HIV-POSITIVE BLACK MEN: A QUALITATIVE STUDY

BY

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ABSTRACT

Despite the global figures on male HIV infection rates, and the vulnerability of men to HIV as a result of social constructions of masculinity, not enough attention has been paid to the seriousness of the problem of HIV in heterosexual men. Most research has concentrated on either homosexual or bisexual men, neglecting the experiences of heterosexual men diagnosed as HIV positive, and the implications thereof. This study aims to explore the lived experiences (emotional, cognitive and social) of black heterosexual males who are living with HIV.

The focus of this study was thus on the subjective experiences and circumstances of these men, to enhance understanding of how they managed to adapt to the stress of being HIV positive. Health professionals, such as nurses, psychologists and doctors at Tshwane District Hospital, can use the results of the study to assist men when they are diagnosed, and to help them cope effectively with their subsequent challenges.

The study used the phenomenological theoretical framework. It explored the lived experiences of being HIV positive through in-depth, semi-structured interviews, which were audio-recorded and transcribed. Non-probability sampling was used to identify the 5 participants in this study. Data was analysed in terms of thematic analysis and 15 themes were derived from the analysis and described using quotations from the raw data. These themes were then contextualised and explored with relevant literature.

The research found that these men initially struggled to adapt to their HIV-positive status and exhibited denial, fear and loss, complicated by the sense that their masculinity was compromised. While there was some evidence of limited internal and external stigma, the men were able to find support from partners, family and friends, and were able to rise to the challenge of 'living positively'.

KEY WORDS: Black men; psychological consequences; HIV and AIDS; masculinity; condoms; violence; power; culture.

ACRONYMNS AND ABBREVIATIONS

ABC – Abstain, Be faithful, Condomize

AIDS – Acquired Immunodeficiency Syndrome

ANC – African National Congress

ART – Antiretroviral Therapy

ARV – Antiretroviral

CSA – Centre for the study of AIDS

HIV – Human Immunodeficiency Virus

NGO – Non-governmental organisation

NSP – National Strategic Plan

PLHIV – People/ persons living with HIV*

PMTCT – Prevention of mother-to-child transmission

SANAC – South African National AIDS Council

STI – Sexually transmitted infection

TAC – Treatment Action Campaign

VCT – Voluntary counselling and testing

WHO – World Health Organisation

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CHAPTER 1

INTRODUCTION

1. Introduction

This chapter seeks to introduce the reader to the research carried out by this researcher who is concerned about the extent to which HIV and AIDS is affecting heterosexual men and impacting on their daily experiences. Among the issues that are discussed in this chapter is the global HIV and AIDS epidemic, followed by a section on the South African epidemic, highlighting the history of the HIV and AIDS in South Africa and the impact that the epidemic has had on the government and households. The researcher will also briefly discuss negative and positive responses from selected government officials, gender as a key factor in the epidemic, as well as motivation and the aim of the study. Finally, an outline of the structure of the research will be discussed.

1.1 The global HIV and AIDS epidemic

The former Secretary-General of the United Nations, Kofi A. Annan, said the global AIDS epidemic is one of the greatest challenges facing our generation. AIDS is a new type of global emergency, and an unprecedented threat to human development requiring sustained action and commitment over the long term. The epidemic shows no sign of weakening its grip on human society. The AIDS crisis continues to deepen in Africa, while new epidemics are growing with alarming speed. No region of the world has been spared (UNAIDS, 2004, p. 7).

The first case of AIDS was reported in 1981. Since then the world has seen the explosion of a worldwide epidemic. Around the end of 1981, there were 257 identified cases in the United States. This number rose to 2 000 by the end of 1983 and 360 000 a decade later. PLHIV have experienced incidents of pain and loss, of tragedy and prejudice, and of neglect. However, through the involvement of marginalised groups such as the gay community, and with the efforts of the few leading professionals, denial and ignorance have begun to be addressed, and HIV/AIDS has been recognised as a major threat to humanity (Aronstein & Thompson, 1998).

AIDS has from the outset been as much a battle of ideas as a battle about bodies, viruses and cells. In the beginning, the disease was stigmatised, initially associated with gay men in the USA and Europe. Later it was associated with stigmatised minorities in the USA and elsewhere. An important difference between the first diagnosed case of AIDS in June 1981 and the millions of cases we see in the present is, of course, that the disease now overwhelmingly affects poor heterosexuals in the developing world (Walker, Reid & Cornell, 2004).

Since the discovery of AIDS in 1981, more than 60 million people have been infected with HIV and it is estimated that about 24 million people have died. According to UNAIDS, AIDS claimed approximately 3.1 million lives worldwide in 2006, while an estimated 2.5 million people were infected with the disease. Worldwide, the number of people currently living with the virus is approximately 40.3 million (Brouard & Maritz, 2008). Although effective prevention strategies have been put in place, the number of PLHIV globally is still continuing to rise.

1.2 The South African epidemic

1.2.1 History

The South African epidemic began during a period of extreme state of violence and political oppression, which included a government-imposed state of emergency from 1985 to 1990, and continued to develop while the country was largely preoccupied with the efforts to negotiate the end of apartheid in the early 1990s (Amnesty International, 2008).

Since then HIV/AIDS has rapidly become the leading cause of morbidity and mortality in South Africa. It has created an epidemic of immense proportions, affecting people of every race, culture and economic status, while the poor and the powerless have been disproportionately affected. The complex social, psychological, ethical and physical problems confronting PLHIV sets it apart from any other disease. Soon after the time when HIV/AIDS was first identified, there was wide-scale recognition that PLHIV face a range of psychological stressors, potential adjustment difficulties and coping challenges (Katz, 1997).

HIV/AIDS was initially perceived in South Africa as a disease affecting gay men, people receiving blood transfusions, sex workers and, to a lesser extent, drug users who used needles. But it soon became obvious that HIV/AIDS was not restricted to a particular risk group but that it was creating a generalised epidemic affecting not only women and children but also heterosexual men. From 1991 onwards most of the transmissions in South Africa were through heterosexual intercourse (Amnesty International, 2008).

Many people who believed that they were not part of a high-risk group thought that they were immune from infection. Understanding of HIV/AIDS was heavily influenced by moral judgements. Minorities on the edge of society were frequently blamed for the spread of the disease. Those who were infected were believed to be the victims of their own immoral or antisocial behaviour. These perceptions fuelled the stigma attributed to HIV/AIDS (Walker, Reid & Cornell, 2004).

1.2.2 HIV and AIDS impact

Today South Africa is still continuing to experience a severe HIV/AIDS epidemic. The epidemic developed at great speed from the first cases recorded in 1982 in South Africa. From 1985 it became apparent that other sectors of society were also affected. Approximately five-and-a-half million South Africans are currently HIV infected, the highest number of people in any country in the world. UNAIDS estimates that in 2006, 320 000 people died of AIDS-related illnesses in South Africa, and so about 900 die every day (Knights, 2006; UNAIDS, 2004). South Africa as a country is faced with a human capacity crisis as it fails to develop sufficient skilled staff essential for government departments to deliver vital public services, due to skilled employees dying of AIDS. As a result the country is unable to meet its needs for essential social services, and extraordinary multisectoral response in affected areas are needed more than ever (UNAIDS, 2004).

Not only are individual households affected by the HIV/ AIDS epidemic, but government and governance is suffering because of the epidemic. HIV/ AIDS results in a loss of income, and if the person infected is the sole breadwinner, the impact becomes much more severe. Special care needs must be fulfilled when family members are ill, often causing younger family members to leave school or older employed family members to resign from work to care for the sick individual. In addition HIV/AIDS may also cause household expenditure to rise due to increasing medical costs and related costs, including funeral costs. As a result poor household are the ones that are hardest hit by HIV/AIDS, faced with the challenge of losing their economic independence while the coherence of the family unit comes under severe strain (UNAIDS, 2004).

Recent studies of PLHIV suggest that the number of infected people could reach 7.5 million by 2010, representing a fifth of the population of South Africa (Walker, Reid & Cornell, 2004).

1.2.3 The responses

AIDS activist and Treatment Action Campaign (TAC) founder Zachie Achmat said that denial is generally an individual or collective inability to face an intolerable challenge by pretending that it does not exist. It is portrayed as a problematic but common phase in coming to terms with a pathological moment in the personal or national psyche that has to be overcome if appropriate responses are to evolve. The slogan "breaking the silence" has become a kind of global *leitmotiv* in the AIDS epidemic, suggesting that denial is a universal phenomenon (Schneider & Fassin, 2002, p.46).

This denial was evident in the responses of the then South African President Thabo Mbeki and other African National Congress (ANC) figures such as the late Peter Mokaba. Both refused to acknowledge the link between HIV and AIDS, implying that HIV tests were pointless and that antiretrovirals (ARVS) were poisonous (Schneider & Fassin, 2002).

President Mbeki suggested that people do not actually die of AIDS, but rather of the effects of poverty, such as poor diet and poor sanitation, and the opportunistic infections the syndrome produces. This view was supported by then health minister Dr Manto Tshabalala-Msimang who advocated the African potato, garlic and beetroot as appropriate African alternatives to antiretrovirals (Jones, 2005).

The unwillingness of government officials in South Africa to accept that they had been personally affected by HIV/AIDS, for example, knowing that Mr Mokaba and others died of AIDS-related causes, has played a significant role in perpetuating AIDS-related stigma. Early in 2005, former President Nelson Mandela declared publicly that his eldest son died from the complications of an AIDS-related illness. This highly public gesture appears to have not changed people's perceptions about the disease. Stigma, fear, ignorance and discrimination continue (Demmer, 2007; Aronstein & Thompson, 1998).

There seems to be a new urgency with which the government has started to address HIV/AIDS, with a united effort to implement the country's new HIV and AIDS National Strategic Plan (NSP) for 2007-2011. In the second half of 2007 the NSP was adopted by both cabinet and the restructured and revived South African National AIDS Council (SANAC). Before its adoption, there was extensive consultation with a wide range of stakeholders, including the Treatment Action Campaign (TAC). Essentially the plan has two primary aims:

- To reduce the rate of new HIV infections by 2011 through a number of innovative and conventional prevention strategies, and
- To treat, care for and support 80% of those already living with HIV/ AIDS and their families.

(Brouard & Maritz, 2008, p.4).

The push for the legalisation of commercial sex workers, programmes against alcohol abuse (since alcohol both encourages risky sexual behaviour and interferes with people's inability to adhere to their ART), subsidies for people who adopt orphans and food support for HIV-positive mothers who breastfeed exclusively, are some of the new interventions proposed in the plan. It also proposes a public awareness campaign involving high-profile people taking HIV tests every month for the next five years, to encourage people to follow their example (Brouard & Maritz, 2008).

The plan's implementation will be costly. There is a high probability that it may exceed the entire health budget by 20% - and cost up to R45 billion. Currently the biggest cost is ARVs (40%), followed by support for orphans and children affected by AIDS (7%). Implementation relies on efficient systems and political will, both of which have been lacking previously. A number of provinces have not been able to spend their current AIDS budgets, due to a lack of doctors, nurses and pharmacists to implement the plan (Brouard & Maritz, 2008).

While there is some debate about the role of voluntary counselling and testing (VCT) at the individual level, most international agencies such as UNAIDS see it as an important aspect of national HIV and AIDS campaigns. The goals of VCT are to prevent HIV transmission, to encourage the early uptake of services for the infected, to produce social benefits (normalising HIV and AIDS, challenging stigma, promoting awareness and supporting human rights) and to promote adherence among those on treatment (Brouard & Maritz, 2008).

The following progress been made in the government's VCT strategy:

- By the end of 2007 more than 4 000 facilities were offering VCT.
- Between April 2004 and December 2006, 4.5 million people had received pre-HIV test counselling and 3.3 million (76%) of them had actually tested, compared to 691 000 people in 2002/2003 (Brouard & Maritz, 2008).

The South African prevention of mother-to-child transmission (PMTCT) programme has expanded significantly since its inception in September 2001. A total of 3 064 facilities countrywide offered PMTCT services during 2005 (Brouard & Maritz, 2008, p.12).

The South African government started to provide ARVs in the public-health sector in 2004 in what is one of the largest roll-outs of ARVs in the world. By the end of 2007 it was estimated that 889 000 people in South Africa needed ARVs. By the end of 2007, 371 000 were receiving treatment. Of this number, 252 000 (68%) were being treated in the public sector, and 119 000 (32%) were being treated by the private sector and NGOs. The largest number of patients on treatment were in KwaZulu-Natal (74 528), followed by Gauteng (69 231) and North West (31 904). The Northern Cape had the smallest number of patients on treatment (6 372). Some 55% of patients were female. In 2007 the estimated number of children (under 15 years) needing ARVs was 65 000 and 32 000 children received treatment in that year (Brouard & Maritz, 2008).

In addition to these notable efforts by the government there were prevention and awareness campaigns such as "The Soul City Project", which began in 1994, educating people about HIV through the media, using dramas and soap operas to promote its message. There was also the "Beyond Awareness" campaign, which ran between 1998 and 2000, and concentrated on informing the youth about AIDS through the media. However the "loveLife" campaign became the most prominent prevention campaign to be carried out in South Africa, targeting the youth and attempting to integrate HIV prevention messages into youth culture. The campaign was launched in 1999, with the objective of decreasing rates of teenage pregnancy, HIV and sexually transmitted diseases amongst young South Africans. The campaign seeks to facilitate a network of telephone lines, clinics and youth centres that provide sexual health facilities, including an outreach service that travels to remote rural areas, to reach young people who are not in the educational system (Pembrey, 2009).

Although these campaigns may have saved lives, the actual difference they may have made in reducing the number of new HIV infections is very difficult to measure. The current rates of HIV infection across South Africa suggest that the prevention messages are not reaching many people or that people are receiving information but they are not doing anything about it (Pembrey, 2009).

A wide range of NGOs have responded to the HIV and AIDS crisis. These NGOs have been responsible for raising awareness, training, advocacy, education, welfare and health service provision, materials production, orphan care, counselling and other activities. NGOs have played a significant role in facilitating the campaign for access to treatment, reducing drug prices, improving care, and improving policies on HIV and AIDS. As a result large sums of money have been invested in NGOs to facilitate the fight against HIV (Jones, 2005).

1.2.4 Gender as a key factor in the epidemic

Walker, Reid and Cornell (2004) state that women are more biologically vulnerable to contracting HIV through sex, and that men have a greater chance of contracting and transmitting HIV when they determine the circumstances of sexual intercourse and refuse to protect themselves and their partners. Many men are under social pressure to behave in a domineering and sexually aggressive way. The discourse surrounding norms and expectations of masculinity, which states that young men should be informed and experienced about sex, makes it difficult for them to seek information about safer sex. They may also be forced into experimenting with unsafe sex to prove their manhood (UNAIDS, 2000).

Therefore, it is important to realize that men's risk-taking around sexual decisions increases their vulnerability to HIV and AIDS. Dominant ideas about masculinity and manliness encourage men to show sexual prowess by having multiple sexual partners, and to use alcohol and other substances that may expose them to sexual risk and violence. Similar ideas encourage men to see the provision of care as a woman's responsibility rather than a man's responsibility. These dynamics show how gender systems influence the vulnerability of both men and women in relation to the epidemic (Aggleton, 2000).

