diagnosed with an advanced prostate cancer that also killed them. With these occurrences it is possible that maybe prostate cancer actually does kill. Without having the knowledge of lifestyles led by the men that passed away, it becomes quite difficult to judge whether it was lifestyles that led to these deaths so soon after diagnosis. However, these deaths point out that maybe the approach to prostate cancer should move from the current watchful waiting and monitoring. It would also be worthy to look at whether early diagnosis would achieve different ends.

To argue for the second point where men do not die of prostate cancer but other conditions, (unrelated/related) it is possible that when the prostate cancer spreads it makes the body susceptible for other diseases. It has been argued, for example, within the HIV pandemic that HIV/AIDS in itself does not kill, but allows the body to be susceptible to opportunistic infections (Casarett, Pickard, Bailey, Ritchie, Furman, & Rosenfeld, 2008). The resultant death is what is therefore referred to as HIV related deaths. In a similar vein maybe there are certain diseases that kill men with prostate cancer, being opportunistic in that they have power over the immune system once it's fighting prostate cancer that has metastasised.

There seems to be mistrust of modern medicine by some African men, who rather choose to use traditional medicine. The fear of death allows these men to resort to traditional methods that they have trusted for years. In a support group meeting in Soweto, one of the things that African black men alluded to was the mistrust of modern medicine. (the support group comprised of men who are survivors of prostate cancer and some who are still on treatment. It was established to offer continuous support for men who expressed interest, especially after the interviews). A major point mentioned by Lennox, and supported by most men is as follows:

"I think one of the reasons for not going for check-ups, is because we, as black people, believethat cancer is a white man's disease. So when we get sick, we first think of going to consult sangomas and not doctors. …. I think that our black cultures sort of prevent us from consulting doctors, we can't trust them like our sangomas" (**Support Group Meeting, Soweto, 20/08/13)**.

In support of this view, yet another view that stood out from this particular meeting was the idea that sangomas and doctors do basically the same thing hence it should be by preference to go to

either. Championed by Gwebu, there is distinction between these two equally important healers. He said,

II think, because there are different kinds of illness and diseases [that] we believe can be healed by traditional healers. I believe in going to a sangoma first, to get cleansed then if not healed,choose an alternative treatment method" (**Support Group Meeting, Soweto, 20/08/13)**

Consequently some Black men therefore use herbs for cure. Steve, had this to say,

"Sometimes l do take some, some Bantu muti yah….Yah sometimes it does [work] for me, let me show you some. (laughter as he takes off to get the Bantu medicine). You see, it does work because it keeps my marriage in shape not just sleeping for the whole year doing nothing ,ok my wife knows my status but sometimes l do say no a man should do something you can't just sleep doing nothing. This is why l am taking this" (**Interview, Dobsonville, 13/07/2013)**

5.6 Conclusion

From the discussion above and the interviews conducted the most important question to answer concerns what we can learn about men's health-seeking practices, the availability of services that are user friendly for men and whether there is going to be a change in the use of health services. What we can learn about men's health practices is thus informed by their use of health services, whether, intentionally or unintentionally. What we can learn about the availability of health services that are user friendly for men is informed by the methods used by health providers, the attitude of staff and the existing policies to cater for men's health needs. What we can learn about whether there is going to be a change in the utilisationof health services is however

dependent on the aforesaid. These conditions become yardsticks to measure or rather indicate the progress or lack thereof.

This chapter showed the complexities in men's health practices. Where it can easily be assumed what position men would take to tackle a health issue, this research showed that it is not as clear cut. There are other issues that inform the decisions men will take to further their health position. In terms of Black men, the various disadvantages they have faced within the health sector continue to reinforce their mistrust of public health officials. Their preferences include sangomas, which are culturally in-line with their belief systems and practices. The differences in approaches by these men, indicates or rather confirms that when it comes to preferences or use of health services, men are not a homogenous group. There is such a heterogeny in practices and preferences. This diversity explains the plurality in masculinities hence the complexities in the health practices.

Chapter 6: Psychological Effects of Prostate Cancer on Survivors

6.1 Introduction

Illness impacts everyday life. It changes one's self concept and it affects relationships. Prostate cancer makes men look at who they are in particularly different ways. It changes how they position themselves in the world. This chapter looks at how prostate cancer affected the lives of the interviewed men. It presents the psychological effects of prostate cancer diagnosis as well as the everyday living with cancer. It also dwells on the effects and side effects of treatment. These psychological reactions build into the cognition of how men perceive and interpret masculinities. These reactions then build into the definitions of how some men define themselves and ultimately use health services. Understanding this is key to developing interventions with men. When men are diagnosed with prostate cancer, like any other cancer, they experience a range of emotions. Among these emotions are fear, anxiety, anger, initial denial, mild depression, persistence of denial leading to refusal of medical involvement and fatalistic behaviour amongst others. This research will explain those psychological reactions as encountered throughout the interviews.

6.2 Fear and anxiety at initial diagnosis

Being diagnosed with prostate cancer comes as a shock to many men, this is because many of them did not anticipate it. The causes of prostate cancer, other than genetic factors are relatively unknown and worse still, it presents with no visible or easily identifiable symptoms. Therefore, being diagnosed with prostate cancer where there are no extenuating circumstances identifiable, sends men into a panic mode. However to cope with the news some men show initial denial, a defense mechanism to help them cope. Initial denial refers to the initial rejection of the news that a man has prostate cancer. This is mainly because the men are in shock.

In my interaction with men through interviews, focus group discussions and support group meetings, men admit to have denied the news when they were first diagnosed. They were in total disbelief so much so that some of them considered the diagnosis 'unfounded'. It was difficult for them to readily accept that they had prostate cancer. To these men, they had no symptoms, visible at the time; rather they had other problems to deal with. For instance, Mpho had a hip problem when he got diagnosed. To him, it was a strain he picked up whilst playing golf. In his defense Mpho chose to believe that he did not have prostate cancer, the pain was going to heal eventually if he stopped playing golf for a while. It so happened that the pain stopped in the hip but weakened his legs which was when he then chose to go for another test, and then a final one to confirm he actually had prostate cancer. Similarly Stan also had a hip problem that he was battling with. He had at the time not established the cause but had attributed it to a strain he picked up at a golf day. Golf in this regard, for both these men, seems to be an activity they chose after retirement from active duty and as such they found it believable to make an excuse for it.

In another example, when Steve was diagnosed he did not believe it. The doctor at the time had told him soon after diagnosis that he had to go into surgery if he was to live. Steve did not believe any of that and instead flew overseas to Canada for a holiday. He waited for two years before he would go to another doctor for screening. This waiting speaks volumes of this man's attitude towards looking after his own health. Other than the fear and denial that he had prostate cancer, it is possible that he might not have known the consequences. Since most men in this study suggest to have known nothing about prostate cancer until diagnosis, the case might be that there was insufficient information for him to make a decision at the time.

Fear tends to be central for men in how they react to diagnosis. The same was also true for Stan who stated that,

"There's a fear that goes through you when you are told you have cancer. It's so hard in the beginning to think about anything but your diagnosis. It's the first thing you think about every morning". (Interview, Sandton, 2013/07/12)

This quote from Stan indicates that anxiety begins to grow as men seek answers as to why they have prostate cancer. There is a fear that hits them about the cancer. They sit and dwell on it, wondering what is going to happen next. It's a reality that begins to shatter their world and the lack of answers increases their anxiety. So they in turn beat themselves up. If left unattended, this fear marks the starting point of behaviour that is detrimental to a man's well-being. In case there are no immediate avenues for support, like support groups' men often find themselves stuck. In this case there have been no support groups for men with prostate cancer.

The lack of such support and the fear of death allowed some of the interviewed men to embrace their fears. It came to a point where the thought of death just became a reality some men entertained. For instance, Stan said,

> *"…there's nothing fair about cancer and no one deserves to have it. A cancer diagnosis is hard to take and having cancer is not easy. It's especially hard to face your own mortality".* **(Interview, Sandton, 2013/07/12)**

Prostate cancer like any other cancer, is difficult to live with. The news on diagnosis that one has prostate cancer brings questions about the end. Men start thinking about the day when they finally leave the earth. Feelings of fear and anxiety crop up. There is the fear that one is going to die and their death is only a matter of time. Even though research by Bach, Schrag, Brawley, Galaznik, Yakren, & Begg, (2002) has pointed out that men in most cases die with prostate cancer and not

of prostate cancer, just the knowledge that one has cancer, builds enough anxiety and fear to keep men stuck on thoughts of the end.

