

Reviewing the Situation:
Men and Antiretroviral Treatment
in Soweto, South Africa

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ABSTRACT

There have been great strides in increasing access to antiretroviral treatment for HIV-positive people in South Africa. However it has been observed that men are not accessing treatment to the same extent as women. In Soweto only 30% of the people accessing treatment are men, where the expected rate would be around 45%. Whilst there have been some studies observing treatment uptake, they do not explain the behavioural component.

This thesis explores men's help-seeking behaviour with regard to the HIV/AIDS epidemic in Soweto, South Africa, as reported by the men themselves. Men's voices in South Africa have seldom been reported in the literature on the epidemic, where the major focus has been on women and children because of their perceived vulnerability. However, men cannot be ignored, as they are part of the epidemic and can play an important role in mitigating its impact. This thesis attempts to fill this gap by exploring the perceptions of men on three themes: men's beliefs and understanding of illness, the HIV/AIDS and stigmatisation, masculinity and men's help-seeking behaviour, and the public health HIV services.

The advances in HIV/AIDS treatment, prevention, and care have presented new opportunities to include men as a solution to the HIV/AIDS problem. Antiretroviral treatment (ART) has proved to be an effective prevention and treatment tool. However, in order to maximise ART's potential, men need to access the treatment and become part of this positive trend.

Unfortunately, the reality on the ground is that men, relative to women, form the minority of people accessing HIV/AIDS services, including ART. The literature speculates that men are not interested in their health and that masculinity inhibits men from admitting that they are ill. Help-seeking behaviour is also influenced by beliefs about the causes of illness. These views emanate mainly from observational and quantitative studies based on health care workers reports or clinical records, but do not include the voices of the men. For this reason, a deeper understanding of men's views on the epidemic, their health, and their help-seeking behaviour is required if they are to be mobilised and engaged as part of the solution.

This thesis explores these conjectures with a group of men living in Soweto using an exploratory qualitative research methodology. The central argument is that men's health is influenced by three forces: Firstly, their

understanding of the HIV/AIDS epidemic and HIV-stigma, secondly, by masculinity and related men's health practices, and finally, the health system and men's help-seeking behaviour. Reviewing this situation with the participation of the men gave the researcher a greater insight into how these men cope with illness, particularly HIV. Through the men's voices a nuanced understanding of the interplay of the forces related to their help-seeking behaviour is obtained, and this goes some way towards explaining the relative absence of men at the ART clinics.

The study concludes that men's help-seeking behaviours are complex and influenced by multiple factors. The men in this study were keenly interested in their health, had a good understanding of HIV and AIDS, were knowledgeable about antiretroviral treatment, and said they would access clinical HIV services if they were to become HIV-positive. However, these intentions are not being realised and are being hampered by HIV stigmatisation, clinical barriers and men's poor help-seeking behaviours. The situation may improve as HIV stigmatisation decreases over time – a trend which was observed in this study. Clinical barriers are more difficult to overcome as the demand for these services increases, but the men were able to provide some useful suggestions on how to mitigate these. Men's help-seeking behaviour could be improved through health promotion and changing norms.

One can argue that the limitation of this thesis is the attempt to investigate three rather broad topics. While each topic is worthy of additional in-depth study, it was felt that including other perspectives that might offer a more complete understanding of the issues was important.

In this thesis, which is an exploratory study in medicine, such wider scope provides knowledge that is more useful in order to understand and mitigate the problem. In addition, this approach has the potential to stimulate further social-behavioural research on some of the topics that require more in-depth interrogation.

The results are not generalizable to all men as the qualitative approach limits the findings. However, they provide useful insights into men's help-seeking behaviour in the context of HIV/AIDS. Future research can build on the insights of these men by including a broader sample from diverse areas in South Africa and focusing on specific issues.

DEDICATION

In memory of my mother,

Mary Elizabeth Struthers

20-04-1927 – 23-10-2012

without her support this thesis would not have been completed.

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There are too many people who have provided me with encouragement and support during the planning and execution of this thesis to mention them all by name, but without them I would not have completed this task.

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Finally, I would like especially to thank all the people who participated in this study for their valuable time engaging with the topic, but especially the men who shared their life stories with me. I hope that this work will contribute towards better health services and outcomes for all men in South Africa.

DECLARATION

I, Helen Elizabeth Struthers, declare that this thesis is my own unaided work. It is submitted for the degree of Doctorate of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination in any other university.

Helen Elizabeth Struthers

2 September 2014

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ACRONYMS

AIDS	<u>A</u> cquired <u>I</u> mmunodeficiency <u>S</u> ndrome
ART	<u>A</u> ntiretroviral <u>T</u> reatment
ARV	<u>A</u> ntiretroviral drugs
CSW	<u>C</u> ommercial <u>S</u> ex <u>W</u> orker
GRID	<u>G</u> ay <u>R</u> elated <u>I</u> mmune <u>D</u> eficiency
HIV	<u>H</u> uman <u>I</u> mmunodeficiency <u>V</u> irus
IDU	<u>I</u> njecting <u>D</u> rug <u>U</u> ser
MSM	<u>M</u> en who have <u>S</u> ex with <u>M</u> en
PMTCT	<u>P</u> revention of <u>M</u> other- <u>t</u> o- <u>C</u> hild <u>T</u> ransmission of HIV
SIV	<u>S</u> imian <u>I</u> mmunodeficiency <u>V</u> irus
STI	<u>S</u> exually <u>T</u> ransmitted <u>I</u> nfection
THP	<u>T</u> raditional <u>H</u> ealth <u>P</u> ractitioner
UK	<u>U</u> nited <u>K</u> ingdom
UNAIDS	Joint <u>U</u> nited <u>N</u> ations Programme on HIV/ <u>A</u> IDS
USA	<u>U</u> nited <u>S</u> tates of <u>A</u> merica
VCT	<u>V</u> oluntary <u>C</u> ounseling and <u>T</u> esting
WHO	<u>W</u> orld <u>H</u> ealth <u>O</u> rganisation

PART 1: INTRODUCTION

The HIV/AIDS epidemic is most severe in sub-Saharan Africa (UNAIDS, 2012), and South Africa has approximately 6.4 million people living with HIV/AIDS in 2012 – the highest in any country – and over 2 million people on ART (UNAIDS, 2013; Shisana et al., 2014). In this region the epidemic is predominantly heterosexually driven, but women are more adversely affected than men are, and have higher human immunodeficiency virus (HIV) prevalence. Physiologically, women are more susceptible to HIV infection, and their sub-ordinate socioeconomic and political status compounds this situation (Jewkes & Morrell, 2010; UNAIDS, 2012). As a result, women and children have been the main focus for research and prevention initiatives (Shand et al., 2014). To a large extent, these efforts have disadvantaged men.

In terms of antiretroviral treatment (ART), there is evidence to suggest that fewer men access treatment than women and have worse outcomes (Hudspeth et al., 2004; Cornell, 2013; Druyts et al., 2013). Men have been framed in an essentialist way as the perpetrators of sexual violence or the benefactors of patriarchy. This is despite the fact that men play a significant role in the transmission of HIV, and are infected with and affected by HIV/AIDS themselves. Furthermore, men engaging in high-risk activities for HIV such as commercial sex work, injecting drug use and having sex with men continue to fuel the epidemic (Mayer & Beyrer, 2007). For these reasons, more attention needs to be paid to men and their role in the epidemic, but without compromising the gains made for women, children and other vulnerable groups (Druyts et al., 2013).

ART is the key intervention for people infected with HIV, reducing morbidity and mortality, and allowing them to live with the virus for many years as if it were a chronic condition (Johnson et al., 2013). More recently ART has been found to have a significant impact on preventing new infections (Cates, 2011; Cohen et al., 2011; Granich et al., 2012). Thus, ART can play a dual role in turning around the epidemic by reducing the number of new infections, and by increasing the quality of life for people who are infected with HIV.

At southern African public health HIV treatment facilities there is a noticeable absence of men visiting clinics where antiretroviral (ARV) drugs can be obtained (Hudspeth et al., 2004; Muula et al., 2007; Johnson, 2012). The big question therefore is “Why are men conspicuous by their absence at ART clinics?”

Data from South Africa show that only 37.8% of men compared to 55.0% of women are aware of their HIV-positive status (Shisana et al., 2014) and similarly fewer men were found to test in Soweto (Mhlongo et al., 2013). In Soweto, only 35% of people receiving ART are men, compared the 45% that would be expected, if men were accessed the clinics at the same rate as women¹. What is not known is why men avoid HIV testing, care and treatment services. There is some literature speculating on men's help-seeking behaviours, but little has been found that examines men's perspectives of the problem, particularly in South Africa. There is no doubt that in order for ART to be effective, more men need to know their HIV status and seek help. This thesis, attempts to fill this gap by exploring the problem from the men's perspectives.

A number of factors have been identified to impact negatively on men's health outcomes aside from their gender (Cornell, 2013; Johnson et al., 2013). These factors are influenced by the complex social context and the cultural construction of masculinities (Morrell, 2001; Connell, 2005; Hunter, 2010; Connell, 2012) and include men's help-seeking behaviour (Robertson, 2007), men's poor health practices (Courtenay, 2000; Mahalik et al., 2007), particular beliefs about HIV/AIDS and the roles of allopathic medicine, witchcraft and spiritual healing (Ashforth, 2002; Delius & Glaser, 2005; Pearson & Makadzange, 2008; Steinberg, 2008; Dickinson, 2013), HIV-related stigma (Stein, 2003a; Campbell et al., 2005; Deacon et al., 2010; Gilbert & Walker, 2010; Abrahams & Jewkes, 2012), and the public health system constraints such as staff attitudes, a predominance of female staff, overcrowding, and limited opening hours (Preston-Whyte, 2003; Bassett et al., 2007; Coovadia et al., 2009; Bogart et al., 2013; Galdas, 2013). These explanations are a useful starting point to determine their relevance to the situation in Soweto where this study is based.

The HIV/AIDS epidemic puts additional pressure on men to seek help and the health system to provide it. However, in resource constrained settings this problem needs to be approached in the most effective manner. This thesis explores the factors identified above with men in Soweto to ascertain whether or not they affect men's help-seeking behaviour for HIV/AIDS. In addition, the outcomes can give direction on how to proceed to address the problem in the public health sector.

¹ Anova Health Institute NPC, 2013, unpublished ART statistics from Soweto clinics gathered from routine clinic data and the District Health Information System.

Men in Soweto live in a patriarchal society and hold a privileged position. They are leaders and decision-makers at political and household levels. The social context of Soweto and the construction of masculinities there are likely to influence the factors determining men's health and help-seeking behaviour, and these may differ from the explanations offered in the literature. It is intriguing that men do not seek help to the same extent as women. So a more specific question is "What are the barriers holding men back?"

Research on men's health and help-seeking behaviour has to a large extent concentrated on observational or quantitative studies on the differences between genders for example in terms of different illnesses (MacIntyre et al., 1996; Bird & Rieker, 1999), and morbidity and mortality (Tsuchiya & Williams, 2005; Bradshaw & Timaeus, 2006). Qualitative research has focussed on men's illness experiences (Robertson, 2007) but men's health and help-seeking been eschewed and the voices of men have less often been heard (Blaxter, 1997; Lohan, 2007; Robertson, 2007). Little of this qualitative research has been conducted in South Africa. This exploratory qualitative study hopes to address this gap by exploring the issues raised above as reported by the men living in Soweto, in order to gain a greater understanding of their help-seeking behaviour.

The aim of this study is to explore men's understanding of ART and their help-seeking behaviour with regard to ART in Soweto, South Africa. Men's experiences form the central focus of this thesis, and the assumption is that their help-seeking behaviour is shaped by the context in which they live. Three major themes are explored:

1. the HIV/AIDS epidemic, and related beliefs and stigma;
2. patriarchy, masculinity, and men's health practices; and
3. health systems and men's help-seeking behaviour.

The rationale for this study is to provide a platform for men to express their views on these issues. The voices of men provided a nuanced understanding of men's attitudes towards HIV/AIDS and related issues have been missing from much of the research to date. This study therefore is an attempt to fill this gap. Since the study is located in Soweto, the findings may not be generalised to other contexts, but will nevertheless provide a nuanced account of men's help-seeking behaviour in relation to HIV/AIDS in a particular place, at a particular time. It will complement findings from other studies in the region and elsewhere, and give greater insight into men's engagement with the HIV/AIDS epidemic. Men's opinions are critical to gain an

understanding into how they approach health and illness, the reasons why they choose to access or choose not to access health services, and what can be done to encourage them to take an active interest in their health.

The results of the research provide a greater insight into the reasons why men access or do not access HIV/AIDS services and ART. These findings may therefore inform policy around HIV/AIDS services and ART provision to improve men's uptake of the services.

PART 2: LITERATURE REVIEW

In Part two a summary is provided of the literature centred on the HIV/AIDS epidemic, masculinity, and men's health. It includes the development of theories that have informed research related to men, men's health, the HIV/AIDS epidemic, men's help-seeking behaviour, and HIV treatment. The review concentrates on research conducted in Africa, in particular South Africa; however, these frequently draw on research from other regions, and have been included where they are relevant. Through this investigation, key concepts have been identified that have pertinence to the discussion of men accessing HIV treatment in South Africa, the topic of this thesis.

The review is divided into five chapters. The first two chapters provide contextual background for the study by initially summarising the literature on the HIV/AIDS epidemic and its impact in South Africa, including popular beliefs surrounding it and then delving into stigma and HIV/AIDS. Chapter three summarises masculinities and their relationship with HIV/AIDS. Chapter four provides an overview of the health services and other options for HIV care. Chapter five explores men's help-seeking behaviour and health. Emanating out of the literature the conceptual framework for the thesis is presented in Chapter six.

Chapter 1: HIV/AIDS

In order to understand men's role in the South African HIV/AIDS epidemic an understanding of the epidemic's historical context is necessary, taking into account the origins of HIV, the nature and evolution of the epidemic, and how it unfolded in South Africa. As Barnett & Whiteside (2002:24) comment, "[HIV] is a disease that is changing human history."

1.1 Emergence of HIV

HIV is not a new phenomenon. Iliffe (2006) provided a comprehensive account of the origin and spread of the epidemic in Africa and describes the emergence of HIV around 1930 when the Simian immunodeficiency virus (SIV) crossed over from monkeys or chimpanzees to humans in western equatorial Africa. HIV was positively identified in a stored blood specimen taken in 1959 from an African man in Leopoldville, now Kinshasa, in the Democratic Republic of Congo. At that time only a few people would have been infected and were likely to be found in isolated groupings. Over time, due to increased mobility, conflict, migration, and urbanisation, the infection would have spread more rapidly and the various accounts of increased disease, including Kaposi's sarcoma, diarrhoea, and "Slim" disease, are likely to have been HIV-related (Iliffe, 2006). In Africa, by the early 1980s health professionals became aware "... that a new epidemic of unprecedented proportions was spreading throughout sub-Saharan Africa" (Mboup et al., 2006:237); however, they were ignorant of the cause. In this region the epidemic quickly became a generalised heterosexual one.

Elsewhere, the epidemic unfolded somewhat differently. At about the same time, in 1980, the first cases of AIDS were diagnosed in Los Angeles, in the United States of America (USA), in a group of young gay men, where it was initially referred to as Gay Related Immune Deficiency (GRID) (Barnett & Whiteside, 2002). The exact means of transmission were unknown, but it was speculated that the disease was sexually transmitted. Many people viewed homosexuality negatively and once HIV/AIDS was also associated with being homosexual the disease was stigmatised, making it a medical, political, and cultural problem (Herek, 1999; Herek & Capitano, 1999).

HIV/AIDS became politicised and gay activist groups demanded government intervention, treatment and care. For a short while thereafter, the rapidly increasing number of new cases was concentrated in populations at high risk of transmission, including injecting drug users (IDUs), men who have sex with men (MSM), and commercial sex workers (CSWs) (Ilfie, 2006), before moving out into the general population.

The uncertainty about how HIV was transmitted and that it initially emerged in gay, high risk and minority populations encouraged homophobia, racism and stigma. This dual association led to people who were infected with HIV being discriminated against and inferring that they were in some way “deviant” (Sontag, 1990; Herek & Capitano, 1999; Parker & Aggleton, 2003). In South Africa, during the political transformation diverse sexualities became public and visible, possibly increasing the HIV-related stigma and homophobia (Berger, 2004; Reid & Walker, 2005). MSM are at a high risk of being HIV-positive, but there has been little research on MSM’s help-seeking behaviour in South Africa, and they are purposively included in this study to gain a better understanding of their needs.

However, when relatively rare conditions started being diagnosed more frequently in the general population it quickly became apparent that HIV/AIDS was not limited to the gay population. Infections in the Haitian community emerged and it became evident that HIV could be spread between injecting drug users and through blood products (Farmer, 2005). Cases were soon being reported in the United Kingdom, France, and Uganda (Ilfie, 2006).

Over time, new HIV infections began to increase rapidly. Initially men were more likely to be infected, but very soon growing numbers of women were diagnosed with it (Foreman, 1999). It was only once it was evident that anyone could be infected with HIV and that it could be transmitted through heterosexual sex, which is when governments started to take the epidemic seriously. The epidemic remained political, and even the scientific isolation of the virus was internationally contested between France and the USA as to which country was the first to discover it (Connor & Kingman, 1989).

However, by the time the first cases of HIV were diagnosed, the HIV/AIDS epidemic was already well established with hundreds of thousands of people infected, as described in the Frontline documentary “The

Age of AIDS.”² In addition, the first cases were diagnosed in marginalised groups such as sex workers and MSM and it was not clear that these indicated the beginnings of what was to become a generalised and highly politicised epidemic (Pisani, 2008). The initial prejudice shown towards HIV-positive people and the politicisation of the issue delayed a coordinated response to the epidemic (D’Adesky, 2004).

1.2 HIV in South Africa

HIV/AIDS spread southward from west equatorial Africa entering South Africa in the early 1970s. This was the beginning of a period of violent unrest that culminated in the transition from apartheid rule to democracy in 1994 (Iliffe, 2006). During this time, racial discrimination, migrant labour, and political turbulence meant that many people spent extended periods away from their partners and families and engaged in casual and multiple sexual relationships (Fourie & Meyer, 2013). This is likely to have contributed towards paving the way for the very rapid increase in HIV prevalence, resulting in South Africa being the worst affected country in the world (UNAIDS, 2013).

Apartheid was the system of government in South Africa from 1948 to 1994. Apartheid disenfranchised the majority black³ population, and racial discrimination influenced all aspects of everyday life, including employment, education, housing, and health systems. Health for many, but particularly the black population, was negatively affected by inferior social conditions (such as migrant labour), segregated health services, unequal spending according to race, and the “failure of professional bodies and civil society to challenge apartheid health” (Hassim et al., 2007:11). Apartheid’s migrant labour system forced thousands of mainly black men and women to spend many months away from their partners, families and communities. On the mines men were housed in single-sex hostels and unable to live with their families, a setting that encouraged casual sexual relationships and new partnerships with “town” wives, leading to a higher HIV infection in these migrant workers (Lurie et al., 2003). The impact of this is still being felt today (Hunter, 2007; Beresford et al., 2008; Hunter, 2010).

² Frontline 2006 video “The Age of AIDS” <http://www.pbs.org/wgbh/pages/frontline/aids/>

³ The race categories used in this thesis are based on the racial classifications used during the Apartheid era – their use here does not justify the practice but highlights the social significance of this abhorrent legacy.

These events contributed to the development of South African masculinities. From the mid-1970s increased unrest and violence throughout the country heralded the end of apartheid. Men played a major role in leading the liberation struggle and frequently were involved in violent conflict (Morrell, 2002). This situation, together with the legacies of apartheid – including the migrant labour system – put South Africa in a highly vulnerable position for the expansion of the HIV/AIDS epidemic. This history played an important part in fostering “specific forms of masculine identity” that included taking risks, working in dangerous settings such as the mines, having multiple sexual partners, and engaging in violent sexual intercourse and rape (Marks, 2002:20). This form of masculinity promotes particular sexual practices and relationships, and a weakened bargaining position for women that are known to facilitate HIV transmission and ultimately fuel the epidemic. What is less clear is whether this type of masculinity influences men’s rationalisations to seek or not seek help for HIV.

It was in 1982 that the first case of AIDS was diagnosed in South Africa in a white, homosexual South African Airways airline steward who was probably infected in the USA (Gevisser & Cameron, 1995). Like the epidemic in the USA, the majority of the reported AIDS cases in South Africa remained in the homosexual population until the mid-1980s when progressively more cases were diagnosed in the heterosexual population, and particularly amongst migrant workers on the mines (D’Adesky, 2004; Iliffe, 2006). In 1986, the Chamber of Mines conducted a study of 300,000 miners and found that 800 men were infected with HIV, of whom 760 were from Malawi and central Africa. These miners were deported or did not have their contracts renewed (Cameron, 2005). Discrimination against these workers and others led to a human rights approach being adopted for HIV testing. It included requiring written informed consent for testing and protected the individual from being unfairly treated based on their HIV status, and was incorporated into government policy (Barrett-Grant et al., 2003).

In 1994 a new democratic era began with a bold new constitution that protects the rights of all South Africans. The newly elected government’s mandate was to transform the country in such a way that all South Africans would benefit equally (Beresford et al., 2008). The health system in particular was reviewed, policy and legislation were redrafted and finance was committed to meet these needs (Hassim et al., 2007). The right of access to health care, specifically reproductive and emergency health care, is enshrined in the South African Constitution, and informs South African law (Statutes of the Republic of South Africa, 1996).

The South African Constitution is one of the most progressive in the world and ensures that injustices that were evident in the past are avoided in future. The Promotion of Equality and Prevention of Unfair Discrimination Act, 2000, attempts to ensure that people can access care particularly in an emergency, and the Act prohibits the denial of access to health services or facilities (Hassim et al., 2007). In addition, the Constitution advocates equality in access to health care and allows some level of control over private medical care and medicine prices. Furthermore, the rights of the public health system users are addressed in legislation through the Patients' Rights Charter, which governs the relationship between the health care worker and the patient, but also highlights the patient's rights and responsibilities (Berthiaume & Padarath, 2003; Hassim et al., 2007). The post-apartheid government adopted a primary health care approach to public health that requires it not only to be accessible, but also to provide an equitable service to all (Hassim et al., 2007). Therefore, legislation guarantees the right to health care, but putting it into practice remains a challenge. In the case of HIV/AIDS it does not necessarily translate into people accessing HIV testing, care, and treatment, as appears to be the case in Soweto where men refrain from using the available facilities.

In South Africa health disparities persist across social dimensions such as class, gender, race, and location, and are complicated further by cultural and religious factors (Gilbert & Walker, 2002). Although there has been substantial reform in the health system, challenges remain, including addressing inequitable access, lack of leadership, management and stewardship, shortage of human resources, HIV/AIDS, international trade laws regarding pharmaceuticals, and regulation of the Ministry of Health (Hassim et al., 2007; Coovadia et al., 2009). With the surge in HIV infections, the health system struggled to cope and became caught up in political manoeuvring. As Lawson (2008:81) notes, "AIDS issues soon became snarled up in the complexities of political transition: the plain challenge of restructuring a divided health sector was compounded by party politics, vested economic interests and the racialised thought patterns of the past." These factors complicated the messaging about HIV, hindered prevention efforts, and stalled the rollout of ART.

1.3 Politics and HIV

In South Africa, politics and the lack of political leadership surrounding HIV/AIDS hampered efforts to deal effectively with the epidemic. Elsewhere, progress was being made on the prevention and treatment of HIV/AIDS, but in South Africa political leadership was inadequate and government was tardy in their

response (Fourie & Meyer, 2013). Rather than government leading the process, civil society groups such as the Treatment Action Campaign and Médecins Sans Frontières led the treatment agenda. They campaigned against the slow progress of government by lobbying and demonstrating that ARVs used in HIV treatment programmes could be successful in South Africa. In early 2000, the Treatment Action Campaign resorted to taking the Department of Health to the Constitutional Court in order that it provide antiretroviral prophylaxis to HIV-positive pregnant mothers to prevent HIV from being transmitted from mother to child (PMTCT) (Geffen, 2010).

The failure of government to take a progressive stance on HIV/AIDS restricted what the health system could offer HIV-positive people and, as in the USA, HIV/AIDS treatment became a political issue (Schneider, 2002). Political wrangling delayed the roll-out of antiretroviral drugs for PMTCT and treatment for HIV/AIDS (Geffen, 2010). At the time of this study, antiretroviral drugs were available in the public sector, but not at all facilities. The politics surrounding ART may have influenced men in their help-seeking behaviour.

Black people's health and social networks were already severely disadvantaged when the HIV/AIDS epidemic reached South Africa, and prevalence in this sub-population remains the highest of all at 13.6% compared to 0.3% for whites, 1.7% for coloureds and 0.3% for Indians (Shisana et al., 2009). This situation is likely to be similar in Soweto, a predominantly black urban community that was established to house black migrant labour for Johannesburg, and has experienced decades of violent unrest. In this community, HIV prevalence in 2012 was very high at approximately 21%⁴ of the general population and 30% of women attending the antenatal clinics. This is expanded on in Part three.

The HIV/AIDS epidemic raised issues that political leaders were reluctant to discuss such as use of condoms, sexual issues, and illicit sex or drugs, as they sought to avoid being seen as condoning or tolerating these behaviours (DeWaal, 2006). Political leaders denied that HIV/AIDS was a problem and were reticent to be at the forefront of dealing with the HIV/AIDS epidemic (Fourie & Meyer, 2013).

⁴ The HIV prevalence is calculated from people testing in the primary care clinics in Soweto. Arguably these may be slightly higher than the general population, as the people who are testing could be the worried well.

In Africa, as elsewhere, HIV/AIDS was intrinsically linked to politics and sexuality, and this inhibited political leadership from engaging with the epidemic (Gevisser, 2008). Initially, when HIV/AIDS was thought to be a disease affecting homosexual men, African leaders denied that men in Africa would be susceptible to it as they believed or stated that homosexuality was “un-African.” This resulted in stigma, discrimination, denial and silence, all of which have been on-going features of the epidemic (Epprecht, 2008). Although many leaders failed to recognise HIV/AIDS as a national problem (Bor, 2007), some leaders such as Presidents Diouf (Senegal), Museveni (Uganda), and Masire and Mogae (Botswana) recognised the seriousness of the epidemic, and promoted various AIDS awareness and other campaigns as early as 1987 (DeWaal, 2006). Botswana, a relatively rich African nation, began its ART programme in 1999, soon after triple therapy or Highly Active ART (discussed in more detail later) was known to be effective. These leaders adopted different approaches, but it is thought that their leadership played a significant role in reducing infections in these countries (Low-Beer & Stoneburner, 2003; Allen & Heald, 2004; Parkhurst, 2004). Although some countries have made great strides in tackling the generalised HIV/AIDS epidemic, there has been little effort made regarding marginalised high-risk groups. In many African countries, the persecution of men who have sex with men continues, and in 2012 an anti-homosexuality bill was tabled in the Ugandan parliament.⁵

In South Africa, presidential controversy and denial of HIV/AIDS issues dominated the early years of democracy. Nelson Mandela (1994-1999) concentrated on reconciliation and seldom discussed HIV or AIDS. However, in 2005 he acknowledged that his son had died of AIDS and he subsequently supported AIDS initiatives (Heywood, 2005). Later Thabo Mbeki (1999-2008) denied there was a link between HIV and AIDS and promoted poverty as one of the main drivers of the epidemic (Beresford et al., 2008). He aligned with AIDS dissidents or denialists who held a “fringe position with no scientific credibility” (Natrass, 2007:34). Steinberg (2008:6) further comments that Mbeki “questioned with bitterness whether dying was caused by a sexually transmitted virus after all, and [Mbeki] asked caustically whether antiretroviral drugs were for the benefit of Africans or pharmaceutical companies.” By not addressing the HIV/AIDS epidemic from an established scientific basis these stances fed into AIDS denialism and

⁵ see for example <http://www.bbc.co.uk/news/world-africa-20463887> accessed 1 December 2012

encouraged quackery with a variety of products being promoted to cure or treat AIDS (Geffen, 2010). These views were widely reported on in the news media (Stein, 2003b). Mbeki's views hindered the public health system from fulfilling its mandate to provide ART (Coovadia et al., 2009). The lack of leadership on HIV/AIDS issues and government officials taking inconsistent and unscientific positions caused confusion. The extent to which this affected people's beliefs and help-seeking behaviour is not known. In order to understand this more fully, men's beliefs and understanding concerning HIV/AIDS and where to seek help are explored.

Political leadership continues to be challenging with male leaders acting as problematic role models for men in society, and influencing the way that masculinities are defined. For example, Ratele (2006) explored the concept of a "ruling masculinity" and its relationship to sexuality in the context of Jacob Zuma's term as president (2009-present). Ratele (2006:50) described ruling masculinity as "assertive heterosexuality, control of economic decisions within (and outside) the home, political authority, cultural ascendancy, and support for male promiscuity." President Zuma has taken a more progressive stance on promoting HIV/AIDS services than his predecessors, but his personal sexual relationships—which are risky for HIV infection—are a negative influence. Zuma believes in polygamy and has married six times. In late 2005 he was accused of raping a young HIV-positive woman who was a family friend and 30 years his junior. During the trial he stated that he had taken a shower to lessen the chances of being infected with HIV after having sex without a condom. This incident was widely reported in the press and instigated debate in the public sphere.⁶ Although he was eventually acquitted of the rape charge, his views on mitigating HIV risk and his sexual practices influenced others (Ratele, 2006). The ruling masculinity in South Africa is directed by heterosexual behaviour and patriarchal power relationships, with alternative masculinities and sexual minorities being side-lined (Connell, 2005; Hearn & Morrell, 2012). Men are influenced by their leaders' behaviour, and neither Mbeki nor Zuma have been role models for men regarding HIV prevention or treatment.

Political leadership influences individual attitudes as described above (Ratele, 2006), health sector development (Geffen, 2010), and plays a key role in determining the progression of the HIV/AIDS epidemic.

⁶ see for example <http://mg.co.za/article/2006-03-21-timeline-of-the-jacob-zuma-rape-trial> and <http://news.bbc.co.uk/2/hi/4750731.stm> accessed 15 September 2012.

Whereas a number of African countries have stable or decreasing HIV prevalence, South Africa's prevalence only started to level off in 2006 (Department of Health, 2012a). Surprisingly, some countries such as Zimbabwe, with little political leadership, have experienced a decline in HIV infection. There the decline is thought to be partly due to the natural course that epidemics follow, as well as to an observed reduction in the number of sexual partners, speculated to be owing to the downturn in the economy as people are unable to sustain the expense of multiple partnerships (Halperin et al., 2011).

In South Africa the lack of political leadership and communication about HIV/AIDS fuelled rumour, myths, and misperceptions about the disease, resulting in stigma and blame. The leadership vacuum was filled by civil society organisations, activists, and medical personnel working in the field. The paucity of political will to deal with HIV/AIDS has been criticised by many and was detrimental to the fight against AIDS (Heywood, 2005; Geffen, 2010). AIDS denialism hampered progressive public policy, slowed the roll-out of ARVs, and fostered an environment where there were misunderstandings about ART, and conspiracy theories flourished (Nattrass, 2012; Fourie & Meyer, 2013). Mbeki considered ART to be secondary to political and social reform (Beresford et al., 2008), although in 2006 he noted that South Africa has the largest HIV/AIDS programme in the world, but according to Nattrass (2007) it should have been a great deal bigger, and if it had started earlier approximately 330,000 lives could have been saved (Chigwedere et al., 2008).

Political wrangling was rife in 2006 causing debate on the best way to tackle HIV/AIDS and allowing the Department of Health to stall on providing ART in the public sector. These political agendas determined the Department of Health's policy, even after the rollout of ART started. The then-Minister of Health Manto Tshabalala Msimang refused to endorse ART. Rather, she promoted nutrition and micronutrients over ARVs (which she regarded as toxic), derailing efforts for international funding. More outspoken public servants such as the Deputy Minister of Health Nozizwe Madlala-Routledge tried to change HIV/AIDS policy, but this resulted in the termination of her appointment (Nattrass, 2007). These political agendas are likely to have caused consternation for HIV-positive people. They may have been wary of using "toxic" medicine, and therefore looked for help outside of the public sector (McGregor, 2005).

The extent to which the views of political leadership have influenced the uptake of ART is not known. In this study, men’s help-seeking behaviour is interrogated to understand where they would seek help for HIV/AIDS.

1.4 Where are we now with HIV?

HIV/AIDS is now a worldwide phenomenon affecting all populations, although in many countries HIV remains concentrated in high-risk populations, including MSM, IDUs, and CSWs and their clients (UNAIDS, 2013). In countries where HIV is a generalised epidemic, these high-risk groups should not be ignored. In Africa limited data exists for these high-risk groups, because national surveillance does not include information about sexual orientation, drug use, or sexual behaviour. Where data exists, these groups have higher prevalence (Rebe et al., 2011). Recent studies of HIV prevalence in MSM in a number of African countries have shown that HIV prevalence in MSM is significantly higher than the general population.

Table 1: HIV prevalence in African MSM (Johnson, 2007)

Country	MSM HIV prevalence	HIV prevalence in adults
Senegal	21.5%	0.2% (adult men)
Kenya	>40%	6.1% (all adults)
South Africa	40-50% est.	12%

In South Africa adult HIV prevalence is estimated to be 17.5% in the general population and 11% in the no-risk population, and although the high-risk groups are relatively small, prevalence in these groups is high: 20% in IDUs, 50% in CSWs, 30% in clients of CSWs and between 10% and 34.5% in MSM (SACEMA, 2009; Lane et al., 2011; Rispel et al., 2011; Tucker et al., 2012).

Sub-Saharan Africa remains one of the most affected regions, and Potts & Walsh (2003:1389) suggested that the rapid expansion of HIV/AIDS was “one of the greatest failures in the history of public health.” The impact of the epidemic is complex and difficult to quantify, as it affects all aspects of society: social, economic, and cultural, but especially health (Barnett & Whiteside, 2002; Gilbert & Walker, 2002), and has retarded economic growth in much of Africa (Sachs, 2005). The failure of governments to react quickly to the expanding epidemic allowed it to become established as generalised and predominantly heterosexually

driven, with proportionally more women than men being infected. Women in this region are especially vulnerable to HIV infection due to sexual violence, the imbalance of gender power in relationships, and their greater biological susceptibility to HIV infection (Dunkle et al., 2004; Jewkes & Morrell, 2010). This vulnerability has led to a focus on women and children, promoting them as the face of the epidemic and targeting campaigns and interventions towards these groups (Gilbert & Selikow, 2011). However, men are also vulnerable to HIV infection through heterosexual sexual intercourse, and in this region male-on-male sexual violence victimisation is fairly common (Dunkle et al., 2013), and particular groups of men such as MSM have high HIV prevalence.

In South Africa, the epidemic’s rapid progression is reflected in the HIV surveillance data collected on pregnant women attending antenatal clinics where prevalence has increased quickly from 0.7% in 1990, peaking at 30.2% in 2005 and levelling off thereafter. These data suggest that the epidemic is beginning to stabilise, albeit at a very high rate (Department of Health, 2011; Republic of South Africa, 2012).

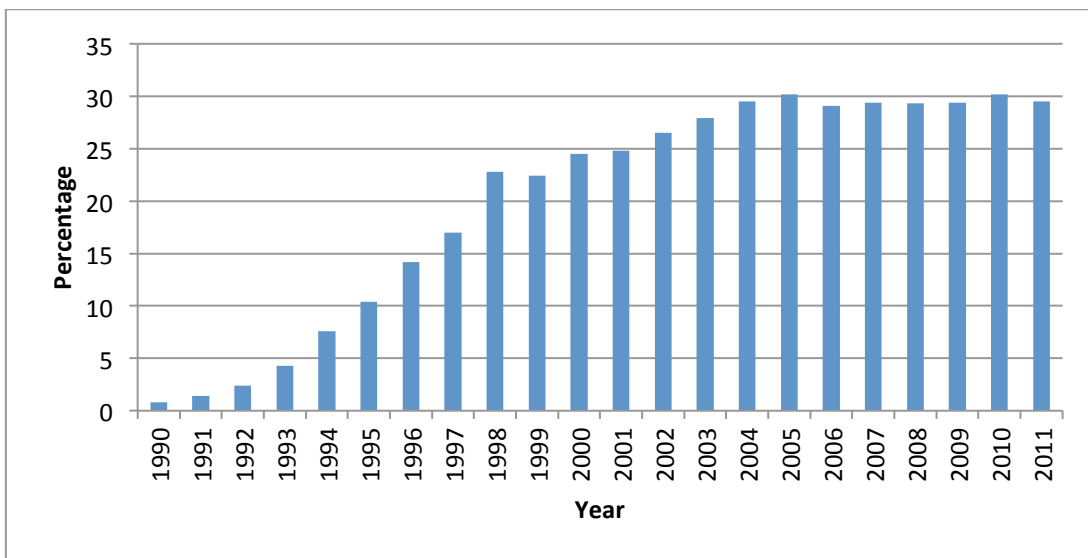


Figure 1: Antenatal HIV prevalence trends in South Africa (Department of Health, 2012a)

In 2013 South Africa’s population was estimated to be 52.982 million, with between 5.29 and 6.4 million people being infected with HIV, an HIV prevalence of over 10% (Statistics South Africa, 2013a; Shisana et al., 2014). However, prevalence varies considerably by province, race, age, sexual orientation, and gender,

implying multiple sub-epidemics (Department of Health, 2007) and these are not measured adequately. The Human Sciences Research Council's national HIV/AIDS study attempts to measure the scale of the epidemic in the general population, but has failed to do so in high risk or marginalised minority groups (Shisana et al., 2005). Similarly the antenatal HIV prevalence survey data only reports on women who are sexually active and have recently engaged in unprotected sex. These studies are unable to measure HIV prevalence in these sub-populations.

HIV/AIDS is often discussed in global, regional, or national terms by epidemiologists, with the more nuanced sub-epidemics or local variations being ignored. Data collection and reporting have followed the same route. In South Africa, HIV is largely spread through heterosexual sex and mother-to-child transmission, and the reported rates reflect prevalence in the general population, with prevalence in high risk groups being unknown. Yeboah (2007) argues that social sciences, such as medical geography, can provide policy-makers with useful insights by combining results from micro-scale research to show the multi-faceted nature of the epidemic and the interconnectedness of phenomena. An in-depth understanding of the impact of the epidemic in these sub-populations is needed. Furthermore, the emphasis has been on the generalised epidemic without obtaining a nuanced understanding of the different groups, including men, which comprise this population. This small, qualitative study investigating men's perception and understanding of the epidemic provides valuable insight into a section of the population that until recently has been largely ignored in HIV/AIDS research.

In general, men are less affected by the epidemic, as reflected in the South African HIV estimates. In 2013 adult female HIV prevalence was 17.4% compared to 15.9% in the general adult population (Statistics South Africa, 2013a), with this disparity being especially marked in the younger age groups where poor, young women are particularly vulnerable (Gilbert & Walker, 2002; Shisana et al., 2009). However, as can be seen in Figure 2, the disparity between males and females is not as marked in the older population (Dorrington et al., 2006). Therefore, men may be more vulnerable to HIV/AIDS as they get older.

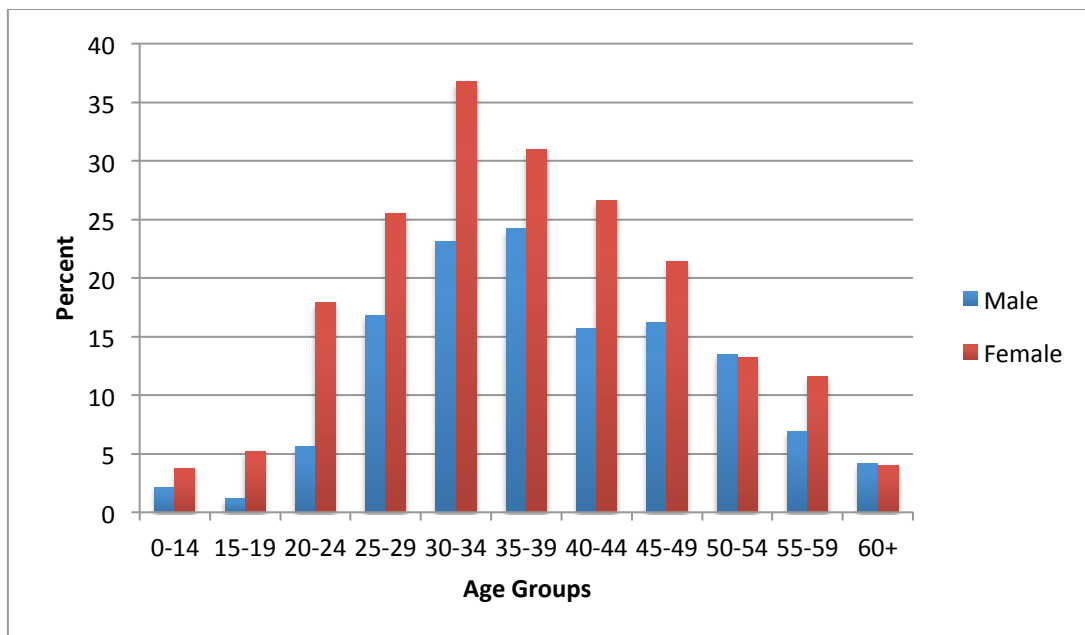


Figure 2: Disparity between male and female HIV prevalence in South Africa, 2012 (Shisana et al., 2014)

A number of factors driving the HIV/AIDS epidemic have been identified, including lack of social cohesion, socio-economic inequalities, and cultural norms (Redelinghuys, 2006). Both men and women are affected by these, but to differing extents, and neither group should be ignored. As described earlier, women’s vulnerability to HIV infection is ascribed to a number of socio-economic and cultural factors, including violence against women as outlined by Stewart et al. (2006:295): “Transactional and coerced sex, biological vulnerability, entrenched patriarchy, financial dependence on men and polygamous relationships all contribute to a climate where women are unable to negotiate safe sex practices with their partners.” Women’s relatively inferior position in society allows HIV/AIDS to impact more severely on women than men. Women are physiologically more susceptible to HIV infection, and they have borne the brunt of increased care-giving in the household due to HIV infection (Shisana et al., 2005; Gilbert & Selikow, 2011). Gupta (2002) notes that power imbalance and gender inequality limits women’s access to information and their ability to negotiate safer sex practices, and suggests that by empowering women there is a chance that the HIV/AIDS epidemic will be contained. These factors have led to women being the focus of attention. However, men are also vulnerable to HIV infection. Men’s vulnerability is increased by factors such as migration for work, urbanisation, long-distance trucking, unemployment, discrimination due to illness in the

workplace, and lack of education. Social and cultural norms such as polygamy, not using condoms in stable relationships, and sexual violence also increase the likelihood of HIV infection, and are often controlled by men (Redelinghuys, 2006). An understanding of men's vulnerability to HIV infection and factors affecting men's health is important to gain a fuller insight into the HIV/AIDS epidemic, but has been neglected in the past.

The South African government recognises that the spread of HIV is closely related to risky sexual behaviours, but that other factors are important too. The National HIV, AIDS, and STI Strategic Plan for South Africa (2012-2016) identifies various behavioural, social, biological, and structural determinates that may mitigate the impact of the epidemic including gender roles and norms that "... increase women's vulnerability to HIV and compromise men's and women's health; address the position of women in society, particularly their economic standing; and engage with men on changing socialisation practices." Men are included as a key population (i.e. most at risk for being infected with HIV) needing special attention in order for the epidemic to be brought under control (Department of Health, 2011: 23).

In order to redress the lack of understanding of men's vulnerability to the HIV/AIDS epidemic, this study explores men's health needs and some of the gender dynamics that may influence men seeking or receiving help. Men's help-seeking behaviour is an aspect of men's behaviour that may explain why men have been identified as a vulnerable population in South Africa.

1.5 Mental health and HIV

In various studies, higher rates of suicidal ideation and actual suicide have been found among HIV-positive people compared to the general population. A literature review conducted in 2005 by Colibazzi et al. (2006) found prevalence rates of depression and suicidal ideation to be similar in people with HIV/AIDS to those with other chronic diseases, but higher than prevalence in the general population. Common attributes linked to HIV/AIDS-related stigma and suicide were social isolation, hopelessness, anxiety, poor social support, loss of relationships, and poor coping skills.

In Swiss HIV-positive patients it was found that pre-ART suicide was driven by disease progression. Suicide rates declined significantly after ART was introduced, but remained above those in the general population. Associated with suicide was a diagnosis of mental illness, with depression being most common, followed by

anxiety and psychotic disorder (Keiser et al., 2010). Similarly, in a study in England, Wales, and Northern Ireland, higher suicide rates were found in HIV-positive men (6.3%) than women (3.0%), and again higher than in the general population (Rice et al., 2010). In a USA group of HIV-positive people, aged 45 and above, 26% had thought about suicide, with men being more susceptible to suicidal thoughts than women. Interestingly men were more likely to have disclosed their status to someone close, but perceived that they received less social support (Kalichman et al., 2000). A South African study of 112 patients admitted to a hospital found that more women than men attempted suicide, many of whom were unemployed; however, most had an underlying mood disorder. Again the attempted suicide rates calculated for HIV-infected individuals were much higher than in the general population, with a real increased risk of between 13% and 19% (Schlebusch & Vawda, 2010a).

Although aspects of mental health such as depression and suicide were not specifically explored with the Soweto men, they were mentioned frequently and are discussed later.

1.6 Lay interpretations of HIV

The scientific and epidemiological evidence of the origins, mechanisms, and spread of the virus are now well documented. However the complex lay interpretations of the epidemic are not, and can be broadly divided into two categories: firstly, unnatural, supernatural, or spiritual causes, and secondly, natural or biological causes (Goldin, 1994; Pearson & Makadzange, 2008). In South Africa the former have been found to include racial, traditional African and Christian religious causes (Dickinson, 2013). These interpretations or belief systems determine what action or help-seeking people are likely to take regarding their illness.

In numerous sub-Saharan African countries, many people believe that HIV – as with other illnesses – is a curse that can be attributed to witchcraft (Stadler, 2003; Thomas, 2006; Steinberg, 2008). Illness caused by unnatural or spiritual forces can be the result of conflict either in social relationships or in the relationship between people and religious or ancestral forces (Pearson & Makadzange, 2008). Secrecy and witchcraft often go hand in hand, resulting in rumour, gossip, and stigma (Stadler, 2003). These beliefs may affect where, when, and how people seek help either for themselves or for others, as described by Thomas (2006:3182) about a young HIV-positive woman who had been ill for a number of years. “However, because her condition had failed to improve, and her relatives suspected witchcraft (requiring ‘traditional’ medicine),

they were unwilling to spend further resources to take her back to the hospital.” In this case, the young woman’s family thought that she was bewitched and they opted for treatment from the traditional sector.

Research among black South Africans conclude that there are differing points of view regarding the extent to which people attribute illness to supernatural causes. Ashforth (2002) suggests that the belief that illness is caused by witchcraft is common, and results in stigma and isolation. But Delius & Glaser (2005) oppose this view and suggest that sexual taboos and death associated with HIV/AIDS have fed into other beliefs around pollution and contagion in order to explain the epidemic.

Ashforth (2002) noted that the symptoms of HIV-related illnesses are vastly different to those of sexually transmitted infections (STIs), which are commonly associated with witchcraft. But Steinberg (2008: 29) found that many symptoms of HIV-related illnesses were ascribed to witchcraft. He explained that symptoms of cryptococcal meningitis and AIDS dementia were described as “a demon sent to him by an enemy” and shingles was “to have had a witch’s snake crawl over her skin while she slept.” Depending on the affected person’s belief system he or she would seek help from the practitioner he or she believed would be most appropriate, and he or she was likely to seek help from both traditional and Western medicine.

Although some of the symptoms of HIV/AIDS and STIs may be similar, HIV/AIDS differs from many other sexually transmitted infections in that it is relatively difficult to transmit and has a long incubation period before signs or symptoms appear. When symptoms appear, which could be years after initial infection, it is difficult to directly link them to a particular sexual encounter. This is unlike STIs, where symptoms appear fairly soon after infection and can be directly linked to a sexual encounter, since they appear in or on the sexual organs (Ashforth, 2002). STIs and HIV/AIDS may be believed to be linked to witchcraft, but the extent to which this happens is disputed. The Soweto men interviewed are all black South Africans, and the extent to which they subscribe to the belief that HIV/AIDS is caused by witchcraft is explored to determine if and why they consult traditional health practitioners (THPs), which may explain the lack of men attending clinics.

The complexities surrounding understanding illness and help-seeking behaviour are highlighted in a South African-based study on STIs where it was found that people engaging in sexual intercourse are expected to conform to certain rules and taboos, but by transgressing these a disease such as an STI could result. In this

case the disease is thought to be spiritually-caused and a THP would then be able to diagnose and treat it. However, it was found that a variety of treatment routes were followed, including self-treatment, engaging one or more traditional healers at the same time, and consulting with the formal health sector, often simultaneously. The health sector cured the symptoms whilst the traditional sector cured the cause (Meyer-Weitz et al., 1998). This health care pluralism or engaging with different sources of help at the same time is fairly common, and is discussed in more detail and explored with the men.

As described in this chapter, confusion about HIV/AIDS has persisted since the first cases of AIDS were diagnosed in the early 1980s and this has often sown doubt about what the disease is, how it is contracted, and where, or from whom to seek help. Over time there have been huge advances in understanding the routes of transmission and the progression of the disease. Further scientific breakthroughs in treatment and care have been made, but in many cases these still need to translate into accessible help for the most vulnerable groups. Understanding the complex interplay between lay explanations of the illness and the relationship between STIs and HIV/AIDS is important. These explanations determine the most appropriate agencies from which to seek help. This study engages with the questions of whether these explanations impact on or shape men's reluctance to engage with HIV/AIDS services in Soweto.

Chapter 2: Stigma

For over 25 years, since the first cases of HIV/AIDS were diagnosed in the mid-1980s, stigma has been a central feature of the epidemic. Issues such as gender, sexual orientation, marginalisation, and secrecy have contributed towards perpetuating it (Stein, 2003a; Walker et al., 2004). As Cameron in Walker et al. (2004:7) commented: “From the start, the disease was stigmatised, its first known bearers being gay men on the west and east coasts of America, of London and Paris, and of Sydney, Johannesburg and Cape Town. Thereafter it was associated with stigmatised minorities in the United States and elsewhere ... the disease now overwhelmingly affects poor heterosexuals in the developing world.” The late Jonathan Mann, founder of the World Health Organisation’s (WHO) Global Programme on AIDS, described the HIV stigma as “the denial, blame, stigmatisation, prejudice, and discrimination which the fear of AIDS brings out in individuals and societies” (Panos Institute & Norwegian Red Cross, 1990:i). This chapter outlines the debates around defining stigma, examines how HIV being sexually transmitted contributes to stigma, investigates stigma in respect of HIV/AIDS services, analyses how stigma impacts on the individual, and on disclosure.

2.1 Stigma and discrimination

Defining stigma is not straightforward, and has been the subject of considerable debate. Much of the literature on stigma refers to Goffman’s seminal work, which describes stigma as an attribute that is “deeply discrediting” or an “undesirable difference” resulting in a “spoiled identity” and someone to be avoided (Goffman, 1963). He differentiates between the “normals” and the “stigmatised” and identifies three attributes that, individually or combined, can result in stigma. These are, firstly, visible signs such as changes in physical appearance or physical deformities, secondly, character blemishes that could include homosexuality, mental illness, or imprisonment, and, lastly, tribal or inherited attributes referring to race, nationality, or religion.

This individualised static approach to stigma has been criticised by various researchers who suggest instead that stigma is a complex context-specific phenomenon with dynamic social processes linked to social power relationships that change over time (Parker & Aggleton, 2003; Deacon, 2006; Yang et al., 2007; Scambler, 2009) and perpetuates social inclusion and exclusion (Campbell & Gibbs, 2009). Therefore stigma is based on difference and can be used by more powerful groups in society to distinguish, protect, and distance

themselves from others. In many societies men are relatively more powerful, have a higher social standing than women, may experience less stigma, and be better off than women (Mfecane et al., 2005; Skinner & Mfecane, 2005; Wyrod, 2011). However, Campbell & Gibbs (2009) note that HIV/AIDS threatens male society by undermining male-dominated institutions and revealing the failure of patriarchy to control women.

The tensions between individual and social explanations of stigma led Deacon et al. (2005) to suggest that an integrated approach should be taken, and that stigma should be defined on its own and not in terms of discrimination, since stigma does not necessarily lead to discrimination. Stigma may be felt or anticipated by the person who has the stigmatising disease, also known as internalised stigma, or it may be enacted by others through discrimination, or both can occur. All forms of stigma impact negatively on a person's wellbeing (Scambler, 2004; Gilbert & Walker, 2010). Further, stigma perpetuates existing social inequities including class, race, and gender, and Scambler (2009) proposes that stigma and deviance – the shame and the blame – need to be dealt with separately.

Disease stigma may be defined as “negative social ‘baggage’ associated with a disease” and is a social process influenced by the cultural, biological, situational, social, and political context, which results in people distancing themselves from others (Deacon et al., 2005). Drawing together the individual and the social aspects of stigma, the following dimensions of stigma emerge: instrumental stigma being the fear of infection, symbolic stigma including moralistic shaming and blaming, external stigma being enacted or expressed views, internal stigma where the diseased individual feels or perceives stigma, and courtesy stigma, which is directed at people associated with the person who is ill (Deacon et al., 2005; Deacon, 2006; Deacon et al., 2010)

Stigma affects people's everyday life and impacts on what “matters most” (Yang et al., 2007). However, stigma is not a hegemonic process and people can resist both enacted and self-stigmatisation. A recent South African study found that people with HIV/AIDS are able to resist stigma and regard themselves as normal, even though stigma formed part of their everyday lives and they were afraid of it and the related gossip and insults (Abrahams & Jewkes, 2012). Campbell & Gibbs (2009) suggest that the key to resisting stigma is for people to have the confidence to withstand marginalisation. In summary, stigma impacts negatively on people's lives, but it can be resisted and be reduced over time.

Discrimination is what people do to unfairly disadvantage others and can be a result of stigma, but it can also result from other factors, including resource concerns, fear of infection, racism, and sexism (Deacon et al., 2005). But there is a need to separate discrimination from differential treatment based on “rational assessment of risk” that may be fair or unfair and can be used to redress inequalities, to prevent infection, for social distancing, and to balance social contributions. Unfair discrimination includes practices such as not shaking hands to reduce risk, or making moral judgements such as inferring that an HIV-positive person was promiscuous.

Internalised stigma, where people expect to be stigmatised or discriminated against, can have a negative impact on HIV-positive people by preventing them from seeking help, whether or not others are aware of their status (Scambler, 2009; Deacon et al., 2010). It also decreases their ability to garner support from the family and community. As Nyirenda et al. (2006:75) note: “Stigma invokes powerful psychological feelings in people living with HIV/AIDS, including how they view themselves in relation to other people.” Internalised stigma may therefore inhibit people from accessing help.

This sentiment is endorsed by Cameron (2005:52) who deems that many people think that HIV-positive people are “contaminated with a vile, self-induced affliction”, and many HIV-positive people believe the same of themselves. Although in the studies of Green (1995) and Maman et al. (2009) only a minority of their respondents admitted to holding stigmatising views, they suggested that other people held them. However, the majority of their HIV-positive respondents had experienced stigma and engaged in behaviours that protected them from it. As a result, many HIV-positive people are inhibited from disclosing their status to others and end up isolating themselves (Sengupta et al., 2011).

Internalised stigma, discrimination, and depression were found to be common in a group of HIV-positive men and women in Cape Town. Men experienced higher rates of discrimination than women did, such as being treated differently and losing a job or place to stay because of their HIV-positive status. Men also did not discuss HIV/AIDS with their friends, received less social support, and used more alcohol and drugs (Simbayi et al., 2007). Men are adversely affected by stigma and discrimination, and perhaps even more so than women. This study explored men’s experience of stigma and the influence it had on their disclosing their status or seeking help.

Against this background of social stigma, at an individual level people may be inhibited from testing before they are ill because “they may not wish to spoil the experience of feeling well by finding out they are HIV-positive, especially in the absence of a cure” (Deacon et al., 2005:60). There is a relationship between HIV stigma, prejudice such as racism or disability, and social inequalities that assert negative meanings on physical difference (Goffman, 1963; Sontag, 1990; Deacon et al., 2005). However, physical markers of HIV/AIDS are not visible for many years after infection and perpetuate the denial. This encourages secondary markers to be used to confer a diagnosis of HIV/AIDS onto a person. These markers may include illnesses such as tuberculosis (TB), weight loss, or a person being associated with a group known to be at higher risk for HIV/AIDS, such as being homosexual or promiscuous (Sontag, 1990; Deacon et al., 2005). The absence of physical markers means that it is not apparent who is infected and who is not, and this endorses the notion that HIV/AIDS affects “other” people. In this case the invisible may be more scary than the visible, and thus supposition is made on a person’s status based on factors that may have no bearing on the illness. The extent to which the physical markers of HIV/AIDS disease influence men to take care of their health was explored. In addition, the men were asked if they could identify people who they think are HIV-positive and what these markers of HIV/AIDS disease are.

Euphemisms or metaphors, although not always stigmatising, are often used when referring to HIV/AIDS, and allow the person using them to distance themselves from the “other” (Goldin, 1994). These metaphors often arise from myths and superstitions about a disease that is not well understood, and they attribute fault, guilt, and shame to the person who is infected. HIV/AIDS has attracted many genres of metaphors including military ones usually associated with cancer that suggest an invasion and a crafty enemy, and ones of pollution more often associated with syphilis suggesting contamination (Sontag, 1990). Sontag also notes that these metaphors can make people “irrationally fearful” of the disease, and delay seeking help or being tested.

In South Africa metaphors have proliferated and Stein (2003a) suggests that this is due to the stigma surrounding HIV disease, noting that in the Western Cape people use the term “ulwazi” which means “that thing” instead of HIV or AIDS. Steinberg (2008) uses the term “the three-letter plague”. However, there is evidence that metaphors in the media have changed over time as the epidemic has progressed from images of pollution and contamination, which engendered blame to those of travel and transport that are more

informative, explaining HIV transmission (Hanne & Hawken, 2007). Metaphors are a gauge of the level of HIV stigma, and their nature and usage was included in this work.

2.2 Stigma and sex

As indicated, stigma is not a new phenomenon and has been associated with a wide range of diseases including HIV/AIDS (Scambler, 2009). However, it is particularly associated with diseases that are sexually transmitted or terminal. HIV/AIDS is predominantly sexually transmitted and until the relatively recent introduction of ART, was a terminal illness, so the dual nature of HIV/AIDS has exacerbated HIV-related stigma (Deacon et al., 2005). In South Africa the provision of ART was delayed until 2004, resulting in many deaths that may have heightened the HIV-related stigma.

HIV-related stigma has resulted in people anticipating being stigmatised and thus keeping their HIV-positive status a secret. At the same time, people who are HIV-positive may be discriminated against and isolated. However, HIV/AIDS has real health disadvantages as it is contagious and potentially dangerous to HIV-negative people, therefore people with HIV may be avoided even if they are not stigmatised (Deacon et al., 2005).

Stigmatisation may be further differentiated according to how the virus was contracted. For example, “innocent” people may get infected through blood transfusions, but infection through sexual transmission and what is considered reckless or immoral behaviour may be interpreted as a person being deviant and “blameworthy”, and may result in “othering” (Deacon et al., 2005; Maman et al., 2009). Further moral judgements about sexual misconduct have isolated people infected with HIV/AIDS (Yang et al., 2007). Therefore, HIV-related stigma is not only associated with the disease but also with other attributes that are determined by the level of prejudice and social stereotypes in society, such as what is considered to be immoral conduct, and sexual and racial differences (Sontag, 1990).

Blame for spreading HIV has been attributed to various groups, but mainly those that are marginalised, or in a minority, such as MSM, CSWs, IDUs and Africans in Eastern Europe (Foreman, 1999). This compounds the HIV stigma (Sengupta et al., 2011). Foreman (1999) maintains that ignorance and prejudice are the main contributors to blame, but Deacon et al. (2005:18) suggest that “Stigma is a fundamental emotional response to danger that helps people feel safer by projecting controllable risk, and therefore blame, onto outgroups”

These outgroups include “‘oversexed’ blacks, white people, ‘promiscuous’ gay men, commercial sex workers and women in general” (Deacon et al., 2005:7), thus stigmatising a tribe or group as described by Goffman (1963).

Blame for HIV infections is often attributed to “others”, to groups that are different to one’s own group, and is exacerbated by practices or behaviours that feed into existing prejudices such as drug abuse, and by social power relations (Deacon, 2006). The perception of threat can either be tangible, for example life threatening, or be symbolic to the “moral order”, such as deviant behaviour. Blaming models draw on the notion of prejudice and help to explain an individual’s role in constructing and perpetuating stigma, which is seen as a problem of “fear and blame” rather than an individual’s ignorance or a function of social control (Green, 1995; Deacon et al., 2005). The extent to which HIV-positive people are considered to be blameworthy or innocent victims in Soweto is not known, nor is it known whether this affects HIV stigma or men’s help-seeking behaviour. This study explored men’s views on HIV-positive people to understand the level of prejudice in the community and whether this influenced their help-seeking behaviour.