Male sexual violence towards women, as well as the physical abuse perpetrated by men on women, deprives women of their rights, choices and abilities to protect themselves. Through such violent sex, men may be at risk of acquiring HIV if their partner is already HIV positive (Mane & Aggleton, 2001). In many cultures men are socialised into thinking that it is essential for them to take risks, especially of a sexual nature, such as having sex with multiple partners. Expectations of risk-taking and taboos surrounding health-seeking may increase male exposure to injury and illnesses such as HIV.

1.3 Motivation for the study

As stated above, the HIV epidemic first became evident in marginalised groups in society, such as gay men, sex workers and intravenous drug users. Many countries and communities responded with fear and prejudice. AIDS became a disease of the other, i.e. of people that differ from socially prescribed norms. As it became clear that HIV was also heterosexually spread, women became a research focus because of their greater biological vulnerability to infection (Albertyn, 2003). But testing HIV positive represents a health issue for men and women, and is also a matter of concern for the rest of society as every sexually active person with HIV can infect others and women can pass on the virus through pregnancy (Emmers-Sommer & Allen, 2005).

Men often tend to have more sex partners than women (Steinberg, 2008). HIV is more easily transmitted sexually from men to women than vice versa. HIV-positive drug users, who are mostly male, can transmit the virus to both their drug partners and sex partners. A man with HIV is therefore likely to infect more people over a lifetime than an HIV-positive woman (UNAIDS, 2000). So a focus on heterosexual men would help us understand male behaviour and motivation, and could contribute to lessening the impact of male behaviour on women, children and the rest of society.

Heterosexual men are not as vulnerable biologically as women, but there are social factors which may also put them at risk. According to Kalichman et al. (2005), these risk factors may include lack of condom use, which increases the risk for sexually transmitted infections including HIV; violence, and in particular sexual assault, which has a risk for HIV and sexually transmitted infections; and traditional views about masculinity.

Men are more likely than women to use alcohol and other substances that lead to unsafe sex and increase the risk of HIV transmission (UNAIDS, 2000). According to a study of men by Simbayi et al. (2006), alcohol use was associated with multiple concurrent partners and a lower rate of condom use. Men who had too much to drink were more likely to report having forced someone into non-consensual sex without protection.

Migration has also contributed to male vulnerability to HIV. Over the past century, migration became common among rural men seeking employment in the mining industry, and it still persists today. Other men also migrate to South Africa from neighbouring countries. Many of these men have set up new, parallel families where they worked or they would use the services of sex workers. Several studies have shown that people who are more mobile or who have recently changed residences tend to be at higher risk for infection with HIV and other sexually transmitted infections (Campbell, 1997; Lurie et al., 2003).

Research suggests that men are less likely to pay attention to their sexual health and safety than women, such as accessing HIV services, including testing and other care or support services. Fewer visits to health care services and delays in getting advice may reduce a man's chances of early detection, or prevention of, a chronic illness such as HIV (O'Brien, Hunt & Hart, 2005).

Although it seems that heterosexual men are at risk for HIV because of the above-mentioned factors, there is little research on heterosexual men's vulnerability. On the contrary, there is a large body of South African and international literature on the impact of HIV on women and gay men. Where there is a gap, it is suggested, is regarding a deeper and more qualitative understanding of how heterosexual men live and cope with HIV in their daily lives. This research project attempts to understand the lived experience of heterosexual men, particularly black men, regarding HIV, to guide and inform planning and implementation of health and social care.

1.4 Aim of the study

The aim of this study, then, is to explore the experiences (emotional, cognitive and social) of black heterosexual males who are living with HIV. The focus will be on the subjective experiences and the circumstances of these men, in an effort to enhance the understanding of how they manage to adapt to the stress of being HIV positive. The results of this study may be used by health professionals in addressing the problems men may face when diagnosed, and how to effectively cope with the problems that may arise.

As a result the research results may improve our understanding of these experiences and have several results: (a) an appreciation of and sensitivity towards those involved in these experiences, which may be a particularly significant consequence for those in the helping professions; (b) policies can be amended so as to be more responsive to the needs of heterosexual men who are HIV positive.

1.5 Chapter overview

Chapter 1provides an introduction to this study.

In Chapter 2 there is a literature review of HIV and AIDS and men. This section will discuss various factors that contribute to the spread of HIV infection in straight men. The chapter begins with a discussion on how masculinity and gender as social constructs influence a man's behaviour, thus placing him at risk of HIV infection. The impact that cultural aspects have, and the power relations and violence perpetrated by men are all explored. A discussion of factors that result in men refusing to use condoms during sexual intercourse, and the resulting physiological and psychological consequences of an HIV-positive diagnosis are discussed. Lastly, there is a discussion of how social support as a buffer can help to boost the well-being of those living with HIV infection.

Chapter 3 looks at the use of qualitative research methodology. The chapter will describe the research process in a detailed manner, focussing on the research design, how the sampling process was conducted, and the manner in which the data collection and data analysis were dealt with.

Chapter 4 discusses the results of the qualitative research methodology used by this researcher, and analyses the results, thereby drawing conclusions and recommendations to be presented in Chapter 5.

Chapter 5 provides an interpretation of the results, integrating the findings and recommendations are made.

In Chapter 6 the researcher discusses and reflects on the research and the outcomes of the study.

CHAPTER 2

HIV AND MEN

2.1 Introduction

In this chapter, a gendered understanding of HIV and AIDS and the ideologies and beliefs regarding masculinity will be highlighted, based on the impact that gender has on human relationships. Pertinent discussion of what constitutes men and how they live their lives is provided, based on the socially constructed roles of what society determines to be a woman and a man.

This chapter then looks at how men are globally under pressure to conform to ideologies that emphasize sexual prowess, and result in encouraging men to have multiple sexual partners and exercise their perceived authority over women. These traditional images of masculinity at times encourage men to engage in risky sexual behaviours, reject condom use and use sexual violence as a confirmation of their manhood (UNAIDS 2001).

The chapter also explores how existing gender relations and dominant ideologies of masculinity exert a powerful effect on men and their actions. In preparing to work with men there is a need to start with an understanding of gender, and more importantly, the role played by masculinity and power, and how sexual violence contributes to the spread of HIV infection. This chapter continues with a discussion of HIV-related stigma and disclosure, the physiological and psychological effects of a positive diagnosis, as well as an exploration on how social support as a buffer can impact on the overall well-being of individuals living with HIV.

2.2 Masculinity

Masculinity is a collective gender identity and not a natural attribute. There is not one universal attribute but rather many "masculinities". These are "not fixed character types but configurations of practice generated in particular situations in a changing structure of relationships" (Morrel, 1998, p. 607).

2.2.1 Hegemonic masculinity

This study will use the framework of hegemonic masculinity to understand how black South African men deal with living with HIV.

Hegemonic masculinity is a term first introduced by R.W. Connell. It refers to the dominant forms of masculinity within the gender hierarchy. Although hegemonic masculinity subordinates other masculinities and femininities, it can be challenged. In many western societies today, hegemonic masculinity is associated with heterosexuality, marriage, authority and physical toughness (Dalley-Trim, 2007). It is a concept that has been developed and used widely in critical studies of men and masculinity to explore power dynamics between men, as well as to illustrate the differences and interconnections between the cultural norms of masculinities and the realities of men's lives (Alsop, Fitzsimons & Lennon, 2002; Connell & Messerschmidt, 2005).

Hegemonic masculinity also represents the form of masculine identity frequently aspired to by many boys and men, and that comes to dominate the world we live in. Many men aspire to, and actively seek to even live up to, this hegemonic masculinity. In many societies or particular contexts there seems to be a culturally dominant construction of masculinity, which becomes a version of the hegemonic masculinity above. Any man who fails to view the self within this particular framework of hegemonic masculinity may feel unworthy, incomplete and inferior in comparison to other men (Donaldson, 1993; Alsop, Fitzsimons & Lennon, 2002).

Hegemonic masculinity includes a particular strategy for the subordination of women. According to the core elements of hegemonic masculinity, women exist as potential objects for men, whereby women provide heterosexual men with sexual validation and men compete with each other for this validation. Therefore the male sex role is best visualised as a hegemonic masculinity, in which the culturally idealised form of masculine character reinforces a structure of dominance and oppression (Donaldson, 1993).

Such dominance and oppression in the gender realm legitimates a broad structure of power representing patriarchy, whereby men hold most or all power, especially over women. This dominance over women most commonly takes the form of sexual assault and sexual/physical violence. Literature has shown that many men who resort to sexual violence against women subscribe to traditional and patriarchal views of male power, and supremacy, traditional gender roles, and to the view that violence is an acceptable way of resolving conflict. Many men still believe that men are superior to women and possess a natural right over them, in that women are their property and they can legitimately control them (Kenway & Fitszclarence, 1997).

In many societies most men are seen as having a strong desire to engage in sex with as many partners as possible. Cultural beliefs that men are unable to control their own sexuality, and that relationships with women should be characterised by aggression and force, underly the social acceptance that sexual violence and force is a normal behaviour for men (Lee & Glynn-Owens, 2002).

Power imbalances at a relationship level, reinforced by hegemonic masculinity, may affirm and contribute to broader dynamics of inequality in various societies. This may lead to a number of health risks associated with being a man: in their quest for power and privileges they may harm themselves by engaging in risky sexual behaviours that may eventually expose them to HIV infection (Courtenay, 2000; Lee & Glynn-Owens, 2002).

Earlier criticisms of hegemonic masculinity have raised the question as to who actually represents hegemonic masculinity. A hegemonic masculinity can be constructed that does not necessarily correspond to the lives of all men in a particular society. Although hegemonic masculinity may be the dominant type, this does not necessarily mean that all men will conform to this (Connell & Messerschmidt, 2005).

2.2.2 Gender and masculinity as social constructs

A social construction or social construct is any institutionalised entity or artefact in a social system invented or constructed by participants in a particular culture or society that exists because people agree to behave as if it exists or follow certain conventional rules. One example of social construct is gender (Babylon's Dictionary, 2009).

Gender is not a synonym for sex. Gender refers to the widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles. It is a social and cultural construct that constantly changes and varies, depending on time and place. Gender differentiates women from men and defines the ways in which women and men interact with each other, owing to the high agreement in our society about what are considered to be typically feminine and typically masculine characteristics (Gupta, 2000; Courtenay, 2000).

These shared norms and expectations about gender provide collective and organised meanings regarding what it means to be a man or a woman, which then become widely accepted. As a result, men and women are encouraged to conform to stereotypical beliefs and behaviours about what women and men are, and finally to conform to and adopt the dominant norms of femininity and masculinity (Courtenay, 2000).

According to the social constructivist perspective of masculinity, gender is accomplished through and by people within their context. Gender is not something we are but something we act out in social interactions. Gender as a construct is influenced by historical, social and cultural factors rather than anatomical factors and therefore does not form a part of a human's basic natural 'true' self (Moynihan, 1998; Cassimjee, 1998).

According to Lee and Glynn-Owens (2002) social roles prescribed for traditionally masculine men are constraining. In particular, hegemonic models of masculinity provide limiting perspectives on men and their roles in their families, presenting them almost exclusively as material providers whose relationships with their partners and children are unimportant. In western societies, men are socialised to see their careers as the most significant aspect of their lives, to choose work over family and to be less involved in domestic affairs and childcare.

These socially constructed roles have failed to keep up with the changed realities of work and family life, and as a result many men experience stress and stress-related illnesses as a result of having to deal with conflicts between social expectations and the real aspects of their family and personal lives. Men who are unemployed, underemployed, or living in role-reversed or in same-sex relationships that otherwise do not comply with these stereotypes, are often stigmatised and find it difficult to avoid a perception of negative self-worth (Lee & Glynn-Owens, 2002).

Research has shown that men and boys encounter a greater social pressure than women and girls to meet gender/societal expectations, such as the belief that men should be tough, self-reliant, independent, strong and robust. According to a social constructionist perspective, men and boys are not passive victims of socially constructed roles or simply conditioned or socialised by their cultures. They are active participants in what constitutes and reconstructs dominant norms of masculinity (Courtenay, 2000).

The association of masculinity with sexual conquest makes gender one of the most significant factors that contribute to the spread of HIV infection. Looking at the sub-Saharan African region, it is evident that gender norms have empowered men to dictate the terms of sex, which often led men to expose themselves to HIV infection (Courtenay, 2000)

As a result, men exhibit health beliefs and behaviours that express dominant and hegemonic masculine ideals as a way of trying to show that they are true men. These health-related beliefs and behaviours include a denial of weakness or admitting vulnerability, demonstrating physical and emotional control, appearing robust and strong, dismissing any expression of need or help, having an insatiable appetite for sex, and displaying aggressive behaviour. By denying their health-care needs men are reconstructing gender and through the enactment of hegemonic ideals regarding their health behaviour men will reinforce the strongly held cultural beliefs that they are powerful (Courtenay, 2000).

In the light of the preceding information, many men fail to show concern about their health. Men's comparative low use of HIV/AIDS facilities in South Africa has been noted and is becoming a serious cause for concern. This may have consequences for men's health and well-being, creating risks and vulnerability for contracting HIV (Lee & Glynn-Owens, 2002).

2.3 Masculinity and HIV

2.3.1 Cultural norms and practices in South Africa

Culture affects all aspects of life. According to Mukamba (2009, p. 29) "culture is defined as a way of life for a family, community or society. It defines and identifies people, why and how they do what they do through everyday practices such as language, arts, and sciences, thought, spirituality, social activity, interaction".

Certain cultural norms and practices around maleness and male behaviour, which interact in complex ways with hegemonic forms of masculinity, could put men and their partners at risk of HIV infection. One practice which has become culturally accepted, and which may contribute to the HIV epidemic, is transactional sex. This practice involves women accessing necessary goods such as food, shelter and school fees (and even material goods such as cell-phones or designer brand clothing) in exchange for sex. Transactional sex has arisen from income inequality combined with inherited cultural norms, and may encourage risk behaviour in men and the trading of sex as a symbol of power (Albertyn, 2003).

Cultural or customary practices that reflect patriarchal ideas of masculinity may reinforce men's vulnerability to HIV infection, since they accept male infidelity and expect female monogamy. Polygamous relationships may also put men at risk of HIV infection if they go beyond traditional, structured, forms of polygamy and practise multiple sexual relationships. A case in point is migrant workers who have a customary wife at home, in the rural areas, and then marry or cohabit with urban wives. This practice increases the vulnerability of both men and women, and other sexual partners that they might have (Mukamba, 2009; Albertyn, 2003; Rose-Innes, 2006).

A common customary practice in South Africa is that of lobola or bridewealth, which is interpreted by some men as a licence to own a woman's body and have sex with her without protection. This may increase the risk of HIV infection for men and women. In addition, young boys are taught to believe that they must show their sexual prowess in order to be recognised as men. They are encouraged to have sex with many girls to prove their manhood. While boys can have sex with whoever they want, girls are not allowed to do so, and should culturally embody norms of passive, modest femininity. Confusingly, this is the kind of young woman a man will want to marry, preferably a virgin, yet they will have had sex while dating women, often with many partners, who will not be able to offer their virginity when they get married in turn (Mukamba, 2009).

Another cultural norm that has been identified by Rose-Innes (2006) and Mukamba (2009) is that many African men have been taught to believe that a woman's vagina should be dry as this is a sign of sexual modesty. The friction induced by a dry vagina increases sexual pleasure for men, which is considered to be more important than the sexual pleasure of women in many patriarchal societies. Remedies and practices to dry vaginas may cause tears and bruises during sex, and when a condom is used, the condom may tear because of the dryness, exposing both men and women to the risk of being infected with HIV.