Some people fear cancer itself, while others may be afraid of cancer treatments and wonder how they will get through them. The fear of pain and suffering is one of the greatest fears people with cancer and their loved ones have. During the focus group interviews and also in the support group meetings, the participants indicated that they feared that their bodily functions were going to degenerate and therefore put their families through trauma. One gentleman, Peter's response at the time stood out. He said,

> *"you got to go through this with your wife. I think its lot tougher on her; first of all she's a lot younger than me and in fear for her… l do raise the point quite often with my wife and she always says it's not affecting her. But l am aware that it could be affecting her."*
>
> **(Interview, Randburg, 13/08/16)**

From this, one can also see that there is a sense of helplessness in the men that get diagnosed. They look at themselves critically and realise that their lives are going to change. The lives of their significant others also change and they cannot do anything about that. Instead they battle with the fear of going through pain and an eventual death.

Being diagnosed with prostate cancer make some of the men wary of death. These men therefore choose treatment decisions that reduce the chances of dying of prostate cancer. In a way, they ignore the side effects of treatment, for instance permanent impotence. To illustrate this point, in an interview with Rodney, he pointed out that,

> *"For all of us, whatever gnaws at us is important. Probably we all, at times, use the strategy of bucking ourselves up by thinking of how things could be worse: I think of it as*

the cemetery avoidance strategy (At least I am not dead and buried). I'm still alive & well". (**Email story, 13/07/16)**

Being diagnosed with prostate cancer thus has a death warrant being shown to men. So in a way of avoiding death, they engage in different kinds of treatment to save their lives. After all, for some life is more important than having sex

Some men find accepting that they have prostate cancer difficult. They take an extreme stance that they are not going to admit it and therefore not seek treatment. Studies on HIV illustrate that denial is significant in the way men approach their diagnosis (Skinner & Mfecane, 2004). Similar inferences can be made in cancer as it poses a similar chronic condition, sometimes with a more urgent threat to life than HIV. Eventually these men die uneventful deaths riddled with suffering and pain. In instances when family intervenes, it is usually too late. A case for example, is of two gentlemen in this study who speak of their relatives who hid their illness until it was too late. When some family members took them to hospital to get checked they had become too ill. Soon after diagnosis, the men passed away. In an interview with Kgalema, he said,

"I used to know this old man, my step brother not so long ago. He was sick and used to say that he does not understand why he was still alive. He was a man only because he wore trousers. He could not have erections and could not pee sometimes though he regularly wet his pants. When the doctors finally diagnosed him of prostate cancer, he did not last a few weeks." (**Interview, Soweto**)

This illustrates that when some men persistently deny that they have prostate cancer, they do not react until it's too late. In the case above, had the brother not intervened, no one would be sure of

the cause of the death. A post mortem could surely have identified the cause of death, however, this could only be what killed the man and not necessarily what he was suffering from.

Given the pretext that men in general seek health/ any help infrequently, the above can be used to assert the reasons why some men choose to seek health help infrequently. Firstly, there is the fear of going through pain and facing an inevitable death and secondly the belief that diagnosis could have been wrong resulting in a wait and see attitude.

6.3 Depression and delayed treatment

As men try to figure out the ins and outs of cancer, that is, the cause, the treatment and how their illness would affect their family, and life in general some men end up depressed. Depression has been defined as a state of low mood and aversion to activity that can affect a person's thoughts, behaviour, feelings and sense of well-being. Depressed people feel sad, anxious, empty, hopeless, worried, helpless, worthless, hurt or restless. In the end they may lose interest in activities that were once pleasurable, experiences of loss of appetite or overeating, have problems concentrating, remembering details or making decisions (Salmans, 1997). Some may start to ask if they could have noticed the symptoms earlier, or wonder what they did that may have caused the cancer. Some wonder if they were exposed to something at home or work that led to the cancer or worry that other members of their family will also get cancer. This is because the cause for most cancers is not known but a few are known to be hereditary (passed from a parent to a child). This means if one family member develops it, others in the family may have a higher risk of developing it, too. This can cause even more concerns for the person diagnosed with cancer. Consequently they feel hopeless as they see cancer as a roadblock to a life full of health and happiness. It's hard to feel positive and upbeat, especially if the future is uncertain. Just thinking about treatment and the time

it will take out of one's life can seem like too much to handle. A depressed mood however is not always a psychiatric disorder. It may also be a normal reaction to certain life events, a symptom of some medical conditions or a side effect of some drugs or medical treatments (Rashid & Heider, 2008)

The interviews confirm that the men experience some of the moods described under depression. In most instances there seems to be no one to talk to who may seem to understand all these feelings. The absence of someone to talk to brings notions of vulnerability into question. Notions of vulnerability then are a function of what one's culture is, how vulnerability is expressed in such a culture, when is it acceptable to express vulnerability and to who. These notions of vulnerability, raise an important question, can men be vulnerable and express vulnerability? To touch base briefly on the subject of vulnerability, one can notice that most African cultures do not expect men to be vulnerable, hence when men want to express vulnerability, the entire society doesn't know how to deal with it. Therefore the men who are suffering from prostate cancer find themselves isolated. This isolation adds to their depression

The depressive mood may add up to building deviant behaviour in some men. This form of behaviour where some men persistently deny having prostate cancer leading to refusal of medical involvement confirms why men in general do not seek health help as often as they should. Research as pointed out in the literature review confirmed that men do not seek health help, or help in general as much as they should and this could be a pointer to understanding men's health-seeking practices.

Men that react to the news of their diagnosis with a depressive attitude are less likely to do anything about it immediately. These men constantly deny that they have prostate cancer and therefore take their time to seek treatment. For instance in one interview, when Stan was diagnosed with prostate

cancer, whilst suffering some hip pain after a golf game, he refused to acknowledge that he had prostate cancer. Instead he chose to go to Canada for about two years. So between the time he was first diagnosed till the time he got treatment, two years had lapsed. He said,

> *"I would say 2 or maybe 3 years l don't know to be honest with you . A long time."*
>
> **(Interview, Sandton, 2013/07/12)**

The danger in such a practice of delaying health-seeking practices is that when one finally decides to seek treatment, the disease would be at an advanced stage, where medicine might not cure but can only be used to manage the disease. In this instance, when Stan was diagnosed the second time, two years after his initial diagnosis, the cancer had metastasised into all his bones from the collar bone downwards. The treatment he receives is only to manage the pain that he goes through occasionally. He has been put on hormone treatment which numbs his emotions and the side effects have been extremely uncomfortable.

Instead of taking initiative and seeking beneficial health help, some men find it difficult to express vulnerability. The question of what's normal in the contemporary society determines the attitude that some men carry around in their own lives. Understanding that men do not represent a homogenous group (Skinner & Mfecane, 2004), there is a chance that while some men give up others seek help and continue to lead normal lives. Questions of what is regarded as normal for men in different societies are a significant consideration for men as they seek to express vulnerability. In this case prostate cancer affects a sexual organ while sex organs are taboo topics in certain cultures. For example in traditional African societies, topics about sexual organs are restricted to particular events where there is a ceremony involved, like the initiation among the Xhosa, or virginity testing for Zulu women in rural KZN (Ratele, 2008). Therefore when some

men who follow such traditions are affected, they struggle with disclosing their problem as it would be such an unmanly thing to do in the cultural confines.

Behaviours that can be used in the demonstration of hegemonic masculinity include the denial of weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, dismissal of any need for help, a ceaseless interest in sex, the display of aggressive behaviour and physical dominance (Mankowski & Maton, 2010). This is challenged by the individual experience of men who then value the input of others in their lives. The men affected with erectile dysfunction and incontinence face a tumultuous task of holding their fort together. They constantly battle emotions of not being manly enough. For instance, in trying to keep it to himself Dennis had the following to say,

> *"My wife and I finally reached a point where we could rationally talk about the initial onset of my impotence. I think that she was surprised to learn that I had been going through emotional hell because I recognized that I was having some difficulty, and I didn't want her to know it, so I compensated in ways which she totally misread*." (**Email story, 13/07/20)**

The above citation is important in trying to understand vulnerability in men. Often questions that are unanswered about men's vulnerability are whether men can be vulnerable and whether it is acceptable to express that vulnerability? Vulnerability has been defined as referring to the inability to withstand the effects of a hostile environment. Vulnerability is thus a concept that links the relationship that people have with their environment to social forces and institutions and the cultural values that sustain and contest them (Rick, 2003). In trying to avoid coming over as vulnerable some men engage in compensatory behaviour. Compensatory behaviour in this case

refers to all the activities men engage in, in trying to hide their pain. In the email story Dennis said that,

> "*One thing I remember is cutting down on frequency of sex, hoping I would be able to perform better if I performed less often. She was aware of the reduction, and her own self esteem took a beating because she felt that I no longer was finding her desirable."*
> (**Email story, 13/07/20)**

He thought that he could come up with a solution to fix his erectile dysfunction by reducing the frequency of sex. However, he soon learnt that he never was going to get an unassisted erection if he ever was to regain any erections.