Stigma does not only reside with an individual, but is pervasive in communities, society, country leadership, the health system, and in secular and religious organisations (Deacon et al., 2005). There has been a notable lack of leadership in Africa on issues pertaining to HIV/AIDS, with many governments being in denial about it, particularly early on in the epidemic, and thus they have failed to respond adequately to it. As a public health issue many leaders, health workers, and the public are unwilling to discuss HIV/AIDS since it is a sexually transmitted disease, and sexuality is linked to moral decay (Mboup et al., 2006). Further, HIV/AIDS was perceived by many people to be a racist conspiracy, “bacteriological warfare”, and a means of controlling the African population-growth and discrediting Africa (Sontag, 1990). This resulted in numerous leaders concentrating on issues such as reducing poverty, which they felt were more urgent and perhaps easier to deal with than engaging in discussions on sexual behaviour (Goldin, 1994), but this was detrimental to curbing the HIV/AIDS epidemic.

Although sex undoubtedly plays a role in stigma, Delius & Glaser (2005:29) in their historical analysis of HIV stigma in South Africa found that it was not the only contributing factor, and that “concepts of pollution, belief in witchcraft and popular understandings of contagion” feed into stigmatising beliefs. The

incurability of the disease and the apparent inevitability of death are associated with the belief that those who are HIV-positive are polluting or dirty whilst they are alive. These attitudes endorse silence and secrecy, discourage disclosure and help-seeking, and promote stigma (Green, 1995). The extent to which these factors contribute to the HIV stigma and to inhibiting men from stepping forward for HIV testing and seeking treatment for HIV/AIDS are explored further in this study.

Over the lifetime of HIV/AIDS disease, HIV stigma is likely to become progressively more severe. In the early stages HIV infection is invisible, and the progression unpredictable, but as the disease progresses to AIDS it becomes increasingly visible and disfiguring and people with HIV/AIDS are identifiable. Before ART was widespread, HIV/AIDS was, and in some countries continues to be, a terminal disease. ART reduces morbidity and mortality but the side effects of treatment can result in visible disfiguring body changes (Hurley et al., 2011), which may alert others to their status. In one South African study nearly 50% of patients with lipodystrophy, a side effect of ART, were willing to undergo corrective surgery (Zinn et al., 2013). Further, it was found that MSM are concerned about the effects of ART on their appearance. A study conducted in New York on gay men living with HIV found that men were becoming increasingly aware of their physicality and body image in reaction to the effects of HIV/AIDS and that of ART on their bodies. These effects include weight loss, muscular wasting, and sexual dysfunction (Halkitis, 2001), and may further deter MSM from seeking help for HIV. According to Herek (1999) four attributes of HIV/AIDS elicit stigma. Namely, that it is the “bearer’s responsibility”, is “unalterable or degenerative”, “contagious” thereby “plac[ing] others in harm’s way”, and “readily apparent to others.” Both the disease and the current treatment contribute towards these attributes that are viewed negatively by the public and tie in to Goffman’s notion of stigma.

HIV stigma has adversely affected prevention efforts and hindered people from acknowledging that they may be HIV-positive, testing for HIV, accessing ART, or getting support from their family and community (Deacon, 2006; Nyirenda et al., 2006; Schneider, 2006; Simbayi et al., 2007; Campbell & Gibbs, 2009). ART has proven benefits for people who are HIV-positive, but many people who need treatment do not access it. HIV stigma has been put forward by many scholars (Cameron, 2005; Campbell et al., 2005; Skhosana et al., 2006; Gilbert & Walker, 2010) as the main reason for people staying away from HIV/AIDS

services, suggesting that people would rather die of the disease than face the stigma attached to it. This implies that both enacted and internalised stigma play a role.

In South Africa some communities are more open about sexuality than others, but this changes over time. In their historical analysis of sexuality in South Africa, Delius & Glaser (2005) found that in traditional black communities sex is considered a normal activity. However, they suggest that it was “Christianity which brought shame to the sexual act” (Delius & Glaser, 2005:31). They noted that the church was important in silencing the discussion about sex. Further Christianity often overlaps with indigenous religious practices and there is a “tendency to comprehend epidemics as divine punishment for moral transgression.” These transgressions may include homosexuality and promiscuity, and HIV/AIDS can be punishment from God on a community that is tainted (Sontag, 1990). South Africa is predominantly Christian⁷ with about 80% of the population following the Christian faith. At the same time, cultural and traditional practices are often brought into the church (Reid, 2013). Admitting that one is HIV-positive may be difficult, as it could infer that one has been engaging in behaviour that is unacceptable to the church or the community and this may encourage people to hide their HIV status for fear that they will be ostracised.

The HIV/AIDS epidemic has necessarily put sexual health and issues that were previously considered personal and secret into the public arena. Serrant-Green & McLuskey (2008:2) comment, “Sexual health is in general no longer simply a matter of a physical act with consequences for an individual, but is recognised by Government, health and social care providers as an area of health need requiring planning, assessing and services to support it.” However, sexuality and sexually transmitted infections, including HIV, have been linked to a lack of morality and promiscuity and sexual health matters have been associated with “social taboo, privacy and blame” (Serrant-Green & McLuskey, 2008:3). This was confirmed in a study conducted in Caprivi, Namibia, where it was found that stigma was closely associated with “immoral behaviour and by the terminal nature of the infection” (Thomas, 2006:3175).

HIV stigma has a profound impact on all people who are HIV-positive, including men. At an individual level, stigma prevents people from acknowledging that they are HIV-positive and encourages them to keep

⁷See for example <http://www.info.gov.za/aboutsa/people.htm> accessed 29 March 2013

their status a secret, thereby preventing them from seeking help. In the clinics, health workers may shun HIV-positive people because they fear that they may become infected and they confer moral judgements on their patients for becoming infected. In the community people who are suspected to be HIV-positive are avoided and therefore HIV-positive people are unlikely to want others to know their status, even to the extent that they do not want to be seen going to a clinic. The types and levels of HIV stigma were explored with the men and secondary informants to determine how it affected the men and others seeking help for HIV/AIDS.

2.3 Stigma and HIV/AIDS services

HIV/AIDS services are markers of the disease and people may avoid going to health services to escape stigmatisation and are therefore not tested and cannot be effectively treated for HIV (Deacon et al., 2005). As indicated earlier, HIV-related stigma has been found to be a barrier to accessing HIV prevention and treatment services (Schneider, 2006). Additionally, it has been found that stigma is reduced if people know their status (Day et al., 2003; Kalichman & Simbayi, 2003). This was confirmed in a study conducted in Botswana in 2000 that investigated stigma's role as a barrier to HIV/AIDS services. At that time there was no national roll-out of ART and male participants were recruited from patients attending a private clinic. It was found that 40% of patients had delayed getting tested for HIV, with the main reason being the fear of a positive result (51%), which when investigated further was frequently due to stigmatisation. HIV-stigma was also cited as a reason to delay testing and as a reason not to take ART regularly (Wolfe et al., 2006). People who visit clinics where HIV/AIDS services are being delivered may be tainted as being HIV-positive.

Stigma and discrimination are not only widespread in communities but are pervasive within the health system, and are barriers for people who want or need to access HIV/AIDS services. Research has shown that the quality of the service deteriorates as the levels of stigma increase. Ridding health settings of stigmatisation and discriminatory practices must be prioritised to improve access and public health outcomes. Both experienced and perceived stigmas are associated with reduced access to services and people postponing or rejecting care (Nyblade et al., 2009; Bogart et al., 2013). Stigmatisation and discrimination in the health system act as barriers to HIV-positive people accessing help.

In turn, health workers worry about their own diagnosis and fear that colleagues will reject them or see them as failures should they be HIV-positive. Nyblade et al. (2009) argue that there is also fear of contagion

caused by “lack of awareness”, “fear of casual contact”, and “association of HIV with improper or immoral behaviour.” They therefore suggest that interventions need to be directed at the health worker to reduce prejudice, and at the facility to ensure a safe working environment. At the individual level awareness of, and understanding about stigmatisation needs to be tackled. The real risk of contracting HIV in the facility needs to be determined. Clinic staff need values clarification about “immoral behaviour” and shame and blame to reduce prejudice towards HIV-positive patients. At facility level there must be sufficient equipment for infection control, and policies to protect patients’ rights. There is a need to take cognisance of health workers as an additional barrier for people accessing help.

ART has shifted the outcome of HIV/AIDS from being terminal to a chronic illness. In the South African context, access to ART is not yet universal and there are significant obstacles to accessing it, including the lack of human resources, a non-integrated health service, continued distrust of antiretroviral medication, poverty, and the high use of traditional medicines (Ojikutu et al., 2007). Public debate on ART and the resultant controversy of AIDS denialism may have impacted on stigma reduction and impeded access to treatment (Natrass, 2012).

Few studies have examined men’s engagement with and their perspective of HIV/AIDS-services. Levack (2005) investigated men’s participation in voluntary counselling and testing (VCT) and PMTCT and found that the main reasons for not testing could be divided into three levels. Firstly, at an individual level men feared their results, they assumed their status was the same as their partner’s, they did not value knowing their status, or they did not feel they were vulnerable to HIV. Secondly, on a societal level HIV stigma played a significant role, as well as men’s gender socialisation. Finally, at the institutional level, poor treatment by nurses and lack of confidentiality were major barriers. Reasons for testing included having health problems, being influenced by a friend or partner, knowing someone with HIV, having a sense of responsibility, or wanting peace of mind.

The literature suggests that HIV/AIDS services carry a stigma and may be avoided, and that health workers can be prejudiced towards HIV-positive people. Levack suggests that men find it difficult to engage with the health system. This study explored whether HIV/AIDS services are tainted and avoided by the men in Soweto. The men’s opinions on the health workers and the health system were sought to determine if these

inhibited them from accessing help. In addition, health workers were interviewed to understand their perspectives about stigma, and what they perceive the barriers to be that discourage men from accessing HIV/AIDS services. Health workers' views on HIV-positive men and their help-seeking behaviour were explored.

2.4 Disclosure

Disclosure of one's HIV status is encouraged by international organisations such as UNAIDS and WHO and by health workers in South Africa. It is thought to be beneficial for those who are HIV-positive to disclose their status as they are then able to seek appropriate social and medical help, and it assists adherence and prevents the spread of HIV to others⁸. However, it can also have negative outcomes such as being stigmatised, discriminated against, feeling shame about one's positive status, and having either perceived or real loss of friends (Paxton, 2002; Dageid et al., 2012). This may persuade people to keep their status secret and not to seek help rather than face these negative consequences.

Although disclosure of one's HIV status is encouraged, disclosure can lead to discussions on sexual health that people find difficult as sexual health matters are considered to be private (Serrant-Green & McLuskey, 2008). Stigmatisation makes disclosure difficult as it can reveal aspects about the person and their lifestyle that may previously have been hidden or secret. These lifestyle choices may be considered deviant or immoral, such as being sexually active, not using a condom, being promiscuous, engaging in homosexual activities, or being a member of a risk group or could be innocent, such as being infected through a blood transfusion (Sontag, 1990; Deacon et al., 2005). So for many people, disclosing that one is HIV-positive remains a complicated issue. As articulated by Geffen (2010:109-110) "... many people would find it easier to confront their families with a terminal cancer diagnosis than their HIV status." Further, for men, the fear of stigmatisation after disclosure was higher than the stigmatisation that they actually experienced (Wyrod, 2011; Dageid et al., 2012), and the process of disclosing may challenge their own and society's notions of masculinity (Lynch et al., 2010; Mfecane, 2010). Therefore, issues are explored further to determine if they

⁸ http://www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub02/jc-execsumm_en.pdf accessed 28 May 2013

increase men's reluctance to go to a clinic for HIV testing or for treatment, since going to a clinic could raise suspicion that one is HIV-positive and could confer behaviours on them that may or may not be real.

There is convincing evidence that HIV stigmatisation prevents disclosure, as found in the Botswana study mentioned above, in which 94% of respondents kept their status secret from the community, 69% from their family, and 12% had not disclosed to anyone (Wolfe et al., 2006). Although both men and women were interviewed, the study does not provide a breakdown between sexes. It appears that HIV stigmatisation forces people to keep their status secret. Preston-Whyte (2003) suggested that this secrecy encourages the spread of the disease and threatens intimate social connections. Preston-Whyte and others (Nachegea et al., 2005; Kalichman et al., 2006; Skhosana et al., 2006; Norman et al., 2007) conclude that stigmatisation will be reduced as more people know their status, and if the silence and secrecy surrounding HIV/AIDS can be broken.

It is not easy to determine whether it is stigma or silence or both that perpetuates lack of disclosure. However, what is known is that disclosure is difficult, and people decide carefully who they disclose to. Since disclosure is such a crucial but complex step in the trajectory of HIV/AIDS, it is explored in this study by examining men's perceptions of disclosure, whether they disclose their status or not, to whom they disclose, and their reasons for disclosure.

2.5 Measuring stigma

Having established the importance of stigmatisation in HIV/AIDS and its impact on prevention and treatment, it is imperative to focus on the complexity of its measurement. Deacon et al. (2005) and Stein (2003a) note that measuring stigmatisation is difficult, partly because stigmatisation has been measured in terms of discrimination. In addition, there is awareness amongst respondents that discrimination is not acceptable, and thus do not respond honestly to surveys.

The lack of consensus on defining stigmatisation has made comparing research findings difficult, and although many South African studies suggest a decline in stigma, others suggest only a levelling of internalised stigma (Abrahams & Jewkes, 2012). ART has changed HIV/AIDS from being a fatal disease to a chronic illness — no longer either a terminal illness or severely disfiguring — and with these changes, stigmatisation was found to have diminished in some areas in South Africa (Zuch & Lurie, 2012).

Interestingly, Maughan-Brown (2010) found that although stigmatisation in South Africa was relatively low, despite an increase in ART roll-out stigmatisation has not diminished, and suggested that this may be due to the high prevalence of HIV and the fact that general knowledge about HIV/AIDS is poor. This was confirmed in a Cape Town study that found that higher AIDS stigmatisation correlated with poorer HIV/AIDS knowledge and lower risk reduction intentions (Kalichman et al., 2006). Other factors contributing to HIV stigmatisation include prejudice and fear of particular groups, a lack of HIV knowledge, terminal illness, not knowing people who are HIV-positive, lack of access to treatment, and speculation on how HIV is transmitted (Sengupta et al., 2011).

These studies were mainly quantitative in nature, and it was found that few explored the nuanced voices of HIV-positive people (Abrahams & Jewkes, 2012), and data are scarce on how stigmatisation may, in a variety of complex ways, impact on men. Although ART provides considerable benefit to the individual, HIV stigmatisation remains a problem and is likely to deter many people from accessing HIV treatment.

The literature on stigmatisation has generally focused on population level findings and lacks a nuanced understanding on whether or how HIV stigma specifically influences men accessing ART. For this reason, this qualitative study addressed this gap by exploring the various dimensions of stigmatisation from the viewpoint of men to determine if stigmatisation deters them from accessing HIV/AIDS services.

Chapter 3: Masculinity

Men's studies were spurred on by the feminist and the women's liberation movements of the 1970's that focused on power relations, women's suffering and the impact on women's health (Connell, 2005). These movements largely excluded men and their experiences, and the male identity was generally negatively defined. In reaction to this, men's studies emerged to explore these issues and over the last two decades have multiplied and expanded to include a better understanding of masculinity, the diversity of the male identities and how these have transformed over time (Connell, 2005; Seidler, 2006). Despite the increase in men's studies, the voices of men are seldom included in them, and the focus in this study is to hear what men say about their health, help-seeking, and HIV.

Defining masculinity has been difficult and has changed over time, influenced by context, race, politics, social institutions, and individuals' perceptions (Connell, 2005; Reysoo, 2005). These complexities are highlighted by Foreman (1999:16): "Whatever the roots of masculinity, the word is difficult to define, not only because each society views men differently, but because 'masculinity' combines observations as to how men do behave and opinions as to how they should behave. Furthermore, ideas of masculinity are changing rapidly in many societies, particularly among the middle classes, and behaviour that was accepted in men a generation or more ago is often rejected today." Masculinity is context-specific and fluid, therefore it was examined in the Soweto setting.

As early as 1985, Connell pioneered research into masculinity and proposed the concept of hegemonic masculinity. This was defined as the dominant masculinity observed in society and was based on differential power relations between diverse groups of men and between men and women. Subsequently, this definition has been expanded to include diversity and multiple masculinities (Connell, 2005; Smith & Robertson, 2008). Ouzgane & Morrell (2005:4) support the idea of multiple masculinities observing that "...not all men have the same amount or type of power, the same opportunities, and, consequently the same life trajectories." However, the notion of hegemonic masculinity has not been uniformly applied, has been used differently in different fields, and is still open to interpretation. But as Hearn & Morrell (2012:4) suggest, it commonly contains "a hierarchy of masculinities, differential access among men to power (over women and other men),

and the interplay between men's identity, men's ideals, interactions, power and patriarchy." It is thus important not to cast all men in the same role, but to investigate masculinity from an individual perspective.

This view of hegemonic masculinity, defined by power and subordination, has been criticised by various researchers who propose that culture, race, and ethnicity contribute towards defining masculinities. Factors influencing masculinity are contextual, dynamic, change over time, and may sometimes be contradictory or confused (Gibson & Hardon, 2005; Seidler, 2006). Seidler (2006) raises the concern that the notion of 'hegemonic masculinity' may silence men who do not conform to it. As Foreman (1999:19) states "Masculinity is a very public trait, which on the one hand offers power and privilege but on the other imposes a role model which not all men welcome. Indeed, many live in conscious or subconscious fear that they do not live up to masculine ideals." Masculinity therefore needs to be carefully negotiated, and the perceptions about what masculinity is and how men perceive their own masculinity in relation to others are as important as how men understand their own masculinity. Tensions develop not only between men and women but also between older and younger men, where men jostle for power or fail to live up to what is thought to be a real man. Masculinities are influenced by culture and tradition, both products of society and therefore changeable (Hunter, 2010).

Morrell et al. (2012) suggest that the concept of hegemonic masculinity is still useful and widely used. These authors recognise that in a South African context multiple masculinities exist based on geographical and cultural diversity. In alignment with their suggestions, this thesis does not aspire to define a singular type of masculinity, but seeks rather to explore with the men the many facets that surround masculinity and how these are influenced by HIV/AIDS. For example, trying to emulate hegemonic masculinity may deter men from seeking help if help-seeking is not a component of masculinity.

This study interrogates masculinity in the context of patriarchy, culture, and tradition, with a group of men living in Soweto. The influence that masculinity has on the men's help-seeking behaviour may provide some insight into the scarcity of men at ART sites.

3.1 African masculinities - patriarchy

African masculinities, like those elsewhere, are diverse and in transition. Male power and patriarchal cultures appear synonymous and mask the diversity of masculinities (Seidler, 2006). In diverse parts of Africa there is

a perception that, particularly in relationships, power lies in the hands of men, and especially older men. But masculinities and manhood have changed over time and have been influenced by widespread violence and conflict in the region that engaged men in fighting, by poverty and unemployment that has forced many men to seek employment away from home, and by the empowerment of women that may have forced men to relinquish some of their power (Barker & Ricardo, 2005). These issues are pertinent for the men living in Soweto, where there are high levels of violence and many men seasonally migrate to Soweto for work and live away from their homes for long periods.

South African society is largely patriarchal, racially divided, and has unequal gender power (Morrell et al., 2012). In patriarchal societies there are rules that need to be adhered to including that men demand respect, expect to have authority over others, and should not be questioned. These attributes may differ between the public and private spheres (Seidler, 2006). Furthermore, the characteristics of the ideal black African man in South Africa comprises “toughness, strength and expression of prodigious sexual success” (Jewkes & Morrell, 2010). For these men, being acknowledged as a real man is about maintaining status in the community and not being associated with anything feminine (Holroyd et al., 2008). Men may perceive that seeking help is a feminine activity and implies that they are weak. This may explain men’s help-seeking behaviour, and their lack of attendance at clinics. This situation is explored further with the male participants.

Changes in society can challenge traditional masculinities and increase men’s vulnerability. In Africa elevated levels of unemployment and poverty have made it more difficult and sometimes impossible for men to fill their traditional roles as the head of the household and providers and breadwinners. Being HIV-positive and ill exacerbates this situation, making it even more difficult to remain employed or to find casual work (Seidler, 2006; Hunter, 2007; Fitzgerald et al., 2010). In addition, in South Africa the relatively recent political transition to democracy has resulted in changing perceptions of masculinity (Morrell, 2002). Hunter (2010:177) suggests further that “understanding masculinity and male power at a time when many men especially the poorest clearly perceive themselves to be disempowered” is important since it is likely to be different to the past. These changes coincided with soaring HIV prevalence in South Africa. These factors influence the way in which men perceive themselves, their masculinity, and their position in society.

Hunter suggests that employment, fatherhood, and alcoholic intake influence the construction of masculinities, and being unemployed, not being a father, or being unable to drink with their peers make it difficult for some men to live up to hegemonic ideals. He elaborates that being unemployed reduced men's ability to provide and be the breadwinner for the family. It has also affected their ability to marry, because being without disposable income reduces the chances of attracting women, and in South African society "marriage wins respect" (Hunter, 2010:162). Furthermore, men who are still living with their family or parents are not seen as independent or advancing themselves. Fatherhood is considered an important indication of manhood as "Fathering a child symbolises sexual virility and improves a man's social status" (Hunter, 2010:170). Hunter also notes that the common notion that men are irresponsible perpetuates the status quo that it is unmanly for men to look after children, whereas this is frequently not the case. Finally, alcohol is an escape from the hardships of daily life and drinking is seen as masculine trait: "Alcohol bestows courage and sometimes leads to violence, but, in excess, it can render a man helpless" (Hunter, 2010:158). Being ill further impacts on men's ability to meet the expectations of hegemonic masculinity.

In relation to the HIV/AIDS epidemic men are often described in a negative light. Much of the literature on women's vulnerability to HIV describes a singular African male sexuality that is promiscuous, violent, and lacking moral restraints; but this portrayal is being questioned (Epprecht, 2008). The negative aspects of men's behaviour such as being oversexed, sugar daddies, subject to hormonal urges, and inadequate fathers have been emphasised in the media and in campaigns, and men are blamed for the spread of HIV, particularly in Africa (Barker, 2005). These aspects of men's behaviour tend to be exaggerated, but they influence society's perceptions of men in general. These negative perceptions are reflected in this study and affect men's ability to seek help as will be described later.

Recent research on men and masculinity in southern Africa has centred on gender relations, violence, power, HIV, and AIDS. Although research has progressed from simply investigating "sex roles" to a more holistic approach that takes into account historical, cultural, and other factors, few studies have considered men's "actual desires, aspirations, fears and behaviours" (Bekker, 2005:21). This thesis on men and HIV addresses this gap by listening to the voices of men to increase understanding of their help-seeking behaviour in relation to HIV and other associated issues.

3.2 Men who have sex with men

Although gay men were prominent at the start of the HIV/AIDS epidemic, in Africa MSM have been sidelined in the predominantly heterosexual epidemic, but are important to be included for a number of reasons elaborated on in this section. MSM live in all countries and many also have sex with women. In some cases the sexual act may be coercive, such as in prison or in the instance of rape, and numerous MSM experience violence (McKenna, 1999). Homosexuality and bisexuality are often seen on the continent as being exotic (Epprecht, 2008), but it is normal behaviour for many men. Homosexuality is illegal in many African countries including Kenya, Uganda and Zambia and may incur a penalty that includes imprisonment. It is considered un-African by those in power and many others. Some continue to believe that European colonialists introduced homosexuality into Africa; however, Makgoba notes that homosexual relations occurred before colonialists arrived in Africa and that there are words in African languages describing these relations such as ‘matanyola’ in Sepedi (McLean & Ngcobo, 1995; Cameron, 2005). These discriminatory practices contribute towards homosexuality and bisexuality being publically invisible, silenced, and denied (Barker & Ricardo, 2005; Epprecht, 2008).

These views have made it difficult for MSM to be open about their sexuality even with health workers (Lane et al., 2008; Arnold et al., 2012). As Johnson (2007:12) elaborates: “The denial of same-sex behaviour and identities by African political and cultural leadership makes life a struggle for authenticity and belonging for many same-sex attracted people when advocacy for sexual rights is framed as an attack on African tradition and values.” MSM are frequently victims of violence and are often shunned by their communities, making them a particularly vulnerable group of men. Community prejudice persists, and it is therefore difficult for these men to be open about their sexuality, and they may experience hostility from health workers.

For the reasons outlined above, there has been scant research on MSM in Africa. The number or percentage of people who identify as MSM in Africa is unknown. Whilst studies in the early 1990s have shown that around 3.85% of men in the UK and USA had engaged in same-sex behaviour, Kinsey reported, “10% of American males were exclusively homosexual for at least three years during their adult lives ... more than one third ... had had at least one homosexual experience” (Johnson, 2007:15). McKenna (1999:13) estimates that in developing countries “between 10 and 25 percent of men will have either a single or very infrequent sexual experience with another man, and that between three and 10 percent will have more frequent sexual

encounters with other men.” Any data collected in surveys are likely to underestimate MSM “in part because of the invisibility of men who have sex with men, and in part because men are generally reluctant to admit to same-sex acts because of the shame and stigma associated with male-to-male sex” (McKenna, 1999:12). The only survey located measuring the prevalence of male-to-male sex in South Africa found that 9.9% of men had ever had sex with another man (Shisana et al., 2009). Therefore it is certain that a significant minority of men in all countries have had sex with other men at some stage during their adult lives.

Although many countries criminalise homosexuality, South Africa does not, and the Constitution upholds the rights of all. The equality clause in the Bill of Rights states: “The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth” (Statutes of the Republic of South Africa, 1996, chapter 2, clause 9(3)). Even though diverse sexualities are protected by law and are becoming more acceptable there is still stigmatisation and discrimination (Tucker et al., 2013).

MSM engage in a variety of sexual behaviours including anal sex, which is a known risk factor for HIV, and amongst MSM there is higher prevalence of HIV than in the general male population (Johnson, 2007; Rebe et al., 2011). Therefore, MSM are likely to experience more stigmatisation than other men when it comes to health care, and may avoid going for help when they need it for fear of being discriminated against (Lane et al., 2008). For these reasons, MSM are included in this study to understand the barriers they face when it comes to help-seeking — an issue addressed in later chapters.

3.3 Men’s risk-taking and HIV

Various attributes of hegemonic masculinity have been identified as drivers of HIV/AIDS transmission, and at the same time negatively impact on men accessing help. These include risk-taking, sex drive, sexual conquest and multiple sexual partners, being tough, stoical and strong and dominating over women, heterosexuality that stigmatises same-sex relations, being materially successful, and the subjugation of women (Lindegger & Quayle, 2010). Many men engage in high-risk activities such as being part of a gang, or being involved in dangerous work, such as mining. These activities can impact on men’s notion of risk, health, and death, and can have deleterious effects on HIV prevention (Campbell, 2003; Walsh & Mitchell,

2007). Men's perceptions of risk and denial of HIV are understood to have prevented behaviour change because these high-risk situations are more immediate than HIV/AIDS, so health becomes a lesser priority (Selikow et al., 2002; Campbell, 2003; Walsh & Mitchell, 2007). Men living in high-risk environments are less likely to have positive help-seeking behaviours.

Society's perceptions and expectations of masculinity may put pressure on men to place themselves at risk in order to be seen to be fulfilling the masculine role. Foreman (1999) argues that men drive the epidemic since the majority of infections occur during sexual intercourse with men, but suggests that men are not homogeneous, and the majority of men are not at risk of infection or of transmitting the virus, as they are abstinent, practise safer sex, or are faithful in their relationships. Therefore, infections are driven by a relatively small risk-taking group that does not practise safe sex and has multiple partners, and it this group that fuels the epidemic and should be targeted for prevention messaging and interventions.

Men are integral to any solution to address the HIV/AIDS epidemic. There is a perception that men, masculinity, and differential power in relationships are fuelling the epidemic (Plus News; Barker & Ricardo, 2005; Gilbert & Selikow, 2012). The main drivers of the epidemic include "male attitudes and behaviours, particularly intergenerational sex or age differential over 5 years, gender and sexual violence, stigma, lack of openness about the epidemic, untreated sexually transmitted infections (STIs), lack of consistent condom use in long-term multiple concurrent partnerships. Underlying these biological and social drivers are the structural factors of high mobility, inequalities of wealth, and some cultural factors including gender inequality, with young women rendered particularly vulnerable to HIV infection" (South African Development Community, 2006:5). In these reports men are perceived to be the main drivers of the epidemic, yet there is little research on the impact of the epidemic on them or their help-seeking behaviours.

The health of society requires men, women, and children to have equal access to health care with no one group being treated at the expense of another. Therefore, the focus on maternal and child health needs to be countered with more emphasis being placed on men's health (Bonhomme, 2007). Women's vulnerabilities to HIV infection have been well-described whereas men's vulnerabilities have not. Frequently men are regarded as risk-takers failing to protect themselves even if they have the means and knowledge to do so. This has led to men being criticised as being irresponsible and to blame for the epidemic. However, men are

vulnerable to HIV/AIDS, especially male sex workers, injecting drug users, and MSM (Foreman, 1999). Many men are inclined to take risks, but are they irresponsible? Men need to be able to access health care without fear of stigmatisation, discrimination, or prejudice.

The literature on masculinity is increasing but to date in South Africa, there has been little focus on men's health or help-seeking behaviour. This qualitative study explores health workers' perceptions of men's risk-taking behaviour and their attitudes towards men, and listens to the men's voices to understand what inhibits them from seeking help for HIV in the public health clinics.

Chapter 4: Health services in South Africa

South Africa is an example of “health care pluralism” in that it boasts a variety of health services and practitioners, including traditional medicine, complementary or alternative medicine (CAM), and allopathic medicine. Depending on their illness, people can choose to consult with one or more of these systems either separately or jointly (Gilbert et al., 2010).

Traditional medicine is based on indigenous knowledge, and is defined by the WHO as “...the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness.”⁹ CAM comprises a diverse group of practices and products that do not form part of allopathic medicine, including over the counter medication from pharmacies and health shops, natural products, acupuncture, and yoga that are frequently used together with other treatments.¹⁰ Allopathic medicine is scientific medicine that uses basic science to find cures, vaccines, and other chemicals to alleviate disease symptoms (Hassim et al., 2007). These terminologies are often problematic and politically loaded, but are used here to distinguish between different practices based on different health systems and beliefs rather than to promote one health system over the other.

The focus in this section is to elaborate on the services offered or provided by each of the different systems with an emphasis on the treatment of HIV/AIDS. This thesis explored men’s help-seeking practices in South Africa, including what medicines they used, who they consulted, and for what illnesses they sought help. A particular focus was on their engagement with traditional medicine and the allopathic public health services providing ART.

4.1 Traditional health practitioners

THPs are an important part of the South African health system and play a central role in the health and welfare of a large portion of the population. South African legislation requires that THPs register in order to practise. Further, the Traditional Health Practitioners Bill prohibits THPs from diagnosing, treating,

⁹ <http://www.who.int/medicines/areas/traditional/definitions/en/index.html>, accessed 8 May 2008.

¹⁰ www.nlm.nih.gov/.../complementaryandalternativemedicine.html, accessed 13 October 2012.

prescribing treatment, or claiming a cure for HIV, AIDS, cancer, or a terminal disease (Republic Of South Africa, 2003).

The exact number of THPs in South Africa is unknown, but there could be as many as 200,000, comprising diviners, herbalists and faith healers (Hassim et al., 2007), although Health Systems Trust (2007) suggests that only 133,000 practitioners are practising in this industry, which is worth around R2.9 billion a year. Traditional medicine is a sizable industry in South Africa and allows people to access a variety of practitioners for different needs.

The number of people consulting THPs is also unknown, but people from all income groups and educational backgrounds consult the traditional health system. Studies report between 72% and 80% of the black population consulted THPs for any reason (Sidley, 2004; Geffen, 2010), indicating that THPs play a significant role in providing help in South Africa.

There are no known traditional medicines that can cure or halt the replication of HIV; however, they may be able to alleviate some of the symptoms and assist with opportunistic infections. THPs continue to play an important role for many people in South Africa. This study explored which health issues lead men to consult THPs and the extent to which THPs play a role in HIV/AIDS care and treatment.

4.2 Complementary and alternative medicine

CAMs are used by many people to assist with a variety of illness, and are used either on their own or in conjunction with other medicine. The HIV/AIDS epidemic has enabled a plethora of CAMs to be developed and marketed and has resulted in “quackery” thriving. Many HIV-positive people opt for complementary medicine to cure or assist with their disease. These “cures”, immunity boosters, and vitamin supplements have been purported to cure or impede the progression of HIV disease. Amongst them “Ubhejane” marketed by Zeblon Gwala, “Africa’s Solution” marketed by Tina and Nelly van de Maas, and Dr Matthias Rath’s vitamin supplements have claimed to have an effect on HIV/AIDS disease (Geffen, 2010). The South African government, including Thabo Mbeki, supported the development of Virodene, a drug alleged to be antiviral, but it was subsequently found to be ineffectual (van Niekerk, 2005; Spencer, 2008). This sample of alternative medicines for HIV is by no means complete, but the hope that they promise has influenced many

to use them. Some of these medicines promised to cure HIV and were an alternative to the “toxic” ART, sowing confusion in the minds of many HIV-positive people who are desperate to get better.

4.3 Allopathic medicine and public health care

The South African government has adopted the allopathic approach for the provision of public health care. In South Africa it is estimated that more than 64% of the population relies solely on public health care and a further 21% are dependent on the public sector for hospital care. The high level of unemployment makes the cost of private and other medical care unaffordable for most people. Those accessing private health care tend to be middle or high income earners who belong to medical schemes (Coovadia et al., 2009). Thus the majority of South Africans will access the public services for HIV-related care and treatment, and it is this sector that forms a major focus for this thesis.

There are large disparities in terms of cost and resources between public and private health care. The average annual per capita expenditure in the private sector is around six times higher than in the public sector, and the private sector commands most of the health care professionals for a minority of the population (Coovadia et al., 2009). The quality of care differs within and between these two sectors, but they are interlinked and to some extent dependent on one another (Berthiaume & Padarath, 2003). Although measures have been put in place to regulate and create more equitable access to health care, disparities persist, as expanded on by Hassim et al. (2007: 25) “South Africa still has great inequalities and imbalances between its private and public health services, between provinces, and between urban and rural areas. In reality, the public and private health systems are almost parallel health systems, one serving the rich and the other serving the poor.” The public health service is not always the preferred choice for health care, but it is the only option that is accessible and affordable for the majority of people. Thus, the majority of poor South Africans access public health care, and this is also true for Soweto residents. Therefore, the focus of this research is on the public health sector and the HIV/AIDS services that it offers.

Public health systems need to cater equally for the differing needs of men and women whilst being mindful of the biological, social, and cultural factors. But gender inequity in health has become increasingly visible on the public health agenda and Doyal (2000) suggests that there needs to be more investment in order to reduce these inequities. Numerous health problems such as heart disease, depression, and HIV/AIDS differ

in prevalence by gender, so both men and women need to be taken into account when planning and delivering health services. At the same time, social and cultural issues play a critical role in health outcomes and need to be considered as part of the package (Doyal, 2001).

The South African public sector health services are mandated to provide health care for all people living in South Africa. However, as indicated earlier, there has been greater focus on maternal and child health because women and children are seen as disempowered, vulnerable, and in need of special assistance to ensure they access health care (Hassim et al., 2007). In particular for HIV-prevention and treatment Phaladze & Tlou (2006) observe that despite women's access to information about HIV/AIDS, their social status often prevents them from applying this knowledge to their own lives, and therefore HIV/AIDS prevention programmes have targeted women because of their perceived vulnerability. However, Foreman (1999) suggests that these programmes may have addressed the wrong audience because infection rates have not reduced. There is an urgency to address and promote men's health, but this should not prejudice the gains made on women's health.

The allopathic approach has been criticised as being too restrictive and there has been a move towards a more holistic concept of health care employing a multi-disciplinary team. In this model, health care is not only concerned about the disease, but also with the illness and external factors such as social and economic factors that influence the person's wellbeing. Many modern diseases, including HIV/AIDS, are chronic in nature and need to be managed over a prolonged period of time. This has a profound impact on the public health services as relationships between health care providers and their patients need to be developed and maintained (Nettleton, 1995). Although a more holistic approach has been taken, this rarely includes professions outside of the allopathic system, therefore traditional and complementary sectors are excluded from the public sector. But many people adopt a pluralistic approach to health care, consulting practitioners from various systems for the same or different illnesses (Muller & Steyn, 1999; Moshabela et al., 2012). In the case of HIV/AIDS this may be problematic, as it is known that some traditional remedies and other medicine can interact negatively with ART.

HIV/AIDS has impacted adversely on the health system. The increased burden of disease has boosted clinic utilisation with the numbers of patients and visits growing substantially. In addition, health workers are

infected or affected by HIV/AIDS, which increases the likelihood that they will be booked off and be absent from work. These factors place additional strain on an already overstretched service (Berthiaume & Padarath, 2003; Shisana et al., 2004; Pearson & Makadzange, 2008). Further, ART has changed the course of the disease from one where palliative care was required for a relatively short duration, to a chronic disease that requires life-long support (Samb et al., 2010). Therefore, HIV-positive people will engage with the health system over an extended period of time, increasing pressure at these clinics (Orner & Palmer, 2011). These problems are likely to worsen and have a negative impact on those seeking help and may explain the absence of men in the health services.

4.4 Health care pluralism

Research in Southern Africa indicates that help-seeking behaviour is determined by the beliefs about and the interpretation of disease. For example, in Zimbabwe, health care pluralism, seeking help from both traditional (herbalists, traditional healers, and faith healers) and biomedical providers, was common (Pearson & Makadzange, 2008). There is no single approach to seeking help and the one taken may be influenced by culture, gender, religion, or economic factors.

Seeking help for HIV is no exception, and many HIV-positive people in South Africa adopt a pluralistic approach to health care (Peltzer et al., 2010; Moshabela et al., 2012; Schatz & Gilbert, 2012). Since there was confusion about the origins of HIV and stories about people being bewitched, many people infected with HIV shopped around for help as described by McGregor (2005) in her biography of Khabzela a young, HIV-positive, prominent South African disc jockey.

Despite resistance to involve THPs in the treatment of HIV and AIDS, they have been included in the National Strategic Plan for HIV, STIs, and TB (Department of Health, 2012b). Many HIV-positive people consult both THPs and public health services, combining tradition and culture with allopathic medicine (Geffen, 2010). Although some THPs work hand in hand with public health care services and offer complementary services, the treatment each gives can interact adversely and may be harmful to their patients (Peltzer et al., 2010).

Seeking help from multiple sources may explain the lack of men at HIV/AIDS services including ART.

4.5 Seeking help for HIV

The first step in engaging with HIV and health is ascertaining one's HIV status by testing for HIV, also known in South Africa as VCT. This is critical for reducing the amount of undiagnosed HIV infection, and enables those who test HIV-positive to take precautions to reduce transmission and seek appropriate help. Knowing one's HIV status has been shown to reduce sexual risk-taking behaviour (Cherutich et al., 2013). However, people are more likely to go for an HIV test if they perceive that they are at some or great risk of being infected (McGarrigle et al., 2005). Men are more likely to take the test if they believe that they are at risk for HIV infection; therefore they need to have a basic understanding of the routes of transmission and perceive that they are at risk.

In Africa, experiences and uptake of HIV testing differ from country to country but in general women are more likely to test than men (Sabapathy et al., 2012; Cherutich et al., 2013). In contrast, fewer young Malawian women than men accessed VCT partly because they feared that they would be blamed for bringing HIV into the household, lose family support, and be ostracised by their partners. Barriers for households with limited resources were mainly economic since HIV/AIDS services were not free, and the costs of testing were weighed up against paying for other basic household goods, transport costs, and care-giving duties. In households where the man was the breadwinner they were more likely to purchase ARVs for themselves and not their family. However, once these services were offered free of charge, the number of women testing increased and the ratio of men to women accessing them was 40:60 which is similar to elsewhere in Africa (Nyirenda et al., 2006). Economic factors play an important role in determining whether or not people are able to access health services, as they may not be perceived to be a priority over other household expenses. In a meta analysis on home-based testing in sub-Saharan Africa, Sabapathy et al. (2012) found that the proportion of men to women being offered and accepting testing were similar. From this study it appears that men are not averse to testing and may prefer to test away from the clinic setting.

In South Africa the situation is similar with more women testing for HIV, and this occurs mainly in the antenatal and public health services that are geared towards maternal and child health (Snow et al., 2010). Testing in the antenatal services forms the basis for HIV surveillance in South Africa (Department of Health, 2012a). South Africa's human rights approach to HIV testing made it voluntary and opt-in, but uptake was low. Bassett et al. (2007) found that only 20% of South Africans who are aware of HIV testing have tested

because they are concerned about lack of confidentiality, fear of stigmatisation, lack of treatment opportunities, and the inconvenient location of testing sites. However more recently, provider initiated testing has been introduced, which follows an opt-out model and in 2010–2011 the South African government led an HIV testing campaign during which close to 15 million people were tested (Pillay et al., 2012).

The uptake of men testing for HIV has been lower than for women. Snow et al. (2010) found that men who tested were older than women and more men had been referred for testing by health workers, suggesting that they were already suspected of being HIV-positive and perhaps symptomatic. This implies that men do not voluntarily test but wait until they are ill. Moreover, if men test HIV-positive, they tend to keep this information private as Foreman (1999:21) notes: “Most men, when they learn they have HIV, tend to withdraw from circulation, keep away from their friends and, because of that, they tend to die much earlier than women.” Since many men are unaware of their HIV status and others keep it a secret, they can transmit HIV to their sexual partners. In addition, since few men know their status, they are less likely to access HIV/AIDS services for ART, which may explain the absence of men in the HIV clinics.

Although confidentiality and human rights are integral to HIV testing in South Africa inadvertent disclosure can occur. Steinberg (2008) investigated HIV testing in the Lusikisiki district, Pondoland, and observed that HIV testing was provided in a confidential fashion. However, it took longer to post-test counsel people who tested HIV-positive and the community could deduce people’s HIV status by noting these time differences. His key informant, Sizwe, a young man who had not tested, admitted that stigmatisation deterred him from testing in his own village, because if he were to test positive he would be ostracised by his community. Furthermore, he also observed that health workers encouraged disclosure, which he thought was “dangerous” and may even deter people from testing (Steinberg, 2008). The persistence of HIV stigmatisation highlights the importance of confidentiality and encourages people to keep their status a secret.

In Soweto, where this study was conducted, a community-randomised control trial also found high levels of stigmatisation negatively affected HIV testing. Trial participants were less likely to have tested if they held negative views about HIV-positive people, believed that discrimination persisted, did not believe that HIV-positive people should be treated equally and thought that HIV testing was uncommon (Young et al., 2010).

Further, women (64.8%) were more likely to have ever tested than men (28.9%), and women were more likely to have repeated their HIV tests. The main reasons for not testing included people not believing that they were at risk (37.0%), being nervous about the results (17.0%), or not having thought about testing (14.2%). Generally men were more likely to have tested if they were older, better educated, of a higher socio-economic status, had ever had vaginal or anal sex, or had been sexually active within the last six months. However, if they were students, unemployed, consulted THPs, or did not have a sex partner, they were less likely to have tested (Venkatesh et al., 2011). HIV testing is the entry point for ART. Men's perceptions of HIV testing are explored to determine whether this vital step is a barrier for them to access ART.

Once people have tested positive for HIV they need to consider their treatment options. Currently, the public health services offer ART to treat HIV, which has been proven in randomised clinical trials to suppress the virus to the extent that it is undetectable in the body. Traditional and other health professionals, including some South African Department of Health officials, have made claims that certain products, such as Sutherlandia and Hypoxis, can reduce the effects of the virus on the body, indeed some even claim to be able to cure HIV. However, these products are largely untested and may even “put patients at risk for treatment failure, viral resistance or drug toxicity” (Mills et al., 2005:19). Given these various claims, some of which are contradictory, it is not surprising that people “shop around”, consult more than one health professional at a time, and frequently combine drugs with other products. In a small study of 44 clients in a workplace clinic in South Africa, 84% had ever user traditional medicine and 32% were current users (Babb et al., 2007). The focus in this thesis was on ART and traditional medicine, rather than on complementary medicine, as these are the most commonly reported treatments for HIV/AIDS.

4.6 Antiretroviral treatment

Currently there is no cure for HIV, nor have any successful vaccines been developed to prevent HIV infection. However, various drugs have been found that inhibit the replication of the virus. In 1995 David Ho and his colleagues discovered that a combination of these drugs taken at the same time, known as triple therapy or Highly Active Antiretroviral Treatment slows down replication of the virus, enables long-term viral suppression, and allows the disease to be treated as a chronic condition (Ho et al., 1995). ART is

effective in delaying the progression from HIV to AIDS and significantly reducing illness, therefore improving quality of life and health, and increasing life expectancy (Ekambaram, 2003).

In South Africa, public sector ART programmes are led by the National Department of Health and include universal care and equitable access regardless of “race, colour, gender and economic status” (Department of Health, 2003). The operational strategy includes treating people infected and affected by HIV and improving the health system as a whole (Van Rensburg, 2006: 48). The National Strategic Plans for HIV, TB, and STIs promote social change and cohesion, tackle inequality and poverty, promote equality for women and girls, recognise diversity, ensure equality, non-discrimination, and personal responsibility, and recognise that certain key populations at risk for HIV include men who need targeted interventions (Department of Health, 2007; Department of Health, 2012b). Through these principles the vulnerability of women and girls, gender violence, male sexual health, and high-risk groups are addressed. Given these great strides in public health, men should be able to access health services without prejudice.

As described earlier, political leadership was a major obstacle to acknowledging the seriousness of the HIV/AIDS epidemic and of getting ART into the public sector. However, other barriers such as the high cost of ARVs made affordability questionable. The Medicines Control Council, a statutory body that approves and registers pharmaceuticals for their use in South Africa,¹¹ failed to or delayed the finalisation of applications for up to two years, depriving people in need of life-saving medicines (Hassim et al., 2007). These factors challenged and delayed the implementation of cost-effective and timely interventions and cast doubt on their effectiveness in the minds of many South Africans. These delays may have influenced men and deterred them from accessing treatment.

In April 2004 ART was introduced into the South African public sector health facilities, providing the majority of the population with access to treatment for the first time. Prior to this time, treatment had been available through some medical aid schemes, limited clinical trials, or through private funds, but these options were unaffordable and inaccessible for most South Africans. However, achieving equitable access to ART is not easy because it is a complicated intervention on a massive scale that needs to overcome physical,

¹¹ For more information see <http://www.mccza.com>.

cultural, and economic barriers. Schneider (2006) comments that successful ART programmes need to be comprehensive with HIV testing being linked to care; communities must be knowledgeable and HIV must be de-stigmatised. Thus, simply making treatment available does not guarantee that people are willing to access it.

Achieving ART at the scale needed in the public sector has a number of obstacles. Health services are largely female-focused, and health reforms have focused on maternal and child health, and acute care, with the management of chronic conditions including HIV taking a back seat (Bradshaw & Timaeus, 2006). Similarly, the majority of mortality studies focus on maternal and child mortality, ignoring adult male deaths (Rao et al., 2006). Women's vulnerability to contracting HIV directed many HIV/AIDS programmes to focus on them (Barker & Ricardo, 2005). These programmes have neglected men's health, even though in a patriarchal society men are more empowered than women and are the policy-makers. This situation "perpetuates men's ignorance of HIV/AIDS, and other health information" (Phaladze & Tlou, 2006:27). This emphasis on women in the public health sector may have excluded men from participating in HIV treatment and prevention programmes and therefore from ART.

As noted above, HIV prevalence in women is higher than in men, and accordingly proportionally many more women than men access ART. At the clinics only 35% of clinic attendees are men rather than the 45% that would be expected from the prevalence data (Shisana et al., 2005; Stewart et al., 2006). Reasons cited for this disparity include that men may prefer to access private health services, or are in denial (Stewart et al., 2006), or may access treatment through workplace programmes (Charalambous et al., 2007). The focus on identifying HIV-positive women in PMTCT programmes may have allowed women greater access to ART. PMTCT programmes test pregnant women for HIV to enable interventions to prevent transmission to their infants, but they rarely involve the male partner. Hudspeth et al. (2004) note that the predominance of females in ART programmes prior to the expansion of PMTCT services was less evident. These reasons may go some way to explain the lack of men in the clinics.

ART has given hope to many people as it can prolong life. In South Africa it was found that health care workers are enthusiastic about providing ART and there is renewed optimism in nurses providing ART, compared to prior times when there were difficulties motivating staff because they were unable to help

patients and watched many patients deteriorate over time, whereas now patients' health has improved (Stein et al., 2007; Orner & Palmer, 2011). Health workers' attitudes on HIV services may act as a barrier or an enabler for men to access treatment.

However, not all people who test HIV-positive and need to start treatment will do so. Some make an individual decision not take treatment and others encounter external barriers. A study conducted in a testing site in Soweto in 2009 found that 35% of people testing were HIV-positive and of those 29% were eligible to start ART. However 20% refused to initiate ART mostly because they felt healthy, and 0.5% died within a week of diagnosis. These rates were similar between men and women (Katz et al., 2011). In addition, individuals have their own beliefs and concerns about ART. As highlighted by Sizwe, in Steinberg (2008), who had a few concerns including that it was still relatively unknown how ART worked, the notion that one had to be sick before being given ART, and that the disease was never eradicated from the body. He believed a cure would be better. Other barriers to ART are similar to those for other medical conditions, and include "stigma, expected stigmatisation and discrimination, cost (poverty), denial, ignorance, cultural appropriateness of care, gender discrimination and physical availability and accessibility of health care" (Deacon et al., 2005:62). Thus there are many social and structural barriers that have inhibited people from accessing ART. However, the barriers for the individual, whether internal or external, are not well understood. For this reason, this study interrogated the concerns that men have about ART.

The clinical benefits of ART are well understood and although it was long thought to be useful in HIV prevention it was not proven (Wood et al., 2000; Auvert et al., 2004). Results published in 2011 from the HPTN052 study prove that ART can prevent HIV infection (Cates, 2011; Cohen et al., 2011). Although there are concerns that in developing country settings using treatment – and particularly early treatment – to prevent infection may be unaffordable. Modelling indicates that early treatment may in the long-term reduce costs, whilst at the same time decreasing the burden of HIV (Granich et al., 2012). However, there are fears that treatment optimism may result in increased risky sexual behaviours (Lurie et al., 2008), but these seem unfounded. A number of studies that investigated sexual behaviour post-ART initiation, found this not to be the case. In a review of three African studies it was found that there was no increase in sexual risk behaviour, but rather that there was a decrease (Kennedy et al., 2007). Specifically, some Ugandan studies showed that ART-experienced respondents were more likely to report consistent condom use with their spouses than

ART-naïve respondents. Another study showed that the provision of ART, prevention counselling, and partner VCT reduced high-risk sexual activity by 70% in both men and women (Bateganya et al., 2005). Thus ART is effective both for treatment of HIV and it assists in preventing further infection.

In South Africa the provision of ART in the public sector has challenged health facilities. Veenstra & Oyier (2006) reflect on the “double impact” of the epidemic with the concurrent increase in the number of people requiring HIV/AIDS services with limited numbers of health workers, who in turn are falling ill and dying of HIV/AIDS, and speculated that, given the resource constraints in the health sector, access to care may be reduced in the future. Government and donor funding have increased considerably and are sufficient to provide adequate treatment for people infected with HIV, but staff shortages and inadequacies in the health system still hamper quality services (Coovadia et al., 2009). These constraints were further explored with the secondary informants and male participants to determine if they deter men from accessing health care.

ART has many benefits for the individual, such as reduced morbidity and mortality, but it also benefits society through increased disclosure and reduced risk-taking behaviours. A small study of 123 patients on ART (69% female) in Johannesburg found that after initiating treatment many people disclosed their status, from 18% men and 9% women before the study to 64% and 51% respectively. Similarly, prior to testing 48% of men and 17% of women reported sexual contacts outside of their primary relationship; however, this decreased to 21% and 16% after diagnosis, and to 11% and 13% after initiating treatment respectively. Condom use also increased significantly after diagnosis and further after initiating treatment (Fougelberg et al., 2006). Whilst positive results were noted, what is not known is why these changes came about. These positive impacts should be an incentive to the community to encourage HIV-positive people to access ART, but stigmatisation persists and many people are still not able to go onto treatment.

There have been remarkable gains in the numbers of people on treatment in South Africa from around 47,500 in 2004 to nearly 1.8 million in 2011. However, men are not accessing the ART programme and continue to be underrepresented (Johnson, 2012). The outcomes for men on ART are worse than for women including a 31% higher risk of mortality, and men are blamed for this because of their poorer help-seeking practices. The reasons for this are not well understood, but it is thought that this may be unrelated to being on ART, but rather related to the higher background mortality for South African men (Cornell, 2013).

For men, going onto ART can impinge on their notions of masculinity, as they are encouraged by the health workers to give up drinking and smoking and to eat healthily (Colvin et al., 2010). In one small qualitative study with eight men, it was found that some men had delayed going on ART because they drank alcohol, and although most had stopped drinking, they felt that alcohol alleviated stress and were conflicted about it when they did drink (Fitzgerald et al., 2010). These pastimes contribute to the concept of being a real man, and men may find it difficult to give them up and therefore find it preferable not to take ART. However, there are instances where men have been able to adapt to being an HIV-positive man on ART (Colvin et al., 2010; Mfecane, 2010).

In summary there are a number of barriers at various levels that may deter men from accessing ART in the public sector. Furthermore, men may consider illness to be a weakness and not masculine, therefore they may not get tested for HIV or get treatment. However, there are examples of men embracing help when they go onto treatment. In this study the researcher explored how men view illness and what influences them to seek help.

Chapter 5: Men's health

Health, sickness, and illness are interlinked concepts that are often discussed in relation to one another (Gilbert & Walker, 2010). The notion of health is multifaceted and refers to the physical nature and personal perceptions of the disease, as well as the reactions of society and the individual (Gilbert & Walker, 2002). This complex interaction between individuals and society is summarised by Saltonstall (1993:12) "... health is not a universal fact, but is a constituted social reality, constructed through the medium of the body using the raw materials of social meaning and symbol. ... the interplay between health, self, body and gender at the individual level is linked to the creation and recreation of a sense of healthiness in the social body, the body politic of society." Thus one aspect cannot be considered in isolation from the others.

5.1 Gender and health

The subject of gender has been long included in research on health and illness and women have generally been the focus. However, aside from female reproductive issues, men and women have often been regarded as having similar health needs resulting in little nuanced research being conducted on men's health (Meryn & Jadad, 2001) and even less on men's health experiences (Robertson, 2007). The HIV/AIDS epidemic has brought a resurgent interest in men's health, men's sexual health, prevention of ill-health, and promotion of healthy lifestyles with men's health research gaining momentum more recently (Smith & Robertson, 2008). Although men have been included in recent research there is still very little on men's perceptions of health and illness, and this study hopes to address this gap.

The women's movement in the 1960s and the lobbying by feminists advanced women's health research. However, until recently, little was done on men's health. Health and gender issues have influenced the way in which illness has been approached by health practitioners and researchers. Riska (2002:349) notes that "men's health has been used as a normative standard, which assumed the existence of a 'universal man'... The gender neutral approach to men's health has made the gendered man invisible in most medical research." Men have been regarded as a homogeneous group with little regard to evolving diverse masculinities. Individuals think and experience health in unique ways that is private and personal (Cameron, 2005). This highlights the importance of understanding individuals' experiences of health and illness. Meryn & Jadad (2001) agree that until about 25 years ago women's and men's health was seen as the same, apart

from reproduction, but from that time women's health issues have been increasingly researched. There is now urgency for this gap to be addressed and for men's health to be promoted.

Gender is biologically and socially constructed and context-specific, affecting both men and women. Gender roles impact on health and help-seeking behaviour (Hassim et al., 2007). Gender differences are considered important both in the social context and in health outcomes, as summarised by Phaladze & Tlou (2006:34): "Gender identity, roles and power relations interact with biological, genetic or immunological sex differences to health conditions and problems that are different for men and women — both as individuals, and as population groups." However, Barker (2005:8) suggests "This is to say that sex differences and gender differences are not inherently bad; it is power imbalances and rigidly proscribed gender differences that are the problem." Men play a role in women's health and wellbeing, and in order to improve this they need to be included in research and interventions. In turn, men's health may be negatively affected by how masculinity is defined by society (Barker, 2005). Men's interaction with the health system is affected by the way they are viewed by fellow patients and treated by the health practitioners when they visit the clinic; this was explored further via the voices of the health workers and men.

Gender plays an important role in the health of an individual, is aligned with wellbeing, and shaped through the lived experience, but it impacts men and women's health practices differently. Men are more concerned about appearance and their physical being than their inner selves and they rate exercise as the most important factor over both rest and food (Saltonstall, 1993). Robertson (2006a) investigated male embodiment and health and also found that exercise was very important for men. Unpacking these issues is important in relation to men's help-seeking behaviour and their response to the HIV/AIDS epidemic and help-seeking behaviour.

Health and social context are interrelated. Health is inextricably bound up with economic status, such as being employed, and social inequalities in a society that are related to social class, race, and gender (Harding et al., 1990; Read & Gorman, 2006). Being employed leads to better physical and mental health in contrast to being unemployed, which leads to increased risk of illness and earlier death (Holroyd et al., 2008). For many men in developing countries being unemployed is a way of life and being HIV-positive can impact adversely on men ever getting a job. The high unemployment rate in Soweto is likely to influence the male

participants' views. Most of the men interviewed were unemployed or were employed on a casual basis and the health and help-seeking behaviour of these men needs to be interrogated bearing this in mind.

Men's health has received increased interest over the last decade in both developed and developing countries. However, 'men's health' is not clearly defined, and the term does not explain the diversity that underlies the concept. It can be loosely categorised into three areas: morbidity, mortality, and risk behaviour, and needs to be investigated in relation to cultural, social, and economic aspects. In addition, masculinity and the crisis in masculinity are thought to influence all three (Robertson, 2007). However, research into men's health remains small scale and under-resourced (Baker, 2001). There is still a lack of understanding about how men feel about their health, "Many myths surround men's health, the greatest of which is that men do not care about their health. The fact is that men worry about health but feel unable to talk about their concerns or seek help until it is often too late" (Banks, 2001:1060). Some literature suggests that men are not concerned about health issues, but Robertson (2006a) suggests otherwise, noting that health and wellbeing are important to men although the relationship between masculinity and health is complex. Depending on how important health and wellbeing are for men may explain their help-seeking behaviour and lifestyle choices.

Seidler (2006) suggests that if men show any vulnerability or weakness then they may be exploited by others and lose social status. He remarks that men need to live up to the expectations of those around them, which can be very stressful, so when men are ill they get "angry that their bodies have let them down." Once they are ill they find it difficult to seek help, and when they do, they rely on the medical profession to "fix their condition." As Seidler suggests, men keep their health issues secret and tend not to seek help perhaps explaining their absence in the clinics.

Thus the notions of masculinity and men's health need to be explored together in order to understand them better, but Lohan (2007:493-494) has observed that literature related to men's health is generally divided into two categories. The first focus is on men and masculinity, and "seeks to re-affirm essentialist notions of manhood in light of the changing positions of women in the public and private sphere." The other focus is on inequalities in health, which has concentrated on "material/structural; cultural/behavioural and psychosocial explanations along with a life-course approach." links these two focus areas to gain greater insight into men's health, and this approach was followed in this study.

Sexual ill-health is connected to blame, immorality, and sexual activity outside of marriage, and is associated with guilt and sin. It has been found that marginalised communities, including male homosexual and immigrant communities, are most affected by sexual ill-health. Culture, politics, social context, and the environment impact on sexual identity, sexual expression, health decisions, and the perception of sexual risk. There are fears that open discussion on sexuality in political, public, and private spaces will lead to moral decline. This means that talking about sexual health has yet to emerge in a comfortable space. Therefore, silence generally surrounds matters pertaining to sexual health and has fed into the stigmatisation surrounding HIV. But HIV and AIDS have forced more open discussion on sexuality, sexual activity, and on risk-taking. It has brought sex and sexual health, which used to be considered an individual's private matter, into the public arena (Serrant-Green & McLuskey, 2008). Although sexual health may be discussed more openly, it may not make it easier for men, and particularly MSM, to admit that they have sexual health problems or to seek treatment for them. For these reasons a diverse group of men were interviewed to gain greater insight into their opinions on sexual health.

5.2 Morbidity and mortality

Literature on men's health concentrates on morbidity, mortality, and the crisis in masculinity that negatively affects health practices (Robertson, 2007). Differences in morbidity and mortality between men and women are well documented; however, why these differences occur is unclear. Gender is not the only factor, and others such as age, race, culture, and social circumstances also influence these differences (MacIntyre et al., 1996). In general women live longer than men, but it has been suggested that women have higher morbidity and thus a lower "health-related quality of life" although this is not consistent across diseases, as men have higher morbidity with some diseases (Tsuchiya & Williams, 2005). Gender is not the only factor influencing morbidity and mortality and a more complex approach is needed to understand how disease affects men. This study reflected on what other factors affect men regarding HIV/AIDS and illness.