Lastly, men in some parts of South Africa go through the process of circumcision as a rite of passage to graduate from boyhood to manhood. After circumcision men are often expected to "cleanse" themselves with a woman and may also feel justified in acting out a newfound sense of male sexual prowess with many partners. While medical circumcision may bring partial protection from HIV for men, it is not clear that this same benefit comes from traditional circumcision, which may in some cases only be a partial removal of the foreskin. However, the acting out described above, along with the belief that circumcision is fully protective, may also contribute to spread of HIV infection among men, and of course, women (Mukamba, 2009).

2.4 HIV and power

South African men, like men in most societies, possess greater control and power in their sexual relationships than women. Men who have limited resources and fewer opportunities for social advancement often resort to exerting power and control over women. Power and control disparities in relationships create a context for men to have multiple concurrent partners and fuel their reluctance to use condoms, and men then conceive women as desexualised beings whom they need to control through men's power and promiscuity (Mlambo-Ngcuka, 2007; Heywood, 2004).

Men's use of power and violence over women may increase men's vulnerability to HIV transmission. Coerced sexual intercourse can directly result in HIV transmission, as previously stated. A woman suggesting condom use in the context of a sexual relationship may also be equivalent to implying or admitting infidelity as condoms are associated with prostitution, promiscuity and disease. It can also be seen as an implicit challenge to a man's right to have many sexual partners (Jewkes, Levin & Penn-Kekana, 2003).

Research has shown that in many cultures men have the authority to be sexually adventurous while female sexuality is restricted. According to Heise and Elias, (1995) and Wojcicki and Malala, (2001) there is a higher rate of partner change among both married and single men than amongst young women, resulting in the spread of HIV. Between the ages of 25 and 34 years many men might already have had as many as five sexual partners on average, whereas a woman might have had only one. As a result older men, who obviously have had more sexual partners, have a greater risk of being infected with HIV and/or other STIs.

In most societies gender relations are characterised by power imbalances with men having access to more resources. The construction of male and female sexuality shows the inequalities of the social and economic spheres of life, so that men are more likely than women to initiate and control sexual interactions and decision making (Weiss, Whelan, & Gupta, 2000; Wojcicki & Malala, 2001). Research has shown that economic dependence by women on men makes it more likely that men will exchange money for sexual favours, and more likely that they will succeed in not using protection, and it is more likely that they will engage in risky sexual behaviours that will expose them to HIV infection (Heise & Elias 1995; Gupta, 2000; Weiss, Whelan & Gupta, 2000).

Power as a fundamental aspect of both sexuality and gender can have a huge impact on the power balance with regard to gender relations, translating into inequalities of power within heterosexual interactions, so that male pleasure is privileged over female pleasure, and men have more control than women over when and how sex takes place (Gupta, 2000). Hence, power and risk are situated at the heart of comprehending HIV and AIDS in contemporary South Africa. By making sense of sexuality and gender one is able to comprehend the epidemic better.

2.5 Violence and HIV

South Africa has one of the highest rates of violence against women in the world. The 1998 South African Demographic and Health Survey found that ten per cent of women had experienced physical assault at the hands of men in the past twelve months. Seven percent reported having been forced to have sex, and a further 4.4% reported that they had been raped. The World Health Organisation (WHO) reports that worldwide, between 10% and 69% of women in 48 population-based surveys reported being the victims of physical assault by an intimate male partner (Peacock, Redpath, Weston, Evans, Daub & Greig, 2008).

In South Africa a woman has about a one in three chance of being raped in her lifetime, and the genital injuries that result from forced intercourse may increase the likelihood of HIV infection. The increasing number of rapes may worsen the HIV epidemic for a number of reasons. Firstly, if the rapist does not wear a condom, the chances of contracting HIV are high. Secondly, if both the perpetrator and the victim are HIV positive, chances are they may re-infect each other. In a country such as South Africa, where HIV prevalence is comparatively high, the transmission of HIV via rape may pose a real danger for the perpetrators of rape, as well as the survivors of rape (Low, 2009, Peacock et al., 2008; Rose-Innes, 2004).

Furthermore, some men will resort to physical assault to coerce women into engaging in sex. Men may beat their partners with belts, sticks and shoes, often until injuries are visible. Sexual violence may become part of the daily reality of some women, limiting their ability to negotiate sexual activities. Their chances of resistance are minimal. The consequences of trying to resist can be highly dangerous, further exacerbating the chances of men being infected with HIV. Violence has come to be accepted as a common practice among married and unmarried couples alike (and very likely to be witnessed in the home context), and sometimes accepted as an unavoidable part of a relationship (Wood, Maforah & Jewkes, 1998).

For some men having multiple sexual partners may be regarded as a mark of virility, a consequence of so-called uncontrollable male sexual urges. Research has shown that both men and women believe that male sexuality is determined by biology, and that men posses sexual urges that lead to inevitable behaviours: firstly, the need to have many sexual partners; and secondly the power to use force or violence. As a result some men and even some women believe that a man is at liberty to, or even has a duty to, force himself on a woman. Therefore, the manner in which men achieve this masculinity can have a direct bearing on the spread of HIV (Walker, Reid & Cornell, 2004; Miles, 1992).

Ideas of masculinity emphasizing sexual dominance over women as a defining characteristic of being a male may contribute significantly to homophobia and stigmatisation of men who are secretly in sexual relationships with other men. Men in same-sex relationships and are particularly vulnerable to HIV, and risk transmitting the virus to their male partners. As a result of the stigma and fear these men experience, they are then forced to keep their sexual behaviours secret and deny their sexual risk, and that of their partners (Gupta, 2000; Heise & Elias, 1995).

2.6 HIV and condoms

Despite the fact that condoms are not 100% safe, research has shown that condoms significantly reduce the risk of HIV infection. Regular and proper use of latex condoms is highly effective in reducing the risks associated with HIV infection and other STIs, such as gonorrhoea, chlamydia, genital ulcers and the herpes simplex virus. Condom users are therefore 90% less likely than non-users to become infected with HIV (Pinkerton & Abramson 1997; Roper, Peterson & Curran, 1993).

Despite the widespread comprehension that HIV is mainly transmitted via sexual intercourse, a large number of sexually active men who are at risk of HIV infection still have intercourse without using a condom. Factors contributing to the low use of condoms and the acceptance of risks around HIV other STI infection are complex and not fully understood. However, the notions of masculinity described (seeking pleasure, taking charge, not admitting vulnerability) may contribute to a clearer understanding.

Roper, Peterson and Curran (1993), and Walker, Reid and Cornell (2004) have shown how discourses of gender and sexuality can have an impact on safe-sex behaviour as well as increased likelihood of unprotected sex. The assumption would be that when a man spends money on a woman an expectation is created that he can demand unprotected sex. The more money he spends, the higher the expectation.

Condoms have also been stigmatised due to diseases being associated with them. Some people assume that if you use a condom you are sick. Perceptions exist that sex is a natural and enjoyable encounter, and that it does not need an unnatural interruption such as the use of condoms. As a result some men do not want to use a condom because they think that it interferes with the sexual act. There is a saying that "if you truly love and trust someone, then why should you use a condom?" As a result partners are often requested to show their love and trust by having unprotected sex (Walker, Reid & Cornell, 2004; Wood, Maforah & Jewkes, 1998).

In addition, a study by Agbo (2001) reveals reasons why men prefer not to use condoms. The reasons included a lack of knowledge, misconceptions about condoms, barriers to sexual pleasure and incompatibility with the male ego, creating a lack of trust and love between partners. Since men are the dominating actors in negotiating sex they have a greater influence on the use of condoms as a barrier method in preventing STIs, including HIV and AIDS.

According to Basset and Mhloyi (in Van Woudernberg, 1994), in most cases it is the male partners who introduce HIV infection to the family unit. However, the use of condoms, in or out of marriage, depends on the willingness of the men. A study by Leclerc-Madlala (in Barnett & Whiteside, 2006) found that most young men in South Africa have a perception that contracting HIV forms part of growing up, and that it can be accepted as an unavoidable consequence of being an adult, a position which requires being sexually active.

Limited knowledge of condoms can also impact on their use. Even though they are freely available, for some knowledge of condom use may be limited.

2.7 Consequences of receiving an HIV-positive diagnosis

Receiving an HIV-positive result is a highly stressful situation and being diagnosed HIV positive has a major effect on psychological and social functioning (Heckman, Heckman, Kochman, Sikkema, Suhr & Goodkin, 2002).

Such psychological and social consequences place stress on the coping skills of those who have been diagnosed with HIV. Most of these coping skills are not usually addressed by the health-care worker giving the results of a positive diagnosis. Despite researchers agreeing that a diagnosis can be visualised as an interaction, the affected are often ignored. Health-care workers often work from a medical perspective (and not a psychological or social perspective) and focus on presentation of the HIV-positive diagnosis, as just a mere giving of medical information during a health-care worker-patient encounter (Silverman, 1993; Yallops, Lowth, Fitzgerald, Reid & Morelli, 2002)

The psychological consequences of a positive diagnosis will be explored in the following sections, and the benefits of having an intact support structure described.

2.7.1 Psychological consequences

Research has shown that receiving an HIV-positive diagnosis may present one with a wide range of psychological consequences. Some of these consequences may include fear, loss, grief, guilt, denial, anger, anxiety, depression and suicidal behaviour. The psychological consequences may differ from one individual to the next. Each individual is unique and some individuals may face catastrophic changes in their lives: in personal relationships, physical appearance, self-image and self-esteem (Penedo et al., 2001; Siegel & Lekas, 2002). People cope better if they have access to personal and social resources.

HIV-positive individuals may struggle to adjust to a new lifestyle. Some may view themselves as undesirable to others, who look on them as contagious. In addition, they may withdraw and not disclose their feelings, and feel socially isolated (Semple et al., 1996). Consequently, this may lead to a depressed mood due to suppression of the infected person's feelings. This sense of isolation may have numerous implications, such as the loss of support by partners, family and friends, and the development of symptoms of depression (Penedo et al., 2001).

Depression may in turn worsen the physical impact of the disease, elevating the risk of subsequent physical morbidity and mortality, especially due to the effects that depression has on the immune system (Schmitz & Crystal, 2000). Research has shown that depression may accelerate HIV disease progression directly by altering immune functions and causing behavioural changes, resulting in non-adherence for those taking ARV treatment regimes and a reduced food uptake (Egwang, 2007; Catalan, Meadows & Douzeniz, 2008).

Suicidal ideation is more common among people who are HIV positive and research has shown that there is evidence for increased suicide risk among people who are HIV positive (Catalan, Meadows & Douzenis, 2000). Other than suicidal ideation, the stresses of an HIV-positive diagnosis may increase the chances of smoking, alcohol use or engaging in unsafe sex. These stresses may have a direct bearing on the psychological as well as the physiological, leading to a more rapid progression of the illness (Thompson, Nanni & Levine, 1996).

Anxiety can be a noticeable symptom after an initial HIV diagnosis and then abate, but symptoms of anxiety can often recur and escalate in response to disease progression. Research has shown that for HIV-positive individuals declining CD4 cell counts or the appearance of opportunistic infections may elevate normal worry to full-blown anxiety (Lavick & Vaccaro, 2007; Heckman et al, 2001).

Some individuals may feel hopeless as time progresses, reflecting a negative attitude about their future, and resulting in some HIV-positive individuals giving up and believing that nothing will turn out right for them. Feelings of uncertainty may involve issues such as how long one might survive with the virus and whether there are effective treatments for slowing the progression of the disease (Rogers et al., 2005; Siegel & Lekas, 2002).

The diagnosis of a positive result may also impact on the identity of the infected individuals. Some organise their lives around being HIV positive, volunteering at various HIV organisations, and restricting their social networks to other infected individuals. Others may choose to limit their involvement in HIV issues. Some infected individuals will accept and internalise society's negative attitudes towards them and feel dirty and devalued (Siegel & Lekas, 2002).

It is clear from the discussion thus far that the psychological consequences of being HIV positive are numerous and it has also become widely accepted that individuals with HIV infection are highly vulnerable to psychological disturbances, such as depression, anxiety and hopelessness, and so on, impacting on the individual's quality of life (Huanguang et al., 2004).

For some people, living with HIV does not have only negative consequences. Several studies have emphasised the importance of being optimistic, having a fighting spirit as well as maintaining a sense of purpose. Therefore, hope has been identified to be a part of the reality for PLHIV in that it helps them in facing the prospect of a chronic illness such as HIV. It also helps them in alleviating the emotional distress associated with being HIV positive (Kylma, Vehvilainen-Julkunen & Lahdevirta, 2001; Pretorius, Goldstein & Stuart, 2005).

According to Plattner and Meiring (2006), accepting that one is HIV positive has been found to be a crucial factor in making meaning, which helps the person to maintain a balanced well-being. In the experience of living with HIV some people create a space for discovering a sense of spirituality, religion and compassion. Being diagnosed HIV positive can lead to an appreciation of life, a need to belong and a positive embracing of one's limited time and life on earth (Pretorius, Goldstein & Stuart, 2005).

Summarising what has been said above, HIV and AIDS changes the person and his or her life through losing and receiving. Losing in this context can be described as a multifaceted factor that challenges several aspects of living with HIV and AIDS. This may involve losing joy, self-respect, health and strength or trust in oneself, while for other people experience a reduced ability to control one's own life. However receiving has been described as becoming stronger as a person by going through this difficulty and seeing life from a new perspective, which involves valuing one's life and acceptance of the uncertainty of life (Kylma, Vehvilainen-Julkunen & Lahdevirta, 2001).

2.8 HIV and stigma

2.8.1 Stigma as a concept

Theoretically, stigma can be defined as a negative attitude towards people who are seen to possess an attribute or quality which is discrediting in such a way that they are looked at as shamefully different (UNAIDS, 2002).

Goffman (1963) sees stigma as a social process which offers some feeling of protection to those who are not infected, while increasing the burden on the individual or group who is seen as infected. Stigma may be associated with specific acts such as homosexual sex and/or criminal behaviour – and those who exhibit this behaviour, by virtue of their difference, are negatively valued in society. Suffering from mental illness and physical disabilities may also lead to stigma.

The stigmatisation process may begin with the community's reaction towards the infected person, but eventually the infected person will come to anticipate such reactions and to expect them before they even occur, and even if they do not occur (Parker & Aggleton, 2003).

HIV-related stigma occurs globally and is triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, the fact that HIV is incurable and fears relating to illness and death. The stigma associated with HIV has many effects, including the powerful psychological consequences of depression, lack of self-worth and despair (UNAIDS, 2002).

2.9 Forms of stigma

2.9.1 External stigma

External (or enacted) stigma refers to the experiences of people with HIV being treated unfairly and differently to everyone else. This measurable and observable discrimination may include oppression, rejection, punishment, harassment, blame or exclusion. It can lead to violence towards PLHIV.

Indicators of external stigma (Siyam'kela, 2004) include:

- Avoidance: people avoiding PLHIV or not wanting to use the same utensils.
- Rejection: people rejecting PLHIV. This could be family members or friends no longer being willing to associate with the person or it could be that a society or groups of people do not welcome them.
- Moral judgement: people blaming PLHIV for their status or seeing them as immoral.
- Stigma by association: people who associate with PLHIV are stigmatised because of their association.
- Unwillingness to invest in PLHIV: PLHIV may be marginalised within an organisation because of their HIV status.
- Refusal of benefits: for example PLHIV being denied employment, medical care or access to insurance.
- Abuse: PLHIV being physically or verbally harmed and abused.
- Victimisation: for example children being denied schooling or experiencing bullying in school because of their HIV status.
- Abuse of rights: this could include breaches of confidentiality or testing without consent (Siyamkela, 2004).