These compensatory behaviours are reinforced by men who hold a similar worldview to Dennis that maybe it wasn't his fault, after all. It could probably be the wife's fault. His family doctor is said to have told the wife to lose weight so she remains attractive to Dennis and help him lust for her and maybe have an erection. In the interview Dennis disclosed that he developed,

> *"… courage to casually mention the problem to my family doctor, who assured me that it was all in my head, and just relax and it would all be better. Then he took my wife aside and suggested that she might try to lose some weight!"* (**Email story, 13/07/20)**.

In trying to understand why some men would reinforce such ideas that it is probably not a man's fault, one should get to understand the attitude of men that practice hegemonic masculinity. In a study done in rural Nigeria about infertility, for instance, (Adejimi, 2013**)** found that the women were being subjected to all kinds of abuse. Doctors in the area would secretly advise these women to have sex with someone else and then the husband wouldn't know but raise the child as his own.

The point is that men that perform hegemonic masculinity often find it unacceptable that men have problems, especially with sex. Brannon, (1976) argued that underlying social problems are social expectations and norms, supported by social and organisational systems and practices that expect boys and men to reject or avoid anything stereotypically feminine, to be tough and aggressive, suppress emotions (other than anger), distance themselves emotionally and physically from other men, and strive toward competition, success and power. Normative masculinity operates when a male observer sees what most men are doing in a situation. For example norms such as the idea of men being strong and independent suggest that men should not have problems and may foster perceptions of non-normativeness when problems do occur. According to Morris and Miller, (1975) this is especially so if other men are perceived as unanimous in their attitudes. A large number of men express similar attitudes; as such men see themselves as quite similar to members of their reference group.

These men face challenges in accepting their loss like with any grieving period. In one of the interviews Dennis said,

> *"My lament was for the whole package of losses which going limp seems to entail. I guess I mean the feeling of loss in general, with its sadness and frustration".* (**Email story, 13/07/20)**

Ron concurred by saying,

> *"Recognizing and feeling the loss, with the anger and sadness and frustration, doesn't mean you are caving in to negativity or paralysis (although you probably go through periods of feeling that way). You can feel all those things along the way, I think, and still get on, most of the time, with the process of 'getting on'".* **(Email story, 13/08/01)**

In this state some men start to compare what they would have rather lost. In any case they console themselves that maybe it is better to be unable to have sex than to die. So the treatment options subject men to choose between dying and erectile dysfunction. In the heat of trying to do what is best, some men were unaware of the side effects of treatment. This loss is experienced in many other ways, but when men express that vulnerability, it becomes disheartening. Another example to build from is the following when Dennis said that,

"I miss the familiar easy sexual relationship with my wife. I miss waking up with an erection, ejaculations, getting little signals & messages at random times during the day, getting bigger responses from riper thoughts & fantasies, being able to read alone in bed, idly touching myself & getting a response. I miss masturbating. I miss all of it. There is a lot that is gone." (**Email story, 13/07/20)**

6.4 Reactions to prostate cancer treatment

When one has been diagnosed with prostate cancer, the next thing which is equally daunting is the treatment. The different types of treatment explained in chapter four however elicits different types of reactions. The reactions can be classified into two physical reactions, where the body reacts to treatment and the consequent side effects; and psychological reactions where people react with feelings to the changes in their bodies. The psychological reactions include dealing with loss and grief and anticipatory anxiety.

6.4.1 Urinary incontinence, erectile dysfunction: Physical experiences of men with prostate cancer

There are a range of physical changes that men who undergo prostate cancer treatment face. These changes are dependent on the stage of the cancer when diagnosis occurs and the subsequent

treatment that one undergoes. In this research all the men that participated had stage III prostate cancer. Stage III is where prostate cancer has spread outside the prostate, but only barely. Prostate cancer in stage III may involve nearby tissues, like the seminal vesicles (Sripasad, Fenely & Thompson, 2009). All these men were put through hormone treatment, some received chemotherapy, others radiation, others a combination of surgery and chemotherapy. These types of treatment are explained in detail in chapter 4.

Prostate cancer treatment has a lot of complications. For instance, in surgery there is a bundle of delicate, easily damaged nerves that runs through or near the prostate. Even the most skilled and careful surgeon may not be able to avoid complications (Sripasad et al., 2009). One possible complication is erectile dysfunction. Some surgeons use a nerve-sparing technique. There is, though, no guarantee that erectile dysfunction will not occur and nerve-sparing surgery may not be an option for men with tumours that lie close to the nerves. It also may not be an option for men with large tumours. Unlike erectile dysfunction that occurs on its own because of different factors, usually early ejaculation or late ejaculation, anyone treated for prostate cancer does not have an erection at all (Sripasad et al., 2009). The hormone therapy suppresses the possibility of a man having an erection by suppressing the male hormone testosterone responsible for an erection. In a worst case scenario surgery severs the nerves responsible for enabling an erection.

Common complications of radical prostatectomy include urinary incontinence[3] - the involuntary leakage of urine from the bladder - and fecal incontinence[4] (Scher et al., 2012). These complications may improve over time. They may even disappear completely but some men continue to have problems indefinitely. Research shows that about 25% of men have urine leakage

[3] Urinary incontinence; the involuntary leakage of urine from the bladder
[4] Feacal incontinence: the involuntary leakage of stool from the rectum

after surgery and need to use absorbent pads or disposable absorbent underwear for up to six months after surgery (Scher et al., 2012).

After two years, less than 10% need absorbent pads. In severe cases, some men may need surgery to support the sphincter muscles that control the release of urine (Scher et al., 2012).

In this study almost all the men have suffered both, erectile dysfunction and urinary incontinence. Erectile dysfunction and urinary incontinence present a huge challenge in men's lives. For those that are or have been in sexual relationships where they regularly or occasionally have sexual intercourse, erectile dysfunction is a huge nightmare. They are unprepared for it and it is difficult for them to make their partners understand when they are still battling with understanding what is going on. In an interview with Pule, (a man in his late 50s who has been living with prostate cancer for five years at the time of the interview) he said,

> *"l think sometimes it is affecting because on this thing now l have learnt a new thing that once you diagnosed go to the hospital and then they inject you with hormone therapy and that thing changes your life, even if you at home and then you find out that you change you become slow. Sometimes you cannot do it [sex] and that is not nice to a man once you have a woman next to you, you need that …[erection]….."* **(Interview, Dobsonville, 13/07/19).**

In another interview Stan said,

> *"You know there as l said you have zero sexual feeling, you know playing with a sexual toy would be like drawing with crayons on a piece of paper. It's just the same feeling there is no feeling".* **(Interview, Sandton, 13/07/12).**

Men have since time been diagnosed with illnesses of different kinds. However, for most of the illnesses men are diagnosed with, only a few are specific to men. Prostate cancer is one of those peculiar to men and thus has huge ramifications. Not only does it threaten the core of manhood, it also poses a significant threat to the perception of manliness for most men. Men's definitions of manliness including virility and sexual prowess are put into question, and in some instances disappear. The ramifications of prostate cancer diagnosis extend beyond physical symptoms, to mental well-being.

Prostate cancer diagnostic tests present a challenge for men, who are overly sensitive of their bodies and who detest homosexuality. Among the diagnostic tests, the Finger test, i.e., sticking one's finger up a man's anus, is detested. Dr Ntsiki from Charlotte Maxeke hospital confirmed that the finger test is much easier to determine whether one has an enlarged prostate or not. It is according to her, cheaper and more effective. Sharma, Kerr, Kawar and Kerr (2011) found that the cost of screening for prostate cancer is greatly reduced by employing physical non-expensive methods like the digital finger exam. However, some men feel violated but because that's an easier way to diagnose, it is done anyway. These men regard this test as an act of homosexuality where they are penetrated from the anus. They therefore detest the practice. Pule argued the following on the matter,

> *"….isn't there a way to diagnose men, that does not involve a finger being stuck in your anus? Very soon, they will be sticking other things… its very disgusting and I'm not homosexual."* **(Interview, Dobsonville, 13/07/19).**

Manhood is highly regarded in discourses of manliness, thus anything that affects men's sexual organs, becomes a significant threat to manliness. Furthermore, the perception of manliness is also

preserved differently by diverse cultures. For instance, among Black men interviewed for this study, manliness is an equivalent to being a sexually functional being. Sex organs are therefore a signifier of fundamental basics of being a man. Silence surrounding sexual organs or sex within the black African cultures reinforce the perception that one shouldn't talk about sex except to their sexual partner. For instance, in the interview with David, he indicated that,

> *"You know what about men, they are so difficult you can stay with your wife for more than 30 years but never has she touched your private part the men are so difficult. Even today my wife doesn't know about my private part we can talk about it but l can't allow her to touch it in our culture."* (Interview, Dobsonville, 2013)

Moreover, the anus is despised and very rarely does anyone (interviewed) mention it as a sexual organ. However, the act of pushing a finger up the anus represents a form of violation and carries with it some form of humiliation (Eisler, 1995). All in all, the man involved is very vulnerable. In a support group meeting with black African men, the men concurred that they would not go through such humiliation if they had an alternative. In the support group, issues that were discussed mostly surrounded areas of discomfort when men were diagnosed with prostate cancer. The digital rectal exam (finger test) stood to be the most controversial, where men who participated felt violated. In their cultural knowledge of medicine, a man's anus was never to be touched neither was it an avenue to insert anything. It not only contradicts their beliefs, it also is despised, considering that homosexuality is still not accepted in some circles, particularly among Africans who associate it with Whites (Kimmel & Aronson, 2004).