Bird & Rieker (1999) suggest that a combination of social and biological factors may explain some of the differences between morbidity and mortality among men and women. Men tend to have more life threatening chronic diseases such as cancer and coronary heart disease, whereas women have more chronic disorders such as anaemia and migraines, and acute infections, but these conditions shift over time and with age. The authors suggest that it is necessary to move beyond gender-based assumptions regarding men and women's

health, as these assumptions affect health care provision and health outcomes. This is confirmed in other literature on gender and morbidity that shows that there is a complex interaction between the two, and that the notion that women are more likely to experience increased morbidity over men may not be clear cut. In addition, once socio-economic factors and the influence of race and ethnicity are included the picture becomes even more complex (Read & Gorman, 2006). HIV affects both men and women. Although more women are infected in sub-Saharan Africa, this disparity is not great. Therefore, it would be expected that there would be fairly even numbers of men and women seeking help or accessing treatment; however, this is not the case.

Over time the nature of disease has shifted from short-term infectious diseases to diseases that are relatively long-term and chronic in nature. Infectious diseases are characterised as being of fairly short duration with a person either getting better or dying. On the other hand, long-term chronic diseases are generally incurable, and need to be managed over a long period of time by various health and other professionals, placing an increased burden on health systems (Gilbert & Walker, 2002). This shift has in turn affected the nature of health care, which has changed over the years from a biomedical model focusing on the disease itself to a psycho-socio-environmental model that incorporates people's behaviour and the social context. The increase in the costs of long-term medical care has led to the prevention of disease becoming important, but also more difficult as prevention relies on changing behaviour and attitudes in the population (Fitzpatrick, 1986). HIV is an example of a disease that was initially short-term and fatal, but with developments in treatment is now classified as chronic. HIV prevention is high on the agenda in public health, but if there has been behaviour change it has not resulted in significantly fewer infections. Cures or vaccines have been found for many diseases. HIV is not a highly infectious disease but for the moment remains incurable and no vaccine has yet been found to prevent infection.

Mortality rates provide an indication of how well a country is doing in terms of combating health problems. Environmental factors such as poverty can increase the mortality rate, but at the same time wealth can also contribute to other lifestyle illnesses, such as obesity and heart disease. Economic factors are the main reasons for changes in the patterns of illness (Fitzpatrick, 1986). In most countries men die at an earlier age than women, although this was not always the case. With the increased emphasis on women's health, especially in reproduction and the reduced mortality during childbirth, women now live longer than men.

Men dying younger has also been associated with risk-taking and self-destructive tendencies (Holroyd et al., 2008). These trends are evident in South Africa.

As in most countries in sub-Saharan Africa life expectancy in South Africa decreased markedly due to the HIV/AIDS epidemic from 62 years in 1990 to 51 in 2005 (Geffen, 2010). The most likely cause of the decrease in life expectancy is the HIV/AIDS epidemic, and mortality rates remain higher for men than women in most age groups (Bradshaw & Timaeus, 2006). However, according to Statistics South Africa, life expectancy has increased since then because the availability of antiretroviral drugs has increased and in 2013 life expectancy was estimated at 57.7 years for men and 61.4 years for women (Statistics South Africa, 2013a). HIV has therefore had a devastating effect on the health of the South African population.

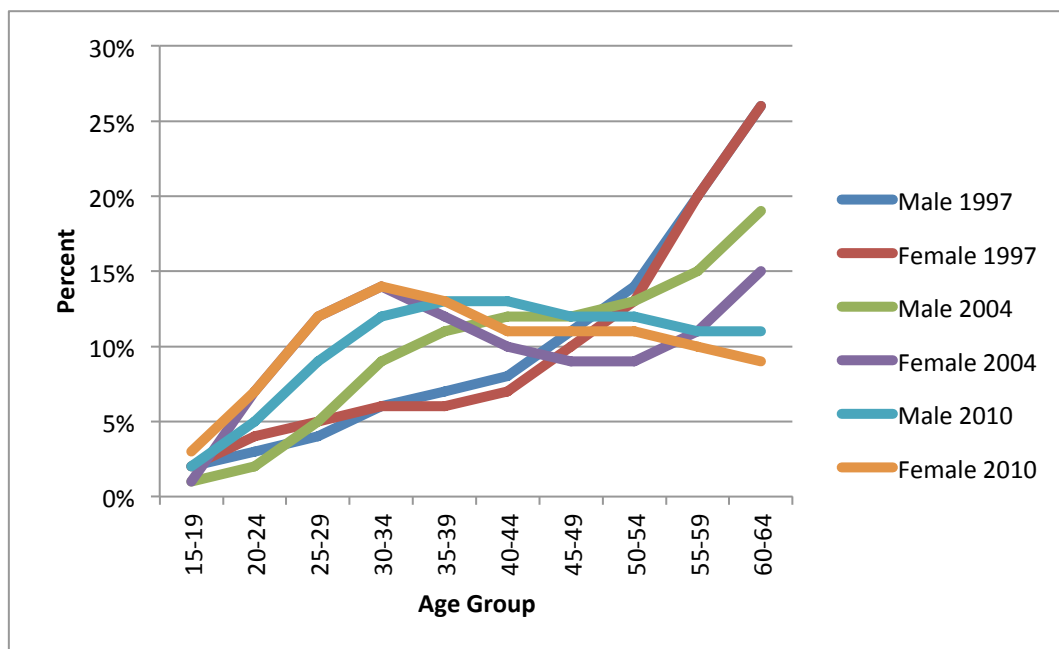


Figure 3: Percentage distribution of all adult (15-64) deaths by gender: 1997, 2004 and 2010 (source, Anderson & Phillips, 2006:8 ; Statistics South Africa, 2013b)

Young men are disadvantaged in terms of health in many parts of the world. Barker (2005) investigated youth (15–24 years old) mortality to determine the likely causes of death. He noted that boys and men are biologically disadvantaged because the XY chromosome makes them more susceptible to certain illnesses but found that masculinity also contributes to mortality, “... they [young men] are trying to live up to certain

models of manhood – they are dying to prove that they are ‘real men’” (Barker, 2005:2). This includes taking risks, being involved in more violent activities, being part of gangs, early sexual debut, and sexual violence towards women and girls. In the case of HIV in South Africa, young men are less likely to be infected with HIV at this age, but the activities associated with being a ‘real man’ are risk factors for becoming infected. The reasons for these behaviours are not well understood but may include traditional gender socialisation, constructions of masculinity, and the context of their lives. Men’s behaviour towards their health is frequently described in negative terms as summarised by Robertson (2007:2), “men [are described] simultaneously as ‘irresponsible’ in terms of health-related behaviours and ‘victims’ of destructive processes of socialisation that negatively impact on their health status.”

In many societies men are encouraged to take part in high-risk activities and do so to be seen as more masculine but this may adversely impact on their health as Doyal (2001:1062) notes, “Though the shape of masculinity may vary between communities, the development and maintenance of a heterosexual male identity usually requires the taking of risks that are seriously hazardous to health.” At the same time risk-taking and the enactment of masculinity are not homogeneous across communities. Masculinity and normative behaviours were found to influence men’s health behaviours and they may adopt poorer health practices (Mahalik et al., 2007). Courtenay (2000) concurs that health behaviours are key to determining gender related morbidity and mortality since men are less likely to visit health facilities, but more likely to engage in risky activities. The social context and the persistence of hegemonic masculinity influence this behaviour, and may undermine men’s ability to access health care and explain the absence of men in the clinics.

In South Africa, male deaths per 100,000 from non-natural causes (accidental injury, transport accidents, intentional self-harm, homicide/assaults, and medical and surgical complications) are between three and four times higher than female deaths, indicating men’s increased risk (Anderson & Phillips, 2006; Statistics South Africa, 2013b).

Men are characterised as risk-takers, which adversely affects their health; in addition they have high mortality rates. However, as revealed in the literature, the situation is more complex. This study explored

both younger and older men's views on their health and their risk-taking behaviours for HIV/AIDS infection to determine if these played a role in them avoiding the clinics.

5.3 Men and HIV

Studies have shown that HIV interventions can influence behaviour change, such as HIV testing, including risk reduction counselling, which can influence men to change their risk-taking behaviour, particularly if they test HIV-positive (Mhlongo et al., 2013). Similarly, being on ART decreases sexual risk practices (Venkatesh et al., 2012). Kalichman et al. (2006) explored the use of the Information-Motivation-Behavioural Skills model in prevention of HIV infection in an STI clinic in Cape Town, South Africa. They found a self-reported reduction in risk behaviour by study participants. However, they noted that HIV-related stigmatisation had a negative impact on behaviour change. Furthermore, it has been shown that HIV counselling and testing can influence behaviour change, reducing risky sexual practices and decreasing STIs, thus reducing HIV transmission (Levack, 2005). Thus, HIV interventions can change men's behaviour by decreasing sexual risk behaviour and improving men's health outcomes, but this requires men to seek help, which is explored in this thesis.

There is little research on patterns of help-seeking when it comes to HIV and men's uptake of HIV and AIDS treatment programmes in South Africa, but in a pooled meta analysis of 23 cohort studies in Africa it was established that only 35% of the patients on treatment were men and they had poorer outcomes than women (Druyts et al., 2013). This pattern is replicated in South Africa, where it was observed that men tend to seek health care only when they become ill, and that the CD4 count of men coming to a treatment site in Johannesburg was lower than women coming to the same site (Hudspeth et al., 2004). This is not surprising since, as discussed earlier, men do not embrace health services.

Understanding the intersection of illness and gender has been of interest to many researchers over the years and is influenced by the cultural setting. Studies in developing countries with specific regard to HIV/AIDS and gender are limited, but anthropological studies conducted in Haiti and Tanzania have provided valuable insights into the epidemic. In Do Kay, Haiti, a study was conducted over a five-year period, from 1983 to 1988, early in the epidemic when AIDS was becoming more visible in the country. It was found that over time a clearer understanding developed of how HIV is transmitted. Initially it was thought that HIV was

caused by dirty blood, but this changed into it being understood to be a new disease that is sexually transmitted. These findings show that community views are fundamental to an understanding of the illness (Farmer, 1994). In Tanzania, a study was conducted in the Chagga community approximately a decade after the first cases were diagnosed in 1984. Here it was found that word of mouth was the main source of information about AIDS. For young men intra-gender hierarchies were established through “reproduction and sexual conquest” involving high risk sexual behaviour. This behaviour played a major role in HIV infection and was increasingly disapproved of (Setel, 1996). For young men in this community the traditional passage to manhood was negatively affected by the HIV/AIDS epidemic.

In sub-Saharan Africa men’s sexual practices have been identified as the main drivers of the epidemic. In order for this to change it is recommended that men reduce the number of concurrent partners, consider male circumcision, take an active role in sexual and reproductive health, and start ART – all of which have been shown to play a role in reducing HIV transmission (South African Development Community, 2006; Halperin & Epstein, 2007). But for men, changing risky practices or adopting safer practices are not always easy or desirable. Therefore, Seidler (2006:140) suggests that there needs to be innovative interventions that can address sexuality: “We need to explore ways of talking about sex, intimacy and desire within cultural traditions that have historically shunned such concerns.” Many of these suggestions go against the notions of masculinity, so these notions need to be challenged for men to adopt these recommendations.

Men have been blamed for the spread of HIV. As Barker (2005:4) explains, it is “largely spread by the sexual behaviour of men, whether with male or female partners. The majority of cases of HIV/AIDS in the world occur via sexual transmission between men and women [...] In sub-Saharan Africa, the vast majority of HIV transmission is heterosexual, often in situations in which men’s greater power in intimate relationships means that they control or dominate sexual decision-making.” He suggests that the constructions of gender, masculinity, and manhood in society must also be investigated, as it is these imbalances that need to be addressed rather than blaming men. Blame may make men reluctant to seek help for HIV.

However, the situation on the ground is more complicated. In a study conducted in the Lowveld, South Africa, Stadler (2003:136) found “... a link between relative affluence, power and mobility, masculine

sexuality and AIDS.” Men were disadvantaged because their relative power influenced them not to adopt safer sexual methods. Their higher status in society did not protect them or their partners against HIV infection. In this case, being a man had a negative impact on their health.

Negotiating relationships in the era of HIV and AIDS adds considerable stress to an already complicated terrain. Rhodes & Cusick (2000:20) examined the roles of risk and trust in relationships of HIV-positive drug users in the UK, which they determined to be a balance between “relationship safety and viral danger.” Whilst this sample does not resemble the majority of HIV-positive people in South Africa, there are lessons that are relevant. Public health management programmes rely on increasing people’s risk-awareness and encouraging people to change their sexual behaviour and how they negotiate relationships. However, in this study it was found that sexual risk management was kept private and negotiated on an individual level. Love and intimacy were the major contributors to relationship safety, whereas viral danger increased tensions in the relationships (Rhodes & Cusick, 2000). These findings endorse the discussion thus far, in that men do not like to talk about illness, and their relationships and sexual practices follow masculine norms that disadvantage their help-seeking behaviours.

In Africa, homosexuality has been ignored in what is seen as a largely African heterosexual HIV/AIDS epidemic. But there is not one single HIV/AIDS epidemic, rather there are overlapping epidemics that affect each other (Epprecht, 2008). Sex between men contributes to the spread of HIV, and in many parts of the world these communities have been very active in mobilising around health care and for research on HIV. However, in Africa, discrimination of MSM has led to a wall of silence around homosexuality and HIV, and sex between men continues to fuel the African HIV/AIDS epidemic (Johnson, 2007). McKenna (1999) asserts that sex between men in most developed countries plays a small but significant role in the spread of HIV, whereas in some developing countries it could play a much bigger role. Makoba believes that HIV transmission through homosexual sex is “significantly under-recognised and understated” (Cameron, 2005:83). Only a couple of South African studies have addressed the issue of MSM and help-seeking behaviours when it comes to HIV/AIDS (Lane et al., 2008; Tucker, 2011; Arnold et al., 2012; Tucker et al., 2013).

Understanding MSM's sexual behaviour is key to providing appropriate and relevant HIV-prevention and treatment programmes for MSM. In the developing world, marriage and family are important cultural features of society, thus making it likely that MSM will also have sex with women — although this may change over time, with men having sex with men at one stage of their lives, having sex with women at another stage, or having sex with both men and women at the same time. However, there is stigmatisation and prejudice surrounding MSM and stigmatisation attached to HIV, and combined, these place MSM at increased risk (McKenna, 1999; Johnson, 2007). This situation is confirmed in Botswana where same-sex encounters are illegal, but Phaladze & Tlou (2006) observe that although MSM are not visible, it does not mean that they are not having sex — a situation that precludes MSM from HIV-prevention programmes. In addition, MSM may have relationships with women, but keep their sexual orientation secret, which may increase the likelihood of HIV transmission to their partners.

Although substantial gains have been made by gay groups, they are still largely excluded from public health planning in many countries. In South Africa, MSM are highlighted as a most-at-risk population in the National Strategic Plans for HIV, but more work is needed to ensure adequate and appropriate health care provision (Department of Health, 2012b). The majority of health workers have not been trained to tend to the needs of the MSM community. As Johnson (2007:57-58) notes, “Hostile and discriminatory attitudes from health care providers make many same-sex practicing people reluctant to share personal and medical information, jeopardising their overall health and their access to sexual health care services in particular.” Governments, donor organisations, NGOs, and private health care have failed the MSM community with HIV messages, funding, prevention information, and health facilities, all of which largely target the heterosexual HIV/AIDS epidemic in Africa. This increases their isolation (Johnson, 2007). MSM are a neglected community but are at high risk of being HIV-positive and they need to be able to access HIV care and treatment.

A diverse group of men including MSM were purposively included in this study to obtain a cross section of men's views on health and on accessing help in the health services.

5.4 Men and messages

Apart from political leadership playing a role in influencing men's behaviour, as described earlier, the free and independent media also plays a crucial role in influencing the path of the HIV/AIDS epidemic. HIV is low on the African political agenda: "Africans consistently rank HIV/AIDS low among their political priorities, preferring government action on unemployment, the economy, poverty, water, and crime" (Bor, 2007:1558). Media can play a crucial role in elevating HIV/AIDS, following debates concerning the illness, and keeping it on the news agenda (Finlay, 2004). Men are influenced by the discussion about HIV in the media and, depending on how men and HIV are portrayed, it could influence them to make better decisions regarding their health.

HIV has been called the "silent epidemic" because it can be kept secret for many years before becoming visible or public. In addition, because it is sexually transmitted and sex is a taboo subject, the media have been less willing to promote HIV/AIDS issues. In a rural South African village Stadler (2003:128) found that "... public secrecy about AIDS gave rise to private suspicions and rumours about the disease." Public secrecy and lack of discussion about HIV, including in the media, has led to rumour, gossip, and confusion about HIV.

Media is a powerful tool and plays an important role in influencing readers on a variety of issues, including masculinity and men's health. Gough (2006) notes that in the UK there is a perception that men's health is in crisis because men are more vulnerable to particular health problems. Gough suggests that health services need to adapt in order to attract men, rather than trying to change men's behaviours, and that the media needs to take a more nuanced approach to men's health and not tarnish all men with the same brush. The health problems that the Soweto men experience are explored to determine what they are, and whether they believe they need help from a clinic.

In terms of gender, South African mass media coverage of the epidemic has largely had a female focus. One study of the news media found that although men are often used as sources of information, most of the coverage of HIV and AIDS focuses on the conflict between government and civil society, and women and vulnerable children (Finlay, 2004). Prevention messages have mainly targeted young adults and programmes have focused on women. More recently, there have been some interventions directed towards men,

particularly encouraging men to be tested and to support women for PMTCT. However, the uptake of men in these programmes remains low (Levack, 2005). Men are largely ignored in the media and therefore are not encouraged to take an active interest in HIV and are thus unlikely to seek help at clinics or elsewhere.

Finally, health promotion has focused on women because they are caregivers, to the detriment of men who in turn believe that health is women's business. Health promotion is directed to preventative messaging, such as encouraging condom use, but this is not appealing to men (Doyal, 2001). Furthermore, in Malawi it was found that the method of delivery was problematic as the written culture was associated with powerful groups, but the oral tradition was still preferred by the majority (Lwanda, 2003). Messages and their delivery play a crucial role in influencing men to take more interest in their health and HIV.

Media has emphasised women's vulnerability in the HIV/AIDS epidemic over men's role in it. Since media has largely been silent about men, this may have limited men's engagement with health services around HIV. The men in this study were questioned about their sources of information regarding HIV.

5.5 Men's help-seeking behaviour

Research on help-seeking behaviour in the UK and USA indicates that men are less likely to seek help or to engage with preventative health services than women. But gender was not the only determining factor, and socio-economic status can play a bigger role than gender in not seeking help (Galdas et al., 2005). These authors concluded that the reasons determining men's help-seeking behaviour are far more complex than only gender differences, that they are inadequately dealt with, and that men's help-seeking behaviour is not uniform — not all men follow the same help-seeking route, and individual men may not behave in the same way in different help-seeking contexts. In contrast to the findings that men are less likely to seek help than women, a South African study based in Cape Town investigating help-seeking for STIs found that young men were able to discuss their problem with their friends who encouraged them to seek help at a health facility. This, together with the fact that the symptoms were often more severe and more uncomfortable for men than women, enabled men to seek help sooner than women (Meyer-Weitz et al., 1998). This thesis further explored men's help-seeking behaviours through semi-structured interviews to determine their reasons for seeking or not seeking help.

Men play an important part in perpetuating HIV infections and their health needs must be addressed if the epidemic is to be brought under control. It has been observed that men contribute towards the spread of the epidemic through their reluctance to adopt HIV prevention methods, which has led to increasing infections in young men in particular (Meryn & Jadad, 2001) and has a subsequent impact on their partners. Although most attention has been on women's health in terms of HIV, as the HIV/AIDS epidemic has unfolded there has been a shift of focus, with more attention being placed on men's health. This has offered educational opportunities to inform men about their health and has enabled them to take more care of their own and their partners' health (Doyal, 2001). Help-seeking behaviour among men can be promoted, and Robertson (2007) suggests that men can be encouraged to adopt good health practices through peer pressure and wanting to keep up their physical appearance and functionality of their bodies. Specialist clinics for men may also encourage their help-seeking behaviour (Serrant-Green & McLuskey, 2008). Men are susceptible to health promotion and can be encouraged to seek help, but the enablers and barriers for men in particular contexts need to be identified for maximum impact.

Seeking help for men is not always easy, and barriers come from a variety of societal and structural sources and also from the individual. These are described briefly below. Barriers include economic factors such as unemployment or the inability to pay for transport for the services, social factors for example HIV stigmatisation (described in more detail in the chapter on stigmatisation), the health system – including the shortage of services and staff, the attitudes and gender of health workers who are mainly women and their insensitivity to men's needs and gender stereotypes, and notions of masculinity where illness is seen as a weakness and unmanly (Hassim et al., 2007; Holroyd et al., 2008). However, some men appear to be able to negotiate these stereotypes and to 'take action' and engage more freely with the health system (Farrimond, 2012; Galdas, 2013). At an individual level it has been noted by a number of researchers that men are "poor, or at best reluctant, users of the health system, particularly health services designed to promote and maintain health" (Robertson, 2007:1). These barriers may inhibit men from seeking help until they are ill, which is detrimental to their health.

Economic constraints due to poverty and high levels of unemployment have been found to hinder people from accessing the health system, because they cannot afford the cost of transport to the facilities, and many people are reluctant to give up the opportunity to work and earn some income even if they are ill and would

therefore delay visiting or not visit a clinic at all (Nyirenda et al., 2006). It has been suggested that men prefer private health care, and this was confirmed in Botswana, where it was found that more men than women are likely to access private health care, in particular for ART, because they are more likely to be able to afford it (Phaladze & Tlou, 2006). Help-seeking patterns differ depending on the context. A study conducted in Soweto in 2007 found that men accessed medical care mainly from the public sector (71%), then the private or non-governmental sector (25%) and traditional sector (4%) (Venkatesh et al., 2011). Although men may prefer to access private health care, the high levels of unemployment in Soweto and the lack of disposable income are likely to preclude most men from accessing private or THPs, who require a fee, and they therefore may decide not to seek help at all. In South Africa the public sector health services at a primary care level are offered free of charge and therefore economic factors should not be a major factors affecting men's utilisation of health services and their help-seeking practices in Soweto.

As mentioned earlier, stigmatisation has been associated with HIV from the beginning of the epidemic. For men accessing the health system at all is socially less acceptable, and may be considered unmanly by their peers and they may be stigmatised. Stigmatisation has played a critical role in the HIV/AIDS epidemic and in men's help-seeking behaviour; this is covered in more detail in the chapter on stigmatisation.

There are many barriers within the public health system that deter men from accessing services. The health services are fragmented, resulting in people having to access various sites for different services. People and men in particular are reluctant to spend time going from one part of a service to another, joining queue after queue to receive holistic health care (Serrant-Green & McLuskey, 2008). Men are disinclined to spend a lot of time at clinics because it keeps them away from other opportunities (Galdas, 2013). This may be a particular concern for men who are breadwinners, such as those whose experiences of the clinics in Soweto are explored in this study.

Further confidentiality is a key concern for many people but particularly for men, and a breach in trust may turn men away from the clinic (Fitzgerald et al., 2010). In the public health services the workforce is predominantly female, and this may deter men from accessing services if they perceive women to be gossips. Preston-Whyte (2003:91) noted that people who are not gossips are "... often highly regarded. This, in itself, may be gendered in that it is often seen as an attribute of men as opposed to women — men who inhabit the

world of affairs and politics as against women whose traditional realm is that of gossip, the home and the domestic.” In this case women are perceived as gossips and men may be unwilling to confide in, or want to consult with female health workers. Pearson & Makadzange (2008) found that this encourages men to seek help elsewhere. Further health workers in Gauteng Province tend to have their own opinions and prejudices about sexuality and sexually transmitted diseases, but they are seldom trained to deal with these, and the resultant service provision is poor (Leichliter et al., 2011). This study explored whether or not female health workers were a deterrent for men seeking help in the clinics.

There is a common perception that men delay seeking help or accessing health services because they are stoical and reluctant to ask for help (Robertson, 2007). Other reasons postulated include that men have poor knowledge regarding health matters, which may contribute to not taking preventing measures and delaying seeking help until they have no option because they are very sick (Banks, 2001). Furthermore, men believe they are invulnerable to illness, will lose social status, and may lose their job if they seek help (George & Fleming, 2004; Bonhomme, 2007). But Holroyd et al. (2008) suggest that men’s health, masculinity, men’s lives, and their experience of illness are interlinked, and that men feel vulnerable when their health fails and are reluctant to admit that they are ill or need help. Seeking help opposes the notion that men are strong and self-reliant.

The barriers based on gender roles that society places on men are described by Mgqolozana (2009) in his book *A man who is not a man* about the experience of a young South African man undergoing circumcision as part of the rite of passage to becoming an adult. During this time, the circumcision wound became septic and the initiate was torn between asking for help and staying in the veld, as prescribed by the ritual. He was told that it was better to die in the veld than to not become a man, but he made the decision to seek help. Whilst in hospital he was confronted by a man enquiring why he was there and questions: “How do you tell another man that you have come to hospital for help, without implying that you have failed to be a man in the supposed way?” (Mgqolozana, 2009:11). Although this narrative is about circumcision, the importance that is placed on being a man rather than his health, and perhaps even death, is indicative of the broader views in society concerning men’s help-seeking behaviour.

This study explored aspects of masculinity, men's views on their health, what health issues they experienced, their understanding of illness, and specifically HIV/AIDS and their help-seeking approach in relation to HIV/AIDS to determine what inhibits men from seeking help in the clinics.

Chapter 6: Conceptual framework

The literature review highlights a number of factors related to HIV that impact negatively on individual men's health (including MSM). Of direct relevance to this study are the issues of the HIV/AIDS epidemic, masculinity, men's health, men's help-seeking practices, health services, stigmatisation, and discrimination.

The conceptual framework for this thesis is centred around the individual man and the influences that determine his help-seeking behaviour for HIV-related issues. Three major influences on men and their engagement with the epidemic emerge from the literature, which are interlinked and influence each other, as summarised and depicted in Figure 4.

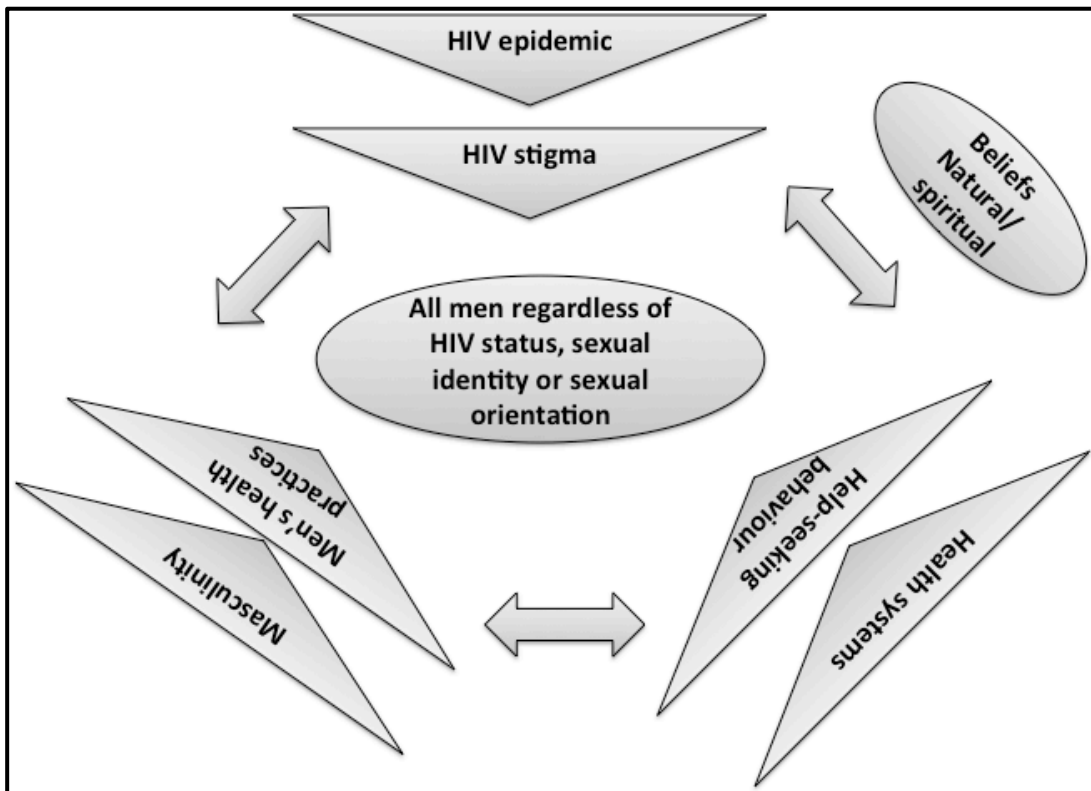


Figure 4: Conceptual Framework

The HIV/AIDS epidemic itself has been a game changer in many people's lives. The emergence of the epidemic and the uncertainties surrounding its spread were a major concern for many people and allowed myths, confusion, speculation, and various beliefs to develop. In South Africa a number of factors shaped the

epidemic. The lack of political leadership and the delays in rolling out ART caused people to look for help from places other than the public sector clinics. The connection of many of the symptoms with witchcraft encouraged consultations with THPs.

Surrounding the epidemic was HIV stigmatisation and discrimination, which caused further hardship on people infected with and affected by HIV. The stigma of being HIV-positive encouraged men to keep their status a secret for fear of being rejected by their peers or the community. The community rejected people who they thought may be infected, including their close contacts for fear of contagion. HIV stigmatisation and discrimination isolated men and discouraged them from seeking help, particularly from facilities where they may be identified as being HIV-positive.

The second area of influence is patriarchy and masculinity, both of which influence men's health practices. The power that is bestowed on men in a patriarchal society gives men an advantage and social standing in society. But this is a double-edged sword, as they also do not want to be seen as weak in any way for fear they may then be taken advantage of by others. This places men in a quandary, as they perceive being ill as a weakness that does not allow them to fulfil their obligations of being a man, such as being the breadwinner, making decisions in the household, and being a father. Thus men's health practices are compromised.

Finally, the health system has been geared towards maternal and child health, which makes most of the clinic patients women. The majority of health workers are women and men are uncomfortable consulting them, particularly on sexual health issues. The HIV/AIDS services are generally separate from the general clinic, which makes people going to these services easily identifiable. With the rise in HIV-related illness the clinics are now crowded and have long queues, and for men who are employed or looking for work the long waiting times detract from visiting the clinics.

The combination of these factors operating at various levels, influence men's help-seeking practices and how they access HIV/AIDS services – these factors were explored in the interviews and provided the conceptual framework of this thesis.

PART 3: METHODOLOGY

Part three outlines the methodological approach to the thesis. The starting point was the observation that the HIV/AIDS services are predominantly populated by women. A literature review was conducted to investigate this phenomenon and the factors that may contribute towards it. This resulted in a conceptual framework that guided the interviews.

In Chapter 7 the study objectives and study area are outlined. The qualitative approach is described and justified. The sampling method is described and a summary of male participants presented.

Finally a brief description is given of each male participant.

Chapter 7: Methodology

7.1 Introduction

Men have been neglected in much of the literature on HIV/AIDS, primarily because women and children have been seen as the most affected and vulnerable populations in this epidemic, particularly in sub-Saharan Africa. Research on men's health has focused on comparing men's health practices and health outcomes to those of women and their biological differences; but little is known about how and why men differ from each other and how societal and cultural influences impact on men's health (Robertson, 2007). Men's help-seeking behaviours, or lack thereof, have been interpreted as negative rather than taking their different behaviours into account. In addition, men's help-seeking has been generalised as one dominant practice, whereas, in reality, as with masculinities, there are multiple and diverse practices that change over time. Men are held responsible for their actions whereas women are excused because external forces are considered to determine them (Smith & Robertson, 2008). These generalisations are not helpful in understanding individual men's experiences and the different approaches that individual men adopt in the context of social and cultural norms. A more nuanced understanding of men's help-seeking behaviour is urgent and cannot be achieved without understanding why and how individual men seek help.

There is a lack of information on men's help-seeking practices and a dearth of men's voices when it comes to understanding their involvement in sexual health issues (Serrant-Green, 2008). Understanding how lay people comprehend illness determines how they respond to it, as Meyer-Weitz et al. (1998) found in their study on STIs in South Africa. Therefore, lay narratives are important in changing the perception that health and illness is purely biomedical, and they are important in reaching a broader understanding that these illnesses need to be treated more holistically (Robertson, 2006a).

In order to fill this gap, the voices of men need to be heard. For this reason, this study adopts an exploratory qualitative approach, investigating what men have to say about HIV, their health, and their help-seeking behaviour and experiences. Since little research had been done in this area previously in South Africa, it was decided to cover all three main thrusts outlined in the conceptual framework to determine what the most pressing issues for men are, rather than any one in depth. In other studies on men's behaviours, the use of lay accounts has provided valuable insight into men's help-seeking behaviour, providing an understanding of the

issues from the men's point of view (Robertson, 2007; Fitzgerald et al., 2010). Robertson (2007) notes that although individual accounts do not provide much insight into issues, as a collective these narratives yield a more holistic picture illustrating what is happening in a specific place and context, with a particular group of individuals, at a given time. He suggests that the collection of views can give insight into social identity and help-seeking practices. Furthermore, a diversity of voices is needed to unpack multiple masculinities and help-seeking practices (Seidler, 2006). In this study the voices are those of a group of black African men living in Soweto.

Men's health practices need to be investigated together with the social context and the views of the traditional and clinic health workers. These external factors influence men's experiences and behaviours. Health workers', also called secondary informants, voices are necessary to understand how they view men and men's help-seeking behaviour, and how they respond to male patients. Robertson (2007:6) describes the issues of power in the lay-professional relationship as a complex process that "both relies on, and (re)constructs, aspects of social hierarchies, of social identities and provides examples of how such hierarchies and identities are gendered in nature." These relationships are critical and important to explore. In this way it is possible to examine the perceived role of the health practitioner and the relationship with the client.

The men in this study were not only asked about their views on certain topics, but they were also asked to provide what they thought other people's views were. Seidler (2006:25) observed that "men often learn to talk for others rather than exploring the complexities of talking more openly and directly for themselves." Thus, the questions were framed to include the individual's views, as well as what they perceived the community's views to be.

7.2 Study objectives

The main objective of this thesis was to explore men's understanding of and help-seeking behaviour with regard to ART in Soweto, South Africa.

Sub-objectives include exploring:

- men's perceptions of the HIV/AIDS epidemic;

- men's behaviour regarding VCT and HIV/AIDS services;
- levels of stigmatisation associated with men and HIV; and
- health workers' attitudes towards men.

7.3 Study area

Soweto is a township on the outskirts of Johannesburg, the economic hub of South Africa. The township was established in the early 1900s to accommodate migrant workers for the mines and other industries.

Starting on 16 June 1976 a series of protests took place, mainly by school children who opposed Afrikaans as the medium of instruction (Ndlovu, 2006). This is known as the Soweto Uprising, and heralded nearly two decades of turbulence and unrest in the township and throughout South Africa. These events would have impacted heavily on men in the township, who would have had to play an active role in the violence and/or bear witness to many atrocities (Barker & Ricardo, 2005).

Soweto comprises a range of cultures and economic and social strata. In 2004, an estimated 1.14 million people lived in the township. The gender ratio was 47% male, 53% female. Fifty five percent of residents live in council or private houses and 45% live in hostels, informal settlements, or backyard dwellings. Men were more likely to have been educated to a higher school level than women. Unemployment is a problem, with only 43% of the working population employed, and the majority (56%) of these men (Gray et al., 2006). Of the women attending the public sector antenatal clinics, about 30% of them test HIV-positive (Mnyani et al., 2009).

Prior to April 2004 there was limited access to ART in Soweto. Some non-profit organisations (NGOs) provided treatment with funding from donor organisations or private funds, and there were limited spaces on clinical trials. It was only in April 2004 that ART first became available to adults and children in the public sector tertiary hospital, Chris Hani Baragwanath Hospital. Later, four primary health centres were accredited to provide treatment, but by 2012 all 58 clinics in Soweto were providing treatment.

7.4 Antiretroviral Treatment gap

In December 2013 over 65,000 Sowetans are on ART, and 22,100 of these are men, but the ratio of men to women has remained consistent over time at 35:65. The recent SA national HIV survey also found more

women than men on treatment and attributed this to gender differences in help-seeking behaviours and the expanded PMTCT programmes that target women (Shisana et al., 2014).

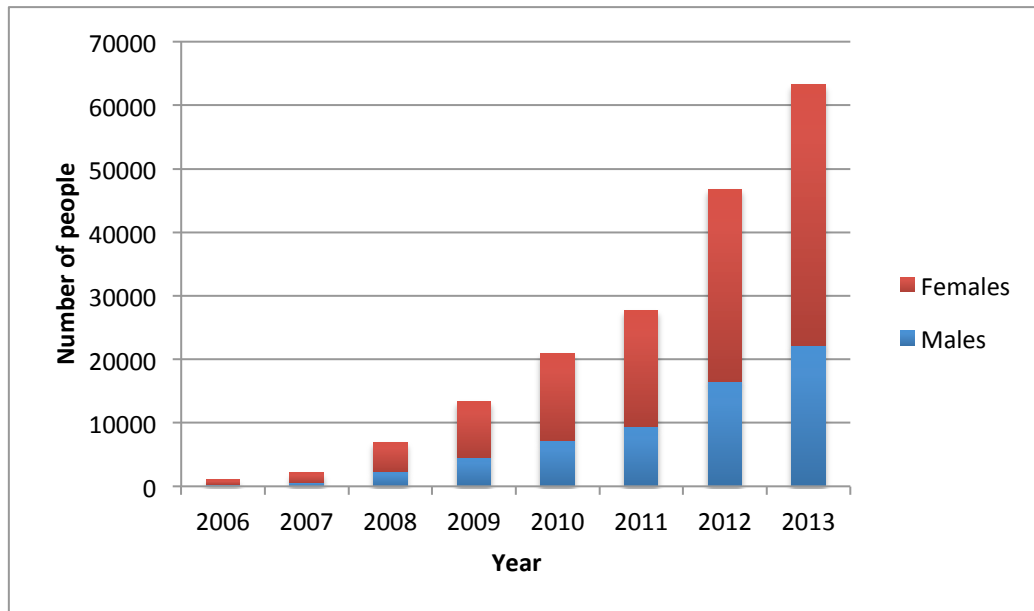


Figure 5: ART uptake in Soweto (Anova, 2013)¹³

The gap of ART uptake between men and women is estimated for the study area at the end of 2013. By the end of 2013 Soweto's population had grown to an estimated 1.9million and an adult HIV-positive prevalence of 15%. A total of 236,000 adults are HIV-positive and 50% or 118,000 eligible for ART. Given that women have higher HIV prevalence the estimated ratio for men to women eligible for treatment is 45:55. Thus of the 118,000 eligible for ART 53,100 are men, and only 40% (22,100) are on ART. Whereas 64,900 women are eligible for ART and close to two thirds (41,230) are on ART.¹² Although there has been a rapid increase in HIV-positive people being treated there are still many more people, particularly men, who are eligible and need to access ART. With a minority of Sowetans in formal employment, most access the public health service, which is where these men need to go for ART.

¹² These data have been sourced from Anova Health Institute NPC, 2013, unpublished ART statistics from Soweto clinics gathered from routine clinic data and the District Health Information System.

7.5 Qualitative Approach

To gain a better understanding of the issues raised earlier in the literature review, a qualitative research design was adopted because it is suitable for research that “attempts to understand people’s perceptions, perspectives, and understandings of a particular situation” (Leedy & Ormrod, 2001:153). Green & Thorogood (2013) confirm that qualitative methods of social inquiry are appropriate for “studies for health” and enable better insights of health, health behaviour, and health services to be obtained. In public health social research is used to understand how to improve health and health care – an approach adopted in this study.

Research on gender and health has focused on the differences of health between men and women, often relying on quantitative methods. However, in South Africa little attention has been given to qualitative methods. Interviewing men has raised particular difficulties, as highlighted by Oliffe & Mróz (2005:257) who remark that the gender of the interviewer can influence what information is divulged: “However, it can also be a daunting task, especially when two men, who are often strangers, agree to talk about ordinary private matters such as health and illness. The sex of the researcher and participant affects the dynamics and information shared in qualitative interviews.” The research assistants chosen to administer the interviews were both male as it was decided that men in South Africa would be more likely to discuss sexual issues with another man rather than a woman.

7.6 Focus groups

Focus groups were chosen as a tool to explore particular themes, to confirm that the interview schedules covered the topics sufficiently to answer the research questions, and to verify or clarify issues raised in the interviews. A total of four focus groups each were held, three prior to the interviews and one after all the interviews were conducted. These were used to obtain a wide range of opinions on particular topics as suggested by Green & Thorogood (2013)

The focus group participants comprised men with the same HIV status. Of the four focus groups, two were with HIV-positive men, and one each with HIV-negative men and with men who had not tested and therefore did not know their HIV status. The men were separated for each focus group according to their HIV status or if they had not tested to enable a safe environment where they could speak freely as HIV stigmatisation

persists and is a sensitive issue. Each focus group comprised eight to ten male adults. A focus group guide, with questions relevant to the group, was used to explore the following themes: understandings of HIV, AIDS and health; perceptions of the health services in Soweto; perceptions of HIV/AIDS services such as VCT and ART; and what improvements could be made to these services.

The first set of focus groups was used to determine whether or not the questions in the interview guide adequately covered the themes to be explored, and whether or not there were any gaps that needed to be addressed. The results were used to refine the questions for the semi-structured interviews.

The focus group with men who had not tested explored what inhibited the men from testing for HIV, what would encourage them to test, and from where they seek help when they are ill. The group with HIV-negative men explored their experience of HIV testing, HIV risk factors, health worker attitudes, traditional health practices and practitioners. The group with HIV-positive men explored HIV testing, their understanding and experience of ART, disclosure, and their experience of the public health clinics.

The focus groups confirmed that the interview schedule had covered all the important themes and the men shared a nuanced understanding of the issues. After considering the focus group discussions it was decided not to alter the questionnaire in any way.

After all the interviews were completed a focus group with HIV-positive men was held to address a concern. The HIV-positive men in the interviews had been recruited from clinics and the researcher was concerned that their views may be biased towards favouring help-seeking in the clinics rather than elsewhere. These men were recruited from two community organisations in Soweto working with HIV-positive men. The focus group included discussions on HIV testing, preferred clinics, adherence to ART, improving the services and barriers to accessing ART. The focus group's opinions were similar to those of the men who participated in the study

The researcher attended the first focus group. The focus groups were led by the research assistants in the focus group participants' preferred language. The focus groups were recorded, translated (where necessary), and transcribed. The participants in the focus groups were not invited to participate further in the study. The

information from the focus groups was not used in the analysis of results as it did not add new or different information from the interviews.

7.7 Interviews

Semi-structured interviews were chosen to enable the research topics to be covered in a systematic fashion, whilst allowing the participant to determine, in their own words, their response. The participant is free to elaborate and give importance to each of the topics (Green & Thorogood, 2013). The interviews were directed by a semi-structured interview guide, and the interviewer was able to probe topics of particular interest that were raised by the participants.

HIV/AIDS has been stigmatised since the onset of the epidemic and further men have been reported to be reluctant to discuss health issues with women. (Miller & Glassner, 2004). In order to mitigate this, male research assistants were employed to conduct the interviews with the men. So that the participants could be put at ease and build trust the interview guide was structured in a manner that allowed a set of general questions to precede those of a more personal nature (Green & Thorogood, 2013).

The researcher participated in the interviews with the clinic managers. The research assistants conducted all the interviews with the men and the health workers. All the interviews and focus groups were tape-recorded. The interviews were conducted in the participant's preferred language, which included English, Zulu or Sotho,, and transcribed near verbatim. The translations were checked by a second research assistant who is familiar with these languages.

7.8 Study sample

A diverse sample of 33 primary informants comprising men with known positive or negative HIV status or men who had not tested and 10 secondary informants were purposively selected as this allows for "systematic comparisons of theoretical and analytical interest" (Rhodes & Cusick, 2000:6). In addition purposive sampling enables the selection of participants who are expected contribute towards answering the research questions (Green & Thorogood, 2013). This sampling technique permits including participants that may otherwise be hard to reach, such as HIV-positive individuals.

Comprehensive HIV services are provided in the public sector clinics and NGO sites provide VCT in standalone facilities or in mobile units. Of the 10 secondary informants, four were health care workers working in public health clinics providing HIV-services or HIV testing sites. Public sector health workers comprised two clinic managers, a doctor and a community outreach officer. This provided a representative cross section of staff in a primary health care ART service. The clinic managers were nurses and ran the HIV treatment and care service including ART. The doctor initiated HIV-positive patients onto ART and consulted on difficult patient cases. The community outreach officer assists HIV-positive through lay counselling, basic HIV and ART adherence education and connects patients to community based NGOs for support.

The VCT site secondary informants comprised health workers from a mobile and a standalone VCT service. The two VCT site coordinators not only coordinated the VCT service but also provided HIV counselling and testing. The two counsellors are lay health workers who provide counselling and testing.

The majority of the health care workers selected were female, reflecting the overwhelming number of female staff in the HIV services and public health care clinics in general.

In addition, two THPs, one male and one female, who were associated with the clinics, and had knowledge of HIV were interviewed.

Table 2: Summary of secondary informants

Reference	Description	Gender
MGR2	Clinic Manager	Female
MGR5	Clinic Manager	Female
CNS1	Counsellor	Female
CNS7	Counsellor	Male
CORD4	VCT site coordinator	Female
CORD8	VCT site coordinator	Female
DOC9	Doctor	Male
COO6	Community Outreach Officer	Female
THP3	Traditional Health Practitioner	Female
THP10	Traditional Health Practitioner	Male

Thirty-three black African men were selected, comprising 11 HIV-positive men, 11 HIV-negative men and 11 men who did not know their HIV status because they had not tested. These participants were purposively selected so that a diverse range of men were reached, including younger and older men, and men who have sex with men. Thirty men identified as heterosexual, and three self-identified as MSM. Their ages ranged between 18 and 52 years, and all lived in the Greater Soweto area.

The men with known HIV status were identified at clinics with HIV/AIDS services, such as ART or VCT sites. To identify men who had not tested, the research assistants approached men in the community to determine if they had tested for HIV. The prospective male participants were approached by the research assistants or a health worker, whichever was appropriate to ensure confidentiality. The purpose of the research was explained to them and they were invited to participate in the study. There was no consequence to any person who was approached and declined to participate. The male participants were not paid for the interview, but were reimbursed R50 for transport costs.

The male participants were not required to be identified, and were able to provide the information anonymously.

7.9 Research assistants

The interviews were conducted in the informant's preferred language. The researcher participated in the interviews with the clinic managers and observed one focus group. Since the researcher is unable to speak any African language, two male research assistants who were experienced interviewers were employed to conduct the interviews and to run the focus groups. The researcher worked closely with the research assistants, going through the transcribed manuscripts and indicating where more probes or emerging themes could be explored in future interviews if the topics arose. This is common practice where such language barrier exists between researcher and participant (Green & Thorogood, 2013).

7.10 Limitations

The interviews with the male participants were limited to one interview each. The trust needed to gain very personal opinions may not have been obtained during the interview. Therefore, some responses may contain

bias, and may not contain deeply personal opinions and thoughts. In addition, their publically reported views may not reflect or agree with their personal views, as observed by Green (1995).

The interviews were guided by a semi-structured interview guide and with open-ended questions for each topic of interest. Probes for questions were suggested in the guide. The interviewer was able to probe other issues when they were raised by the participant. This limited probing to topics in the guide and to those raised by participants. For example, topics raised by one participant and no others would not have been explored with all the participants.

Bekker (2005) found that male study participants felt vulnerable in discussions about masculinity. Oliffe & Mróz (2005) provided useful insights into interviewing men and these insights were taken into account, such as starting off with broad non-threatening questions before moving into probing more personal information. But, as mentioned earlier, both research assistants were men and this may have inhibited male participants revealing their personal thoughts. The research assistants were trained not to express their own opinions, but occasionally the male participants asked them direct questions, which they sometimes responded to, but generally avoided doing so. These responses did not appear to influence the male participant's replies thereafter.

The interviews were only conducted with men; therefore no direct comparison can be made to women's viewpoints.

The interviews were all translated (if required) and transcribed. The transcriptions were checked against the recording, but there may be inaccuracies, and nuances may have been lost during translation.

Although there are limitations to the study, the data from the interviews have provided rich insights into men's thoughts, concerns, and behaviour in the context of HIV.

Soweto is a microcosm of a large portion of the urban population in South Africa. Whilst the findings from this research may not be generalised to the population as a whole, they may be pertinent to other urban areas in South Africa. Many townships have comparable population demographics to Soweto, and it is likely that men encounter similar issues.

7.11 Data analysis

The interviews were analysed inductively as described by Terre Blanche et al. (2007). Each interview was analysed to extract the major themes emerging from the discussion and relevant to the context. These themes were categorised and the common and diverse themes, and similarities and contradictions were identified. The themes were given codes and Atlas.ti was used to code each interview. The data was extracted from the interviews and drawn together into chapters. The interviews were read numerous times to ensure that the quotes used to illustrate points were not taken out of context.

The themes were quantified in terms of the number of male participants raising them, however this quantification must be taken with caution and is not generalizable. These figures supplied in the results section provide a general idea as to whether a theme was popular or not. The less common themes often highlighted matters of relevance in the broader context of men and help-seeking behaviour.

The HIV status of the male participants is noted in the text where it is relevant, and a brief synopsis of the characteristics of each is provided for easy reference.

The interviews and focus groups were cross-correlated to determine consistency and reliability. Finally, the results were interpreted and compared with those presented in the literature.

7.12 Ethics

The study followed recommendations from Hassim et al. (2007), who emphasise that strict ethical procedures are needed and that human rights must not be violated when research on human subjects is conducted. The study protocol was submitted and received ethical clearance from the University of the Witwatersrand Ethics Committee for Research on Human Subjects.

All prospective study participants were given a study information leaflet to read prior to asking them to participate in the study. They were given the opportunity to ask questions before being enrolled. Written consent to participate in the study was obtained from all participants. Although some participants agreed that they could be identified, it was decided that all participants would be given pseudonyms. Written consent from the participants was obtained for all interviews and focus groups to be tape-recorded, and all interviews

and focus groups were translated and transcribed near verbatim. The recordings will be destroyed once the study is completed.

7.13 Male participants

A total of 33 interviews were conducted with men aged 18 to 52 guided by semi-structured interview schedules. Approximately half of the male participants were below the age of 25, half were unemployed, and the majority were single. Most had some education up to Grade 9, but many had not gained their matriculation. This reflected the demographics in Soweto that has a relatively young population and high unemployment. The majority lived with their parents and relied on the household income, which was mostly under R5000 per month. A summary of their demographics is given in Table 3 below.

Table 3: Summary of the male participants' demographics

Characteristic	N = 33	%
Age Group		
<25	16	48%
25 – 34	9	27%
35+	6	18%
Employment status		
Unemployed	18	55%
Casual or Part-time	5	15%
Employed	1	3%
Student	6	18%
Highest level of education		
<Matric	14	42%
Matric or above	9	27%
Marital & relationship status		
Single – In a relationship	15	45%
Single – Not in a relationship	12	36%
Married	4	12%
Separated or widowed – Not in a relationship	2	6%
Household Income		
<4000	14	42%
4000 – 10000	4	12%
>10000	3	9%

A brief summary of each of the male participants' characteristics is given in Table 4.

Table 4: Detailed characteristics of male participants

	Name (Pseudo nym)	Age	HIV status	Marital and relationship status	Employment
1	Abel	27	Negative	Single – Not in a relationship	Casual
2	Lucky	20	Never tested	Single – In a relationship	Unemployed
3	Tshepo	30	Positive	Single – Not in a relationship	Employed
4	Albert	21	Never tested	Single – In a relationship	Unemployed
5	Kabelo	33	Never tested	Married (Traditional)	Student – piece jobs
6	Matthew	20	Negative	Single – Not in a relationship	Casual
7	Jackson	34	Positive	Married (Traditional)	Unemployed
8	Sipho	23	Negative	Single – In a relationship	Employed – part-time
9	Thabo	52	Positive	Widower – Not in a relationship	Unemployed
10	Bongani	35	Positive	Married	Unemployed
11	Zakes	38	Positive	Single – Not in a relationship	Casual
12	Nhlanhla	18	Never tested	Single – Not in a relationship	Unemployed
13	Mark	19	Negative	Single – In a relationship	Unemployed
14	Reuben	21	Negative	Single – In a relationship	Unemployed
15	Mdu	18	Negative	Single – Not in a relationship	Student
16	Martin	25	Negative	Single – Not in a relationship	Student
17	Amos	36	Positive	Single – In a relationship	Unemployed
18	David	30	Positive	Single – In a relationship	Unemployed
19	Emanuel	19	Negative	Single – Not in a relationship	#
20	Andrew	24	Negative	Single – Not in a relationship	Unemployed
21	Lebo	#	Positive	Single – In a relationship	#
22	Enoch	#	Never tested	Single – In a relationship	#
23	Phil	18	Never tested	Single – In a relationship	Student
24	Clement	18	Never tested	Single – In a relationship	Student – part-time dancer
25	Patrick	36	Positive	Married	Unemployed
26	Noah	19	Negative	Single – Not in a relationship	Unemployed
27	Musi	20	Never tested	Single – In a relationship	Student – piece jobs
28	Thulani	22	Negative	Single – In a relationship	Casual
29	Tebogo	27	Positive	Single – Not in a relationship	Unemployed
30	Jabu	28	Never tested	Single – In a relationship	Unemployed
31	Brian	26	Never tested	Single – In a relationship	Unemployed
32	Xolani	41	Positive	Separated – Not in a relationship	Unemployed
33	Eugene	19	Never tested	Single – Not in a relationship	Unemployed

Information not given

A brief description of each male participant is given here to provide insight and context to the comments that they make in this section. All their names have been changed. Although some participants agreed that they could be identified, it was decided by the author that all participants would be identified using pseudonyms.

Abel is 27 years old, with a Grade 11 education and is HIV-negative. He considers himself single, as he just got “dumped.” He has another partner but he is not in love with her; “all we do is have sex, there are no strings attached.” He doesn’t have any children but helps out with his sister’s children, as she has passed away. He lives in a backyard shack behind the family house where his mother, two brothers, and three sisters stay. He is self-employed, working in a hair salon that he owns with two others. He sometimes earns R400 in a month, but other months he takes home nothing, and then he relies on the household income, which is around R2000 per month. According to him he has few health problems but recently had a kidney problem, a lump on his leg, and has had problems with his eyes from an early age.

Lucky is 20 years old, with a Grade 12 education and does not know his HIV status. He is part of a group of friends that “takes things lightly.” He has a girlfriend and does not have any children. He lives in a house with his mother, sister, and younger brother. He is unemployed and relies on the household income (mother and brother) which is around R5000 per month. He is fit and healthy and seldom has to visit a clinic.

Tshepo is 30 years old, with a Grade 11 education. He is HIV-positive and has been on ART for 2 months. He has experienced some side-effects: being exhausted, thirsty, and dizzy. He has disclosed his HIV status to his mother and sister. He regards HIV to be a normal illness. He is currently single as he broke up with his girlfriend about six months ago. He does not have any children. He lives with his mother in a shack in an informal settlement. He is employed at a company that produces magazines. The household income is R2000 per month.

Albert is 21 years old and has a matriculation (Matric or Grade 12) certificate. He does not know his HIV status. He says he is single, but he is involved in a relationship and does not have any children. He is unemployed. He lives in a house with his mother, three older sisters, and two nephews.

Kabelo is 33 years old and does not know his HIV status. He is traditionally married and has paid lobola (bride price or payment to the woman’s family in order for the man to marry her) but has not signed a legal marriage contract. He supports his two children that live in the Eastern Cape. His wife lives in Gauteng, but he does not stay with her. He has matriculated and is studying. He is unemployed but does piece jobs from time to time, earning R40-R50 when he does work. He lives on his own in a shack in an informal settlement where some friends stay. They help each other out by providing food.

Matthew is 20 years old and is HIV-negative. He is “single, very much single” and not in a relationship. He lives with his grandmother, mother, and sister in a “very big” house. He has achieved Grade 10. He is unemployed, but helps his grandfather delivering newspapers.

Jackson is 34 years old and HIV-positive. He learnt of his status in 2005, and is on ART. He has disclosed his status to his wife and two children, who are supportive. He is traditionally married, but has not signed a legal marriage contract. He lives with his wife and two children. He lives in a shack in an informal settlement. He started Matric but did not finish it. He is unemployed, but his wife works part-time and does some domestic work. The household income is between R800–R900 per month.

Sipho is 23 years old and HIV-negative. He is going out with a woman. He lives in a house with his father and stepmother. He has completed Grade 9. He works part-time. The household income is around R7000–R8000 per month.

Thabo is 52 years old and HIV-positive. He is a widower and believes his wife died of AIDS although she never tested or accepted that she may be HIV-positive. He has four sons, none of whom live with him. He lives by himself in a shack in an informal settlement. He was offered early retirement when he fell ill, and is currently unemployed.

Bongani is 35 years old and tested HIV-positive in 2002. He is married with a Grade 10 education. His wife is also HIV-positive and he believes he infected her. He has one child (13), who is HIV-negative. He has been unemployed since 2007. He lives in a house. The household income is between R400-R500 per month.

Zakes is 38 years old and is currently single. He lived with the mother of his child, but while he was in prison she had affairs and when he was released, she split up from him and left him with his child. He found out he was HIV-positive in prison, and has been on ART since 2004. The mother of his child died of AIDS. He is a Christian. He is now single; his girlfriend left him because he did not disclose to her and she heard from others he was HIV-positive. He lives with his mother, brother, and sister’s child. He is unemployed, but earns some money doing motor car repairs. The household income is R2000 per month.

Nhlanhla is 18 years old, single and has never been in a relationship. He does not know his HIV status and does not think it is important to know it as he doesn’t “sleep around”, although he knows he is at risk. He

lives in a house with his mother. He tried Matric but did not pass. He is unemployed. The household income is around R3000 per month.

Mark is 19 years old, and has relationships with two women. He completed Grade 10 schooling and is still a scholar. He tested HIV-negative at school. He has never been employed. He lives in a room in the backyard of his family's house where his grandparents and cousins live. The family pools their income, which amounts to R500 a month. He is well versed with HIV as his aunt runs a support group, which he attends from time to time.

Reuben is 21 years old and has never tested for HIV. He says he is single but is involved in a relationship. He completed Grade 11. He has never been employed. He lives in a house with his mother and two brothers.

Mdu is 18 years old and HIV-negative. He is single, his relationship ended last month. He is the first-born and feels responsible for setting an example to his siblings. He lives in a house with his parents and his younger brother and sister. He is not working but is studying information and communications technology (ICT). The household income is around R24000 per month.

Martin is 25 years old. He tested HIV-negative in 2007. He is not married and is not seeing anyone at the moment since he "cheated" and they decided to end things. He lives with his three brothers in a two-roomed house. He has completed his Matric but is trying to upgrade his subjects. The household income is around R2500 per month.

Amos is 36 and completed his Junior Certificate (Grade 10). He is HIV-positive, but not yet on treatment. His wife died of AIDS, with whom he had daughter who is now 17 years old. He has a partner, but is not staying with her. He lives in a house with his daughter and grandchild. He is unemployed, but does occasional electrical repairs to earn enough for electricity and water for his dependants. The household income is around R600 per month.

David is 30 years old, he has a partner that he has been with for three years. He does not have any children, but his partner has two. He completed Grade 10 education. He has been unemployed since 2006. He lives in a shack with his partner. He and his partner are HIV-positive.

Emanuel is 19 years old, single, and not in a relationship because “ladies are too much work.” He lives with his sister and her daughter in a house most of the time, but occasionally with his mother and father who live in a shack. The household incomes are R3000 and R1700 respectively. He is HIV-negative and he feels he is “normal like other people.”

Andrew is 24 years old, HIV-negative, he says he is single and has a girlfriend of two weeks. He has a Matric. He lives in a house. He had a relationship with a man the previous year and after a drinking spree had unprotected sex with him. He was afraid he may be infected and went to test. He has been experimenting sleeping with men and women, “I am sleeping with men to experience if I would be able to sleep with men and women.” He says has a masculine identity and does not look “gay.”

Lebo is HIV-positive and identifies as gay. “I am feminine. Gay people are feminine like in attitude and behaviour.” He has a partner who is living overseas, but practices polygamy. He believes “during the year 2012 all gay guys will be HIV-positive.” Sex happens quickly and is not protected. He is dating a straight man but this relationship is kept secret. “I prefer people that I date to have their own relationship. I don’t want to be disturbed with my relationship.”

