

https://dspace.org/

Exploring masculinities in the context of ARV use: a study of men living with HIV in a South African village

Mfecane, Sakhumzi

2010-08-19
http://hdl.handle.net/10539/8477

Downloaded from a DSpace repository. https://dspace.org/

EXPLORING MASCULINITIES IN THE CONTEXT OF ARV USE:
A study of men living with HIV in a South African village

Sakhumzi Mfecane

A thesis submitted for Faculty of Humanities, University of Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy

June 2010

ABSTRACT

The dominant social constructions concerning what it means to be a man have been studied in relation to various HIV risks that they may pose for men and women. It has been shown that men worldwide tend to embrace notions of manhood that encourage them to have multiple partners and not pay attention to their health needs. This study focuses on men who have taken an HIV test, disclosed their HIV results and are using antiretroviral medicines provided in a public health facility in South Africa. It investigates their experiences of living with HIV in relation to how they constructed and experienced their masculinity. This focus is unusual in South Africa. Most research focuses on men who are resisting health services and who have not taken an HIV test. Based on a fourteen-month ethnographic fieldwork in a South African village, findings show that living with HIV poses unique challenges for a man. From the onset of a disease men are faced with difficult decisions to make, such as whether or not to seek help, where and with whom. These decisions, I argue, are not made in a vacuum, but are highly mediated by pre-existing views about manhood, culture, HIV stigma, perceptions of treatments, and other belief systems. Thus when someone becomes ill he draws from the various meanings offered by these discourses to decide on how to respond to a physical discomfort. Most men in this study embraced the dominant social definitions of what it means to be a 'real' man before they became ill. These definitions discouraged men from using public health facilities; they encouraged men to have multiple partners as a way of proving manhood and gaining social respect, and they constructed manhood as a powerful, controlling and an independent gender. This thesis engages with men living with HIV to find out how they dealt with these expectations when they became ill and needed to receive help. Most importantly it investigates how these definitions and experiences of masculinity have been challenged and then transformed by the experience of being ill and what 'alternative' definitions of manhood have been forged out of experiences of being sick and using lifelong medications.

Contents

ABSTRACT iii
DEDICATION vii
ACKNOWLEDGEMENTS viii
DECLARATION x
CHAPTER 1 1
INTRODUCTION 1
Background and context: AIDS as a political issue in South Africa 13
Methodology 19
Ethics 33
Outline of chapters 33
CHAPTER 2 36
MASCULINITY, MEN`S HEALTH, HIV STIGMA and THE BODY 36
Introduction 36
AIDS research in Africa 36
Masculinity and HIV 46
HIV, masculinity, stigma and the body 58
Conclusions 63
LIFE BEFORE HIV: MASCULINITY AND HEALTH BEHAVIOUR BEFORE HIV 65
CHAPTER 3 66
LIVING LIKE A MAN: MASCULINITY BEFORE HIV 66
Introduction 66
What it means to be a man 67
Alternative masculinities 97
CHAPTER 4 102
HEALTH BEHAVIOUR BEFORE HIV 102
Introduction 102
Health behaviour in context 104
Choice of medicines 106
Men and Public health settings 118
Men and HIV/AIDS 127
'Tindzhaka' and 'mafulara' 134
Conclusions 137

BECOMING ILL: HIV TESTING AND DISCLOSURE DECISIONS 139
CHAPTER 5 140
'DOES IT MEAN I`M ALREADY DEAD?' - MEN AND HIV TESTING 140
Introduction 140
HIV testing in Bushbuckridge 144
Becoming sick: men doing an HIV test 156
HIV testing outcomes: men reaching out to other men 167
CHAPTER 6 174
TO TELL OR NOT TO TELL? - DISCLOSURE DECISIONS OF MEN LIVING WITH HIV 174
Introduction 174
HIV disclosure in Bushbuckridge 176
Partner disclosure and its outcomes 182
Gender issues in disclosure 199
Conclusions 207
LIFE ON ARVs: EXPERIENCES AND CHALLENGES OF USING ARVs AS A MAN 209
CHAPTER 7 210
EXPERIENCES OF USING ARVs 210
Introduction 210
Men and ARVs 213
Philani Support Groups 217
Experiences of using ARV 226
Treatment narratives: facts or '*performances*'? 239
Conclusions 250
CHAPTER 8 252
LIVING WITH HIV AS A MAN: CHALLENGES AND CHANGES TO MASCULINITY 252
Introduction 252
HIV and problems of being an independent provider 255
Reconstructing masculinity 273
Living 'new' masculinities in everyday life 283
Conclusion 288
CHAPTER 9 289
CONCLUSIONS 289

Discussions 289
Men, masculinities and HIV 290
ARVs and citizenship 293
Health, body and stigma 295
Lessons learned and policy recommendations 298
REFERENCES 303
APPENDIXES 317
Participant profile 317
Participant Information Sheet 336
Informed consent for tape recording 340

DEDICATION

To my parents, Zanemvula and Nowongile

ACKNOWLEDGEMENTS

I wish to thank the following people for their different roles in enabling me to complete this research: My supervisor Prof Deborah Posel for her intellectual support and guidance and for giving me an opportunity to study at WISER and University of Amsterdam. Without her support I would not have completed this thesis.

Anita Hardon, my promoter at University of Amsterdam added a valuable contribution to my research project. I would like to thank her for opportunity to study at University of Amsterdam and opportunities that she created for me to present my research work in international conferences.

The staff at the Rixile clinic where I conducted this research. In particular Mosa and Helen; thanks for allowing me into support groups and trusting me with confidentiality of the information that I collected from your clients. Theunus, and Paul, for allowing me to do research study at the clinic. Support group facilitators; for their patience and negotiating access for me into the discussions groups. For helping with translations where I did not understand and for the informal conversations that I have cited in this thesis.

Rixile clients. For accepting me as their friend and a member of support groups and for allowing me to enter in their private and confidential space without feeling threatened by my presence.

I would like to thank all the 25 men that took part in my study. I was struck by your willingness to share even the most intimate stories about your lives. I wish I can mention your real names but this is not allowed in research. These are people, I think, if we look up at and learn from their experiences, we can defeat the problem of HIV in South Africa.

Wits Agincourt Research Staff: Mark Collinson, Doreen Nkuna, Margaret Shabangu and Rhian Twine, for giving me a space to work and providing logistical support throughout fieldwork.

I would like to thank the Mnisi family for adopting me as their family member for 6 months. During my stay in their home I met several other friends who made Kildare a real home – Tinyiko; Vusi in particular became my close friends. Dudu, my friend and colleague who took care of me and taught me the language and also introduced me to community members who became my research participants. Ndlovu and Induna in particular unselfishly shared with me their knowledge about the social context and culture, which became useful for analyzing my findings. I met both of them through Dudu.

I am indebted to my friend and 'brother', Benjamin Makhubele, for his unending support during difficult times. You made your house a home for me to come back to after demanding and lonely months of fieldwork. You helped me out financially at times and I appreciate that.

My friend Nkululeko Nkomo for emotional support and encouragement and for sharing very interesting ideas and literature relevant to my research. My friend Mzi Nduna who made her house a place to rest after difficult times in the field.

I would like to thank my colleagues at WISER who read some draft of this thesis – Irma Duplessis; Pamila Gupta; and some from University of Amsterdam – Gert Hekma and Josien de Klerk. My friends at the University of Amsterdam, in particular Marie Lindgaard and Damien Raes.

And finally, my brother Sithembele Mfecane, who supported me throughout my university studies and encouraged me to pursue this PhD. Enkosi Mtungwa!

DECLARATION

I declare that this dissertation is my own unaided work. I it being submitted for the degree of Doctor of Philosophy in the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in any other University

CHAPTER 1

INTRODUCTION

The main aim of this thesis is to investigate how the experience of HIV shapes, and is shaped by, men`s notions of their masculinity. I have chosen to examine this issue by focusing on the relatively unusual case of men who have disclosed their HIV status, chosen to take antiretroviral medicines (ARVs)[1] and have stayed on this treatment for a sustained period. Masculinity has emerged recently as an important concept to consider when dealing with health experiences of men worldwide: the ways in which men deal with health has been associated with the ways in which they construct their masculinity (Moynihan 1998). Literature dealing with men`s health shows that when men make decisions about health - such as whether or not use certain health services and when to use them - they take into account how these decisions would impact on their manhood (Courtenay 2000; Moller-Leimkuhler 2002). On the other hand, recent literature focuses on how the experiences of being sick and using health services may threaten certain constructions and practices of masculinity and then prompt men to re-negotiate their manhood beliefs as a response to challenges of being ill (Olliff 2004; Emslie, Ridge et al. 2006; O`Brien, Hart et al. 2007).

This thesis investigates both perspectives, with a stronger focus being on how masculinities are impacted by being sick. In the first instance I am looking at how certain beliefs about manhood shape men's decisions to seek or not seek help for HIV illness, as well as their decisions about HIV testing, disclosure and treatment adherence. Secondly I investigate how these masculinities may be challenged, and then transformed by the experience of being sick, using health services and experiencing certain side effects from using ARVs. By exploring masculinity and health in these ways, this thesis overcomes a gap that currently exists in research work on men, masculinities and HIV/AIDS in South Africa. Much of the research in this area has focused on masculinity as a barrier to responding positively to HIV prevention messages. There is scarcity of research that

[1] These are standard medicines used to manage AIDS and can lengthen one's life. They do not cure but have been shown prolong life when used correctly with good adherence.

focuses on men who are already infected with HIV and using health facilities, to determine the impact of this experience on their understanding and experience of manhood.

The argument pursued in this thesis is therefore twofold. Firstly, I want to argue that in dealing with health experiences of men and various decisions that they make about HIV – such as testing, disclosure and adherence to treatment - we need to consider seriously how they construct and experience their masculinity. Understandings of masculinity impact significantly on health choices that men make (Broom 2004). Secondly, this thesis argues that being sick and using ARVs constitutes a key moment of reflection and change in how these masculinities are constructed and experienced by men. This however does not mean that when men are ill they completely abandon their previous beliefs about manhood. Instead, this thesis focuses on the challenges that men face in needing to change their lives as a response to a life-threatening disease and treatment demands, yet still needing to continue with other practices in order to fit into the category of 'real' manhood as they understood and experienced it before they got sick from HIV.

Central to my investigation of these masculinities and how they shape – and are reshaped by health decisions – are the notions of power, dominance and control. Manhood is usually constructed in most societies, including the society that I studied, as a powerful, dominant and controlling gender and it is perceived to be superior to womanhood. My investigation looks at what happens when a man who subscribes to this notion of manhood becomes sick to the point of being unable to exercise control over his life: What happens to a social position of a man as a powerful and dominant gender? What happens to his manhood when he relies on a woman for his health and emotional support; or when he loses his job and becomes dependent on other people; when he attends support groups that are facilitated by women; or when he can no longer perform sexually due to being ill? What role do ARVs play in helping him restore his manhood, and control that he might have lost from being sick? All these questions acquire additional salience in communities marked by pervasive stigma of being HIV positive.

This study was undertaken at a historical moment in South Africa`s fight against HIV and AIDS. After years of procrastination, the South African government finally agreed to provide free ARVs at public health facilities in 2003. ARVs are powerful drugs and they have changed the face of AIDS from being seen a 'death sentence' to being treated as a chronic and manageable disease (Persson 2004; Robins 2005). In the South African context, the presence of ARVs in public health facilities has a potential to attract more men, a group popularly known for being averse to using these health facilities. This offers research opportunities to investigate their experiences and challenges with ARVs and medicines in general, as well as exploring the entire context in which they receive treatment. Their commitment to ARVs further provides us an opportunity to question some of the existing portrayals of men in the anthropological literature. For example, in her research among men in KwaZulu-Natal, Leclerc-Madlala (1997) reported that men prefer to spread HIV to other people in order not to die alone, rather than try and protect them. She also reports on – and explains – the prevalence of the virgin cleansing myth among men in KwaZulu Natal, who believe that the rape of a virgin will cleanse them of HIV (Leclerc-Madlala 2002). My research findings contradict these observations, thereby inviting us to view men who are HIV positive (at least men in this study) in a different light, as needing to protect rather than infect other people.

Secondly, research on ARVs in South Africa has focussed mainly on women and we know very little about experiences of men. We know more about men as resisters of ARVs than active participants in the programme. The dominant mindset that informs most research and intervention work with men sees them as a problem, rather than part of the solution in the fight against HIV. My premise in exploring male perspectives on ARVs was that we need to shift this mindset and start engaging with men as partners in the fight against HIV (Bujra 2000), recognising that they too are infected with HIV and have certain needs and fears that must be addressed. Too much focus on experiences of women gives a one-sided perspective on ARVs. We need both perspectives in order to develop interventions that are inclusive and address different needs of both genders.

Lastly, the availability of ARVs in health facilities has been associated with the transformation in health care arrangements, from a top-down approach to a more consultative system of care (Biehl 2007, p. 121). HIV support groups in particular are portrayed as a 'conversion' and 'empowering' centre for patients. Most scholars are of the view that the belonging to these support networks locates patients into new categories of citizenships, that are empowered and knowledgeable about their rights (Nguyen 2005; Nguyen, Ako et al. 2007). They draw from their collective HIV identity to lay claims on these rights (Cataldo 2008). According to this perspective, patients who adhere to ARVs embrace HIV as a guiding identity for their life choices. Writing in the South African context, Robin's research work documents experiences of using ARVs in relation to these perspectives. His research confirms that ARV users do indeed become empowered and converted through their commitment to ARVs and belonging to support networks of PLWHA. He argues that these experiences produce new forms of subjectivities – what he calls 'responsibilised' subjects, which become an important catalyst for adhering to ARVs (Robins 2006).

In this study I interacted closely with ARV users outside the clinic context where they received help and attended support groups, to determine to what extent their overall lives and subjectivities have been transformed by belonging to these treatment networks. I argue that rather than portray commitment to ARVs as 'drastically transformative', or support groups as an empowering, conversion context, we should pay closer attention to ambivalences that users may have about their commitment to these drugs and the HIV identity as a whole. Most of my participants were content with using ARVs, but they were not equally content with changing their lives in order to fit into the biomedical model of adherence. They shared personal experiences with using ARVs, attending support groups, and adherence behaviour, which made me to question whether they could be unproblematically inserted into the category of 'converted', 'responsibilised' subjects.

Data to be presented in this thesis is drawn from 14 months of ethnographic fieldwork conducted between February 2006 and May 2007, as part of the larger collaborative project between Wits Institute for Social an Economic Research (WISER) and

Amsterdam School of Social Science Research (ASSR), entitled '*AIDS Medicines in resource-poor settings: Learning from district level transformations in health cultures and care arrangements in Uganda and South Africa*'[2]. The overall aim of the collaborative programme is to 'maximize learning from local level transformations in health policies, health cultures and care arrangements that result from increased access to ARVs in South Africa and Uganda'. Before I expand on the study itself, I will first provide a brief historical background on how I became involved in research on men and HIV. This will illustrate how my previous research experience informed the development of this thesis.

Trajectory

My involvement in research with men and HIV began in 1999 while I was doing post - graduate studies at the University of the Western Cape, South Africa. After completing my degree in 1998, I was awarded a scholarship by the Department of Anthropology/Sociology to conduct an honours research project within a larger programme, on the topic of men and their involvement in reproductive health issues. I had no previous experience of doing research with men, nor was I particularly interested in studying men and HIV. My acceptance of the study grant was motivated primarily by financial needs and an opportunity to further my studies. Having come from a modest economic background I had no other means of furthering my studies after finishing my degree. The scholarship therefore came as a welcome relief.

When I entered the project, I was advised to choose my own research topic amongst the project's several themes. I decided to choose the topic of HIV/AIDS and men, and my choice was motivated primarily by personal observations and experiences. First, as a man living in the informal settlements of KTC (near Gugulethu township) at the time, I knew little about HIV and AIDS, except basic information about its transmission modes and prevention measures that I gained from media and other sources of information. I knew

[2] Fieldwork in Uganda was conducted by M Kyakuwa for her own PhD research project. See Kyakuwa (2009) "More Hands in the Complex ART Delivery? Experiences from Experiences from the Expert Clients" African Sociological Review 13 (1): 143 – 167.

no one in the township who had died of AIDS or living with HIV. HIV was generally a taboo subject in the township and we normally referred to it as '*Amagama Amathathu'* (Three Letters). My decision to do research on HIV was therefore aimed at educating myself further about the virus, and to elicit other people`s views on it.

Secondly, my decision came out of the observations that I made while living in the township, on how men in particular were responding to HIV. I observed that men tended to be silent about HIV. In their conversations about women, sex and relationships, men hardly discussed AIDS. When men talked about HIV/AIDS they did so in a form of a debate that questioned the orthodox scientific perspectives and also raising doubts about condoms as a preventative measure (for example saying that they break; they carry the virus; or, are a means of discouraging sex). It became clear that men did not internalize HIV risks; they viewed HIV as a distant disease that affected a selected group of people, such as prostitutes. There was also a tendency among men to discourage any behaviour that could deter HIV and AIDS, such as having one sexual partner, abstinence or using condoms. Men generally encouraged having multiple partners and viewed it as a necessary way to express their manhood. Even married men that I knew had extramarital sexual affairs and these were not frowned upon in society.

Based on these observations my honours research project investigated men's knowledge, beliefs and attitudes about condoms as prevention against HIV and AIDS. I interviewed men who sought help for sexually transmitted infections (STIs) and other health problems at the public health facility in the Imizamo Yethu Township, near Hout Bay, and others that I met in the community. I adopted an ethnographic approach that took me to local shebeens[3] where I interacted informally with men and asked them questions about their sexual behaviour, as well as attitudes towards HIV, abstinence, monogamy, and condoms. The results showed that men were generally sceptical of HIV prevention messages. Some of my participants disputed the existence of AIDS and they preferred to attribute illnesses and deaths in the community to witchcraft and other misfortunes - such

[3] Shebeens are informal businesses selling alcohol in the township. They operate like a bar where someone buys alcohol and then consumes it inside a sheebeen, often with other people. They are a sociable environment, making it easier to initiate conversations.

as misfortunes that someone could experiences if he did not observe certain rituals. Others expressed strong opposition to condoms, saying they reduced sexual pleasure and were an indication that someone was being unfaithful.

The findings from my honours project encouraged me to pursue the topic of men and HIV in my MA research. It became clear from my honours research that the rejection of HIV messages and condoms by men did not take place in a vacuum but was rooted in a particular understanding of manhood and how 'real' men should behave sexually and in relationships. Men often referred to condoms as 'not good for a man'. Others were anxious that they might lose erection while still putting on a condom and this was seen as an unacceptable situation for a man`s image as a woman might go and publicize his sexual 'failures'. There was also strong opposition to using a clinic for STI`s as men viewed the clinic as 'a place of women' (*indawo yabafazi*). I then decided to explore constructions of masculinity and how they influenced men's response to HIV messages in my MA research. The study was based in Khayelitsha Township where I worked mainly with men who attended a youth programme on sexuality facilitated by the Planned Parenthood Association of South Africa (PPASA). I chatted with them about sexuality, perceptions of masculinity, knowledge about HIV, condoms and safe sex, in both formal and informal ways. I also visited shebeens in Khayelistha where I socialized with other men and interviewed them about their constructions of masculinity and sexual behaviour. From this I made my own observations on how men and women behave towards each other in the shebeens.

My MA project revealed strong association between certain manhood beliefs and responses to HIV messages. The majority of participants subscribed to masculine ideologies that encouraged men to have multiple sexual partners in order to prove their masculinity. From their early teens boys were pressurized by their peers to be in a sexual relationship in order to prove their manhood and gain respect. Failure to do so resulted in someone being labelled negatively as '*isishumane'* (the one who doesn't know anything about women), which made it likely that he would be excluded from peer conversations about women and sex because of his sexual inexperience. On the other hand, terms such

as '*mancula'* (playboy) were positively associated with men who had multiple partners. The above expectations resulted in some men rejecting certain HIV prevention messages, such as having one partner, abstinence, condom use, because of a need to prove their manhood through sex. It was clear from my MA research that masculinity was a significant barrier to practising safer sex and that this contributed greatly to the spread of HIV and AIDS in the townships.

During my MA research I came across other studies on men and HIV in South Africa and elsewhere (Whitehead 1997; Asencio 1999; Makhubele 1999; Wood and Jewkes 2001; Campbell 2001) and they supported my findings, showing clearly how certain constructions of masculinity could pose serious problems to adoption of safe sex measures. These studies confirmed that the problems posed by masculinity to successful prevention of HIV are not limited to Cape Town townships, but are national and international problems. I decided then that when I pursued a PhD project I would build on this previous research experience because of the importance of this topic in the fight against AIDS.

PhD study

I took a break from studies on men and HIV for three years while working as a researcher for Human Sciences Research Council (HSRC). In April 2005 WISER awarded me a PhD fellowship to do a project on the topic of ARVs within a larger programme. I decided to focus on men and further pursue the topic of masculinity and its impact on HIV health behaviour. My view was that 'if masculinity poses problems for responding positively to HIV prevention messages, there is a need to explore how it impact on responses to treatment messages'. Based on my previous research experience, I was convinced that men would reject ARVs for a number of reasons.

Firstly, successful use of ARVs requires total commitment and strict discipline from patients. It involves taking medication everyday indefinitely, and adopting healthy lifestyles. My first assumption therefore was: if masculinity is generally achieved through

acts of indiscipline - for example excessive drinking and having multiple partners - commitment to ARVs would not suit men. Instead, men would perceive ARVs as an inconvenience to their lifestyles.

Secondly, ARVs are only accessible in public health facilities that are dominated by females. Research has shown that men are generally reluctant to use public health facilities even when they are seriously ill (Courtenay 2000). Men feel that if they use these services it would send a message that they are weak and emasculated. I therefore felt strongly that men will resist ARVs if they are only accessible in public health facilities because such non-use would enable them to escape these negative judgements. Men would be concerned about their image and how it would be undermined by seeking help in the presence of women. Thirdly, ARVs have serious side effects for all users. These side effects can impose severe limitations on someone`s life (physically and socially), and they can also make it difficult to perform certain tasks expected of men - like work, sex, and others. I assumed that men would be threatened by the knowledge of these side effects and then shun ARVs. Those who use them would interrupt their treatment or even discontinue their medicine because of unbearable side effects.

With these assumptions in mind I began fieldwork in February 2006. My initial research question was: 'to what extent do constructions and practices of masculinity prevent men from using ARVs?' The first phase of my research was exploratory and it was aimed primarily at gaining the background knowledge about the study site, men's lives and their attitudes towards HIV and ARVs. I lived in Kildare village near Mkhuhlu, and I travelled everyday (50km`s) to the ARV clinic at Tintswalo hospital, where I attended support groups of People Living with HIV and AIDS (PLWHA). Through inhabiting these two worlds of Kildare and Tintswalo I learned much about men and how they normally deal with health, as well as how as a group they are responding to HIV messages and ARVs. The dominant response that I received when I spoke to community members and health workers about male health behaviour was that men are generally not in favour of using public health facilities and pharmaceutical drugs. When men are sick they either self-treat or consult local traditional healers who normally prescribes traditional medicines. It is

rare for a man to be seen in public health facilities. One community member that I interviewed informally described men in this way:

> You see, if you see a man in clinic then you must know it's too bad for him; he is really sick. And most of the time he will be driven by a wheelbarrow... you know, men have this saying that '*kungcono ngife'* (I would rather die). If he says that, then you know he is not going (Informal conversation community member Kildare, 4 March 2006).

When I enquired about the reasons for reluctance to use health services, notions masculinity emerged immediately as problematic. Participants said men are socialized to view themselves as a strong and healthy gender; therefore to be seen in public health facilities implies that they are weak and emasculated. This was put clearly by one of my informants who lived in Kildare, when he said: 'The thing, it also relates to the ways we were brought up. Guys are brought up not to acknowledge being sick. When they are sick people want to deny it and look strong'. His views were equally shared by his friend who added:

> …yhaa, like you don't want to appear weak; you want to look strong…Now if you go to the clinic you start appearing weak…Like if someone has a minor pain he feels he can't take it to the clinic; it must be something serious (Informal conversation community males Kildare, 19 April 2006).

Another participant, a community leader and a former teacher, made a direct link between seeking medical help and losing masculinity, when he remarked: 'they feel that their manhood is weak' (Informal conversation community male, 12 June 2006). Comments like this seemed to confirm my pre-fieldwork assumptions that men would not respond positively to ARVs because they pose a challenge to their manhood. However, it was not long before these assumptions were challenged in a way that completely changed the focus of my thesis.

While attending support groups of PLWHA I met a group of men who acted contrary to these descriptions of men and their apparent approach to health. These men had

undergone an HIV test and the result was positive, then they enrolled for ARV treatment at the HIV clinic. Contrary to the belief that men are embarrassed by being sick and using health services, these men appeared to be at ease with their presence at the clinic. They were active in support group discussions, which are dominated by women. I met Tito[4], one of them, on my first day of attending support groups. He was taking the register of patients who were in support groups; he sat on the front seat next to a facilitator and appeared to be comfortable among other patients. Later, when support groups discussions were finished, Tito distributed small food parcels to other patients. He later told me he was doing this voluntarily as part of his commitment to the clinic and a passion for helping other people.

Other men were not as active as Tito, but through their body language and active participation in group discussion I deduced that they were equally comfortable at the clinic. Khaya, one of them, was sitting comfortably in the back row, wearing a Kaizer Chiefs T-shirt and a cap (Kaizer Chiefs is a popular soccer team in South Africa); his arms spread across two chairs (both arms) to indicate his familiarity and comfort in the support group. He made little contribution during discussions, but when a topic about safer sex was initiated he became animated and commented jokingly, saying:

> No, I think we (HIV +) men should not have sex anymore. Because we have already caused a lot of damage! [Laughter]...I mean, if you are having sex what are the chances that you will not use condoms (Support group observations, 24 February 2006).

For four months I interacted with these men informally while still waiting for ethics approval from Wits University to conduct formal recorded interviews. During this period I learned that most of these men were fully committed to treatment: they were using medicines every day as prescribed by a doctor and said they stopped drinking and smoking because of their commitment to ARVs. For example, in the four months that I had known Tito and Khaya, both men never missed an appointment date. Khaya lived far

[4] Participant`s names have been changed to protect their confidentiality. The names of the villages and clinics have not been changed.

away, but he was always among the first patients to arrive at the clinic and would stay longer to socialize after receiving his treatment. He told me:

> I like coming here; here is like home to me. I mean this support group! The support group gives me life (*isupport group iyangiphilisa*)…I like coming here and interacting with people and helping others (Informal conversation Khaya, 16 March 2006).

I was struck by this response because, as far as I knew from previous research and informal conversations with other males in the community, men were supposed to detest public health facilities, particularly because they are dominated by women. And here Khaya is embracing it and calling it 'home'.

I decided to focus on these men who were using the ARV clinic and adhering to treatment as my main research participants. Their behaviour raised three critical questions. First, if men are generally opposed to using health facilities, as my informants indicated, what prompted these men to use them against this norm; how did they arrive at decisions to come to the hospital where other men don't go? Secondly, what has enabled these men to embrace ARVs and support groups? Thirdly, if these men are using health facilities against the norm, something must be said about their masculinity: is their masculinity challenged because of using these facilities, in the presence of women; or does it get strengthened? How do they feel about their masculinities as men who are sick, using lifelong medicines and being unable to perform certain tasks due to being ill? What about the fact that these men are treated by female health workers? Does if somehow affect their manhood?

Through a fieldwork process that spanned a 14 month period, I explored these questions in greater details with 25 men living with HIV that I met from support groups of PLWHA at the Rixile clinic. They shared with me their life experiences before and after testing HIV positive; the everyday challenges of using ARVs; adherence behaviour; and how the experience of living with HIV and using ARVs impacted on their lives. The narratives are rich and complex, but provide us with an idea of what it means to be a man living

with HIV and how certain ideas and practices of masculinity impact on decisions to seek help, do an HIV test, disclose and use treatments. Most importantly, what I learned from these interactions was how an experience of living with a chronic disease can enable a man to reflect in a critical manner on what he previously took for granted as being a definer of his manhood identity.

This thesis therefore departs from analysis of men and HIV in South Africa, including my own previous research work that I referred to above. Rather than focus only on masculinity and how it prevents men from responding positively to HIV messages and using HIV services, I am also looking at how masculinity itself may be transformed by the experience of being sick and committed to treatment. I hope that this line of enquiry can shed further light on how masculinity is achieved and then lost, and then regained through having access to lifesaving drugs, ARVs.

The next section contextualizes this study within the situation of AIDS in South Africa, focusing specifically on politics that have shaped government`s responses to the epidemic. These politics cannot be overlooked when doing research on HIV and ARVs in South Africa.

Background and context: AIDS as a political issue in South Africa

The mass rollout of ARVs in South Africa was approved by cabinet in 2003 as a response to the growing numbers of people living with HIV in the country and deaths attributed to AIDS. Since the early 1990`s, South Africa witnessed dramatic increases in HIV prevalence from a mere 0.8% in 1991 to about 22.4% in 1999 (Whiteside and Sunter 2000)[5]. The apartheid government did not do much to deal with it (Ramphele 2008), resulting in HIV prevalence more than doubling in the post-apartheid era (from 1994), and making AIDS a major health and development threat in the country. South Africa now has a dubious reputation of being a country with the largest numbers of people living

[5] These stats are based on women attending antenatal clinics. It was only in 2002 that the first survey results were released by HSRC, which were based on nationally representative sample (HSRC 2003).

with HIV and AIDS in the world (UNAIDS 2008). About 10.9 % of South Africans were living with HIV in 2008 (HSRC 2009).

Before the cabinet's decision to provide ARVs in December 2003, the government's approach to fighting AIDS lacked urgency required to deal it. Under the leadership of former president, Thabo Mbeki, the government refused to offer ARVs as part of the state health intervention for a long time, citing affordability, toxicity and sustainability as the main reasons. The main argument was that the efficacy of ARVs in prolonging lives was not yet scientifically proven (despite contrary evidence from other countries that already provided ARVs), and that the government could not afford to roll out a national treatment programme. Mbeki himself was not passionate about ARVs; he preferred an approach to dealing with AIDS that focussed on prevention and took into account its socio-economic dimensions, such as poverty (Ramphele 2008). This approach was inspired mainly by views of a certain group of scientists - so-called 'AIDS dissidents' - who denied the viral origins of AIDS and rather explained it as being a consequence of poverty, malnutrition and other developmental challenges (Mbali 2003).

Mbeki`s approach to AIDS did not take place in a vacuum. Rather it followed a series of other controversies that characterized AIDS management in South Africa since the inception of democracy in 1994. These controversies are documented in the writings about Mbeki and government response to AIDS by authors such as (Fassin 2007; Roberts 2007; Gevisser 2008) and others[6]. These authors, while disagreeing on whether Mbeki was right or wrong in questioning the orthodox scientific perspectives on AIDS, seem to share one common observation: AIDS in South Africa is a political issue. This means that while there may be certain biomedical and scientific 'facts' that are agreed upon about the disease - including the existing scientific data on the magnitude of the problem; modes of transmission; what are the key driving factors; best known methods of treatments, etc - the reading of these 'facts' and subsequent intervention programmes that follow, are highly influenced by certain political agendas and other identity politics that different stake holders want to pursue.

[6] Shisana and Zungu-Dirwayi 2003; Posel 2005; Robins 2004).

Gevisser`s analysis of the government`s approaches to AIDS focuses mainly on the management of AIDS in South Africa as a political issue. He takes us through the processes involved in strategizing about AIDS pre-and post 1994, as well as what was at stake for the country at a time. He shows that AIDS presented a precarious situation for the newly elected government:

> This was the era of birth of democracy, of the emergence of a life force out of the cavadier of apartheid, and yet here were portents that the fear of death – rather than the celebration of life – would drive the country into the future (Gevisser 2008, p. 732).

In particular the liberators themselves were the key suspects as they came from other Africans regions that were already heavily affected by HIV. The stigma that surrounded AIDS at a time and the fact that AIDS is transmitted primarily through sex - particularly promiscuous sex - made it even more difficult to confront.

This state of affairs resulted in a situation where scientific 'facts' about the disease did not have much influence on the government responses. What mattered the most was how to respond in such a way that certain political agendas are achieved or the perpetuation of certain stereotypes about Africans were averted. At stake for the government was to build a positive image of Africans and affirm their right to self-determination - including finding their own solutions to their problems. Part of this entailed avoiding topics that perpetuated negative views about Africans, such as sex. In this respect Gevisser focuses on Mbeki`s 'lifestyle' explanation for AIDS (as opposed to sexual explanation) in which he attributes the spread of the epidemic either to being poor or being rich too quick. Gevisser views this as an attempt by Mbeki to evade questions about sexuality that are at the core of AIDS because they would destabilize his political project:

> This is a far safer ground than having to wonder about the workings of sexuality, and the reasons why people cannot – or will not – change their sexual behaviour, even if they do know that they would be saving their lives in doing so. If we are dying because we have too little (or too much, too quickly), then Mbeki`s prevails. If, on the other hand, we are

> dying because we cannot control our primal urges, Mbeki`s own libratory paradigm is shattered. We are the Africans that our colonial oppressors said we were, and we had not been able to liberate ourselves from their definition of us (Gevisser 2008, p. 231).

Posel (2005) deals specifically with this tendency of Mbeki to evade referring to sex when dealing with HIV. She wonders why Mbeki refuses to talk about sex in a context where sex has become an openly debated and publicly contested affair. Posel (2005: p. 145) sees the debate about HIV as transcending the topics of sexuality to those of nation-building such that 'the debate about HIV/AIDS becomes a reflection of the national identity and values of the national subject, along with the moral character of the nation'. This is what makes it difficult for Mbeki to confront sex – particularly sexual practices of black men - as a cause of AIDS, because it reflects badly on the nation:

> The symbolic association of nationhood with order rather than chaos, life rather than death, with sexuality at the fulcrum, is at the very heart of Mbeki`s imagery of nation-building – with a particularly strong evocation of the forces of chaos and death which threaten to destroy the fledging nation at the very vulnerable moment of its birth (Posel 2005, p. 146).

There are however deeper political and social issues that we cannot overlook when trying to make sense of Mbeki and his government`s handling of HIV, as well the responses of his critics. These issues are explored in great detail in Fassin (2007). Fassin situates the AIDS 'dispute' within a South African social and political environment that is still characterized by racial and political divisions, as well as heightened social inequality and cultural differences. Hence when different parties enter the AIDS 'debate' they have different vested interests and some of these interests may have nothing to do with their need to improve the situation of the affected people. This is clear from the way in which different political parties may use the AIDS 'platform' to discredit each other, either as 'incompetent or uncaring' (as seen in the DA`s criticisms of the ANC government)[7] or 'racists' (as seen in the ANC criticism of the DA); or the media and academics using it to

[7] DA (Democratic Alliance) is a leading opposition party in South Africa and ANC (African National Congress) is a ruling political party.

label and judge Mbeki as 'unfit' (Roberts 2007). AIDS drug lobby groups and pharmaceutical companies also enter the debate with their own interests, and so do patients, doctors and traditional healers.

The disputes over traditional medicines and their role in the fight against AIDS present a good example of racial politics concerning HIV in South Africa. Traditional medicines are used by up to 85% of the population – mainly black Africans - as a first step to address health problems (DoH 2004). As part of recognizing this practice the government has incorporated them as a strategy in combating AIDS, alongside ARVs (DoH 2004). The reception of the public has however been mixed, with race being the mediator of these responses. For example, in response to a newspaper article reporting on the plans of the Kwa-Zulu Natal health department to incorporate traditional medicines, a blogger wrote:

> Only a few blacks in Africa understand the white man`s medicine and science. The rest are total primitives, and this does not exclude those who hold high political office…If you were to ask a western chemist to demonstrate why a disprins work, he would be able to show chemically how the medicine works in the human body. NO traditional healers' remedy can stand up to this type of test. Yet, these primitives keep going to these witch doctors and taking their poison (Cullinan 2008, p. 11 of 23).

Clearly then, in an environment where racial politics dominate public discourse and responses to health interventions, it is difficult to implement a programme that satisfies all stakeholders. The government has done its part to demonstrate its allegiance to orthodox approaches in recent years, including announcing publicly that its interventions are based on the premise that HIV causes AIDS, as opposed to earlier times during Mbeki`s active involvement in the AIDS debates, when this was not clearly articulated. We have now seen more concerted efforts in the fight against AIDS that involve all stakeholders who seem to speak with one voice in their commitment to fighting the epidemic. There is an updated National Strategic Plan for South Africa (2007-2011), the main target of which is to reduce new infections by 50% by 2011 (Matjilai, Hooseni et al. 2008). The ARVs programme has grown remarkably over the years since its inception in

2004, with an estimated 43 % of patients in need of ARVs receiving them in 2007, an increase from 36% (Matjilai, Hooseni et al. 2008). The backlog is still large but it is an indication of how late the government started, rather than a lack of commitment to provide ARVs.

The challenge now faced by the government and other ARV implementing partners is how to deal with resistance towards ARVs that comes from potential users themselves. This resistance is informed by the stigma associated with HIV and AIDS, which makes it difficult to freely access ARVs in public health facilities even if they are within easy reach. The problem begins with testing, because when someone tests HIV-positive he may be negatively labelled and judged, and that makes it difficult to seek further help (Mills 2006). Steinberg`s (2008) research in a rural village in Lusikisiki, Eastern Cape, shows how even in situations of desperation some people are still reluctant to test and then access ARV due to the prevailing stigma assigned to the disease. Others are questioning ARVs on racial terms, preferring to use traditional medicines.

The above discussion does not exhaust the context and politics of AIDS in South Africa. I hope that in this brief account I have provided enough background to demonstrate that AIDS in South Africa is more than a medical issue; it is a political issue and research must be conducted with an awareness of this. In this study, however, I did not dwell much on national politics on AIDS. I focused mainly on the local politics, particularly politics of identity and health, and how these intersect with stigmatisation of AIDS. This approach has enabled me to overcome the simplistic approaches to studying men where in most cases they are labelled as being in denial for refusing to test, disclose or use ARVs, while in fact there are deeper political and ideological issues that inform their various health decisions.

Methodology

Bushbuckridge: the study site

Bushbuckridge is a suitable context to undertake this study for a number of reasons. Firstly, over the years the Mpumalanga and Limpopo provinces where Bushbuckridge is located has experienced a rapid increase of HIV from 1.7% in 1992 to about 25 % in 2003 (Kahn, Tollman et al. 2007). When this study was conceived in 2005 the HIV prevalence in Bushbuckridge was approximately 16% (based on estimates made in 2000). The latest statistic (2007) is 24.6%, up from 21% in 2006 (Kahn, Tollman et al. 2007). In addition to this there has been a significant increase in deaths in the surrounding villages, coupled with a rapid decline in life expectancy. The Wits Agincourt Research Unit, which conducts annual household surveys (in 21 villages) on life and death trends, reports a rapid decline in life expectancy of 12 years for males and 14 years for females since 1997 (Posel, Kahn et al. 2007).

Secondly, the ARV programme had not made much impact in the region before I started this fieldwork. In 2005, 3000 people were receiving treatment from a public health facility. Another facility in Tintswalo hospital did not provide ARVs to the public until August 2005; its ARV programme was privately funded and therefore available to a select few. The fact that only a few people were using ARVs meant that we did not know much about the experiences of users and how much impact ARVs had in their lives, and men in particular were missing from the analysis. I was also interested to know how people - users and other community members - felt about using ARVs in comparison to other measures that they usually relied on to manage health (like traditional medicines).

Lastly, as an anthropologist this site offered me an opportunity to experience a new cultural environment. I originate from the Eastern Cape Province and have spent most of my life amongst Xhosa speakers in Eastern Cape and Western Cape provinces. My previous research as indicated above was conducted in my own community of Xhosa speakers, though my work at the HSRC involved doing research in other cultural settings,

albeit short visits. The opportunity to do a research project in another cultural setting, therefore, enabled me to build on my previous research in a way that added a cross-cultural perspective on the topic of men, masculinities and HIV.

Demographics

Bushbuckridge Local Municipality was established in 2000 'after the amalgamation of three former Transitional Local Councils of Northern and South Midland' (Business Trust 2005, p. 4). Before then it encompassed the 'homelands' of Gazankulu and Lebowa: the former was 'home' to Shangaan speakers and the latter to SePedi and Northern Sotho speakers. Currently the area is populated by an estimated 500 000 people, in an area that covers 2 123 km2. The majority of the population is women and young people (females comprise 53% while those aged under 40 make 72% of the population). Black Africans make up the largest portion of the population in racial terms and whites are the minority. There are 133 rural villages dispersed amongst four main settlement areas, namely Mkhuhlu, Bushbuckridge Town, Acornhoek and Thulamahashe. The language compositions of these villages still reflect the ethnic segregations of the past where certain villages are dominated by Shangaan speakers and others by sePedi/sePulana speakers. There is however, less emphasis on ethnically defined groups in the areas closer to commercial centres, such as Acornhoek.

In terms of infrastructure there has been a reasonable improvement in recent years. There are three hospitals, seven health centres and 57 clinics. There are 207 primary schools and 112 secondary schools, and one tertiary institution (IDP 2008). According to the municipal IDP these services are accessible within a 5km distance prescribed by the government. This increased access to infrastructure however, does not automatically translate to its use by locals. Clinics remain underutilized as some people continue to use other treatments options, such as indegenous medicines and other spiritual healing systems, such as churches. In most cases, when people are sick they prefer to use health facilities that are distant from their own homes in order to safeguard their privacy and

confidentiality. During my fieldwork men were cited as being the most difficult group to reach in terms of health interventions. Reasons for this form a central part of this thesis.

The same under-utilization of public services is also seen in relation to education facilities. During my stay in the region I was struck by a high numbers of young people who do not attend school and who have not finished matric (grade 12) for various reasons. For girls the main problem is pregnancy; for boys it is either peer pressure to work or a sudden disinterest in education, or because they have impregnated a certain girl and must therefore look for work to support a child or pay the 'damages'. This trend is reflected in the current statistics on education in Bushbuckridge: according to the Bushbuckridge IDP (2005) an estimated 17% of the population is illiterate while the majority is only able to read and write. Very few proceed to get matric and even fewer achieve tertiary education.

Remittances are a dominant source of income for the majority of the people. Most people, particularly men, work outside Bushbuckridge, either in big cities such as Johannesburg or in other smaller nearer towns such as Sabie, Nelspruit and others. Most of them do unskilled work because they have low educational qualifications. Tourism and agriculture form part of the local economy and government provides approximately 33% of all jobs. The overall unemployment rate is estimated to be at 85% and affects mainly the youth (IDP 2008).

Participants[8]

Participants who took part in this study (25 men aged between 28 - 50) reflect the demographics of Bushbuckridge that I have outlined above. All of them come from a poor background and have low educational qualifications. Only one person completed matric; two could not read and write and the rest are literate or semi-literate. A total of 23 men speak Shangaan as a home language and two speak SePulana, a local dialect of SePedi. All of them are fluent in isiZulu, which is spoken by the majority of people in the

[8] See appendix for a brief biographical description of each participant

district. The isiZulu was our medium of communication as I was not fluent in Shangaan and SeSepulana at the start of fieldwork.