This occurrence is in line with what researchers have found out about men already. In Cornell's writing, she points out that there is something about being male that prevents men from expressing

vulnerability (Cornell, 2001). Notions of normativeness spread throughout the male species reinforce being strong and tough and therefore their behaviour follows popular norms. In this instance where dominant norms prefer heterosexuality, it is difficult for any man who performs dominant masculinity to cede to actions that question his preferences. The finger test therefore stands as a pertinent test to men who disregard homosexuality as a sexual preference. therefore, the digital rectal exam (finger test) subjects these men into experiencing sensations that are against their values thereby becoming an obstacle.

6.4.2 Urinary incontinence and erectile dysfunction: psychological effects on men with prostate cancer

Urinal incontinence and erectile dysfunction tend to have lasting emotional effects on men that have undergone any treatment for prostate cancer. Urinary incontinence and erectile dysfunction are the major changes that have negative ramifications on ideas of manliness based on virility and sexual prowess. These conditions challenge the ability of a man to function independently and therefore affect his ability to assert manly behaviour through maintaining an erection as well as the ability to urinate. The men that suffer from incontinence therefore have an incessant fear of not being man enough.

Interviewing men on how they have been affected by prostate cancer treatment, especially on their ability to orchestrate sex, these men showed fatal resignation. In one interview Rich, a 57 year old man who went through nerve sparing surgery to remove the prostate was married and lived with his wife. Rich also went through surgery in 2006 and only regained un-aided erections 5 years

later, in 2011. At the time of the interview he was happy he had natural, though infrequent erections however he still misses certain parts in the sexual encounter. He shared his experiences thus said,

> *"Each male who has undergone Radical Prostatectomy (RP) will tell you that sex after (RP) is not the same. Period'. Immediately following RP, my concerns were fourfold:(1) the pathology report (2) the catheter and, once that was removed, (3) incontinence, and (4) the apparent shrinkage in the size of my penis*." (**Email story, 13/08/06)**

For the first time in his life, Rich had to face incontinence as well as the reality that his penis had shrunk in size. These concerns are indicative of the internal prisms of fear that develop as the reality of radical prostatectomy[5] sinks in.

Incontinence in its own negatively affects men's well-being. They cannot go around with their daily business as freely as they used to since they cannot control their urine leaks. They cannot survive in comfort. The urine leaks are inconsistent and sometimes can be sporadic. However, they are untimely and unpredictable. Men that suffer from incontinence therefore have to watch how much water they drink, where they are going, how long they will be far from an ablution point and how to regulate their sleep, since urine may come out at any time. Men therefore are restricted in performing their daily routine because it is an embarrassing moment when one wets their pants, especially if it was in public. Men that suffer from incontinence usually have a catheter placed in their urethra with a bag for the urine, so as to avoid urinating on themselves, (Sripasad et al., 2009). However, such experiences have been found uncomfortable by some men hence the discontinued use of catheters for the majority of men.

[5] Radical prostatectomy: is an operation to remove the prostate gland and some of the tissue around it. It is done to remove prostate cancer.

Several men in the interviews indicated that they have been suffering from incontinence for a while. The following quotes from Rich illustrate the point:

> *"I was able to endure the catheter with very minor problems; when it was removed (exactly two weeks -- to the hour -- after surgery), I was 90% incontinent… I did leak a fair amount of urine… . I think the urine leakage disturbed me,"*. **(Email story, 13/08/06)**

It is evident that this incontinence was unfamiliar and unprepared for. When something is unfamiliar, men do not know how to handle it. David had this to say,

> *"… was in the morning l was going to Joburg for the treatment l just came out from the taxi in town now then comes that mind, now I need to go to the toilet. Then l had a problem there l looked for a place then there was a building l went there and asked a man there, Hey man am like this…(incontinent).. man please help me otherwise am gona have a problem, he pointed to the toilets. Once l got to the door…[I was] … already wet wet wet wet. Then l was Oh, My God, what am l gonna do now? it was my first time to become that weak . I was wet and l went to the guard and said, Hey look what happened l won't be going out now just give me a chance so that l can dry a bit and he gave me that chance l was dry, then l went to the hospital".* **(Interview, Dobsonville, 13/07/17).**

The problem of incontinence persists in these men's lives. Pule said,

> *"sometime when l wake up from bed l have urine in my bed… my wife is understanding and she doesn't react badly"* **(Interview, Dobsonville, 13/07/19).**

This occurrence is not an isolated event. Kgalema shared his experience saying,

> *"Let me tell you about the incontinence. I experience very slight leakage if I lift something heavy (like lifting a heavy box of books from my desk to the floor). The other times I leak are sometimes when I have an erotic thought (very slight leak), sometimes during foreplay (very slight leak), and sometimes (about half the time) when I reach orgasm."* (**Interview, Orlando East, 13/07/25)**

In another interview, Pule said,

> *"Now the problem is the urinating if the urine starts coming it comes out on its own, it leaks quick you see. l remember one day l was doing a delivery l urinated myself in the car my heart was so so and l said no no no ,l must wait until l dry myself".* **(Interview, Dobsonville, 13/08/14)**

The above quotations are indicative of how men's ordinary lives are affected. They are not free to be themselves without worrying what will happen to them, they in fact are always anticipating the urine hence, their joy comes only when there is a bathroom nearby. The fact that they urinate even in their beds, has negative consequences on their self-esteem. In most of the interviews conducted, one thing that these men emphasised about being a man was control. They said that a man is in control, of his life, of his body, of other people's lives. Incontinence challenges that, men can't control their penis and passing out urine. Steve said,

> *"Boys learn pretty early on that a penis has a mind of its own…Of course, later on there are the opposite concerns, when I learned that it doesn't always do what I want it to do, or as much, or as often, or as well, or whatever. Don't you think it is ironic -- considering how the penis and erections are so often connected with male power, control, etc. -- that a penis is the one part of a man's body (and we learn this early on) that he has little*

control over. It hadn't really occurred to me until after the surgery" **(Inteview, Soweto, 13/07/12)**

It seems that socialisation of men begin early on when they are boys, being distinct and remorsely powerful. Images of having a penis are synonymous with having power and control. Consequently it is thus a man's responsibility to chase sex, initiate it and perform extremely well, (Governder, 2012). When the culturally prescribed standard for sexual performance is not met, this loss "extends to the entire male-body, disabling him, de-sexing him, and submitting him to powerlessness—to 'impotency' (Brown, 1995). Therefore a man experiencing sexual difficulties often feels that his masculinity, and not merely his sexuality has been threatened. There are no suggestions of how a man can thus function normally when erectile dysfunction occurs.

Apart from the incontinence, erectile dysfunction is yet another great scare. Men that have had no erection problems in their lives prior to surgery find the inability to have an erection emasculating. Sex for, many had been something that ravished their minds since teenage years. They can still imagine how in teen years, having an erection even at random, sometimes inappropriate times, was ideal. Having an erection then and until recently has been an indication of how manly they have been throughout their lives. It is something they take pride in. As seen in an interview with Rodney, a man living in Cape Town. Rodney has had surgery as treatment for his prostate cancer. He suffered permanent loss of erection. Rodney, recalled memories from the past where,

"..there are memories of being nervous as a kid, before a physical exam , that 'it' would get hard when the doctor checked me. And what about, later on, knocking books off my desk to stall before standing up and having the lump in my pants revealed for all to laugh

at? Or dancing & having her notice it? Or making out on the couch and having to leave unexpectedly because there was this sudden puddle in my pants? (Only twice, much to my adolescent regret.) Or wet dreams? (Only 3. Damn! Even more regret". (**Email story, 13/07/16)**

Dennis, a man living in the Western Cape has also had surgery as treatment for his prostate cancer. He suffered permanent loss of erections. He shared a similar regret about the inability to have an erection. He said,

"Imagine now: the music is erotic, the girl undulating in front of me and I sat there unaroused. I remembered my younger days when the scent of a woman would bring me to attention without hesitation. The slightest erotic touch would arouse me into a frenzy.". (**Email story, 13/07/20)**