2.9.2 Internal stigma

Internal stigma refers to the internalisation of shame and blame associated with an HIV diagnosis. Also termed self-stigmatisation, it can lead to protective strategies used by PLHIV (Mohlahlane, Wassenaar & Brouard, 2005).

Internal stigma, also defined as felt or imagined stigma, includes the fear of being discriminated against as a PLHIV. It often causes refusal or fear to disclose HIV status, or denial of HIV status (Mohlahlane, Wassenaar & Brouard, 2005). For example, internal stigma may lead HIV-positive sexual partners who are aware of their status to engage in unprotected sex (despite the dangers of transmission to the other partner) because of fear of the revelation of status arising from using a condom.

Indicators of internalised stigma include:

- *Self-exclusion from services and opportunities*

  When PLHIV exclude themselves from services because they fear rejection, it has the impact of driving the epidemic underground. People do not access voluntary counselling and testing (VCT) and care and support programmes, including ARV rollout programmes. Negative attitudes of the community and health-care workers contribute to this self-exclusion (Mohlahlane, Wassenaar & Brouard, 2005).

- *Negative self-perception*

  When people see themselves negatively because of their HIV status, they internalise blame and responsibility, even in situations where they knew about their partner's infidelity. As a result they feel they are sinners because they are living with HIV, and they feel moral judgement from religious/faith leaders and congregants. These negative self-perceptions may therefore lead to a lowered self-esteem, inferiority complexes and helplessness, which can then lead to the weakening of one's health status. These emotions may be pre-existing and exacerbated by a positive HIV diagnosis (Mohlahlane, Wassenaar & Brouard, 2005).

- *Social withdrawal*

  After learning about their positive diagnosis, PLHIV may withdraw from society and friends because of fear that others can see that they are infected with HIV. This behaviour may be present before and after disclosure of HIV status. PLHIV may worry about how others see or perceive them as a result of their HIV status. For example, PLHIV may hesitate to get involved in intimate relationships and may lose interest in activities they used to enjoy (Mohlahlane, Wassenaar & Brouard, 2005).

- *Overcompensation*

  PLHIV may be more dedicated and focused on their work than before, as a way to avoid dealing with their feelings. They may also try to prove a point to others that they are worthy human beings. They may do so as a way of earning respect from others. This could be a way of trying to feel good about themselves. However, overcompensation can bring about negative implications for one's health. For example, PLHIV may want to work extra hard or work overtime just to prove a point. They may also accept having their human rights violated due to thinking that they deserve to be punished (Mohlahlane, Wassenaar & Brouard, 2005).

- *Fear of disclosure*

  The fear of disclosing one's HIV status does not only undermine preventative strategies (VCT and ABC campaigns), but also impacts on health-seeking behaviour, drives the epidemic underground and promotes the vicious and silent nature of the epidemic (Mohlahlane, Wassenaar & Brouard, 2005).

PLHIV may be afraid to disclose their HIV status for fear of being rejected by family and friends. The rejection phenomenon will be discussed later, and will include the fear of stigma and discrimination from community members, colleagues and health-care workers. The impact of not disclosing one's HIV status may pose several challenges such as infecting others or being exposed to re-infection with HIV (Mohlahlane, Wassenaar and Brouard, 2005).

2.10 Impact of stigma

HIV-related stigma has increased the prejudice and discrimination directed at people perceived to be HIV positive, and the individual groups and communities with which they are associated. This has been fuelled partly by ignorance and misconceptions about the modes of transmissions of HIV, but also by fear of infection. This has led to beliefs that one can get infected by shaking hands with, talking to, sleeping in the same room as, sharing toilets with and sharing of eating utensils with someone who is believed to be HIV positive (Kalichman & Simbayi, 2004; Herek, 1999). But ignorance may also be a consequence of stigma as fear prevents people from learning more about HIV and AIDS.

HIV-related stigma profoundly impacts on individuals and communities, resulting in a range of excluding behaviours towards people thought to be HIV positive, and those associated with them. It can isolate, divide and break down communities, undermine human rights and result in the internalisation of blame and shame.

Stigma may also reinforce misconceptions regarding HIV (Parker & Aggleton, 2003). Some of the misconceptions regarding HIV include:

- HIV only affects gay, bisexual men, men who have sex with prostitutes and black people.
- HIV is a punishment either by ancestors or by God. PLHIV are often believed to deserve what has happened by having done something immoral, or the ancestors may either send the illness themselves to the afflicted person or will have withdrawn their protection.
- Some employers may terminate their employee's contracts with the belief that someone with HIV will be unproductive and have unbearable consequences for the company. In addition, colleagues may feel uneasy in sharing an office space with someone perceived to be HIV positive due to the fear of being infected.
- Some people will be rejected by their families and communities due to the belief that they will bring shame upon them. As a result people have been banished and even killed for being open about their HIV status (UNAIDS, 2002; Kalichman & Simbayi, 2004).

It is evident that disclosing one's HIV status may have detrimental effects on the social bearing of an individual perceived to be living with HIV. As a result individuals may be unwilling to publicly discuss sexual issues and this could have undesirable consequences for their sexual behaviour.

In addition, HIV-related stigma may result in acts of murder and violence. Examples are:

- The murder of Gugu Dlamini in December, 1998 for openly stating that she was HIV positive
- The murder of Mpho Motloung, together with her mother, by her husband, who then committed suicide, and

- The rape and murder in 2004 of Lorna Mlofane after her rapists had learned that she was HIV positive (Baleta, 1999; Skinner & Mfecane, 2004).

These and many other examples show that a lack of effective education, people's ignorance and the stigma associated with HIV and AIDS are major problems which need urgent attention.

2.11 Efforts in addressing the stigma

Anti-stigma work based on sound principles will not only improve the quality of life of PLHIV and those who are vulnerable to HIV infection, but built a greater cohesion in responding to the epidemic both at individual and community level (UNAIDS, 2002).

The Centre for the Study of AIDS (CSA) at the University of Pretoria has been active in challenging prejudices and attitudes among both staff and students. The CSA has introduced HIV- and AIDS-related concerns into elements of the higher education curriculum, including subjects such as law, agriculture and engineering, and has a comprehensive youth leadership volunteer programme which contextualises HIV in the governance challenges of an emerging democracy. This has led to greater understanding of the issues within the university context, and has contributed to de-stigmatising HIV and enhancing discussion of HIV- and AIDS-related concerns (UNAIDS, 2002).

In South Africa, the Treatment Action Campaign (TAC) was formed in 1998 to improve access to treatment and medication for PLHIV. Its struggle for human rights has simultaneously used a number of strategies aimed at challenging stigma, including the popularisation of T-shirts with the phrase 'HIV positive'. This re-appropriation of the stigma associated with HIV and AIDS has led both wearers of the T-shirt and observers to question what the virus does to the individual's personality, leading to greater awareness (UNAIDS, 2002). In its litigation work the TAC, along with the AIDS Law Project, has taken on a number of test cases and has successfully changed laws or their applications, contributing to a climate of rights and openness about HIV.

A study by Herek (1999) has revealed that people who have had an experience of, or who have lived with HIV-positive people are less likely to have discriminatory attitudes, as compared to those who have never had an experience of, nor lived with, an HIV-positive person. In other words, close contact breaks down the 'othering' process and challenges previously held ideas that PLHIV are bad, immoral or blameworthy (Kalichman & Simbayi, 2004; Herek, 1999).

Since HIV stigma serves psychological and social functions, simply focusing on education about HIV and HIV stigma, while important, is insufficient to address it. An integrated, holistic country-wide programme is necessary to challenge this entrenched social attitude. This programme should have some or all of the following elements:

- Getting buy-in from all sectors of society for stigma work and building their capacity to execute it.
- Leadership from key opinion-makers, politicians and government officials who have the resources to change laws and policies.
- Laws and policies which protect the rights of the infected and affected.
- Good, clear and legitimate messages which unambiguously address information, myths and fears.
- HIV-friendly services in all branches of government, especially health.
- Addressing stigma in places of learning.
- Mobilising civil society institutions of influence and power such as faith and cultural organisations.
- Constructive messages about HIV from the media.
- Effective workplace policies and programmes which also address stigma.
- Support and growth opportunities for PLHIV, including a mobilised and empowered PLHIV leadership.
- Spaces for experiential learning about HIV and stigma, in multiple settings but especially in communities.
- Poverty alleviation programmes which make PLHIV less vulnerable to abuse (Brouard, 2007).

2.12 Disclosure

According to Bennetts et al. (1999), disclosure may psychologically unburden and reduce the feeling of isolation, by increasing avenues of support. Disclosing one's status may put one at risk, but failure to do so can also put others at risk, such as the uninfected partner. There are many forms of disclosure and one of them is voluntary disclosure, which means the act of divulging one's HIV status through a decision made and undertaken without force. The person is in control of when, how and to whom disclosure takes place (Varga, Sherman & Jones, 2005).

At the time of getting an HIV-positive result, individuals are encouraged to disclose their status to significant others. The rewards or positive consequences of disclosing one's status can be substantial, such as the acquisition of emotional, physical and social resources. These resources may include assistance with medical attention, the provision of medical information, acceptance, and freeing the individual from hiding the taking of medication from friends, family and colleagues, thus indirectly increasing the support for adhering to treatment regimens (Serovich, 2001).

Through disclosing their HIV status to significant others, an individual may be taking a pivotal step towards gaining support in terms of HIV-related matters, as stated above and discussed later in detail. Social support buffers the effects of psychological stress and facilitates coping mechanisms. Among the mechanisms for coping with HIV infection, satisfaction with informal support reduces the effect of HIV-related physical symptoms on psychological distress, and integration in social networks is also found to be better related to psychological adjustment. Furthermore, an additional benefit is that disclosing to an intimate partner may lead to safer sexual practices that may prevent the spread of the disease (Mansergh, Marks & Simoni, 1995).

Reasons for disclosure may vary across the spectrum and may also differ from one individual to the next, such as a sense of ethical responsibility, or the need for social support, education and treatment. For example, disclosure of HIV infection to sex partners may be associated with protecting others from possible exposure to HIV, which implies that the disclosure is focused more on others than on the infected individual. On the other hand, a decision to disclose one's HIV status to family members and friends may be to maintain the honesty in a relationship, relieving the stress of concealing one's HIV status or to access social support. Here the disclosure is focused more on oneself than on other people (Kalichman, Simbayi, Cain, Cherry, Henda & Cloete, 2007).

However, several factors may discourage certain individuals from disclosing their HIV status to significant others and community members. These factors may include fear of rejection and abandonment, discriminatory treatment such as eviction or termination of employment, retribution, violence and other forms of abuse. Most of these possible outcomes are based on social stigma, which is widely acknowledged to be associated with an HIV diagnosis. The possible impact of perceived HIV-related stigma on disclosure of HIV status has been reported regardless of how one may have contracted the HIV infection (Derlega, Winstead, Greene, Serovich & Elwood, 2002; Simoni & Palantone,

2.12.1 The process of HIV disclosure

The decision to disclose one's HIV-positive status is a very difficult process, and must include to whom, when and how to disclose one's HIV-positive status to others. Discovering that one is HIV positive will always create an internal struggle such as whether or not to disclose one's HIV-positive status. Although the disclosure of sensitive information is generally thought to have beneficial effects on an individual health, deciding who, when and how to reveal one's status to others, especially to family members, may be difficult (Sowell, Seals, Phillips & Julious, 2003).

According to Kimberly and Serovich (1995), in spite of the difficulties associated with the challenges of disclosing one's HIV status, numerous factors that influence the decision to disclose have been stated, such as low stress levels and better psychological health, as well as the individual's motivation for disclosure. Serovich, Oliver, Smith and Mason (2005) developed a framework for the decision-making process for disclosure. The framework describes the steps that one may follow to disclose HIV status. The identified steps are the following:

- The first step may involve stage setting once the person has accepted and adjusted to the diagnoses, followed by an assessment of personal disclosure skills. The individual may use a variety of hints and symbols that work to prepare for a disclosing event, beginning with cues that one is HIV positive.

These cues may eventually result in an overt event in which the individual's HIV status is disclosed.

- The second step involves verbal hinting in which an individual may start dropping verbal hints that one may be HIV positive or starting a general conversation about HIV. This strategy may serve to provoke comments from the sexual partner and family members that might better inform the infected individual about their attitudes towards HIV.
- The third step may involve symbolic hinting in which the individual may leave HIV-related material in conspicuous places, such as on coffee tables, in magazine racks or on a car-seat so as to provoke questions about HIV.
- The fourth step may involve insisting on the practice of safe sex, especially with the sex partners they were not practising safe sex with before. The individual may start talking about sex and condoms as another way to start the disclosure conversation. Once the issue of condoms is raised, the discussion about why such barriers are important will progress more naturally.
- Buffering will involve the intervention of the third party to facilitate HIV disclosure. The third party may serve as a cushion between the discloser and his sexual partner (or even family) to prevent each party from hurting each other's feelings. The person acting as the facilitator must be well experienced in terms of facilitation skills (Serovich, Oliver, Smith & Mason, 2005).

From this literature, it is clear that people who are aware of the variety of disclosure strategies are more likely to be able to find strategies that are comfortable for them and match their environmental and relational circumstances. Therefore, a mixture of knowledge, creativity and the ability to minimise risks and costs of compromising relationships with significant others may be the key to successful HIV disclosure (Serovich, 2001).

2.13 Coping and HIV

Coping is defined as cognitive and behavioural efforts made by an individual to change and manage the issues created by a specific stressful situation, such as being HIV positive (Grassi, Right, Sighinolfi, Makoui & Ghinelli 1998). According to

Vassend and Eskild (1998), psychosocial factors, and in particular stressful life experiences, psychological distress, and coping resources are capable of altering the course of HIV infection by influencing immune functions. The association between stress and suppression of immune functions may serve as a basis for suspecting that stress and coping might affect the course of the HIV infection.

Among other things, research has shown that coping styles enormously influence the psychological impact of HIV infection. Coping styles and a number of variables such as an intact support structures are positively associated with an improved quality of life (Grassi et al., 1998; Vassend & Eskild, 1998). Coping has been considered an imperative factor impacting on adaptational outcomes such as psychological well-being, especially in the long run (Moneyham, Hennesy, Sowell, Demi, Seals & Mizuno, 1998).

There is no coping strategy that is considered to be inherently good or bad but rather each should be judged on its effectiveness in meeting the demands of the situation. Individual coping responses may vary across situations in which they are used. The choice and effectiveness of coping strategies used in stressful situations such as an illness may also vary over time, as a function of changes in factors such as the stage of disease and related physical symptoms.

Coping with chronic illness by using avoidance strategies will elevate psychological distress, including anxiety, depression and poor adjustment. Avoidance strategies are more likely to be invoked as the disease progresses because signs and symptoms become more intrusive (Moneyham et al., 1998).

2.14 HIV and support

Research shows that the availability and provision of support for HIV-positive individuals is imperative. Kimberley and Serovich (1996), and Cohen and Wills (1985) have shown that people with spouses, friends and family members who provide psychological resources are in better health than those with limited social support. This kind of support could be related to overall well-being because it provides positive affect and a sense of predictability and ability in one's life situations (Cohen & Wills. 1985).