Their employment history is similar to most men in the region who are not educated: from late adolescence most of them left Bushbuckridge to look for work in Johannesburg and other nearby towns. With little or no education they found jobs as unskilled labourers either in mines, on farms, in construction companies or in other industries. Of all men that took part in the study only two have no history of migrant work. One of these two men, who has matric, was employed locally as a teacher and at the time of his illness he worked at a retail store in Bushbuckridge. Another participant was physically disabled, therefore could not leave home to look for work; he was supported by the government through a disability grant. During the research all participants were unemployed as a result of being sick from HIV or because of a voluntary decision not to return to work after recovering from TB and or other HIV-related opportunistic infections.

The participants' statuses as parents also reflect the issues faced by the majority of men in the district. All of them have at least one child and most of their children were conceived outside marriage. Of all 25 participants only two said they had their first child within marriage. This situation is common in Bushbuckridge and reflects both a decline in marriage rates as well as serving as an evidence of increase of sexual activities outside marriage at a younger age (Richter and Mlambo 2005). For example, Magwa, one participant, has eight children from three different mothers; he married one of them and then later divorced her. Only six of my participants lived permanently with their children during the research. The children of the others were cared for by family members and or the mother of a child. HIV illness was the main reason for not living with children, but some had never formed a family with their offspring either before or after the illness.

I met and recruited all participants at Rixile clinic, one of the two sites in Bushbuckridge that provide free ARVs. The Rixile clinic was founded in 1999 as a Rural AIDS Initiative of Wits School of Public Health. The demographics of the clinic clients reflect those of the general population I have described above: About 19.7% of clients have no education;

9.3 completed grade 12; and only 1.6% have a tertiary education. More than 85% are unemployed and only 9.9% are salaried workers (Radar 2005). Women are the majority users of the clinic, accounting for two-thirds of the clinic population (in December 2008 the clinic recorded a total of 6638 users; 2381 of those are men and 4257 are women).

The rollout of ARVs in Rixile began in late 2005 following approval by the provincial government to provide free ARVs to the general population. Prior to this period ARVs were provided to a limited number of clients through private donors. The availability of ARVs saw a significant increase in the number of clients. Since 2005 a total of 3137 people have received treatment from the clinic; by December 2008 2654 patients were receiving treatment (822 are men and 1832 are women). As an indication of this demand, the clinic operates for a full day everyday from Tuesday to Friday (Monday is a filing day). Patients start queuing up from as early as 4:30am and the last patients may leave as late as 6pm or later (they must also queue for pills at the dispensary). The staff often complained privately to me about the load increase, saying they do not get enough rest.

Methods

Participants were recruited and interviewed through the use of ethnographic methodology (Ager 1980; Babbie and Mouton 2001). Ethnography is considered an appropriate methodological approach to study sensitive and secretive topic, like AIDS. In anthropology, ethnography is a highly valued approach to research because it immerses the researcher into the lives of the study participants in order to learn their ways of life and, subsequently, gain an *emic* (insider) perspective into events. This does not mean that a researcher comes into a research context as a 'blank slate' or that he shuts off his own cultural beliefs and knowledge during fieldwork. Indeed, it is in recognizing the 'baggage' that he brings into the field - such as his gender, age, and cultural upbringing - in a reflexive manner, that enables a researcher to produce fair and unbiased accounts about the studied situation (Davies 1999; Bourdieu 2003).

As an outsider in Bushbuckridge, who researched a sensitive topic, I found it important to adopt an ethnographic approach, first as a way of learning about people's everyday lives and belief systems and how these impact on health behaviour; and secondly, as a way of creating rapport with my male participants and other support group members. Hence, between February 2006 and April 2007 I lived permanently in the region, first in Kildare village near Mkhuhlu and later at Wits Rural Facility near Hoedspruit. My initial plan was to first live in a Shangaan speaking area for 6 months and then move into SePulana speaking area for another 6 months to gain perspectives in both cultural settings. Unfortunately this plan was cut short because when I moved into SePulana speaking area near Acornhoek in August 2007, my house was burglared. I then decided to abandon the plan and went to live at Wits Rural Facility, approximately 18km from the Tintswalo hospital.

I adopted participant observation as a strategy to recruit and solicit data from my participants. Participant observation is a hallmark of an ethnographic enquiry (Davies 1999). The approach, as I used it in this study, entailed attending support groups of PLWHA at Rixile clinic for a period of 14 months. These groups were established in 1999 by PLWHA as a response to a need to educate and support each other about positive living in the absence of treatment (Interview with focus group facilitator, 30 August 2007). Support groups are a common occurrence for people living with HIV and they have been credited by certain authors for their role in subverting HIV stigma and imparting a positive identity on the affected people (Whittaker 1992; Robins 2005; Steinberg 2008). They also become a 'community' in their own right, with their distinct set of rules and certain behavioural expectations from their members. In Bushbuckridge these groups were established at a time when AIDS was seen by many people as a shameful and embarrassing disease. As a result most of the infected people were very discrete about their condition and did not acknowledge that they had contracted the virus.

During my informal interview with one of the support group founders she shared her own experience of the stigma that prevailed at that time:

> ...it was my first time to come to Rixile and I didn't know where the clinic was...so I was looking around trying to find it when I came across this nurse. I felt 'Ok I can ask this nurse'. I said 'Sorry *Sisi*, do you know where I can find the HIV clinic? She looked at me in a sort of a puzzled way, and then she came closer, and whispered 'No...We don't use that word "HIV clinic"; we call it "Medical Clinic".

She then shared how stigma shaped the nature and form of support groups:

> We would sit...say maybe we are discussing and there is a knock on the door; I would go and open the door slightly just to see who is there, and then I ask 'Can we help you?'. If she is one of us I open the door, otherwise it`s not allowed (Informal conversation support group facilitator, 30 August 2007).

My entry into support groups followed a long process of negotiations with the management, support group facilitators and then clients. I first met with the clinic manager in August 2005 and requested permission to do a study at the clinic the following year. The manager then advised me to submit a summary of the research proposal and an interview guide, which he used to review my request. Following this, he introduced me to the support group facilitator who made her own assessment of the proposal and whether I should be allowed into the discussion groups.

The next step was to negotiate access with the clinic clients. This process was facilitated by a support group facilitator who first met with patients every morning before support group discussions started. Then she introduced me in *absentia* and sought their permission for me to enter and observe the activities. This was to ensure that clients were not pressured to accept me. Since none of them objected to my request I was invited to join in the group and take notes. Throughout the 14 months of fieldwork no one refused me entry into the groups and as fieldwork progressed they became familiar with me and these formalities became redundant, though we still followed them each time I wanted to join group discussions.

Through attending support groups, I identified and recruited 25 men living with HIV and using ARVs from the Rixile clinic. There were no strict criteria for inclusion, except that someone is HIV positive and using ARVs, aged above 18, and is willing to share his personal experiences of living with HIV. My initial bias was towards younger male clients; however at the clinic there were few of them. I then decided not to have age limits. Thus the age range of participants is 25-52. The recruitment process entailed a brief introduction of the study and the roles that participants would play. This was followed by an explanation of their rights to refuse, and an assurance that their refusal to take part would not affect their services from the clinic or a relationship with me. In most cases this process was redundant as most people were already aware of my research and some men approached me voluntarily to find out if they could participate. Of the 30 men that I approached none refused to participate. However, recorded interviews took place with 25 men; others proved difficult to follow-up after agreeing to participate.

All interviews followed a long process of building rapport. I first interacted with participants informally at the clinic and then visited them at their homes, before conducting formal interviews. We typically began by chatting informally about life in general, covering such issues as boyhood/manhood, relationships, and sport, before entering into discussions about HIV. While I made my research intentions clear during the introduction and recruitment, I found it appropriate to initiate the research process by first covering less sensitive topics and creating familiarity between myself and participants. This interviewing approach proved a useful strategy to gain data on a sensitive and secretive topic of HIV and AIDS. It allowed me to build familiarity and trust with men and their families that enabled an easier flow of information sharing during formal interviews. All participants were comfortable with tape recording because of familiarity with me as a friend and informal member of support groups. The boundaries between my position as a researcher and a friend were often blurred in some situations, as men and I shared stories about lives as men, and experiences of living in South Africa and growing up in rural areas.

This ethnographic approach further served as a useful validity check to data gained through formal interviews. As noted by Ager (1980, p. 70) '...people have different sides to themselves that they display under different sets of circumstances, making it essential to see group members in different situations, not just during a brief interview'. By visiting participants at their homes, I had an opportunity to observe how they interact with family and the community and to confirm what they shared in formal interviews. Thus I structured each formal interview on the basis of what I observed and learned from informal encounters. While I had themes that I developed for all interviews, I placed an emphasis on different aspects, based on my knowledge of each individual and his circumstances. For example some men don't have sexual partners; there was therefore no point in asking about sexual performance. Some live alone; this made it irrelevant to ask questions about whether or not they were receiving treatment support within a household.

Later in the research process I extended formal interviews to the participant's families and their partners. I initiated this process in order to get a better understanding of the context in which men lived and made important decisions about their lives. Family members and partners were asked to talk about men and how they are doing on treatment (adherence), to provide histories of how they as a family addressed his illness and motivations for these choices, and what kinds of support they provide to ill men. Most importantly I decided to include partners because of the growing recognition in gender research that that we cannot study gender issues from a perspective of one sex (Khunou 2006). Gender is widely recognised as a relational issue, therefore needing us to seek for perspectives from both sides. In this study it was important to talk to women on how they feel about their partners who are HIV positive, unemployed and sick, and how they make sense of their situation in relation to their own expectations of their gender roles. Families also play an important role in defining what it means to be a man, as noted by Khunou (2006).

In total, I interviewed twelve family members; six of them were partners and another six were either a biological mother or a sibling. They were all recruited via a male participant, who spoke to them on my behalf and asked if they would be willing to do an

interview with me. All of them already knew me, so they freely agreed to be interviewed. Unfortunately, my attempts to include family members proved less successful as I only formally interviewed a tota of twelve people. This was due to the fact that some men lived alone without partners, family members living too far away, or because he has not disclosed his HIV status to his family or partner. The dominant focus of the study, however, was on the experiences and perspectives of the men themselves, and the majority of my time was spent with them.

Reflections on fieldwork

The ethnographic approach used in this study proved a useful way to research a sensitive and secretive topic, HIV and AIDS. Being in support groups gave me an 'insider' perspective into everyday challenges that PLWHA faced in using treatment and living in a society that still stigmatizes them. My presence as an observer seemed to have no impact on the content and structure of discussions, as I found people to be open and freely shared their most intimate stories even in my presence. I was struck by this as I had expected that my presence would somehow interfere with openness and general willingness to share.

I attribute this openness primarily to the fact that I was an outsider in Bushbuckridge, from the Eastern Cape. As such, I knew no one in the community; I was therefore not perceived as a risk person who may disclose someone`s results to other people in the community. This fact was made clear by the way the facilitator introduced me during early days of fieldwork. She first told the participants who I am and what my purpose of attending support groups is. Then she concluded the introduction by emphasising my 'outsider' status, saying '...he comes all the way from Eastern Cape. He came just to listen to you. And he doesn't know anybody here; so don't be worried about him'. Being a black South African man who understands local languages also worked in my favour in support groups as my presence interfered less with normal flow of activities. I needed no translator and this made my presence less noticeable during discussions. There were certain times in which I was mistaken as being a patient myself (by certain patients who

came late after I was introduced, new staff, and visitors who came to distribute food) due mainly to being black African.

The openness of my male participants struck me greatly. When I conducted my exploratory fieldwork in August 2005 I received strong warning from other researchers and health providers about problems that I may encounter in working with men. Men were described as a 'problem' and a 'very difficult' group to research, particularly on HIV and AIDS issues. I was told that men are generally absent from public health facilities and that those who use them are uncooperative. It is easier to attribute men's openness to the fact that I am also a man. This would however overlook the background work that I undertook to build rapport and trust with participants. This background work conferred on me a position that Goffman (1968, p. 41) calls the 'wise'. According to Goffman 'wise' persons are 'the marginal men before whom an individual with a fault need feel no shame nor exert self control, knowing that in spite of his failing he will be seen as an ordinary other'. He is viewed as being different from the rest of the society, which is generally holds antagonistic attitudes towards those with a 'fault'.

My position as the 'wise' was made clear through certain comments made by participants on how they perceived me in comparison to other community members. During one of those conversations I was walking one of my participants to the gate after he came to visit me. We were talking about life in the village and his experiences with ARVs when he suddenly changed the topic and said:

> You know, I like talking to you…you are not like those boys who stay in my neighbourhood. You don't judge me. Those people don't understand me; they just don't understand me, and they like teasing me....Just one day I was walking past and they were *braaing* some meat. You know what they said...they said 'Hey you Spinach (referring to his eating healthy food), come and eat meat with us; stop this Spinach of yours!' You see, that hurts, but those people know nothing...one day when they get sick themselves they will realize what I'm going through (Informal conversation Zita, 11 July 2006).

And during one of my visit to one of my participants, Joe, he made the following comments, as I was about to leave his place:

> You see, I always feel good when you are here (*ngiyaphila ma u la*). You see, in these rural areas that we stay in people always laugh at us; they say we will die soon. But seeing someone like you...you are educated but you can come and stay with us at the support group; be amongst us. Now you are here…the fact that you are here means that even if I die *ungangingcwaba* (you will bury me). You can't come here while I'm still alive and yet not come when I'm dead (Informal conversation Joe, 4 May 2006).

These conversations indicate that unlike other men in the community I was perceived by these men as sympathetic and less judgmental of them. This enabled them to be open and free to share their experiences with me.

The downside of being too close to my participants was that it created dependence on me as their support person. Most people did not have friends and families with whom they openly shared their experiences with HIV. Thus I became their confidant. For most people, sharing with me was cathartic; it relieved pain and stress that they normally experienced, as expressed here by Mathe immediately after our 2 hour interview:

> You know, I feel like something has been taken away from me; just talking to you...You see; we don't normally talk about these things to other people because they judge us. But with you...I feel much better (Informal conversation Mathe, 2 February 2007).

There were also ethical difficulties involved in these dependent relationships. One of my participants who became my close friend used me as his treatment supporter because, according to him, his family 'abandoned' him. As a result when I left fieldwork he stopped his treatment because there was no one to support and encourage him. I returned to the clinic in August 2007 and was told he has been asking for me and that at one stage he stopped treatment and then got ill. When he heard that I was back he rushed to the clinic to look for me, looking weak and sick. In our conversation I asked why he stopped

treatment and he said ‘because you are not here; now I have no one to motivate me and say “you are doing well”’.

Another dilemma was posed by the problem of poverty. Some males had no sources of income and they asked me to negotiate government support grants for them at the clinic. At least two of my participants asked me directly to do this, while others posed the issue indirectly. I responded to this request by asking clinic coordinator to look at their eligibility status. When I told them they are not qualified I was met with disappointed faces and one of them pushed me further saying ‘No, but you must tell them “this man is suffering”. I mean you can see my situation here…Please my friend…’. I began to wonder to what extent my inability to help them affected their attitudes towards my research and their willingness to participate. This state of affair made me reluctant at times to arrange interviews or visit them; I felt like I was the only beneficiary in the relationship. Often I eased this feeling by buying small tokens of meals or drinks, but this raised other ethical questions about whether I was not bribing them to participate.

Limitations

This thesis must be viewed in relation to the ambitions that it sought to achieve. As an ethnographic enquiry, its aim was not to measure behaviour or make generalizations from a small sample to the general population. My participants (those whom I interviewed formally and followed for a lengthened period) are 25 men who are living with HIV, using ARVs and adhering to treatment. This means that I left out other categories of men unexplored, such as treatments ‘dropouts’; men who are HIV positive but not using ARVs; and HIV negative men. These people have different stories to tell and their inclusion in formal interviews would have enabled me to get a deeper contextual understanding of my primary subjects. The inclusion of women would also likely provide an interesting comparison in terms of the impact of ARVs on these two different genders. These omissions were, however, deliberate and in agreement with what I wanted to achieve. As I pointed out earlier, the existing research has not paid close attention to men who are active users of ARVs and what sorts of challenges the treatment poses to their

masculinity. My primary aim was to address this gap; it was not to compare their experiences with other categoes of men or women. My long stay in the research site and my attendance of support groups were sufficient to enable me to understand the context in which they live, as well as how their behaviour departs from that of other men in the villages from where they come. I also gained useful insight about experiences of women by attending the group discussions. I draw from these informal encounters to strengthen some of the arguments that I make in this thesis.

I cannot claim that everything that was shared with me is truth or that it represents genuine feelings and experiences of my participants. Rather I prefer to view its truthfulness in relation to the type of a relationship that I had with them, as well my position as a researcher. The phrase 'positioned truths' is used in anthropological writings to reflect on the fact that truths are context dependent and relational (Abu-Lughold 1991). Participants do not share the same 'truth' about their situation to all researchers irrespective of how they judge and perceive them. The investigator`s gender, cultural background, age, socio-economic status, bear heavily on what kinds of truths he/she is able to generate from the research participants.

It is in recognition of these potential limitations that my analysis is contextual, rather than a simple reporting or narration of what was said in formal interviews. By linking what people said to me during interviews to the observational that I made outside formal interviewing, I was able to discover some discrepancies in their stories. For example, one of my participants told me that since he started using ARVs he stopped drinking, yet when I entered a *shebeen* a few days after our interview I found him sitting inside and drinking a cider. Another man said he stopped smoking and drinking. But one afternoon I stopped at a shopping mall to go to the bank and I saw him smoking. These discrepancies are expected and reflect the complexities involved in doing research on humans. Yet, had I relied solely on formal interviews to gather my data, I would not have discovered them. I would have taken for granted whatever they told me as representing the 'truth' about their situation. But these observations made me more sceptical of their accounts and then I questioned them further during interviews and other informal interactions.

A final point: As a South African black man researching other black men I cannot claim to be completely outside of the situations that I describe in this thesis. The danger that researchers make is to want to present themselves as distant, disinterested, neutral observers to the situation that they observe. This misses the point made by Bourdieu (2003, p. 291), that there is nothing wrong in drawing from our own experiences to make sense of the situations that we observe during fieldwork, as long as we reflect on these experiences and subject them to 'rigorous scientific examination'. I entered the research on men and HIV with a certain identity as a black South African man. This means that I bring into the field certain knowledge of how things are done in black communities from personal experience and observations from my own participation in these events. My interest is not to suppress this knowledge in the pretence of having entered fieldwork as a 'blank slate', but I will draw from it to question some of my findings and enrich my data.

Ethics

This research received ethics clearance from Wits University and Mpumalanga provincial department of health. All participants signed a consent form to indicate that they agree to be interviewed in each of the formal interviews. The consent form contained information about the study, participant`s rights to participate or refuse, permission to record the interview and assurance of confidentiality of the information that they provided. The consent form was written in English, but I read it word-by-word in isiZulu (simultaneous translation) to participants during each recorded interview before asking them to sign it. No participant refused to sign the consent form or decided to withdraw from the study in the middle of the interview.

Outline of chapters

The chapters are presented as an ongoing narrative that begins with these men as they lived 'normal' lives in the society before they got sick. The discussion therefore proceeds chronologically, from prior to the knowledge of HIV infection, through the process of

testing, disclosure and the onset of treatment, the experience of support groups and the decision to adhere to treatment. In chapter three (first results chapter), I present detailed narratives about constructions and experiences of masculinity before the advent of an HIV illness: who are these men and how did they live their lives before they sickened? This is followed in chapter four by a description and analysis of their pre-illness health behaviour: what were their health beliefs and practices; what were their attitudes towards public health facilities; and how did they responded to HIV prevention messages.

In chapter five and six I focus on decisions to test and disclose. These experiences are explored in relation to what it means to be a man and how HIV testing and disclosure challenge masculinity. I enter deeply into men`s lives to explore how they dealt with initial HIV symptoms; where they sought help and what prompted them to finally test. Discussions on disclosure focus on guilt and shame as the main barriers to disclosing a positive diagnosis. This is explored by comparing different approaches to disclosure that participants adopted. In the last section I look at disclosure as a strategy used by men achieve gender dominance and social respect.

Chapter seven deals with experiences of using ARVs. It problematises the view that someone can enter into a treatment programme holding certain beliefs about health, HIV and manhood, and then immediately abandons them as soon as he starts treatment, and adopts a biomedical approach to the management of his health. Here I draw from interviews to show how men are content with using ARVs, yet they are doubtful about their overall commitment to the HIV identity that is being imposed on them in support groups. This identity is experienced by men as emasculating and socially alienating due to restrictions that it imposes on their lives. A large part of this chapter, however, focuses on positive experiences of using ARVs.

Chapter eight is a final results chapter and it deals with what it means to be a man living with HIV. Here I focus on certain challenges that men experience as a result of having HIV and their impact on masculinity. My main interest is to theorize about the notion of ‘change’ or ‘transformation’ of masculinities as it appears repeatedly in recent research

on men. I argue that in the midst of certain challenges that men experience in their lives as a result of having HIV, they do not completely abandon their previous manhood beliefs. Instead they tend to be cautious in living their lives due to health concerns.

Chapter nine is conclusions. It sums up the arguments made in this thesis as well as its contribution to HIV research and men`s health research. The chapter also makes policy recommendations on ARVs in South Africa and other developing countries. The next chapter reviews literature on HIV and masculinities and also indicates where my study departs from it.

CHAPTER 2

MASCULINITY, MEN`S HEALTH, HIV STIGMA and THE BODY

Introduction

This study is being undertaken within a larger body of research work on the topic of AIDS. In this chapter I provide a brief review of research on HIV and AIDS in Africa before dealing with the concept of masculinity and its association with men's health experiences. Research scholarship on AIDS cannot be covered in one section of a chapter: I will focus on theoretical trends that have emerged over the years, which have informed studies of HIV and AIDS in Africa. This will enable us to see, at a later stage, how masculinity entered HIV research as a central concept in explaining the responses of men to AIDS prevention messages. Indeed, masculinities in Africa were studied before AIDS, and are still studied outside AIDS and other health problems faced by men. But in this chapter I argue that AIDS has made the case for studying masculinities even stronger.

AIDS research in Africa

Social science research on HIV and AIDS has come a long way to where it is at present. When AIDS emerged as a critical public health threat in the 1980s it was treated as a medical problem; social science perspectives did not feature in AIDS research or interventions. Focusing specifically on the discipline of anthropology, Parker (2001) provides a review of how social science became involved in AIDS research over the past decades, and gives theoretical perspectives that have informed research over time. He shows anthropological perspectives to have lagged behind in AIDS work for a long time before they gained recognition in the late 1980s. Parker attributes the late entry of anthropology into AIDS research to the mindsets that informed research and intervention work at one time. According to Parker (2001, p. 164) the research work on AIDS in the

early 1980s was 'characterized by a heavily biomedical emphasis and largely individualistic bias in relation to the ways in which the social sciences might contribute meaningfully to the development and implementation of an HIV/AIDS research agenda'.

This paradigm had a significant impact on the types of research agendas that researchers pursued and forms of interventions that were developed. As Parker (2001, p. 164) puts it:

> Most of these studies had aimed to collect quantifiable data on numbers of sexual partners, the frequency of different sexual practices...and any other issues that were understood to contribute to the spread of AIDS. On the basis of such data the primary goal was to point the way for prevention policies and intervention programmes designed to reduce behaviours associated with increased risk for HIV infection. By focusing on links between empirical data on sexual behavior and largely psychological theories of individual behavior change, it was hoped that more broad-based prevention programs could be developed in order to persuade individuals to change behaviors in ways that would ultimately reduce the risk of HIV infection.

The behavioural research and interventions, however, did not prove successful when applied to various socio-cultural contexts. The experience from working in these contexts showed that sexual behaviour was mediated by larger complex issues that went beyond whether or not an individual was informed about the risk of HIV infection. In the words of Parker (2001, p. 165):

> on the basis of both research findings and practical experience around the world, it became clear that a far more complex set of social, structural, and cultural factors mediate the structure of risk in every population group, and that the dynamics of individual psychology cannot be expected to fully account, let alone produce, changes in sexual conduct without taking these broader issues into account.

Anthropological research on AIDS flourished out of this need to focus on the complexities involved in sexual conduct, with the hope that they would provide answers to social and cultural issues that worked to facilitate HIV. This does not mean that

anthropologists were passive in their inclusion in HIV research; indeed, as Parker (2001) notes, anthropologists were the first to recognize the limits of behavioural surveys on HIV research and to point to a need for a more complex approach to studying HIV risk behaviour. Anthropologists therefore challenged the previous paradigm and set in motion a new paradigm whose main goal was to interpret cultural meanings and their association with HIV risk behaviour - though in most cases, this still goes hand in hand with larger community surveys of Knowledge, Attitude and Behaviour.

The early anthropological work on AIDS in Africa focused mainly on how African cultures imposed barriers to successful implementation of AIDS messages, such as practising abstinence, being faithful, and using condoms. In particular there was a specific focus on how Africans engaged in sex, what meanings they assigned to it, and what moral codes governed their sexual conduct. The ultimate aim was to link these sexual behaviours and cultures to the risks of acquiring HIV and thereafter proposing interventions to change them, or practice safer sex. Indeed this was not the first time that African sexuality became a focus of research enquiries by (mainly) outsiders. Sex has always formed part of western curiosity about Africans and their ways of life, represented through the work of missionaries, anthropologists and scientists (Gausset 2001; Saint - Aubin 2005).

Amongst those who have emerged as noticeable contributors to this knowledge about African sexual systems and their link to HIV risks are Caldwell, Caldwell et al. (1989). In an essay entitled '*Social Context of AIDS in Sub-Sahara Africa*' they provided detailed descriptions of what they term the 'African system' and how it is structured in such a way that it facilitates the spread of the HIV. The essay draws from a variety of research work conducted in various parts of Africa, dealing with sex and other aspects of African life, to postulate that Africa has distinct sexual arrangements that help fuel the spread of HIV. Amongst other things observed in the essay as 'distinct' features of African sexuality are the practice of polygamy; weak marriage systems; prostitution; transactional sex; premarital sex and many more practices. The authors claim that Africans are permissive towards sexual practices, including forms such as pre-marital sex that are normally

frowned upon in the 'Eurasian' system to which Africans are compared. The overall impression that the essay creates is that Africans are generally permissive and this partly explains why Africa has high HIV prevalence rates.

Along with Caldwell, Caldwell et al. (1989) other research work on social dimensions of HIV risk behaviour emerged. For example, we saw research work that focused on such things as prevalence of dry sex (Civic and Wilson 1996); sexual cleansing practices (Malungo 2001); circumcision rituals and their sexual aspects (Ahleberg, Kimani et al. 1997), and other culturally informed sexual practices (Mc Grath, Pearson-Marks et al. 1992). This work makes a quite clear link between African notions of sexuality and the risk of acquiring HIV. It demonstrates that sex is not entirely an entity practiced by an individual, but can be deployed to achieve certain cultural goals and meanings. Most importantly, it seems that during the time that this research work was conducted, condoms were not popular among the majority of the population studied. This meant that most people ran a higher risk of contracting HIV through sexual contact.

These early ethnographies did much to foreground AIDS as a socio-cultural issue rather than solely a biological problem. The risks of contracting HIV are determined in large part by certain cultural environments that individuals live in, rather than being entirely under the control of the individual actor. It was through this work that we became aware of how certain cultural beliefs of people and their ways of life could make it difficult to respond positively to health interventions aimed at protecting them from diseases. For example, condoms were perceived as not being necessary in the sexual cleansing process. This means that if one person is infected with HIV, he/she may pass the virus to another sexual partner during the cleansing ceremony. AIDS was therefore shown to be a disease that could not be addressed solely through education or the dissemination of condoms. Intervention programmes needed to engage deeply with cultures and ways of life, and if possible, change them through a process of education.

Subsequent studies have critiqued these earlier ethnographies as being based on a superficial understanding of Africans, their cultures and their ways of life (Hunt 1996;

Paton 1999; Gausset 2001; Craddock 2004; Oppong and Kalipen 2004). Craddock (2004) notes that the literature tends to generalize about Africans on the basis of small-scale studies. Africans, though residing in diverse cultural and social contexts are portrayed as exhibiting similar traits. Diversities that exist not only amongst societies, but within groups are often overlooked in favour of collective representations. This results in generalizations being made about Africans as a people, which may not be applicable to all contexts. Hunt (1996, p. 1291) supports this critique in this quote:

> If there is a unified, coherent, African cultural approach to sexuality and reproduction that increases the likelihood of transmission of HIV/AIDS, why there is such a varied patchwork of prevalence and infection rates across the continent?

The other critique that emerges from these scholars is that this literature reproduces the colonial representations of Africans as backward, barbaric and hypersexual, as asserted in this comment: 'Such representations, damaging enough by themselves, in turn imbricate with and help reproduce vestigial colonial images of Africans as ignorant, hypersexual, and culturally backward' (Craddock 2005, p. 4). An 'othering' discourse is evident in most of the earlier writings about African sexuality, and culture is often used as an 'othering' tool (Gausset 2001). The discourse, according to Paton, (1999) presents Africans as exhibiting unique cultural traits and sexuality, which are not compatible to those of Westerners. Hence interventions target culture and neglect other broader structural factors that shape peoples' sexual and health choices.

While concurring with most of these criticisms, I think what can take us forward in integrating a cultural analysis in studies of HIV and AIDS in Africa is an approach that neither romanticizes culture nor wholly criticizes it. This approach must not shy away from exposing certain cultural norms and practices that may hinder successful prevention of AIDS; however, it must also recognize that culture has a positive role to play in the fight against AIDS. This point was made clearly by Airhihembuwa (1999, p. 271) in his observation that '…every culture has something positive that must be recognized and promoted'. So far this challenge has not been taken up by social science researchers who

work in HIV issues. Instead research focuses on the negative side of African cultures; very little research looks at how culture can be drawn upon as a weapon against AIDS. This leaves us with a view of African cultures that is wholly bad, with nothing good coming from them.

A good example of how African cultural practices can contribute to fighting AIDS is the practice of circumcision. Until recently (late 2000`s) the potential role of male circumcision in protecting against HIV infections had not been explored. Instead, circumcision - particularly traditional forms of circumcision – was viewed as a risk factor that could encourage HIV due to use of 'unsafe' instruments and promotion of other potentially risky sexual behaviour (Ahleberg, Kimani et al. 1997). Recent research trials conducted in three African countries have brought a new perspective that shows clearly that circumcision can reduce a man`s chance of contracting HIV by up to 60% and more (Auvert, Taljaard et al. 2005; Bailey, Moses et al. 2007; Gray, Kigozi et al. 2007) What is important is that the practice be undertaken under controlled and safe conditions to ensure safety and maximum protection of men against HIV.

Delius and Glaser (2002) also point us to another perspective about African sexualities and their impact on AIDS. These authors reject the view that the rampant sexual practices currently observed amongst Africans are a consequence of certain primordial sexual practices of Africans. Instead they show how in the past, African cultural systems played meaningful roles in controlling contemporary youth problems such as pre-marital pregnancy, through strict monitoring of sexual activities. Sexual experimentation was allowed as long as it was not penetrative, and pre-marital pregnancy was highly stigmatized; societies had structures that monitored the sexual activities of youth, and parents played active roles in educating their children about sex. These rules were violated by missionary education and other intervening events such urban migration where sex was less controlled and became commercialized. The work of these authors should guide us to consider whether we have given a fair account of the role of culture in facilitating HIV risks. Most importantly it must direct us towards viewing cultures as part of the solution to the problem of HIV, rather than merely an obstacle to be overcome.

Latest developments

The latest developments in social science research on AIDS have seen a move away from culture alone as an explanatory framework for people's sexual behaviour. Researchers are now paying more attention to a combination of factors including culture, socio-economic and political circumstances, and broader global factors as they impact on people's health choices and sexual behaviour (Farmer 1992; Atman 1999; Setel 1999). As noted by Parker (2001, p. 168):

> since the start of the 1990`s it has also become increasingly evident that the range of factors influencing the construction of sexual realities is far more complex than previously perceived. It has become evident that not just cultural, but also structural, political, and economic factors shape sexual experience to a far greater extent than we had previously understood.

Farmer (1999) is probably the most recognized social scientist to have dealt with the political economy of AIDS. His work in Haiti showed how the decline in economic activities and political instabilities can impact heavily on social stability and people's sexuality. Young women were forced to leave home and look for work in the cities. With limited job opportunities they engaged in transactional sex with working males, which increased their risks of contracting HIV. Setel`s (1999) work amongst the Tanzanian population also revealed the impact of economic restructuring on people's sexual behaviour. Here the collapse of the rural economy drove young men and women into cities. Unlike their rural areas where sexual activity was constrained and monitored, sexual life in the cities was characterized by greater laxity, which further increased young people's risks of contracting HIV.

In South Africa, Hunter (Hunter 2002; Hunter 2004) emerges as notable recent scholar to use the political economy approach to study AIDS. Based in KwaZulu-Natal, Hunter`s research is an attempt to link sexuality with political and socio-economic situations, in the past and present. He demonstrates how the decline in economic opportunity for both

men and women has resulted in sex being used as both a means of survival by women through having transactional sex, and also a means of acquiring respectable manhood by men, through having multiple partners. He however, links these structural constraints with the kind of ideas that men in particular embrace about sex and its role in the constructions of manhood, showing clearly how a decline in economic opportunity can shift the meanings of sexual partnerships from being pursued as a progression towards building a stable partnership and independent household, to being seen as a means of achieving respect. Younger men who have no means of paying '*lobola'* and building independent households are now relying on having multiple partners to define their manhood. According to Hunter this was not the case in the past, where someone who had multiple partners with no intention to marry was viewed negatively in the society and would be called '*isoka lamanyala'*. Presently someone with multiple partners is assigned the term '*isoka'*, and its meaning has been twisted, from depicting someone who has entered into adulthood, to being used as a celebratory mark of 'achievement' with multiple partners.

Hunter`s work is different because it refrains from presenting African sexuality - particularly promiscuous sexual conduct - as being a product of certain innate attributes of Africans. Instead he views sexuality as 'unstable and…produced through men and women`s practical engagement with shifting economic and cultural (factors) and special conditions and relations' (Hunter 2002, p. 101). Similar approaches have emerged from the work of Selikow (2004) in unpacking and contextualizing the meaning of the terms used by young people in Alexandra Township to justify their multiple sexual partnerships. She notes a tendency by young people in Alexandra to celebrate having multiple partners as a sign of 'success', seen in the use of the term '*ingagara*', to refer to a man with multiple partners. However, rather than attribute these sexual activities to certain 'innate' attributes of these young men, she focuses on their socio-economic situation:

> The discourse of ingagara, where status is defined primarily by how many sexual partners a man has, may not have developed if there were educational or job opportunities

> whereby men could achieve status. As well, the ingagara and cherrie/regte discourse may not survive in a context that is not patriarchal or that is not poverty stricken so that women have resources other than sex (Selikow 2004, p. 6).

Another development that has emerged in recently HIV research is a focus on sexual networking as one of the key drivers of the AIDS epidemic in African communities (Thornton 2007; Halperin and Epstein 2007; Mah and Halperin 2008; Morris, Kurth et al. 2009). In intervention work these networks are commonly referred to as concurrent sexual partnerships, or concurrent partnerships, defined mainly as 'two or more partnerships that overlap over time' (USAID 2008, p. 11). Concurrent sexual partnerships present risks for HIV because of how they link someone to a network of partners and, as noted by Halperin and Epstein (2007, p. 20) '...as soon as one person in the network of concurrent relationships contracts HIV, everyone else in the network is placed at risk'. Research conducted in Africans societies shows that these communities have certain unique patterns of concurrent sexual partnerships that further increase their risks of acquiring HIV. Halperin and Epstein (2007) show how in African societies these partnerships tend to last longer and partners are often changed over a short period of time. These two conditions present further risk, the first one because of the lengthened period of sexual exploration; the second one due to higher risks of transmitting HIV during the 'window' period.

A recent South African study by Morris, Kurth et al. (2009) comparing patterns of sexual networking among South African blacks, coloureds and whites in the Western Cape, found that concurrent sexual partnerships as practiced by black participants place them at a higher risk of acquiring HIV. These partnerships are characterized by what the authors call 'multiple concurrent relationships', where both partners are likely to be involved with more than one person at a time. Most importantly the authors found that among black participants fewer people believed that they were at higher risk of acquiring HIV through having concurrent sexual partnerships than did participants in other racial categories. Also, the age of sexual debut tended to be lower among black participants, thus having the likelihood of exposing youth to these networks earlier in their lives.

A particularly striking feature of these concurrent partnerships in Southern Africa is the prevalence of intergenerational sex (Leclerc-Madlala 2007). These are sexual relationships that involve partners who are far apart in terms of age. Studies conducted in African communities show intergenerational sex to be common, and it often involves a wealthier man having sexual liaisons with less wealthy women or girls (Kuate-Defo 2004). In a minority of cases, women who are wealthy also initiate sexual relationships with poorer men/boys. Often these relationships are transactional where a wealthy partner provides financial or material support in exchange for sex. Research shows clearly that women do not always stick to one partner in these types of relationships (Hunter 2002; Leclerc-Madlala 2002). It is possible for one woman to have concurrent intergenerational relationships from which she derives various benefits – such as financial assistance, transport, sexual pleasure, and other benefits. It has also emerged from research that such types of relationships are characterized by low use of condoms. Partners who provide material and financial support have the authority to decide on condom use, and the age and class gaps between partners dis-empower women even more (Machel 2001; Jewkes, Levin et al. 2003). Sexual relationships that involve gift-giving in general have been shown to present problems for practice of safe sex (Kaufman and Stavrou 2004).

The social science approaches to AIDS that I have described above have helped us move away from thinking about AIDS as purely a biomedical issue to seeing its cultural, social, political and economic aspects. The implications for doing research that come from this different mindset are that we cannot limit ourselves to an individual actor as a sole unit of analysis. Research and interventions must be informed by an understanding of the context and how one's socio-economic circumstances and cultural background shape his sexual decisions. This approach to research enables us to move away from labelling individuals negatively for their sexual choices and then blaming them for not changing their behaviour. Instead the whole context in which they live is interrogated to find out how it influences the behaviour of individuals.

The challenge currently faced by social scientists is how to produce accounts about sexuality and AIDS that, while being sensitive to these structural determinants of sex, do not present individuals as being passive to them. For example, the fact that not all poor women enter into transactional sex to earn a living raises the question of what differentiates them. Is it a matter of self-esteem, knowledge of risk, greed, etc? Or are there personality issues that influence sexual decision-making? In short, my point is that structural constraints alone do not fully explain what individuals do. They must be compensated by research that takes into account individualistic characteristics and differences, since these have an impact on sexual decisions. If we only pay attention to constraints in relation to sexual decision-making, we overlook resistance that certain individuals have developed towards the dominant sexual behaviour, and therefore do not make use of their experiences when developing HIV interventions.

Masculinity and HIV

Research on men, masculinity and AIDS came out of these developments in AIDS research and interventions. Initially this work focused on cultural constructions of gender roles and how these interacted with certain socio-economic conditions of women to increase their vulnerability to HIV (Mc Grath, Pearson-Marks et al. 1992; Varga and Makhubalo 1996; Leclerc-Madlala 2001; Vallaeys 2003). Carried mainly from feminist perspectives and also conducted by female researchers, this research – and subsequent intervention work - focused mainly on women, and asked the following key questions: to what extent does the position of women in patriarchal society increase their vulnerability to HIV? How can women be empowered to protect themselves against HIV?

These questions became particularly relevant in African contexts where HIV is predominantly heterosexually transmitted and women bear the greatest burden of the epidemic. Scholars viewed gender inequalities as playing a significant role in increasing female vulnerability to HIV, along with other biological factors (it is easier to transmit HIV from a man to a woman than from a woman to a man). The African patriarchal systems construct men as powerful and dominant in domestic matters and in society at

large. This meant that they made decisions on important matters in their lives, such as when to have children. When it comes to sexual matters and prevention of HIV infections, the positions of men as the dominant gender and decision-makers translated into exercising control over when to have sex and whether or not to use condoms.

Researchers and interventionists felt that these gender disparities needed to be addressed if AIDS interventions were to succeed in changing sexual behaviour in Africa. Hence we saw a plethora of interventions beginning in the late 1990`s aimed primarily at improving situations of women through such things as micro-finance; women empowerment programmes; gender-sensitization, and other interventions. It was hoped that if women were sensitized enough about gender and their sexual rights they would use that knowledge to negotiate safer sex and other conjugal rights.

Along the way, researchers recognized how harmful these gender ideologies were to men themselves. Men who used their dominant positions to reject condoms or engage in other risky behaviour such as multiple partnering not only place their sexual partners at risk, but increase their own vulnerability to HIV through their behaviour. It was in recognition of this fact that studies of masculinities and its association with HIV flourished in the African context in recent years. It was out of a need to change men from embracing 'risky' masculinities to adopting 'healthy' ones, for their own benefits. Before I expand on these studies and what they have achieved I will first provide a brief overview of certain theoretical perspectives that have developed in conceptualizing masculinity. And then in the subsequent section I will show how my own research contributes to this scholarship on men, masculinities and HIV. In the final section of this chapter I will discuss the body and its relevance in understanding HIV experiences.

Theorizing masculinity

The term 'masculinity' is understood generally to refer to 'social roles, behaviors and meanings prescribed for men in any given society' (Kimmel and Aronson 2000, p. 503). Contemporary social science perspectives on masculinity are now in agreement that these

'roles' 'behaviours' and 'meanings' are culturally relative rather than universal, though some of them tend to have universal applicability. This is seen in the work of such scholars as Guttman (1997) who has researched masculinities in various cultural environments and discovered that societies have different ways of defining and measuring masculinity. We should also view these 'roles' 'behaviors' and 'meanings' as being flexible and susceptible to change rather than fixed. Thus what defines a 'real' man now cannot be thought of as having been the same throughout life, nor can we expect it to remain the same all the time. Definitions of masculinity are also contested within one cultural context.

In theorizing about masculinity, contemporary social scientists are in agreement that masculinity is a socially constructed rather than a biological attribute (Moore 1994). Thus the attributes that men demonstrate as part of their gender identity - such as toughness, dominance, control and others - are not inborn attributes; they are acquired through the process of socialization into these gender roles. Bourdieu (2001) is one of the scholars to have theorised about gender as being socially constructed and also embodied attribute. He argues that the social world itself is organized in such a way that a process of socializing men and women into different gender positions – which are often asymmetrical – becomes successful. Thus in the ways that societies divide labour or organize social arrangements, they inadvertently reproduce certain ideologies that exist about the 'internal nature' of men and women in that society. These ideologies often construct women as being inferior, obedient, passive, while men are viewed as a dominant gender who are in control (Bourdieu 2001, p. 33-49).

This process of socialization into gender roles is, however, not imposed willy-nilly from above to a passive actor. Bourdieu (2001) argues that the 'masculine domination' succeeds because actors, both men and women, recognize it and then organize their everyday lives – such as how they manage their individual bodies, division of labour, etc - according to its principles. Thus women and men 'know their place' in the society and in relation to each other, and they behave according to what the society expects from them. Bourdieu sees these gender structures as being deeply embedded into the bodies of

individuals - rather than being external to them - to an extent that they appear to them 'natural' and taken-for-granted, rather than a product of social construction or their own actions. Their 'naturalness' is further affirmed by the objective conditions (*field*) in which individuals live, which according to Bourdieu, are structured in such a way as to be in harmony with these embodied perceptions of gender (*habitus*) (Bourdieu and Wacquant 1992, p. 94-115; Bourdieu 2001, p. 33-49).