This inability to get aroused after radical prostatectomy continues to boggle minds for many prostate cancer survivors. Even when there is hope for them to build their relationships in other intimate ways, there is very little that can be done to regain their erections. Researchers have previously indicated that men are goal oriented in sex and their ultimate goal is penetration and a subsequent orgasm (Munatswa, 2013). Therefore the view of sex has been genitalised to mean that if there is no penetration then no sex has occurred. In this light, some men experience extreme difficulty in mindset shifting. An example is Ron who said,

"I am permanently impotent. I am unable to achieve a natural erection no matter how great the stimulation, and there is no possibility that at some time down the road the

*nerves will be healed. I can't get it up, can't keep it up. I'm losing my manhood!"***(Email story, 13/08/01)**

Ron is a man living in Northern Johannesburg, who was diagnosed with prostate cancer about 12 years ago, went through surgery, and has been impotent since then. He is married with children and a grandchild. He did not share his age. The statement that because he can't get it up hence losing his manhood is consistent with what literature says on erectile dysfunction and masculinity. In a discussion with Dr McIntosh, a sexologist, on how men experience loss and discomfort when they are experiencing erectile dysfunction, she indicated that the penis' ability to erect and penetrate is significant towards constructing men's identity. She added that boys learn early in their lives that what distinguished men from women is having a penis, more interestingly that the penis was powerful and could be used as a form of control. So by losing the ability to have an erection, men lose that sense of control. Therefore, they just become worse than women, in that, not even their erotic feelings can save them (McIntosh, field notes, 2013).

Perceptions of what is normal and what is the standard for all men have a lot of ramifications towards each man's interpretation of his situation. This follows that masculine norms stress values such as "courage, inner direction, certain forms of aggression, autonomy, mastery, technological skill, group solidarity, adventure and considerable amounts of toughness in mind and body" (Connell, 1995, p. 4) The opposite can be expressed by terms such as "unmanly''. Kimmel, (2000) suggest the health behaviours and beliefs that people adopt simultaneously define and enact representations of their identity. Popular masculine norms therefore require, for example, that men suppress their needs and refuse to admit or acknowledge their pain. However, the side effects of prostate cancer treatment expose them to feelings of vulnerability, which present a challenge to the norms.

Whereas, researchers on masculinities have emphasised that men are a reference point for other men, some researchers have also emphasised the importance of women in the socialisation of men. In her essay on mothering Nancy Chodrow, (1978, 1999), suggests that women have the capacity to reinforce and reconstruct desirable behaviour in their interaction. In the light of that statement, it is possible that women have a significant contribution in the socialisation of men. So when men face problems they turn to their wives for support and or validation of their actions. These women become significant in the way that men can accept their situation or remain in denial.

Interviews conducted illustrate that the men turned to their partners. The following quotes attest to this point. In an interview with Steve, he said,

> "*My wife is smart, savvy, sympathetic, & supportive, yet I knew I wasn't getting across what was going on. At first I was only able to say to her that I was missing erections & our old sex. She did/does too, but we are working our way through that (different) problem. So it didn't seem to be such a large issue to her."* **(Inteview, Soweto, 2013/07/12)**

In another interview Peter concurred that,

> "y*ou know at least l am thankful to my wife because she took it and then she does understand it"* **(Interview, Randburg, 13/08/16)**.

From the above quotations it can be deduced that representations of masculinities are performed in liaison with women. Men thus are cognisant of the fact that to accept their condition, they thus need that validation that it will be alright.

Significant to the above is the realisation that men who suffer from erectile dysfunction experience some levels of loss and grief. In this study men expressed this loss very articulately. In the email from Rich, the following was expressed,

> *"First and foremost, as I stated earlier, sex will never be the same. You have to accept that and move on. I miss the ejaculate and the feeling that went along with it. But I realize that with my prostate gone, the ejaculate will never come back. Those days are over".* (**Email story, 13/08/06)**

In another interview, Ron said,

> *"Now here I am with more concentrated stimulation than any man could dream of and I got no physical response at all. What a shame. With that thought in my mind, I then reflected upon this strange turn of events and wondered if I should take 100mg of Viagra and come back in a hour. Amazingly, I was able to walk out of the room without carrying something like my book bag which I did in high school in front of my pants to hide the bulge I would get from fantasizing about the girl who sat just across from my desk in English class. Ah, those were the days.."* **(Email story, 13/08/01)**

6.5 Conclusion

There is evidence in this chapter that diagnosis and consequent treatment greatly affects men both physically and emotionally. The sudden loss of control of bodily functions, represent a physical challenge with disparaging emotional ramifications. In this instance urinary incontinence and erectile dysfunction become two important bodily changes that contribute largely in the reconstruction of masculinity and consequent emasculation of men. On the other hand there is a fear of dying that persists from diagnosis. Men diagnosed with prostate cancer are highly alerted

to dying, since most equate cancer with a penultimate death. The ramifications of having such thoughts include constant mood alterations often leading to depression and in other instances, denial of treatment. Depression sometimes has observable symptoms and can be managed, whilst denial of treatment has greater health risks. These risks include worsening of the condition, that if and when the men decide to get treatment, it might have advanced. Evidence from the interviews suggests that the longer the delay, the worse the condition gets.

Chapter 7: Conclusion and Recommendations

7.1 Conclusions

The different chapters of this dissertation canvass a picture depicting the complexities in men's health. The first chapter introduces or rather problematises the context in which this research was set. It argues that there are disparities in issues of health access pertaining to prostate cancer and more importantly for Black men. Even though, in the research, White and Indian men were included, it shows that Black men are at the periphery in prostate cancer care. The first chapter also introduces the concept of masculinities, paying attention to the plurality. Where lay language categorise and stereotype men into one category, or rather a homogenous group, this research points out the plurality in men. Thereby introducing a relatively new understanding of masculinities suggesting that as an identity, men perform different masculinities depending on their situation. However, prostate cancer has a marked effect on those men that perform hegemonic ideals, where they idealise what a man should and shouldn't be. These perceptions of what a man should/shouldn't be are important signifiers of men's attitude towards their own health.

The second chapter builds from this understanding and attempts to unravel the context in which these claims can be asserted. Chapter two is an attempt to bring various perspectives in research on masculinities and health-seeking behaviour and the chapter defines and discusses masculinities. It also discusses the position in which masculinities affect health-seeking behaviour, pointing to research that has been done that shows that some masculine identities are detrimental to the beneficial observance of health-seeking practices. Research that has been done on men and women, focusing on frequency of using health services portray men as marginal users of such facilities when in comparison. This chapter further argues that there are different stereotypes in

society that have been used almost as prescriptions for men's behaviour. Such include the persistent denial of weakness, the avoidance of showing negative emotions that may be depicted as weak, such as shedding tears and the use of over the counter medicine as opposed to going to a general practitioner (GP). This chapter continues to discuss that as a result there has been no language permissible for men to express vulnerability. So when men are faced with illness, they would try the 'manly' thing. The result is that when they do seek help, the illness is quite advanced. In areas where disease is considered taboo, particularly the sexual organs, the ramifications are beyond simple. Things get even more complex in talking about the disease, treatment and management as well as palliative care. There is often an absence of support mechanisms to facilitate the continued psychosocial healing for such men.

The third chapter details the research methods employed for this dissertation. This chapter delves in detail into the methods of data collection, the selection of the sample, the data analysis process as well as the ethical issues encountered. Being a qualitative research, the chapter discusses purposive sampling, paying attention to sample selection as well as the interview techniques. Given the complex nature of masculinity research, the sample consisted of Whites, Indians and Blacks, even though the emphasis was on Blacks. The unavailability of a bigger sample required that the sample selection criteria be broadened in so far as getting participants was concerned. It also provided an avenue with which to compare the disparities among races.

The research used data collection techniques as the one on one interview, focus group and support group meetings as well as training on cancer care support. Using multiple techniques was quite important in so far as gathering data was concerned. It was somewhat difficult to ascertain availability for participants therefore, each of the techniques was unique to the setting. The availability of participants determined what technique was to be used. Ideally, one on one

interviews are more preferred, but it was difficult to get those in time. The use of multiple techniques also had its own ethical challenges. For instance the focus group and support group meetings. Where, in one on one interviews, I could guarantee confidentiality, this was quite difficult, even though during the meeting, I would emphasise it. The extended care in the support group also allowed the participants to relate more with me as the facilitator and not the researcher, which allowed them to confide in me beyond the scope of the research.