Generally it is believed that people will cope better when faced with stressful life conditions if they have social support (Kimberley & Serovich, 1996). According to Cobb (as cited in Kimberley & Serovich, 1996), social support comprise three components: 1) belief by the recipient that he/she is cared for and loved, 2) belief by the recipient that he/she is valued, and 3) a belief by the recipient that he/she belongs to a network of communication and mutual obligation.

Shumaker and Bronwell (as cited in Zimet, Dahlem & Farley, 1988) define social support as an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient. Because of the physical and psychological stresses on individuals who are HIV positive, it is imperative for them to establish realistic expectations about who can and will provide support. The support may not be easy to obtain since the providers of support such as family and friends may not be readily available for HIV-positive individuals seeking support because of stigma (Kimberley & Serovich, 1996). Therefore, the perception of family and friend networks as sources of support may be idealistic.

Thus having family friends and a circle of associates does not necessarily make one the automatic beneficiary of support in times of trouble. The degree to which people draw on social relations for support is dependent on more than the extensiveness or the relations of frequency of interaction. Support may come when people's engagement with one another extends to a level of involvement and concern, just as with family members or close associates. Therefore, being embedded in a network is only the initial step, and having access to support the final step depends on the quality of the relations one finds within the network (Pearlin, Menangham, Lieberman & Mullan, 1981).

PLHIV have specific stressors to which support can be directed but they have difficulty in that their disease impacts directly on the support they receive. The stigma attached to the illness may make it difficult to garner some forms of support. Furthermore, PLHIV are often alienated, both emotionally and geographically, from the natural support or their own families (Friedland, Renwick & McColl, 1996). Despite family support being a fairly robust resource, there are complex factors that infiltrate the process of family support. In the first place a family has its belief and value systems that shape patterns of behaviour. Because HIV is attached to values about sexuality, religion and lifestyle, relatives may experience family dissonance, shame and fear around a family member's disclosure of HIV. Thus, when an HIV issue surfaces, the family may have no way of processing feelings as the rule has been: do not talk about difficult issues (Britton & Zarkis, 1993).

It is highly likely that PLHIV will benefit from the stress-moderating effects of social support. Research has even shown that social support may moderate the effects on the health of those who are HIV positive, adjustment, longevity and general well-being (Kimberly & Serovich, 1996).

2.15 Conclusion

In this chapter a review of literature on men and HIV has been presented with an emphasis on how masculinity, gender and violence impact on the spread of HIV in men. Included are HIV- and AIDS-related stigma, disclosure and a focus on how a positive HIV diagnosis can have adverse effects on the physiological and psychological aspects of PLHIV.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents a description of the research process undertaken. A summary of the research design is given, a brief description is provided of the researcher's position, the setting in which the research study was executed, as well as the motive for choosing a qualitative research design. A description of the phenomenological approach is also introduced. Of importance in this chapter are issues of sampling, method of data collection and method of data analysis, which will be discussed in detail. Issues of reliability and validity are addressed. Finally, ethical considerations are discussed.

3.2 Research design

The research method used for this study is qualitative in nature, using a phenomenological approach with an emphasis on the lived experiences of the participants and the meanings that participants give to their everyday lives.

3.2.1 Phenomenological approach

Phenomenology as a discipline began with work of the philosopher and mathematician Edmund Husserl (1859-1938) at the beginning of the twentieth century. The main aim of phenomenology was to create a firm foundation of knowledge as a basis for creating meaning for human experience (Giorgi & Giorgi, 2008). This approach was motivated by the fact that the phenomenological method is particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives (Karlsson, 1995).

Husserl (1970) describes phenomenology as starting from a stance free of either hypothesis nor preconception. According to Giorgi and Giorgi (2008), in order to comprehend the meaning of a phenomenon, one needs to be able to see it exactly the same way as the participants see and experience it. Rather than reducing a phenomenon to a number of identifiable variables, the phenomenological approach remains loyal to the context and phenomenon and to the context in which it appears in its natural context (Ashworth, 2003). This means that as researchers we are concerned with participants' experience in the context in which it takes place.

Phenomenology seeks to explore the participant's meanings that constitute the phenomenon by investigating and analysing the lived experiences of the phenomenon within the context of the participant's life (Smith & Osborn, 2008). Consequently, an analysis of the meanings being lived by the participant from a phenomenological approach may provide an insight into participant's actions and lived experiences.

3.3 Qualitative research

The objective of the study is to investigate the experiences of black men diagnosed with HIV. The study stems from a stance of "not-knowing" about the participants, and shifts to a stance of gaining insight into how they are experiencing and coping with their daily lives. Qualitative research was deemed appropriate to gather and analyse these experiences.

Qualitative research is any type of research that produces findings not arrived at by statistical procedures or other means of quantification. This refers to research about people's lives, lived experiences, behaviours, emotions and feelings (Strauss & Corbin, 1998; Creswell, 1994; Denzin & Lincoln, 2000). Thus when one considers the fact that living with a highly stigmatised chronic illness such as HIV can be very difficult, a qualitative research paradigm will create space for participants to elicit accounts of meaning, experiences or perceptions in their own words.

A qualitative approach to inquiry allows the researcher the opportunity to gain an in-depth understanding of the social phenomenon under study and creates an opportunity for the researcher to maintain direct contact with the participants, to have access to their worlds, to lend an ear and to follow through as they guide the researcher on their journey. Finally, it makes possible for the researcher to view and understand reality from the participant's perspective as well as being able to determine the themes (Creswell, 2007).

For the purpose of this study the researcher had the opportunity to come face-to-face with the participants, to partially enter their worlds and to be able to see and comprehend reality as the participants perceive it and comprehend it.

3.3.1 Trustworthiness in qualitative research

Many quantitative researchers recognise and document the worth of a project by assessing the reliability and validity of the research (de Vos, 1998). However, according to Krefting (1991), the same detailed attention is far less common in qualitative research. If qualitative research is evaluated against the criteria appropriate to quantitative research it will be found lacking. Terms such as reliability and validity do not easily apply to qualitative research (Krefting in de Vos, 1998). However, just as there is a need to assess the accuracy and trustworthiness of quantitative research, in the case of qualitative research certain steps can be taken to achieve trustworthiness, as well as to increase the study's validity.

According to Agar (in de Vos, 1998) a different language is needed to fit the qualitative view, one that will replace reliability and validity with such terms as truth-value, applicability, consistency and neutrality. Guba's model, as outlined in Krefting (1991), provides a framework for these concepts. Each of these concepts will be discussed.

3.3.1.2 Truth-value

Lincoln and Guba (in Krefting, 1991), are of the belief that truth-value deals with the confidence of the researcher in the truth of the findings based on the research design, participants and context. In qualitative research truth-value is usually obtained from the discovery of human experiences as they are lived and experienced by the participants: this is termed credibility. Sandelwoski (in Krerfting, 1991) emphasizes that qualitative research is credible when it represents such accurate descriptions or interpretation of human experience that people who also share the same experience would immediately recognise the descriptions. In order to enhance truth-value a number of strategies are employed in this study.

3.3.1.3 Peer examination

According to Lincoln and Guba (in Krefting, 1991), peer examination is one way of keeping the researcher honest and may contribute to deeper reflexive analysis. In order to ensure that the process is carried out effectively the researcher should have continuous supervision and discussion with his or her research supervisor.

3.3.2 Structural coherence

According to Guba (in Krefting, 1991) it is the responsibility of the researcher to ensure that there are no unexplained inconsistencies between the data and their interpretation. However, the data may conflict. Credibility will be increased when a valid interpretation can explain the contradictions. This may also be dependent on the researcher's integrating abilities in presenting the final results of the study.

3.3.3 Applicability

Applicability refers to the degree to which findings can be applied to other contexts and settings or with other groups (de Vos, 1998). However, it should be noted that the purpose of this study is to describe a particular experience and not to transfer or generalise it to other contexts. This statement may be supported by the following perspectives. Firstly, the ability to generalise is not relevant in many qualitative studies, owing to the fact that the strength of qualitative research lies on the fact that it is conducted in a naturalistic context with few participants. Secondly, each situation is defined as unique and less applicable to generalisation (Krefting, 1991).

3.3.4 Consistency

Consistency refers to whether the findings would be found to be consistent if the inquiry were repeated with the same participants in a similar context (de Vos, 1998). According to Field and Morse (in Krefting, 1991), qualitative research emphasises the uniqueness of the human situation, and variation in experience rather than identical repetition being sought. In order to check for consistency certain strategies will be discussed.

3.3.4.1 Dense description

According to Kielhofner (in Krefting, 1991), the researcher will have to explain the methods of data collection, data analysis and interpretation to provide information on how repeatable the study might be or how unique the situation is.

3.3.4.2 Peer examination

The use of the researcher's supervisor to check the research plan and implementation thereof will aid in building consistency in the interpretation.

3.3.5 Neutrality

The fourth criterion of assessing trustworthiness is neutrality, that is, the freedom from bias in the research procedure and results. According to Guba (in Krefting, 1991), neutrality refers to the degree to which the findings are a function solely of the informants and conditions of research, and not reflect other biases, motivations and perspectives. The researcher is seen as scientifically distant, and as someone who is not influenced by, and who does not influence the study (de Vos, 1998).

3.3.6 Reflexive analysis

A researcher becomes part of the entire research process and cannot separate themselves from it. The researcher is also considered to be a participant and not only an observer. In the process one continues to analyse oneself against one's background and perceptions, so as not to affect the neutrality of the research.

3.7 Researcher's position

As an intern clinical psychologist, during this researcher's internship year I worked intensively with black males who were HIV positive and developed an interest in conducting research on this topic. Looking at the most recent studies this researcher discovered that not much research had been done on heterosexual males who were HIV positive. As a black heterosexual male living in a multicultural society, proficient in Southern Sotho, Setswana, Sepedi and English, the researcher felt that such characteristics would give him access to a research context, a description of which follows.

3.8 Research question

In the context of a generalised HIV epidemic where the experiences of women, children and gay men living with HIV have been well described, how do heterosexual African men at Tshwane District Hospital experience and live with an HIV-positive diagnosis emotionally, cognitively and socially?

3.9 Research setting

The study was conducted at the Antiretroviral Clinic at Tshwane District Hospital. The clinic renders services such as voluntary counselling and testing (VCT), prevention of mother-to-child transmission (PMTCT) and Antiretroviral provision, and also has tuberculosis as an integral focal point. The clinic serves the whole of Tshwane District, Pretoria Academic Hospital and Central Pretoria's HIV-infected patients. Participation was voluntary and the participants were obtained from the hospital's ARV clinic.

3.10 Research sample

The concept of sampling is one of the most important in a research attempt and therefore it needs careful consideration and is determined by a number of factors such as the research method, which determines the type and the size of sample required (De Vos, 1998).

Purposeful sampling as a form of non-probability sampling was used for this study because the objective of the study was to explore the lived experiences of men who are HIV positive. Purposeful sampling is a sampling method in which participants have the characteristics or elements the researcher is interested in. Patton (2002) describes the logic and power of purposeful sampling as being to identify rich information which will provide us with the in-depth understanding needed to answer the research question.

The sample was chosen based on the objectives and aims of the study. For the purpose of the study the researcher interviewed a sample of five black HIV-positive males. The study was conducted primarily in English. However, the participants could use their mother tongue if they so chose.

Using a small sample was befitting based on the fact that this was done with the phenomenological research paradigm in mind. The small sample-size set a platform for capturing the richness and the fruitful avenues of the participant's responses (De Vos, 1998).

The participants were chosen on the basis of the following inclusion criteria:

- The participants were black heterosexual South African men diagnosed as HIV positive.
- The participants knew of their diagnosis for at least a year or more, and so were able to relate and describe their experiences and how they had been coping. Interviewing someone who had been only recently been diagnosed with HIV might not have resulted in rich descriptions of living with HIV.

3.11 The interview

For the purpose of this study a qualitative research interview was used to create an opportunity for the researcher to obtain qualitative research descriptions of the life-worlds of HIV-positive men with respect to interpretation of their meanings. Interviews are a specific form of conversation that produce different kinds of knowledge (Kvale, 1996). Qualitative interviewing begins with the assumption that the perspectives of others are meaningful. Thus, by interviewing participants we are able to enter the participants' worlds and gather their experiences of living with HIV (Patton, 2002).

The motivation to use interviews as a method for data collection was influenced by the following reasons, as cited by Rothe (1993): (i) interviews provide an opportunity for participants to express their views about issues they cannot adequately express in response to questionnaires; (ii) researchers have the opportunity to reflect on the participant's thoughts, beliefs, knowledge or points of view during the interviews; (iii.) in addition, they create an opportunity for expansion of ideas and clarifications, whereby participants give an insight into how they construct answers, and how that construction reflects certain ideologies or interests. Interviews create a space for on-site verification of answers.

Therefore, the qualitative interview was particularly suited to this study since responses were not constrained by pre-existing categories (Burck, 2005; Ziebland, Robertson, Jay & Neil, 2002).

3.12 Data collection

For the purpose of this study, semi-structured interviews were used to ensure that particular areas were covered. The researcher made use of open-ended questions to enable an in-depth exploration of the topic at hand, creating room for feedback and exploration of more particular meaning with the participants. The researcher used an interview guideline, and as the interview progressed the researcher generated questions based on the responses that were given by the participants. An example of the interview guide is attached. See Appendix B.

In shedding light on the participant's experiences of being HIV positive, using semi-structured interviews helped the participants to give a fuller, richer account which might have proven impossible had a standard quantitative measure been used (Bradburn, Sudman & Wansink, 2004).

Five interviews were conducted, each interview lasted for approximately 30-45 minutes each. The interviews took place over a four-day period. The first interview was conducted in the counsellor's room inside the clinic and the remaining four interviews were conducted in the doctor's consultation room. The counsellor's room was not free from distractions because it was used as an exit from other wards, whereas the doctor's consultation room was private.

During the interviews the researcher was relaxed and focused on the interview process. The interview process was facilitated by the use of an audio recorder to ensure a complete record of the interview in its entirety. The researcher thus had the space to make an effort to take note of non-verbal communication, such as the facial expressions of the interviewees, tone of voice, body posture and intonation of voice. The researcher ensured that note-taking of non-verbal communication did not interfere with the flow of the conversation.

3.13 Data analysis

Data analysis is the process of bringing order, structure and meaning to the large amount of collected data. Therefore, "qualitative data analysis is a search for general statements about relationships among categories of data" (Marshall & Rossman, 1995, p. 111). The general goal of data analysis was to locate patterns or themes that were embedded in the data. Themes, which are present in data, become the first line of analysis (Kvale, 1996). For the purpose of the study, thematic analysis was used to analyse data.

Thematic analysis as a method of data analysis has been described as a messy, time-consuming, creative and fascinating process. It is said that it is a non-linear qualitative approach. This means that it searches for general statements about relationships among categories of data as a way of building a grounded theory (Marshall & Rossman, 1995; Braun & Clarke, 2006). Thematic analysis increases the researcher's sensitivity in understanding and interpreting observations, about people, their experiences and situations (Boyatzis, 1998).

Several steps guide thematic analysis such as organising the data, generating categories, themes, and patterns, testing emergent hypothesis against the data, searching for alternative explanations of the data, and writing the report (Marshall & Rossman, 1995; Aronson, 1994; Braun & Clarke, 2006)

3.13.1 Data transcription

Interviews were recorded by means of a tape recorder and then transcribed. After the data were collected, verbatim transcriptions were conducted for the purpose of a thematic analysis. For this study the transcriptions were done in the native languages of the participants where participants chose to speak in their home language and then translated into English.