Other scholars have made similar observations about gender as being actively constructed and reproduced by individuals through social interaction and other forms of recognition. The ethnomethodological approach to gender developed by Fenstermaker (2002), conceives of gender as an achievement, something that is achieved in interaction with others, rather than a biological given. It is relational rather than being owned by an individual person (Gibson and Lindegaard 2007). Thus one`s identity as a man does not follow automatically from his sex or looks; manhood must be demonstrated to others through engaging in certain acts that are recognized by them as being masculine - including in some situations, risky or violent behaviour. This will obviously differ according to the context, class, age, social status, etc. Thus these means of achieving successful masculinity will change based on context and social situations.

Connell (1995) is one of the critical contributors to the development of theoretical perspectives about masculinity worldwide. His work emerged mainly as a critique of the sex-role theory (Nye 2005; Demetriou 2001; Donaldson 1993); he exposed its limitations in theorising about power between men and women and among men themselves 'and its subsequent failure to grasp change as a product of contradictions within gender relations themselves' (Demetriou 2001, p. 338). Connell argued that there is no one masculinity, but multiplicity of masculinities and roles (Jensen 2008, p. 92). He further recognised that these masculinities are not ranked equally; some have more power and dominance over others. In this respect he coined the term 'hegemonic masculinity' to refer to an ideal type of masculinity that is powerful and dominant over other masculinities at a given time. In the words of Morrell (2001: 7), hegemonic masculinity is 'one that dominated other masculinities and which succeeded in creating prescriptions of

masculinity which were binding, and which created cultural images of what it means to be a man'.

Hegemonic masculinity prescribes what sorts of behaviour is recognised as acceptable for a 'real' man; it then negates and marginalises other masculinities which do not conform to its principles. Hegemonic masculinity, however, does not go unchallenged; the term 'alternative masculinities', is used popularly to refer to other forms of behaviour that seem to challenge or resist conformity to the hegemonic ideals on what it means to be a man (Robins 2009; Becky 2006; Renold 2004).

The concept of hegemonic masculinity is central to my analysis of men and their behaviour pre and post – HIV diagnosis. However, is it being used with caution, recognising that some scholars have raised doubts about its usefulness and relevance as an analytical concept for men`s behaviour. For example, according to Lindegger and Maxwell (2005, p. 97) Wethererl and Edley (1999) questioned the argument that boys either align themselves to hegemonic masculinity or are marginalised from others: 'they are interested in how men/boys position themselves in relation to conventional notions of the masculine, and how they take on social identity of "being a man"'.

Certainly, if we use the concept 'hegemonic masculinity' to refer to a dominant behaviour of men in the society, we need to demonstrate that such behaviour is indeed 'dominant'. This is a difficult task for a study in Bushbuckridge where understandings of masculinity are changing and shifting all the time due to political and socio-economic conditions of men (see chapter 3). In this study I use the term 'hegemonic' masculinity to refer to what men and other people told me to be an ideal or dominant type of manhood, though I am aware that such a man might exist only as an ideal rather than a lived reality (Connell 1995). I use 'alternative masculinities' to refer to other forms of behaviour from my own participants that contradicted some aspects of this ideal manhood; however, I do not imply that no other men engage in such a behaviour or that it is completely 'new'. I also question whether men who 'behave differently' (Reid and Walker 2005) can be

immediately characterised as belonging to the category of 'alternative' or 'resistant' masculinities.

The interesting question that has been posed by social scientists is how individuals 'choose' to identify with a particular gender identity and not the other (s) (Moore 1994). This question emerged out of a recognition that there is no one way of being a man or woman, but multiple and often contradictory ways (Hollway 1984). Social contexts offer various discourses on what it means to be a man and individual actors must somehow assign themselves to one of these discourses. This question is particularly relevant for the purposes of this study because this study deals with men who are making decisions on how to reconstruct their manhood following a health crisis which impacted on their pre-illness definitions of manhood: how do they 'choose' what kinds of men to become after recovering from a long persistent illness and are having difficulties in living according to dominant social definitions of manhood? Do they assign themselves to these dominant discourses or do they find other 'alternative' discourses more appealing to their present condition?

Studies conducted with men living with chronic illnesses – such as prostate cancer, physical disability, depression, arthritis etc – found them to still subscribe to dominant social definitions of masculinity even in the light of challenges posed by these diseases to their manhood lives (Broom 2004; Olliff 2004; Gibbs 2005; Gibson, Young et al. 2007). However, unlike before, these men tend to be more reflexive – rather than passive - in their subscription to these ideals. In a study by Gibbs (2005) men with arthritis are renegotiating the terms of being a 'real man' taking into account their needs to manage their health condition. They no longer rely on hegemonic principles to measure their manhood. In Olliff (2004), penetrative sex as constitutive of 'real sex' is questioned by men who have prostate cancer. They engage in other forms of sex, like cuddling and touching, and perceive these as being sufficient for their needs as sick and older men. Broom (2004), however shows how a need to remain sexually active still informs the health decisions of men with prostate cancer to an extent that it overrides their health concerns. In Gibson, Young et al (2007) men with physical disabilities exhibit what the

authors call ‘embodied marginalisation’, a situation where participants internalise dominant social discourses on what it means to be a man and then measure their own worth according to these social expectations. Hence some of them feel inadequate in sexual relationships because they cannot do what ‘real’ men are supposed to do to their partners (‘like sweep her of her feet’). They duly decide to refrain from intimate relationships.

These studies show that men with chronic diseases adopt varied responses with respect to how they position themselves in relation to various social discourses about manhood. There is no outright rejection of hegemonic masculinity as a consequence of having a chronic disease; nor is there a smooth and unproblematic insertion into other ‘alternative’ discourses. Instead men with chronic diseases seem to oscillate between embracing the ideals of hegemonic masculinity and also rejecting them. Age, length of illness, type of social network, and other social and psychological factors, also play a role, making it difficult to predict how men would typically respond to the challenges of being ill to their definitions of masculinity or how they would position themselves in relation to various discourses about manhood once they contract a lifelong disease.

Masculinity and HIV

Research work on masculinity and its association with HIV has drawn from the above conceptualizations of masculinity as a social construction; culturally relative; an achievement; multiple; and an embodied attribute. Mainly this work focused on what it means to be a man in various cultural contexts and how men enact or perform their masculinity. It then linked these meanings and performance to the ways that men are responding to HIV messages - such as abstinence, faithfulness, using condoms. AIDS messages, as I have shown in the previous discussion, tended to ignore social meanings assigned to sex in favour of an educational approach. Studies on men and masculinities filled this lacuna by looking at meanings that men assign to sexual activities and relationships in terms of their masculinity.

In particular, the notion of hegemonic masculinity has dominated the analysis of men and their responses to HIV messages in African countries. If we look at research work on men, masculinities and HIV/AIDS in Africa, it has shown hegemonic masculinity to be having a negative influence on men`s responses to HIV messages (Wood and Jewkes 2001; Mfecane 2002; Selikow, Zulu et al. 2002; Walker, Reid et al. 2004; Brown, Sorrell et al. 2005; Leclerc-Madlala 2005; Walker 2005; Sathiparsad 2007; Simpson 2009). Particularly this work has looked at hegemonic masculinity in terms of what it says about men`s sexuality. What emerges clearly from this research is that masculinities are generally constructed in ways that are counter to HIV messages about the importance of safer sex, monogamy, faithfulness and abstinence. Two key features of masculinity that defy these messages have been identified by these authors, namely, (1) a need to prove masculinity through having sex, often with multiple partners; and (2) a common – and to a certain extent socially acceptable - use of violence against women, either as a way of asserting dominance or a way of attempting to restore 'masculine domination' when it is felt to be lost. These two issues will be discussed further below starting with sexuality.

Being sexually active has long been identified as a socially recognized way of gaining entry into manhood worldwide, but in Southern Africa it has unique patterns that directly put men at risks of acquiring HIV and then spreading it to their sexual partners. Ethnographic research conducted in South African communities shows that being sexually active is not enough to enter someone into a manhood (or keep him there); one must have more than one sexual partner at a time in order to be recognized by others as a 'successful' or 'real' man[9]. Men who have multiple partners are admired by others and assigned such positive terms as '*isoka'* (Hunter 2005) or '*mancula'* (personal observations, a concept used in Cape Town townships), while men who have one or no sexual partner may be labelled negatively as '*isishimane'* (Leclerc-Madlala 2005). In most South African communities there are no other 'alternative' ways of getting respect from peers except to conform to these expectations (Indeed the communities, including

[9] It must be kept in mind that in South Africa this research has been conducted in black African communities; therefore these findings reflect practices as observed in those communities rather than the entire South African population. There is however, still a strong need to conduct similar research work among other racial group, even if not in the context of AIDS, to avoid stereotypical representations of these sexualities as being unique to black South Africans.

elders, have their own way of measuring manhood that may differ from how peers evaluate it. Caution must therefore be made not to conflate what peers demand from boys, with what the society demands as a marker of manhood).

Recent research has further foregrounded the finding that despite Southern Africa having the high rates of HIV prevalence, expectations such as the above still prevail and most men still pursue 'successful' masculinity through having multiple partners (Soul City 2008). In fact the AIDS epidemic seems to have done little to discourage the practice of multiple partnering amongst men, as shown by recent research (Parker, Makhubele et al. 2007). Research further shows that amongst men, some interventions against AIDS - such as safer sex, condom use, faithfulness, and monogamy - are not favoured, as they contradict these dominant social constructions of masculinity (Leclerc-Madlala 2005). Thus the literature overwhelmingly portrays the key role that dominant forms of masculinity amongst South African men play in driving the HIV/AIDS pandemic.

Other scholars have looked at masculinity and its links to HIV in relation to the problem of sexual/gender violence (Varga and Makhubalo 1996; Jewkes, Levin et al. 2003; Walker, Reid et al. 2004). Here it has emerged clearly that sex among couples is not always a consensual act. Walker, Reid et al (2004) report on the findings that men tend to have a sense of entitlement to sex with their partners and they often enact it through violent means. This makes it difficult for women to refuse sex for fear of being physically abused. Even more difficult is the negotiation of condoms in such unequal, violent sexual encounters (Varga and Makhubalo 1996). Mfecane (2002, p. 76) showed that when men were refused sex they interpreted it as a challenge to their manhood. Hence some would use all sorts of persuasive skills, including violent means where necessary, to emerge as 'winners'. As one of the participant remarked:

> …the thing is if you let your girlfriend go…the next thing is that she will go and sleep with another man and then the following day she will tell her friends '*uyikaka yomntu'* (he is a shit person).

Sexual violence can also be used as a means of asserting masculinity when it is felt to be lost or threatened. Niehaus (2005) illustrates this point clearly in his study of men and their involvement in rape in Bushbuckridge. His view is that rape cannot always be viewed as an expression of men`s dominance over women, as only a few (privileged) men hold powerful positions (at least in the study context observed). Instead he sees rape as an expression of loss of power by men, and most importantly, as a means of trying to assert an idealized masculinity that men are failing to achieve through other 'traditional' means – like having an independent household.

Masculinity and use of ARVs

The research work cited above has done much to foreground masculinity as an important factor to consider when doing research and intervention work on men in African communities. Men appear in these writings to be playing a central role in perpetuating the spread of HIV through internalizing and then enacting certain risky gender ideologies. Men enact these ideologies by engaging in behaviour that ultimately places themselves and their partners at risks of acquiring HIV. As Bourdieu (2001, p. 49) observed about the dangers of masculinity, '…men are also prisoners, and insidiously victims, of the dominant representations'. In the research, the 'dominant representations' to which they are victims portray them as controlling and ultimately, entitled to sex. This has serious implications for their lives.

The review of this research shows that it has offered a negative picture of masculinities as constructed and lived in African communities, and their association with the problem of HIV. Shefer, Ratele et al. (2005, p. 81) protested against such negative representations, commenting:

> The over-riding picture of boys and men emerging from contemporary research on sexuality and male violence in South Africa is extremely negative. While women and girls emerge in the literature as inevitable victims, inherently powerless in the face of male control, men are constructed as predominantly powerful and controlling in relation to women and heterosexual relationships.

The negativity here can be attributed to the fact that these studies emerged during a time of HIV crisis, when for purposes of intervention it was necessary to document the negative aspects of masculinity in order to develop successful interventions. However, as the authors above argue, a certain 'blind spot' was created by this focus, where research failed to document other constructions of masculinity in these communities.

In addition to being negative, this scholarship tended to generalize by portraying a 'homogenous, unitary and singular experience' of manhood in Africa (Shefer, Ratele et al. 2005). African men are painted with the same brush as being potentially dominant, powerful, violent, sexually promiscuous, etc. My own view is that this negative picture emerged as a result of overreliance on the notion of hegemonic masculinity as an entry point to studying men and their sexual behaviour in South Africa. Hegemonic masculinity, as noted by Donaldson (1993), presents an overwhelmingly negative picture of men and their lives, such as that they are violent, risk-takers, irresponsible, and so forth. This has had an impact on how scholars in South Africa write about men, mainly in the negative.

There is now an emerging scholarship that tries to address the problem of one-sidedness and negativity in research involving men and HIV in South Africa. It does not stop at exploring masculinity through a hegemonic lens, but instead looks at other 'alternative' or 'resistant' masculine identities that may be existing in the studied context (Morrell 2003; Sideris 2005; Walker 2005; Lindegger and Maxwell 2007; Sathiparsad 2007). Walker (2005) is a good example of this new approach. Her paper, based in Alexandra township, Johannesburg where violence is rife and somehow tolerated, documents experiences of men who are constructing their masculinities in 'alternative' terms that entail resisting violence, embracing women and children as equals, and a desire to be good fathers. These 'new' ways of being a man are constructed against 'traditional' ones that are embraced by fathers, peers, and other men, where violence is commonly accepted. Morrell`s (2003, p.58) study amongst school-going youth shows that contrary to the dominant public masculinity that encouraged promiscuity, some youths at school

chose to be monogamous. Based on these observations, he says '…masculinities are changing…'.

It is within this emerging scholarship that tries to avoid a generalized, negative portrayal of men, and which attempts to document resistances, alternatives, and change with regards to masculinities, that I am situating the arguments for this thesis. Before I elaborate on this I wish to point to some limitations in the extant literature. This will enable us to see clearly where the gaps are and where the contribution of this thesis is.

Certainly the scholars cited above are doing much to debunk previously negative and often judgmental approaches to studying masculinity and its association with male lives in previous research. Through this work we are seeing different sides to men that were previously not shown, supporting contemporary theories about masculinity which view it as being a highly contested terrain. My overall impression of this scholarship, however, is that while its intentions of documenting change, resistance and 'alternative' masculinities are good (because they avoid negative labelling and generalizations), the approach towards documenting these resistances and changes is limited by theoretical and methodological approaches used to study them. Both limitations have led to simplistic conclusions being made about men as 'changing' or 'resisting' while not interrogating in greater details these changes/ resistances and their direction.

The over-reliance on theoretical perspectives offered by Connell means that we have an overall perception of the hegemonic masculinity in Africa as being predominantly negative (especially with regard to contracting HIV/AIDS). This research then looks for resistance to this dominant image and at instances where men are 'changing'. In my view this does not do much to challenge the previous representations of African masculinities that this work attempts to address. Instead, this research creates the impression that only a few men (mainly young) are good and the majority are still adhering to traditional conceptions of masculinity that are bad. Sideris (2005), who did a study amongst men who construct their masculinity in non-violent ways and support gender equality in a supposedly violent community, described them as 'unusual'. By implication such

remarks create an impression that these men are a small minority; other men in the community are portrayed as if they are in support of violence and other unequal gender practices that the minority men seemingly oppose.

We should also not underestimate how research participants may exaggerate the situation from which they are supposedly changing in order to present themselves in favourable terms. Thus in my view the notion of 'change' and 'alternative masculinities' requires further interrogation than is the case at present. My research therefore builds on this scholarship but it adds an ethnographic approach to the topic, which problematises the notions of resistance and change. I move from the premise that resistance and change are fraught with ambivalence rather than a uniformly smooth rejection of hegemonic masculinity. Men who want to change are still held back by the need to prove their masculinity through engaging in certain activities that validate the hegemonic masculinity that they are supposedly rejecting.

Lastly, in this research I avoid characterising men who are using treatment and adhering as 'unusual' or 'exceptional'. Such characterization, while giving a positive impression of these men as being progressive, would inadvertently reproduce a stereotypical portrayal of other men in the community who are for various reasons not using public health facilities, as being somehow backward, as opposed to a few who have seen the light[10]. I would think that more men in Bushbuckridge are open to the experience of using western medicines than we know. Because of a focus on negative masculinities, their experiences have been ignored. This thesis hopes to provide a basis to address the gap.

HIV, masculinity, stigma and the body

This thesis deals with men who are living with a disease that carries a social stigma. Their dilemma is therefore not limited to considerations of masculinity and how it will be impacted by being sick; but there are further challenges on how to live with HIV identity

[10] This may seem to contradict the point I made in chapter 1 where I argued that I became interested in these men because of their decisions to seek help where others normally do not.

in everyday life. In this respect this thesis explores the following aspects of living with HIV: Secrecy, Disclosure and Stigma. Particularly important in this exploration is the notion of the body. As has been noted in sociological and anthropological literature, the body is central in the experience of illness and assignment of stigma to a sick person (Goffman 1968; Crawford 1994; Kelly and Field 1996; Bury 1997; Nettleton, Watson et al. 1998; Nettleton 2006). Bodies are also central in the constructions of social identities (Goffman 1959). They convey social information about someone - through looks, dress codes, style of walk, etc - and in so doing, shape how others will judge and position someone based on appearance (Stone 1962). Since certain diseases manifest through the body, a main locus of identity, this will arguably impact on how a sick person feels about his identity and how others in his social environment judge him, based on how his body looks. Most importantly, diseases are experienced through the body (Kelly and Field 1996) and this experience determines whether one would want to keep it secret or disclose it (and to whom, when and how) and how the person generally copes with it (Kelly 1991).

Throughout this thesis I will reflect on the salience of the body in experience and management of HIV/AIDS, as well as looking at its role in how people manage secrecy, disclosure and the stigma of HIV. The virus resides in the bodies of individuals and, through its progression into AIDS, has the potential to damage and transform them, sometimes in a 'disgusting' manner (Posel 2004). When this occurs, it has serious consequences for sick people in terms of his identity, self esteem and how to manage secrecy. Some research has also shown how certain treatment interventions may transform the body in unacceptable ways – such as having lipodystrophy – thus rendering AIDS more visible than it was before taking them (Persson 2004). In this respect people are left with scant or few strategies for managing information about their disease as it can be read easily through the body (at least to those who know what the symptoms represent). Treatment can therefore have the unintended consequence of inviting stigma rather than reducing it.

In her study amongst PLWHA in the South African township KTC, Mills (2006) shows how being sick from AIDS can embarrass an infected person and their family. HIV results in downward social mobility, prompting those who are positive, and their families, to resist using HIV services because this impacts heavily on their social status. AIDS itself can be 'read' by others from a distance and then communicated through bodily gestures such as the use of 'three fingers', indicating the three letters (of the disease). In this thesis I will share similar findings where a sick and emaciated body may become a source of embarrassment and shame for sick men, resulting in refusal to use available public health facilities. This will be linked to perceptions about masculinity, which normally construct men as being healthy, strong and independent. Men who are weak due to being ill therefore feel that they do not conform to the social standards of manhood, and this makes it even more difficult to seek help.

The focus on the body in the context of the HIV stigma is even more important when we consider how the body has been conceptualized in contemporary anthropological and sociological literature. This literature no longer treats the body as a given fact, but acknowledges that bodies are socially and politically constructed (Bury 1997). The way we experience or manage our bodies is not completely under our control as individual actors, but highly mediated by existing social discourses and political agendas on what constitutes an acceptable body. Scheper-Hughes and Lock (1987, p. 25) make this point clear in this remark:

> societies regularly reproduce and socialize the kind of bodies that they need…In many societies (including our own) the culturally and politically 'correct' body is the beautiful, strong and healthy body, although the meanings given to obesity and thinness, to the form and shape of body parts, to facial and dental structure, as well as values placed on endurance, agility, fertility, and longetivity (as indicators of strength and health), vary.

Because bodies are socially constructed it follows that illness experiences are also a product of social construction. Thus, while diseases are located in our own individual bodies and experienced at this level, the meanings assigned to them are not entirely our own. This explains why a certain disease may enter a body and alter it yet not induce

embarrassment or serious emotional reactions, while another disease may have a serious impact on someone's self-image and the judgement of others.

This brings us to the question of HIV stigma. It has been noted that stigma is not inherent in a disease, but a product of social construction (Parker and Aggleton 2003). Stigmatizing takes a form of hierarchy where some diseases may enter someone`s body, damage or change it, yet not affect his social judgment. Other diseases, by virtue of their acknowledged presence in a person's body (without necessarily damaging it, altering it or being visible at all) may impact negatively on how he is judged socially. HIV/AIDS, the focus of this thesis, falls into the latter category of diseases. Over the years, ethnographic and survey research in Africa and elsewhere have shown how an HIV positive status may induce feelings of hate, anger, social exclusion, and avoidance in other people (Green and Sobo 2000; Posel 2004; Skinner and Mfecane 2004; Simbayi, Kalichman et al. 2007; Zhou 2007). These reactions may have nothing to do with the physical effects of the disease on an infected person or how his illness interferes negatively in the lives of other people. Instead, they reflect the negative societal construction of the disease that someone is having.

The physical dimensions of the stigma surrounding HIV are explored in greater detail in a paper by Posel (2004), based on a study in Agincourt, Bushbuckridge. Here Posel locates the assignment of stigma at the intersection of 3 key factors: sex, death, and embodiment. She looks at how the body of an AIDS sufferer can be given social meaning as a marker of 'bad living' (promiscuous sex or prostitution), thus provoking disgust, shame and embarrassment both on the part of the sufferer and the community. This follows from AIDS being seen as a 'verdict' on the moral status of a society in terms of its sexual mores. Posel locates the stigma surrounding AIDS in the context of democracy, where it is perceived to have eroded previous ways of life that were characterized by control over sex as well as respect for sex and death (see also Posel, Khan, et al. 2007). An AIDS sufferer becomes an embodiment of what has gone wrong in society, bringing about stigma and shame both at an individual and societal level. Most importantly, according to

Posel, the AIDS sufferer receives less sympathy because he/she is believed to have asked for it due to bad living (disrespect for culture 'wrong' sex, disrespect for death, etc).

Researchers have now begun to look at how these negative social responses towards HIV and AIDS are being internalized by PLWHA themselves and then shape their own experiences of the diseases and how they cope with it (Green and Sobo 2000; Mills 2006; Simbayi, Kalichman et al. 2007; Zhou 2007). Here a clear picture emerges where a positive diagnosis is not experienced in a vacuum. Instead, when someone is diagnosed with HIV he immediately draws from social meanings of this diagnosis and then deals with it according to these meanings. Hence, in most cases PLWHA feel ashamed of their disease and this leads to reluctance to disclose to immediate family members and friends because they fear that they may be negatively judged. Or someone may shun HIV services because he fears that he would be looked down on by other people or that he would receive poor treatment from health providers.

Green (1995) assessed stigma beliefs of PLWHA and found them to be more severe than those of the general population in which they lived. The general population holds less stigmatising beliefs about PLWHA than the sufferers do. Mill`s (2008) study among PLWHA in a South African township cites people who refused to use HIV facilities because they feared that people would identify and then label them as having AIDS. Zhou (2005) focuses on people living with HIV in China and shows how the fear of stigma prompts PLWHA to conceal rather than reveal their diagnosis. Someone with HIV is treated as an outcast in his/her family. In Simbayi, Kalichman et al. (2007) PLWHA perceive themselves as dirty, guilty and ashamed of their HIV infection.

These research findings, and others not cited here, provide evidence for the observation that the HIV stigma is both a social construction and an internalised aspect. Its power rests in having the infected people internalise society`s beliefs about them, and that informs how they to deal with their infection, mainly as a shameful, embarrassing and a secretive disease (see also Cameron 2005). Diseases therefore are not abstract events;

they have social meanings and these meanings impact heavily on the coping strategies of the infected people.

Throughout this thesis the impact of the body on health decisions will be explored – from decisions to do an HIV test, disclose, adhere to treatment, and how men construct their masculinity afterwards. I will show how a sick and weak body can be a source of embarrassment and shame, prompting most men to 'hide' rather than seek help, and how certain men can perceive themselves as 'outcast' due to the damage caused by AIDS to their bodies. However, I will also show how the same body which was a source of shame can become a source of pride and a basis for resisting certain negative categorization of someone with HIV as 'already dead', once it has been restored by ARVs. My research indicates that when men recover from physical symptoms of AIDS they gain more confidence to disclose and live openly with the virus and then challenge others who previously looked down at them as 'already dead' because of being sick.

Conclusions

Masculinity has emerged recently as a central concept to be considered in dealing with men`s responses to HIV messages. This chapter began by reviewing HIV literature in general before focusing on literature that deals with masculinity and its impact on HIV. Here it has been shown that HIV research comes a long way from being too biomedical, to seriously taking into account social, cultural and political factors as they impact on HIV risk and prevention behaviour. I have documented different trends that have emerged in studying AIDS, such as cultural, political economy and a recent focus on multiple concurrent partnerships.

Studies of masculinity and health have been reviewed, with the main focus being on how these masculinities impact on male responses to various HIV messages, like safe sex. Previous research tended to homogenise men; however, recent research is looking at multiplicities of masculinity and also paying attention to the resistances of certain men to the concept of hegemonic masculinity. This study, however, treats resistance with

caution, taking into account the fact that it is fraught with doubts and contradictions. This will be reflected throughout this thesis in dealing with experiences of men who are reconstructing their lives following long illness from HIV.

Lastly this literature review discussed the body and its centrality in the experience of a disease and the imposition to HIV positive people. It has shown that the body is central to construction of social identity. Stigma therefore originates mainly from physical looks of someone, which are perceived as being disgusting and needing to be avoided and marginalised. Stigma is a social construction; it is not inherent in diseases, but emerges out of how the society perceives and treats people with certain diseases.

LIFE BEFORE HIV: MASCULINITY AND HEALTH BEHAVIOUR BEFORE HIV

CHAPTER 3

LIVING LIKE A MAN: MASCULINITY BEFORE HIV

Introduction

This chapter focuses on constructions and experiences of masculinity among men who are living with HIV before there were diagnosed with the virus. These notions of being a man, as argued earlier, have been seriously impacted by the experience of being sick from HIV. As a result some of the men experienced difficulties in their lives and others had to adopt certain lifestyles changes in order to accommodate the demands of the treatment regimen. In this chapter I want to show how, prior to being sick these men subscribed to, and lived according to socially defined standards of 'real' manhood, such as being an independent provider; having a 'wife'; being powerful and gender dominant; and having a healthy and strong body. These attributes earned them social respect, as well as self-confidence in their own manhood. Then, in later chapters I will look at how these 'achievements' are challenged by being ill, thus impacting severely on their sense of themselves as men. The main point of this discussion is to enable this thesis to demonstrate in later chapters, what the influence of living with HIV is on men`s lives. The focus is on the ways in which their manhood has been impacted and transformed by the experience.

It cannot be expected that all participants endorsed the same views about masculinity or that being ill had the same impact in their lives. Nor can it be expected that their views about masculinity would have stayed the same throughout their lives - even if they did not get sick. As the discussions will show, men`s beliefs about masculinity differed, as they drew from various sources such as, peers, religion, and work experiences. These variations, I argue, impacted differently on how individual men experienced being ill, what treatment options they adopted, as well as their decisions on whether or not to test, disclose, and adhere to treatment. The men came from diverse social circumstances and positions, such as: young/old; married/unmarried; drinking/not drinking; having multiple partners/single, employed/unemployed, and other differences. The impact of being HIV positive therefore differed in relation to their understandings, feelings and practices

related to their manhood. It depended on the ideas about masculinity that each man had embraced prior to being ill, as well as his personal circumstances at the time of getting sick.

My ambition, however, is to try and construct – amidst these differences – an account about these men that will assist us here and in subsequent chapters, to answer the following questions: What kind of notions about masculinity had predisposed these men to HIV risk behaviour? What are dominant social ideas concerning what it means to be a man in the area that I studied and how does HIV illness challenge these ideals? To what extent do variations in constructions and experience of masculinity impact differently on a range of health decisions that men must make, such as testing, disclosure and adherence -.e.g. are men who embrace 'traditional' views about masculinity more or less adherent to their treatment; are they more or less likely to test or disclose their HIV status than men who resist these views?

Masculinity, though central in this thesis, cannot be singled out as a sole factor that influences health decisions, particularly if men subscribe to different definitions and had different experiences of manhood. This discussion will therefore be followed by another detailed description of participants' lives and health behaviour before they underwent an HIV test. I hope that, at the end of these two chapters the reader will be familiar with most participants and who they were and what they believed and enacted concerning manhood before they became sick.

What it means to be a man

> Well, for one to be recognized as a man he needs to have a wife and his own stand, for people to recognize him. Because if you don't have a wife and a house, people will not regard you as a man – *indoda;* they will regard you as just *umfana* – a boy (Interview Kenneth, 18 February 2007).

> For people to recognize you as a man you must have your own plot, you do the right things and not the wrong things. You should relate well with other people…like treating

> your wife well, supporting your children, being around your home and being at home at not later than 6pm. You shouldn't be going around at night with other men (Interview Lizo, 11 January 2007).
>
> If you are a man you should live well with people (*kumele uphile nabantu*). You should respect other people…things like that; but *eish,* I don't know how to put this… it's someone that lives well with other people (*uhanya navhanu kahle*), someone that has respect for another human being (Interview Bob, 28 November 2006).
>
> I can say a man shows himself by having a girlfriend– *ujora.* The moment I start dating, then I realize 'I am now a man', you see (Interview Koko, 2 March 2007).

The above quotations are some of the replies offered to a question: what does it mean to be a man here or how did you experience your manhood? As can be seen, participants offered varied responses based on their personal experiences and different levels of investment in these roles. Kenneth assigns importance to being independent and having his own stand, wife and children. Lizo is passionate about responsible fatherhood and the fact that a man must be always close to his family. Bob feels that real men must have respect for other people (particularly other men). Koko cites the idea of having multiple partners as a key marker of real manhood.

Overall, responses offered by most participants highlighted the fact that real manhood is about being powerful, strong, respected and in control. Such attributes are achieved through involvement in three main activities, namely, being an independent provider; having (multiple) sexual relationships; and bodily appearance (having a healthy-looking body and feeling healthy and strong). Being an independent provider gave men control and authority within the household as well as social respect and easier access to women. Having multiple partners earned them peer respect and was a public proof of their sexual virility. Finally, a healthy body – as an observable and experienced fact - was associated with gaining social respect and self confidence. Thus in the lives of these men masculinity was a constantly achieved and proved phenomenon, through their enactment of these attributes. Being sick from HIV was therefore experienced as emasculating by

most men because it directly affected their abilities to deliver on these expectations, thus rendering them less masculine.

This chapter unpacks these experiences of manhood, beginning with an analysis of the provider role. The discussions will illustrate that, although most men wanted to be providers, this role was not necessarily aimed at providing for others. It related mainly to the ability (financially and physically) to take care of oneself and thereby to gain power, confidence and social respect. I will then focus on the body and its role in constructions of masculinity and the achievement of social respect. This section illustrates how having a sickly and weak body can impact on someone`s social image as a man, as well as his confidence in his own manhood. In the next section attention shift to the sexual behaviour of these men. In the latter case I want to highlight the roles played by having multiple partners in gaining peer respect and personal confidence as being and representing a 'real' man. I then discuss AIDS as a consequence of these men`s need to gain power and respect through having multiple partners.

Two more topics will be explored towards the end of the chapter, namely, drinking and 'alternative' masculinities. Drinking is discussed in relation to its role in the performance of masculinity, and 'alternative' masculinities are explored in order to highlight differences that existed among men.

The following narratives about experiences of manhood are retrospective and they were shared with me by men who were already sick and claimed to have 'changed'. This inevitably raises the question whether some participants were selective in what they shared with me about their past lives. Although most of the men emphasised that their behaviour had changed, they may nevertheless have omitted certain personal experiences that may be embarrassing or damaging to their present images. I am nonetheless confident that my long rapport with them resulted in them being quite open even about confidential issues. I also made my own observations during fieldwork – including visiting their homes and interviewing their family members and partners - to enrich and verify data obtained from them about their 'healthful' lives.

Becoming a man: Provider role

In the literature, the importance of being financially independent, as well as a provider, or breadwinner, is emphasised as central aspects of the achievement of manhood (White 1997; Brennan 2004; Tatyana 2004; Morrell and Richter 2006; Khunou 2006). 'Real' men are those who provide for themselves and their families; men who are dependent on other people for their upkeep may not be taken seriously and their masculinity is constantly under question. Studies on fatherhood show that being a father is predicated mainly on playing a provider role. Thus biological fatherhood is not enough to confer someone the status of being a 'father'; he proves his fatherhood abilities by taking care and being responsible for supporting his family. Hunter (2006) showed that when men are unable to provide, they may decide to shun fatherhood. This was the case with his participants, young men from KwaZulu - Natal province in South Africa, who preferred to deny paternity partly because they did not have the means to support their children. This was mostly because they were unemployed.

It should however, not take it for granted that all men aspire to be active providers and that failure to do so undermines masculinity in all contexts. In a study done in the Dominican Republic, Brennan (2004, p. 726), the author shows how migrant men in the city shun the provider role in favour of being dependent on their female partners who work in the entertainment industry as sex workers. Here women earn more money than men and male partners encourage them to have sexual liaisons with European tourists in order to bring in cash. Some men leave their low-paying jobs to become entirely dependent on their women for their upkeep. Interestingly these men have not lost social respect; instead they are recast as macho because, unlike other men who work but earn little, these men can make money 'without actually working' and 'they become the envy of other men in town, not stigmatized objects of their gossip' (ibid).

Ethnographic research conducted in Bushbuckridge shows that being an independent provider remains central to definitions of manhood. Someone is recognized socially as a

man – *wanuna* or *mona* - when he shows that he can live independently from his parents and establishes his own household, with a wife and children. In the past the process of becoming a man began when a male underwent circumcision rituals. Then, males of a similar age group spent an extended period of time away from home - three to four months - while they were educated about manhood and their social responsibilities (Ritchkin 1995). Circumcision was often immediately followed by initiation into migrant work, through which men earned money to buy land, pay *lobola* (bridewealth) for their wives and build their own independent households. Elders were key gatekeepers in men`s progression from boyhood to manhood because they controlled land and also contributed towards payment of cattle for *lobola* (for their sons (Ritchkin 1995).

My participants said circumcision no longer plays an important role in the transition from boyhood to manhood. Firstly, circumcision is no longer practised widely by locals; among Shangaan speakers it is almost non-existent. Secondly most people felt that it has been reduced to a surgical procedure (removal of foreskin) rather than an institution for transmission of cultural values. And thirdly, boys are now circumcised at a much younger age than before, making it difficult to immediately assume the responsibilities of manhood when they return from circumcision. Three of my participants shared their own experiences of circumcision as having played no role in shaping their own manhood. One of them, Jozi, reflected thus:

> They taught us *umlawo; angithi* (isn't it) they would teach you at school: *a e i o u;* so they will teach you every morning: *a, e, i, o, u*, until you can say it perfectly. But to say that 'if you are a man you should live like this and that and that', no, they never taught us anything about that. No they never taught us anything (Interview Jozi, 5 September 2006).

Ethnographic research has also noted the limited role and influence played by adults in the individual progression into manhood (Stadler 1994; Ritchkin 1995; Niehaus 2005). Elders no longer control land and cattle, and young people gain independence and access to resources outside parental control through involvement in migrant work. Nowadays

lobola is also paid in monetary terms, and young men can buy land directly from the government, using cash. Stadler (1994, p. 66) accurately sums up the shift in power dynamics occasioned by these developments in this comment:

> ...the move towards complete labour prompted a shift in domestic power relations. The dependency burden fell heavily on younger wage earners. This places the young and employed in positions of power.

The next discussion looks at the provider role as it was achieved by the study participants, with a particular interest in how it enabled them to gain independence, social respect, dignity and power. Their narratives will show that when a man looks for a job, he is also looking for a way to situate himself in a certain masculine arena that constructs men as the dominant and controlling gender, and women and children as his subordinates. Thus, most men without having a job felt that they had not yet 'entered' into manhood.

Provider role pre-HIV

All the participants endorsed the provider role as having been an important definer of their manhood before they became ill from HIV. They said in order gain social respect and recognition, a man must live on his own, be financially self-sufficient and independent from economical support by his parents or family. Independence was gained through involvement in migrant work. Typically, someone grows up in the village where he herds cattle, attends school, or both. Once he reaches adulthood – either in his late adolescence or early twenties - he leaves his home to look for work outside Bushbuckridge, either in Johannesburg or other nearby towns.

Most of my participants followed this route. Out of 25 men, only two have no history of migrant work. Of those two, Mathe was employed as a teacher in Bushbuckridge and Thabang was dependent on a government disability grant. The age at which men left home ranged from seventeen to twenty. The two examples that follow present a typical route taken by men as they sought independence - and manhood - through employment.

Bob told me he left school when he was eighteen years old because of poverty. He was living with his mother and four younger siblings. His father stayed somewhere else and his mother was unemployed. Bob felt unhappy about his economic situation and he suddenly decided to look for work:

> ...my parents were not living together; I was looked after by my mother. My father was wasting money with other women. So my mother was also not working, you see, and the trousers and clothes were expensive. So she couldn't afford to buy us clothes, you see. Now I looked and thought 'Ey, this is not right!' so I decided to leave school. You know, I would go to school with a torn trouser and barefooted, and others were laughing at me. I couldn't concentrate, so I decided to leave school…
>
> And from there I went to the farm; I didn't even know the place. And I was barefoot and tired when I arrived there…my first job was at an orange farm. I worked there for two weeks and, ey!, it was tough; working there was quite tough! So I stopped and came back home; I bought myself some clothes. And after two weeks I joined this group that was cutting the grass. Ey, I went away with them; that was my first time to have money – it was R580 (a month) – it was a lot of money; I thought maybe that white man made a mistake [laughter]. Hey, it felt like a lot of money. So I took the money home with me, I bought some clothes and other things I needed. That was the end to the first part of that *piece job* (temporal work)…after two months those white guys came back again to take us for another contract; we had to harvest some beans. So I had now gotten used to money, so I worked until the end of the month. *Angithi* (isn't it) I wasn't used to money before! So just having R100 as mine, as belonging to me, was a big thing. So that's how I started, and until now… (Interview Bob 09 February 2007).

This extract highlights poverty as the main reason for Bob to leave school and look for work. He seems to imply that his decision to find a job was driven not so much by a personal ambition to be independent and thereby become a man, but as a result of being poor. Yet the job – and the wages in particular – were instrumental in his achievement and performance of manhood, since he became an independent and dignified man. School days were characterised by poverty, the inability to afford decent clothes and a sense of

embarrassment and shame for being laughed at by other children. Bob spent his first salary on clothes in order to improve his image. Image, as we will see later, is an important aspect in constructions and performances of manhood and Bob was not alone in wanting to look good in order to feel like a decent man.

Thandi followed the same route as Bob. He comes from a poor family; his father died while he was still young and Thandi was raised by his grandfather on pension money. At the age of seventeen Thandi decided to leave home and look for a job:

> …then in 1980 I was doing standard five, so I got the standard five certificate. So I felt 'No, if the conditions are like this (poverty) I would rather go and look for a job…' That's where I started experiencing more life from there…I got a construction job. I met this Portuguese guy and I told him 'I'm looking for a job'. So yhaa, he gave me a spade and then he showed me how to dig…I worked, and worked, and worked…and he was just busy with his own things, you see. And whenever I say 'Ey I'm now tired', he said '*sebenza boy* (you must work, *boy*). I said to myself 'Yhaa, today I have arrived'…ey Sakhumzi, I was sitting like this in the car [demonstrating with a tired body], and when I arrived at home they asked 'How did it go?'; I told them 'I got a job', but didn't tell them [both laughing]. And when I tell people this story they think I'm joking, but I'm not joking, it's tough out there, you see (Interview Thandi, 8 September 2006).

The progression into the status of manhood through work is clearly illustrated in these two narratives. Both Thandi and Bob refer to the experiences of their first jobs as having been tough, yet they stayed in them. This seems to suggest that having a tough job – and enduring it - was seen by these men as a necessary test of their 'real' manhood. The implications of being sick and unable to do 'hard' work are therefore vast for man, as we will see in the next chapters.

The two stories reflect experiences of other participants in the study. All of them come from poor backgrounds and they said poverty was the main reason for leaving school to look for work. Two of them (Jozi and Lucky) decided to find employment because they each impregnated a girl and had to pay 'damages' to her family (money paid to the family

of a pregnant to show respect and apologise); Xola said he decided to look for work in order to follow on his late father`s footsteps, who was a soldier before he died. He also found a job in the military.

The accounts shared above show the importance of having a job in building self-confidence and enabling someone to address poverty and a sense of feeling undignified. It has been argued earlier that masculinity is relational, in addition to being an achievement. Someone relies on responses of other people to judge and validate his manhood. Accounts shared by male participants showed that in addition to building their self esteem, having a job enabled them to furthermore acquire social and peers respect as well as having easier access to women. It also accorded certain men power and dominance in the household.

Mathe told me that as soon as he got his first job as teacher, the community - including elders - started to treat him differently. He was no longer perceived as an insignificant person with no social influence or value, but most people began to interact with him as an adult and respectable man. For Mathe, this change of attitude was further facilitated by the positive role that he played in his family as a primary provider. When I visited him at his home he showed me the two three-room house that he erected to add to a four-room house that his father built. Afterwards Mathe set up his own household in Bushbuckridge and then got married. Mathe said these achievements earned him respect in the community:

> You see here, if you take care of your parents people respect you. It's unlike in other cultures where you can just leave your parents without taking care of them...Here you start with your parents, and then you can do your own thing (Informal conversation Mathe, 6 August 2006).

For Vusi, having a job was a turning point in his life as a man. When he grew up Vusi wanted to acquire three important things: a job, a house, and a wife. At the age of twenty he achieved the first goal when he was employed as a soldier by the South African

Defence Force: 'For me I began to feel like a man when I started working…I was still young when I joined the army'. Vusi worked in the army for seven years before he resigned in 2000. He subsequently joined a security company based in Johannesburg. In 2004, before he became ill; he built his own house a kilometer from where his mother lives. He said that having his own house gave him more authority and power in his household:

> Yhaa, it`s always good when you have your own house. You can make your own rules; you don't have to live under someone else's rules. And even your wife, if she doesn't want to play by your rules you just tell her 'leave my house!' She either plays by your rules or leaves your house. My wife knows; I tell her all the time 'if you don't like my rules, leave!' (Interview Vusi, 8 February 2007).

For Koko and Magwa, having a job increased their confidence and they pursued multiple partners and experimented with sex. Both men had little or no sexual experience before they started working. As soon as they earned wages both men started to chase after women. Koko said:

> Well for me I left school at standard 8 (grade 6), I was nineteen; and I went to look for a job in Randburg (Johannesburg). I worked for a construction company. So after a while I came back home briefly to do my ID. That's when I started being curious about women because I was working during that time, I had money...yhaa; because I had money and they could also see 'he has money'. I knew if I approach her she will agree because I have money; I am working (Interview Koko, 2 March 2007).