The following three chapters give perspective into the research questions. They shed light on the experiences of men with prostate cancer and continue to confirm what the literature in chapter two discusses. Men's health issues and experience form a complex dialogue, which spins across various disciplines of reason. Chapter four, details what prostate cancer is, it explains the treatment as well as discuss the current issues in prostate cancer care. The major thrust of this chapter is giving an account of what prostate cancer is and what kind of treatment is available as well as some of the side effects to be expected. Surgery and hormone therapy seem to have lasting effects on men, with some never regaining natural erections for the remainder of their lives. Urinary incontinence is common during treatment as well as erectile dysfunction. Other issues discussed included the debate on toxicity of chemotherapy, the lack of funding in prostate cancer care and research.

Chapter five speaks to the complexities in men's health. These complexities make it difficult to explain men's health practices. For instance some men act based on perceptions of normality. It is difficult to explain normativeness except when it is embedded in context. This has the same difficulty in that it homogenises men, when men perform different masculinities. Diagnosis with cancer is mixed with different reactions, some prompting urgent medical care, whilst for some, periods of extended vacation in denial. Knowledge of the disease also influences the choices. It

has been evident that public knowledge on prostate cancer is minimal, with some of the participants only knowing about it at the time of diagnosis. This subsequently influenced the treatment choices.

Chapter six delves into the psychosocial experiences of men with prostate cancer. The treatment choices often result in a range of single or multiple side effects that men grapple with emotionally. Erectile dysfunction is one of the permanent side effects with the capacity to emasculate men. The sudden change in these men's lives had significant ramifications on their lifestyles. For those married, sexual intercourse greatly changed, in some instances became non-existent. A range of emotional challenges have been encountered, including, depression, fear and anxiety. In essence diagnosis of prostate cancer opens up a chapter of vulnerability in men, where expressing this vulnerability is met with a hostile reception in society.

Findings from this research consequently point out that once a man has been diagnosed with prostate cancer, there is a gradual change in the ways in which he handles himself. These changes can be viewed as both deconstructing a masculine identity to reconstruct a new masculine identity. Although masculine identities change over time, some men tend to behave being influence by one masculine identity over a longer period of time than others. For instance, where a man carries a masculine identity that is tough and strong, denies weakness and emotional expression, he may change such an identity when he experiences a scenario that demands from him, expression of weakness and emotion. Consequently, the masculine identity he assumes thereafter is one that is emotionally expressive and accepts portrayal of weakness. In this research several factors can be pointed out, such as that in reaching optimal functioning there is an urgent need for masculine identity reconstruction.

The issue of permanent side effects, allows men to adopt other kinds of masculine identities. For instance men that are on hormone therapy and those that have gone through surgery, experience erectile dysfunction or permanent loss of erections. To adopt to this new way, some men choose to expand sexual intercourse beyond genitals and ejaculating. Some men learn how to use other methods of arousal and sex, like oral sex, use of toys, assistive devices and drugs such as the Viberect (device for erection) or Viagra and Cialis (drugs to achieve an erection). Other men choose to not engage in sexual activity at all. They thus define their relationships as purely non sexual. Trust and dependability matter more than sexual encounters. Even though these men are likely to encounter problems with their sexual partners, they are not willing to compromise. The likelihood is that they end up alone.

7.2 Recommendations

Beyond the sexual, other issues determine whether men will seek help or not. These issues are threefold, the toxicity of chemotherapy drugs, the absence of support after treatment, and the limited funding and resources in prostate cancer care. The toxicity of chemotherapy drugs has been one of the determinants in the practice of seeking help. It has been established that other than curing or treating the cancer, chemotherapy drugs weaken the body and expose it to excruciating pain. Some men with knowledge of this find every reason to object going for cancer treatment. Other than their hair falling out, they would thus resist being sick when they could have lived without pain, though with the discomfort of prostate cancer.

Furthermore, unlike breast cancer which has support groups everywhere, survivors of prostate cancer have limited psycho-social support. For example, in Johannesburg there is only one support group, and it was formed to offer psychosocial support as a result of this study. Previously there

was none in existence. So men who experience changes in their life after prostate cancer treatment have had no space to talk about issues that bother them, like incontinence, erectile dysfunction and impotence. These fears have existed in each of the men interviewed who formed part of the support group. Therefore the non-existence of this support mechanism allows men to find excuses and justify their behaviour of not seeking treatment.

Thirdly, prostate cancer treatment is quite expensive. The existing funding patterns confirm that prostate cancer is largely underfunded even though it is the leading killer cancer in men. The evidence from the pharmaceutical companies confirms that for example, there are seven breast cancer drugs for every prostate cancer drug. In as much as prostate cancer is to men what breast cancer is to women, the funding in prostate cancer makes the treatment quite expensive since there are limited options. This makes the bulk of the population of men fall short on payments and this would undoubtedly affect lifestyles. It should thus be noted that there should be an increase in funding for prostate cancer care, whether it's in research, drugs and treatment or palliative care.

7.3 Recommendations for further research

The study brings into perspective the complexities of men's health. It brings to attention the limited funding in prostate cancer care, the unavailability of ready racial statistics as well as the complexities in diagnosis and treatment. These are important perspectives. There is need for future research that takes this research into a broader national study that utilises both qualitative and quantitative methods.

References

Addis, M. E. & Cohane, G. H. (2005). Social scientific paradigms of masculinity and their implications for research and practice in men's mental health. Journal of Clinical Psychology, 61, 633-647.

Addis, M. E., & Mahalik, J. R. (2004). Men, masculinity and the contexts of help seeking. *American Psychologist, 58*, 5–14.

Adejimi, A, (2013). Misconception and Myths about cancers among adults in a rural community of Osun State, Nigeria, (Conference paper): AORTIC Conference, Durban

Anderson, K. L. (2005). Theorizing gender in intimate partner violence research, in *Sex Roles, 52*, 853–865.

Andrew, G. J. (2001). "class, definition of". In Jones, R.J. Barry. *Routledge Encyclopedia of International Political Economy:* Entries A-F. Taylor & Francis. p. 161

Arnst, C, (2007). Study Links Medical Costs and Personal Bankruptcy, BusinessWeek, New York

Baade, P. D., Youlden, D. R., & Krnjacki, L. J. (2009). "International epidemiology of prostate cancer: geographical distribution and secular trends." *Molecular nutrition & food research 53* (2): 171–84.

Black,J.M, Hawks, J.H and Keene, A.M (2006). Medical surgical nursing. 6th ed. Philadelphia: Elsevier Mosby

Babbie, E. (1992). The practice of social research. Belmont; Wadsworth

Babbie, E. & Mouton, J. (2001). *The practice of social* research. Cape Town: Oxford University Press

Bach, B. P, Schrag, D., Brawley, O. W., Galaznik, A., Yakren, S., & Begg, C. B. (2002). Survival of Blacks and whites after cancer diagnosis. *Journal of American Medical Association, 287*, 2106-13

Barker G, Ricardo C (2005). Young men and the construction of masculinity in sub-Saharan Africa: implications for HIV/AIDS, conflict and violence. Washington, DC, World Bank.

Brannon, R. (1976). The male sex role: Our culture's blueprint for manhood and what it's done for us lately. In D. David & R. Brannon (Eds.), *The forty-nine percent majority: The male sex role* (pp. 1–48). Reading, MA: Addison-Wesley.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3* (2), 77-101

Brehm, J. W. (1966). *A Theory of Psychological Reactance*. New York: Academic Press

Bolger, N., Zuckerman, A., & Kessler, R. C. (2000). Invisible support and adjustment to stress. Journal of Personality and Social Psychology, 79,953–961.

Brown, I. (1995). *Man medium rare: sex, guns, and other perversions of masculinity*, New York,: Plume,

Brown H, Paranjothy S, Dowswell, T & Thomas T, (2013). 'package of care for active management in labour reducing caesarean section rates in low-risk women' in Brown H (Ed) *Cochrane Database of Systematic Reviews, 9*, John Wiley & Sons Ltd

Casarett, D., Pickard, A., Bailey, F. A., Ritchie, C., Furman, C., & Rosenfeld, K. (2008). Do palliative consultations improve patient outcomes? *Journal of American Geriatric Association; 56*(4): 595-9

Centers for Disease Control and Prevention (2005). *Sexually Transmitted Disease Surveillance: 2004,* Atlanta: Centers for Disease Control and Prevention.

Charmaz, K. (1995). *Identity dilemmas of chronically ill men, Men's Health and Illness: Gender, Power and the Body*, Thousand Oaks, Sage Publications, 266-291

Cheatham, C. T., Barksdale, D. J., & Rodgers, S. G. (2008). Barriers to health care and healthseeking behaviors faced by Black men. Journal of the American Academy of Nurse Practitioners, 20, 555 – 562

Chodorow, N, (1978,1999), The Reproduction of Mothering, Berkeley, CA: California Press

Cleaver, F. (2002). *Masculinities matter! : men, gender, and development ; foreword by Michael Kimmel*. London ; New York: Zed Books.