3.13.2 Organising the data

In order to familiarise himself with the data as is suggested by Marshall and Rossman (1995), the researcher read the transcripts multiple times to gain familiarity with the data. During this reading process, the researcher kept notes of what was important in order to distinguish important ideas from what seemed irrelevant.

3.13.3 Generating categories, themes and patterns

Once the researcher was familiar with the data, the researcher transformed it by generating categories through a process of selection, simplification and abstraction. As indicated by Marshall and Rossman (1995), relevant themes, recurring ideas, language and patterns of belief linking people and settings are constructed through this analysis of the data. This was the most important and challenging task, which this researcher actually completed by questioning the data and reflecting on the conceptual framework with which the study was associated. Marshall and Rossman (1995), emphasise that categories are generated from data rather than imposing preconceived categories being imposed onto the data. Through this process the researcher was able to explore the relationships within and between categories.

3.13.4 Testing emergent hypothesis

Marshall and Rossman (1995) indicate that testing the emergent hypotheses requires a critique of identified categories – the researcher looked for connections in the data, continuously challenged hypotheses and patterns that became obvious as the analysis proceeded and assessed the plausibility and credibility of themes against the data. It was during this step that the researcher probed for contradictions and incorporated these to challenge and expand the constructs identified.

3.14 Ethical considerations

Before the decision to participate in research was made, potential participants were fully informed about the nature, duration, and purpose of the study, the method in which it was to be conducted, all inconveniences and hazards to reasonably be expected, and any effects upon health or persons that could result from their involvement. Participants were also informed of their right to withdraw from the study at any time and that should they wish to do so they would not suffer any punishment or be barred from receiving treatment at the clinic (Vadum & Rankin, 1998). The participants were informed that all the information which was to be obtained concerning them during the study would be kept strictly confidential.

3.14.1 Informed consent

After providing the participants with adequate information on the goal of investigation, the procedures which would be followed, the possible advantages and disadvantages, and risks to which the participants could be exposed, participants were asked to give consent if they wished to participate in the study (de Vos, 1998). In line with the ethical requirements of the University of Pretoria, potential research participants did not participate in the research study without providing written consent.

3.15 Conclusion

This chapter looked at the methodology followed in the research study. Qualitative methodology was discussed, together with the motivation for choosing this particular methodology for this study. A discussion on the semi-structured interviewing used was provided, and a detailed description of phenomenological approach was given, and the process of selecting the participants also elaborated on. The manner in which data were analysed was also mentioned and will be discussed in more detail in Chapter 4. Lastly, this chapter also considered the ethical considerations as well as the issues of trustworthiness in qualitative research.

CHAPTER 4

RESULTS

4.1 Introduction

This chapter presents the interview data. The data were analysed according to different themes that emerged from the interview process with the participants. Each theme is discussed and excerpts will be used from the interviews to make clear the issues proposed by the researcher. The main themes that emerged from the interviews will be presented in conjunction with a brief introduction regarding the participants.

4.2 The participants

4.2.1 Participant no.1

He is a 33-year-old male who lives in Mamelodi (Pretoria). He is single and self-employed, specialising in carpentry. He has been HIV positive for approximately 4 years.

4.2.2 Participant no.2

He is a 32-year-old male who lives in a flat in central Pretoria. He is single and unemployed and has been HIV positive for approximately 4 years.

4.3.3 Participant no.3

He is a 45-year-old male from Mamelodi He is married with 2 children, a boy and a girl. He is currently unemployed and has been HIV positive for approximately 6 years.

4.3.4 Participant no.4

He is a 43-year-old male from Gezina in Pretoria West, and is a widower. He stated that his wife did not die from AIDS-related illnesses. He is currently employed and has been HIV positive for approximately 1 year.

4.3.5 Participant no. 5

He is a 29-year-old male who lives in a flat in Pretoria central, sharing with someone. He is not married but is in a relationship with a woman. He is unemployed and has been HIV positive for approximately 5 years.

4.3 Research results

After collecting data through the interviews, the researcher familiarised himself with the data, searching for common themes. The researcher categorised the material into common dominant themes. Throughout the analysis process the researcher attempted to gain an insight into the lived experiences of the men by extracting the main themes that would strongly reflect the study being undertaken.

The study was conducted from a phenomenological perspective which describes the lived experiences of the participants. As one of the objectives, the researcher made an attempt to search for themes that lay deep within the unexamined events of everyday life experiences of these men, to search for meaningful, shared common themes in their lived experiences of being HIV positive, as well as attempting to reach their lived world by making the invisible visible through the participant's eyes (Kvale, 1996).

After protracted exercises trying to identify common themes, themes reflecting the lived experiences of the participants were identified. These themes were identified according to how the participants experienced their lives from the time they were diagnosed as HIV positive. Therefore, the dominant themes are grouped and then integrated to give the reader overall findings in relation to the focus of the research question in mind.

The following are the main themes that emerged strongly from the participant interviews:

- Awareness of physical symptoms
- Denial
- Loss
- Fear
- Stigma
- Lack of condom use

- Disclosure of HIV status
- Availability of support
- Availability of medical support
- Importance of counselling
- Accepting one's condition
- Change of lifestyle
- Lacking knowledge regarding how HIV entered one's life
- Education about HIV, and
- Hope for the future.

These are not the only themes that emerged, but were those that the researcher found to be dominant. Dominant themes are also influenced by the objectives and the aims of the study, including the questions the researcher asked during interviews.

4.3.1 Awareness of physical symptoms

The first theme represents how most of the participants came to know of their HIV status. All the participants felt the need to state how they all came to know that they are HIV positive which then led to them taking an HIV test. Four of the participants stated that they had to go for an HIV test because they had been noticing and experiencing physical changes such as losing weight, developing sores all over their bodies as well as persistent coughing. The fifth participant found out he was HIV positive when his wife fell pregnant and then went for an HIV test.

Participant no. 5 stated: "I started coughing and losing a lot of weight. I then realised that something was wrong and I immediately went to the clinic whereby they advised me to take an HIV test, which I did and my results came back positive"

Participant no. 3 commented, "I was weak and I felt the need to go see the doctor, the doctor advised me to go for an HIV test, he then took my blood and told me that I was HIV positive." At that time participant no.3 stated that he had lost so much weight and was always tired. He recalled that time by mentioning that: "I could not lift up anything heavy and this was really causing me a lot of frustration".

Participant no. 1 said, "I was sick the whole time and I got admitted to the hospital. All these times that I was being admitted to the hospital, my state of health was not improving and I had lost so much weight, so a doctor friend of mine sat me down and said to me, I am not implying that you are HIV positive but if I were you I would do an HIV test. However we never agreed, instead we ended up being at loggerheads about the testing issue." He then left and did not heed his friend's advice. After a month or two he fell ill again and went back into the hospital and was admitted for a week and while at the hospital he felt the need to test. His test results came back positive.

Participant no. 2 said, "Eish, before I discovered that I was HIV positive, I developed bad sores and at the time I was still employed. They took me to a clinic whereby they gave me an ointment to apply on these sores, after that they advised me to go for an HIV test, which I never did. After six months I was bedridden and throwing up the whole time, they then took me home and at home they said to me it would be best if I go for an HIV test. I then went and tested and my results came back positive".

4.3.2 Denial

The initial reaction of all of the men was that of denial. For some of the participants accepting that they were HIV positive was a difficult issue, because they had different beliefs about HIV infection. Some believed that if you have sex with only one person you will never get infected with HIV.

Participant no. 2 said, "Initially when they said I must go for an HIV test, I refused because I never considered myself as one of the people who could be easily infected with HIV, I asked them where will I get it from? I mean at the time I was only sleeping with my girlfriend from a place called Nkangala".

When participant no.3 was initially diagnosed he could not believe it because he believed that it could never happen to him. He described his reaction in the following manner: "I took my certificate of results and I tore them, I realised that it was bad because I did not believe that I was HIV positive."

Some participants associated being diagnosed as HIV positive with witchcraft, as two of the participants indicated.

Participant no.1 told me, "When I first told my family that I am HIV positive they did not believe it, they all thought that I was bewitched. As a result they decided that I must consult a traditional healer which I did but it never helped, still I was getting thinner and thinner".

Participant no. 2 said, "My brother I am telling you, I went to Nelspruit, I paid R1 500, and spent two weeks at that old man's house. That old man gave me all the concoctions to make the HIV go away. I went back home, I started throwing up and lost a lot of weight, because my family believed I was bewitched".

4.3.3 Loss

The participants felt that, being diagnosed as HIV positive often left them feeling like they had lost almost everything that was worthy or beautiful to them. This loss manifested in different forms for each individual. Three participants indicated that it also involved a loss of employment.

Participant no. 1 said, "I left my work because I was sick, everybody started speculating that I could be HIV positive. My head was covered with sores and I had lost a lot of weight. Almost everybody at work had distanced themselves from me. I couldn't cope, so I left without a proper goodbye."

Participant no. 4 told me, "I am a qualified hairdresser and I used to run a hair salon. However as soon as my CD4 count dropped, I had to stop working because I was too weak, I could not do anything."

Participant no. 5 commented, "You see currently I am not working, I was supposed to have been at work right now, and unfortunately I can't because I have got feet problems, they feel so numb, it feels as if there is no blood flowing down to my legs". He continued by saying "I remember going back to work and I couldn't last no more than two weeks, and because where I worked we specialised in production, on realising that I couldn't cope my boss terminated my contract and he told me to come back when I am feeling much better".

As seen in the case-studies, some participants expressed a loss of control over their lives because they were in need of constant care and support, as being diagnosed as HIV positive left them feeling vulnerable and out of control of their lives.

Participant no. 2 said, "I remember that I couldn't do anything, I was lying flat on the bed, I couldn't feed myself and my mother had to bath me because my wife had to leave early for work. Imagine having to undress before your mother and being bathed by her at my age, I felt so out of control. I mean literally I couldn't do anything for myself. Sometimes they would take me to the sitting room during the day and I would be lying on the sofa and watching TV the whole day. I couldn't even walk from here to there."

Being HIV positive presented a number of losses at the same time. According to **participant no. 1,** "HIV killed most of my dreams and aspirations, at the time when I tested positive, I became so frustrated and lost many things, including the good job I had and the woman of my life. There were days where I would wake up and decide not to go to work. If it wasn't for HIV I would have accumulated a lot of things in my life by now. This year would have been my ninth year if not the tenth year working for the same company I used to work for. I earned a lot of money at that company and right now it is difficult to find the job similar to that I was doing at that company and thinking about it just breaks my heart."

4.3.4 Fear

Being diagnosed as HIV positive, presented participants with many fears. They particularly feared death, isolation or rejection from significant others, as three of the participants indicated.

Participant no. 1 commented, "When I went back to the hospital for the second time, I tested again for the second time and still my results came back positive, I received counselling while at the hospital, but still the thought of knowing that I am HIV positive was still lingering on my mind and I feared that I was going to die soon."

For **Participant no. 2,** "Eish, the first time I was told I am HIV positive I immediately thought that I am going to die soon. I was scared and constantly thinking about it, the thought of me dying was always on my mind."

Participant no. 3 said, "The first time I knew that I am HIV positive I became so stressed to such an extent that I feared that I was going to die anytime soon."

Not only did the participants express their fear of dying, some expressed how they feared rejection if they disclosed their HIV status to significant others as **Participant no.3** indicated. "I feared telling my brother about my HIV status because I feared rejection, but in the end I built up the courage to tell him."

For other participants the fear was not only centred on rejection or death, but about being in a relationship with someone who was HIV negative, and so the chances of infecting their partner was high, as **Participant no. 1** stated: "I have a problem of finding a girlfriend because I fear infecting her with HIV. My problem is to approach her and promise her that we would use a condom and I know we would use it for a first week to second week, either the condom would burst or breaks, and that is where the problem might start because I would have infected her with HIV. This is still bothering me that is why I chose to remain single and I so wish that we could find a cure for this virus."

4.3.5 Stigma

Not only did some of the men fear death, isolation and rejection as a result of being HIV positive, but they also feared being stigmatised and discriminated against, based on their own perceptions of how people would think and act towards them. It was evident that some of their perceptions of other people's reactions were very negative. Accompanying their fear of being stigmatised was fear attached to disclosing their HIV status to others as stated by **participants no. 1, 3 and 4**.

Participant no. 3 commented, "I feared telling my brother about my HIV-positive status because I feared rejection but in the end I built up the courage to tell him."

Participant no. 4 feared being rejected by his customers if he disclosed his HIV status to them. "If people could know about that hairdresser's status they are going to have problems, they will no longer come to my hair salon because my status will be a problem for them."

A study by Kalichman and Simbayi (2004) found that it has also become common in many traditional African cultures to attribute an illness to supernatural forces and these beliefs may be related to stigmatising afflicted persons, as indicated by the following participants:

Participant no. 1 told me, "When I first told my family that I am HIV positive they did not believe it, they all though that I was bewitched. As a result they decided that I must consult a traditional healer which I did, but it never helped. Still I was getting thinner and thinner."

Participant no. 2 said, "My brother I am telling you, I went to Nelspruit, I paid R1 500 and spent two weeks at that old man's house. That old main gave me all the concoctions to make the HIV go away. I went back home, I started throwing up and lost a lot of weight, because my family believed I was bewitched."

4.3.6 Lack of condom use

This theme relates to the lack of use of condoms which contributed to the men becoming infected with HIV. For example, **Participant no. 2** stated that he had a wife and two girlfriends and he never used a condom with any of them.

Participant no. 2 commented, "Let me tell you what was happening, I had one here, one in Krugersdorp where I worked, and on Friday when I go home to my wife we would also have sex without a condom."

For other participants the use of alcohol had a huge impact on how they think they may have become infected with HIV. When they were under the influence of alcohol they had not thought about using condoms during sexual intercourse, as **Participant no. 3** and **Participant no. 1** stated:

Participant no. 3 suggested, "Eish, you know this alcohol makes you go to these filthy places where they sell alcohol and when you are drunk you end up picking any girl with whom you have sex without a condom because you are both drunk and you do not even think about using condoms."

Participant no. 1 shared the same sentiment as **Participant no. 3**. He stated: "You can travel the whole world, and I tell you that no one thinks about condoms when they are drunk, being drunk and thinking about a condom? There is no such a thing even when you have it within reach or in your pocket, but I still maintain when you are drunk you do not have time to think about it, and that is what I used to do."

For other participants it was all about trust which they measured according to the time that they had been with their partner, as **Participant no. 4** stated: "Initially we would start by using protection, but this would last for a short period of time. During the time we were using protection I would tell myself that I am still trying to figure out what type of a person my girlfriend is. As soon as I feel that I could trust her based on the fact that she shows signs of loyalty to our relationship we would then stop using condoms. This is what I used to do in most of my relationships, I would date someone for about six or seven months using a condom then we would start having flesh to flesh sex".

4.3.7 Disclosing HIV status

Disclosing one's HIV status is about making one's status known, and the resulting reactions of others to this news. According to most participants, they stated that they did not experience difficulties when it came to disclosing their HIV status. In fact some stated that they first disclosed their status to their family members and they were lucky to receive love and support.

Participant no. 3 told this story, "When I told my family that I am HIV positive, they said, you are our brother and that will never change as we will continue supporting you with everything that you need."