According to Magwa he had one girlfriend when he grew up in Mozambique. His 'real' experience with women started in the mines where he got his first job. During this time he earned money and was able to provide for women:

> In my case, you see, I grew up until I reached 23 years without knowing how to sleep with a woman. I learned from that woman that I dated, you see. We grew up together, you see; so she also didn't know anything cause she was young, you see. And when I

> reached 24, 25, that's when I began to realize '*Ey kanti umfati u so* (Ey, this thing is so nice!). That's when I started making silly mistakes, you see. I started running around, telling myself 'Ey, I have wasted so much time…hey this thing (sex) is nice!' [Laughter]. Now I started having this one and that one, this one and that one. I was really confused, you see (Interview Magwa, 4 October 2006).

These two participants illustrate the importance of having a job and money in being able to pursue other things associated with successful manhood (women in this case). For Koko having a job improved his self esteem, it enabled him to freely approach women. He thus used money to attract them. For Magwa, money enabled him to experiment sexually with several women; he left his childhood girlfriend with whom he had five children. Koko told me that, without having money, a man cannot attract women because the latter are only interested in men who can provide for them. He explained:

> A woman doesn't want you if you don't have money. No! Forget! It's all about money these days. She wants food, she wants clothes, and she wants to be beautiful! So she won't stay… (Interview Koko, 2 March 2007).

It can be seen from these discussions that having a job and money was an important component in these men`s experiences of their manhood. It gave them independence, household dominance, social respect, and easier access to women. The implications of being unemployed are therefore vast for a man: a male who is unemployed struggles to enter into manhood because he lacks the resources necessary to do so and women may not be attracted to him. For these reasons most men wanted to work in order to be perceived as independent and gain respect from the wider society. A job furthermore increased their self-confidence and made them feel equal to their peers.

Providing for others

Earlier in this chapter I observed that for most of the participants the role of being a provider was not primarily aimed at providing for others, but was directed towards fulfilling their own personal needs. A family was secondary to the necessity to dress

appropriately and to be able to afford certain masculine lifestyles. In this regard White (1997, p. 3) criticizes gender and development literature in general, and argues that these present men as '...hazy background figures...relatively autonomous individuals, putting their own desires for drink and cigarettes before the family`s needs'. She views such representations as '...colonial stereotypes about "lazy natives"...'. My aim is not to perpetuate these 'stereotypes', but rather to problematise them. I will argue that there can be a gap between the socially circumscribed role and assumption that men are and should be providers for their families and involved in their children's lives. Let me elaborate further on this point.

Out of 25 participants, eleven lived with their children before they became sick. Of these, nine were frequently absent from their homes due to their involvement in migrant work. One participant had two children who were already adults and lived on their own; two had no children and eleven had children outside marriage. These children were living with their mothers or mothers' family. Some men who were married – such as Mathe, Vusi, and Magwa – also had 'other' children (outside their current marital relationships) and they were not actively supporting these offspring. Magwa told me he has thirteen children with three women. He supported only five of them when he was still working: 'Some are in Mozambique…yhaa… and others are here. And if you ask me what they eat there in Mozambique I wouldn't tell you' (Interview Magwa, 4 October 2006).

Mathe reported that he financially provided for his five children from a previous marriage when he was still healthy enough to work. At the same time, there were nonetheless three children from other women that he neglected: 'Yhaa, that's where I feel the pain, because I did nothing for them' (Interview Mathe, 9 February 2009).

Unmarried men were more likely to be uninvolved with or to financially provide for their children. This was either because the children grew up with their mothers and their maternal relatives and men had restricted access to them; or simply ignored them. Thabo told me he has two children with different women. He did not know either of these offspring. Zola described his involvement with his two children as having been mainly

financial, but not in relation to their upbringing or as emotional. When I asked him if he played any role in their lives he sternly replied: 'Yhaa; whenever I had something I give her. But since I am sick I can't play any role- it's difficult for me to do this-and-that' (Interview Zola, 26 November 2006).

Bob denied paternity of one of his children, citing mistrust of his ex-partner:

> ...the reason why I denied him…you see, this is my girlfriend, and we agree that 'I will be coming to you around late at 4 (pm)'. But the minute you arrive you don't find this person and when you ask they say she went away with so-and-so (another man). So now she came to my home pregnant (I'm sure she was 3 months pregnant at that time); they said they had brought her to me. I said 'She is just wasting your time; you must ask her to tell the real truth (Interview Bob, 2 February 2007).

The role of being a provider as discussed in this section therefore departs from how previous scholars documented it - as being directed mainly towards supporting a family. Here I have focussed on what this role means for an individual in terms of independence, dignity, respect, and gaining social recognition as a 'real' man. This focus is significant for this research because this study deals with men who have lost their jobs due to HIV illness. The question is: what happens to their dignity and social respect as unemployed men, and to their self esteem? How does unemployment affect their abilities to fulfil desires for women, clothes, and such? I will return to these questions in the next chapters; below I focus on the body, another important factor in constructions – and performances – of masculinity.

The body

The body emerged in this study as being central to constructions and performances of masculinity. Many of the aspirations of manhood could be mapped onto, and read off, a man's body: in his physical prowess, on the one hand, and in his dress, on the other. Being a 'strong' man was often inseparable from having a 'strong' body; likewise, that

being assertive and in charge in relation to women and children was both emotional and physical.

When talking about male-to-male behaviour, however, participants emphasised what I shall call a 'respectful body' as a key marker of someone`s real manhood. They said a 'real' man must show respect to other men through his dress code and respectful public conduct. A man who behaves in an arrogant manner towards other people – particularly other men - does not deserve social respect, irrespective of his age and success in other areas of life. Thandi said: 'If you want to prove yourself as a man, be open to everyone – whoever is it, whether he is educated or not. Don't look down at the other person' (Interview Thandi, 4 October 2006).

And Bob added:

> For me a man is someone who lives well with other people… someone that has respect for another human being. If you are a man you should live well with people (*kumele uphile nabantu*). You should respect other people…things like that (Interview Bob, 18 December 2006).

The above perception, always excludes some males – e.g. criminals and other social deviants, like rapists. Participants said a criminal is not worthy of social respect irrespective of how he looks or behaves towards other people. Someone who steals from others for a living was constructed as a social outcast rather than seen as a successful man or envied by others (see Jenson 2008, for an alternative perspective of how certain gangsters still gained social respect and dignity irrespective of how they made a living).

Direct comments about the body and its place in men`s constructions and performances of masculinity came specifically from two participants, Lizo and Sabu. They both commented on the importance of dress code and neatness as key components of respectable manhood, arguing that if someone is dirty or dresses shabbily other men will not respect him. Lizo said:

Lizo: You shouldn't be going around at night with other men…and you must dress well

SM: And what happens if you don't fulfil these expectations? How will people perceive you?

Lizo: They will not respect you, even if you are a grown-up. Even when calling you they will say: '*Ekse, Ekse*' (a township lingo indicating disrespect for someone). But if you behave well they will call you in a dignified manner; they will call you by your child's name if you have a child. But if you are out of the way you will hear us saying '*Ekse zwakala here* – Ekse, come here'. We will not respect you. (Interview Lizo, 8 January 2007).

Sabu added:

> ...you must always keep your place clean so they can look and see 'le *auty le iphila grand* – this guy takes good care of himself'; it must always be clean. I'm not against smoking; yes you can smoke, but be clean all the time, you see. So that we can see you are *iauty* (young lad), so we can recognize you as *umuntu ophilalyo* (a man amongst other people) (Interview Sabu, 11 October 2006).

I began to think of these demands in relation to the situation of men who are sick from HIV. Clearly, if body looks are an essential factor in getting social respect and recognition as a man, they must appear in a particular way: not only as clean and well-dressed, but they must also be healthy, strong and attractive. Most men who were sick from AIDS did not have such bodies; they were thin and physically weak, and probably less attractive. Part of my enquiry into pre-HIV lives of my participants was to find out how they felt about their bodies as 'manly' before they sickened: did they possess these bodies demanded by Lizo and Sabu? Secondly, I looked at how they felt about their bodies when they became ill and weak and whether these changes impacted on their self perception and decisions to test and disclose. The latter question will be dealt with in subsequent chapters; here I will focus on the first question since it deals with pre-illness life, the focus of this chapter.

There were two ways in which men talked about their bodies as they lived and experienced them before they sickened; firstly by showing me pictures of themselves while they were still healthy, and secondly, by making comments during interviews on how their bodies looked now compared to the past. Both ways revealed that AIDS significantly altered these men`s bodies from being strong and attractive to being weak and probably less attractive. Pictures that were shared with me showed these men smiling, dressed fashionably and being in upmarket areas in their previous workplaces. For example during my visit at his home, Sipho showed me a photo of himself taken with his older brother at their previous workplace in Johannesburg. They are both smiling, looking straight into the camera while holding hands. He commented, as he handed me the photo: 'you see, that was still me!' (Informal conversation Sipho, 7 August 2006).

Thabo made similar comments when I visited him a year after my meeting with Sipho, in August 2007. As I entered his one-room house for the first time, I saw a photo of himself hanging over his bed, next to a photo of his late younger brother (whom Thabo said died of AIDS). In the picture Thabo sits next to a car and is dressed in a white T-shirt, black pants and shiny black shoes. He holds a pair of sunglasses. He is smiling and looks strong and energetic. I immediately remarked 'Is that you!', and he replied 'yhaa *mnganam* (my friend); that's how I looked before this thing' (HIV) (Informal conversation Thabo, August 2007).

Sam`s photo is placed on top of his cupboard next to his ARVs, inside his bedroom. On the wall is an AIDS poster from the department of health with the message 'condomise...'. After spending 40 minutes with me, in which he shared his painful experiences with HIV, Sam stood up and took the photo off to show me, and then remarked: 'You see, that's me while I was still right (*ngesikhathi ngise right*…)' (Informal conversation Sam, 17 September 2006).

All these men seem to communicate a sense of loss, of a previous self. They feel that they are no longer the same; illness has taken away the previous self as it was constructed and

experienced through bodily appearance. Other men were equally critical of the way they looked and constantly paid attention to their weight. For example Sabu, after using ARVs and gaining some weight was still not happy about his body. During one of our encounters I asked him about his experiences of using anti-retroviral treatment. He commented:

> ...so far it's treating me well (*ingiphethe grand*). But you remember how big I used to be, *Joe*; but now I have lost weight. Now I ask myself what's going on here [both laughing]…But well, I just accept everything as is.
>
> .

I challenged him, asking 'have you lost weight? I don't see any loss of weight', and he replied 'well I feel like I have lost a bit of weight. In the past I used to be nicely fit; now I ask myself "what's wrong here; am I not eating properly?" (Informal conversation Sabu, 17 January 2007).

The same feelings were expressed by Magwa. On our first interview at his home he dwelt much on the losses that he experienced as a result of having HIV, including weight loss. He commented thus: 'My main problem is weight. You see, I used to be big, man. But now I don't know, my weight is not making progress. I eat; I eat, but no…'. During our interview Magwa stopped in the middle to bring me his photos taken before he got ill, as an evidence of what he has lost. In the photos he looked much younger and happier than he did at the time of research (Interview Magwa, 4 October 2006).

The impact of being sick on self perception has been widely explored in social science research (see chapter 2). Scholars have observed that being sick directs more attention to the body. In the absence of illness or physical discomfort we hardly pay attention to our bodies (except when hungry or needing to look good), instead we take them for granted (Csordas 1990; Nettleton, Watson et al. 1998). Here, due to being ill, these men are critical of their bodies; they constantly watch them for evidence of loss or improvement of weight and comparing it to the previous selves. At stake here is need to look and feel 'normal' - and therefore be treated with respect - through having a healthy-looking body.

Also at stake is a need to manage 'information' about one`s HIV status, gained mainly through bodily looks, and therefore being able to 'pass' (Goffman 1968, p. 92). Bodies that are weak and frail can easily be 'read' as a sign that someone has AIDS and can result in negative social judgments concerning him.

The above discussion highlights the psychological dimensions of the change from a healthy-looking body to one that 'displays' signs of illness, and in particular of HIV-related sickness. Such a metamorphosis can contribute to a loss of self esteem. The social consequences were expressed in stories of men who experienced difference in the way others in society treated them when they became visibly sick and lost weight. Sabu said his friends were avoiding him due to being sick '...because they tell themselves 'Sabu is sick; we will visit him and do what?' (Interview Sabu, 11 October 2006).

Tito, who had a rash all over his body before undergoing HIV-testing said: '*Abanye bayeka nokungibulisa, abanye benginyanya* (some even stopped greeting me); some found me disgusting. My family didn't want to see me. Women just vanished, no woman wanted to talk to me' (Informal conversation, 6 June 2006). And Koko said 'Some don't even greet you; they just walk past. So what do you do; I just watch them. Maybe one day he will be in the same situation as me, and I will also pass him' (Interview Koko, 6 March 2007).

These findings illustrate the importance of having a healthy-looking body in order to feel good and be respected by other men. This issue will be explored further in the next chapters dealing with HIV testing and disclosure.

Sex and relationships

Sexual activity and its association with the achievement of manhood has been discussed in chapter 2. I have shown that sexual experience is recognized by most men in South Africa as an acceptable way to enter into adulthood, and it involves early sexual debut and having multiple sexual partners. Someone who has no sexual experience or keeps one

sexual partner is not taken seriously by other men. In this section I will highlight sex and multiple partnering as another instrument used by men to gain manhood and peer respect. I will furthermore highlight HIV infection as a consequence of a felt need to be a respected man and gain status, through having multiple partners.

My interviews with men living with HIV revealed that, before they got sick from HIV, and in line with other men in South Africa and elsewhere, the former invested profoundly in sex and relationships as important definers of their manhood. From adolescence these men pursued women and viewed them as an important site for constructing a positive image of themselves as having 'grown'. When I asked them 'at what stage did you start to realize that you are a man?', most of them referred to sexual experience as having been a turning point in their lives. My interview with Jozi illustrates this point:

SM: So according to your own upbringing what were you taught about proper manhood...for people to acknowledge you as a man, what are the things that you were expected to do?

Jozi …for me the first time they recognized that I am grown up was when I would not be home in the evening. I would go out and come back at my own time. And they would ask 'Hey *wena*, where have you been?' I say 'I've been out playing with the others…and as time went on they became curious to know 'Is this person really with friends or he is a talking about a girlfriend?'. Cause at home we used to sleep in one place, and now I started chasing these young ones away 'Hey get out of my house! Go and sleep somewhere else' [Laughter]. So they left and they were sent to another house. Now they became curious to know why I've chased them out of my house. And then there was this day, early in the morning I was escorting her (a girlfriend) out of the house and I found my mother just outside, she was sweeping. And we were already outside, you see. But she didn't say anything then, but when I came back she started shouting 'You don't want to listen; you are learning the wrong things; tell me if you no longer want to go to school so I don't waste my money, cause now you are behaving like a man. The minute you impregnate that girl you will have to find your own way – you will have to go and look for a job, and if you don't get it that will be your own business…'. And when this girl came here pregnant I couldn't deny it because

even my mother already knew her…so from there I left and went to look for a job.

SM: And your friends; at what stage would they get to recognize you as a man.

Jozi: *Angithi* they saw, maybe your friend is not yet involved in relationships, and now you don't want to be in his company. And then he starts to say 'Oh now you think you are a man cause you are going out with that girl' [laughing]

SM: So it's about girls *neh*

Jozi: Yhaa, you also change, you see. Cause you distance yourself from the guys that you used to hang out with (Interview Jozi, 25 October 2006).

This interview seems to suggest that for someone to perceive himself as having reached adulthood/manhood he needs to be in a sexual relationship with a woman. This sets him apart from his peers who are still sexually inexperienced. This view was repeatedly expressed by other study participants. For example, Xola agreed:

> The way I see it *neh*; for him to see himself as a man. *Ngaphandle kokuthi ahlangane nomuntu wesifazana akakaziboni ukuthi uyindoda* (until he engages with a female partner he doesn't recognize himself as a man). But as soon as he meets her he feels '*manje sengikhulile, sengiyindoda'* (now I have grown up, I am a man)….then someone would feel 'I am now a man' and from there he can do whatever he wants (Interview Xola, 11 October 2006).

Having a girlfriend was, however not enough for someone to get respect from his peers. Most men said it was expected of them to have more than one partner in order to prove their manhood and be respected. This practice was further justified by using the local phrase that says: *wanuna i n'hwembe wa nava* (a man is like a pumpkin he spreads; his roots are here while his branches spread to other places). This phrase means that a man can have a stable partner while at the same time he has other sexual relationships. A woman, on the other hand is not allowed to have multiple sexual partners. The phrase

suggests that multiple partnering by men is tolerated – or even promoted – in Shangaan culture[11], it also uses biology to justify what is, in fact, culturally constructed behaviour.

Most of my participants endorsed these views, as evidenced by their pre-HIV sexual conduct. For example, out of 25 men, 23 said they had been with multiple sexual partners in their lifetime. Lizo and Joe, two men who described themselves as devoted Christians, were an exception, saying they always had one partner at a time. Justification for having multiple partners differed among participants, ranging from a perception which constructed men`s sexuality as being 'naturally' uncontrollable; to citing peer pressure; seeing men as having a 'natural' right to promiscuity; sexual greed; and involvement in migrant work. The two extracts that follow, however, focus on multiple partnering as a means of gaining peer respect and status.

Koko said that for him, being involved with multiple partners happened naturally as a product of being a man and belonging to a peer group that practiced and supported his behaviour. His friends were all promiscuous and Koko said someone who had one partner or two was generally perceived as a failure. Also, there was always competition amongst his peers as to which man had more partners. In this extract from our discussion he gives a scenario of how this competition would typically unfold:

Koko: Well, *ushukuthi* if you see another man being with a girlfriend you feel weak; you ask yourself 'why is he with a girlfriend; we are of the same age but he is with a girlfriend and I don't have one'. Then I will try and get my own girlfriend so I can also point at someone.

SM: So you feel weak if you don't have a girlfriend.

Koko: Yhaa you feel weak, and you stress about it a lot; your neighbour starts asking you 'Hey your friend has a girlfriend; why don't you have one?'. He laughs at you and makes you feel like a fool (*isilima*). Or maybe a guy brings a girl to you, but you don't show an interest in her; he asks you 'Hey, a dog that doesn't eat

[11] I am thankful to Benjamin Makhubele (personal conversation) for problemtatising this phrase and arguing that it has been taken out of context from its original meaning. Makhubele says this phrase originally meant that a man can be 'borrowed' to help in another family where there is no man, for example ploughing for them. But most people are using it wrongly to justify multiple partnering and saying it is part of Shangaan culture.

meat, just looking at it! Where have you seen a dog that doesn't eat meat?'. So you also feel the pain when things like that are said.

SM: Would you then say men pressurize each other to have girlfriends?

Koko: Yhaa they pressurize each other because, let's say we both have girlfriends here in Acornhoek. And maybe we go to the Plaza together and you get another girlfriend there. Now you are putting me under pressure to try and surpass you at the Plaza. And in the end I will say 'Ey I beat you at the Plaza; I beat you by 2-1, two goals, 2-1. Now you must also fight back and make the score 2-2'. So that's where the problem starts (Interview Koko, 22 February 2007).

This extract clearly illustrates how manhood and peer respect can be achieved by having multiple partners. Firstly Koko talks about feeling weak and emasculated if he does not have a girlfriend to show off. This feeling can be further exacerbated by describing a man who shows no interest in women, as *isilima*, thereby judging them negatively.

Secondly, he talks about competition that exists amongst his peers, forcing each man to always want to do better in order to be respected. The equation of men with 'dog' and women with 'meat' suggests the sexualized nature of relationships in Koko`s circle of friends. Women are mainly seen as objects utilized to build someone`s positive masculinity and peer respect; they are a site for competition, used by certain men to publicly demonstrate their sexual prowess rather than building strong emotional bonds with them (the women). Thus a man who has no interest in women is simultaneously communicating his lack of sexual virility that 'real' men should naturally possess and demonstrate by being always ready for sex.

Koko lived according to these ideals before he sickened from HIV. He had several partners and this earned him respect amongst peers. He was duly nicknamed 'Zonke' (the one who takes all), as a sign of admiration for his sexual 'success' with women. In August 2007 I visited him at his house during a brief fieldwork trip. When I asked for directions to his place he said '...as soon as you enter (the village) just ask for 'Zonke'; everybody there knows who 'Zonke' is'. It seems therefore that Koko wore this tag with pride; it was a key definer of who he was amongst his peers.

Koko was in a stable relationship with a woman that he later married. But this did not preclude his having other sexual partners. I asked him why he was sexually promiscuous and he replied:

> The thing is I would date a girl; we go to bed but she is not enough for me. I get another one, we go on well…and these women also talk amongst each other, that 'Ey that guy! *Eishhh*!'. And you don't even use condoms with some of them. Now you feel that if you use a condom with this one and not with that one you feel some difference, and you go after this one (not using a condom with), but I'm still not finished with that one. Or maybe I visit Bushbuckridge – I will be there for only two days, but already I will see someone and feel 'Ey this one will be a nice girl for me'. Now you are adding into the total – you have 3 here and you have one there (Interview Koko 22 February, 2007).

There are more men like Koko, who had multiple sexual partners and felt that it gave them status and respect of their peers. For example, in my interview with Mathe he proudly recalled - and then later regrets - how women fought over him mainly because of his sexual strength. He changed lovers constantly and attached no emotions to his involvement with them. To have women competing and fighting for him was a good marker of his sexual virility:

> Mathe: You see, for me...I had many girlfriends that I dated, and I was just having fun, and I must tell you I had real fun! [laughter]. The way they used to like me, I really enjoyed it. And they used to like me, man. I would sleep with this one today, that one tomorrow. Maybe this one enjoys me a lot and now she starts fighting with others about me; I keep her for a while but the following week I change her and bring another one. This one also starts fighting with another one. So I would have 3 in my village; maybe two at Buffelshoek; two in Cottondale, and one somewhere else. So I was really a busy man.
>
> SM: I'm sure other men used to respect you...
>
> Mathe: Even today they still greet me...they know very well that 'Ey this man!' Even the

> women, some are now married...but this same respect has brought me into the trouble today. Ey it has brought me into trouble (Interview Mathe, 9 February 2007).

Migrant work emerged as an important contributing factor to having multiple partners among participants. Partly it was used as a good excuse to justify what certain men believed to be a biological necessity, with some of them saying it is biologically unrealistic for a man to have one sexual partner. At least fifteen of my participants worked outside Bushbuckridge and a total of eight were either married or in a stable partnership with a woman who was living in Bushbuckridge. Vusi worked as a soldier (away from home) for about ten years while being married to his wife. He returned home occasionally. Whilst in the army he also had sexual relationships with other women. For him this was 'normal' and all men – irrespective of their marriage statuses - did it:

> You see sometimes it`s difficult for a man to have one partner...For example I remember when I was in the army. I would be away for so many months, and really the guys there wouldn't wait that long; they would start seeing women, so I did the same. I'm sure you have the same experience; I'm sure you have a girlfriend here even if you maybe left a partner at home. No man can live alone *mos*...[Laughter] (Interview Vusi, 20 February 2007).

The consequences of this behaviour were that it made it difficult for men to account for being HIV positive. Very few of them could pinpoint exactly who might have infected them with HIV. I asked all participants if they know who infected them with HIV and they offered the following responses:

> …I don't know who I slept with who gave me this sickness; who I can go to and say: 'Look, now I'm sick from this. It means you are also sick, let's go so you can get help too'. I don't know who it is, cause I would have this one, and then change and get this one, and then that one. And now I have got my 'salary', this is what I'm having with me now (HIV), you see (Interview Zita, 25 October 2006).

> Yhaa I have an idea of how I contracted it. I can say, for example I used to have many girlfriends where I worked, even though I had a girlfriend back here at home. *Utholo'ukuthi* (you find that) I would have this one, we break up and I get another one. Remember I told you we used to compete? I think that's how I contracted HIV (Interview Koko, 22 February 2007).

> Ey man! I can't tell you how I actually made contact with it. The thing is *gangijikajika kakhulu* (I used to be after women) – Tswanes, Sothos, Ndebeles, Boesman, all! So I can't really say which one of them infected me… (Interview Magwa, 4 October 2006).

> No, I cannot tell you exactly how I got it; but I can say I got it through sex, because *vele bengingimuntu othanda abafazi* (I used to love women). Yhaa…and they also used to love me…I was always with women all the time. *Ushukuthi* there are no types of women I never slept with – Venda, Sotho, all…all sorts of people – coloureds, Indians, all that; and even whites, I had slept with them as well. So I can't tell you how I got it, where, from whom (Interview Tito, 20 October 2007).

These responses indicate a clear link between the pursuit of masculinity through having multiple partners and the risks of acquiring AIDS. This link has been widely acknowledged by previous scholars (see chapter 2) but difficult to prove through empirical research (Lurie and Rosenthal 2009). All the men cited above acknowledge that sex, an instrument that they used to acquire respectable manhood, placed them where they are presently. Most importantly they acknowledge that their own promiscuous sexual conduct contributed directly to their present situation of being HIV positive.

The admission of personal responsibility for being HIV positive, as it emerges from these responses, struck me as being quite significant because it contradicts what is commonly known about African men, as being always in denial of HIV and their own contribution to the spread of the epidemic. According to much of the literature on HIV, which draws mainly from experiences of women, men tend to blame their female partners for having HIV, and often they react in violent ways towards them (Long 2009). Men in this study

are not blaming their stable partners or wives for being HIV positive. Instead, they admit to their own active involvement in acquiring the virus due to having sex with multiple women. Only three of my participants said they were infected by their stable partners, but as I will show, through further discussions of their narratives, these accusations were not easy to prove. Although they blamed their stable partners for their infection, these men also had other, additional sexual partners at the same time.

A final point to be made about multiple partners concerns men who were married. As noted earlier in this chapter, having a wife was perceived as a significant achievement by most men. At total six men had wives before they became sick from HIV. All of them had at least one child with her. Being married, however, did prevent them from having other sexual relationships. All married men had at least one extra sexual partner outside marriage. My interview with Jozi explores why men followed this path:

> SM: Why was it important for you to have relationships while you were also married?
>
> Jozi: Ey! Here, that's why I say I can take a wife and stay with her here in the house. Then I leave and go to Bush (buckridge), and there I see another woman. We talk and we are in good terms, you see. And from there I go to another place and I get another girlfriend. And definitely you will want to sleep with all of them. You ask me why we do this! I don't know; I can say *isezintlitiyweni zamadoda* (it's in the nature of men) (Interview Jozi, 26 October 2006).

This, however, does not mean that men with extra-marital sexual partners are celebrated in the studied society or that they engage in such relationships in order to gain respect. Extra marital sexual relationships - as I observed them- were characterised by what I shall 'the paradox of acceptability and secrecy'. This means that, while 'everybody' knows that married men have extra partners and somehow accept this as a social reality and biological necessity, nobody wants to be open about it. Compared to single males, married men were generally secretive about their sexual affairs outside wedlock. They felt that they would be publicly demeaned, particularly by their in-laws, if they were found out to have an extra sexual partner. It is therefore not entirely true that African men have an unbridled permission to be promiscuous, irrespective of their commitments to

marriage. At least from the experiences of my participants and my ethnographic observations this was not the case.

Drinking

Thus far I have discussed masculinity in terms of how it was achieved by most men through engagement in three main activities, namely being an independent provider; having a healthy respectable body; and being sexually active with multiple women. This section focuses on another practice that was associated with performance or achievement of masculinity by certain men: Drinking.

Alcohol consumption has been noted as an important activity for achieving and performing masculinity by certain authors (Kaminer and Dixon 1995; Patman 2001; Peacock, Redpath et al. 2009). When a man drinks alcohol he communicates a message that he subscribes to a dominant social view that constructs drinking as a manly thing to do (not all alcohol consumption communicates the same message though. My observations among South Africans are that a man who drinks ciders tends to be perceived as being somehow feminine compared to men who drink beers or 'hard' spirits). Research conducted in Soweto Township shows that a man who does not drink is not taken seriously by other men. In private conversations he may be referred to in derogative terms, such as '*umfundisi'* or '*umzalwane'* (Mfecane, Struthers et al. 2005). These labels somehow imply that he is stupid or inferior to drinking men. A drinker on the other hand can be recognized by other men as '*iauty'* (streetwise) and may fit in easily into male peer groups. Thus there is pressure for men to drink in order to gain acceptance and recognition from their peers.

I began to think of these demands in relation to the situation of men who were using ARVs. One of the key messages that patients receive from support groups was that ARV users must refrain from drinking alcohol because it may have harmful health effects and may also interfere with treatment adherence. The first question that I pursued therefore was: to what extent do men in Bushbuckridge view alcohol as an important aspect of

their manhood identity, and how is a non-drinking man generally perceived and judged by drinking men? Is he seen as a real man? Secondly, what role did alcohol play in the lives of my participants, who are now HIV positive: Did they drink; was alcohol an important aspect of their lives? Did they associate thier alcohol consumption with beng a 'real man?'

To deal with the first question requires a brief departure from narratives and behaviour of men who are HIV positive, and to draw from interactions with other men in the community. While living in Kildare I befriended two men, a drinker (Lolo) and a non-drinker (Zizi). Zizi was a recovering alcoholic who turned to Christianity as an alternative lifestyle, after nearly losing his wife because of his excessive drinking. Zizi visited me occasionally at my place of residence and we spent much of our time together talking about my work and his own struggles to find a job. Lolo was my close friend and he also visited me regularly and we talked about my work and other social issues.

One Thursday afternoon I escorted Zizi after his visit. On our way we walked past Lolo`s house and saw him sitting outside. When we greeted him he simply nodded and then looked away. I was surprised by his reaction because Lolo is normally a friendly and talkative person and would always stop me to converse when I passed his home. On my way back I stopped at Lolo's place to chat with him. The first question he asked was '...now, Sakhumzi what are you doing with people like these?'. I explained that Zizi was helping me with local contacts for my research and that he is a friend. Then I followed with a question 'what is wrong with Zizi...is there something I should know?'. Lolo paused before answering me, and then said:

> No, there's nothing wrong as such. Just that people like Zizi are not my types of friends. I mean he doesn't drink; what am I going to talk with him? *Phela* that man talks the Bible all the time... Bible, Bible, Bible!! (Informal conversation Lolo, 12 May 2006)

This conversation seems to suggest that imbibing is recognized as an important indicator of someone`s 'real' manhood by certain men - someone who does not drink is not

considered a ‘real’ man. During my stay in Kildare my own acceptance into men`s circles was influenced by whether I drank or not. In my early days of fieldwork I spent much of my time travelling between Rixile clinic and Kildare and hardly interacted with men in the village. Men who saw me would simply greet and pass. My breakthrough into men`s circles happened through drinking. Two men that I met at a party took me to a local shebeen where we sat outside and drank. During the course of our stay more men came to join us and introduced themselves to me, saying they know me. Afterwards they visited me at my place and also took me out to other drinking places on weekends. I was both surprised and humbled by the experience, but it was clear that if I was a non-drinker I would have struggled to make friends.

Most of my participants said they drank regularly before they became ill. Only three of them – Lizo, Joe and Duma- never drank alcohol, and all of them belonged to Zion Christian Church (ZCC). Drinking, however, took on different patterns and meanings among men. Some drank excessively, spending long hours and nights in shebeens and other drinking places. For these men liquor consumption was an important part of socializing and relaxing. It was also a means of showing off to others, particularly women - flouting money and other material resources in order to attract them. Sam described himself as belonging to this category of drinkers. He said he was a ‘hard’ drinker who spent most of his spare time in shebeens imbibing with friends and women:

> Next to where I used to stay there is a shebeen, kwa Zita. You see, that place was always full. I used to stay there the whole night, drinking. And there were lots of women. We drank the whole night and when you go home you go with a woman…and these women! Women can drink, my friend (laughing). You find that you`re drunk, but a woman is still strong; watching you! [Laughing] (Interview Sam, 27 August 2006).

Mathe had a similar approach to drinking. He said using alcohol was a way of socializing with other men and meeting women. As a teacher he was a respected community member. Therefore, when he was in a shebeen he surpassed other men in drawing the attention of women:

> The thing is when you enter a shebeen you want to show who you are, and if you have money you fill the table and everybody starts to look at you… for me I drank a lot and I would go to a shebeen alone, but I would never go back alone [laughter]...I'm telling you Sakhumzi, I would never go back alone! (Interview Mathe, 09 February 2007)

Eight other men said they were 'hard' drinkers before they got sick. Among these, two belonged to ZCC, but this did not prevent them from drinking. For these men the social intake of alcohol was an important aspect of their male identity. Drinking happened in communal settings (like shebeens) and can be understood as a way to show off.

Other participants said they did not attach importance to drinking as part of their manhood identity. Most of them described themselves as 'mild' drinkers who imbibed at home with friends or in 'quiet' shebeens. Zola identified himself with this category of drinkers, saying:

> I wouldn't finish five bottles at a time; it killed me. I was happy with just two bottles; I would feel just fine…most of the time I drank alone; if I drink with someone it would be one guy that used to stay somewhere there (pointing). But I wouldn't drink five or six bottles, No…I couldn't manage it. The thing is if I drank too much I would get dizzy, you find that my eyes are closed and I can't see anything. So I decided 'No' (Interview Zola, 26 November 2006).

Magwa felt the same way as Zola. He said drinking was an important aspect of socializing with other men in the mines where he worked. Men gathered everyday in the bar after work. But unlike most men in the mines he drank occasionally and with a few friends:

> But it's not that I would walk and hunt for alcohol, No, I would just buy my own alcohol, you see. And we are maybe just two, or I am one. Cause I never really liked the noise, you see. A noise is something I never really liked, you see. Noise and that! No, I never liked that….I would just watch them, cause I was not raised up like that. I was raised up to take good care of myself; you see (Interview Magwa, 28 October 2006).

These different approaches to drinking are another way to illustrate that masculinity was not experienced in the same way by men. There are men who assigned importance to drinking as an important activity in performance of their manhood and there are men who did not. These differences are important to keep in mind for analysis that follows on in the next chapters. For example, are men who were 'hard' drinkers more or less likely to accept support groups messages to stop drinking? To what extent is masculinity challenged by messages to stop drinking and how do men respond to such challenges? How do men who stopped drinking view their manhood in relation to the past?

Alternative masculinities

This chapter has thus far focused on experiences of manhood that conform to the dominanly held social beliefs and practices regarding what it means to be a man, and it has shown that most of the participants subscribed and adhered to these definitions of manhood before they got sick from HIV. This section discusses other versions of masculinity that certain men subscribed to. The aim of this discussion it not to compare these different masculinities in terms of their social value or judgement, but to highlight differences that existed among participants regarding their gender beliefs. These differences are crucial for the analysis of various health decisions that they make in dealing with HIV illness.

The church[12] emerged in my interviews as offering alternative views on what it means to be a man. Firstly, churches do not encourage people to have multiple partners, instead they preach about monogamy as an acceptable sexual order. Someone who has several sexual partners is not seen as successful, as is the case in the community; instead he is viewed as being irresponsible. Lizo said: 'They tell us to have one woman, that it's not acceptable to have more than one partner. You shouldn't be found doing all these ups-and downs. You must be strict with one woman' (Interview Lizo, January 2007).

[12] There are several denominations; most of my participants belonged to Zion Christian Church (ZCC).

His views were echoed by other men who have since committed to church. For example Koko, a newly-converted Christian, belonging to ZCC, pointed out:

> For example, maybe we are dancing or so, and the minute we sit down they start advising us that 'you are still young; you mustn't rush after women. You must get one wife that you love and then you stay with her for the rest of your life'. They do try to guide us on those issues; you see (Interview Koko, March 2007).

Secondly, in addition to promoting faithfulness, the church promotes the idea of love and caring as the foundation of relationships. It is not enough that a man has a partner; he must love and take good care of her. Thus violence against women and other forms of assault are discouraged. Mathe elaborates:

> They teach us to live peacefully with our women, and if I want anything from her I mustn't use force to get it. For example, sex; I can't have sex with her if she refuses. I must talk nicely to her and tell her I want this. And then we do it if she says 'yes'. We don't fight, and if we have any problem as a family we must go to them as our leaders. We sit down and tell them our problems 'we have this problem and we need help'" (Interview Mathe, 9 February 2007).

Where the church shared the same perspective with the local community on definitions of manhood was in its emphasis on the provider role. In church discourse and rhetoric men were constructed as heads of household and breadwinners; women are subordinate to their husbands. Contrary to Vusi`s earlier suggestions, however, the provider role does not entitle a man to dominate and violate his wife. Instead he uses it to discharge his responsibility towards her and the family, as a carer, a lover and a protector. Sipho explains:

> You are supposed to arrive at your home, greet your neighbours, and at six o'clock you must be at home. You mustn't be outside home at around 10pm. What will you do if someone attacks your family? Or maybe you are attacked. What will you say in church?" (Interview Sipho, 24 October 2006).

There were also strong views that unlike in the community, men in church support each other during difficult times. For example, when a man is unemployed, others pray for him to get a job and when he is sick they visit and pray for him. Thus there is less emphasis on the attitude of toughness and independence that the society normally expects from 'real' men. Instead men are encouraged to be open. A man who hides his problems deprives himself of a collective help that is available through prayer.

The church seems to fill the gap created by a lack of cultural guidance that most men used to get from circumcision rituals. It church offers strict and direct guidelines on what it means to be a man, instead of letting men learn on their own or from peers. It must be noted, however, that not all churchgoers internalized these teachings from the church. For example, despite being raised in the faith, Mathe had multiple partners and he drank excessively; he was also an ardent believer in traditional medicines. Zita did the same and so did Tito, who joined church later in his life (before he got sick). Their identities as Christians had little influence on their everyday life decisions.

Two participants, who appeared to have deeply internalized these Christian beliefs about manhood, are Lizo and Joe (both belonging to ZCC). Both men said they lived their everyday lives according to Christian principles and that they do not succumb to social pressures to conform to what other men in the community do. Both men were critical of definitions of manhood in wider society. They opined that it promoted wrong messages which may promote multiple partnerships and excessive drinking.

> Lizo ...but there is this thing that if you have many girlfriends you are better. The thing is *siyaphikisana* – we compete. Say maybe the two of us are walking down the street. Now we must compete about speaking to the girls so that when we are together with other men I will laugh at you and say '*Ey ubhari wena uhlulekile yile ntombazana. buka mina, ngibambe 3; wena awubambanga nicks'* (Hey look how stupid you are. You couldn't win that girl. Look I got 3 and you got nothing).
>
> SM: So that makes them feel better as men if they have girlfriends like that.

Lizo: Yhaa, even if you go to the shebeen you will find some men that just come in and fill the table (with beers) so that girls can see 'he is the man!'. You find that he doesn't even sit down; he walks up and down. But the minute the money is finished he sits down... (Interview Lizo, 8 January 2007).

It is worth noting that these criticisms of the dominant social beliefs and practices about manhood were not limited to Christian men. Among other participants there were men who rejected certain practices, which are normally understood to enhance a man`s status. For example Thandi criticised men who pursue status and respect through having multiple partners, saying:

> If for example we are hanging together the conversation was always about women; always! It shows that basically there's no progress, you see. They didn't think much about the future. Cause if you did think 'what do I want for tomorrow', then you would think 'this will get me into trouble; this will lead me there, this will lead me there…'. So that used to make them proud, you see, that they are better than you… (Interview Thandi 8 September 2006).

Thandi said he focussed on one woman - whom he later married - even though he would occasionally be 'naughty' (having sex with another woman). Other men showed opposition to these beliefs and practices by refusing to drink excessively, or refusing to use traditional medicines, as is expected of 'real men' (chapter 4).

Lastly, the gap that normally exists between ideology and practice in men`s talks about their pre-HIV manhood needs to be acknowledged. Most men in my research had met key standards of 'real' manhood, as outlined in a society, before they sickened. However, we do not know what happened in their private lives in areas such as sexual performance and respect within the household. Were they good in sex? Did their partners and children respect them? This knowledge gap makes it difficult to make a direct link, in subsequent chapters, between being ill and loss of masculinity. Surely illness played a significant role in destabilizing these men`s lives, physically, socially and emotionally. But it cannot be singled out as a sole cause of these changes. In addition, some men in the villages who

are not ill also face similar problems as HIV positive men - for example unemployment, sexual underperformance and others.

It is also not my intention to attribute all of these men`s health choices to their masculinity. Hence in the next chapter I will provide more of their pre-illness lives, focusing on their health behavior. Here it will be evident that masculinity is one among several factors that influence health decisions and HIV risk behaviour. Someone`s health beliefs are a critical factor to explore in order to understand how he arrives at certain health decisions, including those decisions that place him at risks of acquiring life-threatening diseases, including HIV and AIDS.

CHAPTER 4

HEALTH BEHAVIOUR BEFORE HIV

> Well, men are like that... they don't pay attention to their own health, unless something is too painful, then they will come to the clinic. But if it's just a small thing he will just go and get some herbs. So, yes I was also resistant; I totally refused to come here (Interview Kenneth, 4 July 2006).

> Here when people get sick - maybe he has flu - because you do get flu sometimes - they go to the clinic and from there they go to traditional healers. They believe a lot in *izangoma* (traditional healers). Especially black people believe much in *izangoma*. Even if a child is sick they will go and throw the bones with *izangoma* and then they get medicine to drink (Interview Vusi, 28 February 2007).

Introduction

The previous chapter provided detailed descriptions of the versions of masculinity that the men in my study subscribed to before they tested HIV positive. I have shown that most men subscribed to dominant social views that construct masculinity in terms of a provider role, having multiple partners, and having a healthy-looking and respectable body. At the centre of these perceptions of manhood was the male idea of being powerful, controlling and respected, and most of them relied heavily on being an independent provider in order to achieve all this. I then reflected on HIV risks posed by various interpretations of masculinity, particularly the idea of having multiple partners.

This chapter builds on the previous one by looking at the health behaviour of these men before they sickened and did an HIV test. The health behaviour of the Bushbuckridge population was identified by health workers as being one of the risk factors for acquiring HIV and not using HIV services. As a result it was recommended as one of the key areas

that the newly diagnosed patients needed to change in order to maximise the effects of treatment. HIV positive men were encouraged adopt a 'healthy' approach to life: to stop smoking and drinking, use condoms, abandon traditional medicines, have regular medical checkups, eat healthy food, reduce stress and effect other changes. The main aim of imposing these changes is that ARVs alone do not offer a return to health unless they are supported by a patient adopting healthy and responsible behaviour.

This chapter explores to what extent these suggested changes are compatible with how these men lived their lives before they were diagnosed with HIV. I move from the premise that the health behaviour of someone is linked to his identity beliefs, rather than taking place in a vacuum; therefore a change in health behaviour is likely impact on his/her identity. My main interest is to focus specifically on how the idea of being a man may be challenged by the health messages provided by the ARV clinic. It emerged from my findings that most men were reluctant to use public health services due to their mistrust of these institutions. They perceive them to pose a threat to their manhood, whereas women were presented by participants as being more receptive to using public health facilities. This was attributed to the ways that they construct their gender. These health messages given at the ARV clinic are therefore likely to impact differently on men and women, depending on their different gender beliefs[13].

The chapter has four sections. Section one looks at belief systems about health, illnesses and deaths, as well as health behaviour before HIV testing. It asks the following questions: what general health strategies did these men employ; what types of medicines did they prefer and why? Section two investigates attitudes towards public health facilities: did men favour them; if not, what were their reasons for resisting them? How was their manhood challenged by using the facilities? Section three deals with knowledge, beliefs and attitudes towards HIV before testing: in the world of these men, was AIDS an important health threat; what were their attitudes towards HIV messages, like condom use? My interest in this chapter is not merely to describe these health

[13] This chapter is not comparing men and women`s different experiences and attitudes with health services. Its focus is on men and their previous attitudes to health. I discuss gender differences in order to highlight certain concerns that are specific to men.

choices and belief systems; I want to enter deeply into a social worldview that informs them. To this end, I will first look at health beliefs and practices at the community in general as part of my attempt to contextualize the pre-HIV health behaviour of participants.