Courtenay, W. H. (2000). Constructions of masculinities and their influence on men's health and wellbeing: A theory of gender and health. *Social science and medicine, 50*(10), 1385-1401.

Connell, R. W. (1995). *Masculinities.* Cambridge: Polity.

Creswell, J.W, (2003) Research Design: Qualitative and Quantitative approaches. London: Sage

CSDH (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health.Geneva, World Health Organization.

Croyle, R.T. (2005). Theory at a Glance: Application to Health Promotion and Health Behavior (Second Edition). U.S. Department of Health and Human Services, National Institutes of Health

D'Arcy, C. D., & Schmitz, J. A. (1979). Sex differences in the utilization of health services for psychiatric problems in Saskatchewan, *American Journal of Psychology, 24*, 19-27

Department of Labour Annual Report (2006) Source URL: http://www.pmg.org.za/node/9580

Doll, R. & Petro, R. (1982). *The causes of cancer*, Oxford, UK. Oxford University Press.

Doyal, L. (1995) What Makes Women Sick: Gender and the Political Economy of Health. Macmillan, Houndmills.

Easthope, A. (1992). *What a man's gotta do: the masculinity myth in popular culture*. New York: Routledge.

Eisler, R. M. (1995). The relationship between masculine gender role stress and men's health risk: The validation of a construct. In R. F. Levant & W. S. Pollack (Eds.), *A New Psychology of Men* (pp. 207–225). NY: Basic Books.

European Society for Medical Oncology, (2007). The burden and cost of cancer, *Annual Oncology, 18*(supplement 3): iii8-iii22

Farrell, Svoboda & Sterba, (2008).Does Feminism Discriminate against Men? A Debate. New York: Oxford University Press.

Fergus, Gray & Fitch, (2002)Sexual dysfunction and the preservation of manhood: experiences of men with prostate cancer. J Health Psychol.;7(3):303-16

Genevieve, L. (1993). *The man of reason: 'male' and 'female' in Western philosophy*, London: Routledge.

Gitterman, A. & Germain, C. B. (2008). *The life model of social work practice*. (3rd ed.) New York: Columbia University Press

Gough, B. & Robertson, S. (2010). *Men, masculinities and health: critical perspectives*. Palgrave Macmillan

Governder, K. (2012). *Researching young masculinities: theorizing processes of identification in the research setting*. A paper presented at the 2nd International Conference on Social Science and Humanity, Singapore

Hochbaum, Rosenstock, Kegels & Rosenstock, (1974) Theoretical Foundations of Health Education and Health Promotion,Jones & Batlet Learning

Hofstede, G. (1998). *Masculinity and Femininity*, Thousand Oaks, CA: Sage.

Husaini, B.A, (1994), Psychiatricsymptoms and help-seeking behaviour among the elderly: An analysis of racialand gender differences. Journal of Gerontological Social Work, 21

Krahé, B. & Fenske, I. (2002). Predicting aggressive driving behaviour: The role of macho personality, age, and power of car. *Aggressive Behaviour*, *28*, 21–29.

Kimmel, M. & Aronson, A. (2004). *Men and masculinities: a social, cultural, and historical encyclopedia:* Santa Barbara, California.

Kimmel, M. S. (2000). *The Gendered Society*. Oxford: Oxford University Press.

Khunou, G. (2013). *Men's Health: an analysis of representations of men's health in the Sowetan Newspaper.* Pretoria: Communica.

Khunou, G. (Forthcoming). Are men's health care needs important? A critical analysis of the South African Health Policy. Pretoria: HSRC PRESS.

Khunou, G. & Munatswa, E. T. (Unpublished paper). Complexities of men's health in South Africa, Wits University.

Kirby, R.S, Kirby, M.G and Farah, R.N (1999). Men's Health. Taylor & Francis.

LaVeist, T.A. (1993) Separation, Poverty and Empowerment: Health consequences for African Americans, Milbank Quarterly, Vol. 73, no. 1, pp. 41-64.,

Levant, R. (2008). How do we understand masculinity? An editorial. *Psychology of Men and Masculinity, 9*, 1–4.

Lindsay, L. A. & Miescher, S. F. (2003). *Men and masculinities in modern Africa* . Portsmouth, NH : Heinemann,.

Lozano, R. (2012). "Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010." *Lancet 380* (9859): 2095–128.

Luck, M, Bamford, M & Williamson, P (2000) Men's Health: Perspectives, Diversity and Paradox. Wiley

Mahalik, J. R. (2000). Men's gender role conflict as predictors of self-ratings on the. Interpersonal Circle. Journal of Social and Clinical Psychology, 19, 276-292

Mankowski E.S, & Maton K.I. (2010) A community psychology of men and masculinity: Historical and conceptual review. American Journal of Community Psychology.;45:73–86

Maurer, T.W., & Pleck, J.H. (2006). Fathers' caregiving and breadwinning: A gender congruence analysis. Psychology of Men and Masculinity, 7(2), 101-112.

Marcus, B.H, Rakowski W & Rossi R.S, (1992). Assessing motivational readiness and decision-making for exercise. Health Psychology.;11:257–261

Martinez, G. M. (2002). Fertility, contraception, and fatherhood: data on men and women from Cycle 6 of the National Survey of Family Growth, *Vital and Health Statistics*, 2006, Series 23, No. 26.

Mfecane S, 2010, EXPLORING MASCULINITIES IN THE CONTEXT OF ARV USE:A study of men living with HIV in a South African village, PhD Thesis, Wits University

Minino, A. M., Heron, M. D., & Smith, B. L. (2006). Deaths: Preliminary data for 2004. *National Vital Statistics Reports*, National Centre for Health Statistics, 54, 1–50.

Mizrahi, T. & Davis, L. E. (eds). (2008). *Encyclopedia of social work*. 20th ed. Oxford: Oxford University Press.

Mosher WD, Chandra A and Jones J, (2005), Sexual behavior and selected health measures: men and women, 15-44 years of age, United States, 2002, Advance Data from *Vital and Health Statistics*, No. 362.

Morrell, R. (2001) *Changing Men in Southern Africa*. Pietermaritzburg: Natal University Press.

Morris, W. N. & Miller, R, S. (1975). Impressions of dissenters and conformers: An attributional analysis, *Sociometry, 38*, 327-339

Munatswa, E. T. (2013). Disparities in Gender: A Case for Prostate Cancer, *Longevity Magazine* Vol XIII, Longevity, JHB

Mwangi-Powell, F. (2007). Palliative care and public health, a perspective from the African Palliative Care Association. *Journal of Public Health Policy, 28*(1): 59-61

Naslindh-Ylispangar, (2008) Health status, symptoms and health, Kauriintie 3 G49, Helsinki

National Center for Health Statistics. (2005). Health, United States, 2005 with chartbook on trends in the health of Americans, Hyattsville, Maryland. www.cdc.gov/nchs/data/hus/hus05.pdf

National Healthcare Disparities Report. (2005). Agency for healthcare research and quality, Rockville, MD. AHRQ Publication No.06–0017. www.ahrq.gov/qual/nhqr05/nhqr05.htm

Neighbors, H. W., & Howard, C. S. (1987). Sex differences in professional help seeking among adult Black Americans. American Journal of Community Psychology, 15, 403–417.

Ndom, P. (2008). Challenges of anticancer chemotherapy in Africa. *The Canadian Journal of Urology, 15*(1): 3909-39

O'Dowd T, Jewell D, (1998), (eds), Mens Health, Oxford University Press.

Ouzgane, L. & Morrell, R. (2005). *African masculinities: men in Africa from the late nineteenth century to the present.* New York: Palgrave Macmillan; Scottsville,South Africa: University of KwaZulu-Natal Press,.

Padget, D.K, (2008). Qualitative methods in social work research: challenges and rewards.2nd ed. Thousand Oaks, CA: Sage

Pappas G, Queen S, Hadden W, Fisher G. The increasing disparity in mortality between socioeconomic groups in the United States, 1960 and 1986. New England Journal of Medicine. 1993;329(2):103–109.

Pleck, J. H. (1995). The gender role strain paradigm: An Update. In R.F Levant & W.S Pollack (Eds), *A New Psychology of Men*. New York: Basic Books

Pleck, J.H. (2007). Why could father involvement benefit children? Theoretical perspectives. Applied Developmental Science, 11(4), 1-7. Polit, D. F & Beck, C. T. (2004). *Nursing Research: Principles and Methods*. Lippincott: Williams & Wilkins

Pope, H.G, Phillips, K.A & Olivardia, R, (2000). The Ardonis Complex, How to identify, treat and prevent body obsession in men and boys. New York, NY-Touchstone

Potter, P. A. & Perry, A. G. (2010). *Canadian fundamentals of nursing (4th ed.).* Toronto: Elsevier.