Enoch describes himself as a “proud” gay man, but has not disclosed this to his family or friends in his hometown, although in Johannesburg people know he is gay. He has not tested for HIV, although he has engaged in risky sex.

Phil is 18 years old and says he is single but is in a relationship. He has not tested and does not know his status. He does not have any children. He lives in a house with his parents and older brother. He has Grade 10 schooling and is studying an IT course. He is unemployed. The household income is around R15000 and both his parents are working.

Clement is 18 years old, with no dependants. He is adamant that he does not want to know his HIV status. Two of his sisters are HIV-positive and his brother died from an HIV-related illness. He is in a relationship. He completed Matric and is studying to become an engineer. He is a dancer and gets paid for gigs. He lives in a three-bedroom house with his parents and brother. The household income is around R30000 per month.

Patrick is 36 years old and HIV-positive. He is married and has one child with his wife and four other children with different mothers. He lives in a house that was built for him by his grandparents who wanted him to expand the family name and gave him money to assist him. He has been unemployed since 1992 and has managed to secure temporary work from time to time. He repairs electrical goods. He now finds it difficult to work as he is not well and has a catheter at present.

Noah is 19 years old and HIV-negative. He is happy about this as “it affirms that [he] has been taking care of [him]self.” He lives with his grandmother and sister in a house. His mother passed away and he never knew his father. He is single and not in a relationship. He plays basketball and enjoys Hip-Hop dancing. The household income is around R2000.

Musi is 20 years old, unmarried and in a relationship. He has not tested for HIV as he feels that he is not ready to do so. He does not have children. He lives with his mother and two siblings in a shack in an informal settlement. He is at school, but he gets occasional work on weekends to help his mother, so he is not completely dependent on her.

Thulani is 22 years old. He has matriculated. He is HIV-negative and tests each time he gets a new partner. He is unemployed currently but used to promote products. He lives in a shack in the backyard of a house on his own. He supports himself and earns on average R1500 per month. He is estranged from his family and has been on his own since he was in Standard 5. He is in a relationship: “there is one steady and others are just at that time when I need a roll-on.”

Tebogo is 27. He is single and says it is because he is HIV-positive. He learnt of his HIV status when his baby passed away, and this ended his relationship. He has been involved with other women, but the relationships have not worked out. He says: “I’ve decided to stay single until such time I feel that I’m ready to try again.” He wishes that he had an “HIV-positive woman with whom [he] could talk.” His family “turned their backs on him” on learning that he was HIV-positive. He lives in a shack with his father who is mostly absent. He is unemployed and his father does not earn much (around R500 per month), he feels that he is a burden: “it’s heavy for him to care for me.”

Jabu is 28 years old. He has not tested but “since my girlfriend got tested I thought I was clean.” He is not married, but is planning to get engaged “very soon” to his girlfriend with whom he has three children. He wants to get engaged so that they can live together. He lives in a house with his parents, three cousins and one of his children. His girlfriend stays with his other children. He is not working. The household income is around R5000 per month.

Brian is 26 years old, single and in a relationship. He has not tested for HIV, as he is afraid to do so. He has no children and lives in a house with his grandmother and three cousins, as his family is in the Eastern Cape. He completed Matric. He is currently unemployed, but occasionally drives taxis to earn some income. The household lives on his grandmother’s pension and his sporadic income, which amounts to around R5000 per month.

Xolani is 41 years old. He is separated from his wife and has one child. He is HIV-positive and on ART. He lives in a shack with his mother, sister, and younger brother. His mother supports the household.

Eugene is 19 years old. He does not know his HIV status. He lives in a house with his mother and one brother. His other brother lives with his father elsewhere. He has two girlfriends “but they don’t live in the same area” so he sees them occasionally. He has no children. He has completed Grade 10. He is unemployed, but looking for a job. His mother earns around R5000 per month.

PART 4: PRESENTATION OF FINDINGS

This part of the thesis presents findings from interviews conducted with primary informants comprising men of varying HIV status, living or working in Soweto, and secondary informants, comprising clinic and traditional health workers. These are presented by theme in eight chapters. Chapter 8 highlights the men's understanding of the HIV/AIDS epidemic and their beliefs surrounding it. Chapter 9 investigates their knowledge of HIV transmission and treatment. Chapter 10 investigates HIV stigmatisation and discrimination in Soweto and in the health facilities. Chapter 11 explores what it means to be a man in Soweto and the influences of masculinity on their lives. Chapter 12 explores men's views on health and illness and their help-seeking behaviour.

Chapter 13 explores men's engagement with traditional medicine and reasons they visited THPs. The remaining chapters examine men's thoughts and use of the public health HIV/AIDS services. HIV testing is essential for men to know their status and to access ART. In Chapter 14 their thoughts and experiences of HIV testing are examined. Chapter 15 explores who the men talk to about their health and personal issues. Chapter 16 examines this in more depth through their interaction with the public health system.

The semi-structured nature of the interviews enabled some men to give detailed personal accounts of particular issues. These accounts were prompted by the interview questions, by probing questions or were voluntarily provided. Some of these accounts were deeply personal and reflected an individual's opinion on or experience of an issue and are therefore not generalizable to all men. However, they give rich information on the research question and related matters. They highlight issues that men experience with regard to HIV, illness and masculinity.

Terminology

The men are the primary informants in this study are referred to as "men" or "male participants". "Secondary informants" refers to the "clinic health care workers" and "traditional health practitioners." "Study participants" refers to both the men and secondary informants.

The men's voices are used throughout this section. They are highlighted as such in italics and inverted commas.

In order to give an indication of the number of men who are subscribing to a particular viewpoint the following terminology is used: “some” or “a couple” are two men, a “few” three men, “minority” is 10 or less men, “half” is between 11 and 16 men, “majority” is more than 17 men, and “most” is 28 or more men.

The men are identified by their pseudonyms, together with their age and HIV status i.e. Pseudonym (HIV status, age). For example, Lucky has not tested for HIV and is 20 years old is identified by Lucky (ntst, 20). Siphso who is 23 years old and HIV-negative is identified as Siphso (neg, 23), Lebo who is HIV-positive and his age is unknown is identified as Lebo (pos, --).

Chapter 8: Men's beliefs about the HIV/AIDS epidemic

In this chapter the men's views on HIV/AIDS and related issues are explored, including their understanding of where and how HIV emerged and what caused the epidemic. As is evident in other studies, men's views on HIV/AIDS and their understanding of illness can determine their help-seeking behaviour, including from whom, when, and where they seek help (Meyer-Weitz et al., 1998). As discussed in the literature review, if illness is understood to be the result of unnatural or spiritual causes, then seeking help from religious pastors, faith healers, or THPs would be appropriate. On the other hand, if illness results from natural causes, then help would be sought through allopathic sources.

The literature highlights that early on in the epidemic the uncertainty about the origin of HIV/AIDS and how it was spread caused confusion and fuelled gossip and speculation. This resulted in various explanations and myths being proffered, depending on the context, such as it being a gay disease or a result of witchcraft. Although it is more than 25 years since the first cases were diagnosed and HIV/AIDS is much better understood, myths persist (Stadler, 2003; Delius & Glaser, 2005; Steinberg, 2008; Ashforth, 2011; Dickinson, 2013). This is reflected in the interviews with the men who offered a number of explanations as to how the HIV/AIDS epidemic emerged, including the conventional explanation that it came from SIV. However, this was intertwined with politics and racism. Spiritual explanations regarding witchcraft and God were also explored. These notions are explored below.

8.1 Emerging epidemic

In South Africa the HIV/AIDS epidemic surfaced early in the 1980s at the beginning of the period of political turmoil and transition from apartheid to democracy, and exploded during the 1990s as can be observed in the HIV prevalence recorded at the antenatal clinics (see Figure 1) (National Department of Health, 2011). A minority (6/33) of the men brought political and racial elements into their narratives. These men, or the community, believed that whites had played a part in the spread of HIV/AIDS, saying that HIV/AIDS had been "*brought*" or "*created by white people*" and "*[it] came with a white man from overseas.*" The emergence of the epidemic post-apartheid when whites were no longer in power was thought to be another strategy by whites to "*destroy*" the majority black population, as Lucky described:

“There’s a story that says this guy was looking for a polio vaccine and he used guinea pigs to run his experiment. When they finally found the vaccine it happened that they did not detect a certain virus from the guinea pig. When they used the polio vaccine on humans the HIV virus was also injected into humans and that’s where they say it all started [...] In the community they say HIV is a political issue. They say it appeared as soon as black people gained power. They say it started to dominate from that time till now. They say people fought for freedom and they got it. Then white people found another strategy to destroy blacks by vaccinating us with the HIV virus.” Lucky (ntst, 20)

However, it was well known that HIV/AIDS emanated from SIV (Iliffe, 2006), and although this view was mirrored by a couple of men it was again distorted by the addition of a racial element. Emanuel recounted that it was believed that “*black people*” were the intended victims of the virus:

“I heard some time ago they said some people were [looking for] a cure for the people who were sick. ...[In] baboons it was called SIV and then they transfer[ed] it to human beings and it became ...HIV. People believe that there is a place somewhere where the virus is kept as the virus has been engineered for black people.” Emanuel (neg, 19)

Sipho suggested that white people were responsible for spreading the virus:

“Well it comes from monkeys [he laughs] someone brought this disease. It’s not something that God created like they all say. [...] I read [about] it somewhere. They said white people took blood from a monkey and it had the virus and so people got infected.” Sipho (neg, 23)

Introducing racial or political views into discussions on HIV/AIDS have been reported elsewhere in Africa (Goldin, 1994; Epstein, 2007; Dickinson, 2013). In South Africa HIV/AIDS became visible soon after the transition to democracy. The effects of apartheid still lingered in people’s memories, so it was not surprising that some discussions on HIV/AIDS had political or racial overtones, but it was interesting that the younger men also reported on these although they were likely to be less affected by the apartheid years.

Interviews highlighted that HIV/AIDS was frequently debated and discussed in the Soweto community. Although it was widely accepted that HIV was transmitted through sexual intercourse, the issue of contagion was contested. Some men were certain that unlike influenza it was not contagious unless one had direct contact with infected body fluids. As Eugene argued:

“If we share the same glass then I won’t be infected, or if we use the same toilet seat I still won’t get infected. What I’m trying to say is it’s not contagious, it’s not like ‘flu ... unless if you come into contact with infected blood and you also have a cut.” Eugene (ntst, 19)

However, other men were not so sure, and also mentioned that many people in their community believed that one could be easily infected. Although Albert knew that HIV could be transmitted during sexual intercourse,

through “*blood to blood*” or through breastfeeding, he explained that people in the community were concerned they could be infected by merely being in close proximity to an HIV-positive person:

“There are people who will say they won’t get close to a person who is infected, because what if he coughs and part of his saliva gets to me and I become infected? [This] is not the correct version [...] Others think through touching you can contract it and through breathing, because others have the mentality that you can be infected by HIV through touch without any cuts. There are people who have stereotypes.” Albert (ntst, 21)

The view that HIV was contagious was linked to some men’s impression that that HIV infection was unavoidable, inevitable and everyone would eventually be infected. They said “*It’s a virus that nobody can escape*” (Nhlanhla (ntst, 18)) and further, it was likely to end in death: “*people were saying that it’s a disease that kills*” (Bongani (pos, 35)). Such beliefs linking HIV/AIDS to contagion and it being fatal were likely to perpetuate stigmatisation and people suspected of being HIV-positive being ostracised, as noted by several scholars, including Deacon et al. (2005) and Stein (2003a) and described in more detail later.

8.2 HIV/AIDS is witchcraft

The reviewed literature found contradictory perspectives on the role of unnatural or spiritual forces in HIV/AIDS disease. As discussed earlier, some studies indicated that HIV/AIDS was commonly thought to be caused by unnatural or spiritual forces including witchcraft and other religious beliefs (Stadler, 2003; Thomas, 2006; Pearson & Makadzange, 2008; Steinberg, 2008; Dickinson, 2013) but in other studies that it was not connected to witchcraft or supernatural forces (Delius & Glaser, 2005). Thus, for those who believed that HIV/AIDS was caused by witchcraft seeking help from traditional medicine would be appropriate behaviour. Ashforth (2002) found that there were men who consulted THPs and used traditional medicine for sexual health matters including HIV, and Lebo substantiated this.

“If they have found out that they are [HIV-]positive they will have to drink Imbiza [traditional medicine to clean the system]. It will clean their blood. This is done more especially by Zulu speaking people. [...] They believe it cures sexual transmitted diseases including HIV and AIDS.” Lebo (pos, --)

However, most (28/33) men did not believe that HIV/AIDS was caused by witchcraft and would not consult THPs for HIV/AIDS, although they indicated that others might. Xolani’s opinion below reflected the viewpoint of these men:

“There is nothing like witchcraft. People should know that witchcraft is witchcraft and HIV is HIV. This thing with witchcraft only happened with our grandmothers and grandfathers, it’s not happening now. [...] All I can say to advise people with HIV is to go [to] the clinic and get treatment so that they can live longer because if you don’t get access to ARVs you are going die.” Xolani (pos, 41)

The men mentioned that the belief that HIV/AIDS was related to witchcraft persisted in the community but it was not the dominant perception. The men reported they would be unlikely to consult THPs if they were worried that they were HIV-positive. Rather, they suggested that going to a clinic was the correct course of action. This may reflect a bias as many of the men were recruited at clinics, but given their perceptions one would expect that more men would be attending the clinics for HIV/AIDS services.

Indeed, many (18/33) of the men were sceptical of THPs and their powers to cure or alleviate the symptoms of HIV/AIDS and would not consult them at all. Around half (14/33) said they would consult THPs for spiritual or other matters not related to HIV. Some men suggested that because THPs were unable to treat HIV, they told their clients that they were bewitched and perpetuated the myth saying, *“...they [THPs] never tell you the truth. For example they’ll say your neighbour is bewitching you and in fact nothing of that is true”* (Abel (neg, 27)), and *“... traditional healers ... can’t tell them straight that they have HIV. The healers just tell them that they’ve been bewitched”* (Sipho (neg, 23)).

Some men mentioned that people who were HIV-positive were scared, desperate for a cure and sought out explanations from a variety of sources including witchcraft as Tshepo reflected:

“...one of the reasons why they would insinuate that HIV/AIDS is witchcraft is that they have all this fear and have actually lost hope about the disease.” Tshepo (pos, 30)

By linking HIV to witchcraft there was still a chance that they could be cured.

None of the HIV-positive men believed that HIV/AIDS was caused by witchcraft. The fact that a blood test could identify the virus was proof for David (pos, 30): *“I saw when they took my blood and told me the results. I mean the blood was from my body. So it is not witchcraft.”* Although a couple were unsure how HIV/AIDS originated, they were convinced that witchcraft was not the cause and explained that if it was witchcraft then a different type of epidemic would result. As Bongani noted:

“If people say HIV and AIDS is witchcraft I will disagree with them, but as to how it came around I have no answer to that. [...Because] if it was witchcraft then we would all be sick from it.” Bongani (pos, 35)

This view was in line with that of Ashforth (2002) who explained that witchcraft was an issue of power with an imperative to identify and punish perpetrators, rather than a health issue. The perpetrator would not be able to prevent being infected. People who believed that HIV was caused by witchcraft would consult THPs to identify and act against the person inflicting the illness on them, rather than accessing public health facilities, but this appears to be a minority viewpoint in this setting.

A couple of study participants suggested that men were more likely than women to hide behind the notion that HIV/AIDS was caused by witchcraft. In this case when men were ill they claimed that a family member or neighbour had bewitched them. One clinic manager described the behaviour of her neighbour who she believed was HIV-positive:

“Some [men] are just in denial. I know of a policeman who is my neighbour. He has got a herpes zoster. He cannot believe that it is happening to him. I check him every day morning and night. His house is full of traditional muthis [medicine]. He is busy finishing his money with consulting traditional healers. When I ask him what is the problem. He says he is bewitched, that he is getting better.” MGR5

This policeman stayed with his chosen course of treatment because he believed he was bewitched, even though his condition was not improving. Like the manager above, Enoch suggested that men were in denial about HIV/AIDS, would not admit that they were HIV-positive and offered alternative explanations for their illness:

“men are in denial, especially black men. They will say they are negative even if when they are positive. Some will [even say] that this virus has been brought by white people. When that person has a full blown AIDS and it is time for him to die he will say he has been bewitched.” Enoch (ntst, --)

For these men it was preferable to deny that they were HIV-positive or ill and blamed it on witchcraft. This stance may be associated with HIV stigmatisation that was pervasive in Soweto (described in more detail later) as suggested in the literature (Deacon et al., 2005; Serrant-Green, 2008; Maman et al., 2009; Scambler, 2009).

Stadler (2003) and Stein (2003a) found that the stigma of being HIV-positive was shameful for many people, and they kept their own status or that of their relatives secret. The men provided examples of families attributing illness in the household to witchcraft saying they were “*bewitched*” or “*cursed*.” As Emanuel explained:

“I saw this with my next-door neighbour’s house. You see they didn’t tell us that the person had HIV because obviously they were hiding this [...] thinking that their dignity will be tainted. They kept the secret by telling people that he needed to go to a traditional doctor because he was bewitched or things like that. They didn’t want us to know that he had AIDS.”
Emanuel (neg, 19)

HIV stigmatisation fuelled secrecy and the notion that HIV/AIDS was witchcraft. As Scambler (2009) suggests, being bewitched externalised the blame for being ill and exonerated them from any wrongdoing. Therefore, since the person was bewitched and not HIV-positive the related stigmatisation and shame should fall away.

A couple of men explained the difference between illnesses being caused by witchcraft or by HIV/AIDS. They described witchcraft as elusive, “*...something happening in the evening*” (Emanuel (neg, 19)) and “*...issues of witchcraft are issues that have an element of illusion and hallucination if not magic*” (Patrick (pos, 36)). HIV/AIDS, on the other hand, was described as “*a disease that affects everybody and any human being, regardless of whether you believe in it [witchcraft] or not*” (Emanuel (neg, 19)) and “*with HIV/AIDS it is the reality. People are dying and people are sick. It is quite tangible. People can touch it and feel it*” (Patrick (pos, 36)).

Witchcraft was something that a person had no control over whereas a person played a role in being infected with HIV as Albert described:

“No [HIV] is not witchcraft. If it was witchcraft I would also get it. But anyway I also don’t believe in witchcraft. If... okay... let’s say there is witchcraft. We would all be sick because if a person bewitches you they just do that from a distance. Maybe they just light a candle and call your name and you are done. The reality is if I sleep with an HIV-positive person without protection I will definitely be infected and that is not witchcraft.” Albert (ntst, 21)

The men reiterated that being HIV-positive was caused by risky sexual behaviour, not witchcraft. However, they conceded that HIV stigmatisation might encourage some men who were ill to attribute their illness to witchcraft rather than admitting that they were HIV-positive.

The notion that HIV/AIDS was caused by witchcraft persisted in the community, but these men were adamant that they did not believe that this was the case and would seek help from the public health clinics for HIV/AIDS if and when they needed it. Those in the community that subscribed to the witchcraft belief would seek help from the traditional health sector.

8.3 God created HIV/AIDS

An alternative explanation proffered for HIV/AIDS was that “God” created it. Many (15/33) of the men mentioned that they were Christian and some (6/33) believed that “[HIV is] just a disease created by God to punish us on earth” (Eugene (ntst, 19)). They said that God was punishing HIV-positive people because they were “sinners”, “bad”, or a “trouble maker in the community.” One man, Matthew (neg, 20), believed that “sex before marriage” was against God’s will and those that indulged would “suffer the consequences.” In this case, and as described in the literature (Sontag, 1990; Deacon et al., 2005; Serrant-Green & McLuskey, 2008) being HIV-positive was ascribed to “immoral behaviour” and therefore carried a stigma.

This position was expanded on by Jackson, an HIV-positive man, who was convinced that his God was angry and was punishing him:

“God our creator is really trying to communicate his anger by punishing us so that we may also feel the pain that he is feeling as a result of us not listening and obeying his commandments... He [God] is exposing us to all challenges as you can see them today in the world. It is difficult to live these days with all these ailments. I think he could have rescued us by now, but I think he still wants us to feel the pain.” Jackson (pos, 34)

Jackson and his wife were HIV-positive and he believed it was a result of not following tradition, as they were not married when they had their children. He failed to send his parents to negotiate their marriage and this was “viewed as an act of disrespect by her family.” They separated for some time and he had other relationships but they were eventually reconciled. The couple were resigned to being HIV-positive and Jackson believed that “both of us we were wrong” for getting infected and also for infecting others. A family meeting was held where “everyone spoke their minds.” Fortunately all turned out well for them and they were now a “happy family.” He was relieved that his family knew about his condition, that he was on ART, and he could take care of them. As he said: “My kids don’t have to worry that [their] parents are sick and who is going to be [their] guardian or take care of [them]. They are happy and they understand the situation you see.”

For Jackson things have turned out well even though he had not fulfilled his cultural obligations and what was expected of him as a man. He was able to look after his children. His openness about being HIV-positive had enabled his family to accept the situation. Although Jackson believed that God was punishing him, and that was why he was HIV-positive, he was confident that allopathic medicine would help him.

This was not the case for others, who believed that if HIV was caused by God then help could be gained through prayer. For example Albert (ntst, 21) noted: *“there are many social beliefs out there... if you go and be prayed for, you will be negative, but I don’t know that because I have never tried them”* and Jabu (ntst, 28) commented: *“If you strongly believe... sometimes you know [it] is all up in the mind. If you believe that you can live for more than fifteen years with the HI virus I guess you can.”* It was suggested by these men that there were people who believed that prayer could help and perhaps even cure HIV. These people were unlikely to go to a clinic for help but would rather go to their church.

Religion was a fundamental part of many of the men’s lives, but perhaps especially for those who were HIV-positive. Patrick (pos, 36) prayed frequently and had asked God *“not to take me now as I still want to raise my child and also build some future for him.”* He described how being HIV-positive had brought him *“... closer to God. I knew about God before, but now I have learnt to acknowledge him more. There have been times that I have seen and witnessed his greatness.”* He believed God helped him to live with HIV. Patrick was on ART, but was taking a break while he completed TB and STI treatment. He combined prayer with his treatment, trusting that God would sort out his daily life and that the treatment would assist him in combating his disease. This multi-pronged approach to health was adopted by many of the men and supported findings in the literature (Muller & Steyn, 1999; Pearson & Makadzange, 2008; Gilbert & Walker, 2010) that people consulted multiple sources for help.

8.4 Discussion

Drawing any direct relationships between men’s beliefs about HIV/AIDS and their help-seeking behaviour is necessarily complex and multidimensional. Popular understandings are intertwined with beliefs about politics, race and religion.

The discussions about HIV/AIDS in the community and amongst the men acknowledged that there might be influences other than natural causes that could be attributed to the spread of the disease. These included that

HIV/AIDS was caused by God or by witchcraft. However, the majority of men in this study did not believe this, although they acknowledged that people in the community did. The belief that HIV results from unnatural or spiritual causes could lead to a proportion of men seeking help from either THPs or their local church, rather than from clinics or hospitals. A question that could be raised here is since clinics are much better attended by women, do women believe less in unnatural or spiritual causes, or have they overcome the fear of stigmatisation?

These beliefs that HIV/AIDS is spiritually caused fed into the issue of contagion and that HIV/AIDS was difficult or impossible to avoid. The men were concerned as to how contagious HIV/AIDS is and about the myths that spread around the township. Given the multiplicity of explanations about where HIV/AIDS comes from it is not surprising that many men adopt a multi-pronged approach to understanding and dealing with HIV/AIDS.

Most of the men in this study did not believe that HIV/AIDS was the result of unnatural or spiritual causes, nor, according to them, was it a widespread belief in the community. The HIV-positive men were recruited at the clinics and went there for treatment although some consulted traditional healers or prayed at the same time. The men appear to adopt a layered approach to help-seeking and add and subtract options depending on whether or not they benefit them. Therefore it is likely that reasons other than men's beliefs keep them away from the clinics. These are explored with the men and discussed in following chapters.

Chapter 9: Knowledge and understanding of HIV/AIDS

Some literature suggests that the greater the understanding about and knowledge of HIV/AIDS the more likely a person is to seek help (Banks, 2001; Schneider, 2006). How this information is interpreted determines where they seek help (Meyer-Weitz et al., 1998). Furthermore, the better the understanding of HIV the more likely that stigmatisation will be reduced (Kalichman et al., 2006). Men's knowledge and depth of understanding about HIV/AIDS is explored to determine whether this may assist in explaining their help-seeking behaviour.

The clinic health workers suggested that men had little knowledge or were in denial about HIV/AIDS, which was why they were not attending the clinics. However, the men were generally well informed about HIV/AIDS, understood HIV transmission and disease progression, and recognised that being infected with HIV eventually led to AIDS. Given that most of the HIV-negative and HIV-positive men were recruited in the clinics, this sample may provide a biased view; however, the men who had not tested were similarly well informed. This is illustrated by Albert's statement "*HIV is the beginning of the chapter and AIDS is where [it] is going to end*" (Albert (ntst, 21)).

The HIV-positive men were particularly well informed as provided in detail by Jackson, who said:

"HIV is a disease that you can control, but you cannot cure it. You can only contain it for a certain period, just keep yourself safe and be able to live longer. But the thing is if you get to the stage of AIDS it is quite serious, because [by] that time the virus has already attacked almost every white blood cell in your body in a way that you may not get any help either way."
Jackson (pos, 34)

Generally these men considered HIV to be a normal illness, no different from any other disease, and not a "life sentence." Tshepo (pos, 30) described HIV as "*just a life process*" and that an HIV-positive person was "*still a normal person who can still live with other people ... When you have AIDS is when you start showing the possible symptoms and are also vulnerable to lots of sicknesses.*"

Interestingly Zakes, also HIV-positive, believed that other diseases were much more problematic:

"[HIV] is a disease like any other disease such as high blood pressure. I mean a person can live with a chronic disease until they pass away [die]. So I take it like a chronic disease but not like cancer. I see cancer as far more dangerous than HIV because [with] HIV and AIDS you can live longer if you take good care of yourself unlike cancer." Zakes (pos, 38)

Cancer was also a concern for Phil (ntst, 18) because “*people suffer*” and cancer “*destroys a person’s immune system and [there could be] memory loss depending where the cancer has attacked you.*” For these men cancer was much more challenging than HIV because there was no cure for cancer and these patients suffered badly, whereas HIV was controllable and could be managed, like other chronic illnesses. They were concerned about the suffering that other diseases caused and were more fearful of these. The HIV-positive men were confident that ART would control their condition.

The men regarded HIV-positive people as equal, normal, and ordinary and said that they would be “*friendly towards them*” and not discriminate against them. David (pos, 30) suggested that HIV had become normalised because it was so widespread. However, as described in more detail later, although HIV prevalence in this community was high with many people infected, HIV-related stigmatisation persisted.

9.1 HIV transmission

Only one man claimed not to know anything about HIV or AIDS. Brian (ntst, 26) initially stated: “*I really don’t have any idea what the disease is all about ... I know nothing ... I have heard about [it] but I did not take it seriously.*” After some discussion he opened up and in fact was quite knowledgeable about HIV transmission and gave some examples: “*...if you have unprotected sex with someone who is infected you’ll get the virus, things like you could kiss that infected person and you both have cuts in your mouth you could infect each other.*” It turned out that Brian’s initial reluctance to talk about HIV/AIDS was because he was afraid that he may be HIV-positive. He did not want to test and would rather not engage with the issue at all.

Brian was not alone in being scared to test, as most of the men expressed some fear when the discussion turned to HIV testing (see Chapter on HIV testing). Brian explained that neither he nor his partner had tested because they were afraid, but he was considering it and contemplated:

“...if you have it, you have it, if not, you don’t [...] You know when you [are] at the edge, like you’re holding a knife in your hand, at the knife point. You know you’ll get hurt so that’s where I am. I’m afraid of knowing my status, [...] I’m very scared of that because I know I’ve had unprotected sex with a lot of girls. It was with these girls who are very busy sleeping around, so aah... [he pauses] I can’t. I’m scared, too scared.” Brian (ntst, 26)

Brian acknowledged that having engaged in unprotected sex with multiple partners he could be HIV-positive, but was now too scared to test for HIV.

Engaging in unprotected sex and not seeking help were not uncommon masculine behaviours. However combined they amounted to poor health outcomes since the former increased the likelihood of being HIV-positive (Halperin & Epstein, 2007). Brian's reluctance to test or engage with the health system mimics men's behaviour that has been observed elsewhere (Banks, 2001; Robertson, 2007).

The men were knowledgeable about HIV transmission and how to prevent infection. However this did not change their behaviour. The men engaged in unprotected sex and were nervous that they may be HIV-positive before they tested, or were in denial and had not tested. They recognised that it was risky behaviour but mentioned how difficult it was to protect themselves because they were "*stupid*", "*irresponsible*" or "*careless*." Although these men were knowledgeable about risky behaviour they continued to take risks, aligning themselves with their peers.

The sexual behaviour described here confirmed what other studies have found; that men were risk-takers (Foreman, 1999). About a quarter of the men (7/33) cited situations where unprotected sex became a risk factor, such as being at a party, not having condoms and wanting to have sex. In addition, "*flesh to flesh*" sex was highly prized despite the increased chances of HIV transmission. The men (28/33) agreed that condoms or "*protection*" were the best means to stay HIV-negative. "*I can say stay protected all the times in any situation. [...] I am not saying you will be 100% protected. Maybe the body fluids get transmitted in some other ways*" (Albert (ntst,21)). However, they expressed reservations about using condoms because they were difficult to use or not desirable. A counsellor suggested that myths surrounding condoms made men reluctant to use them and noted that condoms were not totally effective, as also found by Strebel et al. (2007). Further, she explained that men did not like using condoms when they were in a relationship and that men made the decision on whether to use them or not. For example, if their partner looked well, they would not use them. The majority of the men knew that using condoms vastly decreased HIV transmission, but a proportion of them were prepared to take risks and not use them because they preferred having sex without them. They recognised that certain sexual behaviours were more risky than others, but were influenced by their peers.

For some men being diagnosed HIV-positive was a wakeup call to take better care of themselves and they commented that condoms were now an essential part of their lives. As Xolani explained:

“I have accepted that I have the disease. What I can do, to move on, is to take very good care of myself. Even when I feel like having sex I always use a condom unlike in the past when I always had unprotected sex. I did not believe that there was such a disease as HIV and AIDS. Now I have very good knowledge about it. I know that it is alive and I use condoms at all times.” Xolani (pos, 41)

Xolani was willing to go against the dominant notion of masculinity as being a risk-taker in order to move forward with being HIV-positive. He was now embracing a new way of operating like the men in the Mfecane (2010) study who reconstructed their image in the community once they started treatment.

Some men believed that HIV could be transmitted during foreplay, but that kissing was not risky. Abel graphically described how he believed HIV could be transmitted:

“He [pauses]...HIV...[pauses again] it’s caused by the STIs we contract from our sexual partners by not protecting ourselves. We don’t use condoms. The other thing is we men are very stupid. You go to a party and its fun and let’s say you do have a condom with you. You’ll want to finger fuck your girl. Then you’ll forget to wash your hands... Maybe those germs could contribute to you having STIs. [...] These STIs lead to you having HIV, so we guys have this tendency that I want to have unprotected sex with this girl and that’s it, I won’t get infected. Not knowing that we’ll be exchanging body fluids during the sexual intercourse. So you end up getting infected with STIs, some of which are minor and others which are dangerous. But knowing us guys we tell ourselves that aagh! I’ll bath tomorrow, not knowing that this thing is developing in you and makes it worse for you.” Abel (neg, 27)

Abel described how men were keen to engage in risky sexual behaviour and believed that washing hands and bathing would protect them from being infected with HIV. The myth that cleanliness or bathing would protect one from STIs and HIV was fairly common. It was reinforced in the well publicised statement by President Jacob Zuma during his rape trial in 2006 that he showered after having sex with an HIV-positive woman as he believed that this could protect him from becoming infected.¹³ Martin suggested that during foreplay there was a possibility for HIV infection:

“There are many ways but the point to make is that whenever there is some blood contact or transmission, like in a case where I would fiddle with a woman’s private part during the time when we prepare to have sex, I could be having cuts on my fingers and my finger could contract the virus from the vagina as there would be body fluids that may enter through your finger and the fluids may have higher concentration of the HI virus.” Martin (neg, 25)

¹³ For example see: <http://mg.co.za/article/2006-05-11-manto-media-sensationalised-zumas-shower-statement> (accessed 25 August, 2012)

Martin and Abel recognised that HIV infection was spread through the exchange of body fluids. The men were aware that condoms offered the best form of protection against HIV, but some men were unwilling to use them.

Many HIV prevention campaigns used the ABC (abstinence, be faithful, condomise) message but with limited success, because it was human nature to have sex and condoms were not always freely available or even desired (Epstein, 2007; Pisani, 2008). Abstinence was mentioned as one method to prevent HIV transmission by a couple of the men, but they noted that it was not always possible or desirable for men to abstain from sexual intercourse. They described that for men “[sexual intercourse] is nature, sometimes one cannot control himself” (Abel (neg, 27)) and abstinence was not a long term solution: “There is no young person my age who will say ‘I will abstain until I am forty-five.’” (Albert (ntst, 21)).

Two young men, Lucky and Albert, have never been tested for HIV but were concerned about becoming infected because HIV “kills” and reduces ones “lifespan.” Lucky (ntst, 20) knew he should abstain or use condoms and Albert (ntst, 21) said: “If I am faced with a beautiful girl but have no condoms I will not continue. I would rather lose that moment than lose my life.” Although both men said they would abstain rather than have unprotected sex, as described earlier, it was difficult to do so. Abstinence was not considered to be appropriate masculine behaviour for these men.

A minority of men (4/33) described other ways in which HIV could be transmitted including “blood to blood” transmission through a blood transfusion or an accident. Unlike being able to protect oneself by using condoms when having sex, these types of transmission were not under their control. “I can’t predict whether I’ll be involved in an accident and whether the person next to me is infected or not” (Abel (neg, 27)), although protection such as rubber gloves could be used. This type of chance infection was also discussed during HIV counselling as Matthew recalled:

“I was involved in a car accident before and that person who tested me told me about being infected through being involved in a car accident but I did not take it in because I was not badly injured.” Matthew (neg, 20)

Fewer men (5/33) mentioned mother-to-child transmission of HIV with the infant being either born with HIV or infected whilst breast-feeding, and one man suggested that breast-feeding should be avoided. Others

(4/33) suggested that HIV could be transmitted through injections or sharing needles saying, for example: “...*the needle which was used by somebody and then having to be used by somebody else*” (Noah (neg, 19)) and “*like taking drugs with the same needle when they have pricked like five other people*” (Clement (ntst,18)).

The men were adamant that the community was aware how HIV was transmitted, but were prepared to educate people where necessary and “*challenge some of the misconceptions*”, such as the disease being caused by witchcraft. They said these misconceptions were used by people as excuses to blame external forces rather than accepting responsibility for their own behaviour in contracting HIV/AIDS. For example: “... *playing risky with many multiple partners without using condoms*” (Andrew (neg, 24)).

Contrary to the beliefs of the secondary informants that men were ignorant about HIV/AIDS matters, the men were well versed in the intricacies of HIV transmission. They recognised certain situations when HIV infection could be avoided, for instance by using a condom, and there were others when it was unavoidable, such as accidental contamination, and one may become infected without taking any risks. The situations of being an “innocent victim” or being to “blame” for being HIV-positive are described in more detail later.

Most men indicated that embracing a healthy lifestyle enabled them to avoid contracting HIV and assisted with HIV treatment. This included avoiding smoking, drugs, and alcohol use, and being around people with a positive attitude. A healthy lifestyle was considered especially important for the HIV-positive men as health workers emphasised that they must give up alcohol and eat healthily, but this was not always easy. As Zakes (pos, 38) noted: “*they told me to stop drinking alcohol and I asked them to please let me drink Milk Stout because it’s healthy [he laughs].*” He liked drinking with his friends at parties.

9.2 Curing HIV

There is no known cure for HIV. However, as the literature review found, many people claimed that they had a cure for it. This was no different in Soweto where rumours of cures or people having been cured endured in the community. However, the men interviewed were not convinced that they were true, as Abel remarked:

“In the location I hear people saying there’s a traditional healer who is able to cure AIDS, but I don’t believe that [...] I hear it from my older brothers. They say the disease can be cured. Others are saying the government has a cure and they just don’t want to help us.” Abel (neg, 27)

Jabu related a story about a child who had been healed at a church, but he did not believe it:

“Some people go to the extent of going to church and actually believe that God will heal them and actually deal with their health related issues. There is a story of this boy who got HIV/AIDS disease from his mom when he was born because the parent didn’t get the medication that prevents transmission from mother to child. Apparently he came to church and started praying and then went to the doctor for the test and the test came out positive. Then he kept coming to the church and praying. They went back to the doctor to do that same test again and they came out negative. He was no longer HIV-positive. I don’t know how they brought that or if it is really true. But it can happen because with children when they do something they truly believe in it, even though they don’t know how it works... So if he believes that he was going to get cured, then his body has responded to the mind. If is the time to be healed one will be healed. That’s how your body operates, it is controlled by your mind.” Jabu (ntst, 28)

Although these rumours persisted, it was a common understanding amongst the men that there was no cure for HIV and that perhaps one would never be found. Around one quarter of the men (6/33) were hopeful for a “*breakthrough*” and one man suggested that traditional and Western medicine should join forces to find a cure for HIV. Phil was hopeful that a cure could be found:

“Yes I think there is a cure for AIDS. [...] There is a cure here in South Africa. They just have to look for it properly. There is a cure out there just that people need to think about it and make a proper cure for HIV.” Phil (ntst, 18)

The belief that a cure may be found was important for the men, but particularly for the HIV-positive men, as it gave them hope for the future.

9.3 Knowledge of ART

Knowing about the treatment options for HIV/AIDS is a pre-requisite when making an informed choice about appropriate help-seeking behaviour. For this reason, the men with a negative or unknown status were asked what they know about HIV treatment options and ART, while HIV-positive men were questioned about their experience of treatment.

Most men with a negative or unknown HIV status and all of the HIV-positive men were aware there was treatment for HIV, but some had a limited understanding of how it worked. One man, Lucky (ntst, 20), explained: “...if it’s already full blown AIDS then there’s so little you can do. But the best way to fight it is to treat it while it’s still the HIV stage.” But he was not sure about what exactly ART entailed, saying: “I’m trying to avoid going to each person who will give me their own understanding of ARV/ART.” He recognised

there were many different views on HIV treatment and did not want to be further confused, so he would rather wait until he needed the information.

A few of the men were aware that ART involved pills or some medication and that it appeared to be effective as they, like Nhlanhla, had observed that people seemed to be healthy when they were on ART:

“The good thing is that people become a little bit healthy, they become fit if they take the medication and exercise regularly. If that person is determined to get well then they will, but not that the person will be cured. They will just overcome the sickness and look as if they’ve never been sick.” Nhlanhla (ntst, 18)

The men described ART as medication that helped the body “fight AIDS”, it “cools down” the virus, prevented it from spreading too quickly and stopped it from becoming AIDS. ART “boost[ed] the CD4 count and your immune system so that it can balance” (Tebogo (pos, 27)) and gave the body “natural energy” and “power.” Jabu explained that although HIV could be a “deadly virus” ART was people’s only hope until a cure was found:

“It [ART] is used to mostly slow the effects of HIV in one’s body, like just to prolong the time limit that one has when HIV-positive. [...] Like just to let the person to live longer and to make them a bit stronger, it’s like it boost them.” Jabu (ntst, 28)

The men were hopeful about ART, as it allowed HIV-positive people to “live a longer life”, but it did not replace maintaining a healthy lifestyle including eating good food, exercising, and being in a supportive environment.

ART was introduced into the public sector in 2004 and limited to certain accredited facilities, but had subsequently become widely available. Jabu (ntst, 28) was aware of these limitations and suggested that it was more likely to be available in private clinics, because “tycoons or people who have the money usually are the first people to get everything before the government because they can afford to pay for such treatment or medication.” However, the majority of men would not be able to afford ART in private clinics because they were unemployed, part-time workers, or students. The controversies that surrounded HIV/AIDS and the delay in getting treatment into all the public sector clinics, as described in the literature review, were likely to have influenced the men’s understanding of its availability.

A few of the men were aware that HIV/AIDS was a difficult virus to control and that ART needed to be monitored to ensure its effectiveness. Martin had a nuanced understanding of HIV/AIDS and ART and noted that ARVs needed to be taken regularly and at the same time each day. He explained:

“...the virus has a way of hiding itself or rather resembling the other white blood cells. Hence it becomes difficult for the white blood cells to identify, isolate and deal with it. So the treatment is just there to minimise the impact of the viral load in one’s body [...] at times the virus can’t be clearly detected by the tests [...] that does not mean you should be off the treatment [...] it only means that the tests cannot detect the virus because it has [changed] itself [to look like] one of the white blood cells or DNA [...] the virus has a way of hiding itself and once it resurfaces from hiding, it becomes more dangerous as it now has familiarised itself with the treatment and that is where it is mostly dangerous, evil and fatal.” Martin (neg, 25)

Martin was one of few men with a thorough understanding of the complicated mechanisms of HIV/AIDS and of how ART suppressed the virus but did not eradicate it. Most men knew that ART was not a cure and that it must be taken for the long-term “*you don’t stop taking such treatment [...] it is a lifetime commitment*” (Martin (neg, 25)).

Other factors were raised during the interviews that impacted on ART’s effectiveness included risk-taking behaviour and accidents. As Eugene explained:

“... you can be taking the treatment then live carelessly and just live for a month. Or you can take the treatment and live healthily and live for years like a normal person and be killed by a truck. I mean you died of being hit by a truck (he laughs) not by AIDS (he laughs again).” Eugene (ntst, 19)

Eugene’s explanation supports the idea that HIV/AIDS could be managed like other chronic illnesses, but that being on ART did not guarantee a longer life. This backed the earlier discussion that HIV/AIDS was an illness like many others, and that a person who was HIV-positive could live a normal life.

About half (5/11) of the HIV-positive men were on ART and one had stopped taking it. The rest had little experience or knowledge of it. Bongani mentioned that when one started ART depended on “*your immune system and how strong or weak your body is ... I’m not sure if AIDS is treatable*” (Bongani (pos, 35)). Being HIV-positive did not automatically mean that one had better knowledge about the disease or how to treat it.

9.4 Discussion

Some studies on HIV/AIDS have argued that knowledge empowers individuals and enables them to make rational choices in their help-seeking behaviour (Banks, 2001; Schneider, 2002). However, this chapter indicates that there is not a clear-cut relationship between knowledge and action.

The men's knowledge about HIV prevention, transmission, and treatment was good, with some having an in-depth and nuanced understanding of it. Overall the men were optimistic about ART even though they would prefer a cure. They recognised that ART allows HIV/AIDS to be treated as a chronic condition and helps people to live a normal life, and was therefore beneficial. These findings are contrary to the belief of the clinic health workers that men are ignorant about HIV/AIDS. However the men found it difficult and undesirable to translate this knowledge into action. They preferred maintaining a relatively high-risk lifestyle that was influenced by their peers' behaviours and continued to have risky sexual encounters.

The HIV-positive men were more likely to have adopted a healthy lifestyle approach as it aided their treatment. An unhealthy lifestyle weakened their immune system and increased the likelihood of opportunistic infections. However, healthy living sometimes included giving up pastimes associated with masculinity, such as drinking alcohol with their friends. Embracing healthy lifestyle choices may be easier for the HIV-positive men as they are encouraged to do so by health workers. At the same time it compels them to adopt a different lifestyle from their friends, and perhaps be stigmatised, in order to cope with their illness.

Chapter 10: Stigmatisation and discrimination

Stigmatisation is exacerbated by the social and political environment and is manifest in many ways, including denying the existence of HIV/AIDS. As found in the literature review, HIV has been shrouded in stigmatisation, silence and secrecy, and rather than talking openly about HIV/AIDS people use euphemisms instead of the words “HIV” or “AIDS” (Stein, 2003a; Steinberg, 2008). This difficulty in verbalising HIV and AIDS was reflected in the interviews during which phrases such as “*a certain virus*”, “*the disease*” and “*the stupid sickness*” were used. To explore this further the men were asked what common words or phrases were used when referring to HIV-positive people. Many of these included references to death. As Abel described:

“...others will tell you that one is leaving us [dying], he’s got Z3 [HIV] or now he’s got Z4 [AIDS] meaning he’s not moving at all [dead] ... he’s crossing the river [dying]. There’s a lot of names, you won’t get finished.” Abel (neg, 27).

The men suggested that these phrases were used to stigmatise HIV-positive people but at the same time, for the person uttering them, were used to create some distance from HIV/AIDS and the seeming inevitability of death, as articulated by Thulani:

“there are names like ... err ... he has got Z3 [HIV], he is in Elijah’s car [dead] [...] If someone wants to hurt you, they will hurt you [with what] they are saying. He will make sure that you hear what he could be saying [inferring]. Someone will use it [a name] as if he wants to protect himself, he doesn’t want to use the word AIDS. He can say look he has a takeaway [dying], now he is gone [dead]. ” Thulani (neg, 22)

Some of the HIV-positive men agreed that they were treated differently from people who were not known to be infected. Patrick, who was HIV-positive, was resigned to hearing these sorts of phrases and recalled other methods that people used to identify HIV-positive people, saying:

“Most call it simply AIDS. Others use signs with their fingers to alert others [that] he’s dying. You would realise that they are referring to you. Others call it Tsunami [...] Yes we are used to this kind of treatment.” Patrick (pos, 36)

The on-going use of euphemisms indicated that HIV stigmatisation persisted and was enacted in Soweto as in other parts of South Africa, and also found by Stein (2003a) and Steinberg (2008). Their use supported the notion of “othering” by distancing the “normals” from the stigmatised as described by Deacon et al. (2005) and Goffman (1963).

The topic of HIV stigmatisation was explored with the study participants to gain an understanding of their perceptions of the severity of the problem, and what could be done to mitigate it. All the study participants, except for three men, said that HIV stigmatisation was “*still a major problem*” in Soweto. The HIV-positive men were more verbal about stigmatisation than the others, and thought it was severe. As Jackson (pos, 34) described: “*There is a very serious discrimination and stigma by other people to those infected or living with AIDS in the community.*” The HIV-positive men were more likely to have borne the brunt of stigmatisation than the other men. The men described the stigmatisation they witnessed in a similar manner to Deacon et al. (2010) and Campbell et al. (2007), as negative actions or thoughts enacted or expressed by stigmatising others through labelling, discrediting, distancing, and discriminating against people in a way that disadvantaged them.

10.1 Declining levels of stigmatisation

Stigmatisation has been observed to be complex, context-specific, and changing over time (Parker & Aggleton, 2003; Deacon et al., 2005). The secondary informants described noticeable changes in Soweto with a positive trend in that stigmatisation had declined. One THP noted that stigmatisation was “... *changing for the better. For those people who are HIV-positive they are no longer being stigmatised like before. The community is getting used to that person who is sick*” (THP3). A counsellor observed that the changes may be more noticeable amongst the youth who “*are speaking more openly about HIV and AIDS*” (CNS1) but she expressed concern that there was little or no communication between parents and their children. These secondary informants suggested that HIV/AIDS was becoming more accepted in the community and that stigmatisation was declining.

The literature review highlighted a number of factors that correlated with the decline in stigmatisation levels, including increased knowledge about HIV/AIDS, understanding of HIV transmission (Kalichman et al., 2006) and that the disease has become a normal part of daily life (Jewkes, 2006). The health care workers had noticed that there was improved access to information. They observed that as more people were affected in some way by HIV/AIDS the community had become better informed, and this elicited more discussion and openness about the disease.

10.2 Contagion and stigmatisation

Although it was agreed that there had been an increase in general HIV/AIDS knowledge, the men suggested that there was still a lack of understanding in the community about HIV transmission. Abel (neg, 27) noted: *“Some people know about HIV others don’t. Some say they’ll never get infected. There’s certain people who’ll get infected. Some people don’t understand how one does get infected.”* Not understanding how HIV was transmitted fuelled stigmatisation, and the men suggested that the community was concerned that HIV was contagious and just being around, having casual contact, or even speaking to someone who was HIV-positive could lead to becoming infected. As Brian (ntst, 26) described: *“They [people who don’t understand] just stay away from them [people who are HIV-positive] they don’t want to be close to them or touch them.”* Therefore they would rather *“just run away”* from HIV-positive people. This view was summarised by Mdu who believed that although the community was becoming better informed they were still anxious about getting infected:

“Despite the increase in knowledge about HIV transmission and the general recognition of HIV in the communities, there is still fear that one can be infected through casual contact. I think it depends on where people are coming from and how much they know about the illness.”
Mdu (neg, 18)

Stigmatisation led to HIV-positive people being rejected, isolated, shunned, or chased away by the community. Examples included that people would not visit or share anything with HIV-positive people, and passengers in a taxi would not sit next to another passenger they thought might be infected. The fear of contagion was one of the reasons for stigmatisation (Deacon et al., 2005; Delius & Glaser, 2005). One man was concerned there may be a chance of being infected by work colleagues: *“I mean sex is the first thing, and is the highest, and to work with people without knowing what’s happening to them is another risk.”* (Thulani (neg, 22)) These views reflected the concern that HIV was contagious and that one does not know who was infected. Therefore there was always the risk of infection, even more so if the person was known to be HIV-positive.

Although the community was better informed about HIV/AIDS it was not sufficient to give them impetus to support HIV-positive people, as Albert described:

“Not everyone will support you. But for instance I would support someone if I know they are positive because I now have some information about the virus. I know that people who are

positive need [all] the support they can get. [...] For instance if a person asks me to go to the clinic with them or to go and fetch tablets on their behalf, I will certainly do that.” Albert (ntst, 21)

Many of the men also observed that HIV/AIDS was becoming normalised as they came to know more people who were infected, such as family members or acquaintances. The community was learning to live with HIV-positive people as those with any other disease. Being HIV-positive was no longer an exceptional condition. As Tshepo described:

“I think it’s because most families have been affected by the HIV/AIDS pandemic. They have grown to understand that if someone close to them can be infected with HIV/AIDS and they can live with that person, then they can also accept other people. This thing has actually educated them about the disease... I think these days most of the people are sick and that stigma is [not] still there. Most people have accepted that even if they are not sick they know that a person who has HIV is still like a normal person, just like other people.” Tshepo (pos, 30)

There was a general impression amongst the men that the majority of community members felt sorry for and supported HIV-positive people. The men stated that most community members were sympathetic towards HIV-positive people as Lucky (ntst, 20) mentioned: *“Yes! And others think it’s very sad to be infected.”* But this was not always the case and people reacted differently, as Kabelo (ntst, 33) noted: *“People are different, some they treat them good, some bad you see.”* Martin summed up the men’s overall response:

“People are generally saddened by the horrific effects of the virus and are also becoming more caring. The whole notion of stigma is also beginning to be dealt with and discouraged.” Martin (neg, 25)

The men believed that HIV stigmatisation in the community was declining. Most said that they would not discriminate against HIV-positive people; however, they expressed concern that some people in the community continued to do so. Only two men said that there was no discrimination in their communities.

This enacted stigmatisation negatively affected the HIV-positive men who had either experienced it first-hand or had observed others being stigmatised, as found elsewhere (Scambler, 2004; Gilbert & Walker, 2010). Patrick (pos, 36) described his response to stigmatisation: *“These kinds of people make it difficult for us to cope with living with the disease and we end up isolating [ourselves].”* The result of this stigmatisation was that HIV-positive people did not disclose their status and were secretive about their disease, as also found by Preston-Whyte (2003).

Amos, who was HIV-positive, believed that in order to curb the spread of HIV it must become a matter of public debate and open discussion. He would like to be completely open about his status but was unable to be because of the gossip and speculation that was rife in his community:

“We are not the same. There are some people who are hiding and some don’t know [their status]. I feel the pain for those who do not go and test. Maybe you can point fingers and allege that others have HIV. Like the time you came to pick us up. There was one of my next-door neighbours who was gardening. He knows me but well. He knows what is actually happening to me. I know that he is going to tell other people that he saw a car picking me up and it had something to do with AIDS. What I am proud of is that can he say it at anytime [...] and that is giving him the power to say. He doesn’t know his status and it is not a problem to me, because I know that I am HIV-positive. [...] He doesn’t know and that thing consumes him bit by bit. That is the reason you will find people are dying quickly because of they don’t know anything about their status.” Amos (pos, 36)

Amos expected that the community would talk about him, but he felt empowered by knowing he was HIV-positive and did not get distracted by what other people thought. He had overcome some of his concerns about being openly HIV-positive, but he has not been able to tell everybody and he wished that he could. He has started to resist stigmatisation. He and a couple of other men believed that people who didn’t know their status were more likely to point fingers at HIV-positive people because they were worried about whether or not they were HIV-positive.

Bongani was concerned about this discrimination:

“It is really difficult for the community to understand what this disease is all about and why they should not discriminate and frustrate HIV-positive people. They should stop chasing them away from the community. They don’t deserve to be treated like this. They never can know if one day some of their family members will be faced with the disease. How will they feel if their family members or themselves are discriminated against?” Bongani (pos, 35)

As described in the literature, stigmatisation was linked to social power relationships that changed over time (Parker & Aggleton, 2003; Deacon, 2006; Yang et al., 2007; Scambler, 2009) and resistance to stigmatisation could be developed (Abrahams & Jewkes, 2012). The uncertainty that some people had regarding their own status caused them to discriminate against or “other” HIV-positive people.

10.3 Persisting HIV stigmatisation and association with death

The study participants were frustrated that HIV stigmatisation and discrimination persisted in the community. The men said that they did not discriminate against HIV-positive people, but most felt that they were powerless to change the situation in the community. The enacted stigmatisation described by the men

encouraged people to keep their status a secret because they were concerned about being stigmatised; this perpetuated stigmatisation, because it was not addressed in the community.

Through the literature numerous factors were identified that fuelled HIV stigmatisation. These included: HIV was sexually transmitted and was fatal until ART was introduced (Deacon et al., 2005), and that it was associated with pollution and contagion (Delius & Glaser, 2005). The consequences of stigmatisation were increased silence (Preston-Whyte, 2003) and discrimination (Cameron, 2005). The study participants referred to these factors during the interviews, as noted below.

The study participants agreed that the notion that HIV/AIDS and death were closely associated was common. Some of the secondary informants suggested that men in particular believed that HIV was fatal and that little could be done to avert death. One clinic manager elaborated:

“[Men] fear death. Look at it in the house when a man is sick. Men are very much afraid to get sick. It is the same with HIV. They fear that once they are HIV-positive they are going to die.”
MGR5

The secondary informants suggested that given men’s social standing in society and in the household, men were afraid of becoming sick and of dying. They therefore did not want to deal with illness, denied that they were ill and delayed going to the clinic for treatment until they had no alternative. Similarly they thought that men did not want to test for HIV because they feared knowing their status, and that men believed that if they tested HIV-positive then death was inevitable. A minority of the men (4/33) agreed, suggesting that because there was no cure for HIV it was fatal. As Kabelo (ntst, 33) comments: *“[HIV] ... cannot be healed ... and cannot be treated. Either way it just stays and kills you.”* Although Emanuel was HIV-negative, he was despondent about HIV because it was debilitating and fatal and said:

“It kills very bad, very, very bad. People are afraid that they going to die terribly. I will not even be able to do things for myself and what is waiting for me is death.” Emanuel (neg, 19)

According to these men being infected with HIV inevitably ended in death and, as Goffman (1963) and Deacon et al. (2005) noted, the more severe the disease the greater the level of associated stigmatisation.

ART allowed HIV/AIDS to be treated as a chronic disease, increasing life expectancy, reducing mortality, and the severity of the disease. These advances should reduce HIV stigmatisation. Although the study

participants had observed a decrease, stigmatisation had not declined at the rate that might have been expected with the growing number of people on ART. This may happen when ART has gained more credibility and been widely accepted as a successful intervention that prolongs life and separates being HIV-positive from death.

10.4 Identifying HIV-positive people

There are no distinguishing physical markers of HIV/AIDS in the early stages of illness and thus being HIV-positive can be kept a secret for a long time. However, the community speculated on who was HIV-positive by identifying secondary markers, including changes in appearance or other illnesses. As the disease progressed the physical markers of disease became visible, making it easier to identify those with HIV/AIDS and to stigmatise them (Goffman, 1963; Sontag, 1990; Deacon et al., 2005).

Although a person's HIV status was generally kept secret, the men (7/33) recounted how they were able to identify people who they thought were HIV-positive, either by changes in their appearance or through their actions. There was much speculation and gossip in the community about people's HIV status. Bongani (pos, 35) admitted that he was unable to identify whether a person was HIV-positive or not but observed that the community would *"start accusing people who are sick and say they have AIDS."* These accusations occurred if a person's appearance changed: for example, they were sick, had a headache, or lost weight. Physical appearance was therefore an indication of health status, and people were judged according to their looks. Tebogo who was HIV-positive had experienced HIV stigmatisation first-hand, as he described:

"Isolation is one and people like to gossip. It hurts because I've been there. Just look at my body I have lost a lot of weight and people stigmatise me a lot. This has really depressed me."
Tebogo (pos, 27)

According to the men, changes in people's physical appearance that were ascribed to a person being HIV-positive included *"losing weight"*, *"becoming dark in complexion"* or changes in people's hair. As Mark explained:

"I can tell by the way his hair looks, it changes. His face looks dry and smaller. He loses his hair, it becomes softer and looks like baby hair." Mark (neg, 19)

This speculation was not only confined to the suspected HIV-positive individual, but encompassed people with whom they had relationships, their friends, and their family. This is also known as courtesy

stigmatisation (Deacon, 2006). One counsellor described the stigma and shame that was brought by HIV: *“There’s a stigma to become HIV-positive. It’s a shame to be HIV-positive [...] If you are the one who is HIV-positive you will think that you are bringing shame to people around you. So that’s the real problem”* (CNS1). This counsellor implied that people who were HIV-positive brought stigmatisation upon themselves and to those around them.

Furthermore, the types of relationships an HIV-positive person had engaged in and how they had conducted their life became a source of discussion. As Thulani elaborated:

“[When] I first knew you, you were fat. Next time I see you losing weight and your physical appearance looks bright. I’m going to tell you that you are sick. I am going to trace your movements and say hah...hah...he was in love with so and so and they are all gone [dead]. It means he is on the way to heaven soon. Ya! ... We check who you were committed to, in love with ... so and so, she is sick. She said that she is positive...it means even this one he is on the way [dying]. Can you see that? We look at your background and what were you committed to in life. Then we start to say ... oh, oh ... that’s the thing [HIV] and takeaway [death] is with him.” Thulani (neg, 22)

As HIV progressed to AIDS, weight loss and increased bouts of illness were common and people became visibly ill. Emanuel (neg, 19) observed that at the AIDS stage: *“... in fact you can see their bones coming through skin. They can’t speak properly. They can’t even take themselves to the loo ... toilet.”* With AIDS, HIV-positive people could be clearly identified and were prone to stigmatisation.

At this stage of the illness families frequently denied that HIV/AIDS was the problem, and recognised that being associated with sick person impacted negatively on them. Stigmatisation played a destructive role in family relationships to the extent that families were reported to have rejected members who were HIV-positive. Matthew lived with his family (grandmother, mother, and sister) and his father had *“died of the disease.”* He described what happened when his father was ill:

“When my father was still alive it was like he had no relatives. It was just me, my mom, and my little sister. Everybody did not care what happened to him because he was going to die anyway. It was just like when people see a drunk person on the streets, nobody cares what happens to him. It hurts a lot.” Matthew (neg, 20)

Matthew’s relatives rejected his father when he was dying. After his father died, Matthew and his family went for testing. He thought he would test HIV-positive because his father was, but *“was relieved”* when they all tested negative. Having witnessed what happened to his father, it was his opinion that one should not

disclose one's status. This endorsed the findings in the literature that the HIV-positive person and people they were close to could be isolated because of HIV stigmatisation and this perpetuated secrecy (Stadler, 2003; Deacon et al., 2005).

The fear of courtesy stigmatisation and contagion encouraged people to distance themselves from HIV-positive people. They were worried people may speculate that they were HIV-positive too. The men recalled instances of parents being concerned for their children's wellbeing, discouraging them from mixing with those who were HIV-positive, even if there was little likelihood of transmission. Abel recalled one such situation:

"Where I live there was a guy who died of AIDS. He did disclose his status but we, the guys, did not have any problems. We treated him well. We stayed with him and ate from the same plate with him. Though there were mothers who did not want him to talk to their daughters. But he was a good guy. He even started a football club. He played soccer, he was a trainer and a coach as well." Abel (neg, 27)

Stigmatisation not only isolated the HIV-positive man but also hampered him from developing a relationship with a girl. The parents were unhappy with their daughters associating with him as this may have developed into a relationship in which their daughters could be infected. The issue of being HIV-positive and relationships is dealt with in more detail later.

HIV stigmatisation encouraged many HIV-positive people to keep their status a secret for as long as possible because they anticipated and feared being stigmatised, whether the threat was real or not. These men's stories confirmed other researchers' findings (Kalichman & Simbayi, 2003; Deacon et al., 2005; Steinberg, 2008). As described above, people's self-esteem was affected, and they may no longer be able to maintain their social standing in the community. Men may had more to lose than women in this situation as social standing or being a role model (expanded on later) was an important aspect of their masculinity, and being HIV-positive negatively affected this.