Participant no. 2 said, "I called all my brothers and sisters, including my nieces and nephews. I sat them down and broke the news to them. However, my one sister cried because she was hurt, but for the rest of the family they seemed okay."

Participant no 5 alleged, "Nothing has changed because of my status, they still treat me the same way."

However for **Participant no. 1** things were slightly different. He said that the day he disclosed his HIV status to his family, his parents would not believe him. They alleged that he was bewitched, although they were still supportive. He said that "they couldn't believe, they thought I am bewitched, things like those". His sister reacted negatively towards him when he disclosed his HIV status. He stated, "To tell you the truth my one sister reacted very differently from the rest of the family, she wouldn't eat nor drink from the cutlery I use. She was the only one treating me that way but for the rest of the family they gave me love and support."

4.3.8 Availability of support

Support deals with the involvement of family members and other people as a way of helping those who are attempting to deal with the disease. The support can manifest itself in different forms.

Participant no. 2 commented, "I must say that I have a brave mother who is very much supportive. She would sometimes take me for a walk and on the way she would buy me fruits and she would always encourage me by saying to me, HIV is like any other ailment, you must not be afraid and you do not have to hide yourself from anybody else."

Participant no.5 reported receiving more support from his cousin and his younger brother. He stated, "The person who is more supportive is my cousin because he stays close to my house. He is the one person who is able to come often to my house and check up on me and on some days we go for a walk. My younger brother also helps me with transport money for coming to the clinic and sometimes he would give me pocket money to buy snacks on the way, as a result I feel good because of their support."

For **Participant no.3** the support is not one-sided but is reciprocal. He said that he has a very supportive family and that he also supports them as well. He even pointed out that as far as their support goes they even help each other to find jobs. He said, "My family support me and I also support them, we even help each other to find jobs since I am also unemployed."

Participant 4 is the only person whose entire family does not know about his condition. He only receives support from his wife.

Participant no. 4 commented, "I only receive support from my wife because she is the only one who knows so far, I haven't told my mother yet because she is old and suffers from high blood pressure so I do not want to scare her. If I tell her now I might make things worse because my younger sister is HIV positive as well and I also want to remain strong for her as well."

4.3.9 Availability of medical support

All of the participants are receiving antiretrovirals, which helps to protect their immune systems as well as reversing different HIV-related infections. They all attributed their recovery in part to the medication they received from the clinic. They all stated that it was important for them to see a doctor whenever the need arose, even if it was just for a minor cough or a headache, because it was of utmost importance that they should take good care of themselves. The participants made comments and observations about the ARVs they receive.

Participant no. 3 said, "The minute I started taking these ARVs I recovered within two months, when I went back to work my colleagues were surprised to see me looking so well and healthy. I had picked up a little bit of weight and I was full of energy, since then I realised that it is possible for one to live with HIV and I promised myself that I will continue taking my ARVs for as long I live."

Participant no. 1 commented, "I was sick before I started taking these ARVs, I had sores all over my body and everybody had just given up hope on me. They all thought that I was going to die soon. However, as soon as I started taking these

ARVs I regained my old physique, before you wouldn't be able to recognise me. These ARVs did help me a lot."

For **Participant no. 5**, being on medication brought a sense of hope. "For as long as I am drinking my medication all is going to be fine."

Participant no. 4 attributed his survival to the ARVs in terms of prolonging his life. He said, "As long as I am taking my ARVs I will continue living because they boost me, if it wasn't because of them I think I would have died a long time ago."

4.3.10 Importance of adherence counselling

Another significant theme was the importance of adherence counselling, which the participants reported having gone through after receiving a positive diagnosis. According to Hamilton (2003, p. 219), "adherence counselling is generally defined as the degree to which patient behaviour is congruent with the recommendations of a health care provider". For the participants adherence counselling provides them with the opportunity to explore and discover ways of living more fully, satisfyingly and resourcefully.

Participant no. 1 said, "Through counselling I learnt that it is useless to keep on pointing fingers and trying to figure out who infected who, instead one has to focus on how best they can take good care of themselves by living a healthier lifestyle."

He further stated, "After receiving counselling, I sat down and I realised that my drinking has gone over the limits. Before I became HIV positive I used to drink occasionally, especially during weekends when we were watching soccer games, but after I became positive I told myself that drinking helps me deal with some of my problems. However by going through counselling I figured that what I am doing is wrong and it will affect my health very badly in the long run, so I stopped drinking because of counselling."

For **Participant no. 2** counselling was more informative and opened his eyes to a lot of issues related to HIV and AIDS that he had not previously known about. He said, "I'm so grateful for the fact that I went through counselling because through counselling I learnt that one can still lead a normal life with HIV, provided they take good care of themselves by taking their medication as usual, including eating healthy food like fruits and vegetables and a little bit of exercise. I used to believe that once you become HIV positive automatically you are going to die."

The same held true for **Participant no. 3**, who stated that he thought that if a person and their partner were HIV positive there was no need to continue using condoms because they were both positive. He said, "I did not see the importance of using a condom with my partner because we are both HIV positive until I went for counselling, and the counsellor told me that it is important that one continues using condoms with his/her partner even if they are both positive because they will re-infect each other with their viruses and that will have a lot of implications for their well-being."

4.3.11 Accepting one's condition

Participants reached a stage where they were able to come to terms with the idea of having to live with being HIV positive and had accepted it as part of their lives.

Participant no. 4 decided that there was no use to deny that he was HIV positive anymore. He needed to accept it and move on with life. He said, "I now see myself as a normal person and I have incorporated HIV into my character and told myself that this is my baby, I just have to cope with it. I am going to live with it whether I like it or not and I just have to remain strong for myself".

The same applied to **Participant no. 3.** He said, "I have accepted it is part of life."

Participant no. 5 shared the same sentiments as **Participants nos. 3 and 4**. When asked how they felt about their HIV status, the reply was, "Right now I have just accepted that I am HIV positive."

According to **Participant no. 1** the biggest favour that one can do for oneself is to acknowledge that one is HIV positive. Once one accepts that one is HIV positive and that there is nothing one can change about it, the easier it will be for one to live positively with it. **Participant no. 1** said, "You see, the most important thing is for you to accept that you are HIV positive. Once you accept that you are HIV positive and there is nothing you can change about it, the easier it will be for you to live with it."

4.3.12 Change of lifestyle

For some participants HIV not only provided them with negative consequences, but also brought about a new meaning to their lives.

According to **Participant no. 2**, "What I like about being HIV positive is that my life has changed for the better. I am no longer chasing after girls at night, and I stopped drinking, at seven o'clock in the evening you will find me at home. I see a lot of progress in my life, and I always tell people that if it wasn't because of HIV I don't think I would have gotten married and had two cars. This is all thanks to HIV."

Participant no. 1 also mentioned that he stopped drinking because of his HIV status. He said, "My life has changed because I have stopped using alcohol. AQs a man I have to have a wife, although I have a problem as to where will I find her, maybe I should also find somebody who is also HIV positive."

Participant no. 4 noted, "Eeh, to be honest, I have learnt to take it easy in life and to laugh at myself sometimes when I make stupid mistakes in life. Now I can face up to a whole lot of challenges regarding my HIV status. I used to feel inferior because of my HIV status and I would always feel as if people could see through me even when I wasn't saying anything to them, with time I have come to realise that there is more to life that being HIV positive by drawing strength from other HIV-positive people who are trying by all means to defy the odds in trying to cope effectively with HIV."

Participant no. 3, however, said that his lifestyle hadn't changed because of HIV. For him life was still the same as before he became HIV positive. He commented, "my life has not changed, I still lead a normal life, the same way I used to live before I became HIV positive."

4.3.13 Lack of knowledge regarding how HIV entered their lives

The majority of the participants stated that they did not know how they became HIV positive. As a result they did not blame anybody for being HIV positive.

Participant no. 5 commented, "I don't know how HIV came into my life and there is no need to blame anyone for being HIV positive. You see when my girlfriend told me that she is also HIV positive, I told myself that we don't have to point fingers at each other by blaming one another because when we first met, none of us knew each other's status and we did not think of going for VCT before we could start engaging in unprotected sex."

Participant no. 4 shared the same views as **Participant no. 5**. He also did not know how he became HIV positive. His response when asked was: "I can't say, I really don't know, otherwise I would be lying because I don't even want to blame or accuse anybody for infecting me."

However, **Participant no. 1** initially wanted to blame his ex-girlfriend but with time realised that he might be wrong. He said: "Ai, even now I don't want to lie, even though initially I was blaming my ex-girlfriend, I don't know if at the time we started staying together I was already positive, so it is difficult to tell where one got it from."

Participant no. 2 shared the same beliefs as the remaining participants. He stated that he did not know about how he became HIV positive. "If I can say I know how, I would be lying to you, right now I am still asking myself how I got infected."

4.3.14 Education about HIV

This theme touches on enlightening others about issues relating to HIV. It also highlights on how some participants came to make themselves useful by educating others about HIV.

Participant no. 2 says that he often talks to his friends with the hope of equipping them with the facts of the disease and its implications. He said, "I always talk to my friends about HIV such as the importance of practising safe sex, and always encourage them to go for an HIV test in order to make an informed decision regarding their sexual life."

According to **Participant no. 3**, being HIV positive has made him look for more information about HIV and read a lot about it. This had led him to realise that just because one was HIV positive did not mean one was going to die from it. One could die from other things, such as being involved in a car accident. He said, "Being HIV positive made me start educating myself about the disease. It was also through reading that I learnt that being HIV positive does not mean that you are going die. A lot of things happen in life that you can die from as a result, such as car accidents or other ailments other than HIV."

Participant no. 1 also mentioned that he sometimes gives talks to other HIV-positive people at the clinic and he also teaches his siblings about it. He also mentioned that he always encourages them to always practise safe sex because he does not want to see them experiencing what he went through. He said, "Right now I am able to stand and teach people about HIV, I hope next time when you come around you will see me. I have two younger sisters. I always teach them about HIV because it would break my heart to see them going through what I went through because of HIV. I also teach them about the importance of practising safe sex."

Participant no. 4 stated that through counselling and a little bit of reading he had learnt that one must also eat healthy food to help one's body to maintain strength in order to fight infections. He said, "Reading up on information about HIV has made me realise the importance of eating healthy when you are HIV positive, as a result I now eat healthy food."

4.3.15. Hope for the future

This theme is one in which the participants expressed hope that maybe in the future there would be a cure for HIV, but people should continue using condoms.

Participant no. 4 said, "My wish is for people living with HIV to stick together as one and pray to God that a cure be available for this epidemic."

Participant no. 2 said, "In the meantime let us continue using condoms and maybe one day a cure will be available."

Participant no. 3 said, "I would encourage people to use condoms and to go for testing in the meantime, maybe by God's grace a cure will be found."

Participant no. 1 said, "Let us continue using condoms and stop spreading the virus while we wait patiently for a cure."

4.4. Conclusion

The chapter discussed the lived experiences of a sample of HIV-positive black heterosexual men at Tshwane district hospital. The findings suggest a number of preliminary conclusions which could benefit from further exploration.

Firstly, a HIV-positive diagnosis had psychological consequences for these men and they exhibited feelings of denial, loss and fear. This was expected, similar to when an individual hears they have a condition which could be fatal. These feelings are more likely when individuals lack good information about HIV. Explanations of disease are complex, and individuals may understand illness in the language of western medical terminology, as well as within a framework of indigenous belief system such as bewitchment and ancestral powers.

However, despite traumatic reactions to an HIV-positive diagnosis these men stated that the availability of adherence counselling, and medical, emotional and social support, assisted them to adjust. As a result they were able to rise above the challenges of being HIV positive and to live a better-adjusted life.

Secondly, there are social consequences for such a diagnosis: there were clear signs that the men feared stigma, and anticipated rejection and discrimination if they disclosed their HIV status. As a result they developed protective strategies such as non-disclosure or partial disclosure of their HIV results.

Another social consequence was an interruption of their roles as men and as leaders in their families. They were expected to always be in control. Being HIV positive has threatened their socially constructed definitions of what it means to be a man, because it has involved loss of control over a number of aspects in their lives, including employment. Some were unable to work and had to rely on other people for support. A loss of income involved more than financial loss but also loss of respect in the eyes of their communities and families. In the language of masculinity their status as men was jeopardised. In Chapter 5, a further discussion of the results is presented. It will focus on the men's experiences of being HIV positive in the light of the literature, and will suggest some broader conclusions.

CHAPTER 5

DISCUSSION OF RESULTS, RECOMMENDATIONS AND CONCLUSION

5.1 Introduction

This chapter involves a further discussion and summary of the results presented in Chapter 4. The discussion relates to the lived experiences of heterosexual HIV-positive men interviewed for this study and this will be linked to the literature. The discussion will begin with the experiences of living with HIV, and a discussion on how HIV has impacted on their lives. A critical reflection, including conclusions and recommendations of the study, will also be presented.

5.1.1 Experiences in relation to the self

The men in the study went through a phase of experiencing physical symptoms before they actually went for an HIV test, which resulted in a positive outcome for all of them. They reported losing a lot of weight, having flu-like symptoms and feeling weak. According to Justice, Chang, Rabeneck and Zackin (2001), symptoms play a very important role in a person's experiences of disease. They are the primary reason the person may seek care for what may be perceived as a threat to health.

Because of HIV infection, of which they were unaware, they started developing physical symptoms which led to the awareness of their deteriorating health, prompting them to go for an HIV test. However, the decision to go for an HIV test was not an easy one for any of these men, despite being aware of the physical symptoms. Some had to be hospitalised a number of times before they actually made the decision to go for an HIV test, as was the case with **Participant no. 1**.

Not only did the men go through a phase of enduring physical symptoms, they also went through a psychologically debilitating phase. Heckman et al. (2002) and Siegel and Lekas (2002) state that receiving a positive diagnosis may present one with a wide range of psychological consequences. Some of these consequences may range from fear, loss, grief, guilt, denial, anger, anxiety and depression, to suicidal behaviour. Feelings of denial were prominent in all the participants. Denying that they are HIV positive brought some kind of relief and a sense of shifting responsibility, as some of the participants attribute being HIV positive to witchcraft.

It is obvious that these men were not yet ready to deal with some of the complexities of being HIV positive, and so were in denial about it. Denial is defined as the avoidance of the awareness of some painful aspect of reality in which a person may refuse to accept some aspects of external reality (Kaplan, Kaplan & Saddock, 2003). Denial may also be one way for a person to completely refuse to come to terms with the diagnosis by denying or disregarding the implications. Some of the participants could not believe what was happening to them, and as a result they found it hard to accept the news. Being in denial may have helped them to block out the awareness of what would be too difficult to bear, which in their case was the thought that their lives would have to take a different turn. The most debilitating symptom was the thought that they might die.

Another emotional reaction common amongst the men was loss. This type of emotional reaction is common for most people who are diagnosed as HIV positive, particularly men. In a world where hegemonic masculinity plays an important role in terms of setting the standards with regards to maleness and being a man, losses take on an extra dimension. For a man to be diagnosed HIV positive means a loss of independence, health, physical attractiveness and even financial stability. It could be said that they risk losing their sense of "being a man".

According to Donaldson (1993) and Alsop, Fitzsimons and Lennon (2002) hegemonic masculinity represents the form of dominant masculine identity aspired to by many males. These men aspired to this identity and showed it was important to them: for example the thought of being constantly under the care of a parent was worrying, as **Participant no. 2** stated in relation to his dependence on his mother. Contrary to the popular belief that men should be tough, self-reliant, independent, strong and robust, being HIV positive took away their identity and damaged their sense of self-worth.