Powell, L. (2007). Cancer in South Africa - what are the stats? *Health24,*

http://www.health24.com/Medical/Prostate/Prostate-cancer-in-SA/Cancer-in-South-Africa-what-are-the-stats-20120721

Rashid, T. & Heider, I. (2008). Life events and depression, *Annals of Punjab Medical College, 2*(1)

Ratele, K. (2008). Masculinities, Maleness and (Illusive) Pleasure: Working Paper. Africa Regional Sexuality Resource Centre

Rick, I. (2003). Origins of cognitive vulnerability to depression, *Cogintive Therapy & Research, 27*(1): 77-88

SA Statistics (2004). *National Cancer Registry*. Statistics South Africa.

Salmans, S. (1997). Depression: Questions you Have- Answers You Need, *People's Medical Society.*

Sharma, V., Kerr, S. H., Kawar, Z., & Kerr, D. J, (2011). Challenges of cancer control in developing countries: Current status and future perspective. *Future Oncology, 10*: 1213-22.

Shavers, V. L., Shankar, S., & Alberg, A. J. (2002). Perceived access to health care and its influence on the prevalence of behavioural risks among urban African Americans. *Journal of the National Medical Association, 94*, 952–962.

Scher, H. I, Fizazi, K., Saad, F., Taplin, M. E., Sternberg, C. N., & Miller, K. (2012). Increased survival with enzalutamide in prostate cancer after chemotherapy. *New England Journal of Medicine, 367*(12): 1187-97.

Schulte, M. M. & Sonenstein, F. L. (1995). Men at family planning clinics: the new patients? *Family Planning Perspectives, 27*(5):212-216.

Skinner, D. & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in SA, *Journal of Social Aspects of HIV/AIDS*, *1*(3).

Siegel, R. (2011). "Cancer statistics, 2011: the impact of eliminating socioeconomic and racial disparities on premature cancer deaths.". *CA Cancer J Clin 61*: 212–36.

Smith, D.E, (2007). Perspective as a Radical Critique of Sociology. DOI: 10.1111

Sripasad, S., Fenely, M., & Thompson, P. M. (2009). History of prostate cancer treatment, *Surgical Oncology, 18*:185-91

Sonenstein, F.L. (2000). *Young Men's Sexual and Reproductive Health: Toward a National Strategy-Framework and Recommendations*, Washington, D C: Urban Institute

The Alan Guttmacher Institute (AGI), (2002). *In Their Own Right: Addressing the Sexual and Reproductive Health Needs of American Men,* New York: AGI

Van Rijswijck, E. (2012). South Africa's mortality rates on the decline. http://www.mediaclubsouthafrica.com/index.php?option=com_content&view=article&id=2728:mortality-120112&catid=42:landnews&Itemid=110#ixzz2Mq5I2zse

Weber, R.P (1990) CONTENT ANALYSIS. Basic Content Analysis (2nd edition), Thousand Oaks, Cal.: Sage .

Whetten, K., Leserman, J., Whetten, R., Ostermann, J., Thielman, N., Swartz, M. (2006). Exploring lack of trust in care providers and the government as a barrier to health service use. *American Journal of Public Health, 96*, 716–721.

World Health Organization. (2007). Engaging men and boys in changing gender-based inequality in health: Evidence from programme interventions.Geneva. http://www.who.int/gender/documents/Engaging_men_boys.pdf.

Wills, T. A., & DePaulo, B. M. (1991). Interpersonal analysis of the help seeking process. In C. R. Snyder & D. R. Forsyth (Eds.), Handbook of social and clinical psychology (pp. 350–375). Elmsford, NY: Pergamon.

Winkleby, M., Jatulis, D., Frank, E., & Fortmann, S. (1992). Socioeconomic status and health: How education, income, and occupation contribute to risk factors for cardiovascular disease. *American Journal of Public Health 82*(6): 816-820.

Yeh, E. T. & Bickford, C. L. (2009). Cardiovascular complications of cancer therapy: incidence, pathogenesis, diagnosis and management, *Journal of American Coll Cardiol*, *53*(24): 2231-47

Appendix A: Participant / Key Information sheet

Good day.

My name is Elvis T Munatswa and I am student registered for an MA in Social Work by Research at the University of Witwatersrand. As part of the requirements for the degree, I am conducting a research study to inquire into men's perception on reporting and subsequently seeking treatment for prostate cancer. The research topic is as follows: Are men generally unable to take care of their health? Changing masculinities in the wake of prostate cancer. It is hoped that this information may enhance the understanding of masculinities and health help seeking among men.

I therefore wish to invite you to participate in my study. Please note that your participation in this study is voluntary and there is no reward for participating or penalty for not participating. Involvement in the study requires your participation in an interview for approximately one hour which will be scheduled at a time and place that is suitable for you. You will not be obliged to answer any questions with which you are uncomfortable and therefore have the option to decline or to respond to any questions asked. You will also have the option of terminating your participation at any stage that you choose, without any penalty or negative repercussions.

With your permission the interview will be tape recorded. All data collected through the interview will be treated within the strictest confidentiality. The tapes and interview schedules will be kept for two years following any publications or for six years if no publications emanate from the study. I recognize that what we'll be discussing is a matter of some sensivity; rest assured that if you do become upset in any way as a result of your participation, counseling will be available to you, free

of charge, at the Emthonjeni Centre, at Wits University in Braamfontein. Please note that participants' names will not be used or known by anyone, nor appear in the dissertation.

Please feel free to ask questions regarding the study. I shall answer them to the best of my ability. I may be contacted on email elvis.munatswa@students.wits.ac.za or mobile 078 566 5840. Should you wish to receive a summary of the results of the study an abstract will be made available.

Thank you for taking time to consider participating in the study.

Yours sincerely

Elvis T Munatswa.

Appendix B: Participant/ Key Informant Consent Form

I hereby consent to participate in the research that Elvis T Munatswa is undertaking. The research topic is as follows: Are men generally unable to take care of their health? Changing masculinities in the wake of prostate cancer

- I understand what participation in this research means,
- I understand that my participation is voluntary,
- I understand that I have the right not to answer any questions that I do not feel comfortable with,
- I have the right to withdraw my participation in the research, at any time I so choose and
- I understand that any information I share will be held in strictest confidence by the researcher
- I understand that participants' names will not be used or known by anyone, nor appear in the dissertation.

- **Name: …….**
- **Date: …….**
- **Signature: ……**
- **Signed by: Elvis Munatswa**
- **Signature……**

Appendix C: <u>Consent Form for Audio-Taping if the Interview</u>

I hereby consent to tape-recording of the interview. I understand that my confidentiality will be maintained at all times and that the tapes will be destroyed two years after any publication arising from the study or six years after completion of the study if there are no publications.

Name: …….

Date: …….

Signature: ……

Signed by: Elvis Munatswa

Signature……

Appendix D: Interview Guide

1) At what stage was the cancer when you got diagnosed?
2) Has being diagnosed with prostate cancer had any effects on your manhood? If so, what are they?
3) Has the diagnosis affected your personal relationships? If so, how?
4) Has the problem of incontinence affected your relationship with your spouse? If so, how?
5) What are your views on men seeking treatment for illness?
6) What are your views on men who do not ask for health help?
7) What health concerns would you seek treatment for?
8) What motivates you to seek treatment?
9) Did you ever consider African traditional healing for your condition?
10) What about the health center/doctor you used, did it compel you to use any form of medication.
11) Are you aware of any health programmes to increase awareness on men specific illness?
12) What are your views on the roles of government and civil society on addressing men's health concerns?

Probe areas

Social status, e.g., class, race, age,

Access e.g., level of education, health awareness, affordability

Location e.g., townships, suburbs, informal settlements

Economic situation e.g., employed, unemployed, pensioner, entrepreneur

Appendix E: Letter requesting counseling service provision

To The Social Worker

Emthonjeni Centre

My name is Elvis T Munatswa, I am a student registered for an MA in Social Work by Research at the University of Witwatersrand. As part of the requirements for the degree, I am conducting a research study to inquire into men's perception on reporting and subsequently seeking treatment for prostate cancer. It is hoped that this information may enhance the understanding of masculinities and health help seeking practices among men. Should the participants require counselling, my request is that you assist them.

Regards

Elvis Munatswa

(MA Social Work Student)

Appendix F: Referral letter

To The Social Worker

Emthonjeni Centre

School of Human and Community Development, Wits

Braamfontein

011 717 8663/4513

This letter is to confirm that Mr …….. participated in my study on men's perception on reporting and subsequently seeking treatment for prostate cancer and as a result of the study he requires counseling. Please assist him. May you also provide him with a suitable date for a counseling session.

Regards

Elvis Munatswa

(MA Social Work Student)

078 566 5840