10.5 Maintaining a healthy appearance as a means of avoiding stigmatisation

As described above, changes in physical appearance or being ill could lead to gossip and rumour that one may be HIV-positive, and stigmatisation. The issue of "looking healthy" was explored with the men to determine if it was important to them. They were asked how they maintained their health and whether they

were concerned about other people's opinions should they get sick. The majority (28/33) of men agreed that their physical appearance was important to them and over half said (18/33) their health needed to be maintained to avoid any speculation that they could be HIV-positive, and to escape being stigmatised.

Only a minority (5/33) of the men said that other people's opinions on their health were not important to them. These men were more concerned about how they felt. This was summed up by Eugene (ntst, 19), saying *"as long as I feel okay and everything is on the right track for me then I'll be okay. As for other people I don't care what they think of me."* These men had self-confidence and did not require external affirmation.

However, the majority of men wanted to be accepted by the community and to assist this they needed to be healthy. To avoid speculation and stigmatisation associated with being ill, and perhaps having HIV, it was important for these men to maintain their health so that other people *"cannot jump to conclusions"* and that they *"could be at ease with my health and they can see that I'm well."* Being ill led others to *"judge"*, *"diagnose"* or say negative things. Thulani (neg, 22) explained that being fit and well was beneficial for him, as he needed to be accepted by his basketball teammates. He said: *"It [being healthy] is very important because of the society we are living under."* He did not want them to question his health.

For them men, speculation in the community about their health was problematic as it undermined their social standing in society, hindered communication, and distanced others. Abel was a hairdresser, working daily with people, and it was important for his livelihood that his customers were at ease with him, he explained:

"It's okay for people to see that I'm healthy and not to start diagnosing me. When I'm healthy people will be comfortable with the fact that I'm healthy. They won't be afraid to communicate with me. Then if I'm not healthy anymore, let's say I'm ill, people will be afraid. Like us men we are sometimes afraid to say if we are not feeling well, so they'll be afraid to approach me and communicate with me like we usually do." Abel (neg, 27)

The men were aware that not all illnesses and changes in physical appearance were associated with HIV. Abel mulled over the scenario where he decided to go on a diet to lose weight. If people were not aware of his intentions then they would speculate that he was HIV-positive. This would be bad for his business.

Many of the HIV-positive men had experienced stigmatisation or discrimination and were very concerned about it. They tried hard to avoid it, but most felt that it was inevitable that people would eventually be aware

that they were HIV-positive. Jackson (pos, 34), who was HIV-positive, was fully aware of stigmatisation but felt that it was difficult to escape from it. He said: *“I mean you cannot live in your own world, where you don’t share any [of your own] affairs with other people.”* He was married with children and learnt that he was HIV-positive after he was involved in an accident. He said he had *“always associated it [HIV/AIDS] to things that are bad”* and recalled how an HIV-positive friend was *“treated like an animal by people that were very close to him, including some of our friends and the community at large.”* For him, being healthy was important because it avoided discrimination, not only towards him but also to the people close to him:

“The sad thing about this disease of HIV/AIDS is that you grow up with it and it unfortunately becomes a shame to parents. They have high hopes and dreams about you as you grow up.”
Jackson (pos, 34)

The HIV-positive men wanted to be accepted by, and to be part of, their community. Therefore being healthy, fit, and *“presentable”* was important for Amos as he was able to participate in activities with his friends and not be excluded. He explained:

“I always need to be physically fit and strong all the time. I wish to meet people and greet them nicely and ask them how is life and everything, which is the right thing to do, you see. I push and try in many ways to be healthy all the time.” Amos (pos, 36)

However, David (pos, 30) felt that it was inevitable that people would reject him in time because as his illness progressed his appearance would change and he would not *“look good.”* He stated that it was important for him to stay healthy to avoid rejection for as long as possible. The HIV-positive men made an extra effort to be accepted by others, particularly their peers, so they could continue leading a normal life, without being discriminated against.

The men observed that HIV-positive people were shunned because they were sick and had HIV/AIDS. Thulani (neg, 22), a young HIV-negative man, elaborated on this discrimination and the fear that he and others had for becoming infected. He said HIV-positive people *“are treated differently because of the fact that he is sick and the fact that it is AIDS [...] we stay far [away] from that person [...] you think that once you touch him or you give him a hug maybe you will end up being infected.”* He suggested that whether a person was rejected or not depended on the type of relationship one had prior to the illness: *“if it is a person who has once hurt you in life [then it] is not easy for you to help that person if you didn’t make peace with what he did to you before.”* Strong relationships were important in maintaining friends after diagnosis. Men

may be less forgiving of others because of their more powerful position in society and their perceived loss of status if they associated with those who were ill.

Physical appearance, being healthy, and staying fit were very important for the majority of the male participants regardless of their HIV status. Changes in physical appearance did, in some cases, result in the community not only stigmatising the person but also their family and friends. The men had internalised the concept of stigmatisation. They wanted to avoid being unhealthy or ill as they feared that this would lead to speculation that they were HIV-positive and then to be stigmatised. These findings accorded with those from other research that physical difference could lead to discrimination and stigmatisation (Goffman, 1963; Sontag, 1990).

10.6 Fear of infection fuels stigmatisation

Stigmatisation can be exacerbated by the fear of infection, including casual contact with an HIV-positive person (Deacon, 2006). The men suggested that this fear was rife in the community, and Albert (ntst, 21) noted that the community assumed that if you lived with someone who was infected “*there is 55% chance that you will be infected too.*” This reflected back on the notion that some men expressed earlier that at some stage everyone would be HIV-positive and that it was a disease that no one can escape from.

The fear of infection was a common undercurrent in the interviews. Even if the men felt sorry for or loved the HIV-positive person, there was a concern that they may also become infected. Thulani, who was HIV-negative, described that he felt “*pain*” and “*pity*” for those that were infected, and he wanted to help as long as he was not at risk of infection. He described his dilemma:

“[HIV-positive people] are human beings and they feel pain and they also need to live a better life... A better life. The thing is some of them didn’t get it on purpose. [...] Some of them were raped, some of them they didn’t listen. For some it is a lack of information. But the fact is that he has HIV, he forgets about what happened and you have to take care of that person. But again you’ll have to keep a distance so that you don’t find yourself with the same status. We talk about the information now, you are going to help but you must always be careful. But love for that person will always be there.” Thulani (neg, 22)

Thulani suggested that some people were not to blame for being HIV-positive and they perhaps deserved more sympathy. This is explored on later in this chapter. Thulani knew about HIV and he was willing to help HIV-positive people, but he was mindful of the possibility that he could get infected. Jabu (ntst, 28) agreed

that with increased understanding of HIV transmission people could “*live with them [HIV-positive people], understand them, support them, tell them that you understand them and tell them that you love them regardless of their situations.*” However, he remarked that people in the community still inferred that one could be infected with HIV merely by talking to or eating with an HIV-positive person. Although increased knowledge can reduce stigmatisation, it does not necessarily decrease the fear of infection.

Understanding HIV transmission and getting over the fear of infection was a process that took time. Some of the men described how it took time to come to terms and be comfortable with someone who was HIV-positive before. Lucky described the process he went through. He was angry when his HIV-positive aunt came to stay with his family after the people she had been living with rejected her. He was worried that he might become infected. However, as he came to understand more about HIV/AIDS his attitude towards her changed, saying:

“I was angry at first, because she [his aunt] lived wherever she was and did not come to visit us. Now that she was ill she came to live with us and we were supposed to accept her. I was very angry about that. It wouldn’t have bothered me at all if she had come to stay after such a long time and was negative. It was because at that time I did not have a clear understanding of the disease. So I was angry because I felt she was putting us at risk of being infected. But now I understand what HIV is all about and my attitude towards her is much better. I’m not that angry anymore. [...] She’s just my aunt. I sometimes even forget that she’s HIV-positive. [...] I think it’s because I know more about the disease. [...] I mean at that time I was very confused. I did not have much information. I even thought that by just speaking to her I could be infected. I did not want to have anything to do with her. [...] Now I feel completely different about her situation.” Lucky (ntst, 20)

Over time Lucky was able to reconcile living with his aunt and his views changed. As he became more informed his anger diminished and he felt less at risk. Similarly, before Martin (neg, 25) had encountered HIV-positive people he said he had “*perceptions and myths*” that may have led him to discriminate against them. However, at Chris Hani Baragwanath Hospital he met people who were HIV-positive and “*openly talked about it*” and he realised that he could “*live freely around*” them.

Only a couple of the men were not concerned about getting infected because they understood HIV transmission, as Eugene (ntst, 19) described: “*I will never discriminate against them [HIV-positive people] because I know it’s not contagious and I know how to handle people with HIV. I know the procedures.*”

Stigmatisation is not static as other researchers have noted (Parker & Aggleton, 2003; Deacon et al., 2005), and has declined in Soweto as more people have become familiar with or affected by the epidemic, but has not gone away. The fear of infection remained a real concern for many of the men but had decreased as they became more familiar with HIV and knew more HIV-positive people. They were less concerned about being associated with or caring for them.

10.7 Individual and community levels of stigmatisation

The levels of stigmatisation were explored by asking the men about their attitude and feeling towards HIV-positive people and what their perceptions were of the community's response to HIV/AIDS.

Most of the men disclosed that they knew at least one person who was HIV-positive with only a few stating that they didn't know anyone. Contrary to the fear that some men expressed, the majority of men felt sympathetic towards those infected stating "*that's a really sad situation*", "*I feel very, very bad for him*", "*I just felt sorry*", and "*it's painful because they are like human beings ... we cannot dump them.*" A comment from Abel summed up the men's feelings:

"You know I really feel for them [HIV-positive people] because you don't know what that person is thinking. Maybe he's wondering whether they'll be dead tomorrow or if they still have a day to live. Yes I do feel sorry for them. It's not good to be at that stage." Abel (neg, 27)

The men were distressed by the suffering HIV-positive people experienced. Many expressed their willingness to help and would not reject or isolate them. Martin described his emotions:

"I feel really sad about the situation of HIV/AIDS. People suffering from such a disease really suffer and pain a lot. It really leaves one with the emotion of wanting to do something and helping due to the suffering that HI virus infected people endure. It challenges one to cry in sympathy with what they are going through." Martin (neg, 25)

Although the majority of the men expressed the view that they did not stigmatise others, some admitted that they found it difficult not to judge people who were HIV-positive. Clement (a Christian) shared his dilemma:

"... you actually see that these people deserve it [being HIV-positive] because when you tell them one thing they don't listen, and when you try to tell them again they won't listen ... and you get to a point where you will see that here I'm defeated and there is nothing I can do. [...] I don't think that [it] is fair to judge another person because of their mistakes in the past, rather judge them by what they doing or what they could potentially become." Clement (ntst, 18)

Clement is conflicted about his own feelings. He judged those who were HIV-positive because he felt they had not listened to him and had gone against his advice. At the same time he recognised that they may have changed their behaviour and need his help.

Some men mentioned that HIV-positive people were to blame for being infected. As Brian (ntst, 26) articulated: *“Most people who get infected are partially to be blamed.”* But he also felt sorry for them. He believed that they were living unhealthy lifestyles, being promiscuous, and not listening to advice: *“Then the next thing they’re infected and dying. Now that person will have many regrets and it would be too late.”* He recounted a story about a friend of his: *“They call her names and they say she lived a careless life. I agree with that, but do they have to go and say such things about her?”* He agreed that she lived carelessly, but did not agree with the community calling her names.

Furthermore, one community outreach worker suggested that men blamed themselves for being infected. The HIV-positive men who talked to the community worker said: *“I am the one who went out and collected HIV.’ I think that is a reason for them to stigmatise themselves. They only put themselves first, they don’t think about others, like their wives”* (COO6). Her view highlights that there was not only external stigmatisation, but that people also internalised stigmatisation, as also found by other researchers (Deacon et al., 2005; Nyirenda et al., 2006; Scambler, 2009).

Most of the men felt empathy towards HIV-positive people and said they would help them where they could. However, they indicated that other people still rejected, isolated, discriminated against or resented HIV-positive people, and that they were treated extremely badly in their communities. As Matthew described:

“I feel very, very bad because infected people are not cared for these days. They treat them just like toilet paper. So you when a person comes to you and tells you about their status you care for that person, you feel responsible for them because that person is your friend and your relative.” Matthew (neg, 20)

Enacted stigmatisation was prevalent in Soweto. This, according to the men, was due to ignorance and a lack of information or understanding about HIV and HIV transmission. As Jabu explained:

“Ya, there are people who believed that ignorance is blessed. So in my point of view I think ignorance was the most dumbest that a person can come up with as an excuse. To be ignorant about something, is like you holding yourself back into learning more about the environment, your lifestyle and other things, where you live, how to get help and so on. As soon as you sick

you going to be all alone. People will turn their backs on you because you turned your back on other people...” Jabu (ntst, 28)

The men recognised that these attitudes were stigmatising and some were brave enough to stand up for people who were being stigmatised. Brian gave an example:

“I’ve seen it happen to one person who I grew up with. They always called him names and he eventually passed away from the disease. [...] I did not feel right. I used to tell these people to stop what they were doing.” Brian (ntst, 26)

Jabu (ntst, 28) noted that blame and punishment were particularly prevalent “...in black communities, instead of supporting [people infected with HIV] they would rather point fingers and blame.” Moreover community members denied the existence of HIV: “...the majority don’t like to talk about HIV/AIDS. It is not something that exists to them. Some of the adults would even say ‘in our times there was no such a thing as HIV/AIDS.’” Communities like Soweto, with a predominantly black population and high HIV prevalence were also likely to experience high levels of denial and stigmatisation. This deterred people from seeking help, as also described in the literature (Epprecht, 2008; Geffen, 2010; Gilbert & Selikow, 2011).

These men’s views, namely that they did not discriminate against people with HIV but that people in the community did, mirrored the findings of Green (1995) and Maman et al. (2009). The men’s attitudes have changed over time, some men felt empowered to stand up for HIV-positive people as their own knowledge and understanding of the disease improved. As community level knowledge improved, this may lead to their attitudes changing too.

10.8 Levels of blame determine different degrees of stigmatisation

Stigmatisation was generally higher when immoral connotations or deviance were associated with a disease (Deacon et al., 2005; Yang et al., 2007). The male participants categorised HIV-positive people into two main groups: the first comprised the “innocent victims” who had been infected with HIV through no fault of their own. The second group were those who were “blameworthy” because they “*had themselves to blame*” for being infected and were being punished. Thulani summarised:

“Some of them deserved it because they didn’t listen. Some deserved it because he raped somebody. Maybe it is the way God punishes him. Some do not deserve it because she was raped.” Thulani (neg, 22)

People who were infected with HIV through no fault of their own were the innocent victims. Such cases included being infected through an accident, ignorance, rape, or abuse. Phil (ntst, 18) described how not knowing what precautions to take against HIV infection, such as using a condom or not coming into contact with other people's blood, could lead to innocent people being infected. He was sympathetic, "very sorry", for HIV-positive people because "*HIV ruins people's lives and families. We lose our loved ones through HIV and AIDS.*" Siphso (neg, 23) was also sympathetic: "*I don't hate them. I do love them because they're also human beings. There are some who got infected through rape. I do feel for them.*"

A number of men told stories about men getting infected with HIV in prisons where they were sexually coerced or abused, and not able to protect themselves as they were unable to access condoms. A friend of Albert's was infected in prison: "*Well he did share with me that he got it from prison. They were abused at the prison. People there sleep with each other, men to men. A lot of abuse happens there*" (Albert (ntst, 21)). Men in prisons were placed in a difficult situation and as Lebo (pos, --) mentioned they were "*ashamed*" to take or ask for condoms. Prisons in South Africa were overcrowded and there have been many attempts to get condoms into prisons and made freely available, but with limited success (Muntingh & Tapscott, 2010). HIV-positive men infected in prisons were also deemed to be innocent victims.

Finally, HIV-positive children were also deemed innocent victims because they were infected by mother-to-child transmission or through abuse. However, they were not immune to HIV stigmatisation. Some were rejected for being HIV-positive and others who were not HIV-positive were stigmatised for being associated with people who were, as Siphso related:

"A lot of people reject people with HIV. Like where I live there was a lady who died of the disease last year. She left behind a child. You can see that the child is also infected. Now people don't want their children to play with the child. They tell their kids that the child is infected and if they play with her and they hurt each other and touch each other's blood they will get sick. I look at these people, some don't even know their status." Siphso (neg, 23)

The fact that "innocent victims" were stigmatised or rejected even though they were not to blame for being infected, means that those who were positive because they "deserved it" or were being punished would be stigmatised even more.

The notion that some HIV-positive people could have avoided infection and were blameworthy for their illness was mentioned repeatedly during the interviews. The men indicated that some HIV-positive people were being punished for some wrongdoing, and indicated that some people felt that they deserved their fate because of the lifestyle they had chosen and should be punished for their illness. As Thulani described:

“...people feel differently about people who are infected. There are some who want to help them because they feel that they are still part of their society. But there are those who don't care because they think people who are HIV-positive have invited the virus to them by sleeping around without protection.” Thulani (neg, 22)

The men remarked that HIV infection was associated with a “*careless lifestyle*”, a lack of morals or “*sleeping around*.” Thus, being HIV-positive was deserved punishment for this behaviour and one should not expect sympathy. Furthermore, being HIV-positive one was associated with these behaviours, as Eugene explained:

“Maybe they'll call you a slut and say that you were sleeping around and spending the night out that is why you have HIV. You know people have their own views about HIV-infected people (he laughs) [...] Yes they will say you were sleeping around and you were a bad person, that is why you have the disease. Others would say, like my mother, (he laughs) you have the disease because you never attended church (he laughs).” Eugene (ntst, 19)

The men reflected on the many discussions and speculation in the community about “*the disease*” and people who were HIV-positive. The community had developed firm opinions about why people were HIV-positive and had preconceptions about HIV-positive people's moral conduct.

These findings supported the notion that the HIV stigmatisation was greater when people disagreed or disapproved of the HIV-positive person's lifestyle, although the “innocents” were not exempt from stigmatisation. The men were knowledgeable about HIV/AIDS. Many said that they would not stigmatise HIV-positive people, but others acknowledged that they did. Some were conflicted about this. The means of becoming infected was important for these men to determine whether the person was innocent or not.

The study participants indicated that HIV stigmatisation in the community persisted, and men were often blamed for spreading HIV. One outreach worker noted that men “*blame themselves*” for being infected, and found it difficult to go to the clinic for help “*even though there is no one who is blaming them.*” HIV-related stigmatisation increased men's reluctance to go to the clinics to test for HIV or to seek help, which supported the findings of Kalichman & Simbayi (2003).

Attending the clinics was a form of inadvertent disclosure as it associated the men with illness and perhaps having HIV. Because of this and the stigmatisation associated with being HIV-positive, men were reluctant to seek help at the clinics. The men gave examples of people seeking help from clinics that were relatively far from their homes in order to keep their status secret. Thabo (pos, 52), who was HIV-positive, recounted the story of a man whom he suspected had HIV: *“I heard some rumours about him and I saw him at Baragwanath [hospital], even if I didn’t know the reason why he was there. But I saw him. But where I am staying at Orange Farm they don’t know.”* Even though the man could have been at the hospital for another reason, Thabo was convinced he was HIV-positive. The association of HIV/AIDS care and treatment with hospitals and clinics deterred some men from going to them.

10.9 Gossip, depression, and suicide

Mental health issues were not specifically explored in this study; however the issues of stress, suicide, and depression were raised by the men a number of times. As described in the literature review, suicide, suicidal ideation, and depression were all found to be higher in people who were HIV-positive, and in some cases to be higher in men rather than women (Kalichman et al., 2000; Colibazzi et al., 2006; Keiser et al., 2010; Rice et al., 2010; Schlebusch & Vawda, 2010b).

The men identified that stigmatisation in the community puts pressure on people not to disclose their status because they think that people would *“talk easily”* about them. It was a common perception that the community enjoyed speculating and gossiping about people’s status and secrets were difficult to keep. Noah (neg, 19) elaborated: *“if you tell anyone about your status, it is going to be spread all over the area. There will be the rumours and when you pass through the streets, people will look at you in a bad way.”*

Given these high levels of stigmatisation and discrimination, HIV-positive people tended to keep their status secret and isolated themselves, to the extent that only their family knew it. Noah’s uncle only disclosed that he was HIV-positive when he was very sick. Noah described his uncle as a *“stubborn”* man who did not like being told what to do and refused to take ARVs. *“He only wanted only people from the family to take care of him. [...] He didn’t want to have anyone coming to see him. He would even chase away his friends when they came to visit. [...] then calls me or my sister.”* The stigma of being associated with someone who was HIV-positive, courtesy stigmatisation, puts pressure on the family not to disclose his status to others.

The HIV-positive men recalled being stressed or depressed, crying, and some had even contemplated suicide.

Xolani recalled his suicidal thoughts when people gossiped about him:

“A lot of people thought I’m dying but now they are disappointed because I’m feeling much better. I also wanted to commit suicide when they gossiped but I told myself I need to be strong.” Xolani (pos, 41)

Zakes (pos, 38) was more optimistic and remarked *“I won’t commit suicide, maybe a cure will be found.”* He had come to terms with his diagnosis and was able to have a positive outlook on life.

Other HIV-positive men found it difficult to accept their status and it took them quite some time to come to terms with their diagnosis. Bongani elaborated on the process he went through:

“I felt very sad and depressed [he pauses for a while] and I for almost a week I went without eating. I then decided to tell my wife and she could not believe [it]. We went for [another] test and it confirmed what I had told her. Afterwards I told my parents and I started accepting that I have the disease and I have to live with it.” Bongani (pos, 35)

After disclosing his status to his wife and family Bongani was able to accept that he was HIV-positive. He then felt strong enough to disclose to an HIV-positive friend, helped her come to terms with her status, and invited her to come to a support group.

When the men received their HIV-positive diagnosis most of them were shocked and needed time to go through a process to accept the diagnosis, only thereafter disclosing it to others. Unlike other men who hid their HIV status, Bongani was able to assume a position amongst his friends where he was comfortable to disclose his status and to act as a role model for others.

The men agreed that HIV-positive people needed support in order to mitigate their stress and thoughts about committing suicide. Albert (ntst, 21) suggested: *“If we give them support they will feel that they can live positively with the virus. They don’t need to hang themselves or something.”* They mentioned that if someone disclosed their status to them or if they thought someone was HIV-positive then they would be able to offer them support, but they speculated that other people would judge them. As Thulani discussed:

“[Discrimination] happens. You’ll find people end up committing suicide because the community has already judged them. [...] The fact is that he is losing weight. Maybe he doesn’t understand why he is losing weight. Maybe it is stress. But the fact [is] that community already has [a] name on him.” Thulani (neg, 22)

10.10 Discussion

As the men's accounts clearly reveal, stigmatisation and discrimination arise out of an intricate web of fear, self-blame, ignorance, secondary stigmatisation, community suspicion, and on-going gossip. While some sources in the study and in the literature reported a decline in levels of stigma (Maughan-Brown, 2010; Abrahams & Jewkes, 2012; Zuch & Lurie, 2012), these participants painted a picture of persistent levels of discrimination operating at many different levels.

The community's lack of knowledge about HIV/AIDS and HIV transmission increased their fear of contagion and the concern that they may become infected. HIV-positive people were particularly stigmatised if they were considered blameworthy because they had been engaging in a lifestyle that was not condoned by the community. These attitudes perpetuated stigmatisation and discrimination.

The men were conscious that their physical appearance needed to be maintained in order to avoid unwelcomed speculation. The high level of stigmatisation discouraged them from discussing their illnesses, testing for HIV, or disclosing their HIV status. The men kept their health issues secret to avoid any discrimination.

The men were also aware that they are breadwinners and have family responsibilities. This increased their tendency towards secrecy as they did not want to lose social standing in their community or amongst their friends.

The men were aware that the community stigmatised HIV-positive people, but they said that they would be able to support them if they disclosed. However, it may be more difficult than they anticipate because of their own concerns and because of courtesy stigmatisation i.e. being associated with HIV-positive people.

HIV stigmatisation continued to have serious consequences to the extent that the men associated suicide with an HIV-positive diagnosis. In addition, the fear of losing social standing in the community because of being ill or HIV-positive was of great concern to the men. These two factors combined increased the barriers for men to access help. They were reluctant to discuss their illnesses or disclose their HIV status and it prevented them from seeking help at clinics.

Chapter 11: Being a man

In this chapter the notions of South African masculinity are explored in the context of the HIV/AIDS epidemic and help-seeking behaviour. Common masculine behaviours, including excessive alcohol consumption, drug-taking, and engaging in multiple sexual partnerships, were found to be associated with a higher risk of being HIV-infected (Simbayi et al., 2007; Hunter, 2010). Other factors that contributed towards defining masculinities in sub-Saharan Africa included being employed, being in a relationship, and having children (Morrell, 2001; Morrell, 2002). These factors are explored in this chapter.

In South Africa there are multiple and evolving masculinities but patriarchy persists as a hegemonic masculinity in many groups, with the man being the head of the household, the breadwinner, and the decision maker (Lesejane, 2006; Jewkes & Morrell, 2010). These characteristics of masculinity impact on men's health, and researchers elsewhere have linked them with poor or delayed help-seeking practices (Banks, 2001; George & Fleming, 2004; Robertson, 2007).

The HIV/AIDS epidemic, and related stigmatisation and discrimination, has further impacted on masculinity. Being HIV-positive reduces the chance of getting a job or staying employed, with people either being excluded from employment or losing their jobs because they are infected with HIV and are ill (Sprague et al., 2011). This, in turn, reduces men's ability to provide for the family. These unemployed men are forced to rely on the extended family's income, including their grandparents, in particular their grandmothers, who play an important role in South African society, often providing income for the household through their old age pension, care-giving, and raising their grandchildren (Gilbert & Selikow, 2011). Masculinity and resultant behaviour are examined in more detail in this section through the voices of the men interviewed in this study.

11.1 Risk-taking

The HIV/AIDS epidemic has strained traditional notions of masculinity, because many of the activities that men engage in contribute to an increased risk of HIV infection. Researchers have identified that men, and young men in particular, are risk-takers (Foreman, 1999; Selikow et al., 2002; Campbell, 2003; Walsh &

Mitchell, 2007). Risk-taking behaviours associated with a higher risk of being infected include having multiple sexual partners, having sex without a condom, drinking alcohol, and taking drugs.

A few younger men confirmed that they took part in these risk-taking behaviours, as Noah described:

“We like parties too much and we drink a lot. What happened last year [at a high school party] most young people were arrested by the cops because they were drinking [...] young people smoke drugs and they feel like they are the top dogs, they end up raping kids and doing things like that.” Noah (neg, 18)

These young men reported that they are encouraged by their peers to take risks and to “impress” their friends. They egged each other on to have sex with women they had recently met and were prepared to take risks just for the thrill of it. As Mdu described:

“We go around and say eish... look at that girl’s behind. I want to sleep with her or to have sex with her. We think that it somehow gives us some power or glory to have sex with that person not knowing their status and sexual background [...] It is peer pressure because we want to do things to impress our friends and do not think about the consequences [...] I could say it is the issue of having bad friends who don’t encourage you to stay negative, but will encourage you to get involved in risky sexual behaviours.” Mdu (neg, 18)

Mdu described how having sex with many women and women that he did not know gave him “power” and “glory” and status amongst his friends. He knew this behaviour may result in him being infected with HIV. Mdu’s promiscuity was not unique, as over a quarter of the men (6/33) stated that they had or were having sexual relationships with more than one woman. Despite the known increased HIV risk, they were reluctant to stop seeing any of the women. These accounts confirm that young men believed that having many sexual partners and having control over sexual matters earned them respectability among their peers (Connell, 2005; Hunter, 2010).

Relationship complexities and being HIV-positive: Patrick

Being HIV-positive provided an added dimension to the already complex problem of relationships. Patrick’s story provided insight into the intricacies of these relationships, particularly when ill and unemployed, and how they impacted on masculinity.

Patrick (pos, 36) was married and lived with his wife who was 10 years younger than him. He had five children, four of whom lived elsewhere with their mothers. Although married, Patrick was unable to pay lobola to his wife's family because he had no money. He had been unemployed for many years and met his wife shortly after he was released from prison. She "*demanded*" that he give up stealing and harassing people, which he acceded to because "*I thought it would be worthwhile for me to start afresh with my wife.*" They lived in a house that his grandparents built for him because he was the only male child in the family. His parents had "*high hopes*" for him and wanted him to "*continue and expand*" the family name.

He and his wife tested for HIV during an HIV testing campaign at the clinic. His results were positive but his wife's were negative. He was worried that she might leave him, but she has been loyal and has "*stuck by my side*" and he felt "*lucky to have her in my life.*" When he asked her why she stayed with him she said "*there are guys outside in the community who are proposing [to] me, who are offering me a better environment and life compared to that of ours, but for me [it] is not all about that. I care and love you.*"

Over the years Patrick has tried to support all his children, employing a number of strategies. For a while he relied on his grandmother for money, but she died and although she left him some money he has spent it all. For a time he did part-time cleaning and gardening jobs but he had to give those up because he had TB and was too weak to work. He can no longer support his children and said:

"All I do now is visit my children. They can see the situation. I just try to encourage them as the father and reaffirm to them that everything will be okay, even with my sickness. I encourage trusting [in] God and also praying." Patrick (pos, 36)

He still tried to support his family, saying, "*I am forced to go out and try something so we could find something to eat.*" He said he "*even started with making illegal connections [connecting houses to the electricity grid so that they do not have to pay for the electricity they use] for people in the community and that made me quite popular, but I then realised that what I was doing was going to take me back to prison.*"

Most of the time he was too sick to work and did some electrical appliance repairs at home.

Patrick can no longer support his children, which diminished his ability to be a father and provider. This upset Patrick as he was unable to live up to his expectations of being a man. His family lived off his wife's income and his occasional contributions. He explained that it was important to maintain a good relationship

with his family: *“I have been blessed with a wife who loves me and ensures that we are happy all the time, it even encourages me to want to stay committed all the time to our happiness. I even find myself contributing with everything that I can ... even if it is the last R20 I have just so that we can continue to live in that peace with my wife.”* Patrick was under pressure to contribute financially towards the household income and to maintain his relationship with his wife. Being unemployed and ill had forced Patrick to make lifestyle changes by giving up smoking and alcohol, both common pastimes of the men and *“stay[ing] healthy by eating well and on a balanced diet just to complement my medical situation.”* What little money they have was used for crèche fees and food, and when there was extra money it was used for transport costs to the clinic in order to collect his medication.

When he started ART his illness was advanced, his CD4 count was very low and he had TB. His wife had taken an active interest in his health, sitting with him in long queues at the clinic and asking the nurses about the medication. Since starting treatment he had developed sores around his penis, which he was told was a reaction to the medication. The sores had cleared, but he was still experiencing severe internal pain and had a catheter inserted so he could urinate.

Patrick was struggling with his health but he was happy with his treatment and said: *“In my case the medication really helped me. There was a time when I really felt that I was dying as I was weak but I was encouraged to keep on taking medication. Now I feel much more stronger and better.”* He experienced side effects, but felt that he had little choice but to work through them and talk to the doctors and nurses about the problems. The nurses *“...would also insist that you try and stick to the course. They would even threaten you by saying that they will refer you to the hospital. You think that there is no money at home for your family to visit you if they want to. You end up just forcing them down so as to avoid getting admitted.”* Patrick felt bullied by the nurses and disempowered. He stoically persevered with his treatment because he had seen others who were worse off than he was and some had died. He expressed gratitude that he had a supportive partner who helped and cared for him whilst he had been on treatment and said *“I know I would have passed [died] a long time ago if it was not because of the love, care, and support I’ve received from my partner.”*

Patrick believed that he and his wife were *“doing quite well together as a couple and I am committed to her and our wellbeing.”* But he had relationships with other women behind his wife’s back, as he explained: *“I*

have another girl, woman, that I have been seeing on the side. We have been doing this behind my wife's back. She tells me that she loves me so much and she understands my situation. She doesn't think that she would complicate things for me with my wife. Both of us have really tried to stop as we know that what we are doing is wrong but we just can't [stop]. I however insist that we use a condom every time we have sex. We spend time talking and discussing about a lot of things. I happen to enjoy her company a lot and I guess it is a bit difficult to let go of that." Patrick's relationship with his "other woman" complicated his life, but he felt fulfilled. He enjoyed her company and having sex with her.

Patrick's story reflected the dilemma that other men in similar circumstances may experience. They wanted to retain the social standing that being a man offered and have multiple relationships, but at the same time they had to rely on others for money and support, which undermined this. Patrick was committed to looking after his children but being HIV-positive and too sick to work had rendered him unemployed. He was no longer the breadwinner but there was pressure on him to contribute to the family's income. He had given up his illegal activities, alcohol, and smoking — all risk-taking behaviours associated with masculinity. Whilst he had a number of relationships before he married, he was now conflicted about his extramarital relationship as he was reliant on his wife, and he felt that he was betraying her.

Having multiple and/or concurrent partners was reported to be a common practice within the MSM and heterosexual communities and was one of the main drivers of the epidemic. Some of the MSM participants suggested that they were particularly at risk because they practised "*polygamy*", and Lebo (pos, --) speculated "*[by] the year 2012 all gay guys will be HIV-positive.*" HIV prevention information overwhelmingly focused on women and the risk of heterosexual transmission. Enoch, a MSM, noted that some of his friends did not believe that MSM were at risk of getting HIV:

"I have friends that say 'you cannot have HIV because you are not a woman' or 'you are not sleeping around'. There's still this thing in the community of gay people that if you sleep with the man and you have HIV you are going to be cured." Enoch (ntst, --)

These myths circulating in the MSM community increased the chance of MSM being infected. Because they did not believe that they could be infected with HIV they may be unaware of their status, which increased the chance of HIV being transmitted. They would also be less likely to test for HIV or to seek help.

According to (Hunter, 2005; Hunter, 2010), being in one or more relationship(s) was an important symbol of masculinity; however, relationships shift over time and not all men engaged in multiple partnerships (Bhana et al., 2007). Being either HIV-positive or worried about being infected with HIV complicated relationships. For a few men HIV/AIDS had affected on their relationships and some had adapted their behaviour. The men recalled ways in which they or others had changed their behaviour to avoid being infected. In this study, men having sexual intercourse with multiple partners or on the spur of the moment was common, although some preferred being monogamous. Abel described his friend's relationship with his girlfriend, who always accompanied him so that he was not tempted to have sex with other women.

“So he even told me that at least he has a girlfriend. Even when he goes to parties he does not arrange to take someone else. He always takes his girlfriend with [him]. If he wants to relieve himself [have sex] somewhere he knows he's got his woman. He does not lust for other women who are dressed nicely. He knows he's got his woman beside him.” Abel (neg, 27)

Concurrent and multiple partnerships were common forms of relationships for the men, but it was shown that the HIV incidence had declined where there had been a reduction in the total number of partners (Halperin & Epstein, 2007; Halperin et al., 2011). Having multiple sexual partners was inseparably linked to African masculinity (Jewkes & Morrell, 2010) and was an indication of a man's sexual prowess (Hunter, 2005). A minority of the men interviewed were involved in multiple partnerships and were not planning to change the situation. Some men indicated that this was the norm. However, one should not assume that all men were the same - a substantial number were not involved in multiple partnerships.

Being HIV-positive made embarking on a relationship even more difficult. HIV did not reduce men's sexual desires and they wanted to engage in relationships. This was illustrated by Tebogo's story. He was 27 years old and HIV-positive.

Establishing relationships and being HIV-positive: Tebogo

In 2005 Tebogo (pos, 27) and his wife learnt that they were HIV-positive after a post-mortem was conducted on their baby daughter. It was found that she was HIV-positive: *“She was my first born and I loved her. It was my first time being a father. I sometimes thank God that if my baby was still alive I wouldn’t have known about my status.”* Although Tebogo was devastated when his baby died he was thankful that he learnt that he was HIV-positive and was able to do something about it. He was shocked to learn of his status *“... it was unbelievable. There was no way I could be HIV-positive. I’m proud of myself, [...] I’ve never blamed anyone about the contraction of the virus [...] I told myself that everything happens for a reason.”* Tebogo did not blame his wife who separated from him when *“she realised that we were HIV-positive.”*

Tebogo described the emotions he went through when he was told that he was HIV-positive and how he coped thereafter:

“After I received my results I was very depressed. All I thought about day and night was to commit suicide. I thought of myself as being stupid and pathetic. I wanted to commit crime because I was unemployed because I saw myself as being dead already. I did not see any reason for living. I felt useless. I did not think that I needed someone to sit and talk to. [...] after some time [...] I told myself that I’m HIV-positive and the disease is everywhere. I looked at the situation around the world. I decided to go and volunteer to be a caregiver. After getting into volunteer work I started sharing. I realised that I was not the only one who had the disease and it is not the end of the world. I received much support from a friend of mine who was infected as well. He disclosed to me first without even knowing that I was infected too. We became partners when working and we work together very well. I then decided to disclose at work and it became a problem. I told my family and it did not go well at all.” Tebogo (pos, 27)

Tebogo only revealed his status to others when he had support, but noted that his work colleagues and his family were not supportive. When he disclosed to his family they *“turned their backs”* on him, they made him *“feel like I’m not a human being.”* He felt that he was *“useless and had no purpose on earth.”* He turned to religion and believed in God and that his *“body is the body of God.”* Only his father was supportive, but told him that living with an HIV-positive person was difficult and a burden. His father was not earning much and Tebogo’s job as a caregiver was badly paid: *“I love my job even if I get a small salary. I am proud of myself.”* He had mixed feelings about disclosure: *“I took a while before deciding on how to move on and what to do next. I decided not to share my illness with anyone else again. But right now I feel that enough is enough. We need to stand up and shout and tell people that this disease is real and people are dying.”*

He looked after himself and kept healthy. He lived on his own, felt very lonely, and hankered after a relationship: *“I wish I could find an HIV-positive woman with whom I can talk to”* because *“we will be able to understand each other’s situation, where we are coming from and how to live with the disease.”* He described how his relationships faltered:

“I met another lady at work and we dated but soon there were rumours that I had the virus and everybody at work gossiped about me and we broke up and since then I’ve decided to stay single until such time I feel that I’m ready to try again.” Tebogo (pos, 27)

Tebogo was not in a relationship but believed that both parties should know each other’s status. He said he would be open to his partner from the start of a new relationship: *“I will encourage her to go with me and get tested and also go for couple counselling at the clinic.”*

Tebogo’s story highlighted how being HIV-positive impacted on his masculinity. His hopes of being a father were dashed, he had struggled to form another relationship, and his family had rejected him. He was proud to be employed as a caregiver (even though this was not traditionally men’s work), but the job was badly paid and it would be unlikely that he would be able to support a family. He was trying to start a new life being HIV-positive, but this was proving to be very difficult.

Men in this study had embraced many of the traditional masculine roles, but had been forced to adapt their behaviour because of HIV/AIDS. The HIV/AIDS epidemic had fundamentally affected their notions of masculinity and changed the way men engaged in relationships.

Drinking alcohol was considered to be a manly pursuit, It increased men’s desire for sex, and enabled risky encounters (Hunter, 2010). Many (10/33) of the men agreed that drinking alcohol could increase risk-taking behaviour as it was difficult to be *“responsible”* if you were inebriated. Alcohol was therefore synonymous with having unprotected sex: *“when we are drunk and you see that there’s a girl available (laughs out loud) we forget to use condoms”* (Abel (neg, 27)) and *“it’s risky because when you [are] drunk and you see these nice women; you may just have [sex with] her without a condom”* (Kabelo (ntst, 33)). Whilst acknowledging that drinking and smoking were not healthy, Patrick and Eugene explained that these activities give them an excuse not to be in control.

"[when you are drinking] you don't think of any good behaviour and healthy lifestyle as all you are interested in is the bad things like drinking alcohol and smoking. These things are not good for our bodies in any way. The level of intoxication sometimes commands you to think of women as sex objects only. All you think about when you are around them is having sex." Patrick (pos, 36)

"If you drink a lot you are at risk. Because maybe we are at a party and we are busy drinking then you see a very pretty girl and maybe you don't even have a condom. You know man, when you are drunk you do stupid things. Then the next thing you realise later that you got yourself infected. So yes, you are at risk if you are an alcoholic and don't have self-control." Eugene (ntst, 19)

Being inebriated gave the men an excuse to engage willingly in risky behaviour as they were no longer in control of their actions. Andrew, a young MSM, described how drinking led to him having a risky sexual encounter with a man, which he later regretted.

"I was in a relationship with a man and we have done something that we have regretted. What came to mind what if I have this virus. [...] We were drinking with these guys. I had sex with this guy but we never used a condom. That was my risky experience, I was so afraid because I did not know his status." Andrew (neg, 24)

Abel, a young injecting drug user, knew that sharing needles increased the risk of HIV infection, but continued to engage in the activity.

"... when using drugs and needles We do not sterilise these needles. We just inject ourselves with drugs because I'm addicted to these drugs. So with exchanging these needles one can get infected with HIV." Abel (neg, 27)

Watching pornography heightened Musi's sexual desire and he described how it could lead to risky behaviour.

"Things like watching porn movies. [...] In most cases young people like to watch such movies. Then they want to practically do what they're watching. They also want to experience what's being done and be at risk of being easily infected with HIV." Musi (ntst, 20)

The men continued to engage in activities they knew might increase their risk of becoming infected with HIV. There were external pressures that men encountered on a daily basis and that influenced men's risk-taking, enabled unsafe sexual encounters, and increased their chances of becoming infected, thus negatively affecting their health and wellbeing. These findings concurred with those of other researchers (Foreman, 1999) who classified men as risk-takers.

11.2 Employment

South African men were viewed as patriarchal by the secondary informants who explained that men were the “*head of the family*”, made the key decisions, held the family together, were the breadwinners and needed to provide for their families.

The high rates of unemployment in South Africa hampered the men from getting jobs and being able to provide for their families. Not having an income undermined men’s status as breadwinners in society and had been closely linked with increased HIV prevalence (Hunter, 2007). The majority (22/33) of men in this study were unemployed or engaged in part-time or piecework, one had a full-time job, and a number of the men relied on their grandparents or families for support. This was not unexpected, since the unemployment rate in Soweto was extremely high at around 53%.¹⁴

Finding sufficient casual or part-time work to support a family was difficult and an on-going problem. Amos (pos, 36) took care of his 17-year-old daughter and his granddaughter after her mother passed away in 2004. The three of them lived together. He was in a relationship with a woman, but he was not staying with her. He was HIV-positive. Although he completed his Junior Certificate (Grade 10) he was unable to continue with his studies because his parents could not support his “*ambitions of further study.*” He struggled to make a living as a handyman fixing “*electricity equipment and appliances*” He earned around R600 a month, but this was variable as it depended on the demand for his services. It was important for Amos to work as he had two others to support, and he needed to buy food in order to maintain his health.

These men struggled to find enough work to meet their obligations to be the provider, breadwinner, and head of the household. When this was not possible they ended up relying on their partners or other family members for money. For men, being unemployed and reliant on others for the means to live affects their masculinity.

In patriarchal societies men were expected to take care of and be responsible for their family. This was reflected in the interviews with some of the men who had taken on family duties because they felt it was their

¹⁴ Department of Economic Development (undated), “The Five Year Soweto Economic Development Plan 2008-2013”, accessed 25 August 2012, www.joburg-archive.co.za/2009/pdfs/economic_development/regd_plan.pdf

responsibility as male children. For example, Abel's sister had died so he and his brothers were looking after her three children.

"No there aren't any [dependants], it's like... [pauses] we're helping each other like... [stutters] actually they are my sister's [three] children. So my sister passed away so we altogether as males [support the children]. They're not entirely dependent on me. They also depend on my older brothers. [...] But for me the person that I'm really taking care of is my sister's child who is playing [sport] for Wits [University of the Witwatersrand]. I give him money for transport ... I sometimes buy clothes for him." Abel (neg, 27)

Being the first male child born in a family had social standing but also increased responsibility. Eighteen-year-old Mdu (neg, 18) was the oldest male child in the family. Although his siblings were not financially dependent on him, he considered himself to be their role model. *"Err... I am actually the first born at home. I have actually entrusted myself with the responsibility of setting an example for my siblings. I guess they depend on me in that way... Yes, yes, more or less it's like a big brother."* He was his brother's role model so he needed *"to keep myself good"* and not smoke or come home drunk otherwise his brother might follow his example.

For some of the men, being a man in the family meant taking on additional responsibilities. There was pressure on them to be breadwinners or role models for their younger siblings. Peer pressure encouraged them to take part in masculine activities, such as drinking and smoking, all the while being expected to provide when unemployment in the region was so high.

11.3 Fatherhood

Being a father and having one's own home were important symbols of masculinity (Hunter, 2010). However, being HIV-positive impacted on the realisation of both these milestones. These issues were highlighted by Patrick and Zakes.

Patrick (pos, 36) struggled with his illness although he had *"come from far with this disease."* He had been through difficult times but was spurred on because he wanted to see his child grow up *"to be someone worth something in the future."* Patrick described his own childhood as being difficult as he felt that *"my mother didn't really care that much about me [...] she didn't really input very well in my life."* They had been in conflict about his participation in karate. He had done well and achieved black belt status, but was made to give up both school and karate even though he felt he could have become an instructor. He was resentful as

he was unemployed, but recognised that he could behave differently and said: *“I don’t want to be the same parent [like his mother] for my child. I want to be there and also help him in making such decisions in life.”*

For Patrick overcoming the difficulty of living with HIV and being unemployed was important. He sensed a duty and responsibility to take care of his child, but did not want to be a burden on him.

“Yeah it is important for one to be healthy. Like now I am sick but I try to stay healthy. It sometimes saddens me to look at my child taking strain. Sometimes he would stay with me. At times when I complicate and wet myself and throw up, he would run and try to help me together with his mom. So that on its own becomes a motivation for me as I don’t want to die and leave my child at his age without a father.” Patrick (pos, 36)

Being HIV-positive made it difficult for Patrick to be a father and to be a role model for his son. He was unable to make a monetary contribution to the household as he was unemployed. He was dependent on his wife and son to help him when he was sick. These factors undermined his ability to be the father he aspired to be.

Fatherhood, relationships and being HIV-positive: Zakes’s story

Fatherhood was sought after by men, but being a father it was not always easy, as Zakes (pos, 38) discovered. His daughter was central to his life, but being arrested and having numerous relationships complicated his life. In addition he was HIV-positive, which added to the complexity.

Zakes was 38 years old. He lived with his daughter’s mother for six years before he was arrested for “*hi-jacking*” cars and was imprisoned, where he was refused bail and spent a considerable time (18 months) awaiting trial. During this time he learnt that his partner was having affairs and neglecting their child; this stressed him and he worried about his daughter being alone at home. In prison he started to believe in God and learnt that he was HIV-positive. Zakes was fortunate to receive only a suspended prison sentence, possibly because he was HIV-positive and his daughter needed parental care.

After leaving prison he was happy to be reunited with his daughter and managed to get a temporary job at a retail store. They lived together in a backyard room at his parents’ home.

But it was not long before he started drinking and found a girlfriend. One evening, whilst on a drinking spree in Hillbrow, he bumped into his ex-girlfriend, the mother of his child. She was scared of him because he used to hit her. She made excuses why she had neglected their daughter and said she left him because she thought

he would get a 15-year sentence. He disclosed to her that he was HIV-positive and said *“that means we are both positive.”* She fought with him and told him that she had always been faithful (despite what he had heard in prison). He admitted that he had many relationships whilst he was with her and said: *“I could never tell you now where I got this disease, but I know that I’m the one who infected her.”* Zakes felt guilty about this. He befriended her and she would come on the weekends to see their daughter. Although she wanted to resume the relationship, he would not because he was involved with someone else.

Zakes’ health declined and he was given Vitamin B complex and Bactrim but could feel he was not getting better and was *“standing at one place.”* His health deteriorated and eventually he was put onto ART and struggled for a while with its side-effects. He had to ask his sister to help him because he had not disclosed to his new girlfriend. He kept his medication in the main house and insisted on using condoms. He found it difficult to disclose to her because he thought she would leave him. He was worried that he might infect her too. His girlfriend discovered that he was positive because he had disclosed to others and they told her.

His ex-girlfriend also started ART, but she continued to drink a lot, did not take the medication properly, and eventually died. His family paid respects to her family by giving them some money. His current girlfriend fought with him because she felt that he should have used this money to pay lobola for her. When he went to his ex-girlfriend’s funeral, his current girlfriend packed her bags and left him, leaving a letter stating that she did not want to see him anymore. He thought she might be afraid that she would become infected, but she now had a boyfriend and was still *“okay.”*

His temporary work came to an end and so he fixed cars on an ad hoc basis, contributing about R2000 a month to the household income. He did not want to *“do crime”* and go back to prison. He needed money to buy healthy food that included *“Milk Stout because it is healthy [he laughs].”* He was well and happy that his daughter, who was ten years old, was HIV-negative. He was still single but had a girlfriend who knew his HIV status. He had become an advocate for HIV treatment, and was open about being HIV-positive.

For Zakes, his daughter had been the anchor in his life. He had been able to continue having relationships, but had not always been able to be open about his status with his girlfriends. He made an effort to keep fit and healthy and had given up drinking for the most part. Being HIV-positive and a father had changed the

way he was living. For many of the HIV-positive men keeping healthy has become all-important, to the extent of giving up other “risky” pursuits such as drinking and “doing crime.”

Thus, for some men HIV had negatively affected their family life and their ability to take on the responsibilities. Both Patrick and Zakes had made significant changes in their lifestyle; however, it had not been easy for either of them. As Patrick’s story revealed, he felt he was a burden on his family but also accepted the responsibilities of being a father.

11.4 Discussion

The literature review highlighted how notions of masculinity are associated with higher HIV prevalence (Simbayi et al., 2007; Hunter, 2010) can result in poor or delayed help-seeking behaviours (Banks, 2001; George & Fleming, 2004; Robertson, 2007). These views have been extended into the HIV/AIDS field with research findings drawing out how the epidemic has further impacted on masculinities.

While the life stories presented here support these trends, they equally complicate them. The trends were not linear and competing forces influenced the men to react in positive and negative ways. Relationships are important markers of masculinity, but establishing and retaining them are complicated by the epidemic. The HIV-positive men’s relationships were made more difficult by their positive status. Disclosure to their partner was tempered by their concerns of being rejected and blamed for bringing HIV/AIDS into the relationship. Although both parties may have had sexual relations outside of the relationship the men were generally named as the guilty party.

Men aspired to being a father and took on the responsibility of being a role model to siblings and children. In some cases the men had become the primary caregiver to their children and sometimes to their grandchildren as their wives had left them or had died. This is not a traditional role in a patriarchal society, but the men had adapted to this role and were proud to be in this position. These men took care of their health and wellbeing and did seek help at clinics. However, it also restricted their more masculine behaviours such as drinking with their friends.

Few men in this study were fully employed. The HIV/AIDS epidemic was not entirely to blame as there was a high level of unemployment in the Soweto, the study area. However, being HIV-positive and sometimes being ill made finding and retaining a job even more difficult for these men. The men were disempowered and were unable to be the breadwinner and provide for their families. They were forced to rely on partners and their families for support. This impinged on their masculinity.

In a patriarchal society, such as SA, the HIV/AIDS epidemic has complicated the notions of masculinity and traditional masculine behaviour. Men are forced to change their behaviour if they want to retain their social standing in their community. Some men have summoned up the courage to do this and have been able to seek help in the clinics and are well enough to engage with their families. However, not all men have been able to cease taking risks in a time of high HIV prevalence.

Chapter 12: Masculinity and health

Health and illness are closely related and reflect the disease itself, as well as individual and society's perceptions of it (Saltonstall, 1993; Gilbert & Walker, 2002). As revealed in this study and the literature, HIV-related stigmatisation remained an issue in South Africa (Walker et al., 2004; Gilbert & Walker, 2010). Goffman (1963) noted that physical difference from the norm could elicit stigmatisation. Changes in a person's physical appearance such as losing weight or looking ill may be interpreted as having HIV and lead to stigmatisation and discrimination.

12.1 Physical health

As described in the chapter on stigmatisation, being and looking healthy was important for the majority of the men who remarked that they did not want to look sick in case others would judge them. Being and looking healthy protected them from being stigmatised, but forced men to keep their illnesses secret.

The men expressed the desire to be healthy and to *"feel good at all times."* They achieved this by being fit, exercising, and *"liv[ing] a healthy lifestyle."* For Tshepo (pos, 30), a young HIV-positive man, being healthy increased longevity: *"[health] is important because life itself is important. If you care about your health, you will live longer."*

Many of the men mentioned that they wanted to be healthy and to live a long life, illustrated by Mdu's statement:

"Yes [health is] vital, it is part of life. If you are not fit enough you won't live a long and healthy life. A person has to keep fit and healthy and also eat healthily [to live a] long nice life and being active in sports and everything else." Mdu (neg, 18)

The men were health-conscious and *"wary about what I eat, I also eat lots of fruits"* and exercised to keep fit to avoid getting sick as Siphon (neg, 23) reflected, *"I don't want to find myself sick from all these diseases... these diseases such as flu, eish! All these diseases."*

The men actively engaged in sport including jogging, training, going to the gym, hip-hop dance, push-ups, dancing, weight lifting or body building, and basket ball. This confirmed other researchers' claims that exercise was important to men for their health and their physical appearance (Saltonstall, 1993; Robertson,

2006a). The younger men were even more interested in keeping fit through sport, as epitomised by Mdu (neg, 18), who swam, played rugby, soccer, basketball, water polo, and cricket. He proudly said he was “quite multi-talented” and a role model for his siblings.

Maintaining a good physical appearance through being healthy and fit contributed to being a role model for a small number of men (4/33) who wanted to be respected and admired. This was shown by being physically active and displaying toughness and strength, also described by Jewkes & Morrell (2010) as signs of masculinity. The younger men especially confirmed that they needed to be fit and healthy, as Noah (neg, 19), a basketball player and hip-hop dancer, explained: “everyone would want to look like you, they must see that you are living a better life.” And Phil (ntst, 18) commented: “if they see that I’m fit, healthy and happy they will also want to be like me, fit and healthy.” Thus displaying a good physical appearance was imperative for these men who wanted others to look up to them. However, it put pressure on them to maintain this physical prowess, which may be burdensome as described in the literature (Foreman, 1999) and elaborated on by Jabu who was expected to keep fit and healthy by his family and his partner.

“Yes I believe that, because it runs in the family. I have always been told that it is important to keep fit and strong from an early age. I think my grandfather is about 70 but he looks like someone in his 50’s. ...and my partner also wants to see me fit and healthy.” Jabu (ntst, 28)

In order to keep up the appearance of being healthy the men felt that it was important to hide illness or stress from others, as described by Albert:

“Like...like if they look up to me, they will see that if their lives can be similar to [mine]. It can be straight without ups and downs. [...] You don’t need to show them when you are sick. Even when you are stressed you don’t need to show them.” Albert (ntst, 21)

Being able to be an example to others gave these men social standing in the community and amongst their peers.

For some men, keeping fit allowed them to be in control of maintaining their health. Dancing kept Clement fit, and provided him with a small income when he performed. He was proud of being a dancer and said:

“[Dancing] is keeping fit. Most of the things one should do when dancing includes a lot of jumps and back flops ... Yeah, you need balance, you need the muscles to keep you seriously disciplined to the act.” Clement (ntst, 18)

For others exercise counterbalanced less healthy activities such as smoking or drinking, which they acknowledged were not always beneficial.

“I usually go jogging but I haven’t done that this week [...] Not necessarily to be fit it’s just that I’m a smoker. I just want to exercise to keep my body well and also to refresh my mind.”
Lucky (ntst, 20)

For Phil, being able to play sport was a measure of his health status and by being “*fit, healthy and happy*” his peers would aspire to be like him.

“Yes, because if I’m not fit and healthy I can’t play sport. I won’t be able to know my body. [...] I mean for example if I run now to exercise I’ll be tired and my chest will feel heavy. If that happens and I don’t know my health status it will be difficult to determine whether it’s because of my training and running, or if I would be sick from something else.” Phil (ntst, 18)

Being and appearing healthy was important for these young men. It gave them status amongst their peers and played an important role in defining their masculinity. Being physically healthy was an indication that they were looking after their bodies and reflected that they were not HIV-positive to the outside world. They did not want to be stigmatised or discriminated against in any way.

Physical health was as important for the eleven HIV-positive men. Being healthy, thinking positively, and having a positive attitude were key to allowing them to deal with their condition effectively. As Jackson reflected:

“Yes it is important to be healthy. If you are not healthy, things might get tough for you and you might find that it is difficult for you to do anything on your own, as your body will be getting tired easily.” Jackson (pos, 34)

Many HIV-positive men (4/11) stated that they had changed their habits because of their illness, such as cutting down smoking and drinking alcohol. They were concerned about their diet and those on ART said that they needed to eat well so that they could continue to take their medication. This proved to be difficult for the men who were unemployed and did not have access to money. This negatively affected their health as substantiated by Harding et al. (1990), Read & Gorman (2006) and Zakes who struggled to make ends meet:

“I cannot take in the treatment without eating properly. I must make plans to generate money and not do crime because I will go back to prison. So I have ways of making money so that I can buy healthy food. [...] I do road works. In the afternoon I do exercises and drink my Milk Stout (he laughs) [...] Yes I love it because it’s healthy (he laughs) [So did the doctor tell you that the beer was healthy?] No (he laughs out loud) I did not tell him anything. It’s not an

everyday thing. I only drink about two bottles when we have parties or family gatherings.”
Zakes (pos, 38)

Zakes had changed his habits and engaged in a healthy lifestyle but enjoyed drinking when in company. This reflected the desire of HIV-positive men to be like their peers and to avoid stigmatisation. Physical appearance and health were important visual signs that one was not weak, ill, or HIV-positive, which may undermine their masculinity.

It was evident from the above discussion that, for the most part, men's physical appearance was important to them in order to keep their social standing in the community and amongst their peers. Having explored what men thought about their own health and how others viewed them, it was important to investigate what they felt about other people's health to understand if they would discriminate against others who may be ill. The men had mixed feelings regarding other people's health. For some it was not important at all, although Mdu (neg, 18) said that he would listen to another person if they had a problem and would keep the discussion confidential. Whereas Musi (ntst, 20) would like to help, saying: *“Yes it's important. If you know about their health status then I can see quite easily whenever they're not feeling well and I might be able to help.”*

Being healthy was important for the majority of the men, and most of the men proactively engaged in a healthy lifestyle. They had mixed feelings about other people's health.

12.2 Illness is weakness

The majority of the men wanted to be visibly fit and healthy and were concerned that if they were observed to be ill it may be speculated that they were HIV-positive and then isolated. Men were reluctant to admit being ill as they considered it a sign of weakness and possibly of failing to live up to their masculine ideals. The men did not want to appear weak to their peers. HIV stigmatisation and maintaining their social standing in the community were important factors ensuring that men maintained their health.

The findings in the literature point to men being stoical and not admitting that they are ill. The men confirmed this and aside from the HIV-positive men, denied that they had any health issues, saying they did not get sick easily. This sentiment was verbalised by Andrew (neg, 24), a confident, healthy 24-year-old, who, stated *“there is no concern about my health. I am super”*, although he was worried about being infected with HIV.

However when probed, a few health issues emerged. The men considered hygiene to be important including brushing teeth, bathing, and washing hands. Health issues that they had experienced included kidney failure and eye problems, stomach ache or flu, sinusitis, and a long-term hearing problem. Sexual health and sexually transmitted infections were problems for two of the men, one remarked “*I was caught by drop [an STI] disease*” (Kabelo (ntst, 33)).

The literature highlights that men equated illness with weakness, and this undermined their hegemonic position. It also found that men delayed seeking help when they were ill because they didn’t want to be perceived as weak (Foreman, 1999). The secondary informants further noted that men were reluctant to discuss their health with their families, as also described by (Robertson, 2007). Men were concerned that if they were seen as weak it could lead to the “*collapse of the family.*”

Many men subscribed to a patriarchal culture and believed that they were more powerful than women (Barker & Ricardo, 2005) which influenced their help-seeking behaviour. This attribute was observed by the secondary informants and articulated by one THP working in Soweto, who said:

“It is the way men are raised in the villages and all over. Men have been raised in the way that they are regarded as more powerful than women. They are heads of families. When they are sick the family will collapse. They do not want their weaknesses to be recognised by women.”
THP10

In order not to have this status undermined, men did not acknowledge their “weaknesses” as described by Seidler (2006: xviii) “...they can feel angry at their bodies that have somehow let them down.” This observation was validated by Kabelo (ntst, 33) who said that being ill “... *shows that there is something lacking in your body [...] You may also find it that there is a certain virus which consumes you and that you are not aware of.*”

The men were concerned that they would be judged by others if they were ill. As Emanuel elaborated:

“Yes it’s obvious. To be healthy is the most important thing in life. As a human being you must always be healthy. If you are not healthy you will be attacked by the stupid sickness. [...] Yes I think it is important, so that they [other people] must not judge me that I have got AIDS or maybe I’ve got some sickness like TB or AIDS.” Emanuel (neg, 19)

Furthermore, the men believed that being ill, and weak, would allow other people to take advantage of them as Eugene explained:

“Yes it is, because if I’m weak people will take advantage of [me] so I must always be on top of my game. If you are weak and sick there’s certain things you won’t be able to do on your own so people will treat you bad[ly].” Eugene (ntst, 19)

Being ill diminished these men’s positions of power and may allow others to exploit them, whereas being healthy allowed the men to get on with their lives and be free to do whatever they wanted to do.