Health behaviour in context

In order to understand how individuals make decisions about their own health we must first outline how the society in which they live views life, health, illness and death. Each society has its own worldview regarding the origins of life and causes of illnesses, diseases, deaths and these worldviews inform how individuals who are afflicted respond to their affliction (Onwuanide 1979; Okwu 1979). We do not respond in a vacuum, but society tells us how to feel about certain diseases that are in our bodies, and what are the right ways of addressing them, as well as what happens to our lives if we violate certain socially acceptable ways of dealing with our afflictions. Ultimately then, the choices that we make in addressing an illness can have a significant bearing on our social identity and membership status in the society in which we live.

In Bushbuckridge the existing beliefs about health are informed by a widely held worldview that takes seriously the important role played by supernatural forces in the lives of the living. These include ancestors, witches and God. Thus, when someone falls ill or dies or experiences a misfortune, it is not enough to explain his condition by reference to biological causes or a mere accident; instead locals seek for other explanations - commonly referred to as 'ultimate causes' - in addition to 'immediate' causes. Often there are many explanations provided for one's illness and these may change as an illness progresses or certain initial interventions fail to alleviate a person's symptoms of illness. Locals are therefore open to trying new things and are pragmatic and eclectic in their choice of medicine. Traditional medicines are however, considered as a necessary first step to address a health discomfort. This practice concurs with other findings from South Africa and other African countries (Feierman 1985; DoH 2004).

Some research has been conducted in Bushbuckridge that illustrates different ways that local worldviews shape reactions to health and interpretations of illnesses and death. Niehaus (2002) focuses on the notion of personhood as constructed and lived in Bushbuckridge, and the implication of this for the interpretation of health and other misfortunes, such as death. Through his detailed fieldwork data he casts doubt on the widely accepted view that a modern subject is an autonomous being, and that his body is exempt from external influences. His research shows that in Bushbuckridge subjects are perceived as being able to influence the health of another through contact with bodily fluids and other substances such as breath. Hence, locals have taboos, including sexual taboos, the purpose of which is to minimize bodily contact during high risk periods. This includes the prohibition on sex during the period directly after the death of a relative, or postpartum sex. Illness and death may occur when taboos are not observed, emanating from contact with these 'dangerous' substances, or as a consequence of the anger of ancestors. The implications of this worldview on how health is interpreted is vast: it means that illnesses are not always seen as originating from one`s biological vulnerability. Instead, breaking social norms and taboos can contribute greatly to ill health and even death.

The research of Posel, Khan et al (2007) is enlightening in the way in which it shows the importance of recognizing cultural beliefs systems and practices in dealing with interpretations of AIDS in Bushbuckridge. Based on research in Agincourt, the paper draws from interviews and focus group discussions with young and old people, with the main aim being to investigate how the respondents make sense of the proliferation of deaths in their area, as well as probing their understanding of AIDS. Results show that locals have no one explanation for deaths or AIDS; biological causes are acknowledged (including sexual links), but the interpretation is extended to link these deaths to the broader problems faced by the society. Key among these is a view that tradition is being eroded under a democratic dispensation, allowing sex to be conducted freely without observance of taboos and other forms of restrictions that previously regulated sex - for example those related to the death of a family member. What is biomedically known as

'AIDS' is therefore given the local interpretation of being *tindhzaka,* thus tracing its roots in violation of these taboos and erosion of culture.

Similar findings emerged from a research work by Golooba-Mutebi and Tollman (2007, p. 176), also based in Agincourt. Here the focus is on how residents normally respond to ill health and how this in turn influences their help-seeking behaviour. Findings indicate that:

> ...folk beliefs are important in decision-making concerning choice of therapy, with people adopting multiple strategies believed to constitute an appropriate response… the nature of the response to a particular affliction depends on its presumed severity or threat to well-being, as well as beliefs regarding cause and effective intervention

Key among these health strategies used by locals is the use of traditional medicines. The authors found that among locals, western medicine was used as a last resort. The common practice was to begin by consulting local traditional healers or spiritual healers; when all else failed a patient was taken to a hospital. There is however some flexibility, with patients being pragmatic in their choice of medicines. Thus when an illness is believed to be better managed at the hospital, people are likely to consult with western doctors as a first step towards addressing it.

This brief discussion of health behaviour at a community level, and the world view that informs it, provides a useful background for an analysis, and interpretation of the previous health behaviour of my participants who are living with HIV. In the remainder of the chapter, I look specifically at their health behaviour and whether or not it conformed to these social ideals before testing. I begin by looking at their choice of medicines.

Choice of medicines

The majority of my participants subscribed to the above world view before they tested for HIV, and their choice of treatment reflected their commitment to it. Out of 25 men, only one had no experience of using traditional medicines. Lizo belonged to ZCC church; he said as a family they believe in God and do not worship ancestors or use the use traditional medicines. When someone falls ill in his family he/she is taken to the hospital or they pray for him/her. His mother, Mrs Ndlovu, whom I interviewed, confirmed this practice saying:

> We don't go to traditional healers. I do get sick myself, but I don't even go to the hospital; I just sleep and I wake up feeling better. And here we pray; this family is a praying family – my mother, my children, all of us… (Interview Mrs Ndlovu, 19 March 2007),

Other men said they were regular users of traditional medicines, either out of personal choice or being made to do so by family members. Traditional healers were consulted for various reasons, such as 'strengthening' the household; protecting someone and his family from evil spirits (such as witches); treatment of illness; and various other personal needs. Some of my participants said they have expertise in traditional medicines that they gained from childhood through assisting their grandparents who were either traditional healers or experts in medicines. Thandi, one of them, said:

> Yes, I used to…because my grandfather was a traditional healer. So he would ask me to go and dig a certain herb and use it to treat people. Since he died I lost contact with that world. But if I feel weak or so I do go and get something, maybe a certain herb that I know. Even now I still do that (Interview Thandi, 11 January 2007).

My interviews about pre-HIV treatment choices began by asking the men: 'Where did you go when you felt pain or had a physical discomfort?' Most men said they used traditional medicines as a first step to address an illness or physical discomfort; if the problem persisted and was felt to be serious they proceeded to the hospital. But this did not prevent a person from continuing with traditional medicines even if he was using

western medicines. The two forms of treatment were often used interchangeably or concurrently where there was a felt need to do so.

This extract from my interview with Magwa is an example of how most of the men dealt with a health problem:

SM: Most of the time did you go when you felt pain or discomfort?

Magwa: I would start with traditional medicine, and if it doesn't work I proceed to the hospital... *angithi* you go to the *inyanga* (traditional healer); maybe you know a certain *inyanga*, and you tell him 'Hey man, something is not going right here'. And he goes and digs some medicines for you. And you drink it, you see.

SM: Why not go to the hospital first? How do you decide?

Magwa: No, *angithi* you must first try this one, and if it doesn't work you try the hospital…

SM: [Laughing] why not start at the hospital?

Magwa: No, it doesn't happen like that; you start here! [Laughing] And then you feel 'Ey this one doesn't work', and then you can run to the hospital, and then to Rixile, you see. The hospital does help because sometimes you need some blood (drip), you see, and they give you blood. But *inyanga* will never give you blood; you can only get blood from the hospital, you see.

SM: But according to your own observations would you say there are differences between men and women in using traditional medicines?

Magwa: They differ because men favour traditional medicines a lot, and women favour the hospital. You see, it's like church, you see; you'll find one or two men but the majority are women. Most of the time men are found in drinking places, you see; women are in church. The thing with women is that most of the time *bayavisisa, abaselukhuni* (they listen, they are not stubborn). But men are stubborn. Because you can go to church and find that there are too many women, you see; but there are only two or three men. You find that the house is filled with women and their children (Interview Magwa, 4 October 2006).

Here Magwa presents his preference of traditional medicines as if it were a common sense and an unquestionable choice. The gender differences that he alludes to with regards to medicine use are explored later in the discussions.

Mathe also believed strongly in using traditional medicines before he tested for HIV. I asked him where men typically go when they are ill and whether he followed the same route and he replied:

> Well, generally men don't go to the hospital. They rely on herbs from the forest; that's what they believe in. I also used to believe in that, you see; that if one is sick all he does is consult a traditional healer. That's what I used – just going to get some medicine to cleanse myself, vomit and spading, and I know it will all be gone. It will all be gone. Sometimes I would steam. So that's what I trusted in (Interview Mathe, 9 February 2007).

Mathe said he could not remember exactly when he started using traditional medicines because his entire family relied on it and he must have started using it from childhood. As a result when he got sick he was taken to traditional healers in Bushbuckridge. His family thought that he was bewitched or he had *tindhzaka*.

In addition to these two men, 22 other men had used traditional medicines before. But for the purpose of analysis that follows in the next chapters, we separate men who used traditional medicines and were committed to them, from those who used them passively without assigning special significance or identity meaning to their use. This separation is critical for analyzing subsequent reactions to ARVs and other support group messages on adherence behaviour. Four of my participants said they belonged to a category of passive users. Sabu, Joe, Jozi, and Koko said, while they knew traditional medicine and had used it before, they had an indifferent attitude towards it. In fact all of them said they preferred western medicines. But during the time that they were their ill, family members 'forced' or persuaded them to use traditional medicines. These men presented themselves as having had a different approach to health compared to their peers or family members.

For example, Sabu said he never took seriously the 'tradition' of cleansing himself, as other people did:

> No, I never used these things in my life. I never did this habit of cleaning myself by vomiting and spading; I never did those things. I used to smoke, drink, and I used to love women and all that. But I never really loved these things in my life. Even now they forced me to drink these things, and you find that at other times I wouldn't drink them, you see. They would ask 'why don't you drink them?', I said 'I just don't like them'. Now they say 'we are just wasting our money'. And I ask 'why don't you take me to the hospital where I can get a better service?' I ended up fighting with my sister, that 'these things that you are giving me will not help me (Interview Sabu, 11 October, 2006).

Here Sabu constructs himself as having been similar to other men in term of his overall masculine behaviour – drinking, smoking and loving women. Where he differed fundamentally from them was in his choice of medicine. His reference to traditional medicines as 'these things' indicates his lack of conviction about their efficacy.

Joe said as a Christian he was naturally inclined to dislike traditional medicines in favour of prayer and ZCC tea[14] or western medicines. But his family - some of whom are also Christians – had a tendency to occasionally persuade him to use traditional medicines for various reasons. I became aware of this during one of my visit to his house in May 2006. Joe had spent a month at the hospital recovering from TB. On the day that he was discharged he called me and I made an arrangement to visit him. Joe lives with his wife, but when I arrived at their house neither were there; his brother-in-law who was in the house directed me to where Joe was, at his brother`s house. On arriving I asked Joe why he is not at his house, and the following conversation ensued:

Joe: My family said I must stay away from that house for now

SM: Why?

[14] ZCC tea is given to the congregation as part of daily management of health. It's believed to be blessed with healing powers. ZCC members always have it and drink it on a regular basis.

Joe: *Ey angithi lapha kuse makhaya* (the thing is we are living on rural areas). So people feel that if someone comes from the hospital he can't just go back because it's possible that while you were away some people have placed some evil spirits there

SM: So do you believe they have placed it at your place, for you?

Joe: Well, *basho njalo abantu abadala* (That's what the elders say). They say my house may be infected with some evil spirit

SM: But there are people staying there right now? (Referring to his brother-in-law)

Joe: Yhaa, there are people there…

SM: So why doesn't this also affect them, I mean they are there?

Joe: *Ey angithi thina bantu abamnyama* (we, black people)…they say when they put this thing there; they call it by your own name. So, for example they can put it on the road where people walk and when you stumble on it nothing will happen; but if I stumble on it I get infected, because it was meant for me… (Informal conversation Joe, 4 May 2006).

Joe constructs himself as having been passive and powerless in the whole process of 'cleansing' his house. His use of the phrase 'they say…' situates him as an outsider rather than an active participant in the process. I think that the main reason why Joe agreed to let a traditional healer cleanse his house, against his own beliefs, was because he did not want to offend his family, which has been supportive to him throughout his battles with HIV illness and also accepted him unconditionally when he disclosed to them. Posel (2006) also reports similar findings on someone who received support from her family – through paying for the medical expenses to a local traditional healer - and then found it difficult to resist further association with a traditional healer after receiving help from the hospital. The family believed strongly that she was cured by a traditional healer while in reality she was using ARVs from a public hospital.

We should also not underestimate how being sick can take away power from a man to make his own choices, independently of others. This emerged clearly in my interview with Jozi, who, like Joe and Sabu, said he was opposed to traditional medicines before he

got ill. When he got sick he was forced by his mother to use traditional medicines against his will:

> I got sick, and then I came back (home from workplace). But on coming back they didn't take me to the hospital; they took me to *abantu abamnyama* (traditional healers). I used their medicines, but I wasn't getting better. Then in 2001 they took me to another traditional healer. Now this guy said we must bring a white chicken. We brought it, and what he did was that he boiled water, threw it into the bath, added some *umuthi* into the bath. And from there he made this chicken drink this water. He then squeezed this chicken until it died, and then he opened it and said: 'Ah! This person is sick; his lungs are all rotten, just look at how the blood of this chicken runs on its lungs'. Ey! I was very angry man; I told him: 'You can`t compare me to a chicken; I'm not a chicken'. And from there I left them, I went back home; and they found me at home sleeping. Now they still came with these medications – some needed to be boiled. So they left it just next to where I was lying. There was a fire, and I waited for them to leave. After that I just took all that *imithi,* threw it into the fire, and added some more wood. My mother was upset; she said: 'What should I do now?' I said: 'No! I'm not going to drink this; I would rather die at the hospital (Interview Jozi, 25 October 2006).

It is interesting here that Jozi was forced by his mother – a weaker gender – to use traditional medicines. This illustrates how much power and control he had lost over his life as a result of being ill. In Bushbuckridge women are generally constructed as a weaker and inferior gender irrespective of their relationship status to a man and they normally do not have authority over a man; and here, Jozi`s mother appears as a forceful and dominant figure who makes decisions for him. Later in the thesis I will return to point about power loss experienced by these men, arguing that one of the reasons why certain men decided to test was because they wanted to regain sense of being powerful and in control that they had lost from being sick, through having access to ARVs and not being dependent on someone else to pay for their medical expenses.

These narratives present us with three positions adopted by men towards traditional medicines before they tested for HIV. First there was a group of men who were fully

committed to traditional medicines and perceived them as an important component of their lives. These men regularly used regularly traditional medicines to manage daily health and did not favour western medicines. Secondly there was a group of men who had experience of using traditional medicines, but did not attach significance to them. These men preferred western medicines. And then there was Lizo, who had never used them before, due to his religious beliefs. These different approaches are important to keep in mind for the analysis that follows in chapter 7 on how men are responding differently to ARVs and other health education messages given at the ARV clinic. For example, are men who were committed to traditional medicines likely to resist ARVs? Do men like Jozi see ARVs as a welcome relief from traditional medicines which they previously detested?

Manhood and use of traditional medicines

It has now been established that the majority of men in this study chose traditional medicines over western medicines before they tested for HIV, though with varying commitment to it. My next discussion interrogates the reported gender differences with regards to these choices. During interviews and other informal conversations I was told that men were generally more committed to traditional medicines than women and they were described as being 'stubborn' in their preference and unwilling to experiment with other therapies. A man who believes in the power of traditional medicine adheres to it irrespective of whether or not it suits his present health condition. Women, on the other hand, were described as 'flexible', 'easy-going', and willing to try new things. They were pragmatic in their choice and they used what seems to work at a particular time, rather than commit to one type of treatment. They did not appear to be opposed to western medicines on principle.

These findings are not new and they have been explained previously by referring to the fact that women are exposed to western medicines earlier in their lives and more regularly than men, through their use of reproductive health services. Men on the other hand hardly use these services except when they become very ill or suffer injury. This

argument, however, is limited because it focuses on matters of access and exposure as key factors that produce gender differences in choice of medicines. My findings suggest that we can explain this gap in a far more nuanced manner if we focus on meanings that men assign to medicines in terms of their manhood and their cultural identity. The access/exposure argument is useful as a starting point, but it fails to explain why, even when men and women have equal access to, and knowing about effectiveness of western medicines, men would still reject them in favour of traditional medicines. McGregor (2005) investigated this problem, focusing on Khabzela, a popular South African DJ who died of AIDS despite having access to ARVs, which he stubbornly rejected in favour of other therapies (traditional medicines; concoction of medicines to boost immune system, and others). She found his decisions to be influenced by deeper identity issues than whether or not he knew about, or had access to ARVs. I elaborate further on some of these identity dilemmas.

My research findings indicate that when men make decisions about treatment these decisions are not merely based on whether or not a certain treatment intervention works, or whether it is accessible to them. Instead, men engage in various calculations that take into account how a choice of treatment would impact on their social image as a man and an African. The dominant view shared with me was that commitment to traditional medicines was associated with commitment to one`s cultural identity. Therefore when a man chooses traditional medicines over western medicines, he communicates a message that he shares in the heritage and tradition of his society, as opposed to consuming things 'foreign' and 'white'. Men therefore interact with medicines further than the question of efficacy or access; they worry more about their image and cultural identity in addition to whether or not a treatment works. In order to unpack this observation, let us depart briefly from stories of my HIV positive participants and draw from conversations that I conducted with other men in the village. I will then return to these men to illustrate whether prior to testing they adopted similar positions to others in the village.

One of the conversations that I had, which made a link between medicine choice and identity issues, was with Mr. Manzini, a local traditional healer. Mr. Manzini, a man in

his late 60s is known in Kildare as a 'very educated man', having received his MA degree in Education from Australia. He is also known as a staunch 'traditionalist' and a polygamist. I visited him one evening in June 2006 - accompanied by Lolo - to talk about my research and solicit his views about it. During our conversation we talked in depth about men and their approach to health. I posed two questions to him; firstly where do men normally go when they are ill, and secondly; what motivates them to make that choice? Mr. Manzini was quick to answer my questions. He said men preferred to use traditional medicines '...because they are our medicines'. He contrasted these medicines with western medicines which he described as 'white medicines'. Mr. Manzini said men 'were proud' of their identity and culture, therefore when they choose traditional medicines over western medicines, they want to safeguard their pride.

These views seem to suggest that when men use western medicines something is taken away that defines their cultural identity. Mr. Manzini framed his argument in completely racist terms, saying whites could not be trusted with their medicines:

Manzini: In my view traditional healers should be working together with western healers on this (AIDS). Because there are things we can do best and there are things they can go best. For example, our medicines tend to have cleansing effects because they are holistic. Now if you continue giving them despite this (the low CD4 count) then you are actually killing the person. You must refer him to the doctor. And ideally the doctors should know what we are using, we should show them. But I tell you, traditional healers would never allow that.

SM: Why; why if it is the better way?

Manzini: Mfecane, these people cannot be trusted. You show them your medicine and next thing they take it away and you'll find it in the chemist. Mfecane, do you know that what is called white medicine is in fact our medicine? The medicines started here in Africa…here in Egypt. Whites come here and took our stuff overseas, and they claim it as theirs. They call us barbaric, yet they take our very own stuff and use it for themselves' (Informal conversation, Mr Manzini, 13 June 2006).

This conversation seems to suggest that the so-called 'male resistance' to western medicines is informed by deeper issues than lack of knowledge, limited access, lack of exposure and other structural barriers normally cited by researchers. Here Mr. Manzini is drawing attention to a deep mistrust that men hold towards white people and their medicines (see Posel, Khan et al. 2005, for prevalence of this mistrust in the community). This mistrust is what informs the responses of men to western medicines, when these are being presented to them as a cure. It is beyond the scope of this thesis to examine the historical roots of this mistrust, but it seems to originate from the way white doctors have historically (and still) dealt with indigenous knowledge systems. Most people said white doctors have no respect for local cultures and indigenous healing systems. Instead they impose a western approach to the management of diseases, some of which require 'local' explanations and cures. As a result people die in hospitals because white doctors use 'incorrect' medicines.

Men therefore argued that if they committed to white medicine it would be tantamount to collaborating towards destroying their own culture and ways of life, while simultaneously promoting white culture. Commitment to white medicines would further signal a sense of defeat and lack of trust in their own ways of life. In my numerous conversations with men and traditional healers they constantly mocked western medicines and described them as a 'waste of time for treatment of local ills'. Mr. Manzini was a proponent of this view, saying:

> Western medicine cannot remove the germ. All they can do is give you some lifetime medication which can only make it sleep. But we remove it completely; I tell you Mfecane; we remove it completely. I can tell you of two diseases that western medicine cannot treat: cancer and epilepsy; those two! I tell you they can't treat them. But we can treat them… If you have cancer here, all whites can do is to remove the breast. Now you see lots of white women walking around with one or no breasts… (Informal conversation Mr. Manzini, 13 June 2006).

Similar comments were made with regards to treatment of AIDS. Traditional healers said unlike western doctors who gave patients lifetime treatment, they could remove the HIV virus from the body of a person. The problem was that patients took longer to consult them; by that time the illness was already too serious and could not be cured. Out of seven traditional healers that I visited in Kildare, five claimed that they could cure HIV.

There were however, cases in which western medicines were accepted as being a preferred form of treatment. For example, while living in Kildare I organized a focus group discussion with five community elders and asked them to share their understanding of AIDS, health and treatment in general. All of them were in agreement that western medicines were effective in managing asthma, but not effective in treating other diseases like epilepsy and cancer.

Among my participants who are HIV positive, only one man was open about his criticisms of western medicines and the threat that they posed to his identify. Senzo said although he is a 'true African' he was open to using western medicines, but not fully:

> Sakhumzi, I am a True-Blooded African, I'm a True-Blooded African. When coming to medication and everything I believe in Western culture; I prefer clinics and hospitals. I don't know, maybe it's because I've been exposed; I've learned and everything. I've seen the difference. All in all, in most cases – I don't say I don't go to *inyanga* (traditional healer), No, there are other misfortunes where I consult *Iinyanga* (plural), but I can say 70% I prefer hospitals and clinics, then 30% it's my culture, it's my roots. I cannot run away from that [laughter]. Yhaa… (Interview Senzo, 12 July 2006).

Senzo`s characterization of the '*iinyanga'* medicine as 'my culture; my roots' confirms the point I made in this section, that medicine choice is linked to identity issues. Senzo feels that despite being committed to western medicines, he must make room for his 'roots'. These roots define who he is and they affirm his belonging to the African society. His statements that 'I've been exposed; I've learned and everything; I've seen the difference' supports the model of exposure that I alluded to above, but surely it is not

enough to explain why men choose traditional medicines over western medicines, at all costs.

Other men did not make a direct link between their previous commitment to traditional medicines and their cultural identities. Nor did they express a previous dislike of western medicines or western doctors, as did the men that I spoke to in the community. Instead, their choices came from the fact that they were not used to western medicines or to being sick in the first place; most of them relied solely on traditional medicines to manage their health. Mathe told me '...yhaa, my trust was in '*imithi yesintu'* (traditional medicines); I wouldn't even think of these things (western medicines) when I'm sick' (Interview Mathe, 9 February 2007).
And Magwa said 'because you are used to this, you want to use it all the time. And you don't know that one (western medicines)…and you are stubborn; you are stubborn (laughing)' (Interview Magwa, 4 October 2006).

The discussion on choice of medicines shows that most men chose traditional medicines over western medicines before they tested for HIV, in conformity with the general social norm. This choice is viewed by certain men in the villages as being linked to how they construct their cultural and manhood identities. Among my participants, however, one person openly justified his choice of traditional medicines on the basis of his identity as an African; other men perceived it as 'taken-for-granted'; it was part of their upbringing and socialisation into a family and societal culture of help-seeking. There were however varied levels of commitment to traditional medicines. Some of the men, a minority, were not entirely commitment to traditional medicines, while others wholeheartedly embraced them. The impact of these differences on men's responses to HIV illness symptoms and commitment to ARV treatment will be explored in the next chapters.

Men and Public health settings

> …Men don't want to appear weak in front of women. Now the hospital is full of women. You go there and everybody sees you 'look, so and so is here'...now that's why they run

to us, because traditional healers work with one or two clients at a time... (Informal conversation Mr Manzini, Kildare, 13 June 2006).

This section looks at how men felt about using public health facilities before they tested for HIV. Health facilities, as shown earlier (chapter 2), are normally shunned by men for various reasons. Key among them is a widespread perception that they present a threat to their manhood because they are dominated by women in terms of staff and clients. Men therefore perceive them as 'unsafe' places to use for health problems. Findings from my study indicate that most of my male participants were reluctant to use public health facilities before they tested for HIV. Reasons for this varied among individuals. Some men saw no need to use them because they were committed to traditional medicines; others shunned them deliberately because they perceived them as feminine spaces; others claimed that public health facilities lacked privacy and confidentiality, as well as competence to deal with a variety of health problems that the society experiences. I will explore these various reasons below, starting with the idea of a clinic as a feminine space.

Clinic as 'indawo yabafati' (a place for women)

I became aware of this perception for the first time early in my fieldwork through having a conversation with Mr. Khoza, an Induna based in Kildare. Two weeks week after I settled in Kildare, Mr. Khoza organized a community meeting to introduce me to the community and then encouraged them to participate in my research. During the meeting most men showed enthusiasm towards my study and pledged individually that they would participate in it. Two days later I visited Mr. Khoza at his home to talk about the meeting and how men felt about my research propositions. My visit ended up being a discussion about men and their health behaviour, focussing specifically on why they resist the hospital:

Khoza: I can tell you, men have issues with this (using hospitals). That day after the meeting they started talking '*Ayi phela thina ngeke siye esibhedlele. Ma ufika khona phaya kugcwele labafazi…Ngcono sigule side sife* (we will never go to the

hospital; that place is full of women. We would rather get sick until we die). Men have too many problems but they keep quiet…

SM: So people have a problem with the fact that there are women there?

Khoza: Yhaa! And the fact that these are young women. They say '*futhi laba nurse ngabantwana; basebancane. Manje thina sijwayele imeko yase mayini* (these nurses are even young; we are used to a situation of mines). Some of these guys worked in mines before.

SM: So in the mines they were treated by men?

Khoza: Yhaa in the mines doctors are men...

SM: But some traditional healers are women. Do men not have a problem with that too?

Khoza: With traditional healers they don't have a problem because it is often an older lady and older women will not laugh at your problem. The younger ones! They will be pointing at you saying 'look at him...'. That's why men say they would rather die (Informal conversation Mr Khoza, 4 April 2006).

This conversation reveals two main reasons why men shun public health facilities: the fact that they are dominated by women and the fact that these are young women. Men feel that these women are gossiping and probably disrespectful of them as elders. It is therefore seen as 'safer' to consult an older woman or to stay at home, rather than face the embarrassment of being gossiped about or disrespected by young women.

The health care centres in Bushbuckridge are situated in the villages where people live, so this further exacerbates the reluctance of men to use them for fear of being seen by other people. At the mines, on the other hand, it seems as if health care was a more private affair; as a result men were more open to using them when they were sick. Alternatively, they have fewer options in the mines compared to the villages, where they can choose between western medicines and other systems of care. Let us look closely at how the idea of a clinic as a 'place for women' discouraged some of the participants from using it before they tested.

Thandi said his main fear about using his local clinic was that he would meet a woman that he knows and she would undermine him:

> The main problem that I see is that most of the nurses are young girls; they are still young. And sometimes you'll find that you know her, and you were studying with her at one stage. And men don't want to be treated by those girls. That's why I said it's better if it's an older woman, you see. Or maybe you studied with her…and maybe at school you were arrogant, you see (like I was arrogant I used to think of myself as being better), you see…Now when she sees you there she will come and ask 'Hey Thandi; what's the problem?' And you will be embarrassed now, looking down, saying 'No, I'm OK I just came to look for sister 'so-and-so'. Now you are sick, but you don't want to go down on her (*awufuni kuzithoba*!). And then you will try and figure out 'when is she taking an off?'; you don't want her, you really don't want her [laughing] (Interview Thandi, 11 January 2007).

There is something significant in a statement 'you don't want to go down on her'. Thandi seems to suggest that if a man submits to a female nurse he is somehow lowering his status. For him, his status would be lowered by submitting to a 'girl' that he previously undermined during school days. At the hospital she is in a superior social position than him and Thandi feels that he would rather avoid her than risk losing his status to her.

My interviews revealed that Thandi was not alone in having this fear. At the centre of the problem is that men are used to occupying powerful and controlling positions in the household and the community. In community meetings that I attended in Kildare men dominated the discussions; women sat passively and made little or no contribution. At a health facility the roles are reversed: women control things, they give instructions and men must follow and obey. The threat imposed to men by this latter set-up was summed up by Joe and Lizo in my separate interviews with them. Joe said:

> The problem with men is that when they come to the hospital they become too low (*baba phantzi kakhulu*). They don't have the same power that they have in the house; now men don't like that... (Interview Joe, 23 May 2006).

Lizo made similar comments that alluded to a loss of power, saying:

> The problem with us men is that we like to think of ourselves as being better – *sithanda ukuzibeka tulu.* Men don't like to be told by a woman that 'I have this; we need to use this and that thing'. You find that most men don't want to listen to women. It's as if they will feel weaker. And he will hide his sickness from her to avoid that feeling (Interview Lizo, 8 January 2007).

These comments take us back to the assertion that I made earlier in the thesis that experiences of manhood are bound up with feeling powerful and dominant. Here power and dominance are felt to be under threat due to being subjected to a woman – a weaker gender – for help. I had the privilege of attending support groups where I observed clearly this sense of loss of power experienced by men in public health settings. Here women control things: they are facilitators; they are 'expert clients'; they lay the rules and they generally do more talking than men. Men normally sat on the back row and they talked mainly when being asked by a facilitator to share. Most of my participants complained that support groups favoured women in terms of structure and content. More discussions about these support groups on how they challenge masculinity, as well as how men are responding to these challenges will be carried out in chapter 6.

Apart from feeling weakened and emasculated in the presence of women or distrusting them, some men raised certain 'practical' concerns about using public health facilities and being serviced by female health workers. Chief among them was that a man finds it difficult to open up to a female health worker. For example, if a man has genital problems or sexual difficulties he cannot easily communicate them to a woman. Senzo said in principle men are not opposed to using public health facilities; the problem is that these facilities are insensitive to their concerns:

> Like a typical example, they say they have problems with STIs, but when they go to see a nurse at the clinic most of them are women. And then when he gets in most of them are young, he cannot take out his penis and show this child 'my penis has 1, 2, and 3'.

> They're just a bit shy, yhaa. But if maybe there is a particular place where a male nurse can come, they share with them, they will feel comfortable. That way there would be freedom of expression, a freedom of association… (Interview Senzo, 12 July 2006).

I know one man who decided to 'self treat' because he had difficulty showing his genitals to women. I met Brian once in a support group at Cottondale clinic and I was still recruiting him into the study when I met his cousin, who was with him at the clinic during our meeting, and he told me Brian died. During the support group discussions his carer told a painful story of how Brian refused to come to the clinic for STIs because he was 'scared' of nurses. She said Brian decided to self-treat, using a pair of pliers:

> I found him at his home in great pain. He didn't want to come, but his balls were this big (showing with hands), he couldn't even walk. So what he did was that he used pliers to try and remove 'water' from inside, but it didn't help...I pleaded with him to come…in the end he came (Focus group observations, 23 March 2006).

At the end of the support discussion Brian asked me to give him a lift to Acornhoek. On our way I asked why he was refusing to come to the clinic and he replied: 'yhaa, it's full of women here. Now all these women will be looking at you. So, yhaa, I used that pliers' [laughing]. I know four men from my study participants who refused to come to the clinic for the same reason as Brian, but none of them went as far as he did. Instead they consulted with traditional healers. Traditional healers are known locally as having expertise in dealing with STIs compared to western doctors. Most importantly, some of them are men.

Lack of privacy and confidentiality

Perceived lack of privacy and confidentiality in public health facilities was another reason why men resisted them. Firstly this fear comes from the fact that users know each other, as they come from the nearby villages. It is likely that when someone is at the clinic he will be seen by other people from his village – including family members or in-laws - who may gossip about him. Men expressed more concern about being seen at the

hospital because, unlike women who may be there for other reasons, such as contraceptives or collecting medicines for a sick child, a man who is at the hospital is surely sick. Others will therefore want to know why he is there and then speculate about his sickness, based on the physical symptoms.

It seems as if being sick in a public place was not good for a man`s image; it contradicted the understandings of manhood as a strong, powerful and healthy gender. This embarrassment must however, be put into context. Personal stories shared with me indicate that not all illnesses were perceived as embarrassing, nor do men worry about confidentiality in dealing with all forms of illnesses. It seemed as if the embarrassment was felt more when an illness had physical manifestations such as facial rash, loss of weight, impaired physical activity, and others. These symptoms can be read quickly to deduce that someone has AIDS. In addition, when someone is weak physically or has other disgusting physical symptoms he develops self-judgment, a feeling that the 'whole world' is looking at him and laughing. For these reasons he decides to refrain from using public health facilities.

Lizo said the tendency to laugh at a sick person is common among men and it is due mainly to how someone looks; it is the main reason why sick men 'hide' their sickness:

> The truth about us men is that we like to laugh at each other (*siyahlekana*). And you will notice that when men come here to the clinic they don't just come directly. They come through the back because they are scared of being laughed at (Interview Lizo, 8 January 2007).

Perhaps more important to highlight is the observation that this 'laughter' does not begin or end at the hospital. The whole journey to the health facility and back is fraught with risk because someone must use public transport and will then be seen and judged by others as having AIDS, based on his physical looks. Lizo elaborates further on this point:

> Lizo: It's like if we are in a taxi and a person gets off, they start talking about him, that 'you see this one that just jumped off; he's finished, he wasn't like this before.

He has this and that problem' (AIDS). Now everybody knows, and when these young people get to know about your condition they will be pointing fingers at you as you are going about your own business.

SM: But how do they identify you, that you have HIV?

Lizo: Well, they look at your body; as soon as you start to lose your weight they make speculations about you. And also you have people that come to Rixile just to look at others, to see who is here (Interview Lizo, 8 January 2007).

This quote refers to the fear of being stigmatised and gossiped about because of looking sick and thin. In chapter 5 I will pay a closer attention to the problem of HIV stigma and the effects that it has on testing decisions of a sick person to go out and seek medical help. It will be evident that the longer someone stays away from the public because of being embarrassed, the worse he becomes and the more difficult to go out and access treatment. In the end, medical help is sought as a last resort when someone has tried out other treatment options and is facing death.

Mistrust or lack of hope in public facilities

Lack of trust and hope in public health facilities was mentioned by some my participants as another main reason for resisting them. The dominant view held by these men – which was shared by numerous other people in the community that I conversed with - was that hospitals cannot be trusted with peoples' lives. According to these participants, people entered hospitals looking healthier, but left either dead or looking worse than before. A few cases were shared of family members who either died at the hospital or came back looking worse. These experiences discouraged some of my participants from using the hospital before they got sick and tested.

There were also fears that the hospitals can deliberately 'finish you off', particularly if someone is already too sick. Kenneth said the fear of being 'finished off' was the main reason why he resisted the hospital while he was sick; he consulted a traditional healer in Phalaborwa, more than 100km from his home. We were chatting about men and why they are not coming to the hospital, in the presence of his partner Joyce, during one of my

visits to their house, when Joyce suddenly changed the focus from other men to Kenneth himself, saying he too was resisting the hospital: 'He was the same as those men he is talking about; he was also refusing to go there; he`s here I'm not gossiping about him. He was completely refusing; his brother had to threaten him'. I asked Kenneth why he was resisting hospital and he said '*Ey banokubulalana le esbhedlele* (they can actually finish you off in that hospital)' (Informal conversation Kenneth and Joyce, 9 August 2006).

Aside from the mistrust in public health services, men generally had no hope in the hospital. This emerged clearly during my interviews on what finally prompted them to go to the hospital after resisting for a long time. Six of my participants said their decision to finally go there was prompted by the feeling that 'I would rather die at the hospital'. This statement seems to suggest that the decision to visit the hospital was not based on the hope that they would get help or be cured. Instead it was a sign that they had given up completely on life. These men must have fought hard to resist the hospital because they perceived it as 'a place that kills' or 'a place for women'. But with traditional medicines not helping them they felt it was better to die at the hospital than in the hands of a traditional healer. Death which takes place at the traditional healer is shameful compared to that which occurs at the hospital[15]. Traditional healers themselves do not allow patients to die at their places because it affects their business and their reputation[16]. Thus they would treat someone until she/he is terminally ill and then refer him to the hospital 'to receive drip'. In the end they can be absolved of his death and the blame is laid entirely on the hospital.

Ironically when someone recovers at the hospital, traditional healers are quick to take credit for his/her recovery. A traditional healer can argue that he treated the person but he/she merely needed a drip, which he doesn't have, hence a referral to the hospital. In fact when a patient is sent to the hospital she/he is instructed to come back and be

[15] I find this to be a contradiction because on the one hand traditional medicines are used widely by most people, but on the other hand there is secrecy associated with their use. Hence when someone dies at the traditional healer it becomes a shame.

[16] This came through in a number of my interactions with traditional healers. For example, one female traditional healer I visited said 'I cannot keep dying people here. If they die in my own hands then my business is affected' (Informal conversation, traditional healer, Kildare: 26 April 2007).

monitored by a traditional healer. I am aware of a traditional healer based in Lilydale who claimed to have treated someone who was HIV positive, while this person was in fact using ARVs from the public clinic (see also Posel 2007). I attended an occasion in August 2005 where he invited his congregation (he was also a priest) to come and celebrate his 'success'. Had the person died, her death would have been attributed to the 'incompetence' of the hospital staff than his own incompetence.

In the next chapters, the distrust and dislike of the public health facilities will be explored in relation to various decisions that men make, such as testing, disclosure, treatment adherence, etc. Do these perceptions change as soon as someone receives help or do they remain the same? If they do change, at what point does this happen?

Men and HIV/AIDS

Writings about HIV and AIDS in Africa portray it as a profoundly gendered epidemic. Women bear the brunt of the epidemic as both infected and affected; as a consequence of this they outnumber men as users of HIV services. In this section I look at the beliefs and attitudes that men held towards AIDS prior to doing an HIV test and whether or not they were in favour of using condoms.

Knowledge and attitudes towards AIDS

Knowledge and attitudes differed among participants. There were a few men who disputed the existence of AIDS as a disease. These men ignored AIDS prevention messages such as the use of condoms. The majority acknowledged AIDS as an existing disease but did not internalize HIV risks; another group of men acknowledged AIDS as a reality and acknowledged personal risk, but hardly used condoms. There were age differences with respect to these various perspectives: older men were more doubtful about AIDS and did not internalize risk; younger men were more likely to acknowledge individual risk, but were generally ignorant of HIV prevention messages. Only one man said he was committed to condoms before he tested. About 20 men said they had never

used condoms until they took an HIV test and were instructed to by health providers to use them. I explore these different perspectives on AIDS in greater detail below.

Five of my participants (Duma, Mathe, Zola, Koko and Zola) belonged to the first group of men who held doubts about AIDS. All of them said until they tested HIV positive they doubted that AIDS existed. Koko said:

> People just don't believe HIV exists. Like myself too; I used not to believe HIV exists until I came here (Rixile clinic). At the time I came here I met this *Gogo* (old woman). I asked her 'Gogo, are you also sick?' she said 'Yhaa'. I asked 'how come you are sick; this HIV is a new disease'. She said 'No it's been here for a while; just that it wasn't as much as it is now'. It took me a while to believe that this thing really exists; it took a long time… (Interview Koko, 6 March 2007).

I was particularly surprised to hear these views from Koko, Zola and Lucky because they are younger participants. Youth is portrayed in HIV literature as being more knowledgeable about AIDS issues and also more receptive to prevention messages (HSRC 2002). But, as observed by Posel, Khan et al. (2007), the fact that youth can reproduce biomedical facts about AIDS cannot be taken as proof that they accept these facts or use their knowledge to make sexual decisions. Doubts remain at the back of their minds and may have a negative impact on their sexual decisions.

The majority of my participants accepted AIDS as a social reality, but did not internalize personal risk. Instead, risk was attributed to other forms of sexual lifestyles that they were not individually practicing. For example, men in monogamous relationships perceived themselves as safer compared to men with multiple partners; men in multiple partnerships looked at those who slept with prostitutes and drinking women as being at higher risk than themselves; older men perceived themselves as safer as long as they had sex with women who were in their age group. The latter saw AIDS as a disease of youth.

Tito, a 50 year old participant said he was aware of HIV risks from listening to radio and other sources of information, but did not personally feel at risk because he had sex with his age-mates:

> Yhaa, like when we grew up there was no AIDS; and you grow up with the same people and you have sex with them. Now you don't imagine that she might be having AIDS…So I would hear it on radio, but I didn't believe it… (Interview Tito, 13 October 2006).

Tito said this is the main reason why he never used condoms with his sexual partners; he assumed they were free from HIV, just like him. He was then surprised one evening when he came home from work and his wife presented him with a pack of condoms and asked him to use it for sex:

> I was puzzled and asked her 'What are these for now? What are these condoms for?' She said 'from now on we must use these condoms; you see, these days there is HIV. So, you are my husband, but let's not blindly trust each other. I know you are a man, but I cannot say I trust you completely wherever you are. I cannot say you are my man only'. I said 'why wouldn't you trust me, we have old children, they have finished school and are now independent. So, how come?' So I said 'Fuck, let's rather sleep and not do anything (sex)'. So we did, we just slept together; condoms are here… (Interview Tito, 13 October 2006).

One night Tito decided to 'make this wife happy'. He pulled out condoms and used it: 'I could see that she was really happy when I used condoms'. But he was not pleased; he did not enjoy sex with condoms. And then out of excitement his wife pushed him further saying 'let's go and do VCT, do blood test'. Tito refused saying 'I'm not going there'. He then went out and had unprotected sex with other women (Interview Tito, 13 October 2006).

Other men who knew about AIDS felt safer because they were choosy in whom they had sex with. For example, men looked at a personal lifestyle of a woman, her sexual history, and other 'clues' (such as whether she looks healthy or not) and then, based on these

indicators, determined whether she was safe or not to be with. A woman who drank excessively or smoked dagga or had many partners was perceived as a higher risk. Hence throughout their lives these men never felt at risk because of whom they slept with and despite having unprotected sex with multiple partners. Interestingly, some men confessed to have dated drinking women, but these were somehow constructed as 'safer' because of other having attributes that they possessed – like being pretty or looking 'fit'.

This sense of safety based on knowledge or familiarity with a someone created a situation where even when a woman that men perceived as 'safe' was sick, or rumoured to be having 'AIDS', some of them still had unprotected sex with her. Thabo`s story provides a typical example of this problem. Thabo had sex with one of his partners who lived in Bushbuckridge while she was sick. He came from Pretoria and shortly after arriving at his home he was warned not to visit her because she was sick from AIDS. But he ignored the warnings:

Thabo: She was sick for some time, but didn't tell me. Then this day I came back late from Pretoria. Now at home they didn't tell me what this person is sick from; they only told me 'this person is sick and you mustn't go there'. But since I had some drinks I didn't really care; I went to a drinking place and from there I felt 'Ey, No. I can't sleep alone; why should I sleep alone while there is a woman just next door? [Laughter]…These people are mad!'. So I went there and knocked and she opened the door. She said 'are you back?'; I said 'yes'. She said 'did they tell you?'. I said 'tell me what?'. She said 'didn't you hear the gossips, that I have AIDS?'. I said 'No', and she said 'It is true that I'm sick, but I'm not sick from this disease; at the hospital they said I have TB. I used some medication and I`m now alright'. You see, she was hiding it from me, she didn't tell me she has HIV, and I also didn't know anything.