As previously noted, the loss that a person may suffer as a result of being HIV positive may bring with it extreme fear and thoughts about death. Some expressed profound feelings of grief about the anticipation of death. Not only did they fear death, but they also feared being rejected, isolated or stigmatised if people found out about their HIV status. This was the case with at least one participant, who feared rejection from his brother.

Inadequate condom use or resistance to condoms in general seemed to be in evidence. While condoms remain an effective prevention tool for HIV infection, few men in the study reported regular and consistent use of condoms. In the context of reported multiple partnering, all the respondents said they did not use a condom with some of their sex partners. Their major reasons given were trust ("I believe my partner is faithful or HIV negative"), alcohol (which impaired judgment and decision making) and choice (they preferred the physical sensations associated with unprotected sex). Some men in the study believed that they were the only sexual partner of the woman they were with and rationalised, therefore, that they could not have become infected by her.

These findings are supported by Agbo (2001) who suggests that male resistance to condoms could be based on lack of knowledge and misconceptions about condoms, and seeing condoms as a barrier to sexual pleasure and incompatible with the male ego. For some men, condom use challenges their self-image as healthy, sexually virile men (Walker, Reid & Cornell, 2004; McPhail & Campbell, 2001), and the men in this study were no exception.

5.1.2 Experiences in relation to others

The significant others in the life of a person infected by, and living with, HIV play an important role in the infected person's physical and psychological care. Individuals, when they receive positive results, are encouraged to disclose their status to significant others. The rewards of disclosing one's status can be substantial, such as acquisition of emotional, physical and social resources. These resources may include acquisition of medical attention, the provision of medical information and acceptance, as well as freeing the individual from hiding medication from friends and family. This indirectly increases support for adherence to medical regimens (Serovich, 2001).

Serovich (1996) and Cohen and Willis (1985) have shown that infected people with spouses, friends and family members who provide support are in better health than those with less social support. The men in this study benefited from sharing their diagnosis with their significant others. Family support ranged from emotional and financial support to physical support.

However, one participant reported being rejected by a sister – although he overcame the rejection through moving away from her, he still experienced feelings of deep hurt. He believed family members should accept each other despite the challenge of an HIV-positive diagnosis.

The decision of these men to disclose their HIV status to their families and friends was not forced but was based on how much they trusted their family and friends – and in fact most families were generally loving and supportive. One participant said that although a family member was "hurt" by his disclosure, through the help of the other family members she coped.

One participant anticipated a mixed response from his family – since he felt that they were not ready for disclosure of his HIV status, he still keep it a secret from some family members, to protect them. One participant reported that despite having disclosed his HIV status to his partner he was still keeping it a secret from his parents. This was because they were elderly and sick and disclosure might have had an adverse effect on them, he felt.

Although the participants were not asked directly about experiences of stigma, the interviews showed that it was evident in their inner worlds and social contexts. More specifically, the findings have something to say about internalised and externalised stigma.

It seems firstly, that the participants experienced some level of internalised (or self) stigma. Indicators of internalised stigma include: fear of rejection; fear of consequences of, and unwillingness to embark on, disclosure; fear of blame and moral disapproval; and strategies to minimise rejection.

All the participant feared rejection and disclosure and felt somewhat negatively about themselves, as shown by **participants 1, 3 and 4**. Some participants developed strategies to minimise blame and responsibility for becoming HIV in the first place. For example **participants 1 and 2** blamed their infection on witchcraft, an external force out of their control. Others told some people and not others about their HIV status, to avoid and manage rejection.

Where externalised stigma is concerned, that is actual acts of discrimination, it is clear that few had actual experiences of rejection, as can be seen in the case of the participant who experienced rejection from his sister. Perhaps the lack of other reports of externalised stigma can be put down to gradual changes in social attitudes, and careful choices around disclosure.

It is interesting to observe that once disclosure to significant others had occurred, family support played a big role in reducing stigma. This support enabled the men to accept their condition and to get on with their lives. While stigma is still a reality in South Africa (Kalichman & Simbayi, 2004; Herek, 1999) these findings, although based on a very small and specific sample, suggest that disclosure does not inevitably lead to negative consequences and rejection. This is especially true if individuals with HIV are given the opportunities to plan and discuss the disclosure beforehand.

Acceptance means that the person has come to terms with his diagnosis and has had time to deal with losses and fears, and has found a way of dealing with the negative feelings associated with being HIV positive (Van Dyk, 2005). These men were no longer in denial – for example one participant said that he now saw himself as a normal person just like anyone else and as a result had incorporated his HIV status into his character (HIV is his "baby"). He coped with it, accepted it and remained strong for himself.

Accepting that they were HIV positive generally changed their lives for the better. Some of the men disclosed their HIV status to their friends through educational talks about HIV and encouraged them to practise safe sex. One participant was able to give talks at the clinic concerning HIV and AIDS, while another was reading more about HIV and in the process learning that he could live longer with HIV if he took good care of himself. He was able to challenge the belief that being HIV positive was a death sentence.

Despite the support from significant others, counselling at an individual level also seemed to play a significant role for the men in this study. They reported that counselling helped them to alter their perceptions of HIV and equipped them with information on how to live better and healthier lives. According to Van Dyk (2005), counselling gives the client the opportunity to explore and discover ways of living more fully, satisfyingly and resourcefully. It is concerned with addressing and resolving specific problems, making decisions, coping with crisis, working through feelings and inner conflicts, or improving relationships with others.

Through the help of the counsellor and the support from their loved ones and friends, many of these men came to a point where they realised that life could go on and that HIV was manageable. They had access to health care, counselling and ARVs. Positive living became a factor in their lives; some men reported they had stopped drinking, visiting shebeens and pursuing casual encounters with women. They were spending more time at home with their families and some were practising safe sex with their partners. Although everyday challenges were still a reality, they had learnt to live with HIV and were hopeful of a future cure.

5.2. Conclusions

In this chapter an attempt was made to provide a view of the lived experiences of heterosexual men who have been diagnosed with HIV. Although each man experienced his HIV diagnosis in a unique way, each HIV journey was a similar process of physiological and psychological ups and downs.

The men's experiences ranged from awareness of physical symptoms, denial, loss, fear to acceptance. One participant had struggled to reconcile his HIV diagnosis with his traditional belief in witchcraft, and this had complicated his acceptance.

The most important issue for these men was to disclose their HIV status to their significant others. They indicated that the support they received from their significant others had made it easier to survive the challenges of living with HIV. In addition, the availability of medication had facilitated emotional support as the men reported they have had an opportunity to be involved in adherence counselling sessions, which were enlightening and seen as non-judgemental.

As a result they have managed to come to accept their condition, work through their denial and were facing the challenges of living with HIV. This acceptance had meant they were able to talk openly about their HIV status and teach others about HIV.

Perhaps the most useful and important theme in the findings is the theme of masculinity. Almost every aspect of the HIV journey for these men was shaped by their internalised norms about "being a man". From the participants who refused to test despite HIV symptoms, to those who felt challenged by their dependence on others, job loss and loss of virility, all experienced HIV as an attack on their maleness. Even when they were in multiple-partner relationships before being diagnosed, they could rationalise that the women they were with "must be HIV negative", supporting traditional ideas of male versus female sexuality.

These men were not previously informed about HIV and AIDS because "real men know best". They lost their self-esteem after diagnosis because a "real man does not have a lingering sickness". They resisted safe sex messages and condom use because "a real man does not fear disease". They struggled to disclose their status because "a real man does not show his vulnerability" and they struggled to accept counselling at first because "a real man does not need help and should be self-reliant".

But, encouragingly, these men demonstrated that they were, and are, able to change and grow, and can adapt their beliefs in regard to maleness and accept help. In the process they were able to turn a negative life event into something positive and challenge their internalised gender stereotypes.

5.3 Recommendations

Further research could be conducted on other heterosexual men at other hospitals and clinics, and from other races and age-groups in order to compare the experiences of heterosexual men. It could also be interesting to conduct a similar study on men from rural areas to see if their experiences are in any way similar to men in urban areas, taking into consideration that in rural areas there are fewer resources and lifestyles are different.

A similar study could be conducted on men who are in advanced stages of their illness, to assess whether their experiences are the same or different to those of the men who do not yet have serious or life-threatening symptoms. As the results of the study have shown that men still need access to appropriate information and support on HIV, it is of utmost importance that a support group be formed at clinics which provide services to HIV-positive men, so that they can share their personal experiences.

Other HIV-positive men should be mobilised in these groups to speak out, take action and make a positive contribution towards the fight against HIV. Support groups should target men to help challenge male norms and behaviour that undermine the well-being of men and their partners. Men need to be inspired to assume responsibility in playing a greater role in socially responsible behaviour and the prevention of HIV and AIDS. Finally, the effects of alcohol on sexual relationships, multiple and concurrent sexual partners and transactional sex should be addressed. Support groups could serve as a platform to raise issues, educate and inform men in general.

5.4 The limitations of the study

The objective of the study was not to generalise the findings to a specific population or a general population. The sampling method provided a small sample and this allowed for in-depth conversations and an ability to extract more detailed and interesting information. However, further studies with larger samples could add to and expand on these meanings and findings.

In addition, the study could have considered speaking to men in their first year of being diagnosed as it could have provided different information – if adapting to HIV is a journey, then the journey may have different stages.

It is difficult for HIV-infected people to talk about their experiences. The presence of a researcher and a stranger might have had an influence on some of their responses. The researcher therefore believes that he could also have conducted focus groups or have asked participants to create narratives about how they experienced life in the time they became HIV positive. The researcher believes that this would have created room for the enrichment of data, and contributed to different and equally valuable information.

CHAPTER 6

REFLECTIONS

"There are no shortcuts to success. It takes years for us to grow to perfection, and it takes a season for fruit to mature and ripen. Trying to ripen a fruit quickly will lose its flavour." (Author unknown)

6.1. Reflections on the research

The journey of a thousand miles begins with one step. This describes the researcher's own HIV journey which started during the required internship year served at 1 Military Hospital, where the researcher encountered challenges experienced by PLHIV. Learning to help people with HIV has also challenged the researcher and he believes that growth into a better person has resulted.

The researcher's experiences at 1 Military Hospital resulted in a curiousness, as a black heterosexual man, as to how other black heterosexual men cope with their HIV diagnosis and it is this that led to this research. Through the research this researcher came to see that even though a shared ethnicity and a shared sexual orientation exists, there is not necessarily a sharing of similar ideas and perceptions about HIV transmission. Although the men in the study had engaged in risky sexual behaviours, they disassociated themselves from the risks that come with unprotected sex, in various ways. For example, some believed that they were the only men having sex with the women in their sexual networks, even though in reality this was unlikely.

The researcher was surprised by this belief because if these men had multiple partners then the women they were engaging in sex with were more than likely to have had other sexual partners. The participants in the research had basic information and knowledge about the transmission of HIV but did not act on this information. Perhaps this could be linked to the fact that, unlike this researcher, they still have traditional ideas about maleness and had not received support for behaviour change from within their social circles.

In addition the men did not easily and openly talk about sex, sexuality and gender roles. This can be attributed partly to the hypocrisy of our society – even though sex is happening, talk about it is avoided. Talking about sex can provide a good entry point to talking about HIV, and as someone who has worked in HIV this researcher has been able to have these conversations, which has been of benefit.

The researcher has been left with a thought-provoking question about how one comes to terms with knowing that one's health is dependent on taking medication. The researcher has not experienced this and can imagine that this would be challenging on a daily basis. This researcher believes that acceptance of, and adherence to, lifelong treatment in this demographic is an important avenue for further research.

Doing the research resulted in a shift to critical thinking. Through reading and talking to friends and colleagues about the research this researcher learned that research is not about being an expert, but it is rather about the ability to develop an idea, discover facts and interpret them in the light of recent thinking and literature.

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APPENDIX A

CONSENT FORM

Dear Participant

We invite you to participate in a research study. This information leaflet will help you to decide if you want to participate. Before you agree to take part you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the investigator.

The aim of this study is to understand the social personal experiences of HIV-positive black men, in order to better understand the specific needs of men in the HIV clinic at Tshwane District Hospital. The study will be conducted by a psychology student, Mr. L.A. Mphatsoe, who will ask you a set of questions during a personal interview. This interview will take place in a private room in the clinic and will last no more than one hour. The interview will be tape-recorded by Mr. Mphatsoe, but all recordings will be destroyed after the data have been analysed. Your data will be anonymous-that means that your name will not be used and you will be identified by a number.

Talking about your experiences may be emotionally upsetting, but support will be given by Mr. Mphatsoe and you will be referred for counselling if necessary. There are no financial benefits of participating in the study. Although you may not benefit directly from the study, the results will enable us to provide better care for men in the HIV-clinic.

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the interview without giving any reason. Your withdrawal will not affect you or your treatment and care in any way.

This study has received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria. A copy of the approval is available if you wish to have one. The contact person for the study is Mr. Mphatsoe. If you have any questions about the study please feel free to contact me on this number: 0732464321.

All information that you will give will be kept strictly confidential. No personal identification information like your name will be used. We will only use a number to identify you. Research reports and article in scientific journals will not include any information that may identify you or your hospital.

CONSENT TO PARTICIPATE IN THE STUDY

- I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits of the study.
- I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study.
- I am aware that the results of the study, including personal details, will be anonymously processed into research reports.
- I am participating voluntary.
- I have had time to ask questions and have no objection to participate in the study.
- I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect any treatment or care in any way.
- I will receive a signed copy of this statement of this informed consent agreement.

Participant's name (Please Print):______________________________

Participant's signature:______________________________

Investigator's name (Please Print):______________________________

Investigator's signature:____________________Date:______________

Witness's Name (Please print):______________________________

Witness's signature:____________________Date:______________

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YUNIBESITHI YA PRETORIA

VERBAL CONSENT

- I, the undersigned, have read and have fully explained to the participant the contents of the information leaflet, which explains the nature, process, risks, discomforts and benefits of the study to the participants whom I have asked to participate in the study.
- The participant indicated that he understands that the results of the study, including personal details regarding the interview will be anonymously processed into a research report.
- The participant indicates that he has had time to ask questions and has no objection to participate in the interview.
- He understands that there is no penalty should he wish to discontinue with the study and his withdrawal will not affect any treatment and care in any way.

Participant's name (Please print):________________________________

Participant's signature:______________________Date:_________________

Investigator's name (Please print):_______________________________

Investigator's signature:_____________________Date:_________________

Witness's Name (Please print):__________________________________

Witness's signature:________________________Date:_________________

The witness signs that he/she has witnessed the process of informed consent.

APPENDIX B

EXAMPLE OF INTERVIEW GUIDE

DEMOGRAPHICS OF THE INTERVIEWEE:

Gender :

Age :

Marital Status :

Employment :

1. How did you find out about your status?

2. When did you find out about your status?

3. How did you feel when you first received the news that you are HIV positive?

4. How have you been experiencing you life since you were diagnosed HIV positive?

5. How are you currently coping with being HIV positive?

5.1. How do you feel about your HIV status now?

5.2. Has HIV changed you perspective about your life? If yes, how?

6. Have you disclosed you HIV status?

6.1. Who did you disclose your HIV status to?

6.2. How did you disclose?

7. How did/ do you experience people's reactions?
8. Were they supportive?

9. How did HIV enter your life?

10. What advice would you give to people who are HIV positive?