Men therefore kept their health issues secret. This was endorsed by the secondary informants who observed that men found it difficult to communicate to others about their own health, HIV, or any health issue saying “...they shut their doors before anything” (CNS1). They remarked that men were selective about whom they discuss their personal concerns and were secretive about their sexual health problems. A female THP (THP3) provided an example: men consulted her about their sexual health said “*I have no erection, can you see what is the problem?... he will come alone, he does not even want his wife to know.*” On the matter of HIV she remarked “*Men don’t like to disclose it’s only a few of them who disclose [their HIV status].*”

12.3 Seeking help

Help-seeking behaviour was determined by internal and external factors and in this study it was explored in the context of seeking help for HIV. Men’s help-seeking practices in the public health and the traditional sectors were the major focus. As described earlier, these Soweto men rarely consulted THPs for medical or HIV-related illnesses — instead they said they would go to clinics if they felt they needed help. Furthermore, men were reluctant to admit that they were ill because they did not want to be seen as weak. This delayed them seeking help and made them hesitant to go to clinics for help, as also described by Robertson (2006b) and (Robertson, 2007).

Many of the men had a complex understanding of illness and, depending on its origin or severity, would seek help from different sources, which may not be mutually exclusive. Help-seeking was not necessarily confined to only accessing one form of help and could be a combination of a number of different elements, each providing help for a different aspect of the problem — also known as medical pluralism. The men frequently consulted a number of different health practitioners to seek help for their condition; this was exemplified in David’s story.

David: seeking help from multiple sources

David (pos, 30) was 30 years old, HIV-positive, unmarried, and lived with his girlfriend in a shack (informal house). She had two children who lived elsewhere with their grandmother. David and his girlfriend were unemployed although he tried to get temporary jobs. He sometimes asked his mother for money so he could pay his rent. He believed he needed to take care of himself because as his condition progressed he said: *“I won’t look good. My appearance will change and some people will start to reject me and not want to be associated with me anymore.”* He talked to his mother about his health: *“she is the first person I talk to if I have got a problem”* and then he visited the clinic because he could not afford private doctors. He would have preferred to consult with a private doctor because he had witnessed that they provided better treatment and said:

“You get better treatment because you are paying for the services. Unlike at a public hospital where they don’t care about how they treat you because everything is for free [...] my mother, she once had a terrible flu and went to the hospital and she received medication. But she still had the flu for another week. But as soon as she took her pension money and paid R150 at a private doctor she received an injection and got better within two days.” David (pos, 30)

Although David’s mother may have been on the mend by the time she consulted the private doctor, his perception was that this doctor cured her. This sentiment confirmed observations from other studies (Hassim et al., 2007) that private doctors were thought to provide better service, even if it was not necessarily the case.

David also visited traditional healers when he needed to *“check on my life in general.”* He did not believe that they could assist with HIV because they could not help his partner. He described what happened:

“My partner is the one who went to them in 2006 when she found out about her status and they gave her muthi to drink. She was taking the muthi before she was advised that she can go to the clinic and get ARVs. She was thin and dying and we took her to the clinic and they referred her to Baragwanath hospital. They put her on treatment and then after a few days she was sent home. She recovered and started to go to work. She was not getting better when she was drinking the muthi from the traditional healers.” David (30, pos)

David was worried that as his illness progressed his friends would reject him. He sought help from his mother, public health clinics and THPs. He was expecting to go on ART when he needed to and understood that although it was not a cure it allowed one to *“live longer.”* He believed that in order for his health to improve while on treatment he needed to take care of himself, but he said many people did not: *“some drink*

alcohol and they don't eat healthy food. Every time they go back for check-ups their health is not improving. The treatment is not working because they are not taking care of themselves." David recognised that his lifestyle needed to change in order for him to stay healthy.

David's story summarised many people's approach to dealing with health issues. He consulted multiple practitioners and selected what worked for him from each one.

The main interest in this study was men's approach to help-seeking. All the men were asked when and why they last visited a health care facility. The HIV-positive men visited clinics frequently because of their condition; however, the others were more representative of men in general, and this section explored the views of the latter group.

As expected, the men who were not HIV-positive said they seldom visited clinics. Only one man, Thulani (neg, 22), was a regular visitor to the clinic because he was part of a basketball team and they required monthly blood tests.

Some of the men visited the clinics so seldom that they could not remember the last time they had been there. One man stated "*It's been a while... maybe two or three years ago*" (Eugene (ntst, 19)). They said that they did not get sick or sick enough to warrant going to a clinic: "*most of my time I never get sick up to the point of visiting the clinic*" (Kabelo (ntst, 33)). The overriding sentiment was that they would only consider visiting a clinic if they were "*seriously ill*" or they had no choice, as Clement (ntst, 18) explained: "*So I guess I only go to the clinic when the situation or rather the condition gets serious [...] Yes if it is serious and is out of control then I would go.*" The men were reluctant clinic visitors and only go as a last resort.

Although the men said they would only visit a clinic for a serious illness, many (10/22) had been there for relatively minor complaints, including a lump, flu, for an "injection or something", an allergy, a check-up or for condoms and information. A few of the more serious complaints included having a tooth removed, asthma and a broken arm.

Generally the men avoided visiting clinics, but occasionally they had no choice. This was no different for Brian (ntst, 26), who recounted how he ended up at one: *“About three years back [...] I had fallen. What happened is we were running away from the police and I [tried] to jump over a gate and I fell and hurt myself. [...] I went to a [clinic] doctor and he told me I broke my ribs and I went for an x-ray and got treatment until I got better.”* Brian’s visit to the clinic was the result of risk-taking behaviour.

For minor illnesses the men adopted a multi-faceted approach to seeking help. Some tried home remedies first: *“when I have a headache I’ll take headache pills from the house”* (Abel (neg, 27)). However, if self-medicating was not effective they would then seek help elsewhere. Lucky (ntst, 20) described a time when he had influenza. He first tried some medication that his mother bought for him but it did not work *“so I decided to go to the clinic and check whether what was wrong with me was really flu or something else.”* Lucky only visited the clinic to be reassured that he was not seriously ill.

For some of the men illness was not a simple matter and could be caused by a variety of factors. Depending on the cause, type, and severity of the illness they adopted different approaches to seeking help. An example was provided by Martin (neg, 25) who did not *“really consult with anyone”* when he was sick, particularly for minor illnesses. When he was unwell he sometimes *“sleep(s) my condition better”* or he used traditional medicines such as *“... indigenous herbs to puke [vomit] and also clean my system using indigenous laxatives”*, which were endorsed by the church he belongs to. The adoption by the church of some traditional or cultural practices was also described by Reid (2013). Martin consulted his church and THPs for spiritual but not for medical problems. He consulted clinics for *“more complicated medical cases”* or if the illness did not resolve itself. He summarised his help-seeking behaviour:

“I personally believe that one should not seek help for minor medical cases as you stand a better chance of healing on your own. I guess you could later consult [clinics] when the condition worsened. The other thing is that I don’t just do medical pills and Western or modern medicine. It is something that when I matured I just didn’t go along with.” Martin (neg, 25)

Martin kept his options open by trying different methods to help him but he would go to a clinic if nothing else worked.

Jabu had adopted a different approach to illness. He believed that fitness was very important and trained a lot. When he got sick he tried home remedies and exercises. He explained:

“I just believe that if the sickness is not that serious I don’t see a point of going to the clinic. I would rather exercise or do the things that I normally do because I believe that I got sick in training. I rather go back and take out that sickness at the gym.” Jabu (ntst, 28)

For more serious illnesses he would go to a clinic, although he had bad experiences there. He was unable to afford private clinics, his preferred choice, due to his *“financial situation.”*

12.4 Discussion

The data presented in this chapter highlights the complex interaction between masculinities and help-seeking. While in some cases, the perception that illness equals weakness kept people away from clinics, in other cases, illness drove them to seek help. These strategies form part of an ever-changing range of strategies adopted to try and address illness.

There is not a linear relationship between illness and men’s help-seeking behaviour. The men adopted individual strategies that suited their lifestyle. The majority denied that they were required help because they did not get ill. Whether this was true or whether HIV-stigmatisation and the notions of hegemonic masculinity that promoted illness as weakness aggravated it, men frequently delayed seeking help until they were very ill.

The men are keenly interested in their health and keep fit to avoid getting sick and speculation that they may be ill. Men are reluctant to admit that they have health problems but they do have them and from time to time. The men adopted different strategies depending on the type of illness. When one strategy proves unsatisfactory they move on to something else.

Chapter 13: Seeking help in the traditional sector

According to the literature, THPs played a central role in help-seeking behaviour for many South Africans (Sidley, 2004; Shisana et al., 2005; Geffen, 2010). Muller & Steyn (1999) commented that THPs performed a complementary service and were frequently consulted at the same time as other practitioners. Beliefs about, and understandings of illness and HIV influenced help-seeking behaviour and whether THPs or Western medical practitioners were consulted.

In this chapter the views of the THPs are explored regarding HIV and illness, and the perceptions of the clinic secondary informants about men's engagement with THPs and the voices of the men are examined.

13.1 Traditional health practitioners' views on treating illness and HIV

Two THPs, one male (THP10) and one female (THP3), were asked about the illnesses they treated, who consulted them, their experience with HIV-positive patients, and the epidemic in general.

The THPs explained that they were able to assist with a variety of illnesses: *"I am talented in many ways to cure different diseases"* (THP10). A female THP described how she diagnoses illnesses including HIV:

"We can easily identify a person who is really sick. Even with our bones we are able to see that this person is sick and what disease that person has. Let me say maybe this person is not that sick. That you can see without knowing his or her status. But when throwing the bones you can see." THP3

THP3 suggested that she could diagnose HIV/AIDS in her patients even before they were symptomatic. THP10 recognised HIV/AIDS symptoms which included *"weak(ness)"*, *"constant headache"* and *"non stopping diarrhoea."* Both THPs mentioned that men were reluctant to disclose that they were HIV-positive *"...even if they have just tested."*

The two THPs understood HIV/AIDS and stated that they could not cure it. Both had attended workshops and training on HIV/AIDS: *"if you don't have knowledge about the disease you will kill people."* They acknowledged that traditional medicine was limited to assist with HIV/AIDS, but felt confident that they were able to help HIV-positive people. They treated their patients holistically and besides assisting with HIV/AIDS, they were able to add value by dealing with other issues at the same time, *"not everyone comes*

with the issue of HIV alone.” When patients leave they must go out with their *“heart being at ease.”* These THPs were aware that they could only play a limited role in HIV/AIDS care and treatment.

13.2 Men prefer consulting traditional health practitioners

The secondary informants (7/10) speculated that the absence of men in clinics could be due to them seeking help from THPs. A few suggested that men are more likely to consult THPs because it was customary for them to do so. In addition they commented that men believed that HIV was related to witchcraft as one manager described:

“They [men] were born and raised using traditional medicine. You see men think that when they get sick from HIV, they are bewitched. They think somebody is spelling evil magic on them. For them the only way to fight witchcraft is through consulting traditional healers, not the professional doctor or nurse.” MGR5

As described earlier, men were concerned about people knowing that they were ill or speculating that they had HIV/AIDS and being stigmatised. A few secondary informants made suggestions about why men preferred to seek help from THPs rather than from clinics. Reasons to stay away from clinics included that clinics were associated with illness and HIV/AIDS and a visit there may suggest that one was HIV-positive; and so men go to them as a last resort. In addition, clinics were busy and crowded, people had to wait in queues for a long time before they received attention, and there was a dominance of women *“so that makes them [men] not to feel free. I think if they were not outnumbered [by women] they would come to the clinic”* (CORD4).

THPs, on the other hand were not associated with HIV/AIDS and were consulted for a variety of reasons, so there was less chance of being stigmatised. According to the clinic staff, THPs provided a more conducive atmosphere for men as they offered a *“one-on-one”* service, men did not have to *“spend hours”* waiting to consult, and they could retain their privacy: *“You are always alone. No one will know what the reason for you to be there is. In clinics you have to queue”* (CORD8).

One doctor (DOC9) observed that men avoided going onto ART and rather sought help from THPs. In his experience, *“Men usually come when they are very sick and they don’t have a choice.”* But even at that stage they were reluctant to start on ART as they did not understand how ARVs worked and *“they don’t believe in ARVs as a source that will be prolonging their lives [...] [men] prefer to use traditional methods and some*

of them die while they use traditional methods. So we have noticed something, that even if they come to the clinic they would not access treatment because they end up finding other options.”

A counsellor (CNS7) working at an HIV testing site remarked that they referred men to clinics for ART if their CD4 count was low, but noted *“most of them do not go for ARVs. They go to traditional healers for traditional medicine and this shows that they prefer traditional medicine.”* Another counsellor (CNS1) agreed that men accessed other treatment options because they were not specific to HIV, unlike ART. For example, *“Imbiza. It’s a two litre. It is not labelled, or maybe it can be labelled that it cleans your stomach ... nobody will know that you are positive. Most of the times [men] like to say I am bewitched so that [they] won’t be stigmatised about [their] status”* (CNS1).

THP3 agreed that HIV-related stigmatisation fuelled men’s reluctance to go to clinics because they *“think they will come across people they know”* and *“men don’t like it when their status is being known.”* One THP (THP10) confirmed that men consulted him because *“They [men] like to use traditional herbs and get better. So they say ‘what’s the need for me to go to the clinic while I am feeling better?’”*

However, THP3 observed *“In the case of those who are [HIV] positive we see women most[ly], as men they are scared to be [seen] with us.”* According to these THPs there was reluctance in men to consult them about HIV/AIDS. THP3 mentioned that her patients came from afar to consult with her so they could remain anonymous:

“You will find people coming from another community but the ones who live in your community won’t [come]. It will be just a few of them. But the majority [are] from outside. People don’t want to be known. Even if when your neighbour has problems not concerning HIV, that person won’t come.” THP3

The secondary informants agreed that men consulted THPs because they were not associated with HIV/AIDS. However, men were reluctant to consult THPs or go to clinics if they could be identified by others as being ill. For men, visiting a clinic or a hospital was a sign of weakness, so men preferred to hide their illness and *“consult secretly with the traditional healer or they better die in their house.”*

THP10 suggested that men preferred to be treated by men: *“Men will never want to be helped by a woman, unless when they are seriously sick”* and consulting any female health practitioner was very difficult, since

“They do not see themselves undressing to be checked by a woman, they are not seeing it happening in their life.” A female THP (THP3) remarked that she treated more women than men and thought this was because *“men are scared to be with us”* and *“men don’t like to disclose.”* She also suggested that men were concerned that female THPs may break confidentiality: *“maybe they think [with] us women their secret will not be safe.”*

Although it was considered more likely that men would consult THPs it was noted that, as with other health workers, men preferred being treated by a male practitioner. In both the traditional sector and in public health clinics there was a scarcity of male practitioners.

13.3 THP interaction with clinics and vice versa

Both Western and traditional health workers suggested that working more closely together could be beneficial. THPs could then refer clients to the clinics and vice versa. One counsellor (CNS7) noted *“most men still prefer to go to traditional healers”*, which was why they should work together *“hand in hand.”* One of the THPs (THP10) believed *“that’s the only way to make men go to the clinic.”* However, the relationship between the clinics and THPs was fraught. He mentioned that he had been lobbying government to build hospitals for THPs so that they could refer their HIV-positive clients there. He was concerned that allopathic health workers did not respect THPs and said *“These doctors must not say our herbs are unhygienic. That’s like disrespecting us, because [the doctors] are African people and they were using [herbs] when they were growing up, then when they are qualified as doctors and nurses they disrespect us”* (THP10).

Although these THPs referred clients to clinics they complained that there was seldom a reciprocal relationship: *“we as traditional healers we do refer people to the clinic, but clinics do not refer people to us”* (THP3). This was confirmed by a doctor (DOC9) who discouraged his clients from visiting THPs because although he thought that traditional medicine could boost the immune system the *“disease cannot be cured.”* The traditional sector did not have an equivalent treatment to that of ARVs which could *“prolong their lives.”*

The THPs recognised the antipathy that clinic staff had towards traditional medicine and one told his clients *“they must not mention that they have been using traditional herbs”* (THP10). The THP’s clients liked

traditional medicine and often used it in combination with what they were given at the clinic. He noted that his clients did well taking both.

The two THPs used hospitals or clinics to support them in their HIV-positive clients' treatment. They were not able to test for HIV, so they referred their clients for “*check-ups*” at clinics knowing that this resulted in an HIV test being done. THP3 also sent her clients to clinics to get their CD4 count checked so that she could assess how sick the person was, and whether or not her treatment was working.

THP10 said that his male clients “*don't like to accept the truth. They are always in denial*” about HIV, and so the referral had to be done carefully and it frequently involved subterfuge.

“I ask them if they have gone to the hospital and got checked [to determine] what is killing them. Then I tell them that they are weak and if they are going to use traditional herbs they will make them weaker. So they need to go to the hospital first to get medication to boost their immune system, knowing that when they get to hospital they will get tested.” (THP10)

These THPs used the clinics to gain an understanding of how advanced their patients' HIV illness was. They were able to avoid giving their patients the bad news about being HIV-positive, and used the results from the clinic to benefit their patients.

13.4 Men's views of traditional medicine

In this study around half of the male participants (15/33) indicated that they had consulted THPs at some stage during their lives, but most did not currently do so. This was less than the 72-80% that were reported using traditional practitioners in other studies (Sidley, 2004; Geffen, 2010) that report general population uptake. Around one third of the men said that they did not believe in traditional medicine at all. Soweto was an urban township community and many of the men were fairly young and help-seeking practices may be different for older or rural populations. There may be stigmatisation associated with traditional medicine biasing their responses.

For medical problems, the majority of the men indicated that they preferred to seek help at a clinic or hospital where they were confident that they would receive the help they needed. In addition, as described in previous chapters, the men did not attribute HIV/AIDS to witchcraft, and therefore were unlikely to consult

the traditional sector for HIV-related matters. However the secondary informants, as well as the thriving trade made by THPs, suggested otherwise.

A number of the younger men did not believe that THPs could help them with any problem. Mdu (neg, 18) never consulted THPs and suggested that doctors were better qualified and more knowledgeable than THPs. Clement (ntst, 18) consulted doctors as he had not been brought up in a “*traditional background*” and had never needed to use traditional medicines. He did not think that they would work for him, although he acknowledged, “*people say that it works for them.*” Similarly, Lucky (ntst, 20) preferred to go to clinics and said he had “*never experienced any problems that has made me want to go and consult at a traditional healer*”, even though some of his family members did. Noah (neg, 19) was uncomfortable with the idea of consulting THPs. “*Just like people who are praying eish...[paused]... I am an emotional person so...when it comes to those things it's like praying, things like that I am not feeling comfortable.*” Musi (ntst, 20) belonged to the Zionist church that does not allow the congregation to consult THPs. He consulted with his pastor to pray for him and give him herbs or went to the clinic, depending on the type of illness: “*I go to the clinic if I have flu and if I have a headache I go to church*”

Patrick and Zakes consulted THPs to provide them with protection when they were involved in criminal activities, both landed up in prison. When Patrick (pos, 36) needed protection he consulted a “*powerful*” THP for muthi that would save him from “*dangerous moments*” and allow him “*to escape well whilst we were hijacking and doing other criminal related activities.*” He did not believe that God would have been able to help him then, but since he has been ill he has become closer to God and prayed for help. He went to the clinic for HIV treatment and did not believe that THPs could help him saying: “*the disease is Western and it needs a Western approach and assistance*” and “*traditional doctors cannot possibly have a way of dealing with it.*” He commented that some THPs claimed that they could cure HIV with “*makoropa*”, but that people taking this “*cure*” had not improved, rather they “*became worse and worse*” and it “*finished [killed]*” them. Zakes (pos, 38) also consulted traditional healers for protection, but “*as soon as I was arrested I realised that I've been paying this traditional doctor such a lot of money but the muthi did not work.*” During his stay in prison he started to believe in God, and was now on ART. He also did not believe that THPs could help people who were HIV-positive.

A few of the men explained that they did not believe that THPs were able to help with any medical problem including HIV/AIDS. Albert visited clinics when he was sick, he did not believe either prayer or THPs could help as he described:

“Even the traditional healers, we can say he will make you vomit the virus... and tomorrow when you go to the clinic to test obviously you will be positive, it won't disappear just by night, because this (is) a virus, it can't be curable now because we haven't got a cure as yet, and I am not sure if we will even get it.” Albert (ntst, 21)

Abel (neg, 27) had heard of a THP who claimed he could cure AIDS, but he did not believe this. When he or his family were ill they went to a hospital because they did not believe that THPs could help with any illness including HIV/AIDS. As he said: *“the sangoma does not tell the truth, they will say ... your neighbour is bewitching you and in fact nothing of that is true.”* Enoch (ntst, --) commented: *“These healers they will say that someone is bewitching you, and not try to solve the problem.”*

A couple of men felt that they needed to choose between believing in traditional medicine or Christianity (God). Brian (ntst, 26) and his family were church-goers and they discouraged him from visiting THPs, *“My family used to tell me that sangomas are no good, that if ever I have a problem I should just pray to God, then maybe after two to three days things become better.”* Tshepo (pos, 30) believed in God and not in THPs, because *“I believe in God and that he has got a purpose. He wouldn't have made the hospitals if he wanted people to drink herbals from the traditional healers.”* He consulted a doctor when he was sick: *“I believe that the tablets that he is going to give, or the medicines, will do its job for you.”*

A minority of the men explained that their help-seeking behaviour depended on the problem they were experiencing and that they may consult both traditional and Western practitioners. A couple of men described how they first tried traditional medicine or home remedies and if that did not work then they would seek help from a clinic. Kabelo (ntst, 33) first consulted a THP, but if his condition did not improve then he consulted a doctor: *“If this gives them [THPs] a problem then that's where you can go to the doctors not to the clinic.”* Similarly, Martin (neg, 25) preferred *“healing on your own”*, and went to clinics if it was a medical problem that did not heal by itself. He consulted THPs for *“issues of life”* and to be *“guided spiritually”*, when his life was *“not in the order it requires, or things in my life aren't well.”* Although he

used traditional medicine he had not consulted THPs for medical problems, but he was not averse to doing so.

A few men consulted THPs for spiritual issues and Western medicine for illnesses. Mark (neg, 19) consulted THPs regularly with his mother to “*cleanse*” his system, but when he was sick he preferred Western medicine. He explained: “*traditional healers will just give you Imbiza [traditional medicine] and he’ll tell you to steam yourself and that’s it. At the clinic they will give you the necessary medication which will make you feel better.*”

Eugene’s (ntst, 19) family consulted THPs for a variety of matters. He went with his mother to a THP who told him about his “*future*” like a “*fortune teller.*” He was given “*muthi to wash away all the bad luck so that you’ll have a bright future.*” His father had been ill for a while and had not been helped in the hospital: “*when he goes to the hospital they can’t see what is wrong with him but he cries every day about this pain he is feeling.*” He then consulted a THP and he felt “*much better.*” Eugene believed that “*there are diseases that a normal doctor can’t cure, and traditional healers have got their own ways of healing people.*” He said he would consult a THP if a doctor could not help.

Thulani (neg, 22) kept his options open; he believed in God, and consulted THPs or went to clinics depending on his malady. He consulted traditional healers if he had bad dreams or “*nightmares*” because they may be a “*sign of trouble.*” For “*headaches*” or “*injuries*” he went to the clinic: “*if I feel that I am sick, the first thing I do I go to the clinic and I’ve never get the wrong answer since I go to the clinic.*”

Emanuel (neg, 19) hardly ever gets sick, but when he did he preferred clinics: “*because they know what they are doing because they are the professionals and they are obviously educated.*” He considered many witchdoctors to be “*fakes*” that were out to “*make some money*” and were not concerned about their clients’ health: “*some can even give you the wrong medication and you end up getting sick worse.*” He consulted a trusted qualified THP who was a family member and gave him advice on “*issues of life, like not having to use alcohol and drugs.*”

Some of the HIV-positive men had engaged with traditional medicine and Bongani (pos, 35) was using it to assist with his HIV treatment. He was not on ART and used traditional medicine, but noted that some may

not be good for him and provided an example: *“the traditional healer gives you very strong medication to drink and you end up having diarrhoea which will be very bad for you. I have tried some of the muthi and it did not work for me. [...] I sometimes take in the muthi but as soon as I feel that I’m not well I stop taking it and go to see the doctor for other medication.”*

Thabo (pos, 52) was HIV-positive and on ART. He did not use traditional medicine for HIV, but was grateful for the help he had received from a THP who had assisted him after he had a stroke. He was given medication and consulted him three times. The treatment cost him R80, which he only paid for once he had completed it. *“He was always saying to me don’t hurry, things will soon turn to be alright, and of course it’s true because I can now be able to walk and do everything by myself. [...] I went there to pay and thank him for the big job that he did to me. I told myself that you know what God is there and he is alive.”*

Other HIV-positive men did not believe that THPs could assist with HIV/AIDS and preferred allopathic medicine and ART. Xolani (pos, 41) explained: *“Some traditional healers give you herbs which are very strong and they make you sicker and you end up dying much quicker. But with Western treatment you live a bit longer because they give you the right dosage.”* Tebogo (pos, 27) suggested that THPs were *“not 100% guaranteed because you can get anything from the healers and not know what they are doing in your body. Some healers just want money and they don’t help at all.”*

Amos had never consulted a THP but observed that people who had consulted THPs for HIV had not been helped. He explained:

“Since I was born I have never been to the traditional healers. I won’t even go there just because today I am HIV-positive. I have got an experience. Many people died because they believe[d] [in] witchcraft. [...] [HIV] is a virus. This is what consumes you. No witch doctor could heal it.” Amos (pos, 36)

Contrary to the secondary informants’ belief that men consulted THPs for HIV/AIDS, the majority of men did not consult them for medical problems. Some men consulted THPs for *“issues of life”* or for *“protection”*, but would go to clinics or doctors if they were ill. Only a couple of men visited THPs as a first port of call. This finding was similar to that of Venkatesh et al. (2011) who found only 4% of men in Soweto consulted traditional healers for medical problems. The men did not believe that THPs could assist with HIV/AIDS since they did not subscribe to the belief that the illness was caused by witchcraft. As described

above, traditional healers were able to help with some illnesses and spiritual problems. However, the majority of men were sceptical as to the THPs efficacy in helping with HIV. The absence of men at HIV-services was not explained by their consulting THPs for HIV-related illnesses.

13.5 Money-makers and charlatans

In the men's accounts earlier they alluded to the concern that some THPs were charlatans, did not tell the truth, and were only out to make money. A few other men also held strong negative views about THPs. Matthew's father, who had died from HIV/AIDS, was treated with vitamins and given traditional medicine by his relatives *"because they believe in traditional healers and ancestors"* (Matthew (neg, 20)). But Matthew did not hold the same beliefs explaining: *"That person is dead, I mean really dead, he cannot talk to you, he cannot hear you. That person is dead."* Although Matthew had consulted THPs when he was younger, he was sceptical of them, *"Those guys, I don't believe in them, most definitely I don't believe in them"* and he would not consult them now. He said that they were unable to diagnose the problem, rather *"you always have to tell them what is wrong with you and they give you medicine."* He believed that *"traditional healers make money out of nothing, they tell you lies, they'll tell you to slaughter a cow for your dead relatives and go put the meat on the tombstone, all those kind of things. It's not fair for other people."* Nhlanhla (ntst, 18) held similar views, saying: *"I think they are just making money out of people. They claim to know and they know nothing."*

Jackson (pos, 34) did not believe that being HIV-positive was caused by witchcraft. He did not consult THPs and was concerned about the abilities of many of the THPs who were practicing today. He believed that there was a *"very big gap"* between them and the prophets and traditional healers of the past who recognised if you needed help: *"Before you can even approach him, just at a point that he will stop you and say take off your shoes then he will call his wife to give the water to drink after drinking the water you are going to feel the changes in your body."* He was now *"just in-between"*, believing that some THPs were *"still doing the right job and they can help you"* but others just wanted to make *"quick money."* He wondered if today people were *"ignorant"* or perhaps were *"throwing away our culture."* He noted that *"we as blacks, we are given different ways of dealing with the medical problems we are faced with"* and people reacted differently to treatment. He commented that many people *"seem to be coping well with [treatment] from the traditional healers"*, adding, *"I think for me it is just an issue of resorting to what helps me at the time."*

One THP disagreed with this sentiment: *“we want to help and we are not after money [...] when people are sick we are not affected, we just put it aside. The only thing we want to see is the person recovering, because you can't take a sick person's money”* (THP3). Cost was not raised in discussions with the second THP.

13.6 Discussion

One widely held belief amongst researchers and health workers is that men who are HIV-positive prefer to seek help in the traditional health sector rather than the public health system (Muller & Steyn, 1999; Sidley, 2004; Shisana et al., 2005; Geffen, 2010). However, the data in this chapter complicates any such straightforward link. Instead this chapter demonstrates a difference between the perception of health professionals and the men themselves.

The health professionals suggested that the absence of men in the clinics was because men preferred to consult with THPs. The men however refuted this and most did not consult with THPs for medical matters. A few consulted for spiritual or issues of life.

It is clear that the partial use of traditional medicine does not provide an explanation for the absence of men in the clinics. The rest of the chapters explore men's help-seeking behaviour in the public sector.

Chapter 14: HIV testing

There is consensus in the literature that HIV testing is a key intervention to prevent the spread of HIV. Having an HIV test is the first step to admitting that one might be infected with HIV. Only once one's status is known can appropriate help be sought. In addition, HIV testing empowers people to take responsibility for their health, encourages behaviour change, and protects others from being infected (Mhlongo et al., 2013). However, there are numerous barriers which deter people, in particular men, from testing (Levack, 2005).

This chapter explores the stigmatisation surrounding HIV testing, what men know about testing, why they have or have not tested for HIV, what their motivation was for testing, what the barriers were to having a test, and how they felt about the test results. It also provides insight into men's approach to illness.

14.1 HIV testing, stigmatisation and confidentiality

In Soweto HIV tests were offered in most public health clinics as well as in standalone or mobile facilities usually run by NGOs. Health workers observed that the majority of people testing to know their status were women. They suggested that HIV stigmatisation was the main deterrent keeping men away from health services and played a major role in men's decision to test or not. Perceived stigmatisation elicited fear in men that their family, friends, and community may reject them if they were thought to be HIV-positive. As one VCT site coordinator explained:

"You find men are still afraid to go for testing. They are afraid that if they go there their neighbours will see them. They like to blame their partners that they are the ones who came with the disease. They are afraid if they are positive that they will lose their wives and people who are around them. They won't face HIV head on. They will find excuses like being bewitched. That shows that they are in denial." CORD4

A number of studies found that stigmatisation prevented men testing for HIV (Levack, 2005; Bassett et al., 2007; Young et al., 2010) and men in this study were similarly concerned. The men did not want others to know that they were sick or speculate that they may be HIV-positive. When asked where they would go to for an HIV test, they said they preferred to test in a clinic where they were not known. As Thulani explained:

"We are all human beings that's the first thing ... I prefer a far away clinic for ... my dignity. I don't want people to know about me. That's most important to me. I need to go to a far away clinic where I know that nobody knows me." Thulani (neg, 22)

Stigmatisation discouraged men from testing in their own community. Being tested at a clinic far away from their home where they were unknown reduced the chances of others finding out that they tested or their status. One THP noted, people “*rather go to the clinic of another community where that person is not known so that s/he will not be stigmatised*” (THP3). A VCT site coordinator observed: “*Once you move to another spot, then they will come. But the people who reside in that area they won’t come, because they are afraid to be seen going to the caravan for testing*” (CORD4).

Several men agreed that even being seen at an HIV test site was enough to raise suspicion in the community that one may be HIV-positive as also observed by Steinberg (2008). Therefore, some men made the effort to get tested away from where they lived in order to keep it secret from their friends, so they would not “*jump to conclusions.*” Although he found it amusing, Abel explained that even going to those lengths he met a friend who was also testing at the clinic:

“I realised that if I use my nearest clinic I know a lot of people. If I meet some of them at the clinic and they see me entering that room where you get tested they’ll diagnose me before even knowing my status (he laughs). Regardless of where you go you’ll still meet someone you know. [...] He [a friend] was there to make the same test as myself.” Abel (neg, 27)

Similarly, while Albert (ntst, 21) had not tested, if he was HIV-positive he would keep his status secret. He conceded that no matter where he tested, at some stage, it would have to be disclosed, “*whether or not I go far or closer, at the end of the day there would come a stage when I need to tell people about my status for support.*” Testing away from their homes allowed the men to keep their status secret and to be in control over when and to whom they disclosed their HIV status.

For others the location was not a concern as long as the services were professional, because the outcome would be the same. Eugene (ntst, 19) had not tested but was concerned that the services should be “*sterile*” and the health workers competent. They should not be “*careless and use a needle that is already used and maybe contaminate my blood.*”

Keeping the results secret was highlighted as important for the men, but they were not generally worried that the clinic staff would break confidentiality. They believed they were trained professionals: “*If it’s a clinic... I know that my information will be kept safe. So any clinic will suit me even if I’m not familiar with the staff*”

members” (Nhlanhla (ntst, 18)), and “they wouldn’t just breach that contract that they have with the patients” (Mdu (neg, 18)).

However, the men were worried that if they tested HIV-positive and this became known to their peers or to the community they may be “isolated” or “ill-treated” and it would affect their interactions with their peers.

Keeping their HIV status secret was important for Eugene as he explained:

“If, for example, here in the basket ball team my teammates know I’m HIV-positive and I can’t perform well when we are playing. They will start to laugh and say I can’t play because I’m HIV-positive. They will make fun of me. It will all be a joke to them. They don’t care about my feelings. So that is why it should remain confidential.” Eugene (ntst, 19)

These men were worried that they could lose social standing. Furthermore, others knowing that one was HIV-positive could affect how one felt about oneself and therefore confidentiality was crucial, as Thulani (neg, 22) succinctly noted: “... so that people don’t talk about you as that will affect you negatively. You may start losing your self-esteem and start losing weight. And ... feel isolated and rejected.”

A breach of confidentiality could have other consequences. Matthew was concerned that if he tested HIV-positive and it was publically known, then his future relationships may be put in jeopardy. He mulled over the problem:

“How can a person test me and then tell their friend? (he pauses) I mean it’s not okay. You might find that the person [a girl] likes me. She would like to go out with me and the person who tested me tells this girl that she should stay away from me because I’ve tested HIV-positive. She should stay away from me. So these kinds of things should remain private. They must be kept private no matter what happens. Otherwise I’ll sue those guys. I’ll sue them.” Matthew (neg, 20)

In general, the men felt that if it was known that they were HIV-positive then it would lower their social standing in the community and that their friends and colleagues would no longer treat them as an equal.

The fear that one’s HIV status would become public knowledge was a significant deterrent to HIV testing. Many of the men said they would take or took precautions to test without being seen by people they know. However, at an institutional level it was found that confidentiality could be inadvertently broken. For example, HIV-positive people were identified because they were counselled for a longer time (Steinberg, 2008). In the VCT services Tebogo (pos, 27) described a couple of situations where inadvertent disclosure could occur. Firstly, after one received results: “There is no confidentiality when you come out crying.

People can see that your results were positive.” Secondly, in many clinics VCT and HIV/AIDS services were separated from general clinic services, and merely by going to these services people were presumed to be HIV-positive. He described what could happen:

“Even when going to the VCT section they separate you. Before you even get there people know that you are here for VCT services. If you come out of the room and look a bit sad they already assume that your results were positive [...] They should make an exit door at the back so that people cannot see that you were from the VCT services so that there can be confidentiality between the counsellor and the patient.” Tebogo (pos, 27)

The situation that Tebogo described was difficult to avoid with the services being structured the way they were, but he felt that clinics should do more to protect the confidentiality of people who tested.

This was supported by Amos (pos, 36) who provided three additional reasons why men did not want to test. Firstly, men did not want to be seen standing in the same queue at a clinic with women. Secondly, they were afraid that they may be HIV-positive and they would die. And finally, men did not want to be told by their wives to test: *“He is going to start fighting with her [asking] ‘why should I go and test and what is the main reason for that?’”* He was concerned about health workers encouraging women to bring their partners to test, which could cause conflict in relationships.

14.2 HIV testing for prevention

Some researchers found that men did not embrace preventive care and only attended the services when they were ill (Courtenay, 2000; Levack, 2005). The participants echoed these findings, as one health care worker remarked: *“When they [men] feel fine they don’t go to the clinic”* (CORD8).

For maximum health benefits the earlier that HIV was detected the better the health outcomes. It was advised to test before one became symptomatic with HIV-related illnesses because it allowed for early treatment, and the reduction of complications, morbidity and mortality. In the case of HIV, the practice of men avoiding preventative care was problematic as it can take many years before HIV/AIDS-related symptoms appear. Thus men may be HIV-positive for a long time without knowing it, if they do not test regularly. Of more concern, as Thabo (pos, 52) pointed out, was men who did not know their status often assumed that they were negative because they were not ill. He encouraged people to test, telling them: *“... this thing [HIV] kills very quick[ly]. If you don’t want to get in trouble [then] you better test now and know your status before it is*

too late for any intervention or help from the doctors.” Thabo and other participants recognised the importance of testing early, but acknowledged that this was not a common practice for men.

In order to encourage men to test for HIV one traditional health practitioner (THP10) made innovative plans. When he suspected that male clients might be HIV-positive, because they presented with HIV/AIDS symptoms, he would not tell them directly or refer them for an HIV test. Rather he said: *“I just advise them to go see the doctor first and come back with all that the doctor has told them. If you tell them to go and test they will never go, and they will never come back to you”* (THP10). This THP did not want to be the bearer of bad news. He was concerned that his male patients would not believe that they were HIV-positive or continue under his care. He recognised that he was unable to treat HIV, but believed he could help his patients. By sending them to the clinics for further investigations he was taking a risk that they would not come back. Traditional medicine for the treatment of HIV was not highly regarded by many of the clinic health workers and they discouraged men from seeking help in the traditional sector.

14.3 HIV testing knowledge

All the men interviewed were familiar with HIV testing and many understood that the process included some education and counselling. The men, including those who had not tested, indicated that it was important to know their HIV status. They were supportive of HIV testing so *“people will get to know more about this virus and this sickness”* (Nhlanhla (ntst, 18)). They agreed that knowing one’s status was empowering and enabled one to take responsibility. Tebogo (pos, 27), who was HIV-positive, believed that people were *“lucky”* when they knew their status, as he said: *“People are generally ignorant in the way they behave and live their lives. All I can say is that when you know your status you’re lucky. What about those who have no clue what their status is?”* He echoed other men who thought it was important that they were in control of their health.

These men were fully aware of HIV testing, and agreed that it was beneficial to know one’s status. However, for many men this was not enough to encourage them to test.

14.4 Why men had not tested

This section focuses on the eleven men who had not tested for HIV. These men recognised the benefits of knowing their status, including being able to deal with health issues better and to protect their loved ones from being infected. But they were apprehensive that if they tested HIV-positive it would change their lives and, therefore, they would rather remain ignorant. Only Nhlanhla (ntst, 18) did not think it would benefit him knowing his status. Although he knew he was “*at risk*” of being HIV-positive he was not concerned about knowing his status because he did not “*sleep around.*” He said: “*I’m still at school and I don’t think I have any problems of being positive or negative, I still want to enjoy life.*” But if he tested positive he thought he would have to isolate himself.

The men who had not tested were all fairly young and most (9/11) were under 30 years old as Venkatesh et al. (2011) also found. Their risk of infection was lower given the South African HIV prevalence figures. They were less likely to be HIV-positive. They were happy-go-lucky, risk-takers, influenced by their peers, and did not want to change their lifestyle. As Lucky (ntst, 20) commented: “*The kind of friends I spend my time with influences the way I think, the things I do in life [...] I am part of a group that takes things lightly. You know how boys are.*” He believed that he was HIV-negative, he drank alcohol, smoked and did not “*care about anything.*” He felt free to do what he wanted to because he did not know his status.

One young student, Phil (ntst, 18), stated: “*It has never occurred to me that I should get tested.*” He admitted that it would benefit him to know his HIV status because if he tested positive he could prevent infecting others through unprotected sex. He qualified this by saying he would only protect those he cared about: “*If I care about the person I will tell them of my status. If I don’t care about them [sex] will just happen and she will get infected.*” He believed that it was important to know his partner’s status so he could protect himself from becoming infected. Although Phil was concerned about becoming infected he was indifferent towards those he does not care for.

These young men were embracing life and were carefree. They were aware of HIV and the benefits that testing may bring, but they were unwilling or not ready to test. They acknowledged that they were at risk and vulnerable to contracting HIV but still had not tested, which contradicted findings from elsewhere (Levack, 2005; McGarrigle et al., 2005) that suggested that increased perception of risk encouraged testing.

Over half (6/11) reported that they were afraid of testing and getting the results. Musi (ntst, 20) was invited to test when he went to be circumcised but he declined the offer because he did not feel ready to do so. When probed he admitted: *“I’m actually afraid of the outcome, what if the results come back positive? That’s what I’m afraid of.”* Eugene said he had never had unprotected sex but did not have the courage to test.

“Well I am afraid. Maybe if I could go with my partner to get tested. [...] I really don’t know. It’s just this thing. They came at school to get us tested for free. But there is this thing. I don’t have the guts to get tested. But I’ve never had unprotected sex. Unless if I was born with the disease. [...] I just have this fear I don’t know why.” Eugene (ntst, 19)

Both Musi and Eugene were at school and were less likely to be HIV-positive, but they were concerned that there was a chance that they may be infected and were afraid to test. Eugene believed that if he knew his status he would be able to *“keep on protecting myself.”*

As described above, stigmatisation was known to deter people from testing and it was the main reason why Albert (ntst, 21) did not want to test. He was young and single, and described his concerns: *“I am afraid of knowing my status. I am not sure if I will be able to deal with the stigma related to the virus, especially from the family... they will start isolating me. They won’t look at me the same way, things like that.”* He was worried that if he were to test positive his *“dreams will be shattered and I don’t know how people will judge me... I am scared [to test] even though I haven’t been in contact with anyone’s blood and have never had unprotected sex.”* But he had been involved in fights and did not know if blood *“did touch me or maybe it got into my mouth.”* So he felt there was a chance he could be infected. He said if he was told that he was positive he *“will feel bad and guilty because I have never done anything stupid to make myself positive like sleeping without a condom.”* He felt it was important to know his status so that he would have the *“opportunity to seek help and treatment if you are positive.”* He would like to be able to go *“boldly”* on his own to test, but was scared. The impact of HIV stigmatisation on these young men raised concerns that they will be discriminated against if they were to test HIV-positive, and be judged for having engaged in unprotected sex, even if they had not.

The men were aware that HIV was transmitted through unprotected sexual intercourse. Eugene and Albert state that they never had unprotected sex, yet they were scared that they may be infected and therefore did

not want to test. For the many men who were sexually active testing made them anxious that they may be HIV-positive and they were too scared to be tested.

Testing is difficult: Clement's story

People who were HIV-positive surrounded Clement (ntst, 18). His sister was HIV-positive and another sister and brother had died from HIV-related illnesses. *"Their deaths were like...(silent)... just a month separated. Yes like one month the one passed and then the next one passed away."* He learnt that they were HIV-positive through his parents: *"They don't like hiding things from us. They will tell you even if they think it is the most difficult thing. They would always say it is important that you know."* When asked to elaborate on this experience he said: *"It is the worst thing ever, seeing someone that you love suffering, lying on a bed, clueless, not knowing what might happen, not knowing when are they going to pass away. Seeing them just helpless not doing anything for themselves."*

Although Clement believes that it was important *"to know where you are standing in life"* he did not want to know his status, and aptly described how he felt: *"I love my life and the way I live my life. I don't think that an HIV or AIDS person would live the life that I live. Yes I'm just blunt ignorant."* At first he said he was scared to test but did not know why. He mentioned that his parents had tested, were open and had encouraged him to test but he had *"reprimanded them, I said 'no I'll never, over my dead body'."* Finally he admitted that *"two years or three years ago I had unprotected sex with a girl and it wasn't on only one occasion. We did it several times, more than I could ever remember ...After that, after being with that girl all the things I have heard about her just made me think twice."* Clement was aware that having unprotected sex was risky and was now concerned that he may be infected because he had heard stories about her conduct.

Clement was fully aware of the consequences of being HIV-positive and conceded that it would be good to know his situation, saying *"what you don't know won't kill you now, but will kill you at the end of the day."* He recognised that if he knew his status he would be able to take better care of himself. He was concerned at how easy it was to get HIV because, unlike him, his brother had not been a partygoer and neither drank alcohol nor smoked.

Clement, like many of the young men, was conflicted about knowing his status and preferred to remain “blunt ignorant.” He did not want to change the way he lived but recognised that he could take better care of himself if he knew his status. Levack (2005) suggested that knowing someone with HIV encouraged one to test, but this was not the case with Clement.

Other men claimed to have many sexual partners, increasing the chance that they could be HIV-positive. Brian (ntst, 26) had a steady partner and five or six women “*on the side*.” He was aware that he was at risk of being HIV-positive, but he had not tested. He reluctantly admitted that he was afraid to test, saying: “*I’m very scared of [testing] because I know I’ve had unprotected sex with a lot of girls around. It was with these girls who are very busy sleeping around, so aah ... (he pauses) I can’t, I’m scared... too scared.*” He revealed that his partner was also afraid to test. Although he acknowledged: “*not knowing your status is like not knowing yourself*” he was not sure how knowing his status would benefit him.

One slightly older man, Kabelo (ntst, 33) was traditionally married and although he had paid lobola he did not live with his wife and did not see her for extended periods of time. Both had relationships outside of the marriage but when they got together “*that person you been in love with. You spent a long period not living with her then you just make sex with her not using the condom.*” He was afraid to test, stating that it was “*difficult to go and test because you don’t know what the outcome of the results will be.*” He believed he was negative because he “*hasn’t seen anything*” but he was concerned that the results may be positive. He imagined that knowing his status would fundamentally change his life and the “*thought of hearing the result alone is traumatic for me and I can’t stand that!*” He was worried that if he tested positive he would “*have stress ... lose weight and get loss of mind*” and if he knew his status, he said “*that thing [HIV] is always keeping on consuming you. It does not give you a rest in your heart.*”

Having a number of partners and unprotected sex was not unusual for many of the men although they recognised that these activities carried a risk of being infected with HIV. They were reluctant to test for HIV as they believed that knowing their status would inevitably change the way they conducted their lives going forward.

One man did not think he was at risk of being HIV-positive. Enoch (ntst, --), a gay man, explained that he was not at risk although he was raped when he was younger. He said: “*I think it is just a waste of time*

because I know how I behave. So why must I go and test? [...] I practise safer sex, always using a condom."

He had not tested, but if he did he was concerned that he might be given the wrong results, and he would worry thinking that he was positive when in fact he was negative, therefore it was *"better not to test."*

The men who did not know their HIV status were afraid to test. They were uncomfortable with the uncertainty of the outcome even if they felt they were not at risk. They were also concerned that if they learnt they were HIV-positive, it would fundamentally change their lives, which was not something they were prepared to entertain at this stage.

The secondary informants suggested that men were reluctant to admit that they might be ill and some observed that they even sent their partner to test before they would consider doing so. One community outreach worker observed:

"It's like your man at an early stage denies that he is sick, then he sends you [his partner] to go and test. He is not yet sick. [Men] will only come when they are very sick and their CD4 count is zero that is when they will come." COO6

Certain studies found that men "proxy test", that was they assumed they had the same HIV status as their partner, and depended on them to test (Levack, 2005). One VCT site coordinator explained that some men *"feel if the wife has tested and got the results [that] they will have the same results as their counterpart."* However, one health worker was concerned that men did not understand the complexities of discordant results - where both parties do not have the same status. This VCT site coordinator explained:

"A girlfriend will come and do the test then you will see her afterwards coming with her boyfriend. If the woman doesn't come first then the man will never come. In some cases you will find that men don't agree to do the test, they still think that if the woman has tested negative they are also negative. They don't know about the discordant results. So we try by all means to teach them about the discordant results. [After] they know about discordant results they come and test and they are really surprised. They don't believe that can happen." CORD8

Only one man assumed that he had the same status as his partner. Jabu was in a relationship with a woman he was planning to get engaged to and with whom he had three children. He said he did not have the courage to test. He was scared because the test involved blood being taken and he was afraid of needles. However, his girlfriend had tested HIV-negative so he believed he was *"clean"* because he had not *"really been naughty"*, was *"faithful and loyal"* and had not had sex with other women. He was preparing himself mentally and

emotionally to gain confidence to get tested. Aside from being afraid of needles, he did not want counsellors to tell him what he already knew and patronise him. He only wanted to know his results and not to wait for a long time for them. Jabu suggested: *“Knowing that you are HIV-positive or negative, it helps [to ease] your mind, you sleep easier, you relax.”* If Jabu ever had enough courage to test he said he would voluntarily disclose his status to his partner, because *“I wouldn’t want to endanger my partner by exposing her to any sexual risks that might be related to HIV/AIDS.”* However, he was unsure if he would disclose his status to others:

“... it is up to an individual. If you want people to know your status, you will tell them yourself. You must know what you get yourself into. If you tell people about your status you should know that people may turn against you and not support you.” Jabu (ntst, 28)

For Jabu, using his partner’s status as a measure of his own status was a mixture of being afraid to go through the test, and being concerned that he would be ostracised if it were known that he was HIV-positive.

The explanations given by these men on why they did not test provided insight into the complexities surrounding HIV. Stigmatisation and the fear that they will be ostracised by their peers are major concerns. The men were afraid to test and did not want to know their HIV status because whether they tested HIV-positive or negative, their lives would change. In a patriarchal world, men who knew their status would be able to protect their partners from HIV and allow them to take better care of their health. However, if they were to test HIV-positive they were concerned that if their friends or family were to know then they would be rejected or isolated.

14.5 Why did men test?

This section explored what had motivated the 22 men who had tested to undergo an HIV test. Interestingly many of the reasons that men gave to test were similar to those that deterred others from testing.

Stigmatisation was known to prevent men from testing (Bassett et al., 2007; Young et al., 2010) and this was confirmed by the men who had tested. They explained that men do not want to be observed going for a test by others or to wait in a queue to test. Instead, a number (6/22) of the men who had tested had not planned to test but tested on the spur of the moment, or when an opportunity presented itself such as during an HIV testing campaign or drive. David (pos, 30) made the decision to test when he happened to be passing a TB

clinic: “... *I was passing and I saw people standing outside and they were looking for men to come and test and I tested as well.*” The outcome for David was devastating, as he tested HIV-positive. At first he cried, thinking that it was “*the end*”, his “*days were numbered on this earth*”, and he was going to die. He was grateful for the counselling he received and by the time he left the clinic he felt “*very motivated*” and was able to cope with his result.

Testing during a campaign enabled the men to avoid being singled out as having an issue with their health. They did not have to mull over the possibility that they may have HIV and make the decision to go and get tested. Although HIV testing campaigns were often run by clinics, HIV testing was also offered in the community. Being offered an HIV test outside of a clinic setting may be preferable for men, as found by Sabapathy et al. (2012), where there was a high uptake of men in home-based HIV testing.

A couple of the younger men were encouraged by their friends to test. Emanuel (neg, 19) and Mdu (neg, 18) had been “*sitting around*” with their friends when they decided to go as a group to test. Emanuel and his friends learnt about HIV testing through loveLife, a community organisation that focused on youth and HIV, and were well prepared. They acquainted themselves with the process and made a pact that they would support each other no matter the results. Emanuel tested “*with confidence*”, did not find it difficult and felt it was a good experience. After getting his HIV-negative results he said: “... *everything was alright. It was like all the days, there was nothing different. The thing is if you have it, you have it. But if you don't have it, you don't. You won't run away from the virus.*” He conceded that if the test results had been positive then “*it could have meant a different chapter that needs a different approach altogether.*”

Similarly, Mdu (neg, 18) and his friends decided to test together. He recalled: “*It was just something that we thought about there and then because we were not really doing anything. So since it was something that we had been thinking about, we felt that we should do it that Friday.*” They all tested HIV-negative. He also had support from his parents who were “*open*”, tested regularly, and had encouraged him to test. Afterwards they said “*you have done a good job you have got tested and everything.*”

These young groups of men were able to support each other when they tested. At their age they were less likely to be HIV-positive, therefore it may have been easier for them to make the decision.

Many of the men who had not tested but had engaged in risky sexual behaviour were worried they may be HIV-positive, and were too afraid to test. For others having a risky sexual encounter was the impetus for them to test.

One young man, Mark (neg, 19), had sexual intercourse with a girl without using a condom and was worried that he could be HIV-positive so decided to test. He described his experience: *“I was so scared and the results came out negative ... they were negative... (He laughs) I really don’t know what scared me... I was scared of the fact that in a few minutes time I will know my status [...] Well afterwards I felt relieved when I got my results.”* When asked why other men did not test, he suggested that men feared testing and lacked self-confidence and courage.

Thulani (neg, 22) tested regularly because he had many sexual relationships with women and did not like using condoms. He needed to be responsible and said: *“I have to stay alert all the time so that I don’t have to infect my partner.”* So each time he started a new relationship he insisted they both go for a test so that he could be *“assured”* that neither of them were positive. He recognised he was at risk because *“I don’t know what might have happened to me with my ex-partner and what happened to my current partner in her previous life before we met.”* Thulani was unwilling to protect himself by using condoms and continued to engage in risky sexual behaviour, which he mitigated by testing regularly.

A risky encounter spurred on Martin (neg, 25) to test. He *“had an experience with my girlfriend where a condom burst while we were having sex.”* He was unsure about her status and did not want to live in *“fear or doubt.”* Previously he had accompanied a friend who went for a test and was motivated and encouraged by him to *“know my status and know my stance with the virus.”* He did not discuss his test results with his girlfriend, because she had *“cheated”* on him and the relationship ended. When Martin told his friends that he had tested they *“were not okay about it.”* His friends would not test because they were worried that they may test HIV-positive. He suggested that *“they are afraid of tests as they are mindful of the things that they are doing that could put them at risk of the infection, hence the fear.”* He said they likened the experience to *“torture.”*

Testing empowered these men. All of them tested HIV-negative, which may have given them more confidence afterwards. As Mark suggested, in order to go for a test one needed courage and self-confidence.

These men had done something that others found scary. Could testing be promoted as doing something daring and manly? Martin tested negative and spoke to his friends about his experience, but one wonders if he would have been so forthcoming had he tested positive.

Three older men were ill when they were advised by a health worker to test and found out that they were HIV-positive.

Testing positive, starting over: Thabo's story

Thabo's (pos, 52) story was one of courage and pain. He was 52 years old and was a long-distance trucker and *"became actively in love with different types of people."* Being away from home for long periods was a known risk factor for HIV, as it was likely that men will engage in sex with sex workers or other women while they were on the road (Lurie et al., 2003). Thabo had been ill for a while before he finally went to a clinic: *"I went to the clinic with a very serious painful chest, coughing, and I was shaking very bad[ly], and that was a sign to me that there is something wrong in my body."* After consulting a doctor he was admitted to Chris Hani Baragwanath Hospital, where he tested HIV-positive and was discharged. He accepted the situation but when he disclosed his status to his wife she was *"surprised"* and said *"there is nothing like that"* and could not *"accept it that is true."* He encouraged his wife to test as he believed that since he was positive so was she, but his wife denied that she had HIV. She started drinking excessively and he withdrew from her. Eventually she died without being tested.

Thabo was open about being HIV-positive and relied on his support group and family, and especially his last-born son who *"is very much concerned about me. He keeps on reminding me to drink the tablets. Even in my room I have displayed all of the boxes all over."* For Thabo, disclosure was bittersweet: he lost his wife, but was able to be open about his status and was supported by his family.

Thabo also was able to discuss his diagnosis at work. In 2001, the virus *"started to attack"* him and although he looked well, he got tired and could not work properly. It took him a year before he was able to approach his bosses. He described how difficult it was: *"The issue is I was very much trusted. That made me afraid to even tell my bosses. I thought maybe they will say you have got HIV we don't want you here [...]* In 2002 I told my bosses that I have got this virus called HIV. They were quite surprised because I looked okay and fit.

The only thing was that I was feeling very tired.” He was given early retirement but was rejected by his workmates. Recently he went back there:

“They were very much happy to see me. I told them that it is because of the treatment that I am taking. They affirmed that I look different. I forgive them for having not understood my current situation at the time. What I am always praying is to get the medicine or a cure for HIV so that other people could get help because other people are pointing fingers at us.” Thabo (pos, 52)

Like many men, Thabo did not get tested voluntarily, he admitted that he had sex with many women, but perhaps did not realise or want to consider the possibility that he might be HIV-positive. It was only when he was very ill that he was tested. Disclosing his status resulted in him losing his wife and being rejected by his colleagues. He had taken the stance of being open about his status, which was brave in the face of stigmatisation and the finger pointing that he remarked on.

Mfecane (2010) described how HIV-positive men transformed their lives once they were diagnosed with HIV. He argued that they reconstructed their masculinity and adopted responsible behaviour, taking their health situation into account. Thabo’s and Xolani’s (to follow) stories were testament to this notion.

Getting help from others – Xolani’s story

Xolani (pos, 41) was 41 years old, unmarried and separated from the mother of his only son who was 14 years old. Her family denied him rights over his child because he had not married her. After she left him, he fell ill and was admitted to hospital. He was reluctant to test, but finally agreed and was diagnosed as HIV-positive. He described what happened:

“At first I did not want to test but they encouraged me to test so that I can know my status. Eventually I agreed and they took my blood for a test. They told me to return the next day for my results. The next day I went back to the clinic and the results came out positive... The support group really helped me out a lot because I could not do anything for myself by then. They took me to a certain doctor ... and he gave me ARVs ... He told me to return after two weeks to check how my body was reacting to the medication. He also took my blood to the lab so that they could confirm my HIV status and again the results were positive. He asked if I accept that I’m HIV-positive. I said yes.” Xolani (pos, 41)

After his diagnosis he joined a support group where he learnt about ART. *“I feel better. I thought that I will never see the year 2000, but I have pulled through. I’m [dealing with] my illness just like any illness such as*

TB.” He was very grateful for the help he received from the support group whose members motivated him and brought him healthy food. He lived with his mother, sister, and younger brother, and contributed to the household income with a government grant. This helped him survive.

Xolani had been taking ART for a while and was happy with his progress. He said: *“Honestly they [antiretroviral drugs] are good. They are giving me more power and strength. I have been drinking them for four years now and since I have been drinking them I have recovered.”*

He took responsibility for his health and was fully aware on how to take his treatment: *“I have to take them at the same time every day. I must not forget. I know that I will have to take them in for the rest of my life.”* He had changed some aspects of his life, and took good care of himself. He said: *“even when I feel like having sex I always use a condom, unlike in the past when I always had unprotected sex.”*

Xolani had taken charge of his life and sought help when he needed it. Unlike many men he recognised that he could not go on this journey alone, and sought out and embraced the help that he received from others.

Thabo and Xolani were ill and had little choice but to test. Learning about their HIV-positive status was not easy for them and they had to overcome hurdles along the way. But they had come to terms with their illness and adapted their lives to cope.

The participants suggested that men’s partners could encourage them to test. One site VCT site coordinator explained: *“I think women take more control of their lives than men because even at home it will be always a woman that comes for VCT and then she will encourage her partner afterwards”* (CORD8). A few men agreed that their partner could help them get over their fear of testing by motivating and accompanying them for a test. But Bongani (pos, 35) expressed his concerns about this tactic: *“We as men are afraid to get tested especially if your wife goes to the clinic and they ask her to bring her husband with. You start stressing and [are] afraid to go and get tested. Men are generally afraid to get tested. If you go to the clinic you’ll find that it’s mostly women.”* Bongani’s concern was that men do not like women telling them what to do, and do not want to enter a domain dominated by women.

The fear of testing, the fear of getting one's result, the fear of how one would live going forward, the fear of death, and the fear of others knowing one's status were themes that recurred throughout the interviews. The fear described by the men who had not tested was echoed by other participants:

"[Men] are afraid to test and to know their status. Never mind their status. Never mind their partner's. They cannot face their status. Some will tell you 'I don't want to die'. Some will tell you 'I don't want to know'." CORD4

The men feared that their results might be positive so they preferred to stay ignorant of their status. As Tshepo (pos, 30) described, people felt *"threatened by the possibility that the tests might come out positive"* and they adopted an attitude of *"what you don't know won't kill you"*, and therefore they did not test.

Some men tested but did not believe the health care worker when they were told their result and felt it necessary to confirm it. Xolani (pos, 41) went to another doctor to repeat the test. Abel returned to the clinic to check that the result he was given was correct.