SM: So you slept with her

Thabo: Yes

SM: And you didn't use a condom

Thabo: Yes, I didn't use a condom

SM: But how did you feel after that?

Thabo: I woke up in the morning feeling like I have lost some power; I just didn't have power. She asked 'why are you not waking up?' I said 'I don't have power'. She kept quiet while knowing very well what the problem was.

SM: Why would she do that?

Thabo: I think she told herself she doesn't want to die alone; I think that's what she told herself, that she doesn't want to die alone. So my belief is that I got this sickness from her, because she knew (Interview Thabo, 20 April 2007).

I have focused on men who acknowledged AIDS, but did not take personal steps to protect themselves or consider themselves at risk of acquiring it, and those who doubted its existence. Three men - Sabu, Xola and Vusi - said they took AIDS seriously and acknowledged personal risk, and Sabu said he used condoms regularly - though not consistently - with his sexual partners. Two of these men had previously worked in the army. Xola said he learned about AIDS from listening to the radio and reading magazines; Sabu said he learned from his friends who used to talk regularly about HIV and constantly warned each other against the dangers of having unprotected sex with certain 'suspect women'; Vusi said as someone who worked in the army he received information about HIV risks through workplace intervention programmes. There was however a discrepancy between knowledge and behaviour with regards to Vusi and Xola. Both of them said they hardly used condoms during sex despite being aware of HIV risks.

This leaves us with one participant who appeared to have been committed to condoms before he tested for HIV. Sabu said he was active in initiating condoms with his partners, but they would sometimes resist it. He cited two girls that he dated while living in Johannesburg, both of whom resisted condoms:

Sabu: I used to live together with this girl, you see. Each and every time this girl, you know we used to fight a lot and she would leave, you see. You know if you love someone you see, you stay with her, and sometimes you fight and she leaves. But she would leave, but I go get her back again, you see. She comes back and I sleep with her, you see. And I used to sleep with her using condoms, but she used to tell me she doesn't want condoms, you see.

SM: Mhhhm!

Sabu: Yhaa, *uthol`ukuthi* (you find that) I ask myself 'Why is this girl like this?' And I stayed with this girl for more than 3 years, more than 3 years. *Uthol`ukuthi* in the beginning, in our first year I was using condoms but she told me if I use a condom with her she doesn't feel anything; that if I don't want flesh to flesh with her she will decide what to do, you see (Interview Sabu, 11 October 2006).

The fact that only one man was committed to condoms before he became sick from HIV indicates the level of ignorance that existed among men prior to testing. It seems as if these men considered themselves immune from acquiring HIV, despite knowing about risks associated with having unprotected sex. Condoms were considered as being necessary for specific types of women that these men labelled as high risk, but even then not all men used them.

These findings are not new and recent research has focussed on how certain perceptions of masculinity may lead men to reject condoms in favour of unprotected sex in order to prove their sexual virility (Simpson 2009). From interviews conducted with ARV users, the impact of masculinity on condom resistance was inconclusive; however my informal conversations with other men in the community indicate a tendency to associate condoms with reduced sexual potency and lack of sexual satisfaction for a man and his partner. One man that I spoke to described using condoms as 'not getting the real thing' and another, as 'not giving her the real thing'. These comments imply that the 'real thing' is flesh-to-flesh sex; someone who does not give or get flesh-to-flesh is therefore failing himself and his partner. This can have a serious impact on his manhood because of the importance assigned to sex in the performance of manhood.

I have described three different ways in which men generally responded to AIDS prior to testing: as doubters/non-believers; as believers who felt personally immune; and as believers who acknowledged personal risk and either practiced or did not practice safer sex. These different responses are important to keep in mind for our next discussions on how men responded differently to their positive diagnosis: Are men who held doubts about HIV more or less likely to accept their positive diagnosis; are they more or less

likely to test? Do pre-testing attitudes towards AIDS influence post-testing responses – such as using condoms, adhering to ARVs, and other lifestyle changes?

Perhaps the most commonly shared factor in the lives of these men is that none of them had close experience with AIDS - either as carers or knowing someone close who has HIV – before they became sick and tested. Most of them knew of AIDS as a distant disease that existed somewhere else and affected people other than their close network. Part of this had to do with the silence surrounding AIDS in the villages in which they lived. When someone is sick from AIDS family members find other ways of explaining the illness or a sick person deliberately hides it from family members. Lucky said he knew no one with AIDS before he tested:

> I hadn't seen anyone with HIV before. I would hear people saying 'this and that one has HIV' and some would also judge them, you see. I mean people always judge you if you are sick, so even if you don't have HIV they will be saying you do. That's why most people would rather hide. Yes I would see it on TV and on radio, but not in my area. Here we don't believe much in what's in the news; we think maybe they are just playing or they are just selling their newspapers or so. You only believe when it's someone close and you can see 'yhaa, things do happen in this world' [soft laughter] (Interview Lucky, 21 February 2007).

Lucky said the first time he encountered someone with HIV was when he was sick and had not yet tested. A childhood friend, who had been sick before, approached and advised him to go to Rixile and test because he was looking sick. He disclosed his own HIV results as a way of encouraging Lucky to test. Lucky said he was shocked to discover his childhood friend`s HIV status:

> I never suspected he had HIV because most of the time they talked about TB. In fact I can say most of the time people in my area don't mention HIV, they mention TB. Maybe you go to someone and tell him/her 'I observed that you were sick but now you are OK; where did you get help?', he will never tell you about HIV and the fact that drugs helped

> him; he will say he had TB and that he is now cured. So he will not give you the correct answer, that 'this is what happened (Interview Lucky, 21 February 2007).

For other men their first encounter with other HIV positive persons was at the ARV clinic, either in support groups or at a waiting room. Here people met relatives and friends whom they didn't know were HIV positive. Shock, disbelief and shame were characteristic features of these encounters. For some men these encounters served as a confirmation that AIDS exists 'for real' and that he was not a lone sufferer. For others, the encounters were therapeutic because they enabled them to accept their own positive diagnosis due to seeing other people who are like them. Some experienced more stress and then stayed away from the hospital because of shame.

In the next chapter I will explore how the experiences of doing an HIV test challenged these pre-testing HIV attitudes and knowledge. Below I discuss briefly another powerful social discourse that shaped men`s reactions to AIDS messages, *tindzhaka*.

'Tindzhaka' and 'mafulara'

Among Shangaan speakers, when someone dies, his death is followed by a mourning period involving family members and other people who were directly involved in the funeral activities. During the mourning period these people must abstain from sex for a specified period of time. The period of abstinence differs among families and depends on the person's involvement in the funeral activities. Mr. Khosa describes an ideal situation:

> For example, if one eats from a funeral or during a night vigil he must not have sex for at least 3 days until the food is emptied from the bowels...If a family member dies, sexual abstinence must be observed by family members until such time that they are allowed by (this) law to have sex. Then the family will be called together and told what to do. Normally it starts with the youngest son, up to the eldest son....And in my case, for example I am a priest, so if I preach at a funeral I must abstain from sex for at least 3 days after that...If anyone breaks these rules they will start getting sick, and if nothing is done he will die… (Informal conversation Mr. Khoza, 12 May 2006).

The illness contracted by someone who violates these rules is called *tindhzaka.* It is seen as punishment from ancestors who have been angered (Posel, Kahn et al. 2007).

In recent years there has been an unprecedented increase in deaths in Bushbuckridge and *tindzhaka* is cited by many people as a major contributor to these deaths. The dominant social view shared with me was that younger people no longer respected cultural taboos such as those described above; as a result they contracted illnesses that are otherwise avoidable, like *tindzhaka*. Young people were said to treat funerals as social occasions where they meet partners and then have sex. At the night vigil young people slip out and have sex outside, or organize post-funeral social occasions - called 'after tears' – where they drink and have sex. My informants described youth as being generally ignorant of these conventions and disrespectful of elders.

Young people were not alone in violating the taboos associated with death. Some Christians that I spoke to said they opposed the observation of such taboos. For example my friend, Zizi, a member of a Zionist church, told me he did not observe 'those things':

> My wife goes to the funeral at her family and comes back with food. We all eat and here we are, still alive…I go to the funerals and I come back and live life as normal…I don't restrict myself in any way and here I am still alive (Informal conversation Zizi, 21 April 2006).

According to Zizi, the story of *tindzhaka* is a strategy to deflect attention from AIDS, which he believes is a major cause of deaths in Bushbuckridge. Zizi used the example of my neighbour whom I was told had *tindhzaka*, to support his claims. My neighbour had been sick since I arrived in Kildare and his father claimed he had *tindzhaka*. Zizi insisted that *tindzhaka* was not the cause of his illness:

> ...he has been sick with TB for a while. He stopped coming to the clinic to collect his medication, but now I hear that he is sick from *tindzhaka.* It's possible that he had sex but he did it while being sick with TB. Now because he isn't taking his treatment he is

> getting sick…I don't think it's *tindzhaka*…For me I think he has AIDS... (Informal conversation, Zizi, 21 April 2006).

Part of my interviews centred on the participant's views and perceptions about *tindzhaka* prior to HIV testing and whether these had any bearing on their sexual behaviour or health decisions: Did they believe there was *tindzhaka*? How did it feature in the explanation of their own illnesses when they sickened? *Tindzhaka* is recognized as having similar symptoms to AIDS – like cough, chest pains, weight loss, diarrhoea and others. But the route to curing it is different. According to participants, *tindzhaka* is cured by a traditional healer who specializes in it, whereas AIDS can only be managed by a western doctor.

The implications of these distinctions for health decisions are vast. It means that when someone has *tindzhaka* it is not wise to take him to the hospital because he will be 'wrongly' diagnosed as having AIDS or TB. He will be given incorrect treatment, which may harm him. *Tindzhaka* exists alongside, and is often confused with, another illness called '*mafulara'*. This can be caused by someone who deliberately sends a curse to another person to make him ill.

Most of my participants embraced the idea of *tindzhaka* and *mafulara* as social realities before they tested for HIV and they observed certain sexual restrictions and other precautions associated with it. Magwa said he could clearly distinguish between *mafulara* and AIDS, based on symptoms:

> There is a difference. Yes there is a difference…because the *mafulara* is quite clear; it's very painful, the *mafulara* – you don't sleep if you have that thing. Your other side of the body becomes useless; your blood is unable to circulate, you see. With HIV your body might experience some pains, but with *mafulara* the main problem is legs, and one side of your body gets disabled (Interview Magwa, 2 November 2006).

Only three men (Joe, Lizo and Sabu) did not believe in *tindzhaka* and *mafulara* before they got sick and were tested, and two of them were Christians. Interestingly, among men who believed that they had *tindzhaka,* none of them admitted to have violated a sexual taboo prior to getting sick. Instead *tindzhaka* was seen from a position of victimhood. These men felt that they might have had sex with certain women who were mourning and did not disclose their status. Or someone deliberately planted something in their path, so that he could catch *mafulara*. The role of family members in these instances could not be underestimated. Families, particularly elders, were the first to offer an explanation for someone`s illness and based on observed symptoms they often cited *tindzhaka or mafulara*. Some men felt that they were powerless to contest the diagnosis. The fact that they shared the worldview of their families made it easier to accept and then enter into a treatment programme offered by a traditional healer.

Conclusions

This chapter has documented the health behaviour of men who are HIV positive before they tested for HIV and then entered into treatment for it. This follows from a previous chapter in which I documented their constructions of masculinity before they got ill and were tested. The purpose of the discussions in these two chapters was to look back into the lives of these men before they took ill, in order to get a deeper understanding of what had changed and what remained the same in their lives after testing positive.

From what I have shared in these two chapters, it is evident that most of the participants did not differ much from other men in the society with respect to how they constructed their masculinity and in their health beliefs. These men believed strongly that to be a 'real man' meant that someone had to be powerful, in control, a decision-maker, and sexually strong. There was a heavy reliance on having a paid job to achieve these ideals. I have also touched on the body as an important site for performances and experiences of 'real' manhood and gaining social respect.

Discussions on health behaviour show us that these men believed strongly in using traditional medicines before they sickened. They detested public health facilities and associated them with being feminine, weak and lacking privacy. Most of them were embarrassed about appearing sick in public, as this reflected badly on their image of manhood. Very few of them took AIDS seriously before they got sick and tested, and only one person used condoms - though not regularly. None of them had met someone with AIDS before they tested. Most of them believed strongly in *tindzhaka* as a social reality and this informed their health choices.

The key aspect of these findings is that they do not present men as having been a homogenous group in terms of their gender beliefs and health behaviour, before they got sick. There were men who resisted conforming to certain socially defined understandings of manhood and there were also men who rejected traditional medicines in favour of western medicine. This concurs with the theoretical perspectives that I highlighted earlier in this thesis, that there is no one way of being a man and that there are contestations – internal and external – within the hegemonic masculinity. Throughout this thesis these differences and their impact on health decisions will be highlighted. The next two chapters look at the lives of these men as they begin to change due to HIV. They focus on two important decisions that they must make: testing and HIV disclosure.

BECOMING ILL: HIV TESTING AND DISCLOSURE DECISIONS

CHAPTER 5

'DOES IT MEAN I`M ALREADY DEAD?' - MEN AND HIV TESTING

Introduction

For most men in my study, the decision to have an HIV test was difficult, and initially resisted, and the severity of their illness played a major role in precipitating the decision. For example when Tito became unwell in 2001, he did not consider doing an HIV test. Yet, he described his illness as a horrible experience, saying:

> I was always scratching myself; all the time. Other men asked me *'Ey Ndoda uyasinyanyisa. Why ungashayi chiskop* once (Hey man, that is disgusting…why don't you just shave all your hair?). Then I developed this rash; my body was all covered with rash, even the face. Some even stopped greeting me; some found me disgusting. My family didn't want to see me. Women just vanished, no woman wanted to talk to me. Tito went to church to receive prayers and ZCC tea, but these did not help (Interview Tito, 13 October 2006).

Then in August 2005, after four years of being ill, he decided to have an HIV test. I asked him what finally made him go for the test, and about the process that he followed:

> So in church they told me 'you have some sores inside, so you must drink some tea'… Then I realized 'No man, this thing is on-and-off'. I had been using this tea all the time, and this thing comes and goes, comes and goes. So I felt 'No, man, there is a problem here'…Then I started getting sick, man… And now I decided 'Ey, let me come back home; maybe it's my ancestors'. So when I got here I realized that 'no, this rash is now becoming too serious'; it was now becoming too much. I didn't know what was happening; so I decided to go to Cottondale clinic. They gave me some medication and then they asked this doctor to come; they said 'you know what; if you can agree to a blood test you may find that you have HIV'. I was like 'Yho! Is that so?' I was already thinking 'what if I test and find that I am indeed HIV positive? It means I am already dead *mos*'. So I started thinking 'so I will die and leave my family behind; my children

and my house things. It means this is the end of the world'. So I decided 'Fuck! I'm not going there'...I asked for money from home, but they didn't give me; I wanted to see a doctor. They gave me only R20, I took it and went to the hospital. At the hospital they gave me aqueous cream and some sleeping pills. It didn't get better. So, one day I was at home, and this man came and said 'Hey man, they want someone to work there', that's at that shop just outside the hospital. I went there and they asked me if I would be able to work...I demanded R500. So from there I had some money, at least; so I went to Dr Mchunu (a private doctor based in Acornhoek). And he tried his best; I could see these sores were now disappearing, but they would come out every now and then, and I was spending my money on them. So Dr Mchunu advised 'No, man, It will be better if you do a blood test so we can see exactly what's happening here'. So I said 'OK I will come and do the blood test'. And there was this guy he used to stay there, his name is Sizwe. He borrowed me his medical AIDS card because I was short of money. And Mchunu gave me some medications and treatment. I could see a lot of improvement, all these sores were now disappearing, and my hands were looking good. So Dr Mchunu said 'Hey, this medical aid of yours is getting exhausted. How about we take a test and see what's going on?' I said 'well, I'll do it. This illness comes and goes, so it's better if I do blood test'. So I did the blood test and he told me to come back for results. And when the results came back he told me I'm positive; HIV positive! I said 'Haa! Is that so? Now what do I have to do?'. He said the problem is that my medical AIDS didn't have money; if it did have money he would give me some pills. But I asked 'Now that my medical aid is finished what should I do? Should I go home and wait for my death?'. He said 'No; I'm not saying that…we will give you some pills, but they won `t be as effective as the HIV drugs. What you need to do is go to the clinic in Tintswalo to sister Ndlovu, she will help you'. And from there I went home and wondered 'does this mean I'm already dead? Will I leave my children behind?' (Interview Tito, 13 October 2006).

This chapter describes experiences of being sick and having an HIV test. It focuses specifically on why it was difficult for men to test; what finally made them to test; and what the consequences of testing positive for their manhood are. Like Tito, most of my male participants refused to have an HIV test, despite being ill. Out of 25 men interviewed about their testing experiences, only one participant tested voluntarily and

without first becoming ill. Thandi said, while living in Nelspruit, he went for a test 'out of curiosity':

> We used to listen to the radio, that 'you must check yourself', and all that, you see. So we used to make fun of it, you see…so I decided 'Ag…, let me just check myself', you see. I asked someone here to show me where to go. And even their counselling took only up to an hour, you see. So I didn't know much that time, but I was not sick, you see (Interview Thandi, 8 September 2006).

Other men refused to test despite being urged to do so by supportive family members and were seriously ill. They first experimented with traditional medicines and prayer. Undergoing an HIV-test was a last choice and usually happened when other treatment efforts had failed. Most men had developed opportunistic infections, like TB, skin rash, pneumonia, and other illnesses associated with HIV by the time they underwent testing.

In exploring men`s testing decisions, I will focus on stigma as a barrier. The impact of stigma on HIV decisions – testing, disclosure, use of services - has been investigated extensively in the social and health sciences. However, most studies approach at it from a social perspective, i.e. in terms of how others would react to and behave towards someone with HIV. Attention is mainly given to the effects and processes which turn someone into a social outcast (see chapter 2). We know less about how the stigma is lived internally, and its effects on health choices over time – in other words, the complex psychological effects of the stigma of HIV and how these interact with its social and cultural determinants. Cameron (2005, p. 53) reminds us of the importance of considering internalised stigma and its impact on HIV decisions, when he writes:

> Stigma`s irrational force springs not only from the prejudiced, bigoted, fearful reactions others have to AIDS - it lies in the fears and self-loathing, the self-undermining and ultimately self-destroying inner sense of self-blame that all too many people with AIDS or HIV experience themselves. It is a combination of these two forces investing stigma that renders its effects so powerful and destructive.

This chapter will focus on both the above aspects of stigma with more emphasis on its internalization. First it attends to the ways in which communities perceive someone with HIV - namely as 'already dead' and an 'outcast'. This makes it difficult for people – both sick and healthy - to undergo a voluntary HIV test because they fear rejection if they test positive. Then it looks at how certain individuals who are already sick and suspecting that they might be having AIDS have internalized these negative social judgments, therefore having difficulty to test due to internal feelings of shame and disgust and fear of being rejected. The disgust and shame in having HIV are intertwined with fear of losing social respect and status, as a product of being known in the society as having the HIV virus[17].

Most participants in my study tested after they had personally come to terms with the potentially negative consequences of having HIV and were willing to deal with them. Most importantly, a decision to have a test was prompted by a need to restore their bodies to health. The men's health and physical appearance were deteriorating as a result of AIDS and some of them felt that death was imminent. In this respect testing was a last resort to try and rescue their lives. Testing was also a potential pathway to enable them to reclaim their personal dignity and social respect that were all taken away by an HIV illness, through having access to ARVs. But, as we will see, it was not an easy decision; it needed men to first re-think their priorities and health beliefs in order to finally do an HIV test.

The chapter is structured into four sections. Section one situates testing decisions in a social context, exploring how locals normally approach testing: how do people generally respond to a need to do an HIV test? Here I describe a situation I observed while living in the Kildare village, where certain people who were sick 'chose' to rather die than test. I then examine men and their specific approach to testing, asking the following questions:

[17] Though HIV results are a private and confidential matter participants expressed serious distrust of health workers saying they do not trust them with privacy of HIV results. This made it difficult to test because of a fear that someone`s HIV results will become public knowledge, leading to gossips, labelling and social ostracism.

what is at stake for a man who wants to be tested; how do HIV positive results impact on his self-perception as a man and human being? Section three documents experiences of men in the study who have tested for HIV. The key questions being pursued here are: what enabled them to finally test, following their long resistance to use health services? What initial strategies were used to seek help before finally doing an HIV test? And, in what way was testing seen as a way of restoring these sense of manhood? Section four looks at the impact of testing in changing these men`s attitudes and practices towards HIV.

HIV testing in Bushbuckridge

> Just listening to people talking (maybe they are just having a casual conversation) you come across this view that 'I will never go there and test; I will only go there when I'm unable to do anything'. Or you hear the other one saying '*Mina* (Me), should I test positive I will spread it to others'... (Interview Lucky, 21 February 2007).

As in the rest of the country, HIV testing services in Bushbuckridge are freely available and accessible in public health facilities. There are three hospitals, seven health centres and 57 clinics and all of them offer free VCT services. However, my findings indicate that these VCT facilities are generally under-utilized. In most cases people discover their HIV positivity either through pregnancy or after a long persistent illness. It is unusual for someone who is not sick or pregnant to voluntarily visit a testing site to check his or her HIV status. One of the health providers whom I met in one of the ARV sites in Bushbuckridge summed up the attitude towards testing in this comment:

> People here don't want to test. You see, all these people that are here…some you advise them 'you must test' and they say 'no I must speak to my husband first', and from there she is gone. She doesn't come back again…I don't know why, but people are just scared of testing… (Informal conversation Health worker, Mapulaneng hospital, 14 February 2007).

Zita, one of my participants shared similar observations, saying:

> People here don't want to test. Someone wants to see himself being sick first. And maybe they are already driven by a wheelbarrow. To see someone just walking in and saying 'I want to test'! No. that doesn't happen here…' [Laughing] (Interview Zita, 26 June 2006).

The reluctance to test is not unique to Bushbuckridge. Studies conducted in South Africa and elsewhere show that most people are generally reluctant to use VCT services, including sick people. Researchers have identified several factors that either limit or facilitate use of VCT services, some individualistic and others structural in nature. Individual factors include how people perceive their own individual risk, as either likely or unlikely to have HIV (HSRC 2002); perceived behavioural control (Kakoko, Astrøm et al. 2006); knowledge about HIV and VCT; fear of stigma, and fear of a positive diagnosis (Gage and Ali 2005). Structural factors include such things as having easier access to the testing services; access to information about HIV and VCT; having medical aid; negative social attitudes towards HIV and PLWHA, and others (Gage and Ali 2005; Bond, Lauby et al. 2005).

Perhaps more important to highlight in the case of Bushbuckridge is an observation that even when they are quite sick, most people still refuse to test. I became aware of this problem during my interactions with men living with HIV, and in my conversations with their family members, friends and neighbours. These participants expressed concern over a 'culture' of non-testing in the villages, saying most sick people prefer to rather live with pain, or even die, than test. This section will first elaborate on this practice, with a few examples taken from my interviews and conversations to illustrate this point, before I focus specifically on testing decisions of my male participants.

Sabu is one of my participants who shared his frustrations over people`s reluctance to test, saying it is the main problem for sick people. During our interview he told me a story about his neighbour, a young man who was refusing to test despite being ill:

> ...he is my neighbour, we are relatives somehow. Now this guy is too sick, you see; too much, *Joe*. Now he's busy drinking this (ZCC) tea. You find that this tea isn't treating him well. This tea *iyamlimaza, Joe* (it's killing him). Now I tried to explain to him 'You know what *broer* (brother), why don't you go to the hospital? Go and check your situation, your CD4'. And this guy used to be fresh, now he's losing weight. He looks like a child, a young child, you see…so I decided I would rather not force him, *Joe*. Because I do try; I even gave him this information sheet, I told him 'look what they have written in this information sheet. In fact if you are serious about your health you must check yourself at least twice', you see, *ukuthi* how's your body doing, you see. Cause you don't know what you might have got from your wife, maybe', you see. *Ushukuthi* this guy used to stay with his wife, you see. Now the wife is gone, she can see that the guy is sick; you see (Interview Sabu, 11 October 2006).

Another participant, Ms Mali, shared a similar story about her neighbour, a young woman who was refusing to test. She described her as being 'very ill', being unable to walk properly. She also lost lots of weight:

> She is this size (small size). She is in denial. We sit down with her and say 'Go to the clinic and get some pills', but no, she is refusing. She would leave for the clinic, but then she turns back. When she does go there she only tells them about the pains she feels, but I tell her 'No; don't tell them that. Ask them to check you (test); they will tell you 'this is what you need to do'. But she always turns back. I spoke to her mother 'Please go with her…' (Interview Ms Mali, 28 February 2007).

Ms Mali`s own son, Bob, also refused to test until he was urged to do so by his mother and uncle. She described the difficulties they encountered in getting him to have a test. She said Bob was sick, physically weak and had lost a great deal of weight. They consulted several traditional healers in Bushbuckridge, but in vain. As a last attempt to help Bob, Ms Mali asked him to test, but he refused:

> ... He refused, saying 'if I go to that hospital they will tell me I have AIDS'. I said 'There is nothing wrong in that; if you have AIDS then you have it…there's no problem; it's

> better if you know so you can find a way around it, of how to deal with it. So he kept refusing, kept refusing; I tried to convince him. And then I said 'Please do this for me; would you rather die? Look, you are just lying down here, and I have nothing to give you. Please go to the clinic'. And then he agreed, but on that day he was supposed to test he turned back at the clinic gates in Cottondale because he said people know him there, they will tell him he has AIDS even if he doesn't have it. My brother called me and said he is refusing to get into the clinic. He said he wanted to go to another clinic in Tladish, and then he went there to Tladish; then he told them what his problem was. He allowed them to test him because he doesn't know them (Interview Ms Mali, 28 February 2007).

These narratives confirm the problem of resistance to testing even when someone is sick and in need of help. As someone who lived in the village and interacted regularly with people, I can also attest to the prevalence of this dilemma. I know at least two people who were severely ill but refused to test. Linda, my neighbour, had been sick since I met her in August 2005. She lived in a four-roomed house with her mother, her sister and several children including her own child. Her older sister, who is an AIDS counsellor, said they had been urging Linda to test since she became sick but she refused:

> I don't know why. And it's funny because she sees people coming to me who are positive. Some of them were sick just like she is, but they are fine now. For me that is supposed to encourage her to test… (Informal conversation, 26 July 2006).

Linda`s skin had turned pale; she lost a great deal of weight and her body was covered with rash. In 2007 her condition worsened and her sister ordered a concoction of medicine made up of indigenous herbs to 'boost' her, but she was sceptical of what she was doing, saying: 'I'm doing this so I don't look like I'm not helping. But it's useless; she needs to test and get ARVs'. The medicine did not help. Linda`s physical state deteriorated further and she was taken to Mapulaneng hospital where she died two weeks after her admission.

Another person I know of is Mandla, my neighbour with whom I shared a friend, Lolo. When I met Mandla in March 2006 he was looking ill, but was still physically strong. He

then rapidly lost weight and his skin turned pale. I had several conversations with him about my work and HIV and he showed good awareness of HIV issues, and was supportive of HIV testing. One Saturday morning we were sitting at Lolo`s place talking about AIDS and why so many people are dying, when Mandla commented: 'The problem is VCT. *Angithi* (isn't it that) people are supposed to test so they can know their status. Now people don't do that until they are too sick…' (Informal conversation Mandla, 4 May 2006).

When Mandla made this comment he was sick himself, but had not been tested. Later during fieldwork I spoke to Lolo on the phone and he told me he had been urging Mandla to test because he was getting worse: ''I told him to test. I told him that if he tests he can maybe get a grant. But he has been refusing. Now he said he would go to Mapulaneng and test there. I think he wants that grant…'[18] (Informal conversation Lolo, August 2006).

These stories seem to suggest that most people are knowledgeable about HIV and testing; the problem is how to translate this knowledge into practice. Some people 'choose' to die rather than test, despite having knowledge and support from family. This practice contradicts the public health wisdom, which assumes that knowledge about HIV issues automatically translates into behaviour change. Hence public health interventions tend to focus primarily on imparting 'correct' information about HIV testing issues; the assumption is that the more informed people are about the benefits of testing, the more likely it is that they will test. Men and women who are sick but not testing invite us to re-think this assumption and instead, focus on what people`s fears about testing are. Surely when Linda 'chose' to die rather than live with HIV there is something in living with HIV that she could not face. The same is true of others like Mandla or Bob, who, despite being ill, aware of advantages of testing, and the urging of family members and friends to test, nonetheless resisted. The remainder of this chapter deals with men and their approach to testing and it answers some of these questions.

[18] the issue of the government grant and whether or not it prompted some of my participants to test was not explored in this study. However it is something that is worth exploring for further research.

Men and HIV testing.

Men in Bushbuckridge are generally portrayed by health workers, community leaders and women as being a difficult group to reach in relation to HIV-testing and HIV-issues in general. Health providers were particularly unrelenting in their criticisms of men, labeling them as 'our major problem' when it comes to testing. They drew a distinction between men and women, labelling the former as 'stubborn', 'difficult' and 'irresponsible', while women were presented as being more flexible and responsible. One health worker based in Kildare whom I interviewed described men as follows:

> Men are a problem; they don't like to be tested. They are unlike women. You see, a woman can enter here being sick and I tell her 'let's do counselling', and then I suggest an HIV test; she will agree. But not a man! A man will attend a pre-test counselling and when he needs to come back again he doesn't show up. And they always blame women; hence they become hostile and refuse to test. We have a serious problem with men here... (Interview Health provider, Kildare, 23 April 2006).

Another health worker, based at an ARV clinic in Bushbuckridge, was blunt in her description of men, saying: 'You men are stubborn. You don't want to test; you don't want to consult...and you don't want to listen' (Informal conversation Health provider, 17 August 2005).

In support groups the same portrayal of men as a 'problem' was common. Here female participants shared personal experiences with their male partners. The latter either refused to be tested once she disclosed her own HIV-status to him, or were sick themselves. In one of those cases, a young female participant, Queen, was close to tears when she shared the difficulties she faced in persuading her partner to test. Queen said she disclosed her HIV results to her partner but he didn't believe her:

> He said I'm lying; he said '*wena usdudla* so! (as fat as you are!)'. When I told him the nurse said he must be tested he said he will never do that; he said he is healthy...and he is refusing condoms. Now I don't know what to do (Focus observations, 4 April 2006).

Queen said she even disclosed to her partner's family and also asked them to persuade him to test, but to no avail. Queen was sitting next to me when she made these revelations and as the attention of other support group members shifted away from her, I asked her whether her boyfriend ever gets sick and where he goes for help and she said: 'he goes to a private doctor. *Angithi* he has money…'.

If men have difficulty with testing we need to know why, and what specific challenges a positive diagnosis poses to their lives. But in doing so we must avoid assigning certain stereotypical characteristics to them, such as that they are 'naturally difficult', or 'stubborn', as my informants seem to imply. Instead, the next discussion focuses on social meanings assigned to being HIV-positive and how these undermine manhood and its association with dominance and control. As noted by Parker and Aggleton (2003), no disease condition has a natural meaning or symbol. Instead, societies construct these on the basis of their belief systems - and then assign certain judgments to the infected person. Hence diseases sufferers are not evaluated equally in societies. Some diseases 'acquire' negative judgments that may affect a person's social image while others have no impact on it.

My findings indicate that in Bushbuckridge a positive HIV-diagnosis is frequently followed by stigma, being treated as 'already dead' and as an outcast. There are two constructions of death that are assigned to someone with HIV. The first is biological and is experienced mainly at a personal level by the sufferer. It involves the stress and other psychological consequences of testing positive, as well as opportunistic infections, such as TB, pneumonia, and others. The dominant social view shared with me was that as soon as someone tests HIV positive his days are 'numbered'; he will become sick soon and then die. This is how Tito, cited above, felt when he said **'**…and from there I went home and wondered 'does this mean I'm already dead?'

The other kind of death experienced by someone with HIV (which I will elaborate further in the next chapter) is usually referred to as 'social death' (Williams 2007). This form of death is characterized by social rejection and refusal from others to treat a man with HIV as a normal person like themselves. Instead he is perceived as a threat to other people`s well-being and may be avoided or utterly rejected during social encounters. I was told that certain people even refer to him as a 'thing', as if he is no longer alive, or has no social value and importance. Below I elaborate further on these meanings, starting with how the society treats someone with HIV.

In March 2007 I visited Ms Mali, a mother to one of my participants, Bob, to interview her about Bob`s situation and how as a family they were coping with his illness. I had met Ms Mali two times before our interview during my visits to Bob. Ms Mali lives with Bob, his partner and four grandchildren in a four-bedroom house near Cottondale village. We were sitting in her lounge discussing Bob, when I asked her how someone with HIV is generally perceived in the society. She said when someone has HIV others reject and him as an outcast:

> SM: And, generally how do people talk about HIV and how do they view someone with HIV?
>
> Ms Mali: You are putting it nicely by calling it 'HIV'. They don't mention the name 'HIV'; they simply say you have AIDS. You call it HIV, I think *uyibita kahle; ukuhloniphile* (you are putting it mildly; you respect it). They say you have AIDS
>
> SM: And how do they perceive people with AIDS, as they prefer to call it?
>
> Ms Mali: *Ushukuthi abafani nathi* (they think of them as being different from us). So they wouldn't want to eat with them. They isolate them (Interview Ms Mali, 28 February 2007).

Ms Mali then elaborated on her own conduct towards Bob when he was ailing and had tested positive. She said Bob had disgusting AIDS symptoms and that as a family they decided to isolate him and restrict his freedom in the house. Children were ordered to be

careful around him; he was given his own separate household utensils for use. I enquired why they treated Bob in this way and she explained:

> Ms Mali: I looked at him: his eyes were too white; he was getting thinner; here it was red; you see here? (Pointing at lips), it was red! It was so red I was even disgusted by it; I was disgusted (*benginyanya*) I couldn't even touch the cup that he used, I must be honest with you [laughing]. I told him 'Now this is your own cup; this is your own jug. If they give you *mageu* you use this one. If you want water, tea, here; you know your own dish/plate'. It was so red here, I didn't know what was going on…Then from there I took him for treatment, and he started getting better.
>
> SM: And, as his mother, how did you feel about having to separate his utensils – his own cup, jug, plate…?
>
> Ms Mali: I heard them saying this disease can spread to the entire family. I didn't know what would happen. But as time went on, now that he is well we do sit down and chat about it with him… (Interview Ms Mali, 28 February 2007).

Bob was not the only man who was treated badly because he had AIDS and looked sick. Other participants shared similar personal experiences. Sam told me that after he disclosed his HIV-results to his family, they relocated and instructed their children not to visit him. During my fieldwork the main family abode was locked and Sam lived in a small two-roomed house with his 10 year-old son.

Sabu said his sister instructed his niece, whom he was living with, to stop sharing food with him because he had AIDS:

> I used to cook for us and she eats, you see. Now her mother told her 'you must not eat the food that's prepared by Sabu'. I ask why, she said 'that's what my mother told me'. In other words she tells this girl that 'Sabu will infect you with his AIDS'...I can even hear when she is talking to me on the phone; that she tells herself 'this person; it's the end of the world for him…' (Interview Sabu, 30 October 2006).

Zita's two siblings stopped visiting him after rumours circulated that he has 'AIDS'. His sister lives less than ten kilometers away but has not visited him for the past three years. His brother lives in Johannesburg and comes regularly to Bushbuckridge and socializes in the nearby shebeen, but does not visit him.

Kenneth reported that his sister-in-law started making 'nasty' comments to indicate her disgust with his HIV-status:

> She quoted her mother as having said if her family member can have HIV she would remove him from her house and rather build him a separate shelter, separate his plates and all that…So I told her 'don't just come and disguise by saying 'my mother says this'. It's you; it's your own position'. And obviously I can see the change of attitude. If my wife is away for example, she doesn't even cook. She starts cooking at about half past 3 or 4 when her husband is coming back...since I started getting sick things changed. She no longer buys electricity, we sometimes even sleep in the dark, you know. Just some of the problems I encounter (Interview Kenneth, 17 February 2007).

These stories provide an understanding that the positive diagnosis carries certain negative social meanings and consequences, and that these impact heavily on the decision of a sick person to have a test. It is therefore unhelpful to label men and women who are sick, but do not undergo a test as 'irrational' or 'stubborn' or 'irresponsible'. We need to know what kinds of constraints and judgements they later face in their locality and in their homes as a consequence of testing positive or and/or of using HIV-services. Equally important is a need to investigate how they evaluate themselves as potential bearers of the HIV virus, before they are judged by other people (to be attended to in the next section).

A point that needs further elaboration from the above information is the important role played by physical symptoms of AIDS in how the stigma is constructed and then enacted against an HIV infected person. Physical symptoms seem to reinforce the dominant view that someone with AIDS is 'already dead'; and they further exacerbate his ostracism due to fear of contamination. AIDS is not acquired through the use of the same utensils or by

touching someone, however, some of the people seem to believe so and then react accordingly towards an infected person.

It is important to note how, prior to a positive diagnosis, physical symptoms of someone`s illness were somehow tolerated, but as soon as his test results are revealed these bodily symptoms become a focal point for the enactment of stigma and ostracism. This is apparent in how Ms Mali starts to separate Bob`s dishes; Sam`s family relocated as soon as they knew about his HIV results; and Sabu`s sister instructed her daughter to refrain from sharing food with him. They have to all intents become 'dirty'. This reaction supports observations made by previous scholars that dirt is a social construct and a relative concept, and that its meanings shift from time to time depending on what the society wants to achieve (Douglas 1966).

Lastly, being HIV positive seems to produce a loss of respect and authority for a man. To substantiate this point, it is necessary to return to what it means to be a man. As I pointed out in chapter 3, in the area of my study (as with many other parts of the world), manhood is bound up with perceptions of being powerful, dominant and in control. And, here, as elsewhere, as Moore (1994) noted, certain men invest in dominance and control as important markers of their masculine identities; hence they feel threatened when they are no longer dominant. Most of my participants invested greatly in control and dominance as important definers of their manhood before they became sick. HIV stigma was therefore experienced by some of them as a threat to their manhood. This is because someone with HIV is positioned as a powerless person with no social value or authority in the household and the community.

Take the example of Kenneth, cited above. Kenneth complained that his sister-in-law 'doesn't even cook. She starts cooking at about half past 3 or 4 when her husband is coming back'. We can view Kenneth's frustration at his sister in law`s behaviour as reflecting what Moore (1994, p. 66-77) describes as 'thwarting of investment', as a consequence of being sick. Moore defines thwarting as an:

> ...inability to sustain or properly take up gendered position, resulting in crisis, real or imagined, of self-representation and/or social evaluation…It may also come about as a result of other persons refusing to take up or sustain their subject positions *vis-à-vis* oneself and thereby calling one`s identity into question.

Kenneth`s identity as a man is called into question by the refusal of his sister-in-law to take up her subject position as a subordinate gender – through cooking for and respecting him. Instead she looks down on him and tries to isolate him. Kenneth attributes this change of attitude to being sick from HIV. Had he not been sick – or if he had suffered from another disease - she would probably treat him differently, with the respect and acceptance that a man normally receives from a woman.

The above discussion gives answers to one of the pressing questions in HIV intervention work: why are sick people not testing? In Bushbuckridge this question is made more urgent by the fact that certain people die despite having access to life-saving treatment, namely ARVs. Though based on experiences of a few participants these stories enlighten us on the important role played by stigma in the testing decisions of a sick person. I have shown that HIV testing constitutes a social risk and that this risk is experienced by men in gendered ways as a challenge to their manhood. Knowledge about benefits of testing is therefore not sufficient to encourage someone who is sick to test. The advantages of testing are viewed by sick men in relation to what happens to their social image and status if they test positive.

At what point then, do men who are sick finally decide to have a test? This question will be tackled in the next section, drawing on experiences of my participants. It must be noted that their experiences do not represent a 'typical' scenario or trajectory for a sick person; for example we know that not all men who are in a similar situation finally undergo the test. There are men in their villages who 'chose' to die rather than face HIV results. I however hope that their stories will shed further light on the challenges of being sick and needing to test and how the fear of HIV stigma mediates these decisions.

Becoming sick: men doing an HIV test

> It is one thing taking a position on AIDS when watching others from a distance…falling ill oneself is another matter entirely; there is nothing like the emergency of one`s own failing health to expel dogma and invite openness (Steinberg 2008, p. 193).

This above quote represents the experiences of men who underwent an HIV test. Because they feared social ostracism if they tested positive or thought they will fall sick and die very soon, most of participants initially felt strongly that they will never have the test. Some of them refused to accept AIDS as an existing disease and they relied heavily on traditional medicines to address personal health. They also detested public health facilities. I asked all participants to describe fully the steps that they took towards testing and I share a few of their stories below.

Joe, who belongs to the ZCC, described himself as a deeply religious person. He said since he was a child he has always been devoted to church, and that he lived his life according to Christian values:

> …for example, in my life I have never been a 'player' (having multiple sexual partners). It`s not allowed in church. One must have one woman at a time. I have always been doing that – one woman at a time (Interview Joe, 23 May 2006).

According to Joe, he fell ill in 2004. At that time the thought that he might be having HIV did not occur to him: 'I never thought of it because I had been seeing people sleeping with women all over the place, but they are healthy. So I never thought it might be HIV'. Let us look at what made him to finally test:

> SM: Take me through the process of how you went about testing
>
> Joe: Ey, it was hard for me to go and test for HIV because at work, as men we had this saying that 'no we can't go and test. You will go there without having it (HIV) and they will tell you lies and from there you will start getting sick; your mind will be preoccupied with this thing'. So we didn't want to go there and get

> tested. Now I got sick; I wasn't sick to the state that I would sleep. I got sick and I went to church…I went to church so I could get help, so I could ease my pain. I went even to the traditional healers so I could get some medicine to drink, but after drinking these medicines I didn't get better. And then I went to the hospital and consulted with a doctor; he gave me some pills. I started drinking these pills but they were not making a difference. So I decided, I thought 'No there must be something in my body. Why after drinking all these medications that I thought should help me, I'm still not getting help? So I thought to myself 'no it's better if I test, so they can tell me what the problem is'. And I thought 'now that I'm going for a test what am I going to say at work to my colleagues; what am I going to say to my wife, at home to my family?'; you see. It was hard! Now, that day I went to the clinic and found that nurse, I asked her 'how long does it take to test someone?' - Because it was just after 3 (pm). She said 'no; it doesn't take long; we can go and check you'. And then she took out that form, they talked to me and we signed the form, and she took some blood. And then they told me 'should this thing show a sign like this, it means you have this virus'. Now the first thing we used didn't tell us, but I felt it wasn't accurate. The second one showed us clearly that I am HIV positive...It was in November (Interview Joe, 23 May 2006).