"But it was very scary. Even if they tell you the results are negative you still feel scared. I went back the next day to make sure if I was really negative. They assured me. I felt better and went home." Abel (neg, 27)

Abel described testing as a *"very frightening experience"* and for that reason he suggested *"many people are afraid to go get tested."* He said it was *"great"* to know his status, but it would be difficult to test again. *"I only tested once. Do you think I'd go back the second time? (he laughs) [...] I told myself that from now on I'm going to play safe."*

The younger men, at low risk of being HIV-positive, had the confidence to test with their peers. Other men were motivated to test because they had risky sexual encounters. A few men were tested when they were ill, and were encouraged by the health workers to test. The men who had tested conceded that they were also afraid before they tested and were reluctant to repeat the process.

14.6 Men's reactions to their results

Counselling was integral to the testing process. The men appreciated the counselling saying they would then be informed about the testing protocol, be prepared for the result, and know where to get help.

The eleven men who had tested HIV-negative recounted the huge relief they felt when they learned their results, and said that knowing their status gave them peace of mind. Noah (neg, 19) was “*happy*” and “*relieved*” when he tested negative: “*It means a lot to me, it actually affirms that I have been taking good care of myself.*” Furthermore, they felt in control of their lives. As Abel described:

“Yes! It’s important [to know your status]. [...] You can’t keep on asking yourself whether you’re positive or negative. At least when people talk to you about their status you would be sure of your status as well because you did go for testing. [...] [it is important] for me to have a good lifestyle. If I don’t know whether I’m positive or negative I will just live carelessly then I’ll sleep with whomever I meet. In that way I’ll get infected so it’s good to know my status and I’ll know where I stand.” Abel (neg, 27)

Abel suggested that just knowing his status enabled him to embrace a healthy lifestyle and prevent getting infected, supporting the notion that HIV testing was a prevention intervention (Levack, 2005). Further, they felt that if they got sick they would not worry that they might be HIV-positive. Andrew (neg, 24) tested negative and was convinced that he had remained so. He practised safe sex and used condoms, although he was “*playing around with many partners.*”

The HIV-negative men were empowered by knowing their status and felt they could protect their partner. Martin (neg, 25) elaborated: “*[You] know how to protect yourself and your loved ones by not putting them at risk unnecessarily, because you would not want to take risks or to infect them. If infected you wouldn’t want to infect your partner or loved ones.*” Martin was relieved that he did not have to worry about infecting his partner because he was negative.

For the men who tested positive, the results changed their lives. Most said that they accepted the result, but for some this was easier than for others. Patrick (pos, 36) accepted being HIV-positive as he knew his “*record in terms of my own sexual behaviour.*” Amos (pos, 36) “*took it as it is*” and accepted his status: “*I told myself that this thing won’t stop and I won’t run away from it because it is there.*” Similarly after Tshepo (pos, 30) learnt he was HIV-positive, he made a plan to disclose his status to people who lived around him. “*That was the best thing as I thought it will be better for me to understand my situation and also pursue to live a better and normal life.*” For these men testing positive was a consequence of their prior sexual behaviour, but they accepted the diagnosis and were prepared to move forward as HIV-positive men.

A couple of men had tested and received their results under difficult circumstances. Zakes (pos, 38) was in prison awaiting trial when he developed a rash. *“I realised that this rash is not getting better and it’s itchy and I’m getting black marks. Then I told the doctor that I have this problem and I used calamine lotion and I’m not getting better.”* The doctor recommended that he have an HIV test and asked him how he would feel if he tested positive. *“I said I would accept because right now I’m in prison.”* When he tested he did not have a support system. He went for his test results with other inmates and some of them were “sad” when they came out of the consulting room. He was counselled and they arranged for his results to be disclosed to his older sister. He was concerned about the rest of his family knowing as he thought that his mother would have a heart attack if he told her. Zakes had to come to terms with his diagnosis on his own, without support.

The men who had tested felt empowered to take better control of their lives, to protect their partners and to take better care of their health. These findings support the notion that knowing one’s HIV status encouraged positive behaviour change, preventing further HIV infections (Levack, 2005; Mhlongo et al., 2013).

14.7 Discussion

Regardless of status, the men agreed that HIV testing was important and that there were benefits to knowing whether they were HIV-positive or negative; however, not all were able to take the final step. The interviews with the men reveal that the decision to test is complex and influenced by a number of factors including stigmatisation and masculinity.

Throughout the interviews the men expressed fear of testing and of being afraid of the result. One of the causes of concern was that they had unprotected sexual intercourse and they knew this was a risk factor for HIV infection. Taking risks, including having multiple sexual partners, is typical masculine behaviour. In a situation where there is no HIV it would be something to brag about to their peers. However in this case the results can be detrimental to the men’s health. In a patriarchal setting men are stoic so it is interesting that, going against masculine norms, the men admitted to being afraid of testing.

The men who had not tested did not want to change their lifestyle. Many were young and had a carefree life. They were concerned that going for an HIV test and being given a positive result would impact negatively on their lives. They wanted to keep this carefree existence and to enjoy life. The men speculated that if they were to test positive they would have increased stress because they would know that death was closer. They

were afraid that they may be isolated, mocked or rejected by their peers, and lose the social status that they enjoy.

The men who had tested fell into two groups, those who tested voluntarily and those who tested because they were ill. Men have to conquer their fear in order to go for an HIV test, but may have to come to terms with being HIV-positive. For some young men, peer pressure and their friendships had enabled the process.

The decision of where to test for the men who tested voluntarily was not lightly made. HIV stigmatisation played a big role in men's decision about where to test. Some tested far away from where they lived where they could be anonymous because they did not want anyone that they know to see them at the site. Men keep their health matters private and are secretive about their health status because they do not want others to perceive them to be weak. They were worried about the community speculating about their HIV status and diagnosing them as HIV-positive, and their losing social standing. A couple of men had tested on the spur of the moment during a HIV testing campaign which may be easier for them rather than having to make the decision to go and test.

The men who had been tested for HIV because they were sick did not have much choice about whether to test or not, although one man had resisted being tested.

These men had tested reported that having tested they were empowered to decide how to conduct their lives. The men who tested HIV-negative expressed relief on hearing their results. The men who tested HIV-positive needed to come to terms with being positive, but were able to take better care of their health and to seek appropriate treatment.

It seems that the combination of the dominant notion of masculinity and HIV stigmatisation deter many men from testing for HIV and subsequently from accessing ART.

Chapter 15: Talking about health and illness, and disclosing HIV status

Talking about health and HIV/AIDS in the community and with one's peers was influenced by political, social, and individual factors. Public discussion about HIV was hindered by a lack of leadership in South Africa. As discussed in the literature review, during the early stages of the epidemic the political leaders were either silent about the issue or denied that there was a problem and delayed implementing treatment programmes (Heywood, 2005; Nattrass, 2007; Beresford et al., 2008). Although the situation was evolving there were often conflicting messages about HIV prevention proffered by high profile South African leaders. Political leadership can influence the way masculinities are defined in South Africa and how men respond to the epidemic (Ratele, 2006).

Disclosure of HIV status was considered beneficial for a number of reasons including the person's wellbeing, adherence to treatment, prevention of re-infection, prevention of transmission, and enabled a person to obtain support. Health workers encouraged HIV-positive people to disclose their status because of the benefits. On a societal level the more open people are about their status the more likely HIV-stigmatisation will diminish, and individuals can seek help and reduce further infections. However, social factors hampering disclosure included masculinity, HIV stigmatisation, discrimination, and the link between HIV and sex (Deacon et al., 2005; Mboup et al., 2006; Wolfe et al., 2006). Men were reluctant to seek help when they were sick because it was unmanly (Robertson, 2007; Holroyd et al., 2008). Although, it was shown in some studies that men were able to discuss STIs with their friends (Galdas et al., 2005; Galdas, 2013). These factors were reflected in the discussions with the participants and expanded on below.

This chapter explores the extent to which men discussed their personal issues such as their health with others, and if they did, who they talked to. The first section examines whom men turned to for support when they were ill, and with whom they discussed their private matters. The second section poses the question to the men who were HIV-negative and did not know their status: To whom would you disclose your status if it were HIV-positive? The final section explores the issues around disclosure with the HIV-positive men.

15.1 Who men turn to for support

Personal health generally was a private matter (Cameron, 2005) and stigmatisation influenced people to keep their HIV status secret. Although men worry about their health issues they were unwilling or unable to talk about them (Banks, 2001; Seidler, 2006), and even more reluctant to do so when it came to talking about sexual health or HIV because they were concerned that their secret will be revealed (Preston-Whyte, 2003; Serrant-Green & McLuskey, 2008). These issues were explored with the men in this study who were asked whether they talked or discussed their health issues with anyone, and if so, whom they talked to, and how they felt about these types of discussions.

The views expressed above were supported by the men. The men were secret about their health issues, reluctant to talk about their illness, and selective about whom they confided in. However, most of the men had confidants that they discussed their personal issues with, including health. The confidants' characteristics included that they needed to be trustworthy and had to be able to keep this private information secret. Most often family members, in particular mothers and grandmothers, were relied on for support, and occasionally siblings were confided in. A few men had confided in their partner because they felt she could be trusted and not break their confidence. However, some men could not confide in anyone.

Beyond the family or partner it took courage for the men to engage in discussions with others about personal issues. Thus, friends and neighbours were less desirable because they were not considered trustworthy, and the community was seldom informed of these matters. Although the men choose female partners or family members to confide in, they preferred not to discuss their private or health issues with female clinic staff.

To begin this section, the voices of the HIV-negative men and the men with unknown HIV status are discussed. For HIV-positive men, HIV-related health issues are all consuming, and their personal or health issues were synonymous with HIV.

The HIV-negative men and those with unknown HIV status (22/33) described how their friends could not be depended on for support or be relied upon to keep confidences. A couple of men described how they had lost confidence in their friends because they were unable to keep a secret. As Abel (neg, 27) explained *"Yes I did tell my friends, but you know how friends are, they'll end up telling everyone. I decided not to tell them anymore."* The men took their personal and health matters very seriously and did not willingly disclose

them. Noah (neg, 19) did not feel able to discuss such matters with his friends. He laments: *“Err ... my friends, I am full of naughty friends who likes joking a lot, even [about] serious issues. So they can also make it a joke and is not going to be well with me ... they like to joke around the things which they are not supposed to joke [about].”* Although these men had risked sharing confidences with their friends, these had not been respected or kept secret. This resulted in the men no longer sharing private information with their friends.

Thulani was unfortunate to be in the minority that had no one to confide in; as most men had someone they could talk to about their health issues. He described how he had lost confidence in people and indicated that there was no one that he was close to with whom he could talk about personal issues. He relied on neighbours to assist him when he needed help. He was estranged from his family and has looked after himself since he was in Standard 5. He explained:

“I rather call a neighbour who is close to me and tell him that I won’t be able to do anything ‘could you please call the ambulance for me?’ Like I told you, I have once been poisoned, twice, [...] people who helped me were the neighbours not family [...] My family heard about that after [I] was taken to the hospital by the paramedics while they were in the yard [close by].” Thulani (neg, 22)

A few men said they had confided in clinic staff that were obliged to keep matters confidential. Although the staff were mainly women, the men felt safe confiding in them because they were not part of their social circle, so it was unlikely that this information would be disclosed to their friends. Thus, talking to them would not interfere with how they conducted their lives. As Albert explained:

“I can try to speak to the nearest counsellor. I know he will encourage me that life will still go on. I can still socialise the way I want as long as I stay protected [use condoms].” Albert (ntst, 21)

However, the men were generally reluctant to discuss their health issues with anyone. Whilst Clement (ntst, 18) conceded that it might be important to do so, he would only confide in someone who was with him *“on a daily basis.”* A couple of the men felt that they did not have much to discuss. As Lucky elaborated:

“No I don’t, I don’t discuss everything. I mean maybe they [family] would find me in bed and they’ll ask ‘what’s wrong?’ I would just say I’ve got flu and that’s it. There wouldn’t be anything to discuss.” Lucky (ntst, 20)

Although the men expressed their reluctance to talk about their personal issues, when they did they relied on their immediate family and close friends, or unwillingly approached other people such as neighbours for help.

However, in contrast, a couple of young HIV-negative men were open about their health matters and spoke to many people. Mdu explained why he talked to his “*parents, friends, cousins and just everybody*”:

“I think it is important because, as you know, parents are always concerned about their children’s health and they would always ask you: ‘Have you tested my boy? Are you okay?’ And your cousins and friends would always be on your case about whether or not you are having sex or engaging in some health risks like drinking and smoking. So yeah I think it is important that they know about these things.” Mdu (neg, 18)

Similarly, Emanuel (neg, 19) shared his life with a “*lot of people*” including his friends whom he trusted. They supported and motivated him and they shared information and ideas about HIV/AIDS. He discussed many issues with them “*life as a whole like sex, girlfriends, future, success, and all the other things*” including health issues, and would even share his status with them if he became infected with HIV. He did not believe in keeping secrets. Both Mdu and Emanuel were young, HIV-negative and had no health issues to hide.

The men who were able to discuss their personal issues with others felt supported by the people they talked to. These findings supported those in the literature that it was beneficial to disclose problems with others, provided there was an enabling environment free from discrimination.

The men gave careful consideration to whom they would open up, and about what they would discuss. They made calculated decisions on whether to keep their health matters secret or to talk about them with others. Once they had divulged their issues to others there was always the risk that their secrets could become public knowledge. They needed to be certain that they would be able to handle that situation should it arise.

Contrary to the beliefs of the secondary informants who thought that men were not interested in their health, the men interviewed in this study were keenly interested in it. But this did not translate into seeking help in the clinics. The men were reluctant clinic visitors and were hesitant to discuss personal issues with the health workers, which perhaps explained the secondary informants’ viewpoint.

The men were knowledgeable about where they could seek support if they were to test HIV-positive. They indicated that they would seek support through support groups or their church:

“I also heard there are support groups, but I’ve never been to any of them. There’s even one at my church for people with HIV and AIDS. So if I get infected with HIV I would go to the support group at my church.” Abel (neg, 27)

Being HIV-positive had a profound impact on the eleven men who were infected. They were well informed of the choices they could make regarding their treatment. All of them had been to clinics for help and some had first-hand experience of ART. They spoke about how support from family, partners, clinic staff or support groups had a positive effect on them. The literature highlighted how HIV stigmatisation prevented people and men from getting support, but all the HIV-positive men had managed to find support from someone or somewhere.

Although HIV-positive, neither Amos nor Tebogo were on ART but both attended support groups and were enthusiastic members. They were well aware how ART worked. Tebogo (pos, 27) stated: *“I love ART.”* He knew a lot about it, how it worked, how to take the treatment, and how it was beneficial from his support group as well as from pamphlets, magazines, and the radio. They were committed to looking after their health. Amos (pos, 36) got *“boosters”, “vitamin supplements”,* and *“other tablets”* from the clinic and stated that his *“primary concern is to take good care of myself and hope that I don’t get to a point where I should need ARVs anytime soon.”* He described how ART worked: *“... its function is to lower this virus percentage so that it does not attack the body cells easily and for this virus not to be visible.”* He also explained how the virus operated: *“Like for an example, if you can take the soldiers from Lesotho and compare them with the soldiers of South Africa they almost use the same uniform. You can’t even notice that this one is from Lesotho and this one is from South Africa. It is not going to be easy for you to differentiate them because they look the same. So this virus it gets into the cell and as soon as it gets in there it looks like cells. Actually it changes itself.”*

In summary, the HIV-positive men were interested in learning about HIV and ART. They actively engaged in support groups and garnered support from family and friends. In contrast, the HIV-negative men and those who did not know their status were selective about who they spoke to about their health issues, but most had

a confidant. In general, the men were able to find people to whom they could disclose personal issues and from whom they could seek help. When they did, they found that talking about these issues was beneficial.

15.2 Speculating about disclosing an HIV-positive status

Disclosure of one's HIV status was a complicated business. Health workers encouraged disclosure as it enabled a person to seek appropriate help and to take precautions not to spread HIV (Emlet, 2006). However, disclosing one's HIV status also meant that other private issues may be revealed, such as one's sexual health, lifestyle, or sexual orientation (Serrant-Green & McLuskey, 2008; Steinberg, 2008). In an environment with high levels of HIV stigmatisation and discrimination, disclosure was hampered. The health workers conceded that disclosure was difficult for everyone, but perhaps more so for men. In this section the voices of the HIV-negative and men who had not tested are discussed.

The men who had tested negative were generally happy to share their status with their family, but were less certain about sharing it with their friends. The men who had disclosed their negative status to their families reported mixed reactions. Noah's (neg, 19) family praised him for looking after his health and testing negative. However, he surmised that their reaction would have been different if he had tested positive. Other families were not supportive and Abel's (neg, 27) mother told him *"to stop sleeping with women"* and Siphos (neg, 23) family *"did not care."* Mark (neg, 19) had only told his mother, because *"Friends are just people you hang out with in the streets. For me I would not tell a friend [about] my personal life."*

It was easy for some HIV-negative men to disclose widely, as Andrew (neg, 24) reported: *"it wasn't a problem for me to tell anyone."* Emanuel (neg, 19) told his friends, family, and girlfriend and felt that he was *"normal like other people."* On the whole these men were less concerned that people they disclosed their status to would tell others, as they felt that they would have nothing to gain by doing so. These men were able to disclose their negative status because doing so did not change their social standing in society.

Most of the HIV-negative men and men who had not tested agreed that, if they tested HIV-positive, it would be important for them to disclose to their family and their partner, as they may need help, advice, or support from them in difficult times. A minority (5/22) thought that disclosure could strengthen the relationship with those they confided in. However, they conceded that it was not always easy or desirable to do so, and other factors needed to be taken into account.

The participants confirmed that men were concerned and expressed some reservations about their test results becoming public knowledge if they tested HIV-positive, and that men would be reluctant and scared to disclose. This stance was confirmed by Matthew (neg, 20) who was negative was worried that if his friends found out that he was positive they might use the information to tell girls to stay away from him. He felt that *“those kinds of things [being HIV-positive] should remain private, they must be kept private no matter what happens, otherwise I’ll sue those guys, I’ll sue them.”* Relationships were an important indicator of masculinity, and for Matthew being known to be HIV-positive could impact on his ability to engage in them. Although Matthew thought it was wrong, he observed that people *“withdraw”* from and *“reject”* HIV-positive people in Soweto. He conceded that he could perhaps share his status with his best friends, but not others. He also felt that he could keep a secret if someone disclosed to him. HIV stigmatisation was a concern for Matthew.

The men were aware of HIV stigmatisation and intimated that it would inhibit them from disclosing an HIV-positive status. They preferred to keep it secret. HIV stigmatisation was a concern for Albert (ntst, 21) who was worried that he *“won’t be treated like a person who was responsible and respected”* should he become HIV-positive. On the other hand he described people who were able to disclose their status as *“very brave”* but felt *“offended”* because he did not know his own. He recounted an incident in a shebeen where he and some friends were drinking:

“Yes, we were sitting with some people drinking. He just told me that he was positive. I didn’t know him and he didn’t know me at all. You know where people drink, certain things come out. Then he continued to say a lot of things. We even said to him he should stop saying them. There wasn’t any problem in me finding out their status. But one thing I can say is I think they are very brave. They were brave in sharing their status. I think I would be comfortable in sharing my status only if I am negative. But if I was positive I don’t think I would share with people, more especially [those who are] not related to me.” Albert (ntst, 21)

Albert’s dilemma about disclosure was common. He believed that people were brave when they disclosed that they were HIV-positive, but at the same time he regarded being HIV-positive as a negative attribute. If he were to disclose that he was HIV-positive he was worried that he would lose his social status amongst his peers. In a patriarchal society men wanted their peers to respect them, so it limited men’s ability to be brave and disclose personal issues.

Many of the men cited instances when HIV-positive people had been shamed in public. This deterred Albert (ntst, 21) from testing even though he thought it would be beneficial, as he said, *“I should know which chapter of life am I living [in].”* If he tested positive he would inform his family because *“they are the first structure of support during times of challenge.”* He was uncertain as to whether he would tell his friends because *“most friends are not there to help but rather drag you down or discourage.”* On the other hand, if he disclosed to them then they would visit him if he was sick or in hospital. He had witnessed HIV-positive people being treated differently and cited an example of a friend’s sister who was HIV-positive. Her younger brother would not listen to her, saying *“don’t tell me, because you have HIV.”* He was uncomfortable that he, as an outsider, learnt her status and that her brother had humiliated her in public.

For these men their HIV status was a private matter and should not be a topic up for discussion, gossip, or speculation. Reuben (neg, 21), who was HIV-negative, said he would disclose to people he trusted such as his family, friends and a partner so they could support him. He would not disclose to others as it was *“none of their business”* and *“they’ve got nothing to do with my life so why should they know.”*

The men believed it was at a person’s discretion to disclose their status and did not think that gossip or speculation was helpful. Nhlanhla (ntst, 18) thought it was important for his family and friends to know his status, but he realised that they may react in different ways. On the one hand some may help him, *“if I get sick they will not jump to conclusions”* nor *“judge or isolate”* him, but on the other hand they may react badly, *“if they do that [isolate him] then they should just leave me alone, then I will stay with my wife, that’s if she accepts me and does not isolate me as well.”* Thus, there was always a dilemma of whether or not to disclose an HIV-positive status.

HIV was closely linked with sexual matters as Geffen (2010) noted. Discussing an illness that was so closely related to sex was difficult, even within the family. Discussion outside of the family not only affects the individual, but also affects the whole family. The influence of the family should not be underestimated. Therefore, the issue of being HIV-positive and disclosing one’s status was not only the individual’s decision, but was mediated by partners and family. Matthew (neg, 20) and Sipho (neg, 23) mentioned that they would first disclose to their families, and they would need their families’ permission to disclose their status to outsiders. Family support was important as Thulani (neg, 22) elaborated: *“I think family should be [more]*

important than friends. Friends will know after. [later]. Family are the only people you are living with ... daily, and day and night [they are] there are with you." Therefore family had the deciding vote on whether public disclosure could take place or not. These men recognised that they would need support from their families, and would not jeopardise this by disclosing without their families' permission.

The men who had not tested speculated that disclosure might have benefits for them. They indicated that they would disclose to their family first and then to people who are close to them because they would need support. Brian (ntst, 26) believed that sharing lifted a burden *"because if you don't share your status you won't feel okay."* He said he would disclose to his friends as they *"talk about everything"*, as well as his family as *"they are the ones who give me advice most of the time, and I am able to sit down with them and tell them whatever is happening in my life."* Similarly Musi (ntst, 20) said he would tell his friends and other people who were close to him because *"I would feel free by telling them. I won't feel alone if I'm infected. I know I would get their support."* Eugene (ntst, 19) believed that HIV test results were confidential, but that family and friends should know so that they could take necessary precautions against HIV infection. He provided an example: If you were cut or wounded then *"they will know how to handle your blood"* and could help you without putting themselves at risk. Disclosure for Lucky (ntst, 20) was non-negotiable as his family would give him support and he would need their help to enable him to live a healthy lifestyle, because he *"can't even cook."*

Although these men had not tested they speculated that they would be able to share their status should they test HIV-positive. However, they may respond very differently if they were to test HIV-positive.

Disclosing to a partner enabled a couple to be proactive in preventing HIV infection. When Thulani (neg, 22) went to test, his girlfriend went with him, and when she learnt that he was negative he said: *"She was happy and she said to me, 'You know what, Thulani, the fact that you are honest and you can even talk to me about your status. I have to do the same thing to show you that I love you.'"* He described the approach he would take if he was positive and needed to disclose to a new partner:

"Let's say we are meeting for the first time, ... and [you're] sick, you know your status. If you love your partner, you are going to be open to her ... and say 'my love you know my life is like this and that', so that she must also be open if she has the same problem with you. So that in future you don't have [to] end up counting things or in future you don't have to make things worse for both of you, is very important." Thulani (neg, 22)

Mutual testing and disclosure was also preferred by a few of the men who had not tested, although this was not necessarily easy to do. Albert (ntst, 21) had avoided talking about HIV to his partner because he was scared to test: *“... they say practise what you preach ... so like I am scared. I will not encourage her to go and test ... at least if we get to a conversation and it ends up about talking the health stuff and the testing part comes in, then I will entertain it. If we both come to a conclusion that we must go and test together, then I will be okay with that.”*

A few men felt it was important for their relationship to inform their partner of their status so that they could support each other. If Abel (neg, 27) were to test positive, he suggested that his partner would then be able to *“protect herself”* when they had sex. Kabelo (ntst, 33) thought it was important that both parties in a relationship should know each other's status. Brian (ntst, 26) agreed and said, *“if we love each other and if she tells me she has the virus I won't leave her because she's ill; we would use protection.”* In the same way he expected his partner to support him and to be treated the same *“regardless of whether I have the virus or not.”* The men said that they would disclose to their partner so that she could take care of them.

Sipho (neg, 23) was HIV-negative, and believed that in a relationship there should be mutual disclosure. He would not disclose his status if his partner refused to disclose her status. He recognised that he may be at risk. *“Some of us drink and when we're drunk we fight and stab each other and come into contact with infected blood. Besides that, if you're in a relationship you sometimes don't use protection when having sex, and you'll never know the status of your partner.”* He was aware that all risky encounters could lead to HIV infection, and that the status of partners or other contacts was often unknown.

For the men who had not tested HIV-positive it was perhaps easier to contemplate disclosure, and to whom they would disclose. They were more comfortable disclosing to their families and partners than to friends or their community. They were aware that disclosing would fundamentally change the way that others would relate to them. They understood that disclosure could have benefits such as getting support and preventing further infections, but could also have negative consequences such as being humiliated in public. Due to stigmatisation, disclosure did not only affect the infected person, but also those around them and was mediated by their families.

The HIV-negative men and those men of unknown status were convinced that, should they test HIV-positive, they would be able to disclose their status and that it would be beneficial. However, were they to test HIV-positive they may not be quite so brave.

15.3 Disclosing when you are HIV-positive

For the HIV-positive men whether to disclose or not was a personal decision and one not taken lightly. They had different experiences and thoughts concerning disclosure compared to the men who were not HIV-positive. The majority of HIV-positive men found it hard to disclose to others; some took a long time to do so and they were selective to whom they disclosed.

Lebo, a young gay man, had not told his parents that he was gay and this made it doubly difficult for him to disclose his HIV-positive status to them when he became aware of it. He described his dilemma:

“... it is difficult for the MSM person who is gay to tell your parents that you are gay and that you are sleeping with other men. Because you did not tell them that you are gay, it becomes difficult to tell them that you are HIV-positive, they would be shocked because they never saw your girlfriend. You have to wait until you tell them that you are gay, until they understand and accept you. When they have accepted you, it is then that you can tell them that you are HIV-positive. You will make a serious blunder if you disclose your sexuality and HIV status to your parents at the same time because they will say that you deserve it. Many people out there believe that AIDS is caused by gay people.” Lebo (pos, --)

It took him some time before he disclosed his sexual orientation and HIV status to his mother who was supportive. After that he disclosed to his father and finally to the community “*now everybody in my community knows and they are supportive to me. I am happy with myself and I am using protection all the time when I have sex.*” Lebo’s story confirmed Geffen (2010) assertion that sometimes disclosure of HIV status means that other secrets are divulged at the same time. In order to disclose Lebo had to overcome his fear of being stigmatised because of his sexual orientation and his HIV-positive status.

Some men were able to speak openly with their friends about being HIV-positive. Tshepo (pos, 30) explained: “*I think people [friends and family] who are close to me are the ones. I [discuss] everything with them. I don’t have any secrets with them. Most of the people have secrets. I don’t believe in secrets.*” Tshepo needed and wanted his friends to know that he was HIV-positive so that they could “*treat me properly knowing what kind of precautions to take when they offer care and support.*”

Further afield from the men's close circle, talking about health issues got more complicated because of the stigmatisation that persisted in their communities. For Patrick, being HIV-positive had been a trial. He had support from his wife, but believed he needed a support structure outside of his home. The response from the community has been mixed:

"You need a good support structure to deal with the challenges that are related to the illness, hence I reached out for support to people around me including my neighbours. It wasn't easy, as some of them had been quite difficult and discriminatory. But others have been amazing, and they have continued to support me regardless. Some of them even directed me to the local caregivers. I remember that there was a time when I was not feeling well and as a result I could not walk properly. They would even wait for me by the taxi site when I come back from collecting medication at the hospital. They would assist me by picking me up and walking me home. Sometimes they would even say that they forget that I am HIV-positive and they only remember when I am not feeling well." Patrick (pos, 36)

Patrick was able to engage with the community and get their support because he has accepted his situation, which he no longer kept secret.

On the other hand, Bongani (pos, 35) only disclosed to his wife and that did not go well at first: *"[She was] very angry and hurt. I guess I'm the one who gave it to her. I think I've had it for a long time. But she eventually came around and we continued living our lives. I was surprised that our child does not have it. How [is it] possible ... that we are sick and the child is not?"* He felt guilty that he infected his wife, but was relieved that his child was negative. He had not disclosed to his friends because *"if I tell one of them, then the whole community will know."* Bongani was reliant on his wife for support.

Some men were afraid of disclosing their status because it opened up issues of sexuality and sexual conduct.

Zakes described the difficulties of talking about HIV:

"You know us Africans we are uncomfortable when talking about sexual issues. Now when it comes to HIV and knowing that you get it when sleeping with someone who is infected, then we are not open enough. People fear knowing their status and they don't want to talk about it." Zakes (pos, 38)

Zakes blamed himself for being infected. He felt guilty for infecting his first girlfriend, her subsequent lover, and perhaps his latest girlfriend. His first girlfriend died and he looked after his daughter who was HIV-negative. He was grateful for that: *"She is 10 years old. She stays with my mother in the main house. I support my child."* He recalled how difficult it was to disclose to his latest girlfriend *"I thought she would leave me because of fear that I would infect her."* He tested HIV-positive whilst in prison but it was only

sometime later that he made the decision to disclose. He described why he made this decision. Over time it became increasingly difficult for him to insist on using a condom when they had sex. He was also hiding his ARVs from her. It became more difficult to make up excuses to go the house to take his treatment, and he missed taking it a couple of times. Eventually he made the decision to disclose: *"I told myself that whether she leaves me or not, it won't matter at all because this is my life"* and then *"I told her that I had to be honest with her and I don't know how she will take it but I'm ill. I told her that remember when we met I had boils growing on my skin but now they are gone because of the treatment I'm taking."* He suggested to her that it was likely that they both were HIV-positive. She reacted badly: *"She started to fight and told me that she was always faithful."* She eventually left him. He said: *"I think she was afraid. I mean you and I both know that condoms can burst and she could have gotten infected."* He got support from the clinic and support groups, he encouraged his friends to test and know their status so that if they test positive they could get treatment early. He described a situation when a friend disclosed his status to him, which enabled him to share his own status and he found that it lifted a burden. He said: *"He also told me that he had tested positive. I was free when I was around him. We could share our pain and frustrations. He could go to my home and get things that I needed and bring them to me."* Zakes had to come to terms with possibly infecting both his girlfriends and perhaps others. His relationship came to an end after he disclosed, but he did not believe he had a choice, as he wasn't able to take his medication properly and this would adversely affect his health outcomes.

As Zakes described above, disclosing to one's partner or girlfriend was not easy and could have negative consequences. In order to mitigate against a negative outcome, Amos (pos, 36) made a plan around how to disclose in a new relationship. Amos found out his HIV-positive status only after his wife died. Her death certificate gave pneumonia as the cause, but he was curious about the diagnosis and made some enquiries. Someone suggested that it may be linked to HIV and he decided to test. The results were positive. When Amos met a woman whose husband had died of AIDS, he knew he was positive. He wanted to start a sexual relationship with her and suggested that they test together as he wanted to know her status. Both tested HIV-positive, but *"She was very shocked."* He waited until they were at home before discussing his results with her: *"I said to her don't be like that because this is something real. It is not only you who has this. It's lucky to get a person like me who has HIV. It is lucky to find me as a boyfriend [...] and she understood that."*

Although Amos felt sorry for her, he was pleased that they were both positive as they could “*push life together.*” They were both on ART and reminded each other to take their medication. They made sure that they lived life to the full: “*...we shouldn't have to say that because of we have got AIDS we don't have to be with other people, you know things like that ...(laughing) we are just living a normal life. You won't say [from] the way we are living that we have got AIDS. We enjoy life.*” However, outside of his relationship Amos had only disclosed his status to one friend and a sibling who did not live with him. He had not disclosed to his parents.

For David (pos, 30) disclosure to his partner was made much easier because she disclosed to him first, early on in their relationship. “*At first when I proposed to her, she kept avoiding me and telling me that she did not want a man in her life. I pursued her until she revealed that the reason why she does not want me was because she was HIV-positive and [that] if I go out with her I will be putting myself in danger. I then told her that I was also HIV-positive.*” He said it took them a while before they got used to each other. He tried to keep the relationship going, but they were struggling because they did not have money and could not buy healthy food. He sometimes relied on his mother, but this was difficult because his sister was also HIV-positive and relied on his mother who was unable to support both of them.

Relationships were very important for these HIV-positive men, but negotiating new relationships was difficult. The idea of having a relationship with an HIV-positive woman was appealing for the men, as they felt it would be easier to share their experience. The start up of positive dating clubs in Africa such as “The Positive Connection” and “HIV and Single” suggested there was a need for more open and up-front disclosure.

Unlike most HIV-positive men who were careful about who they disclosed to, Xolani (pos, 41) was completely open about being HIV-positive. “*I told everyone. Some were shocked and told me that I am brave and strong because I was able to tell everyone that I was HIV-positive. I told them that the more I talk about it I will accept that I have the disease much sooner, and I won't stress about anything... They [friends and people in the community] don't have a problem with my status. They share cups and other utensils with me. They are free and open towards me. They motivate me and offer me moral support.*” Being open had allowed

him to build strong relationships with other men who were also HIV-positive. HIV stigmatisation had not affected Xolani and in his case broad disclosure had benefited him and provided support.

The HIV-positive men found it difficult to disclose and made calculated choices on whom to disclose. The majority had only disclosed to families or partners and some to close friends. HIV stigmatisation had inhibited most of them from disclosing to people outside of their close circle. The men had become self-reliant and in some had built new identities. They evaluated whom they could trust to know their status, and they renegotiated relationships, friendships, and their social standing in the community. Similar to the men in Mfecane's study (Mfecane, 2010), being HIV-positive had forced these men to reassess the image they portrayed to others.

15.4 Knowing other people's status

The men had mixed responses when asked whether it was important to know other people's HIV status. Some stated it was important to know and others not. Knowing other people's status allowed one to avoid being infected, but also carried with it some responsibility to the person disclosing.

Some men stated that it was not important to know *"just anybody's status."* Musi (ntst, 20) was not curious about other people's status and would wait until they disclosed to him, but he recognised that this was unlikely, he said *"there's a lot of people who do not feel comfortable with doing that."* Musi, like many other men, avoided talking about health and other personal issues with other people. Similarly, Clement (ntst, 18) did not feel it was his *"business to know other people's status"*, but he would feel comfortable if he did know and could give them support. With his close friends and family he would like to know so that if *"anything happens then I know that it is because of this [being HIV-positive], not because it's just happened randomly."* Clement wanted a better understanding of what the consequences may be of any interaction, sexual or otherwise. Clement and other men agreed it was important to know their friends' and partner's statuses so that they could help them. Some men wanted to know other people's status so they would know *"what precautions to take"* and be able to avoid *"unnecessary risks."* By knowing they would be able to prevent becoming infected. The men said it was important to know their partner's status because it could be dangerous for them if they were unaware that she was HIV-positive. As Mark (neg, 19) stated, *"Yes, Yes, Yes! I need to know whether I'm safe being with her. I should not just risk with my life."* However, Eugene

(ntst, 19) suggested that disclosure of either person's status in a partnership could be delayed until one became sexually intimate.

Some men felt it was important to know other people's status so that they could support or help them when it was required. A couple of HIV-positive men believed that they were in a good position to help others because they had a good understanding and experience of HIV/AIDS. Amos (pos, 36) felt he would be able to offer advice: *"I must be able to advise her and show her the right way to follow so that she must live a little bit longer."* Bongani (pos, 35) described how a group of HIV-positive people took an active role in assisting those who they suspected were HIV-positive: *"They went to her house and talked to her until she felt comfortable in disclosing her status. She also started coming to the support group sessions."* These men used their knowledge and experience to help others.

Disclosure was considered to be difficult and often avoided. In one instance a discussion about HIV/AIDS stimulated a friend to disclose to Matthew:

"I was having a conversation with my friends about my dad who passed away because of the disease. Only to find out that one of the friends whom I had the conversation with came to me later on and told me [that he is] HIV-positive." Matthew (neg, 20)

In this case Matthew felt *"bad for him"* knowing his friend was HIV-positive and he was not.

Disclosure was difficult not only for the person disclosing, but also for the person who was being disclosed to, as Sipho (neg, 23) found out. He did not believe his friend when she first disclosed to him that she was HIV-positive and found it difficult to comprehend. He even checked with her family to confirm what she said. She was not sure how she was infected but he *"treat[s] her well. I don't care how other people treat her. I do not know how I will be treated if I were to become infected. But with my friend we don't discriminate [against] her. We sometimes forget that she has the disease."*

Some men were unsure of how they were supposed to react or what role they were supposed to play when someone disclosed to them. Tshepo (pos, 30) described how a number of people had disclosed their status to him but he was unsure as to how he could help them. He mulled over this, saying: *"they disclosed to me just to make me alert and that I shouldn't be surprised because if he is sick. He is still like a normal person."*

When a friend disclosed to Tebogo (pos, 27) that he was HIV-positive he wondered why his friend had chosen him, what he was feeling, and why he was comfortable disclosing. He believed that God had sent his friend to him *“so that we can share our experiences together and make me feel normal. Eventually I decided to disclose to him as well.”*

Thulani (neg, 22) felt *“special”* that people had disclosed their status to him and wanted his help, but he *“was clueless on how to help.”* Jabu told a story about a female friend whom he had known for a long time, even prior to her becoming HIV-infected. They had a close relationship and cared for and protected each other. He described his anger when he discovered she was HIV-positive:

“I wanted to kill the guy who gave it to her because he is irresponsible and he was only thinking about himself. He didn't think about her. He didn't think ... actually they have a child. He didn't even think about their child. He gave it to her when she was still pregnant. Yes, the only thing that I am glad about is that the child was born HIV-negative. She had to take some medication that prevented the transmission of the virus from her to the baby. It really got me angry. I thought this might actually limit her from enjoying time with her child because she might have to live for maybe ten years or more and then she would start getting really sick from the disease. On the other hand I also got frustrated by the fact that her partner was selfish and cruel. If you are HIV-positive and you don't tell your partner that you are positive and then you sleep with them without using a condom it is the same as taking a gun and shooting them. You are actually taking an innocent life.” Jabu (ntst, 28)

His friend told him that her boyfriend had confessed that he was HIV-positive after he had slept with her, and that he had been infected from a *“one-night stand.”* Jabu was angry and upset that her boyfriend did not respect her or their child and that he was selfish.

Brian talked poignantly about a girl he knew who had died from HIV and how he felt about her.

“I was shocked and I asked myself how can she be positive? ... I felt sorry for her. I felt she was in her own lost world. Finally she is in a peaceful place and hopefully the Lord will forgive her. [...] I only took the important factors like if you're a person you must be careful and not just live life carelessly. [...] You don't just sleep with anyone on the street. I understand we as guys like asking girls out but still we need to control ourselves and say here is where I'll go and there I won't go. No matter how beautiful the lady is we need to control ourselves.” Brian (ntst, 26)

From this incident Brian learnt that he needed to protect himself [use condoms] and needed to alter his traditional modus operandi around women in order to take care of himself and avoid getting infected. It appeared that his notion of masculinity was in transition and he was rethinking how he negotiated relationships.

15.5 Discussion

Men take their personal and health issues seriously and tend to keep these private. Talking about health or illness and disclosing of HIV status is not easy for the men, but they acknowledge that disclosure can be beneficial. Sharing these private issues is not typical masculine behaviour as it shows weakness. For those HIV-positive men who were able to share their status it has reduced their stress, lifted a burden and given them access to support.

The men mainly confided in female family members and their partners and fewer to their friends. They did not mention talking to health workers, traditional healers or religious leaders. For men their health is personal and they do not want it discussed widely.

The men have mixed feelings about the importance of knowing other people's HIV status. Some did not believe it was important unless there was a reason, but others wanted to know.

Engaging in relationships in the era of HIV/AIDS has made them more complicated, especially for men who are HIV-positive. The men believed that it is important to know their partner's status. If they were starting a new relationship they wanted to know their partner's status before they became sexually intimate in order to protect themselves. The HIV-positive men struggled with disclosure because they were worried that their partner may leave them. They also felt guilty that they may have infected their partners or previous sexual partners. In new relationships the HIV-positive men developed strategies to deal with disclosure including mutual testing and suggesting that it would be easier to have a relationship with an HIV-positive women.

Disclosing more widely was hampered by HIV stigmatisation. The men who were HIV-negative or had not tested speculated that they would be brave enough to disclose and the men thought that people who disclosed publically were brave. Although the men thought others who disclosed were brave. However, the HIV-positive men struggled disclosing to the people in and out side their close circle. HIV-positive disclosure reveals more than being HIV-positive but also can be a disclosure of other secrets. The HIV-positive men were aware that their status not only affected them, but also the people close to them. They mentioned that they would need to get permission from their family to disclose to others.

The men agreed that they would support HIV-positive people and would not discriminate against them, however they acknowledged that stigmatisation persisted. Some men were pleased to be disclosed to but others were concerned because they were not sure how to support the person although they now felt some responsibility towards them.

Talking about personal issues and disclosing their HIV status was beneficial for the men, although it is not regarded as masculine behaviour, provided it was done in a supportive environment. HIV stigmatisation hampered the extent to which they could disclose.

Chapter 16: Seeking help in the public sector

Soweto is a relatively poor community with high unemployment and the majority of people in South Africa access public health services (Walker et al., 2004; Hassim et al., 2007). For this reason, men's interaction with the public health service rather than the private sector is explored in this study. These demographics are reflected in the male participants who were mainly unemployed or had limited income (21/33) and are therefore unable to afford private health care.

Only a couple of the men were able to afford private care. Eugene (ntst, 19), depending on his condition, consulted private clinics or his family doctor whom he had known since he was a youngster and was confident in his care. He mentioned that at the public clinics there were often long waiting times before being attended to. He also consulted THPs for life issues.

A few men in this study mentioned that they would have liked to have the choice, arguing that private clinics or doctors provided better services and cared more for their patients. At the same time they noted that private care was expensive and lamented that they could not afford it. The literature also suggests that public health care was of a lower quality than private health care (Hassim et al., 2007). However the men who visited the public clinics reported that they were well looked after and received the right medication although they had other complaints. They were confident that the health care workers could address the *"health issues facing men."* Although some of the men were sceptical of the service offered in the public clinics, the majority (31/33) were willing to go to them if they were unwell.

The choice of health service was found to be based on a number of factors including transport and other costs, the attitude of health workers (Hassim et al., 2007; Holroyd et al., 2008; Serrant-Green & McLuskey, 2008), and issues regarding confidentiality (Preston-Whyte, 2003). These findings were endorsed by the men, as described below.

The men were asked which clinic they would go to if they were ill. The clinic closest to their home was most preferred (6/33) as it was convenient, staff were familiar, had information, or because of cost. As Kabelo (ntst, 33) commented, *"I'll be able to reach there even if I don't have money for transport."* Lucky (ntst, 20) went to the same clinic each time because he was familiar with it; he was born there and has been going there

ever since. A few said that they were not concerned about the clinic location “... *as long as the clinic is good.*” These responses differed from where they said they would test for HIV, which they wanted to do anonymously and preferably away from their neighbourhood.

Two of the HIV-positive men favoured going to Chris Hani Baragwanath Hospital (Bara), one of the first facilities in Soweto to provide ART, even if it meant having to travel quite far. Tshepo praised and was happy with the service offered there:

“If I didn’t go this hospital it means that I would have never become all right [have recovered]. I am currently living in Orange Farm [situated on the outskirts of Soweto, a distance of 30km from the hospital]. There are some clinics and I go there just because they are nearer, but I still believe that Baragwanath is number one and the best.” Tshepo (pos, 30)

Most HIV-positive men preferred going to a clinic that they had become familiar with. Tebogo also went to Bara as he trusted the staff and was treated well. When there, he was able to be open about being HIV-positive, as he elaborated.

“I was born in Soweto and I would prefer to go to Baragwanath Hospital even though people say it’s not a good hospital. I know I will get proper treatment because I was born in that hospital. Bara hospital is very big, I go there whenever I want to. Even if I need counselling I can still go there. [...] I know that I won’t only go to Bara because I’m ill. I will go there to share my experiences with other people that have the same disease as myself. The counsellors at Bara are very friendly and open. We can share anything with them.” Tebogo (pos, 27)

When they were sick these men preferred visiting clinics that were familiar and where they felt comfortable. These clinics were not necessarily the closest ones to their homes, but they were prepared to travel in order to get good service; however, this was constrained by their lack of funds.

16.1 The structure of HIV/AIDS services as a barrier

The literature suggested that men were reluctant to seek help because they did not want other people to know that they were ill, for fear that they may be perceived to be weak. Being observed visiting a clinic could be construed as being weak, and men may lose some of their social standing in the community.

In South Africa, public health HIV/AIDS services were developed and implemented separately as a parallel health service. In most clinics HIV/AIDS services were not integrated into mainstream clinic services, and were provided in a separate space. This may have promoted stigmatisation and discouraged people from accessing them. As one doctor elaborated: “*when you go to an ARV clinic you will find the consulting rooms*”

are at the back of other consulting rooms. I think that has to stop because people think they are isolated" (DOC9). A couple of men agreed that these separate services are a problem. Andrew (neg, 24) observed: *"It becomes obvious that when you go to that building, you must be HIV-positive."* People could be identified as being either HIV-positive or in some way associated with HIV/AIDS when they went to these services. In addition, the clinic staff encourages people to attend HIV/AIDS services in their local area, which prevented men from being anonymous. These factors deterred men from accessing HIV treatment and may cause them to default on their treatment because, according to a community outreach worker (COO6), *"people in the community know each other and others don't want people to know their status."* Therefore, attending HIV/AIDS services was considered a public disclosure of one's positive HIV status.

Stigmatisation remained a constant concern and had impacted on men seeking help. The participants indicated that if someone was recognised as being unhealthy, or was observed at a clinic where there were HIV/AIDS services it could lead to speculation in the community about the person's illness and could *"jump to conclusions"* about their HIV status. Knowing that this speculation could occur was enough for these men to keep their illness a secret.

These separate services further fuelled stigmatisation. Some of the participants expressed the view that the level of stigmatisation in the community was so high that people did not want to be associated in any way with HIV/AIDS services. Whilst the men said that they would visit a clinic close to them if they were sick, they were less comfortable going to a nearby clinic for HIV-related services where they were known or might be recognised.

The health workers proposed that stigmatisation drove people, and in particular men, away from HIV/AIDS services. One clinic manager commented, *"Stigma is still a problem with men. Most of the women that we have enrolled have dealt with stigma because they are informed. Men still have wrong information on HIV. I think that is the reason stigma is such an issue with them"* (MGR2). This clinic manager suggested that men were ill informed about HIV/AIDS and this contributed to stigmatisation. As described earlier, the better-informed people were about HIV/AIDS the more likely stigmatisation would reduce, but in this context stigmatisation persisted. In this case men had internalised stigmatisation and were reluctant to access the clinics for fear of reprisal.

Unfortunately this was detrimental to men's health, as a community outreach worker (COO6) pointed out, saying that men would *"rather not go there [to a clinic] at all"* and they delayed getting treatment: *"When they get sick is when they start coming to the clinic. They are delaying the process because of the stigma."*

High levels of stigmatisation persisted in Soweto and separate HIV/AIDS services were a barrier for men to access help and had played a negative role in men's help-seeking behaviour. It had caused men to delay seeking help until they were sick and had no alternative, as also found by other researchers (Deacon et al., 2005; Schneider, 2006; Wolfe et al., 2006; Nyblade et al., 2009).

Furthermore, the clinic managers stated that many of the men who attended the ART clinics come from far away because they did not want to be identified as being HIV-positive by their acquaintances for fear of being rejected, as one clinic manager explained:

"Some of our patients, when they test positive, they move to other areas fearing that they are going to be stigmatised by their neighbours. As they disclose their statuses, they lose friendships in the process." MGR5

Although the managers tried to encourage their patients to attend a clinic close to where they lived, they had been unsuccessful. One example of the excuses the men make was, *"They tell us that they cannot go to their local clinic because the staff is not friendly, but we know that it is not about staff"* (MGR2). One VCT site coordinator (CORD8) remarked that men asked to be referred to clinics where they were not known. She surmised: *"they are afraid to be seen by the people who stay with them in the same area."*

However, one manager (MGR5) was concerned that travelling may impact on her patients' ability to adhere to their treatment which would be detrimental to their health outcomes in the long term. She explained: *"it is expensive to travel long distances, especially to collect their medication. They may end up not coping."* But she conceded that her patients who come from afar were coping, *"they come and are the first to arrive on the day of their appointment."*

For general health issues the men were prepared to visit a clinic close to their home as long as the clinic staff were professional. However, due to stigmatisation, when visiting any HIV-related service, such as VCT or ART, they were very concerned about who was privy to knowing their HIV status. A key concern for men was that their HIV status and personal issues must be kept confidential. They preferred going to clinics

where they were not known and made an effort to avoid being seen by people who knew them, thereby ensuring that their status remained a secret. This was a practice observed in other studies amongst women (Gilbert & Walker, 2010).

Although the men stated that they would go to clinics when they needed to, in practice they avoided going until they had to in order to retain their privacy. The secondary informants noted that men were averse to speculation about their private business including health, and stayed away from clinics to avoid this. As reiterated by one THP (THP3): *“Men don’t like their secrets to be known”* and they *“are scared of people knowing their problems.”* She suggested that men thought that other patients gossiped about them, that they were the *“topic of the day.”* One of the clinic managers (MGR2) agreed that men were very *“uncomfortable”* being in a clinic because of the possibility of being recognised by someone they knew. She elaborated: *“Men have a problem. If they are seen in a setting like this, it automatically says that they are positive. They don’t want to be seen in and around a setting that has anything to do with HIV and AIDS because they are going to be labelled.”*

The men confirmed that they liked to keep their health matters private and are concerned about being ostracised. Amos (pos, 36) suggested that men thought it was shameful to be seen visiting a clinic and they did not want others to discuss their business. He explained: *“We have got that shame of saying ‘what will other men say when they see me standing on queue following the woman?’ Some feel shy.”* This highlighted a number of issues: men did not want to be seen as being vulnerable by other men as it was an infringement on their masculinity; they believed that they should not have to queue with women and were embarrassed about what other men would think; and they wanted their business to be kept private. Phil agreed, and further emphasised that the community was quick to judge and victimise people going to clinics:

“They [men] don’t want to be associated with such things [HIV/AIDS services]. They fear the kind of victimisation and judgement they would get from people in the community. Because, as you know, people who are seen to be weak or somehow sick and are seen in clinics or such sites are generally diagnosed with HIV, even if they are not. People in the community like poking their nose[s] where they don’t fit. They will say things anyway.” Phil (ntst, 18)

For these men, being seen at the clinics was equated to being ill and either having or suspected of having HIV/AIDS. This was a weakness, and could infringe on their masculinity and social standing in the

community. Therefore they were reluctant clinic visitors, going only when they were very sick and could not avoid it.

Clinic hours were also fixed and were a barrier for working men or men looking for a job. They were likely to be occupied during the day and therefore preferred to visit a clinic in the evening or on the weekend. The health workers agreed that men would rather *“come in the evening when nobody is around”* (COO6). But clinics were not generally open in the evenings. This was problematic, as one clinic manager (MGR2) pointed out, because most clinics, and particularly those that provided HIV/AIDS services, were closed on weekends. For people who were working this was a major challenge as it was not convenient to take time off work to consult or to collect their medication: *“Unfortunately they do not have time to rush to the clinic because they are highly occupied at work.”* Taking time off work to go to the clinic often means that they had to disclose to their employers that they were HIV-positive and face the consequences of doing so. Although HIV-positive people were protected by law against unfair discrimination, in practice there could be reprisals. Therefore, for those men who were employed the barriers to accessing care were even higher and the men may prefer to stay away.

The public health facilities were generally very crowded, especially in the mornings. Some health workers noted that clinic queues and long waiting times were problematic for men who did not want to be seen by others. One counsellor (CNS7) questioned some men and found that a *“major factor”* for not coming to test for HIV was the time wasted at clinics. Men wanted the services to be *“short and quick.”* She said: *“Most of them [men] are willing but the problem is time.”* Men (5/33) also complained about the lengthy waiting time before being attended to in a clinic and suggested that the slow service could be due to staff shortages.

Men liked going to the clinics where there were fewer people and when it was convenient for them. One clinic manager (MGR5) found that if she gave a morning appointment to her male patients then they would stay away: *“If you give the person an early appointment, he will not come. He knows that we are seeing our people in the mornings. He will wait until all the people are gone. It will be then that he can come for his medication.”* In this case the clinic had adapted their procedures to accommodate these men in order to keep them in care. As she noted: *“We just have to accept the situation as it present[s] itself to us in order to keep them with us, because if we try to tell them to stick [to] the time that everybody is coming to the clinic, we*

will lose them, and they will never come back.” However, not all clinics were flexible, and in practice few were able or willing to accommodate these needs.

The men complained about slow and inferior service. Two men went to a clinic after being involved in accidents and were very unhappy about the service they received. When Reuben (neg, 21) arrived at the clinic with a broken arm the service was very slow and there were few staff. He said: *“I felt very angry because here I was in a lot of pain and we were not being attended [to].”* Clement (ntst, 18) had a bike accident and broke his chin. He was in a lot of pain and needed emergency care, but the service was *“very, very, very slow.”* He was afraid when inexperienced *“internship students”* attended to him as *“it was their first time doing a lot of things.”* He felt that he needed someone who was more qualified to treat him, as his condition was serious. He remarked, *“it sucked, yes it was bad.”* These experiences were unlikely to encourage these men to embrace seeking help at clinics.

Although most of the men had bad experiences in the clinics, they had no other options. Martin (neg, 25) felt he had no choice but to accept the conditions in the clinics in order to get help, and remarked: *“well it is disturbing as generally people work within constraints of time. One doesn’t have the time to spend the whole day in clinic and also to not be respected, especially when you are not feeling well.”* Similarly, Abel (neg, 27) said: *“Aah ... There’s really nothing I can complain about, they were just okay... (Sighs) The service is very slow but when you need to feel better you’ll just have to be patient and wait until you get attended [to].”*

The men were not satisfied with the slow and sub-standard service they received, but many were resigned to accept it and did not think it would change. The men felt that the clinic staff neither respected nor cared for their patients. However, the men did not feel that they were empowered to alter the service in any way. Men may prefer not to go to the clinics at all rather than not be “respected.”

16.2 Health care workers attitudes as a barrier

Health workers have been found to have discriminatory attitudes towards their patients (Hassim et al., 2007; Nyblade et al., 2009). These were likely to deter men from visiting the clinics. Health workers in this study believed that their patients were well treated, but that the patients were difficult to satisfy. A VCT site coordinator (CORD4) reported: *“The staff receives them [men] respectfully, kindly. But men would tell things they don’t like. Otherwise the staff has no attitude towards them.”* A clinic manager (MGR5) agreed

that her staff “are good towards our patients [...] But one thing for sure is that patients sometimes will not be happy with the way you are treating them.” A community outreach officer (COO6) suggested that staff did their job well, but patients did not like how they were doing it, so they “say that you are rude.” These health workers believed that they were doing a good job, but recognised that their patients were not in accord.

However, not all health workers agreed with this position. A counsellor suggested that staff burnout and the large volume of patients rendered them unable to provide quality services. A clinic manager conceded:

“At times health workers can be rude to patients especially if they are defaulting on their treatment. [...] Our staff, here at our clinic, know that our patients’ health is the priority to all of us who work in the clinic. They cannot take a chance to mistreat the patients. We have cases where patients report situations in which they were treated badly, and the employee was disciplined for their attitude toward our patients.” MGR2

The majority of men disagreed with the assertion of the health workers that they treated their patients well. They stressed that staff were unfriendly and did not provide a good service. Only a few men had experienced reasonable service at the clinics. They said that staff attitude was “okay” and indicated that staff “know how to communicate with patients”, were patient, friendly and polite. As one man described: “The nurses they’re friendly. They talk to you and help out. I went there 07:00 in the morning and 09:30 I was done” (Sipho (neg, 23)). These men felt that they had received good service, were given the correct treatment, and that the clinic staff were able to cope with the long queues efficiently, but were in the minority.

There were mixed reports on staff attitudes at HIV testing sites. A few of the men reported being “very satisfied”, feeling “comfortable from the beginning” and had good experiences, with sufficient counselling, information, and advice on how to cope with the results. But the service was “just okay” for Tshepo (pos, 30) who suggested that nurses should treat him properly. Abel (neg, 27) commented: “There was just one nurse who was rude to us, she kept moving us from one place to another. The others were okay.”

Similarly some men found that the service in the clinics was variable as Musi explained:

“The services offered at my nearest clinic are okay on some days and on others it’s very bad. They don’t treat their patients well, especially patients who are very ill. They sometimes force a very ill person to stand in a queue for a long time. Some patients even die in the queue. I feel that people who are very ill should be given immediate attention.” Musi (ntst, 20)

The bad treatment Albert had received at one clinic made him “*think twice*” about visiting it again, although he would “*reluctantly*” go back if he had no option because he was very sick. However, he also noted that staff attitudes varied:

“Okay sometime[s] those people act strange. I think it is because they come with their personal vendettas and treat you bad on that day. You start feeling that ... eish! At the clinic, they don’t treat people well. But that does not happen all the time. There are times when they will treat you like a VIP and give you the best treatment ever.” Albert (ntst, 21)

However, the majority of the men (25/33) reported that their experiences at clinics were not good. Staff attitude was a big problem for Jabu who felt that the staff were sexist. He recounted his experience when he went with his girlfriend to his local clinic because she had an STI. He was upset with the nurse:

“They insinuated that she got that sexual infection from her partner. That shocked me because the only person I had sexual encounters with was her [...] But you know how the nurses are, they actually believed that I was the one cheating. We were both thinking that there should be another possibility of getting the infection, because we were both not cheating. That’s when they started talking about the possibility of getting such an infection from a toilet seat. They said that it is possible to get it from the seat if it has been used by someone who has that infection [...] I want to believe that it is possible that she got it from the toilet seat, probably a public toilet [...] I mean I don’t want to imagine that any of us can think about cheating, whilst we have a three years old baby to worry about. For me, contrary to what the nurses thought, my major concern at this point is to raise my child and provide for [times] where there is a need.” Jabu (ntst, 28)

Jabu felt that the nurses were “*sexist*” and “*quick to blame men*” without understanding the full story. He was concerned about the staff’s sexist attitudes and stated: “*A man is always the one who is a cheater in their minds. When a woman cheats they say she is doing that because she has been hurt by a man.*” Jabu said he was not alone and other men had similar experiences:

“Most of the time some of the guys from my community are discouraged to even take their kids to the clinic for the check-ups. The first thing they start thinking about is the sister who is going to shout at them. Before she checks the child she is going to keep on nailing you. By the time she gives the medication, you won’t be having the energy to pay attention.” Jabu (ntst, 28)

The sexism described above would discourage men from visiting the clinic. Men expected to be respected, but the clinic staff did not afford them respect. The nurses, who were mainly women, had power in the clinics that they were unlikely to have at home or in their communities. This change in roles and power being in the hands of women did not sit well with the men.

The men were sceptical of the clinic staff's dedication to their work, and felt that they were lazy. Some men suggested that staff's *"primary interest is to make money out of what they are doing, although they don't do much."* Some doctors came under criticism for only wanting to make money, but the men conceded that others were caring and helpful. One man complained that the doctors only came to the clinic at certain times, *"Then he checks two patients. Then he is off to a tea-break. There'll be patients who are very ill who need his immediate attention. He doesn't care. All he's interested in is his tea-break"* (Lucky (ntst, 20)). Other clinic staff were also noted to take long tea and lunch breaks; they *"talk a lot whilst patients are waiting [...]* *staff members are not fully committed to their work"* (Mdu (neg, 18)) or were simply unhelpful.

Common complaints made by the men included that nurses swore or shouted at patients and were intolerant: *"they reckoned that I talk a lot and also ask too many questions. Some were even starting to be annoyed by me"* Jackson (pos, 34). They also complained that some clinics were short-staffed and had stock shortages of essential drugs such as painkillers.