Joe offers an account about HIV testing that tells us about the role played by his peers and family in his decision to be tested. His peers - like most people in the society - are generally opposed to HIV testing, and as someone who belongs to this network, he shared the same scepticism. When illness strikes, he is caught in-between: on the one hand he is aware of health benefits of testing and the fact that he would receive help if he does so; on the other hand he is worried about the social implications of his decision, particularly the potentially negative judgment from his peers. This is expressed in this excerpt: '… what am I going to say at work to my colleagues?'. This question indicates that testing, while beneficial to a sick individual, is always viewed in context and in relation to what consequences it might have for his social relationships.

In Joe's testimony we clearly see how being sick can challenge someone`s health beliefs, forcing him to re-think them and explore new understandings. Joe lived in the belief that

he was immune from acquiring HIV because, unlike other men in the community, he was not promiscuous. As a result, when his health started to fail he did not think of testing; instead he used traditional medicines, prayers and some pharmaceuticals. His statement 'I thought, 'No there must be something in my body', indicates a point at which a shift occurred in his thinking: conventional treatment methods were not working; illness was persistent and Joe wanted answers. It was at this point that he felt it necessary to test.

There is evidence from this extract that testing is a complex issue influenced by many factors, including whether or not someone perceives himself as being at risk of acquiring HIV; how others would respond to his decision to test and ultimately; how positive results would impact on the existing relationships. It is crucial to note here that Joe did not wait until he was too sick before he tested. Hence he was an exception in comparison to most men in the study who waited until they were severely ill before undergoing a test. Hence, this account highlights more the effects of external stigma on testing decisions than the impact of the internalised stigma. The internalised stigma emerged frequently in the accounts of men who were already sick. These men procrastinated because they feared facing the reality that they might be HIV positive.

Mathe is one of these men who took longer to test due to fear of HIV stigma. We had a long conversation about his testing decisions:

SM: Why was it difficult for you to test?

Mathe: The thing is I didn't really believe this thing (HIV) exists; I thought it was just a joke. I had many girlfriends...But now I started feeling pain here (pointing at the stomach), my kidneys weren't 'OK'. So in 2004 I came here to Acornhoek and they told me my kidney is not functioning properly; it needed to be drained. And they did some drainage. But it was already too late; these women had already killed me (*sebengidlile la mantombazana*). So I started drinking some tablets which I was told would help, but they didn't help. So from there *impilo ayizange ibe mnandi futhi* (my life was never a happy one again). I was always sick, sick and sick, and I also went to some *iinyanga* (traditional healers). And then I worked at this furniture store. There was this lady I met – she was a

divorcee, and she was too sick herself. So she started developing these sores and now I started questioning her about this. But we were advised to both go to a test because we were both sick. She went, but I refused, saying 'I am not sick! Just leave me alone'. So she went and I remained behind.

SM: Why did you refuse?

Mathe: Hey! People would be talking about me and saying I am the one that gives these women this sickness. So I stayed and remained stubborn. I tried some traditional medicines, this and that – boiling this medicine, drinking this. But it never helped. Sometimes my body would heat up; I would have diarrhea; I would eat food but it doesn't stay in. So this other day I was sleeping and as I woke up in the morning I had some sores in my body and they were oozing some water. Then another sore developed; and another one, until there were about 5 or 6 of them; big ones! So I decided to go to the clinic and they asked 'What's going on'? I said 'I don't know'. I was scared to ask them to test me, but some people had already advised me 'Hey, you must test'. So they gave me something and said 'You must smear this, smear this', but it never helped. I would use some calamine, and sometimes I would use betadin, I smear it and even use some bandage to keep it the whole night. And then I went to Mapulaneng hospital. There I met a doctor, and he said 'Ey, my advice is you do a blood test and come back again for results'. So I went to the clinic to do a blood test and I went back to Mapulaneng…So I stayed for a month or two at the hospital, and I came back much better. So I decided: 'Ey, I must just accept this thing; since I am positive I must just join the support groups and learn more'.

SM: and tell me ...you said they advised you to go to the hospital for a test, but you refused; what were you scared of exactly?

Mathe: *Ushukuthi* I was scared, Broer, because we used to hear people saying that once you test HIV positive you will be despised and people will not want you around them, just like a leper. So people wouldn't want to share with you, maybe you will be smelling and all that, you see. So that's what I was scared of, that I wouldn't be accepted amongst other people. We were under the impression that if someone has HIV we mustn't greet him, you see. We didn't know how it is contracted, so that's what I was scared of; I decided to just ignore it (*ngivele ngibhace*) I didn't know what was right. I knew I had to go to the hospital, but I

> acted as if I was just right. And I was enjoying messing around with women because it was fun! [Laughter] (Interview Mathe, 9 February 2007)

This extract provides an indication of the reasons that prevent some sick people from testing and what ultimately enables them to have a test. Mathe struggled for a long time with the HIV sickness before he finally decided to test. He went to traditional healers; he had painful sores all over the body, some oozed fluid; he had diarrhoea and lost his appetite; his kidneys were 'drained', and such. Despite these difficulties Mathe refused to test even when advised to do so by others. Why was it difficult for him to test and what was at stake if he tested positive?

Mathe`s reluctance can be better understood if it is placed in the context of his life at the time that he became ill. Mathe was a teacher before. At the time when he became unwell he was employed as a salesman at a furniture store in Bushbuckridge. He was married to a nurse and they owned a house near Bushbuckridge. Mathe was a respected person in his village because of his success and the contribution that he made towards supporting his parent. Amongst men he was revered for his success with women (see chapter 3). By local standards Mathe was a successful man in all respects.

My own view is that his reluctance to test was due to the fear of losing social respectability and status as a result of an HIV-positive diagnosis. This is reflected in his comment that someone with AIDS would be treated 'like a leper' and others would not greet or touch him. As a proud man with education Mathe feared the impact of such a response because it marginalizes him and relegates him to an inferior social position. This means he loses not only social respect but also recognition as a man. Mathe consequently rejects suggestions for him to test, in an attempt to safeguard his positive social image.

Another loss that Mathe would incur was related to his masculinity or sexuality. This is reflected in his comment that 'I was enjoying messing around with women!'. Mathe is aware that testing positive would force him to abandon women and maybe stick to one partner. He would be required to use condoms and his sexual performance would likely

decline. As we saw in earlier discussions, women formed an important part of how Mathe defined and experienced his manhood. In abandoning relationships with several women Mathe would no longer feel like a 'real' man; he would command less respect from other men and sex would not be the same. This was a dilemma faced by most men who were considering an HIV test, whether sick or not. It was as if testing was tantamount to losing freedom to engage freely in sex as they wished. Testing – particularly post-test counselling - imposed restrictions on what kinds of sexual lifestyles someone should live - one partner; condom use; testing before unprotected sex; faithfulness, and others - and most men felt that it threatened their investment in multiple partnering as a way of proving their masculinity.

Mathe needed the authority of a doctor in order to finally be tested. This behaviour is typical of someone who holds a highly regarded status in the society. As a teacher and a respected community member Mathe probably felt superior to nurses and others who were urging him to test. Testing positive in their presence would drastically lower his status. The doctor, on the other hand, is already superior to him because of his profession and qualifications. The fact that the doctor was a man might have further 'softened' Mathe to a test. As I showed earlier, most men distrusted female health providers because they viewed them as wanting in privacy and confidentiality. While their comments were directed at nurses, it is likely that they viewed female doctors in the same way.

The two extracts discussed above have focused on testing decisions that are based on how someone feels about the potential reaction of others if he is positive. Mathe was worried that he would be accused of spreading AIDS and treated 'like a leper' and Joe was concerned about potential negative reactions of his friends and family members. It has been argued in this thesis that HIV stigma starts from within the individual who is infected; first in how he experiences himself as being disgusting, polluted and internally dirty, and secondly, in how he starts to judge himself through the eyes of others, who perceive him as socially inferior and dirty. The next extract, taken from my interview with Thabo illustrates the effects of an internalized stigma on the testing decisions of a sick person.

Thabo lived in Pretoria when he became ill and like most men he did not test immediately until he returned to his home in Bushbuckridge:

Thabo: The thing is I used to drink too much alcohol! …But then I started having a problem of not having appetite for alcohol. I would buy a beer, open it, drink it, but it wouldn't settle well in my body. So, this day I was just walking to the toilet, but then I collapsed. They tried to lift me up and they asked 'Hey, what's going on?'. I said 'I was just trying to go to the toilet; I also don't know what's going on'. Then I started vomiting, and I also had diarrhoea. And from there I went to the doctor and told him 'I'm having diarrhoea, I'm vomiting', and they gave me some pills. They didn't check me there until I came back home, that's where I got checked.

…I didn't go straight to the hospital when I returned from Pretoria; I first went to a traditional healer. He gave me some bottles of medicines (*mabodlela),* but the diarrhoea didn't stop. Then I went to another one and wanted to know what was killing me. He did tell me (and that was before I tested); he threw his bones and then said 'there is someone that has died and she infected you with this modern sickness (*okugula kukhona manje),* but you have come to the right place; you will be alright'. Then he gave me some medicines to take home. I drank it for about 3 weeks, but I didn't see any change – I would be running to the toilet every now and then; I wouldn't walk a distance. And from there I decided: 'No; I would rather go to the hospital; I would rather die at the hospital (*kungcono ngiyofel`esbhedlele)*' [laughing]…Then I came to the hospital and they asked 'what's the problem?'. I said 'I'm sick and I want to test'. So they checked me, and they asked 'how come you just walk in like that and request to be tested; lots of people are scared of doing that'. I said 'I have been to many places; I'm now tired (*sengijikajikile sengikhathele*')'. So they tested me; the results came back positive and from there I received treatment.

SM: Were you not scared?

Thabo: Well I could see that *hayi ngiyahamba vele* (I'm on my way) [laughing]

SM: So you just wanted to live

Thabo: Yhaa, because I had been to all the other people, but couldn't get help. So I just

handed myself over to the hospital (Interview Thabo, 20 April 2007)

Later in the interview I asked Thabo why he took long to test and he said: '*Ushukuthi* (the thing is) I was so embarrassed to even look at people; I didn't want people to see me in the state that I was in. The way I looked, I was frightening (*ngangisabisa)*; I was finished (*ngangiphelile)*. I would look into myself and feel "I don't look like other people; I'm an outcast" (*sengiyinyamatana)*' [laughing].

The effects of an internalized HIV stigma are well illustrated in this conversation, in Thabo`s assertion that he was not feeling like a human; he was 'frightening' and felt like an 'outcast' as a result of his physical state. Earlier in the thesis it was argued that the body is an important tool for constructing a social identity: people use outward appearances to judge and locate someone into a related social category. Here it seems as if the judgments and positioning that comes from bodily looks begins with a sick person himself, in how he sees himself as deserving a lower social ranking due to the poor state of his body. Thus Thabo sees himself as a 'social outcast' and not equal to other people. This then impacts on his movements, including his avoiding contact with the society.

Based on these findings I began to think of Thabo`s decision to test as a way in which he wanted to restore his normal self, as a man and human being, through having access to treatment. Thabo found being sick to be a socially and personally alienating experience: he could not come to terms with how his body looked and felt; he could not enter public spaces because of embarrassment and he looked different from other 'normal' people. All of these resulted in his own self-judgment and perceiving himself as an 'outcast'. Testing here seems to be a way to determine 'once-and-for-all' what was killing him. This would enable him to get help (ARV`s) and then to reconstruct his life to a state of 'normality'. In this respect he was willing to subject himself to the 'humiliating' situation of the clinic where he would be treated by women who are reputed to not maintain privacy, confidentiality and respect for a sick man. Humiliation would be a temporary process in a long chain of events that would ultimately restore his previous self.

The fear of dying also contributed greatly to Thabo`s decision to test; it enabled him to overcome the barriers that are normally faced by men who want to test – such as identification with AIDS; rejection by others; being undermined by nurses, increased mortality and morbidity due to stress. In this respect Thabo`s situation confirms an observation made by Steinberg, that 'there is nothing like the emergency of one`s own failing health to expel dogma and invite openness'. His 'openness' is reflected in a statement 'I just handed myself over to the hospital'. Here Thabo seems to communicate a state of submission and willingness to let others – women - take care of his situation. In doing so he is dispensing with one of the key 'dogmas' associated with being a man in the study area: Control. By 'handing' himself over to women, Thabo can no longer claim control and dominance over them as most men do; by extension he can no longer claim to be a man. But as noted above, the loss was temporary; Thabo counted on getting ARVs which would enable him to rebuilt his life and then reclaim his manhood - though a man of a different kind than before.

Thabo is not the only man who was prompted by a need to address his physical looks to finally test. Most men felt that they were not looking 'normal', and testing was partly a way of correcting this. For example, Sipho commented: 'I had changed; I was even scared to look myself up in the mirror. When I looked, even my child when I called him and said 'come', he wouldn't even come...'. I asked him: 'what was he scared of?' and Sipho said: '*Phela ngangithusa man* (I was frightening, man). I felt like *ay akusenamuntu* (I'm no longer human), you see. I was too sick' (Interview, Sipho, 26 May 2006). Zita felt the same, saying: 'Even if I can show you my photos you might think I`m dead, that I'm already in the mortuary, that I`m not alive' (Interview Zita, 25 October 2006).
These stories demonstrate clearly how being sick can seriously damage someone`s self esteem. Illness takes away someone`s sense of being a human; it estranges him from his body and this pushes men to test in order to restore his previous selves.

Studies on men`s health have focused predominantly on what men stand to lose in terms of their masculinity if they use certain health facilities (see chapter 2). Testimonies shared in this section impel us to ask an equally important question: what do men stand to gain if

they use health services? And at what point in their illness do they make this calculation themselves? Certainly from what has been shared so far, there was more to gain for men like Thabo, than to lose from testing. However, a lot was already lost - physically and socially - before these men could realize the benefits of seeking medical help. And in order to receive help these men had to first incur further losses – dominance, control, dignity - through their dependence on female health workers as their helpers. The irony here is that while testing can be seen as (momentarily) disempowering and emasculating, it can, in time, become an empowering decision. This is because it sets these men apart as 'brave' and 'responsible' men, as opposed to other men in the society who are still 'scared' to test. This point will be elaborated further in the next chapter on disclosure.

Other approaches to testing

The impact of HIV stigma on testing decisions was not the same for all men who were sick. Lizo emerged as someone who adopted a completely different approach to testing. Unlike other men, he tested within a month of being ill and he went directly to the public clinic:

Lizo: Yhaa! Like there is this girl who was sick with HIV. Ey, we used to laugh at her. If maybe she has a problem, maybe she is struggling to do something, we would laugh at her. But I also started having problems, getting tired, and I decided 'Ey it's better if I go to the clinic'. So I went to the clinic and the sister tested me. And from there they referred me here.

SM: Did you just go on your own to the clinic?

Lizo: Yhaa, I just went on my own

SM: So how did you feel when they told you about testing, that you have to test and all that?

Lizo: The thing is I had already told myself when I went there, that if I am found to have it I will just accept it. I must just be free - there is nothing I can do. I can stress and all that, but it won't help in anything.

SM: So can you give the full story of what happened when you got there; what the nurses did and all that?

Lizo: Well, I came in, and they took me to the room. Then they gave me a book to sign, to show I was agreeing to the test. Then they tested me, and told me 'you mustn't be worried'. I said 'No, I won't be worried; as long as I know my condition I will be happy'. It's better to know than just living in the dark, because if you test you can also have access to treatments, you know.

SM: So you tested *neh*!

Lizo: Yhaa (Interview Lizo, 6 June 2006).

It seems as if Lizo had not internalized the fear of stigma as most men did, though he was aware of its existence and also shared in society`s stigmatizing attitudes towards an HIV sick person. This is what enabled him to undergo a test earlier than other men in the study. And he had already come to terms with the disease itself if his results were to be positive. Lizo was also a Christian and as a family they detested traditional medicines in favour of prayer and western medicines. This must have given him fewer options compared to other men who started by consulting traditional healers before finally going the clinic, or he was already used to using public health facilities and being treated by women.

Lizo was also not afraid of other losses to manhood that most men felt they would incur in their lives if they tested positive and were to enrol for ARVs. He was a non-drinker; he had one sexual partner and he generally lived a disciplined lifestyle that centred mainly on church activities, home and work. Testing positive would therefore not require him to make major changes to his life as a man in order to accommodate a new diagnosis. This is in contrast to men like Mathe, who invested greatly in alcohol and multiple partnerships as important definers of their manhood before they tested, and were worried about giving up these lifestyles if they tested positive.

Lizo is a good example to illustrate how men`s subscriptions to different definitions of masculinity may have a varied impact on health decision. Research has thus far focused mainly on hegemonic masculinity and demonstrated its harmful impacts on health, with

complete neglect of how other masculinities may impact on health behaviour. This has resulted in 'masculinity', rather than 'masculinities' being used as a dominant explanatory framework for men`s health choices. Results from this section demonstrate that we cannot focus on one way of being a man, as this provides a one-sided view of the impact of masculinity on health decisions. Men such as Lizo have a different story to tell in terms of how being a man – differently - informs their health choices, and they cannot be excluded in favour of focusing on a dominant masculinity.

HIV testing outcomes: men reaching out to other men

Part of the argument pursued in this thesis is that the experience of being sick and of using health services was transformative to the lives of the men in my study (it wasn't, of course in the case of the many men who got sick and died, rather than take a test. There is nothing inevitable about being sick leading men to test). Through this experience, men were able to reflect on – and then transform - their previous lifestyles and beliefs about masculinity, health and HIV that they held prior to testing.

This section looks at what forms of reflections and changes took place with regards to men`s beliefs about HIV and AIDS. As shown earlier in the thesis, some of the participants held questionable views about HIV and AIDS prior to testing. There were men who denied the existence of AIDS; some engaged recklessly in unprotected sex with several women because they believed they were immune from acquiring HIV; other men acknowledged that they may be at risk of acquiring HIV, yet they refused to use condoms. Did testing positive change these views and approaches to HIV? If yes, what are new ways of thinking and dealing with HIV that have emerged out of the being sick and receiving positive results?

There are two key ways in which men typically respond to HIV positive results in Bushbuckridge and elsewhere. Firstly, they may deny it and continue with life as before, without considering their HIV positive status. Some continue to drink, practice unsafe sex, use traditional medicines or deny having HIV. Alternatively, men may embrace their

status and then commit entirely to certain lifestyle changes that are recommended for someone with HIV. This includes submitting fully to western medical interventions, refraining from drinking alcohol and having multiple partners, and adhering to treatment. Men in this study adopted the latter response to their positive diagnosis: none of them questioned their positive results; instead they welcomed them as a relief after being ill for a long time from an 'unknown' disease. And as we will see in subsequent chapters, most of them adhered fully to treatment and other lifestyle changes required from someone with HIV.

The major turning point in these men`s lives that followed the positive diagnosis was that for the first time in their lives they accepted AIDS as a reality. Its existence had been proven 'for real'. This was a main point of reflection and change expressed by most men with regards to HIV beliefs. Lucky, who previously denied the existence of AIDS, said:

> I didn't believe this virus really exists, but now I do believe it exists for real. I can say I got it from women, and that was way back, but for some time I didn't detect it. I could see my body was getting smaller from how I looked when I was at school and when I was still working. I didn't know; I would hear about this virus that it is here for real, but I didn't believe it (Interview Lucky, 20 February 2009).

Men therefore had mixed reactions to their positive results. Firstly, results were difficult to accept because they meant that the participants had to deal with the potentially negative consequences of being positive. These include, being looked down on, being treated as an outcast and perceived socially as 'already dead'. Kenneth said, for at least two weeks after testing positive his health worsened. I asked him why, and he explained:

> First you think about what people outthere normally say about HIV, that 'if you have HIV you are done'. So once you get those results the first thought is '*Hayi sengifile* (I am already dead) (Interview Kenneth, 8 February 2007).

Lucky felt the same, saying:

> Ey, it was painful! Yhaa; because normally when people talked about HIV you would just develop a headache because of the way they talked about it. They would frighten you, that if you have HIV it means you are going to die…I think it took me about two weeks and then I felt better (Interview Lucky, 20 February 2009).

Secondly, testing positive was seen as a relief for certain men because it enabled them to access treatment and also to exercise control over treatment choices. There were men who rejected traditional medicines immediately after receiving their results, including those who believed strongly in them before testing. Koko said he instructed his family to refrain from giving him traditional medicines as soon as he tested positive:

> I told them 'should I get sick, please don't use these traditional herbs on me; here are my pills'. They know I am dependent on pills; they don't know what they are for but they know I use these pills (Interview Koko, 6 March 2009).

Other men began to label traditional healers as 'liars' and as 'incompetent' because they (the men) had wasted their money on them. For these participants, testing was liberating because it freed them from being dependent on their family members for medical support – traditional medicines. It brought back independence in decision-making and choice, issues that, I have argued, were key to their constructions of masculinity and which had been negated by their being sick. Most importantly it brought about finality in what has been bothering them (HIV), therefore enabling them to move on and make health choices based on an informed position.

Lastly and perhaps most significantly, testing positive had the remarkable outcome of changing these men into, what I shall call 'testing advocates'. This is despite the fact that they had previously treated AIDS lightly as an insignificant or 'unreal' issue. Some of my participants decided to use their positive diagnosis to encourage others, who were sick or at risk, to be tested. This was seen as part of being socially responsible and contributing towards lowering the overall HIV prevalence in the community, and also as helping those who were already ill. A total of 12 participants said they approached at least one person and encouraged him/her to test; seven men succeeded in persuading someone to test.

Others only raised awareness about AIDS among peers as 'real', though most of their peers were not ready to test because they were 'scared'.

Lucky is one of participants who were recipients of these men` roles as 'testing advocates'. He said when he met Thabo, his childhood friend, he was seriously ill and Thabo had just recovered from being sick himself. Thabo approached him strategically, first through his uncle:

> He didn't know how to approach me, so he went to my uncle and asked him to talk to me and advise me to come here - because my uncle is close to me. But my uncle was also scared, so he went back to him and advised him to approach me himself…so this guy eventually came and talked to me… he said 'I can see you have been struggling for a very long time. There is a place where you can get help; I was also helped at that place…'. So the following day he took me to Rixile; he introduced me to the nurse there and said 'this is my brother, he would like to test'. And from there I tested and they found that I'm also positive (Interview Lucky, 20 February 2007).

By disclosing to them, most men used their positive status to encourage others to test. As it can be imagined, this was difficult because it meant that a man must risk social judgement in order to help another person. The task therefore required these men to have fully come to terms with their own diagnosis before reaching out to others. A number of men described unpleasant responses from other men as soon as they started initiating conversation about testing. Tito said he is often told to 'get off with your AIDS', e.g. when he tries to initiate talks about testing and safe sex. Jozi described similar experiences, saying:

> Once you start conversations about AIDS they tell you '*wena ugula nge AIDS yakho ungasiphapheli thina, asiguli nge AIDS thina; asizelanga kufunda nge AIDS lapha* – If you are sick with your AIDS please keep it to yourself, don't come and bother us here. We didn't come here to be educated about AIDS. If you feel you are sick from AIDS go wherever you want to go, leave us alone'. That's how some respond. (Interview Jozi, 1 November 2006).

There were however more positive responses than negative ones. Most men who were approached acknowledged the importance of testing, though some were not 'ready' to do so. Some of the men said that, instead of undergoing tests, they decided to change their sexual lifestyles. This resulted from interaction with one of my participants and being encouraged by them to test. Jabu, who is Lucky`s older brother, said he has 'reduced' drastically on women, following Lucky`s positive diagnosis:

> It (my approach to sex) has changed a lot; I'm more cautious now, that 'ok, I must limit myself here and there'. Because if I don't have limits I will also end up there (having HIV)…like *ukuthand`abafazi* – being a 'playboy', I have limited a little bit, and felt that I must concentrate on one person. And I also told this one that I'm with now that 'if you want to do something just make sure you know what you are doing, because life has now changed (Interview Jabu, 6 April 2007).

Mdu said he was encouraged by his brother, Mathe to test after the latter's positive diagnosis. After testing negative, Mdu changed his sexual lifestyle. In our interview he described how he felt about HIV prior and post testing:

> Well, personally I didn't believe this disease can be transmitted from one person to the next. I thought it stays with just one person; I never thought I can get it from having sex with a woman who has it. I really never thought so. But then things began to happen which made me realize that 'Ey, this thing exists for real'. I didn't really believe it – *bengingayithembi kahle kahle*….but then I looked and realized 'No, this disease does exist for real, it's becoming more visible', and I also come here to the hospital with my brother sometimes, and I could see 'No, this disease does exist for real' [both laughing]. Now I have great respect for it [both laughing]; I have great respect for it now. In the past *bengigijima kakhulu* – I used to go out with lots of women; you would find me sleeping with all these women. I would just go after them, but since I did the blood test I developed a great respect for it. I respect it now [laughing]. And I can also see from my own brother; he was just well and healthy, but he is not the same anymore... I can see these days he has changed a lot; he is not my brother that I used to know (Interview Mdu, 19 April 2007).

These findings are encouraging and show that in the midst of an uncertain future imposed by testing positive, certain men are dealing with their diagnosis positively and see it as a chance to change and then help others. This response contradicts what we already know about men - that they are likely to react to a positive diagnosis in fatalistic and irresponsible ways. These include drinking excessively, denying AIDS or deciding to deliberately spread it to others - and also keeping their positive statuses a personal secret rather than reaching out to others.

A final point, however, must be made about the fact that these testing advocacy roles were not easy to assume. Men in my study waited until they looked physically healthy and strong again before they embarked on efforts to educate and encourage others to test. This move was strategic and well-calculated because it became a means through which certain men indirectly challenged the existing social perceptions of someone with HIV as 'already dead', which as I have shown, was a key barrier to testing. Because they looked physically healthy and strong, no one could associate them with dying; this made it easier to advocate for testing as the 'right thing' to do. There were also instances in which certain people refused to believe that they have HIV due to how they looked.

The fact that treatment was freely available also made it easier for men to reach out to others who were sick. Some of them took out their own medicine to show someone whom they were persuading to test, either as evidence that they are truly HIV positive or to enable him/her to see that there is life after testing positive. For most of them this strategy worked, as in the case of Kenneth. He told me that he met a woman in the train who was sick; he did not know her, but decided to approach and advise her to come to Rixile:

> …she was coming from Jo`burg, so I advised her to come here to Rixile. I think I saw her in November and then I met her again this year, so she asked 'why are you sending me there?'. I said 'I also go there; I'm on treatment at the moment'. Then I spoke to her mother, and I showed her my own pills. I told her we also take these pills, and I advised them 'don't go to these other places; the traditional healer is going to kill her'. So they

went to her doctor who gave them a referral here (Interview Kenneth, 18 February 2007).

There is therefore a case to be made from these stories that the presence of ARVs in Bushbuckridge is already changing social perceptions, as well as individual experiences of having HIV, from being perceived – and experienced - as something shameful and demeaning, and life-threatening to being viewed as 'just a disease, a virus' (Cameron 2005, p. 42). Whether this has an impact on testing decisions of healthy-looking people still remains to be explored by further research. In this chapter I focused on testing decisions of people who were already ill, and here it is clear that a decision to test changed their lives in highly significant ways. There were, however, more challenges that these men were faced with, as people living with HIV virus - in the society and in their own personal lives. In the next chapter I look at one of those challenging situations: HIV disclosure.

CHAPTER 6

TO TELL OR NOT TO TELL? - DISCLOSURE DECISIONS OF MEN LIVING WITH HIV

Introduction

A few days after receiving his HIV results, Vusi disclosed his status to his family. In my interview with him, Vusi talked about his disclosure process as if it was a simple routine, saying:

> I simply called them and told them. But first I told my mother 'Mama, I have been to the hospital and they told me I am HIV positive'. She said 'well, a lot of people are dying of this, so you must take your medication all the time when they give it to you'. So I did counselling and from there I went to support groups, I think for 3 weeks; I can't remember well because I was a bit sick.

Vusi`s wife also was present when he disclosed his results to his family. I asked if he was not worried that she would leave him and he replied:

> The reason I didn't worry about that was because she was by my side at the hospital; she fed me. And even while I was here at home she was very supportive, together with my mother. So I decided not to hide it because I knew she wouldn't leave me. Even her brothers know that (Interview Vusi, 28 February 2007).

Vusi`s approach to disclosure contrasts sharply with that of Koko, another participant. Koko took nine months before disclosing to the first person, his wife whom he was living with. During this time he was on TB treatment and used it as an excuse for initiating condoms during sex. When nine months passed Koko was pressured by his partner to withdraw condoms and as a result he decided to disclose to her:

> So after 9 months she said 'can you see nine months is finished now; let's stop using a condom'. And then we fought over a child. Now she started having a relationship outside; she would just leave as she pleased…I sat down with her and asked 'If ever we are found to be HIV positive what could we do?'. She said 'I really don't know'. I said 'It shouldn't make a difference; we have been living together for 8 years now. We can just stay together and we will have to use a condom; that's not a problem for me'. She said 'that will be tough!' I said 'we will be together; I will be taking my pills and you will be taking your pills too'. But she didn't like the idea. I said 'well, I have HIV; that's why I'm saying these things. I have had my CD4 count at 226 now (and that time they had improved again)'. But she refused completely, and then she left (Interview Koko, 6 March 2007).

Following the discovery of a positive HIV status, the next step that PLWHA normally take is to decide on disclosure: who to tell, when and how. HIV disclosure is indeed not compulsory, but in public health settings it is often encouraged as a necessary thing to do because of its health benefits for an infected person and his/her significant others. When someone has disclosed he/she can freely access treatment and may receive more support from others; the person is also likely to use condoms and then protect a sexual partner from contracting HIV. Disclosure has also been shown to have psychological benefits for someone – such as improved self-esteem; reduction of shame about having HIV; and general lack of concern for the negative response of others towards infection (Paxton 2002; Cameron 2005). In this respect disclosure is liberating – for an infected person and for those whom he/she interacts with, who can freely choose on how to react to his diagnosis. Disclosure can also have negative consequences, such being rejected and treated as an outcast or physically harmed (Skinner and Mfecane 2004; Long 2009).

In this chapter I want to explore the experiences of men, of disclosing to their sexual partners and others, as well as the outcomes of their disclosure. As the two extracts cited above indicate, disclosure did not always follow the same pattern among participants. There were men who took the same route as Vusi and disclosed freely without having a fear of being rejected or abandoned by their partners. The majority of participants disclosed in the same way as Koko did; they took longer and were worried that a partner

would abandon them, and then accuse the man of infecting her with HIV. All 25 participants finally disclosed to at least one person, either immediately after receiving results or months later.

HIV disclosure in Bushbuckridge

In order to understand the disclosure behaviour of men in this study - and its significance - we need to first look at how people in the villages where they stay normally deal with disclosure, or manage information about their HIV status. I spoke to a number of people outside my selected sample - such as health providers, other PLWHA, community leaders, and friends – to find how people in general approach disclosure. The main questions that I asked were: how do PLWHA generally deal with a positive HIV diagnosis: do they disclose or keep it private; to whom do they disclose; at what stage? How do men in particular deal with disclosure? The dominant response I received from various participants that I interviewed was that PLWHA prefer to hide rather than disclose their positive diagnosis. When someone decides to disclose he/she limits it to selected family members and close friends. It is unusual to find someone who is openly living with HIV. Lolo, my friend and neighbour in Kildare, was amongst the first people to communicate this practice to me, saying:

> I really don't know anyone who has ever lived with AIDS here. The only person I know is that lady from Radio Bushbuckridge (a local radio station). She normally talks about being HIV positive, but not here (Informal conversation, 4 May 2009).

Other informants who shared the same views as Lolo are two health workers that I interacted with while living in Kildare. Zandi, a home-based carer, lived closer to my place of residence and we spoke regularly about her experiences of HIV in the village. One evening during our conversation she described a painful situation she faced where PLWHA are refusing to disclose to her as their carer. She said this makes it difficult to offer care and support:

> It`s difficult. You have to be very patient because people don't just disclose. Some have died...I know a lot of them here who have died...sometimes you go there, you cook for her and you wash her. But she will never tell you what is killing her (Informal conversation Zandi, 23 June 2006).

Her experiences were echoed by another health worker in Kildare, Mrs. Manzi. Mrs. Manzi said at their clinic they try and encourage PLWHA to disclose so as to establish support groups for them. But they are failing because most PLWHA would rather hide their status than share it with others:

> Like now; we were planning to start a support group here for them. You know what they said? They said 'that will be the last time you see us here' ...because they don't want to be seen. Some haven't disclosed even to family members, so imagine if someone walks in and finds his family member at the HIV support group...(Informal conversation, 21 April 2006).

My own observations and experiences confirmed these stories about lack of open disclosure. I was struck by the gap that existed between private and public talk about AIDS. Most people were keen to talk about AIDS as it affected others in their neighbourhood, including gossiping about them. But they were unwilling to discuss their own experiences with the disease, whether as affected or infected. I had friends whose family members died from 'undisclosed' or 'unknown' illnesses; when I enquired about the causes of death I received vague answers[19]. My own neighbour was sick throughout my stay in Kildare, and one of the health community workers took him to Mpilo clinic in Bushbuckridge to receive ARVs. When I spoke about his illness to his father, Mr. Dlamini, he said his son had *tindzhaka*. Mr. Dlamini was open about AIDS; he attended several community meetings about AIDS and we had long conversations about his experiences with the disease in the village. He spoke openly about AIDS and the fact that

[19] These enquiries occurred during casual talks as part of an expression of sympathy to someone. It is normal to ask what someone has died of, but I discovered that this question was becoming harder to ask in case someone died from a disease that must be hidden.

PLWHA must not be rejected, but they needed to disclose in order to receive help. Yet, when it came to talking about his own son, his openness vanished.

My informants shared some interesting views about men in particular, saying they are generally unwilling to disclose their HIV status, whether to a partner, family members or friends. Partly this was due to the macho attitude that most men seemingly embraced, which constructed them as independent, strong and in control. It is therefore expected of them to demonstrate this attitude as a response to their positive diagnosis. Mr. Khosa, the Kildare Induna was the first person to share this view with me, saying:

> *Amadoda vele awakhulumi* (men are like that; they just don't talk). Men are faced with so many problems. But they never talk...you see a man waking up early in the morning and take his cows to the field. He will stay there the whole day; the whole day! He hasn't eaten anything. And when he comes back he goes back straight to his home and sleeps...he doesn't talk to anyone. Men are like that... (Informal conversation Mr Khosa, 12 May 2006).

Another reason offered was that men tend to feel guilty when they tested positive. A man will interpret positive HIV diagnosis to mean that he 'brought' AIDS to his partner and children. For this reason he preferred to hide rather than tell others, to avoid being labelled as having infected someone else. Mr. Sibi, an HIV counsellor based at Rixile clinic was the first person to share this view with me:

> Sibi: The problem with men is that as soon as you tell him he is HIV positive, he immediately thinks 'God I brought it; I'm responsible...', and then he starts to think of all these women that he slept with, that 'Ey, it means I have infected all of them!'...and then he starts to think about his own wife and children and then he gets ashamed. Now all this business that he has been doing outside is being exposed'.
>
> SM: But I remember you said it is culturally acceptable for men to have multiple partners. If that is the case why should they be ashamed if they are found out like that?'

Sibi: Yes, but the fact that they are allowed doesn't mean they do it openly. People hide these things...he looks at his wife and she is sick, and maybe the child is also sick and he feels: 'Ey I caused all this...I would rather die...that's why some men would rather commit suicide (Informal conversation Mr Sibi, 3 August 2006).

Here Mr. Sibi seems to suggest that disclosure brings into public what is normally a secretive thing. In many respects it is a way of confessing to having done something wrong and immoral. I have argued earlier that we need to dispense with a tendency to view male promiscuity within marriage as an open and public affair; I observed that most people would like to keep it secret. Here Mr. Sibi agrees with my observations in pointing to an embarrassment that certain men experience when they test positive, due to their promiscuous sexual behaviour. Here, their shame is intertwined with guilt in having contracted a life threatening disease (HIV) and passing it on to a partner and a child. This is what makes it difficult to disclose.

These accounts about men were supported by individual stories shared by women in support group. Most of them said their partners are unwilling to test; some who have tested are not disclosing their status to them. One of these stories was shared by a woman in her mid 20s who lives in a village near Bushbuckridge. She said her partner is sick, just like her, he also receives treatment from Rixile clinic, but she never sees it:

> I know he comes here, but we don't come on the same date; he makes sure we don't come on the same date. When she was diagnosed with HIV she disclosed to him, hoping that he would do the same '...but he never talks. I mean I can see someone with HIV because I also have it...Her main concern was that they were not using condoms (Focus group observations, 2 August 2006).

In the same group discussion another participant shared a story about her husband who came back from work in Johannesburg and suddenly demanded that they use condoms:

> He never told me why. He just came back with a pack of condoms and said 'from now onwards I want us to use these condoms'. So I didn't ask; I was just happy that he is using condoms (Focus group observations, 2 August 2006).

Both stories did not surprise other participants. It was seen as being 'typical' of men not to disclose, or to make unilateral decisions to use condoms. In relation to the latter story the response from other participants was she was lucky that he was using condoms because other men don't even use them.

In worst cases, men who are HIV positive were said to deliberately go on and spread it to others. This came up in a number of my interviews with male ARV users, such as with Joe. He said: 'Men don't want to disclose...he finds that he is HIV positive and he responds by killing himself or says 'I will spread it'. He goes on and having sex without a condom' (Interview Joe, 23 May 2006).

During fieldwork I met one man who had plans to deliberately infect someone else with HIV. Bob and I were meeting for the first time outside the clinic, where he was having a conversation with one of my participants while waiting for his turn to see a doctor. I joined them and caught up in their conversation about their infection and how they wanted to move on in their lives. Bob was bitter, saying he was infected by his partner who did not disclose to him. He said he wanted to infect his girlfriend`s younger sister as a revenge for his own infection:

> She comes here (Rixile), and while she comes here she never told me she has this thing. *Mina ngihleli* (I'm sitting there) and all along she knows she is infecting me with this thing…she has two other sisters, and you know what I will do? I will date that other sister of hers and maybe something like a month, have sex with her; and after a month, tell her the whole story 'your sister has AIDS, I also have it and you also have it…(Informal conversation Bob, 15 August 2006).

Other than Bob I am not aware of another man, either within my sample or in the community where I stayed who had intentions of deliberately spreading AIDS. I

interacted with Bob for more than a year after he made these threats, but he did not initiate a sexual relationship with his girlfriend's sister.

These discussions provide a context for understanding disclosure behaviour of my male participants as either conforming to, or departing from the 'norm'. From what has been discussed above, there is pressure to hide rather than disclose HIV results due mainly to shame and embarrassment. For men in particular this pressure is exacerbated by a need to portray a strong and independent front as part of conforming to a masculine identity, and by a feeling of guilt in having infected a sexual partner. My participants who have disclosed are therefore, to a large extent, an exception – all the more interesting given that they started off as men sharing the dominant norms of masculinity in their communities. For this reason we need to know what enabled them to disclose; at what point did they decide to disclose? Why and how did they disclose? And how did they take into account problems of shame, embarrassment and guilt felt by most men who want to disclose. I begin with disclosure to partners and then later, I will discuss disclosure to friends and the community.

Partner disclosure and its outcomes

Disclosing to a partner was described by most men as having been a difficult and challenging undertaking. Most of them were worried that a partner would leave him as soon as she discovers his HIV status and then accuse him of having been promiscuous and infecting her. There were also concerns that as a soon as a partner leaves she will 'publicise' his results, thus tarnishing his social image. Disclosure therefore became a carefully managed process where men began by first 'testing the waters' (Green and Sobo 2000) and 'preparing' a partner, before sharing their diagnosis with her. Most men decided to disclose when they were assured of the positive response from a partner such as that she would not leave or accuse him of infecting her. Others 'misread' the situation and disclosed immediately after receiving their results; this resulted in sudden termination of their relationship by the partner after disclosure.

There were differences in disclosure patterns between men who felt guilty of contracting HIV and then infecting a partner and those who did not. The former took longer and they saw disclosure as 'taking responsibility'; the latter group disclosed immediately after receiving their results and they did not attach a significant meaning to it. The length of a relationship, level of investment in it by a partner, and age, also shaped disclosure practices in significant ways. Whether men were ill or not also played an important role on their decisions to disclose; this last point will be explored further in the next section.

Duma lived with his wife and 3 children when he took an HIV test in 2004. He had been sick for a long time and started by using traditional medicines before doing an HIV test. Duma tested alone at Cottondale clinic and was later referred to Rixile clinic for treatment. When his HIV test results came back positive he accepted them, but was faced with a dilemma of how to disclose to his wife. Duma took 5 months before disclosing to her; his main fear was that she would leave him and take their children with her. He was sick at the time so he feared that if his wife leaves there would be no one to care and support him:

Duma: I tested there and they told me I'm HIV positive…And then I wondered [a sigh]…'how am I going to tell my wife?' I had a serious problem of not knowing how to approach my wife. I thought about it; thought about it, and eventually I decided: 'Ey! It doesn't help (*kuyafana veke, akusizi*), because here they are telling me to use a condom. But how am I going to use a condom without telling her what the problem is?' So I decided to tell her: 'Ey; I have this type of a problem, so-and-so'. And by the time I told her it was already too late because she was pregnant, you see. So I told her and she also went to test; she said 'I would rather test as well'. So she went and discovered she is also infected. Then she later enrolled for treatment; she is now on treatment

SM: Was it easy for you to tell her?

Duma: Well it was easy because I told myself if she decides to leave me it would be OK. It would be better than just hiding this disease. Because I wouldn't have someone to share my situation with. But now we share a lot at home; maybe we are listening to radio or so and we make comments about what is said (about HIV) (Interview Duma, 23 August 2006).

During the five month period that Duma had not disclosed he was having unprotected sex with his partner. I asked him to why he continued to have unprotected sex with his partner despite knowing that he is HIV positive, and he explained:

> I was still scared to tell her, that 'I went to do a test and I tested positive'. And I was also worried what she would think if I just stay with her without doing anything (sex). It wasn't easy; it wasn't easy. I was seriously sick that time, and I thought if I can disclose to her that I am HIV positive and then she leaves me, then there wouldn't be anyone to look after me. Because I wasn't like the way I am now; I couldn't even move around, I had to be in one place all the time. She had to cook for me and also do all sorts of other things. So I decided not to tell her for the fear that she might leave me. But I was causing more damage. When I look back I feel I could have told her earlier; maybe she wasn't going to leave me (Interview Duma, 23 August 2006).

.

I then probed Duma further on how he disclosed to his partner, and his response reveals clearly that disclosure was not an easy decision:

> I approached her by making a scenario; I said 'Now as you know there is this disease called AIDS out there, if I can go and test HIV positive how would you react?' She said 'No there is nothing I can do'. Then she asked 'What about you; should I test positive would you leave me?'. I said 'No ways! I will never leave you'. And she said 'The same applies me: if ever you go and test and you are found to have HIV, I will not leave you'. And from there I disclosed to her, that 'I am asking these questions because I have HIV'. She said 'No, I don't believe you!' I said 'It's true!', and I took out a paper and showed her. She said 'Well, what can we do, because I can say you brought this HIV here while in reality I might have brought it myself; because all of us have flaws' (Interview Duma, 23 August 2006).

Duma`s testimony reveals much about what goes on in the mind of a man who is HIV positive and wishes to disclose to his partner. Duma says he was sick and physically weak when he tested for HIV; this shaped how he handled his results towards his partner. His main worry was that his wife would leave him and take away the children and, being physically weak and sick, he would be unable to stop her or take care of himself once she leaves. Duma therefore postpones disclosure until he is feeling stronger and can deal with being abandoned. He also told me he had already resolved that he would look for another woman in support groups if his partner decided to leave him.