The HIV-positive men spent a considerable amount of time at the clinics and generally reported bad experiences. They found the clinic procedures were confusing, the staff unhelpful and they were unhappy with the service that they received. Furthermore, some of the men felt that the clinic staff did not care for their patients at all. Bongani (pos, 35) complained that nurses did not help new patients understand the procedures and said *"they don't care whether you are ill or not. They will tell you to come back tomorrow. They sometimes send patients away and tell them the doctor is not around, he's at another clinic and they should go to that clinic. These people have been waiting for a long [time]."* Jackson (pos, 34) agreed and said: *"Things like that [cause] problems. By the time you go up and down like that your body gets tired. What if you get stuck on the way then what will they do? [...] That is why I am saying their service somewhere, somehow is not good enough at all."*

The men also reported that the clinic staff were *"moody"*, brought their problems from home to work, or that they were tired. A few of the men reported that nurses swore at the patients. Bongani (pos, 35) elaborated: *"The nurses have a very bad attitude. They don't treat us well. They swear at us all the time."* The men also wondered if nurses were disrespectful to them because they were HIV-positive, but Amos (pos, 36)

speculated it was because nurses thought that patients did not know their rights. Zakes wondered if it was because the nurses themselves did not know their own HIV status, and he avoided going to these clinics:

“The nurses at the clinic have very bad attitudes. They think they are better [than us]. Some of them don’t even know their status and they call us [names] because of our status. They treat us badly, so I won’t go to the clinic for treatment even when I have a cold or something I wait for my check up on Wednesday’s then I go to my doctor at Nthabiseng [ART] centre.” Zakes (pos, 38)

However, Thabo (pos, 52) did not believe that nurses were only disrespectful towards HIV-positive patients, but to all sick patients regardless of their HIV status or age, and recalled an incident he had witnessed of nurses swearing at an “old granny.”

Some HIV-positive men had established a modus operandi that enabled them to visit the clinics, as Xolani described:

“I have a lot of friends and many who are HIV-positive. What I do is I refer them to my support group. They then take them to the clinic and they speak to the nurses because they are familiar with them. As for us, the nurses disrespect us and they don’t regard us as normal human beings.” Xolani (pos, 41)

Xolani had resorted to consulting a private doctor because of the bad service at clinics and nurses’ bad attitudes, swearing, and shouting at patients. As previously described, Soweto was a poor community and many of the men were unemployed, but David (pos, 30) indicated that he and other people were still prepared to pay to travel to a clinic that they thought would provide them with better service.

Some men had the courage to fight against staff’s bad attitude and reported that it had improved. Amos (pos, 36) felt that staff disrespected patients and made them “wait for a long time [but gave] themselves the long times for tea breaks and lunch.” The staff also “take advantage by swearing at you.” Amos decided that enough was enough and told them: “what you are doing is not right. I can go and report this and you will lose your job very quick[ly]. That is the time whereby that person will get shaken.” He claimed his intervention had improved the service: “When I get there they already know what to do for me. They stand up and help the clients as quick[ly] as possible. I am proud of that because if I [had] kept quiet they were not going to be aware of that kind of a situation.”

Patrick (pos, 36) also found a way to deal with staff's bad attitude: *"I always tell them that they should not provide service as if they do us a favour. They must just deliver on their deliverables and leave everything else. I have also decided to buy some presents for those that have treated me well during my course of medication for TB."* His wife helped him to choose gifts to say *"thank you"* for staff who gave him good treatment, but *"As for the ones that had some attitude, they are not getting anything."*

Both Amos and Patrick had stood up to the clinic staff and fought for better treatment. Through asserting their rights they felt empowered by what they had done. However, this was unusual as the majority of men accepted the clinic staff's poor behaviour.

The majority of men reported being treated badly by the clinic staff, but only a couple fought back. Although men hold power in the community and they should be able to command respect in the clinics, only two of them felt strong enough to fight back. It may be that the men felt disempowered because of their illness and the need to seek help from clinics staffed by women, which they would normally steer away from.

16.3 Gender of health care workers as a barrier

The clinics in Soweto were largely staffed by female health workers and the participants perceived this was a barrier for men engaging in the services. Seidler (2006) suggested that men did not like to be questioned or challenged by anyone, but particularly not by women. The secondary informants agreed that men did not want to divulge their personal issues, vulnerabilities, or "weaknesses" to female health workers. As a VCT site coordinator described:

"Culturally the man is the head of the family, so some of them won't take it easily to be taken care by a female." CORD4.

Furthermore, another counsellor (CNS1) suspected that prevalent gender roles in society influenced men's experience in the clinic commenting *"men are the head of the house."* The clinic environment did not afford men respect, as they were not given preferential treatment. They had to wait in queues to see a doctor alongside women and children. This counsellor reported that her female clients said that men *"wouldn't want to come"* to the clinic because:

“African men know that they should provide, just provide for their homes. No discussions such as HIV and AIDS are being discussed because of certain issues [...] but I think it is how they were raised ... A man doesn't cry.” CNS1

Furthermore, some secondary informants observed that older men found it even more difficult going to clinics and being attended to by women. As a clinic manager related:

“... especially old men. There was a situation where an old man stormed out of the counselling room accusing one of our [female] counsellors of asking him questions that his eldest daughter has never asked him before. We then had to wait for a male counsellor who was busy to finish so [that] he can help the old man.” MGR2

The health workers observed that men did not like being attended to by women, because they were not used to being cared for by or being seen to be weak in front of women. The fact that most health workers were women could be a barrier for men going to the clinics.

For men being ill was problematic. Going to a clinic for treatment was a sign of weakness, and could undermine their social standing in society as found elsewhere (Seidler, 2006). A number of health workers agreed with this observation. A doctor (DOC9) noted: *“Men would not go to the clinic because they could be seen [as] weak.”* A clinic manager (MGR2) noted that for men *“to be seen in a situation where they are incapacitated and are being helped by women is a situation they are afraid to face.”* They suggested that men would rather go elsewhere to look for help because they did not want to admit to being weak, especially to women. One THP (THP10) suggested that men *“secretly”* consulted THPs, preferring male THPs, or did not seek help at all.

“Men will never want to be helped by a woman. Unless when they are seriously sick. When they are still in a good state, they will never go to the clinic because they know they are going to be helped by a woman, even to the women traditional healers. ...But with men no, they cannot do it, they want to be helped by another man [...] Going to the clinic or hospital, when a man is sick, to them indicates their weakness. They therefore better go to consult secretly with the traditional healer or they better die in their house without going to the clinic or hospital. They do not see themselves undressing to be checked by a woman. They are not seeing that happening in their life. Even myself, I do not see that happening.” THP10

But as discussed earlier, the men did not consult with THPs either for HIV.

These observations of the secondary informants resonated with those in the literature and other findings in this study. Men equated illness with weakness, and they did not want to admit that they were ill, even to their family. They found going to clinics difficult, particularly because they were staffed by women, and thus they

preferred not admitting that they were ill. In addition they found the clinic environment was hostile, not only because of the predominance of women and the unprofessional attitude of some of the health workers, but also because others may observe them at the clinic and may perceive them to be weak. Therefore men were reluctant clinic visitors, preferring to wait until they were very sick before going for a consultation.

The men provided a more nuanced view on female health workers than findings in previous research. For most of them being counselled or treated for general illnesses by a woman was tolerable, however, discussing sexual issues dealing with female health workers was problematic.

The majority of HIV counsellors in Soweto were female. Therefore, the men were asked if this was an issue for them. It was found that for many of the men (6/33) the gender of the counsellor was not a concern, as long as they provided a professional service.

On a positive note, many of the men (5/33) liked being counselled by women and others preferred it because they liked the motherly touch, saying: *“mothers have soft touch”, “women are better to talk to”* and *“they are able to comfort you.”* Eugene (ntst, 19) added that women cared more and they *“will break the news lightly.”* However, Matthew (neg, 20) was concerned that female counsellors would tell him what to do, and perhaps judge him.

Some health workers indicated that men preferred to be counselled by a man. A VCT site coordinator (CORD4) thought that if men were counselled by women they felt *“undermined because the woman must be under [the] man.”* However, she thought men respected older female counsellors: *“some of them when they see us because we are of a higher age they prefer to be counselled by us since there are no men to counsel them. They will say that we must counsel them because we have experience about life.”* These health workers acknowledged that in a patriarchal society men did not want to talk to women about their problems, but that they respected their elders. This was confirmed by Abel (neg, 27) who was surprised that he was counselled by a woman when he went to test for HIV and said that he was not comfortable, but conceded that because the counsellor was an older woman it was acceptable: *“Yes! She did talk to me she told me that from now on I should play safe, I should make sure that I use a condom at all times, she advised me a lot. [...] She was okay because she was a matured person.”*

However, a few of the men indicated that they would like to have a choice about the gender of the counsellor. Although Nhlanhla (ntst, 18) preferred to talk to female counsellors he agreed that there should be the option of having a “*man to man talk*” with a male counsellor. Thulani (neg, 22) suggested that having more male counsellors in clinics might motivate men to go for testing.

Three men stated that they would be more comfortable with male counsellors as it would be easier to open up. However, Martin voiced his concerns about male counsellors:

“I think as men we don’t trust each other. We don’t really believe that a man can comfort you and sympathise with you or rather provide emotional support during the testing process. There is a general feeling that men are not even good in comforting other men, as compared to women. They can’t even go an extra mile in providing that emotional support, hence most men don’t feel comfortable. They would rather refer you to other support structures like support groups, although I wouldn’t say I agree with such sentiments.” Martin (neg, 25)

Throughout the discussions with the men, the issue of trust was raised. The men were prepared to open up to people they trusted. Trustworthy people would keep a secret, would not reveal their secrets to others, and were people they respected. But they were unsure whom they could trust, and although women were considered generally not as trustworthy as men, they were able to offer more comfort and support.

In general, the men were not averse to being counselled by women. In fact, many preferred it and felt comforted by them. However, having the option to be counselled by a man was appealing for some. Although the HIV testing sites were mainly staffed by women it seemed, according to the men, that this should not deter the majority of men from going for a test.

However, when it came to discussing visiting clinics because they were ill, the men were enthusiastic about having more male staff with whom they could consult.

Many of the men raised issues related to being attended to by women. For Thulani (neg, 22) men’s acceptance of masculinity hindered them from going to clinics. He thought this was really the man’s problem and that they were “*ignorant*”, had “*pride*”, and were “*stubborn*”, all of which deterred them from visiting the clinic: “... *so the fact that he would be helped by a female he judges himself low towards a woman.*” However, Andrew (neg, 24) disagreed, saying: “*I think it is because of the treatment they get from the staff. I*

think again, generally men do not want to be treated by females and [at] almost every clinic, the majority of the staff is female.” The men did not want to be treated by women.

A community outreach worker (COO6) suggested that men knew that the clinics were staffed by women, which was perhaps the reason why they avoided them. She believed that provided a health worker was professional, their gender should not present a problem: “... *when a nurse is clear about her job I think there will be no problem between her and the patient, and they must not consider the age because young people are now working.*”

David (pos, 30) was not impressed with any of the staff at the clinic he frequented: “*Most of the males are administrative staff. The females are the nurses. I think there’s only one [male] nurse. [...] I don’t have a problem with both male and female nurses, but looking at the clinic, I would not prefer any of them.*”

The men were conflicted about the gender of the nurses. Their adoption of the South African notions of masculinity prevented them from seeking help because they would be seeking help from women. The older more traditional men were reported to be more adversely affected by this situation.

However, when the men are ill they say they preferred to be helped by a man. Because the clinics were mainly staffed by women, this may deter men from accessing the clinics when they were ill.

Subsequently, the topic of male health workers was explored. The majority of the men had never been attended to by a male nurse. This was not surprising, given the small number of male nurses in the public sector. Many were also unable to consult with a doctor. Doctors were preferred for many illnesses, as they were considered to have better knowledge and were perceived to be more professional, but they were mostly inaccessible. The perception was that nurses in the clinics were very powerful, as Lucky (ntst, 20) commented: “*You first come across all kinds of females. Its nurses all over. So I have a problem with that. You’ll only get to see the doctor sitting in his office. You always have to pass through a chain of female nurses.*” Indeed, nurses acted as gatekeepers, determining with whom the patients consulted. The men felt disempowered by this situation and uncomfortable at the clinics.

For some of the men the second best option after a doctor was a male nurse. Thabo (pos, 52) said: “*it will be much better for me to be helped by a male nurse because the female nurses don’t have respect. The males*

could somehow feel pain or sympathise with you. Females are very bad.” He had a bad experience when he was hospitalised and received inadequate attention from the nurses, some of whom slept on the job:

“You will cry until you are satisfied. Doctors arrive in the morning they find it that you are gone [dead]. So that is why I am saying that if you are sick you must always humble yourself to get help. Even if the nurse is swearing at you, [you] just need to be cool for the sake of your life and you will be okay.” Thabo (pos, 52)

In order for Thabo to get the treatment he thought he deserved or needed he made a conscious decision to “humble” himself and “be cool”, otherwise he thought he would have been left alone and may have died. This reversal of power meant that Thabo had to adapt his behaviour in order to get help. Thabo was prepared to do this, but was unhappy about it.

Eugene (ntst, 19) was the only man who mentioned that he had been attended to by a male nurse. He suggested this was because male nurses were mainly on duty at night as it was risky for females to work at night.

Five of the men said that they were not averse to consulting or being treated by a male nurse. Martin (neg, 25) thought that males attending men was acceptable but believed that if you needed help *“anyone should be allowed to offer you help”* because *“they might be in the right space to heal you.”* Similarly Clement (ntst, 18) commented: *“I don’t mind being checked by a dude ... It all goes down to experience, because you’ll find out that most of the nurses and staff that are at this [clinic] have been working for the past 25 years [...] but not everyone [has] the qualifications that they need and at times they get challenged by the advances in technology as it changes over time and they don’t have [...] the mind-set that we are using in the 21st century.”* He was more concerned that staff kept up to date with latest advances in medicine.

Some men suggested that male nurses would be preferable to female nurses. As Xolani (pos, 41) said: *“I think the male nurses would have a better understanding on how to treat us because the female nurses treat us badly. They are very harsh and angry at us at all times.”*

The participants suggested if the numbers of male staff at the clinics increased it would encourage men to visit the clinics more readily. A VCT site coordinator (CORD4) remarked: *“Yes, maybe they would come because men to men I think it is simpler than man to female.”* The men agreed that male health workers were

scarce, and a few elaborated that having more male staff would be beneficial and make a clinic visit a more comfortable experience. According to Bongani (pos, 35): *“More men will be interested in visiting the clinic because some men are not comfortable in talking to a female nurse.”* Phil (ntst, 18) remarked: *“I would prefer to be treated by male staff nurses because they know how to handle male patients.”*

Amos (pos, 36) was happy to be treated by either a male or a female health worker *“as long as at the end of the day I will be given proper and right treatment.”* But he agreed that most men would be encouraged to visit clinics if there were more male staff: *“They [men] will say [it] is better to be helped by a male nurse than a female because a male nurse would be able to ask lot of questions about his problem. That is when the guy will be free to explain everything to the doctor, but not to a woman.”* These men wanted a choice about the gender of the health worker they consulted at the clinic and suggested that more male staff may make clinics more appealing to men.

The men were enthusiastic about the idea that there could be more male staff in the clinic. They believed that they would be more comfortable attending the clinics and would be able to discuss their problems more freely. However, given the present situation the men were more concerned that that staff were professional and kept up to date with the latest advances in medicine. They would like to consult doctors over female nurses. They were very concerned about the attitudes of the female health workers who did not act professionally and shouted at and were rude to patients. Some of the men thought that as long as the health worker was professional and well trained, it did not matter whether they were male or female.

The topic of a male-only clinic was explored since this surfaced as an important factor that could potentially increase men’s utilisation of the clinic. One clinic manager (MGR2) was of the view that a male-only clinic would be better placed to cater for men’s health issues and HIV/AIDS in particular. A VCT site coordinator (CORD8) agreed, as *“men would be more open with other men.”* Thulani thought a male-only clinic would be helpful.

“I think that will help because of there are some men who don’t want to be helped by women. There are some women who don’t want to be helped by men. The majority of people who attend clinics are women. Men don’t like to go there eventually because of the fact that women are plenty there.” Thulani (neg, 22)

The idea of a male-only clinic was appealing to the participants. The men were encouraged by the idea of being treated by a male health worker and would like to have the choice of provider. In addition, they believed if there were fewer women there would be a more conducive atmosphere in the clinic, and men would feel more inclined to seek help in these clinics.

However, when it came to discussing sexually transmitted infections then most of the participants noted that men were uncomfortable consulting female health workers. A doctor (DOC9) observed: *“if a male has STI it becomes a problem to go the clinic and undress for a female to examine him ... even if the female is qualified, they won't agree to be examined by a woman.”* He gave an example: *“I was at a clinic one day, a cultural (traditional) man who is of the age 50 had an STI, that man refused to be examined by woman. He said he would wait until the doctor arrived. There was no way that he could be convinced.”*

A female counsellor (CNS1) recounted that she made an extra effort to build rapport with her male clients before they opened up: *“you develop this relationship with a client, the client is told to be free even when they go and see the nurse. Then you will find out that they [haven't told] the nurse about the problem of having a STI because they didn't want to be checked in their private parts (genitals).”* She continued, *“What we do is we try to make everybody to feel important. By doing so we make them feel special. Then they will give you a positive attitude, as we have different personalities and different perspectives. I think we wouldn't have much difficulty with men because they know women went to school. The problem is the attitude they get from the nurses and that's the thing that makes them not [want] to be helped.”*

This counsellor recognised that men were reluctant to discuss STIs with female nurses. She suggested that men were comfortable with women as long as they were educated and professional, but acknowledged that the female nurses' attitudes were problematic. However, the men disagreed and said that it was particularly difficult for them to be examined for STIs by female nurses. As Abel recounted:

“... those [female nurses] are okay as long as I don't have to undress and show my private parts (genitals) to a female nurse. I mean, you know my brother, it would also be uncomfortable for you (laughs out loud). Imagine she's holding your penis and asking you where the sore is that you're talking about (laughs). You tell her it's here (laughs again) and you show her. Yes! I have a problem with showing a female nurse my private part (he laughs).” Abel (neg, 27)

Tshepo (pos 30) would rather be treated by a male nurse who he believed would understand him better: *“Some of us men don’t like our things to be known by anyone, more especially [by] women. A male nurse will treat you differently because he knows the condition of your body. Female nurses, sometimes they are careless about where to touch you. She won’t respect that private part.”* He conceded that female nurses did their job, but that he did not get the *“right service.”* Amos (pos, 36) felt that men were reluctant to undress in front of female nurses because *“maybe there is something he is hiding.”*

One man was concerned that if a female nurse assisted him with an STI he would be embarrassed to see her again. As Thulani (neg, 22) related: *“you got Drop [an STI]. The next thing you are going to be helped by a woman. Tomorrow you meet with her on the street. You start having a problem towards her because she has once helped you. Yes, she helped you. But the fact that there is a certain part she knows [about] you, that you wouldn’t want to be known by anyone, not unless they are your partner ... that is something different.”*

Consulting men or women was different for Matthew (neg, 20) as he described, *“Men are okay to talk to if you are infected with HIV. For example, like [when you talk] to a female nurse and say you’ve got HIV it would be like you’re talking to your mother. So talking to a male person would be like talking to you brother. You’ll somehow be relieved.”* Matthew suggested that men preferred consulting male health workers for other health issues such as HIV.

These men were uncomfortable consulting female nurses on sexual matters and for other illnesses. They were not happy with women examining their genitals and knowing that they had an STI. They were not convinced that women would keep this confidential. A woman examining their genitals was disempowering for men and went against their notions of masculinity. They were also concerned that if there was a breach in confidentiality then their social status may be diminished.

Could anything be done about increasing the number of male health workers? The participants debated this possibility. One clinic manager (MGR2) did not believe so, as *“most nurses are females”* and *“even men regard nursing as a profession for women.”* The remuneration was poor and the profession was not attractive to men.

Although the majority of nurses were female some men believed that with “gender equality” this could change, as Nhlanhla (ntst, 18) observed: *“There are female cops. If females can be policewomen, then males can also be nurses.”* Jackson (pos, 34) reflected: *“We have grown up knowing that a nurse is a woman and we never thought that a man could be a nurse.”* He felt that a man would be insulted if it was suggested that he trained to be a nurse. But he felt that it was time to rethink this and that *“parents should be orientated to understand that the nursing profession is not only for females, but for males too. We should be able to encourage our boy children to take up nursing as a career of choice. You find that most men feel shy to be helped by a woman [for] some kinds of the diseases. Because with some of the body parts you can’t even allow your wife to look at it if there is something wrong. So how could that be possible for someone whom you don’t know to do that to you.”*

As women dominated the workforce in the health sector, the men recounted how they had to change their behaviour in order to get the treatment they believed they deserved. As indicated, they were not averse to consulting female health workers on general health matters, but they were uncomfortable doing so when it came to their sexual health or STIs. They did not want women examining or touching their genitals, and preferred to consult doctors or male nurses. Male nurses were likely to remain scarce in South Africa as few come through the nursing colleges, and the traditional health worker gender roles will take time to change. The attitudes of the female nurses, the scarcity of male nurses, and the issues that men experienced in the clinic were barriers to seeking help.

16.4 Sexual orientation as a barrier

Three MSM were interviewed about their experiences at the clinics. Andrew (neg, 24) felt he received good treatment at a clinic because he was not overtly gay: *“You know I think the reason it is so easy for men like me to get treatment easily is that you cannot see if I am sleeping with other men because I do not look so [gay/feminine].”* When asked if overtly gay men were treated badly he said: *“Yes, they are easily seen that they are gay and most people do not like gay people. The community at large do not like gay people and no parent wants to have a gay son.”*

MSM were stigmatised in the community and these attitudes were reflected in those of the clinic staff.

Lebo (pos, --) identified as “gay”, “feminine”, “as a woman in an MSM category” and “female like in attitude and behaviour.” Lebo agreed with Andrew that overtly gay, feminine MSM consistently encountered problems at the clinic:

“Gay people are discriminated [against] right from the time they enter the clinic gate by the security people, by other patients while they are waiting in the queue to be checked and receive treatment. When you get to the nurse, it is worse. The questions they ask you are not bearable, and you will storm out of the room crying.” Lebo (pos, --)

Lebo was HIV-positive and found visiting clinics stressful, and said he experienced discrimination from the time he entered the clinic gate. He indicated that many MSM avoided going to clinics because they were asked inappropriate questions and they thought nurses were under the impression that all gay men were HIV-positive. When he was at school one nurse complained “that I was coming to the clinic on too many occasions, and no matter what because I am gay I must be HIV-positive. After she said that, I was so scared that I told myself I would not go to the public clinics again. The other thing that came to mind was committing suicide. Then I went to go and test and I found out that I was negative. She said you are lucky but I must come for the second time to test after three months so that I can be sure.” He went back after three months and again tested negative, the nurse commented that he was “lucky” he was “not like the others.”

He told a story about a friend of his who was raped:

“My friend, [who] is an MSM, was raped by 16 men and they had to stitch him. The nurses told him that he got what he deserved. She was discussing him with everybody. All the nurses in the ward knew about him. He ended up wanting to be discharged before time because of the nurses. The thing that I have noticed is that nurses and sisters are there ones who are discriminating [against] us. Doctors are keeping patient details confidential.” Lebo (pos, --)

The men sought out health workers who would assist them. They found that nurses were ill-prepared and preferred to treat MSM as if they were heterosexual men, as Enoch explained:

“I believe that if a man who is identified as a heterosexual man and goes to a clinic with an STI then the nurse will know what to do. But looking at MSM the approach will have to be different, especially if one is identifying as a bottom gay [receptive or penetrated gay man]. Yes, because our STI will be situated in the anus and not the penis.” Enoch (ntst, --)

Many of Lebo’s gay friends avoided seeking help at clinics and he suggested that a clinic focusing on MSM health would be a “privilege”. It would encourage MSM to seek help rather than avoiding it, or buying over the counter medication.

Like many of the men, the MSM, and more particularly the overtly gay MSM, found clinics alienating. They were not only discriminated against by the health workers, but by all the staff and by other patients. They reported that they could not get good, competent treatment anywhere. Like other men, they perceived that they would get better treatment from doctors. These findings support those of Lane et al. (2008) who found that health care workers were homophobic, and that these attitudes had a negative impact on MSM sexual health, as they were reluctant to discuss their sexuality with the nurses.

For MSM there is double stigmatisation, being homosexual and being ill. The nurses were prejudiced and had preconceived attitudes and the men felt discriminated against.

16.5 Men's experience of ART initiation and treatment

Most of the health workers observed that men only come to clinics when they were sick. It was observed by one VCT site coordinator (CORD8) that men postponed going to ART sites because of HIV/AIDS-related stigmatisation and they needed to be referred for treatment more than once.

However, the secondary informants' opinions differed on how men utilised ART services once they came. A counsellor (CNS1) observed that once men tested positive they were reluctant to "*confront*" the issue of HIV/AIDS and get the relevant tests, such as a CD4 count test, to determine if they were eligible for treatment, and therefore stopped coming to the clinic. A clinic manager (MGR5) agreed that men were unwilling to access the clinic initially, but found that once they were on ARVs they became familiar with the clinic routine and adhered to and stayed on treatment. She speculated on the reasons for this:

"They are always here when they are supposed to be here... I think they just tell themselves that they survived death and therefore they cannot afford to relapse back to the situation they were before they come [to] the clinic. A lot of men who we enrol into our treatment programme, when they pick up [get better], they come back and thank us with thank you cards. We have a lot of thank you cards from our patients, especially men. They realise that if they do not change their attitude, they will eventually die. That is the reason they adhere this much."
MGR5

Other health workers had opposing views. They found that men stopped their treatment once it started working and they were feeling better. "*They go back to their own lifestyle, then they get sick again. Especially men. Women would continue with their treatment*" (COO6) and "*we enrol men into ARV, and then they disappear*" (MGR2).

The health workers acknowledged that men were not happy with the way in which ART clinics functioned. Before men started treatment the health workers noticed that “[men] fear to start accessing the clinic” (MGR5). Once men had got over this hurdle there were others that they found difficult. After the HIV diagnosis they were required to have a number of tests to determine how far the disease had progressed, and whether they were eligible for treatment. A couple of the clinic health workers found that men were impatient to start treatment: “men don’t like procedures, they want quick things. When you tell them to come after three weeks to check the CD4 count, they say ‘give me the treatment now then I’ll go’” (COO6).

The health workers recognised that the clinic procedures were slow and that treatment initiation for HIV was a long process. One clinic manager (MGR5) stated: “Men are not patient with our system.” Men wanted fast service, to be “helped immediately”, they wanted their laboratory results immediately, and did not want to wait to go onto ART. However, she felt this was not possible: “we have to wait and they will have to bear with us.” Another manager (MGR2) suggested that men felt awkward in HIV/AIDS services and observed:

“Men prefer to have quick services. They just want to come in and off they go. They do not want to be told of many stories. They just want to be given treatment. Some of them get angry with us if we tell them that they have to attend adherence classes first while they are waiting for the ARV treatment to start. If you tell them that, you will never see them.” MGR2

These managers thought that men may be impatient because they were working and did not get much time off, and therefore were reluctant to “wait in a queue.” However, neither manager felt that they could do anything about this situation because “It has to be the way it is in order for us to render effective services” (MGR2).

The clinic managers were powerless to make changes in their clinics regarding the ART initiation process. They recognised that these procedures were problematic for men, but could not see any alternative.

The HIV-positive men on ART were vocal about their experiences of it. Jackson (pos, 34) had taken an avid interest in HIV since being diagnosed. Although he was depressed when he learnt his status, he was on ARV treatment, had a very positive outlook on life, and attended support group meetings where he had learned how to “cope and survive with the virus.” The advice helped him to understand his treatment and his situation. He said: “I feel that I can actually do most of the things that I was not able to do before. I could say they have really helped me to survive.”

He was very knowledgeable about ART and was confident enough to question the nurses in the clinic when they wanted him to start treatment. He refused treatment until he had been seen by a doctor to allay his concerns, and said: *“I was not willing to start with the treatment unless the nurses were prepared to satisfy my concerns.”* He was worried about his family, as he stated: *“Unfortunately I was not prepared to let my children lose out on their father and my wife to lose out on a husband by allowing people who don’t know what they are doing to preside over my course of treatment.”* Through his insistence on consulting a doctor he was placed on treatment under specialised care because it was found that he had a *“serious condition with my liver and lungs.”* He was prescribed sprays for his lungs and ate a restricted diet. Jackson was concerned about the nurses’ knowledge and took on the public health system in order to ensure that his treatment was well managed. He was intimately involved in his health and wellbeing.

The other men on treatment were grateful that they had the opportunity to go onto ART. Tshepo (pos, 30) had a positive outlook on life and said: *“I make sure that everything I am doing is positive. I am positively thinking, learning and doing something. If there is something I am not feeling comfortable doing, I don’t bother.”* However, he had been on ART for two months and was feeling depressed, *“down”*, but was optimistic that the treatment would start working and be good for him *“so that I can get a better life.”* He had experienced side-effects, including being *“exhausted, thirsty, and dizzy”*, but felt he had been adequately prepared for them by the health workers. He was told to *“seek further attention from the doctors”* if he needed to. He had only encountered one man who had not experienced side effects, but noted that the man was surrounded by a *“conducive environment”* and a supportive family who played a *“significant role.”* Tshepo would not drink any alcohol or stimulants because they might interfere with his treatment and *“reduce the chances of living a better life.”*

ART had enabled these men to embrace a new phase in their lives. They had taken an active interest in their health and engaged with the health services on their terms. They had actively sought help when they needed it, and felt empowered to make changes in their lives for the better.

16.6 Men’s suggestions on how to improve clinic services

Given that men were reluctant to engage with the public health services, the men were asked if they had any suggestions on how to improve them and make them more amenable to men. They indicated that more

clinics and staff are needed to reduce the clinic load, and speed up the services. The men would then not have to wait in long queues and thus reduce the chances of being seen by someone they know.

Staff attitudes were problematic for the men but they acknowledged that the staff worked under stressful conditions. Albert (ntst, 21) suggested that debriefing staff might help them not to take out their frustrations on patients but rather *“treat them [patients] with respect and love and care.”* The men postponed going to the clinics because they were treated badly and not respected. A few suggested that dedicated and committed staff who had compassion and who cared about patients needed to be recruited, rather than those who were just doing it as a job.

The men suggested that the clinic staff needed better training, not only on service delivery but also on medical matters (as described earlier). In addition, they should be trained on how to engage better with patients:

“Well, I don’t know if there is much that they [government] can do. These people [clinic staff] are, or should be, taught how to treat patients... They should also know how to deal with patients that might be problematic or difficult. They shouldn’t take that out on every patient as they are angered by only one. The other thing is for them to be reminded of the basic principle of humanity, which is to respect everyone and not to misbehave for no apparent reason.”
Thabo (pos, 52)

Some men were concerned about staff competency and others suggested that the clinics needed better managers who could deal with complaints and manage their staff.

The clinic infrastructure was also a concern. Clement (ntst, 18) found the clinics depressing and felt that the clinic infrastructure needed improvement so that patients waiting in queues could *“get away from funny smells and all of the diseases.”* He felt that hospitals were *“the worst place to go, but then at the end of the day ... (paused) ... yah!”* His view was that patients did not have any alternative.

For many of the HIV-positive men, the amount of time they spent in the clinics was a big concern, and being referred from one clinic to another was time-consuming and frustrating. Tebogo (pos, 27) suggested that the clinic should provide all services under one roof, including grant services, and that people should be given food and information while waiting: *“HIV people are sick most of the time so this will be less travelling for*

them and less spending. They will get all the services in one place." Finally, Thulani (neg, 22) suggested that a hospice would be beneficial because people stayed at home with no one to look after them.

The men gave constructive suggestions on how to improve the clinic services, but many of these were not likely to be feasible options in the public health system. Clinics would therefore remain alienating to men.

16.7 Discussion

The majority of men in this study accessed the public health services when they were ill. They preferred to go to a local clinic because they had limited resources. However the structure of the health services and the separation of HIV/AIDS services were significant barriers for the men.

Men were prepared to travel to HIV/AIDS services away from where they live to avoid being seen by someone that they knew. For other illnesses they preferred going to clinics close to where they live. The men were not as concerned about people knowing they were ill as they were about people speculating that they may be HIV-positive. This tied into their fear of being associated with people who were HIV-positive and the stigmatisation surrounding the disease. Although the health workers were concerned that the men may find it difficult to attend clinics far away from their homes in the long term, these concerns had not been realised thus far.

Men liked to keep their health issues private. Accessing a clinic for an illness was difficult as it was a form of public disclosure, so men tended to avoid going to clinics. This made it doubly difficult for men to go to the separate HIV/AIDS services.

The men raised numerous structural barriers to seeking help in the clinics, these included clinic hours which were particularly problematic for working men or those looking for work, the crowds, queues and long waiting times, and the inferior services.

Staff attitude was a major concern. Men felt it was generally bad and disrespectful, but especially for older men. The clinic staff acknowledged that men were the heads of households and breadwinners, but in clinics they were no different to all other patients. The men were disempowered in this process and many accepted the poor service but were unhappy about it. Only a couple of men felt able to fight back against these nurses.

The MSM in this study were critical about not only the nurses' attitudes but felt discriminated by everyone in the clinics.

The gender of the nurses, mainly women, was a significant barrier for the men, particularly when it came to sexually related illnesses. The men were uncomfortable being questioned by female nurses and having to discuss personal matters. The men were particularly averse to consulting women on sexual issues and being examined by them.

The men were happy about the expansion of HIV/AIDS services and the availability of ART. Men were prepared to travel to HIV/AIDS services away from where they lived to avoid being seen by someone that they knew. The HIV-positive men spent a lot of time in these clinics, but the service was no better than that in other clinics. The men who were on ART were enthusiastic about it even though they had experienced side effects from the drugs.

The men had a few suggestions on how to improve clinic services and make them a more conducive environment for men. These included having more male staff and a male only clinic. However, it was unlikely that these suggestions could be acted on in the short term.

Men did access clinics for illnesses but many waited until they were very sick. This was not good help-seeking behaviour and could result in worse health outcomes. The health services could be improved using the insights of these men and by taking their suggestions seriously. The changes they wanted included more male staff, flexible clinic hours and shorter queues.

Recent changes in the health system include the integration of HIV/AIDS services into the general clinic. This may reduce stigmatisation associated with the separate HIV/AIDS services but may not be enough to encourage more men to seek help. By integrating the services, the queues may be longer, the highly skilled HIV clinic staff may be dispersed and the general clinic nurses may not be experienced in HIV medicine.

PART 5: DISCUSSION & CONCLUSION

The trigger for this research was the fact that men are under-represented at public sector HIV/AIDS services in South Africa (Hudspeth et al., 2004; Mhlongo et al., 2013) and it is no different in Soweto. For this reason, the aim of the thesis was to explore men's understanding and response to health, HIV/AIDS, and ART in order to gain insight into the reasons why they avoid HIV testing, care and treatment services.

Three major themes emanating out of the literature were explored namely the HIV/AIDS epidemic and associated stigmatisation, the health system and help-seeking behaviours, and masculinity and men's health practices. These aspects do not operate in isolation and intersect at various levels, including the political and social context, the health system, the community, and at individual levels.

Men's response plays a critical role in dealing with the HIV/AIDS epidemic, and without men on board, the epidemic is unlikely to be controlled. This statement is germane to the various stages of the epidemic's trajectory, including that of treatment, as in the focus of this thesis.

ART is known to be very effective in reducing morbidity and mortality, as well as in preventing new infections in discordant sexual relationships (Cates, 2011; Cohen et al., 2011; Granich et al., 2012). Currently ART is the main intervention to mitigate the impact of HIV/AIDS and also forms a critical part of the prevention package. This study explored the interaction of men and ART through the voices of a group of men living in Soweto, South Africa. Whilst this group is not representative of all men in South Africa it does provide a glimpse into the challenges that men face regarding the HIV/AIDS epidemic and the barriers and enablers for men accessing HIV/AIDS treatment services. The research uncovered valuable insights into understanding why there is a lack of men attending the HIV/AIDS services in Soweto.

HIV/AIDS epidemic

The HIV/AIDS epidemic is now in its third decade, the disease is better understood, and in South Africa it appears to be stabilising (Department of Health, 2012a; Shisana et al., 2014). The early uncertainties about the disease's origin coupled with the lack of political leadership regarding HIV prevention and treatment options, as well as public debates such as whether HIV causes AIDS, still linger. The men's explanations of the emergence of the epidemic had racial overtones, but these did not cloud their good knowledge and

understanding of HIV/AIDS, including how to protect themselves from becoming infected, the difference between HIV and AIDS, how HIV is transmitted, and that ART is a long-term treatment but not a cure. This was contrary to the secondary informants' belief that men are ill informed and ignorant on HIV/AIDS matters, which was why they did not attend their clinics.

In addition to the scientific explanations of the epidemic, popular beliefs about illness determine what help-seeking routes people will take. Various myths and beliefs surrounding the HIV/AIDS epidemic, including that it is caused by witchcraft or that it was God's punishment (Ashforth, 2002; Delius & Glaser, 2005; Pearson & Makadzange, 2008; Steinberg, 2008; Dickinson, 2013), and how they affect men's beliefs and help-seeking behaviour have been widely debated in South Africa (Ashforth, 2002; Steinberg, 2008). The findings here show similar myths and beliefs were circulating in Soweto. Men's beliefs on illness influenced their help-seeking behaviour. The HIV/AIDS epidemic impacted on the individual men in different ways and each dealt with it uniquely. However, there were general themes that emerged from the interviews with the men that could explain their behaviour regarding accessing health services and HIV services, including ART.

Although the secondary informants suggested that men in particular believe that they are bewitched when they get sick and consult THPs rather than the public health HIV/AIDS services, the majority of men did not agree with this view. They did not believe that HIV/AIDS was spiritually caused, although they acknowledged that some people in the community believed that it was witchcraft and therefore may seek help from the traditional sector. Some suggested that their God was angry and had inflicted HIV/AIDS on people to punish them for moral transgressions, and in this case prayer could help. A few proposed that HIV infection is unavoidable and fatal and that little could be done to avoid it. However, these beliefs did not sway the men's conviction that the most appropriate place to seek help for HIV/AIDS was at the public health clinics. The men had a complex understanding of illness and many adopted a pluralistic approach to seeking help, consulting spiritual, traditional and allopathic sources, often simultaneously.

Some of these men consulted THPs and spiritual advisors for life issues, but not for HIV/AIDS. Allopathic medicine was preferred for physical ailments such as HIV/AIDS. This behaviour resembles the general pattern of help-seeking behaviour in similar communities (Peltzer et al., 2010; Moshabela et al., 2011; Schatz & Gilbert, 2012).

Although the men had differing views on the HIV/AIDS epidemic there was consensus that they would seek help for HIV/AIDS in the public health clinics if and when it they needed it. They would, in addition, seek help from elsewhere if necessary. The lack of men at these facilities is not based on their beliefs or knowledge about HIV/AIDS.

HIV/AIDS Stigmatisation

This study highlights the centrality of HIV/AIDS-related stigmatisation in the various facets of the epidemic and concurs with other studies (Deacon et al., 2010; Gilbert & Walker, 2010). These Soweto men admitted that people who are, or who are suspected of being HIV-positive are stigmatised and discriminated against through negative thoughts or actions, as also described by Campbell et al. (2007) and Deacon et al. (2005). Although the participants thought that stigmatisation had declined, they cited many examples of its presence and still considered it to be a major problem. For example, the participants mentioned that many people prefer to use euphemisms rather than saying the words HIV or AIDS which reflects on-going HIV stigmatisation (Stein, 2003a; Steinberg, 2008). These euphemisms enabled a sense of distance from the epidemic and the reminder of death. Some of the reasons that the participants provided for the perceived decline in stigmatisation concurred with other researchers' findings (Jewkes, 2006; Kalichman et al., 2006), including that it may be due to increased knowledge and understanding of the epidemic. In addition, because of the high prevalence and immediacy of the epidemic with most people knowing someone who is HIV-positive, they felt that the disease had become normalised.

The men described how, in their community, speculation and gossip regarding people's HIV status was rife, with much of it being associated with suspected sexual misconduct. This can lead to HIV-positive people being isolated (Yang et al., 2007). The participants exhibited similar views to those revealed in other studies where HIV-positive people are divided into the "innocents" and the "blameworthy", depending on how it was thought they became infected (Sontag, 1990; Maman et al., 2009; Deacon et al., 2010).

Although HIV/AIDS was quite well understood by these men, they noted that this was not so in the community, and the fear that HIV/AIDS is contagious led to the avoidance of people suspected of being HIV-positive (enacted stigmatisation). The HIV-positive participants affirmed that they had experienced this discrimination and that it had impacted negatively on them, as described in other studies (Scambler, 2004;

Gilbert & Walker, 2010). Courtesy stigmatisation, when people who are associated with someone who is HIV-positive are also stigmatised, was also observed and experienced by the men. Discriminating against people who are HIV-positive and those surrounding them conform to the notion of “othering”, as proposed by Goffman (1963).

Stigmatisation and discrimination are linked to social power relationships that are fluid and change over time. Although some of the HIV-positive men were secretive about their status, others described how they were able to resist stigmatisation and felt empowered knowing their status and were able to be open about their status to others. As Abrahams & Jewkes (2012) and Campbell & Gibbs (2009) found, building resistance to stigmatisation is beneficial for those who can do so.

The men do not want to be stigmatised or discriminated against in any way. They believe that being HIV-positive diminishes their social standing in society. Therefore they fear that their HIV test may reveal a positive result, so they prefer to deny that they could be HIV-positive and few voluntarily tested for HIV, particularly if they were older. However, once the men had tested and were found to be HIV-positive, they generally kept their status a secret and only disclosed to a select few such as their family members or their partners. They do not want the community to know, as they anticipate that they fear stigmatisation. This study highlights that men are adversely affected by stigmatisation and discrimination, and perhaps even more than women, in this setting.

Health system barriers

In an indirect manner, inherent problems associated with the public health care system surfaced in this study. Although the public health system has improved greatly since the formation of democratic South Africa, the HIV/AIDS epidemic has placed strain on the system (Gilbert & Walker, 2002). There has been a dramatic increase in the number of patients attending clinics because they are HIV-positive. In addition, health care workers are both infected and affected by the epidemic, and there is higher incidence of absenteeism (Veenstra & Oyier, 2006). So, in this context, this study found that the health services were alienating for many men. The men commented negatively on the clinic services and the way in which they were run. They noted that the clinics were very busy, there were long queues and waiting times, and the clinic hours were not convenient, particularly for those who are employed or looking for work. The men generally found the

clinic health care workers unfriendly and unhelpful. They remarked that the health care workers shouted and were rude to their patients — men and women. The HIV-positive men commented that the health workers were rude to most patients and were unhelpful to those who were ill. The men speculated that this might be because the clinics were understaffed and the workers were suffering from burnout, but emphasised that the clinic staff attitude was poor. HIV/AIDS has placed strain on the health system and this has affected the provision of quality service. Additional staff and a restructuring of the HIV/AIDS services are necessary if men are to be encouraged to seek help in these clinics.

Health workers attitudes and gender were found to be problematic by the men in this study. Stigmatisation and discrimination were not only identified as occurring in the community, but were also found to endure in the health system with the health care workers and the way in which HIV/AIDS services are provided. The men recounted times when health care workers judged or blamed them for being HIV-positive, or for infecting their partners. They also complained that health workers always inferred that the man was to blame. The health workers poor attitudes are problematic, but men appear to bear the brunt of them. These findings add to existing data on discriminatory attitudes in the public health system (Hassim et al., 2007; Holroyd et al., 2008; Farrimond, 2012; Galdas, 2013) by highlighting the gender dimension of the problem.

A further deterrent for men accessing HIV/AIDS services relates to the predominance of women in the clinics, both in terms of staff and patients. The general clinic services are geared towards maternal and child health and the majority of patients are women. The men indicated that they felt uncomfortable to be in this environment, as they did not want people to know their business and felt humiliated sitting in a queue with women.

Exacerbating this problem is the fact that clinics are mainly staffed by women and this was particularly problematic for the men when it came to matters of their sexual health. Women health workers in the clinics held powerful positions, and could act as gatekeepers to health providers. The men were unhappy with this power reversal, but were not able to counteract it. The men were comfortable being counselled and tested by women as they felt that they had a motherly touch and would break the news gently. However, they were reluctant to be treated by women for sexual health issues and did not want them to examine or touch their genitals. The men reported that female health workers judged them if they had a sexually transmitted

infection and blamed them for their condition. The men expressed the desire to have the opportunity to consult with a male health worker, but conceded that the women staff were generally professional and were able to provide good care. An increased number of male health workers may be beneficial to the programmes and it would be important for future planning to work on trying to bolster the male workforce.

In order to mitigate this situation the possibility of a male-only clinic was explored and found to be agreeable for most of the men. However, the constraints of enticing men into nursing or other health work careers, this idea is one that is unlikely to be realised. It is therefore recommended that other models of health care be considered that would be more appealing to men and take into account the findings from this study. One such model that is currently implemented is Anova Health Institute's Health4Men project. Taking lessons learned from the men in this study, the project is expanding competent clinical services for MSM in the public health sector through sensitising all staff in clinics and training health workers in MSM care, thereby reducing institutional stigmatisation and discrimination. Although this project is in its early stages, over 100 clinics are now MSM competent across South Africa and over 11,500 MSM are in care at the five clinics run by Health4Men¹⁵.

HIV/AIDS services are mostly provided as a special service within the clinic and are often physically separated from the other services (Ojikutu et al., 2007). Therefore, people going to the clinic for HIV/AIDS services can be identified and their confidentiality may be compromised. This renders people vulnerable to stigmatisation, since it associates the person with being HIV-positive. The health workers recounted how some of their patients travelled long distances to get help at their clinics, either to be tested for HIV or for ART, to avoid being seen by people that they know. The men supported this observation and although they were happy to go to a clinic close to their home for a "normal" illness, for HIV/AIDS-related services, many men said they would prefer to go to clinics where they would be anonymous. The men were concerned about confidentiality, and wanted their HIV status to remain secret.

The finding in this study suggests that HIV/AIDS services should not be kept as a special service but needs to be integrated into the general clinic services so that there will be no speculation as to a patient's status.

¹⁵ <http://www.anovahealth.co.za/projects/entry/health4men/> - accessed June 2014 and Glenn de Swardt, Health4men Programme Manager, 2014, personal communication.

There has been a push in South Africa to implement the integration of chronic diseases management including HIV/AIDS services in public health clinics. Thus HIV/AIDS services will no longer be separate from other clinic services. This will be one less barrier for men to contend with. This will enable men to seek help for HIV/AIDS without being concerned that their confidentiality will be compromised and that their HIV status will be disclosed to others.

Masculinity and men's help-seeking behaviour

As illustrated by many studies, men are influenced by the patriarchal society in which they live. They are perceived to be dominant and powerful in society, which shapes their health practices that are influenced by the hegemonic notions of masculinity and by other men (Connell, 2005; Morrell et al., 2012). Given men's privileged position, it may be expected that men would be more comfortable in coping with the epidemic; however, this is not the case for men in Soweto. The men expressed concern about being ill because they equated it with weakness and it impacted on their aspiration to the masculine stereotype of being strong and stoic. As demonstrated in this thesis, HIV/AIDS being a chronic condition infringed on men's masculine ideals even more so.

The HIV/AIDS epidemic has limited men's ability to fulfil the traditional male roles of being a breadwinner, head of the household, and a father. The HIV-positive men lamented that being ill negatively affected their ability to earn a living to provide for their families, complicated forming and remaining in relationships, and reduced their chances of being a father. They often had to rely on others for income and other support, which they found demeaning. Regardless of their HIV status, the men found that they were required to step in to take care of siblings or other members of their family, because they had been affected by HIV/AIDS or needed support. Traditionally it is men's responsibility to do so, but this placed added strain on their limited resources, which they found difficult.

Men's risk-taking behaviours are well noted (Foreman, 1999; Selikow et al., 2002; Campbell, 2003; Walsh & Mitchell, 2007; Lindegger & Quayle, 2010) and were reflected in the discussions with the men. They recounted various incidents when they were prepared to take risks in terms of the health such as having risky sexual relations, having multiple sexual partners, drinking alcohol excessively, or by engaging in illegal practices such as hi-jacking. The men know that they engage in risky behaviour and they know how to

protect themselves; however, these precautions were not always desirable or preferred. For example, the men described how difficult it is to always protect oneself by using a condom and in the heat of the moment they recognised that they may have unprotected sex but may regret it later. These practices form part of masculine behaviour in South Africa and negatively affect men's health and wellbeing. This behaviour however stigmatises the HIV-positive men, and classifies them as "blameworthy" because they could have prevented being infected.

As a result of this risk-taking behaviour men are fearful of testing because they know they may be HIV-positive and avoid or delay testing for HIV. Some of the men were in denial about the possibility that they could be HIV-positive, even if they had engaged in risky sexual behaviour. This results in fewer men knowing their HIV status, and therefore they would have no reason to go to the HIV services and this may then account for fewer men going to ART services than expected. Of the men who had not tested, many preferred to remain ignorant of their status, as they believed that a result either way would mean that they would have to change their lifestyle and impact negatively on them. The men who knew their status described their fear and hesitation before they tested. They were extremely concerned that their HIV status should be kept confidential and were worried that their status may be disclosed without their permission. They were reluctant to go for testing in their own neighbourhood in case people from their community spotted them there. This deep-seated fear is compounded in a patriarchal society where illness is considered a weakness. It has been reported elsewhere that men test away from their homes, but this study found further, that men test on the spur of the moment and want quick and accessible services. Thus setting up HIV testing stations away from clinics that can accommodate easy and confidential access may encourage more men to test.

Interestingly, the men in this study took a keen interest in their health and physical appearance, partly in response to the stigmatisation associated with HIV/AIDS. They did not want the community or their peers to speculate about their health, so they kept healthy and fit. Achieving this was not always easy as although they engaged in various sports they also engaged in manly pursuits such as drinking and smoking, pursuits that were sometimes contrary to this goal.

Many of them men saw themselves as, or aspired to be role models, wanting people to look up to and be like them. Even the HIV-positive men made an effort to look healthy so that they would not be further discriminated against. The men's physical appearance was important to avoid any speculation that they may be HIV-positive and stigmatised.

The men were selective with whom they discussed personal issues, and the majority kept their health matters secret. They mainly disclosed their illness or HIV-positive status to their families or their partners. Although a few HIV-positive men were open about their status, most men mentioned that they would need to seek permission from their family before disclosing an HIV-positive status to others.

The men wanted to be in control of their health, but testing for HIV was a major stumbling block for many of them despite the fact that HIV testing is the entry point to HIV care and treatment. The men's help-seeking behaviour was hampered by not wanting to acknowledge that they could be ill, as this impacted on their notion of masculinity. The men equated illness with weakness, and they were reluctant to admit that they may be ill, let alone infected with HIV, and therefore they delayed seeking help until they had no choice.

Being HIV-positive was perceived as a negative attribute and reduced the men's social standing with their peers. It seems that in the context of general stigmatisation, the existing notions of masculinity contributed to their delay in seeking help, their reluctance to test for HIV, and ultimately the lack of men at the ART services.

Not all men are the same

HIV status and sexual orientation contribute to the multiple masculinities (Connell, 2005; Connell, 2012; Morrell et al., 2012) that exist today. In this thesis the men described how they had to adapt once they knew their status and moved away from some hegemonic notions of masculinity by creating new identities for themselves, as other researchers also have described (Seidler, 2006; Colvin et al., 2010; Mfecane, 2010), but this was not easy.

The HIV-positive men's lives fundamentally changed when they received their positive diagnosis. They recalled how distressed they were and that it took some time to accept their situations. Many spoke about being suicidal at first, but as they came to terms with being ill, they were able to accept that HIV was not a

death sentence and could be dealt with like any other chronic disease. They noted that people's attitude towards them had changed: they experienced discrimination, and were sometimes isolated. These men also reflected on how their HIV-positive status affected their intimate relationships, complicating existing ones and made developing new ones much more difficult. Some of the HIV-positive men moved away from this traditional risk-taking mind-set and used condoms and took care not to infect others.

MSM are doubly stigmatised by the HIV/AIDS epidemic; not only are they a marginalised minority but they also experience much higher HIV prevalence than the general population (Johnson, 2007; Rebe et al., 2011). The few MSM participants in this study described how they were discriminated against in the community and by health workers whether they were HIV-positive or not. Being HIV-positive meant that disclosure was very difficult, especially if one was not open about one's sexual identity, because disclosing one's health status sometimes revealed other intimate secrets too. Men have been neglected in many of the HIV prevention and care initiatives, but MSM have been even more neglected.

Being different from other men, either in sexual orientation or in HIV status, created additional barriers against disclosure and seeking help for HIV. Although South Africa has an enabling environment for minorities to access health care, stigmatisation and discrimination exist at all levels and needs to be tackled if men are going to be enticed into the clinics.

Conclusions and recommendations

The political and social environment in South Africa regarding the HIV/AIDS epidemic has improved with strong leadership and progressive stances being taken on HIV/AIDS. For example, the Department of Health has released new HIV/AIDS treatment guidelines (Department of Health, 2013) that enable HIV-positive people to be treated earlier and therefore avoid the associated illnesses such as TB, which identify them as being HIV-positive. Furthermore, the Minister of Health, Dr Aaron Motsoaledi, is providing the political leadership that was absent in the past. This has improved relationships with civil society and has facilitated them working with the Department of Health to tackle the HIV/AIDS epidemic. From this thesis, it emerges that there is an urgency to address men's health needs if the HIV/AIDS epidemic is to be brought under control in South Africa. As shown, in key populations by Beyrer et al. (2012), unless HIV/AIDS is addressed in all population groups, HIV infection in these groups will continue to fuel the epidemic.

A positive outcome of this is that attention can be given to groups that are most at risk of spreading HIV to others, including men who are recognised by the South African government and the Department of Health as a key group that may have been neglected in the early years of the epidemic because of the urgent need to prevent infections in young children and to protect women (Department of Health, 2012b). However, recognising that men need to be a focus of attention is only one aspect of solving the problem, how to engage men in HIV services is another.

Through the voices of the men in this thesis some valuable insights have emerged on how the problem may be solved. Although men retain a dominant position in South African society, a number of factors influence their ability to maintain their health and access health care. Patriarchy and the hegemonic notions of masculinity inhibit men from admitting that they are ill because it is perceived as a weakness. This results in delayed help-seeking and poorer outcomes, and is especially problematic for men who are HIV-positive. Some HIV-positive men in this study have managed to adapt and adopt alternative masculine behaviour to cope with their illness, but this places them in the minority amongst their peers. Emerging transforming masculinities are important to encourage men who need to come to terms with their illness and to take control of their health issues.

Stigmatisation needs to be tackled so that men can be free to test for HIV and admit that they are HIV-positive. The health services have been largely focused on maternal and child health and the majority of health workers are women. This female focus has alienated men who do not want to access services that are dominated by female patients. It is necessary to provide spaces in clinics where men do not feel undermined because they need to consult with a health worker. Increasing the number of male health care workers may remove one barrier, as men indicated that they would like a choice of consulting a male health worker, particularly for their sexual health. However, increasing male health workers in the short term is unlikely to happen. Innovative solutions are needed, for example the Health4Men initiative could be adapted to cater to heterosexual men's needs.

This study has given a nuanced understanding of the complexities of men's engagement with the HIV/AIDS epidemic and their resultant help-seeking behaviour, contributing towards filling this research gap in South Africa. Through the voices of these Soweto men on a wide range of related issues, insight has been gained

into how the HIV/AIDS epidemic affects South African men and influences their help-seeking behaviour. The men have a complex understanding of illness and contextual factors influences their help-seeking behaviour. The absence of men in the clinics and accessing ART is not explained by them seeking help for HIV from the traditional sector, rather they are not seeking any help. It is partially explained by HIV/AIDS stigmatisation that encourages men to keep their health and HIV status secret. South African notions of masculinity that inhibit men from admitting that they are ill, and the health services environment is alienating men. However, it is not one of these factors alone that is decisive, rather it is a combination. Determining the extent to which each contributes requires further research and is beyond the scope of this thesis. However, these insights are a valuable contribution to the growing body of knowledge about men and their help-seeking behaviour.

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ANNEXURE A1: Interview schedule - Men

Demographic Information:

1. Participant code:	(name provided permission has been granted)
2. Age (in years):	
3. Marital Status:	Single, Married, Living with a partner, Divorced, Widowed
4. Number of dependents: a. Children b. Parents c. Other (specify) _____	a. b. c.
5. Where do most of your family live?	Soweto Other _____ (specify)
6. Highest educational level achieved:	
7. Employment Status:	Employed in formal sector Employed in informal sector Self-employed Unemployed
8. What kind of work do you do?	
9. Residence type	Brick house Informal dwelling Backyard room Other _____ (specify)
10. Living with	Family Friends

	<p>Relatives</p> <p>Alone</p> <p>Unknown people</p>
11. Monthly income	

HIV status and perceptions of HIV and AIDS

1. Have you ever tested for HIV?	Yes/No
<ul style="list-style-type: none"> • If Yes, what was the result? • If No, why not? 	<p>HIV+, HIV-</p> <p>_____</p> <p>_____</p>
2. What do you think about VCT?	Probe: Do you think VCT is a useful intervention?
3. What do you think about the VCT services?	Probe: How do you think that the service could be improved?
4. Please could you tell me about how you understand HIV and AIDS?	<p>Probe:</p> <p>What is HIV?</p> <p>How is it transmitted?</p> <p>How you can avoid contracting the virus?</p> <p>What is the difference is between HIV and AIDS?</p> <p>How you can treat HIV?</p> <p>How can you treat AIDS?</p> <p>How do you feel about people infected with HIV?</p>
5. Tell me how you think other people understand HIV and AIDS?	<p>Probe:</p> <p>How do you think other people would feel about people infected with HIV?</p>
6. How often and why do you visit health care facilities like clinics, doctors?	<p>Probe:</p> <p>How do you find the services?</p>

	Are the staff friendly? For what medical or other conditions would you visit a clinic?
7. How often and why do you visit traditional health practitioners?	Probe: For what medical or other conditions would you visit a traditional health practitioner?
8. Please could you tell me about how you understand antiretroviral treatment?	Probe: Is it a chronic condition or a cure? Is it short term or long term? What are the good and problematic issues around antiretroviral treatment?
9. Do you think it is important to know your HIV status?	Probe: Please explain your answer.
10. Why do you think it would be necessary to know other people's status or for other people to know your status?	Probe: Do you think that people discriminate against people who are HIV-positive?
11. How do you think that health services could be improved to better serve your needs?	Probe: Would more clinics, friendlier staff be important? Is it necessary to have any male staff at the clinic? Why?

If the respondent has tested for HIV ask the following questions:

Please could you tell me your HIV status, are you HIV-positive or HIV-negative?

1. When did you learn your status?	Date
2. How did you feel when you learnt your status?	
3. Why did you test for HIV?	Probe: had you been ill?, Did you think that you were at risk?
4. Where did you test for HIV?	Probe: why did you choose that site?
5. Tell me about your experiences you had when you tested?	Probe: Were the health workers friendly? Did they spend time with you? Did they explain what services you could access?
6. Have you disclosed your status to anyone?	Y/N

<ul style="list-style-type: none"> • If Yes, who have you disclosed to and what has been their reaction? • If No, why have you not disclosed? 	<p>Probe: do you think there will be a negative reaction?</p>
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If the respondent has not tested ask the following questions:

HIV-unknown

<p>1. Do you think that it would be of benefit to you to know your HIV status? Please elaborate.</p>	<p>Probe: What are the reasons for not testing?</p>
<p>2. Do you know anyone who is HIV-positive? How do you know that they are positive?</p>	<p>Probe: Were there any problems when you found out? How do you feel about knowing their status?</p>
<p>3. Have they discussed any of their experiences with you, what were they?</p>	
<p>4. If you were to go for an HIV test, where would you choose to be tested and why?</p>	<p>Probe: Would you choose that site because you know the staff? is it close to where you live?</p>
<p>5. If you need to be treated for an illness, where would you choose to be treated and why?</p>	<p>Probe: When would you go to a clinic and when would you go to a traditional health practitioner or other person? Would you choose that site because you know the staff? is it close to where you live?</p>

ANNEXURE A2: Interview schedule - Health workers

Themes to be covered include:

1. Most clinical sites report that more women than men access HIV-services such as VCT and ART.
Why do you think this is the case?
2. What are the barriers for men accessing these services?
3. What are your perceptions of men's attitudes to VCT, HIV and AIDS?
4. How do you think men understand issues surrounding HIV and AIDS?
5. How do you think that the health services could better serve men?
6. How do you think campaigns have influenced men accessing HIV-services?

ANNEXURE A3: Focus Group guides

HIV negative men:

1. What was your experience of going for an HIV test?
2. Were you able to disclose your status to anyone?
3. What is your experience at the clinics and of the health workers?
4. For HIV issues do men go to traditional healers for help?

HIV-positive men:

1. What was your experience of going for an HIV test?
2. Were you able to disclose your status to anyone?
3. What is your experience at the clinics and of the health workers?
4. What is your understanding and experience of ART?

Men who had not tested:

1. Why are men not testing for HIV?
2. What would encourage men to test for HIV?
3. Where do you go for help when you are ill?

Post-interview focus group with HIV-positive men:

1. What was your experience of going for an HIV test?
2. Were you able to disclose your status to anyone?
3. What is your experience at the clinics and of the health workers?
4. What is your understanding and experience of ART?