At the core of Dumas' approach to disclosure was a sense of guilt that he felt towards his own infection and that of his partner (even though she has not yet tested). Duma felt that he contracted HIV first, through having multiple sexual partners, and then passed it on to his wife whom he thought was faithful to him. In our interview he told me '*bengigijima kakhulu banafati* (I was after women a lot)'. He could not pinpoint exactly which woman infected him with HIV, but was 'sure' that he contracted HIV from one of them. Duma used to work in Nelspruit and later in Johannesburg. These are places where he met most of his extra sexual partners.

It is interesting here to note how Dumas`s partner reacts to his disclosure. Instead of blaming him, she admits to her own previous unfaithfulness - though indirectly. This

enables Duma to feel less guilt and be able to go on in life with her. In my interview with her I asked if she knows who among them infected the other and she replied: 'Well, you never know. Maybe I did something on the side or he did something on the side. So we never talked about it' (Interview Tsakane, 20 April).

I was struck by this response because it contradicts how African women who are HIV positive are normally portrayed in HIV literature - or portray themselves to researchers - as innocent victims of their partner`s previous promiscuous sexual behaviour (Long 2009). Women are depicted in most research as always being faithful to their partners and when a woman is HIV positive it is because of her partner`s unfaithfulness. Here we are seeing a different response where a woman refuses to lay blame on a man; instead she confesses to her own involvement in extra-marital sex.

Testimonies shared by other men reveal that guilt was central to their disclosure decisions. Most men felt strongly that they contracted HIV first, through having multiple sexual partners, and then passed it on to an 'innocent' partner. This then shaped the strategies that they used to disclosure, including how long it took before disclosing to a partner and how to approach her. A few more cases will further illustrate these points.

Sipho tested alone while at the hospital for TB. His wife visited him every day during his stay at the hospital, but Sipho decided not disclose his HIV results to her. He waited until he was discharged and then told her:

> So they checked me. And from there they said 'will you able to tell your wife, or your family?' I said '*ey umfazi wam ngizomngena kanjani* (how am I going to approach my wife?) I said '*Ay, ngiyamlanda (*I have to tell her)'. When I arrived home I said 'My wife, how would you react if I can tell you I have HIV?' She said 'No, that wouldn't be a problem. If they told you that you are like that just tell me'. I said 'They say I have HIV'. She said 'That's not a problem; if someone is sick he is sick'. I said 'You also need to go and check' and she said 'No I will go'. And she really didn't resist; so we came and checked and found that she also has it. *Ey,* we enrolled for treatment. And they found that

her condition was actually bad and they quickly gave her some treatment, these pills; I was still busy with the TB treatment… (Interview Sipho, 26 May 2006).

Sipho`s partner, Nono, made similar remarks as Duma`s wife when I interviewed her on why she decided to stay with Sipho after he disclosed his results to her. She said: 'Well Bhuti, I wouldn't know, because when I met Sipho I already had two children. And we had both been around. So I would sit and blame him whereas maybe I brought it' (Interview Nono, 20 February 2007).

The absence of anger in these partner`s responses struck me as being quite significant and unusual. Perhaps it is an indication that they were already suspicious of HIV as being a cause of their partner`s sickness and were only waiting for medical confirmation. Or in the case of Nono, she might have already tested but had not disclosed her own results. This is reflected in how she seems to lead Sipho towards disclosing by saying 'if they told you that you are like that, just tell me'. Sipho and Nono had a child before he got sick and Nono might have tested during her clinic visits under the PMTCT programme[20]. Getting sick first is what differentiated Sipho from his wife and it put more pressure on him to disclose. Most importantly, it cast him as a guilty party.

The two cases shared above deal with men who disclosed personally to a partner, despite feeling guilty. There were men who used services of the clinic to disclose to their partners. These men were 'too scared' of their partners; the guilt was overwhelming and they could not gather enough courage to tell them. Xola was one of those men. He tested alone while living in Pietersburg where he worked as a security guard. Xola was 'sure' that he contracted HIV first and then infected his partner, saying:

Eish!! I got it from my previous wife, the first one. So we broke up and I met this one. Now this one never really gave me any troubles because I also didn't know I have this thing. The first day (of sex) I didn't use a condom and the second day too. On the third day I said '*ey angizizw kahle marn* (Ey I'm not feeling really well). Let's use a condom

[20] Prevention of mother to child HIV transmission is compulsory for all pregnant women in South Africa.

> because I might be having a certain illness or so'. So I was worried that I might be having this sickness and that I infected her…so I know she got it from me; she didn't get it from someone else. Cause she was at school, at the technikon (Interview Xola, 24 May 2006).

Xola`s main guilt was that his wife was 'still young'; she was still studying at a tertiary college when they met. The thought that he may have infected her with a deadly virus made him feel as if he destroyed her future, saying: '…like now, my wife wants children; I don't want children because I have two grown-up children. But my wife wants children and we have to deal with this problem…and my wife likes studying'. In the next extract he describes how he used the services of the clinic staff to disclose to her:

> Now, I left from Petersburg knowing I have HIV, but didn't tell my wife. So now I came here to Acornhoek; I went to OPD and said 'I would like to do a blood test'. They asked 'why do you want to do a blood test?' I said 'I'm not feeling well'. They took it, but didn't tell me anything. They said 'Bring your wife', so I brought my wife. Now they took my wife aside and said 'if your husband could be found to be HIV positive what can you do?' She said 'No, there's nothing I can do'. They said 'aren't you going to leave him, or maybe commit suicide?' She said 'no'. And they said 'OK, we have checked your husband and we found this virus in his blood; now we would like to test as well'. She said 'No, no problem!' So they also checked her and found that she is also HIV positive (Interview Xola, 24 May 2006).

This way of disclosing illustrates clearly how the sense of guilt overwhelmed certain men, making it difficult to openly approach a partner about his HIV results. Xola feels that he contracted HIV first and then passed it on to his partner who was still a student; the student status here is associated with being free from HIV.

Most participants adopted the same route as the above three men in dealing with disclosure. There were however a few men who took a different route. Bob, Vusi and Lizo disclosed immediately to their partners after receiving their HIV results. Unlike other men, they took no time to 'prepare' or sensitize a partner to the forthcoming news.

The differentiating factor between these men and others was that they felt no guilt in their own infection. Instead they constructed themselves as victims (of partner`s dishonesty), or were 'not sure' of how they contracted HIV. This enabled them to disclose 'freely' without a fear of being abandoned by a partner or accused of infecting her.

Bob tested alone in one of the local clinics after a long illness. As shown earlier, he was reluctant to test and only tested after being 'forced' by his mother to test. A few days after receiving his results Bob decided to disclose to his partner. He explains why he took that approach:

> Bob: You know what I did? I felt that maybe I got this thing from her because she was the first person to take TB treatment; I wasn't sick at that time. But she was even hiding it from me. So I decided to just tell her, that 'this is this'. So there was this day that I went to the clinic and on coming back she asked me about CD4 counts. I was puzzled because an ordinary person can't just know about this thing, you see. So I could see she knows something and she was just checking on me, to see how I would react. So she gave me an opportunity to actually disclose to her, so I just told her 'it's like this, and this, and this…' (I'm HIV positive).
>
> SM: And how did she react?
>
> Bob: What could she do? She just accepted it? She had no choice! (Interview Bob, 2 February 2007).

Again we are seeing how getting sick first can be read as an indication that someone got HIV first and then passed it on to a partner. Here Bob uses all sorts of 'evidence' to buttress the portrayal of himself as a victim – the fact that his partner got TB first; she knew about CD4 counts; and was hiding her treatment. Bob has a history of being sexually promiscuous, yet he does not reflect on it as a cause of his infection.

I interviewed Bob`s mother, Ms Mali to get her side of the story on how Bob might have gotten infected with HIV. She shared the same views as Bob, saying he got HIV from his partner, through her dishonest sexual behaviour:

SM: Do you know how he got HIV?

Mali: This woman he stays with; that's the honest truth (*iqiniso lihle*). She started treatment first, but she said it was for TB. She was hiding it from us (it's a pity she is out now; she still stays with us here), but the minute he started treatment I noticed his pills are the same as hers. This girl is also sick now, but she was hiding it from us. She was already sick when they started dating; she even got pension and is still receiving it even now.

SM: So they met while she was already sick, and then… [Interrupted]

Mali: This girl was sick, and then she got better. And then he met her, not knowing what was going on.

SM: And how does that make you feel towards her?

Mali: Well I asked her and she is not denying it; she will even admit to you, she is not hiding anything [soft laughter]. She has accepted it because we keep raising it. Even one of my children, my fourth girl-child, said 'You keep saying my brother has AIDS, what about you; what are these pills that you are taking for?' She wanted to start a fight with her so she could leave, but I said 'chasing her away will not help. Don't chase her away; just leave her alone….' (Interview Ms Mali, 10 April 2007).

Here, Ms Mali also uses the same indicator as Bob to arrive at a conclusion that his partner infected him – she was sick when Bob met her; she was already using ARVs and she was hiding her treatment from them. To take the analysis further, we can also think of the notion of 'family honour' as having contributed to Bob`s family labelling his partner as an 'AIDS vector'. Iliffe (2005, p. 363) observed that AIDS dishonours 'not only the individual but the entire household', and that this partly explains why families decide to conceal HIV or AIDS deaths. Ms Mali could probably not come to terms with the fact that her son contracted HIV from his promiscuous sexual conduct and then infected someone else; this would affect the honour of his family and also deprive them of sympathy from the society. To safeguard the honour of the family they labelled Bob`s partner – an 'outsider' - as a perpetrator and Bob as a victim of her unfaithful behaviour.

Interestingly, when I spoke to Bob`s partner Noni, three days later in the presence of Ms Mali she denied having HIV. She arrived at Ms Mali`s house one afternoon carrying some parcels and found us chatting casually in the lounge. Noni had previously told Bob she that wanted to meet me, so when she found me in the house she immediately initiated a conversation with me. She dropped the parcel that she was carrying and sat on the opposite sofa and then asked me a direct question: 'Bhuti is it possible that one can test positive and then test negative…?'. I asked her to explain and she continued:

> You know, I was at the hospital and they tested me and found that I am HIV positive. And then they said I must always go to Cottondale to collect some treatment. But at Cottondale they said they wanted to test me again, but my results came back negative…I'm telling you Bhuti, if these people did this; if it is true that I don't have this AIDS I will sue them. The nurse at Cottondale said 'no, Sisi, you don't have this thing'. And she tested me again. Now I'm still waiting for my other results…if they come back negative I will sue them… (Informal conversation Noni, 28 April 2009).

This discussion reveals clearly what can go wrong when disclosure is not properly managed. Bob approached disclosure with a belief that he was 'innocent'; therefore he felt no need to be cautious as did other men who owned up to their infection. His partner on the other hand was defending her own honour - and maybe that of her family too - when she denied having HIV. Being seen by Bob's family as someone who infected him with a deadly virus was not good for her image and integrity. My own view is that her decision to deny having HIV was an attempt to free herself of guilt that was laid on her by Bob`s family, and the subsequent negative judgment that she received from them. Ultimately both of them denied having HIV and Bob later stopped treatment. When I left fieldwork they were still together and living with Bob`s mother and their child who was HIV positive, was reportedly sick.

Lizo is another man who took a less cautious approach to disclosure. Like Bob he disclosed immediately to his partner after receiving his results, based on the belief that he was innocent. He lived in Sabie where he tested during the week and then returned to his home on the weekend and immediately disclosed to his partner. Unfortunately she left

him soon after disclosing. We had a detailed interview on his approach to disclosure and its consequences:

Lizo: Yhaa, I tested. And then I went back home and told my wife. I sat down with her and told her 'I have been to the clinic for this and that purpose. They told me at the clinic that I'm like this and that'. I told her like that, and then I went back to work in Sabie the following day (because I used to do a temporary job there). And on coming back I found that she had taken all her clothes and left.

SM: But at the time that you told her what did she say?

Lizo: She said I brought it, that I got it from other women, but I don't know about that because I'm sure I didn't have a girlfriend in Sabie. Every weekend I would come back home.

SM: And for how long were you together?

Lizo: It was three years…three years full

SM: So she is pointing fingers at you

Lizo: Yhaa; she is pointing fingers at me

SM: But when you think of it, how do you think you got it?

Lizo: (soft laughter) Ey! I can't tell you how I got it exactly. Because they also teach us that this thing comes in many ways; it doesn't only come through sex. Even these machines we use to shave can transmit it – you find that they shave one person, and I also join in the line. Now this person doesn't even clean this machine and he comes straight to me. And maybe that person left his HIV there and I get it too. So I can't say for sure how I got it. No, I can't tell you

SM: Is there a possibility that you may have gotten it from your girlfriend maybe?

Lizo: No, I trusted her a lot; because if I am with someone I just focus on that one person. I don't do this running around (*uphuma-phuma*). That's why I say I can't tell you how I got it.

SM: But tell me; before you dated this girl how were your previous relationships?

Lizo: They were just fine; they were just fine

SM: I mean how many girlfriends did you have before her?

Lizo: I used to live with this other girl, but we broke up, and I never had a problem with her. The problem started with this one from Mariti; that's when I started feeling tired and all that.

SM: And how long did this problem last?

Lizo: For three months; and then I started feeling 'Ey *No man; ngiyaphela manje*! (this is getting out of hand now!) And I couldn't eat properly; I would eat just a little. And then I went to the clinic and they gave me some pills, you see the white pills and some brown ones. At least I was able to eat. So I started recovering again, you see... (Interview Lizo, 18 January 2009).

This extract provides a good example of how disclosure can go wrong if partners are not approached with caution. Lizo approached disclosure under two conditions, namely, trust and belief in his 'innocence'. He trusted that his partner would not leave him and also felt no guilt towards his own infection. I asked Lizo if he regretted disclosing to his partner in this way and he replied:

> I had to tell her; I didn't have to hide it because I lived with her. Whatever problems, I have to tell her and I also expect her to do the same, to sit down with me as her husband and share it. Now I think where I made I a mistake was in my approach – in retrospect I think I could have asked someone else to tell her, because I just told her directly, that 'I have been to the clinic and they told me this-and-that'. So she ended up leaving (Interview Lizo, 18 January 2009).

From the perspective of health providers Lizo`s poor judgment could be attributed to poor post-test counselling. 'Proper' post-test counselling entails that patients are warned beforehand about potentially negative consequences of disclosure, such as being abandoned or accused or 'bringing' AIDS, and most HIV service centres, including Rixile clinic, educate PLWHA on how to disclose 'safely' to others. But in this case I would also attribute Lizo`s oversight to his religious beliefs. As I showed in previous chapters, Lizo was a devout Christian; his approach to life was guided by his Christian identity. It is possible here that his way of disclosing was driven by a need to adhere to the ethic of honesty and openness as required of Christians like himself. To keep secrets or hide, or put someone at risk - through unsafe sex in this case - would reflect badly on Lizo as a Christian. When Lizo says 'I didn't have to hide it because I lived with her… and I also expect her to do the same', he seems to affirm his adherence to the ethic of openness and honesty as guiding principles in his life. This, however, contrasts with the

biomedical ethic which encourages privacy and confidentiality as strategies for managing HIV information.

Lizo was not alone in experiencing this conflict between his own individual beliefs on how to handle HIV information and support group messages on the issue. Even men who are not Christians were faced with similar dilemmas of how to reconcile a strongly felt need to 'tell' and then protect others, with a medical imperative to keep HIV a private and confidential matter. In support groups new patients were strongly advised to keep HIV a private matter until they are 'ready' to disclose to others. But certain individuals found this approach to be alienating and something that deprived them of the support of their partners, friends and family members. Some people felt that family members had a natural obligation to support them when they are sick, and keeping things secret deprived them of their 'right' to this support. Thabo expressed this view clearly in our interview:

> That time (when I tested) I was staying with my mother...And it took me a long time before I could disclose to my mother because when we went to class (support groups) they told us 'Don't tell even a family member'. But then I asked 'Ey, one day my mother will find me being unable to even wake up; maybe I can't even reach my pills and I need her to bring them to me. What am I going to do?' They said 'No, maybe your mother will not keep a secret; she will go and tell others out there; you must tell someone that's younger, whom you can share with. Because some people will be disgusted by you, they won't want to touch your plates and other utensils because of this problem'. I said 'No, my mother will never do that. I am her child; she will never abandon me'. So I told her 'I have been to the hospital and they told me I have this problem, but it doesn't mean I will die. I will live like other people'. So she accepted me and I stayed in with her. If I wanted something she gave me, if I want water, kettle, you see. So we stayed together until I got better now (Interview Thabo, 12 April 2007).

It appears ironic that support groups, a site where a positive and confident HIV identity is normally constructed and imparted to new clients, were active in blocking open disclosure of HIV results. In other settings, support groups are normally active in encouraging people with HIV to disclose in order to break social stigma attached to HIV

and to receive support (Whittaker 1992; Robins 2005). Perhaps the approach taken by this group indicates the extent of HIV stigma in the communities where PLWHA live. But, as seen below, certain men are already challenging it through living openly with HIV.

Lastly, let us look at Vusi, another man who disclosed immediately to his partner. Vusi`s approach was unique because unlike other men he expressed neither guilt nor complete innocence in his own infection. Vusi admitted to having had multiple partners during his work in the military; however, he linked his infection to the risks inherent in his work, saying:

> I can't say I know how I got it. *Angithi* they tell us you get it by sleeping with a woman without using a condom. And *uma ngikhula mina icondom bengingayazi* (growing up I never bothered about a condom). I also worked as a medical, so I would give injections to the soldiers. So I know that if you make contact with an infected blood you also get infected. And sometimes we would carry dead people; especially in KwaZulu-Natal where there was fighting. And we didn't use gloves; hence I say I don't know for sure how I got it: maybe it's from sleeping with women or from that job (Interview Vusi, 8 January 2007).

The first time I learned about his disclosure approach was in support groups at Rixile clinic. A female facilitator was standing in front of the groups, giving advice on how PLWHA should disclose 'safely' to partners. She advised:

> You cannot just walk home and then tell him 'Papa (my husband), I come from the clinic; I am positive'. He will leave you; or he will beat you up saying you infected him with AIDS…you must wait until he is maybe happy. Say maybe you are coming from the clinic, and then you prepare a nice meal for him. He will enjoy it and while he is enjoying it, you ask him nicely 'My husband I have been to the clinic (as you know I have been sick). The doctors said we must go together; they need to do some tests'...don't tell him what the test is for, because if you mention HIV he will jump up. Just say the doctor needs to do some tests on both of you...

Then she fixed her eyes on men who were sitting quietly at the back seat, and said 'These people are quiet; men are really quiet, but men must learn to be more open with their partners. Most men out there don't want to disclose'. Vusi was sitting on the back row at a time and as soon as the facilitator paused he stood up and said:

> ...No, no, no, *Sisi* you are making a mistake. You cannot treat us the same. A woman and a man are not the same. For me as a man I have the right to disclose to her anytime, but she has no right to disclose to me...a woman cannot tell me what to do – she cannot say 'let's go and have a test'; she has no right to tell me what to do.

Vusi then shared with the group how he disclosed to his partner, Sindi. She was sitting on the front row at a time and Vusi asked her to stand up for everyone to see her, then he said 'This is my wife. I disclosed to her...I told her 'I'm HIV positive; if you want to stay you can stay, and if you want to go you can go...'. His wife nodded with a smile in agreement with what Vusi said, and then sat down (Support group observations, 18 October 2006).

I then visited Vusi and his wife three months later, to do an interview at his place. In our interview I asked him why he adopted a confrontational approach to disclosure and he replied: 'This is my house; if she is not happy with my HIV status she can leave...this is my house!...'. Vusi told me that as soon as he disclosed to his partner he immediately ordered her to do an HIV test at Rixile clinic. It turned out that Sindi had tested somewhere else without telling him, during her short stint as a home-based carer for a local clinic. Vusi was angered by this; he then ordered her to do another HIV test:

> I told her that she must do an HIV test where I did mine. So I called *sis* Joyce (the Rixile counsellor) and I put her on the phone with her and said 'Speak to this person. Make an appointment for a test'. They made an appointment and she counselled and tested her. The results confirmed that she was negative... (Interview Vusi, 8 February 2007).

It remains unknown to me why Vusi used a confrontational approach to disclosure. Perhaps it has to do with guilt experienced by most men who tested positive and felt that they infected a partner; but unlike other men discussed above who decided to be cautious and humble, Vusi dealt with it in a confrontational way. Or Vusi was insecure about his manhood because of being sick, and he wanted to assert it, even through near-violent means. Vusi also believed strongly in male dominance, arguing that his wife was subordinate to him as a head of the household and as a man he was entitled to make unilateral decisions in the house (see chapter 3). Being sick from HIV, however, must have threatened his authority due firstly to how he looked physically (weaker than before) and secondly, how he was dependent on his partner for physical and emotional support. He was also unemployed and depended on his siblings. I want to think of Vusi`s confrontational approach to disclosure as an attempt to reassert his manhood, particularly his position as a household head and a decision-maker.

The accounts of disclosure that I have shared above indicate two approaches taken by men: a 'cautious' approach, and what may be called an 'immediate' approach. I have argued that these different approaches are due to whether or not someone felt guilty about his own and partner`s infection, with 'guilty' men taking longer to disclose compared to men who perceived themselves as 'innocent' victims. Based on these observations disclosure can be viewed as 'taking responsibility' for the first group of men; it is a way of owning up to their previous mistakes and willingness to work things out with a partner. And for a second group of men – particularly Bob - it was simply a matter of 'telling', it had no deeper meanings or emotions attached to the act itself.

Much has been written in HIV research and intervention work on whether or not a disclosure approach has any impact on the consequences of disclosure - such as whether or not a partner decides to stay or leave after receiving HIV results. The consensus seems to be that disclosure outcomes tend to be positive if someone adopts a more cautious approach, involving first 'testing the waters' before finally revealing his results (Green and Sobo 2000). Most participants in this study believed strongly that their cautious

approach to disclosure was the main reason that their partners stayed. However, interviews with some of their partners indicated that the issue is more complex than that.

Decisions to stay or leave

I have already shared two stories of women who decided to stay after disclosure, and argued that their decisions may have to do with feeling equally responsible for their own, and their partner's infection. This would however leave out the experiences of women who were 'innocent' or felt no guilt in the infection of their partners. These include women who were faithful to their partners and those who tested HIV negative.

Among men who disclosed their HIV results, four were completely abandoned by a partner after disclosing to her; in 10 cases partners decided to stay; seven men had no stable partner to disclose to (though they had girlfriends that they left where they worked because of being ill and had to return home; in the case of Mathe and Thandi their partners had already died when they got ill). In three cases partners partially left them - either living with family and coming back occasionally or living somewhere else. Among 10 partners who stayed, eight were HIV positive and two tested HIV negative; the status of those who left was not confirmed because they refused to test.

My interviews with partners revealed that decisions to stay or leave were influenced by many factors. There were women who stayed because they felt that they were emotionally obliged to support a husband and a lover during difficult times. For these women, whether or not a partner was responsible for their infection was insignificant. In this respect the cautious approach to disclosure was welcomed but it had no serious bearing on a partner`s decision to either stay or leave. It seems as if these women had made a decision beforehand that they would stay irrespective of what their partner was sick from and how it would impact in their own lives.

Nono, one of these women, said the question of whether to stay or not if her partner had HIV did not occur to her. She perceived herself as Sipho`s wife and therefore obliged to

support him during difficult times. I asked her to describe how Sipho disclosed to her and her response:

> Nono: Initially he was scared to tell me [laughing]. He said 'Ey there is a problem here'; I said 'No don't be scared, just tell me'. He said 'Maybe I tell you, but then you leave me'. I said 'No, don't be scared'. So he told me, and I said 'No that's not a problem; as long as you have accepted it, I also don't have a problem'. He then said 'I would like you to also go and test because you may also be having this sickness'. Then we went there together and I tested...
>
> SM: What made you to decide to stay and not leave him?
>
> Nono: Well Bhuti, for me that wouldn't help. Now he is sick and I also know my own HIV status. And Sipho can`t cook; who will look after him?...*Phela* (the thing is) his family doesn't care; they really don't care, Bhuti… (Interview Nono, 20 February 2007).

The length of a relationship also played an important role in disclosure outcomes. Most partners felt that they have already invested much in a relationship in terms of love and children; therefore they could not just leave. For example, Sipho and his wife had three children; Duma and his wife had three children. Other men who were in stable partnerships had at least one child. Partners therefore put the interests of family ahead of their own individual interests. Indeed it was on the issue of family that certain women that I interviewed differentiated between men and women in terms their responses to disclosure. For example, Duma`s partner, Tsakane, opined 'Men don't think about their family; they think about themselves. That's why when a woman discloses to him he leaves. A woman thinks about her children…' (Interview Tsakane, 20 April 2007).

There was also an issue of a future love life. Some women found staying to be a safer option because her partner had already disclosed and she also tested positive. They feared that if they left they might find another man who was either HIV positive and refused to disclose or did not want to use condoms. Nono said:

> Now if I leave him (and maybe I'm also sick) I may get someone that's even worse. And there aren't a lot of people out there who disclose this disease. A lot of them are sick but they don't disclose (Interview Nono, 20 February 2009).

Condom use was the main problem faced by women who initiated sexual relationships with new partners. In support groups certain women shared the stories of their new partners who were refusing to use condoms; some accused them of lying when they said they were HIV positive, saying '*wena usdudla so* (as fat as you are)!' It was therefore felt safer to remain in an already established relationship than leave and start a new one.

There is no information on partners who left and what prompted them to leave. But from accounts given by their male partners the main reason for leaving was shock and most of them found it difficult to accept the reality that they might also be HIV positive. This is reflected in their refusal to test after a partner disclosed to them. Among partners who left, three had already established a stable family and had between one and three children and several years of being married; two came back occasionally to check on the partner and house but still refused to stay with him. Age played a role with younger partners deciding to leave compared to older ones.

Gender issues in disclosure

This section elaborates on the earlier assertion that disclosure was a way of achieving gender dominance and respect by certain men. I want to illustrate this point by looking specifically at disclosure that took place at the community level – either open disclosure to the public or limited disclosure to peers. Then I will reflect on the men's openness and their supportive health behaviour in terms of what they implied about their masculinity.

This argument must be understood in the context of broader social theories on men's health and how certain health choices that men make can be viewed as a way of 'doing' or 'achieving' gender. For example, Courtenay (2000, p. 1389) wrote '…when a man brags, 'I haven't been to a doctor in years'; he is simultaneously describing a health

practice and situating himself in a masculine arena'. To what extent is this true for men who publicly disclose their HIV results or have disclosed to their partners and are then playing a supportive role? Can we say that their disclosure – a health-oriented behaviour - somehow situates them in a certain 'masculine arena?'. If yes, what sort of an 'arena'; is it a 'hegemonic' or a 'alternative' masculine arena?

We need to look closely at what strategies and timing were used to disclose to the public in order to answer these questions. My observations were that disclosure to the public – more so than to partners – did not take place until men looked physically strong and had recovered from physical symptoms of AIDS. This behaviour can be viewed as a way of achieving gender for two reasons. Firstly, it challenged directly the existing social discourse that views someone with HIV as 'already dead' and an outcast, therefore resulting in more acceptance than rejection from the society. Secondly, it built confidence in these men to view their masculinity in a positive light, as strong and respectable men, despite having HIV. And, as I will show below, some of them became publicly celebrated as new, responsible men because of their openness and supportive behaviour towards their partners. The following two extracts from my interviews with Tinyiko and Duma illustrate these observations:

Tinyiko and I had a long conversation about his disclosure behaviour and what strategies he used to disclose; what motivated him to disclose publicly; and what was a general reaction of the community to his openness. I conducted two interviews with him and several informal conversations; this extract is taken from one of our interviews:

SM: There are some other people that are HIV positive, just like you, but they would rather go with it to the grave than openly disclose to other people. But *wena* you chose to live openly with it, you see. What motivated you to choose that route; what makes you different from them?

Tinyiko: *Eish*! Maybe it's because I grew up poor; so now after I discovered that I'm HIV positive I thought *ngizoshesha ngishone* (I will die soon), but I don't know exactly the date. So I told myself I would rather be brave and encourage other men that 'guys lets go and test'. That's why I push like this. Some that I have

> already helped come to me and say 'Tinyiko, you have helped us a lot, we used to be scared to test'. And I say 'OK, bring your wife so I can counsel her'. And sometimes a woman comes to me and says 'please talk to my husband'. I talk to her husband, thereafter a man comes and says 'OK me and my wife have decided to go and test'

Tinyiko had earlier described to me how he felt and looked while he was sick:

> ...it was a combination of meningitis, pneumonia, TB. So you find that starting from May, June, July, August, September, October, November I was really sick during those months; I could see that '*vele la sengiyahamba (*it's now obvious that I'm passing'). But I told myself 'God knows I will live, but I also don't know when I'm actually going to die'. But I could see that I was really sick, and many people were already pointing out at me and saying '*Ay lento lena sele ishonile* (this thing is already dead').

Tinyiko entered treatment late 2005 and then started to recover:

> So by the time I tested for the first time my CD4 count was 94; 97; 60; 35 – it was rushing; I came here when my CD4 count that was less that 100; it was less that 100! So I enrolled for treatment in September (2005), and by that time my CD4 count was 39. So I kept going with these pills; kept going with these pills, and I could see that this stage that I am in, I had returned back to HIV and all these symptoms were going slowly; like diarrhoea. So until today I'm still just fine, I'm still surviving.

I then asked Tinyiko at what stage he started disclosing and he replied:

> I started disclosing recently; I wanted to help others to see that AIDS is not death; AIDS is nothing, you can live with it for as long as you want…but most of them don't believe me. Some say '*Ey wena, udla nje imali ka government* (you are just abusing government money) (Interview Tinyiko, 29 August 2009).

Tinyiko`s social status and respect were highly enhanced by his openness. He often referred to himself as a 'celebrity' because of his popularity in Bushbuckridge. He interacted regularly with respected government officials and was often paraded by them as a local 'AIDS ambassador'; he said he met visitors from overseas (he carried his photos taken with them as evidence); in community meetings he sat in front next to community leaders as a respected guest[21]. In certain social events he often received preferential treatment due to having HIV (For example, in one group discussion he described how in one social event he was offered a plate or pap with 'fat' meat. He rejected it and demanded a 'healthy' meal: 'I told them I'm HIV positive and I'm not going to eat that food. They just laughed and took my plate away and came back with proper food with veges and less fats').

These 'achievements' situate Tinyiko above his peers, as a respectable community member and a role model despite - or arguably due to - having HIV. No one has power to discriminate him because, firstly he looks 'healthy' like other people and secondly, he is networked to important government officials and overseas visitors. Thus, by disclosing publicly Tinyiko gained respect in addition to redefining what it means to have AIDS, and he relied heavily on looking healthy to achieve it. Had Tinyiko disclosed while he was still sick I doubt he would receive the same response from the community, as certain people had already labelled him as 'already dead'.

Unlike Tinyiko, Duma did not openly disclose to the public, but targeted a few of his close friends from a village where he lived. Duma said he disclosed 'freely' to them and is receiving good support

> If I have a problem I approach them and we discuss it, you see. And they advise 'OK, if things are like this you must do like this'. Like the time I had a problem with my child (who died a few days after being delivered) they used to encourage me, that 'hey man, don't lose hope; these things do happen. You must know that in this life things like this

[21] I made this observation in one of the meetings that I attended. Tinyiko was one of the guest speakers and he addressed the public on HIV.

do happen. So they really encourage me a lot, you see (Interview Duma, 23 August 2006).

Duma also concealed his positive results until he received treatment and had recovered from being sick. The main reason why Duma decided to disclose to his peers was that he wanted to encourage them to test early so as not to experience the same pains that he had experienced, if they were positive. But, as in the case of Tinyiko, his disclosure was carefully managed to make sure it did not result in rejection, and he used his improved health status to achieve that. Duma said he received great admiration from his peers as a result of his openness. Most of his peers are still 'scared' to test and they think he was 'too brave' to test and disclose to them:

SM: So are there men that know that you live with HIV?

Duma: Yhaa there are; there are

SM: What do they say when hearing that?

Duma: They say they are still thinking about it, that it might happen that they go and test and maybe they are found to have HIV. Now they will have stress and all that. I tell them 'Guys, this thing is not a killer. As long as you know that you are HIV positive, you must accept it. You must accept it and tell yourself 'God gave this thing to me'. I see a lot of people live longer with HIV. Like myself, for example; I have been living with this since 2003, but I'm still alive to this day'. They say 'Ey, it's hard to go and test', but I tell them 'No guys; it doesn't help to just sit while you don't know your health status. You must know what's happening to your own health.

SM: So they are scared of knowing and they are scared of the subsequent stress

Duma: Yhaa, they are scared of knowing. And I tell them 'you see, had I gone to test earlier I wouldn't have reached this stage. Because I was also scared; I used to hear them talking from radios and the clinic, saying 'go and check yourself; go and check yourself', but I was scared. And I ended up being sick, and it's only then that I decided 'Ey this will not help; I'm already in a bad state'. That's how I decided to go and test, and that's how I tested (Interview Duma 26 August 2006).

For most people in Bushbuckridge, disclosure is usually associated with the negative reactions of others, such as rejection, social isolation, and labelling of someone as 'already dead'. Most people, as I have indicated above, are not open about their positive results due to the fear of receiving these reactions. The two stories I have shared in this section highlight a need to be strong and healthy before someone can disclose, in order to counteract these potentially negative reactions. For a man in particular, this is important because it reflects positively on his manhood, as a strong and respectful man, despite having HIV.

The antithesis of this argument is that by willingly disclosing their status and encouraging other men to test, these men – including those I discussed earlier, who support their partners - are in fact rejecting dominant masculinity rather than seeking to achieve it; therefore we should view their 'unusual' behaviour as placing them in the category of 'new', 'resistant' masculinities. I am partly sympathetic to this view, but it needs a far more nuanced theorizing of 'resistance' than is presently the case. In particular it should take into account the argument that I made earlier in the thesis that the so-called 'resistances' to hegemonic masculinity are fraught with contradiction and ambivalence, so we cannot easily lump any 'unusual' behaviour that we observe from men as evidence of resistance or rejection of hegemonic masculinity.

Men who disclosed to their partners and were getting support from them were indeed challenging the dominant understandings of manhood that perceived their behaviour as unmanly and a sign of weakness. And in most cases they were celebrated by their partners and health workers as role models and good examples of 'new' 'responsible' manhood. For example, when I interviewed Sipho's partner, Nono, she was glowing with excitement on how different Sipho was from other men because he freely accompanied her to the clinic and had disclosed to her. Nono said she is envied by her friends for having a man like Sipho:

> Ey…I remember some women said to me 'Ey, you are better because your husband also comes here (to the support groups). How did you do it? How did he agree to come to

> Rixile; my own partner is refusing? I tell him 'let's go to Rixile' and he says 'No, you go'. I told her my own partner didn't give me any problems (Interview Nono, 20 February 2007).

Here Sipho appears as a 'new', responsible man and a model that other women would like their partners to follow. A closer look at Sipho`s overall behaviour and attitudes, however, reveals that he does not neatly fit into this category of 'new' masculinities, as conceived by AIDS intervention work. For example, I never heard him speak in support groups. Like most men he comes in and goes straight to the back seat. When I shared this observation with him in our interview he responded:

> *Ngekh`ukhulum`ebafazini* (you'll never speak in the presence of women...Even your own mother; you will never tell her 'ey there is pain here (pointing to the genitals'). You will tell her '*ey* I have a headache…not that you have a headache, you see. You can't point and say 'the problem is here' (Interview Sipho, 22 May 2006).

Sipho was one of my participants who felt strongly that men needed to have their own support groups where they can talk freely among each other without being bothered by female presence. Thus Sipho is choosy in terms of how he wants to differ from other men in the community; he is content with accompanying his wife to the clinic and also receiving emotional support from her – something that most men don't do because it makes them feel emasculated - but he is not equally content with sharing his personal life with other women.

Instead of labelling these men as 'resistant' and 'new', based on their disclosure behaviour and supportive behaviour towards their partners, we should rather focus on the tensions and ambivalence that they experience in embracing their newly-found identities as HIV positive men. Surely from what I have shared above, most participants are committed to protecting and supporting their partners and to playing meaningful roles in society as voluntary HIV educators and 'testing advocates'. And most of them have received unconditional support and acceptance from their partners; some have further

enhanced their social respect because of doing something unusual and socially responsible. The contradiction here is that in order to successfully undertake these activities and gain social respect and acceptance, these men had to first fulfil certain socially agreed criteria for 'real' manhood, based mainly on having a healthy looking body.

For HIV interventions the implications of these findings are both good and bad. On the one hand they are encouraging because they show that in the midst of stigma and social negation assigned to an HIV positive result, certain people are taking brave steps and disclosing, and that their disclosure is being received in good terms. On the other hand it means that the reliance on being healthy in order to openly disclose and be accepted deprives HIV sick people of support from their partners, friends and the community. Intervention programmes need to balance a need to make AIDS look 'normal' – and using 'healthy-looking' people to achieve this - with recognition that this might reproduce a certain stereotypical conception of a 'normal' person as free from disease symptoms. Some of the HIV sufferers are symptomatic and this leads to reluctance to disclose due to fear of stigma.

Lastly, Goffman (1967) made a point that people with a stigmatized condition attempt to 'pass' in order to avoid negative social evaluation, and that an invisible stigma (such as being asymptomatic HIV positive) makes it easier to 'pass'. The behaviour of men who are openly disclosing in a context where most PLWHA want to 'pass', therefore, triggers new questions on why and what there is to gain by being open. In this section I have looked at the notion of gender dominance and social respect as the main goals that these men pursued through open disclosure. Disclosure was therefore primarily aimed at social good - protecting a partner; educating the public - yet it had the far-reaching consequences of making sure that these men were noticed and seen as good, responsible citizens and worthy of social respect from the society. This is what made it rewarding to them as individuals.

Conclusions

This section of the thesis has focused on two key decisions that someone with HIV must make: HIV testing and disclosure. The main aim was to try and understand how men tackled these two aspects, what their main concerns were, how they arrived at decisions to test and then later disclose, and what the outcomes were for their manhood.

The findings of these two chapters indicate that testing and disclosure are difficult decisions to make due mainly to fear of stigma – social and internal - and that for men, the difficulty is compounded by the fear of losing social respect because of having HIV. My main focus has, however, been on men who have tested and disclosed and my intention was to document the processes, as well as the outcomes of these decisions.

Based on the findings, it seems apt to conclude that the experiences of testing and disclosing have seriously impacted on these men's lives and their manhood, though in various ways among participants. Testing forced them to rethink the previous health beliefs that prevented them from using public health services; disclosure became a platform to reconstruct their relationship with their partners towards more mutually supportive and open engagement than before. Due to testing and disclosing, these men have also found themselves entering into spaces and practices that were previously associated with being a woman and weak - such as educating other men about HIV, and encouraging them to test.

The main point of departure was that rather than being emasculated by testing positive and disclosing, or entering into a category of resistant masculinities, these men have in fact gained a new respectable social status because of doing something unusual in their villages. Most people in Bushbuckridge do not test, and those who test would be likely not to disclose – even to their intimate partners. This results in a situation where someone who discloses to his partner and peers is celebrated and treated with respect, or even hailed as an example of responsible manhood that other men should follow.

This argument is not constructed to minimise the problem of stigma that still prevails in the study area. On the contrary, it foregrounds it because it highlights a need to look healthy and strong before someone can disclose and then educate others. In the testing chapter I shared situations of men who suffered blatant discrimination from their families when they were still sick and tested positive; they were labelled as 'already dead', but as soon as they recovered from physical symptoms of AIDS, these responses changed to acceptance and tolerance. The next chapter follows these men as they enter into the ARV treatment programme. Here, this tension between 'change' and 'resistance' will be elaborated.

LIFE ON ARVs: EXPERIENCES AND CHALLENGES OF USING ARVs AS A MAN

CHAPTER 7

EXPERIENCES OF USING ARVs

Introduction

The previous two chapters focused on experiences of doing an HIV test and disclosing to a sexual partner and other community members. These chapters have shown that doing an HIV test and disclosing are difficult decisions and that certain constructions of masculinity impact profoundly on these decisions. However, masculinity is also reshaped by testing and disclosing, though in varied ways among participants.

This chapter focuses on experiences of ARV use, as well as adherence behaviour by HIV positive men. In conformity with the national guidelines, ARVs are offered freely at Rixile clinic to patients whose CD4 counts are below 200 (DoH, 2005). The main purpose of using ARVs is to suppress the activity of the HIV virus in the body, which, in turn contributes to the overall improvement of health and well-being. Research has shown that through taking ARVs, a person's viral load (the amount of virus in his body) may be lowered or even remain undetected during HIV tests. The viral load is normally used as a measure of whether or not medicines are working, though it says little about the overall health status of someone who uses ARVs (Persson 2004).

In looking at experiences of ARV-use, this chapter will attempt to situate its arguments on the recent scholarly perspectives on ARVs and their impact on the lives and identities of their users. Most scholars are of the view that commitment to ARVs normally results in significant transformations in users' subjectivities and their claims to citizenship. ARV users are said to become 'empowered' and 'converted' citizens, through their access to treatment and belonging to HIV support networks. They become knowledgeable about their rights as citizens and can claim them using their HIV condition (see chapter 1). Thus, the experience of living with HIV and using ARVs is portrayed as overwhelmingly positive and empowering; it gives people voice and knowledge which they previously

lacked and it also results in significant transformations of the existing health care arrangements – towards a consultative system of care.

In the South African context, Robins` (2005) research among users of ARVs has produced interesting accounts of ARV users whose subjectivities seem to be 'transformed' as a product of their involvement in the ARV programme and belonging to treatment-based activist groups, like TAC. Robins draws mainly on brief interview encounters with these users, and through attendance of support groups of PLWHA. His work makes the observation that, in conjunction with the traumatic experience of being ill, a patient`s involvement in HIV activist groups can 'drastically' produce the 'new' kinds of subjects – what Robins calls 'responsibilised' subjects – that the public health sector requires for successful adherence to ARVs. These are subjects who are empowered and knowledgeable and are taking responsibility for their own health through adoption of 'disciplined' lifestyles – not drinking, not using traditional medicines, and others. His study cites men and women who speak proudly about their HIV and seem to have a subversive attitude towards stigma, which contrasts the negation that is normally assigned to someone with HIV.

Steinberg (2008, p. 204) makes similar observations among users of ARVs in Lusikisiki, whom he portrayed as being empowered in an unprecedented way. This is due to their dynamic involvement in support groups where they are actively encouraged to demand and stand up for their rights. He cites patients who go out and insist on certain medicines and care. Steinberg argues that this is unprecedented in the study area: 'The social movement to which AIDS medicine has given birth is utterly novel in this part of the world, the relationship between its members and state institutions previously unheard of'.

My findings problematize these claims about ARV users as 'empowered' and 'converted' or 'reborn' subjects; and ARV support networks as being successful in producing these 'new' subjects. Most of the men I interviewed were content with using ARVs and, as I showed in earlier chapters, some of them have taken on the roles of HIV educators, and these actions have earned them respect from their partners and the society. During my in-

depth interviews, however, some of my participants expressed doubt about their commitment to the overall 'HIV identity' and its behavioural implications. Being HIV positive was experienced as constraining and depriving men of their right to 'live' other identities and to independently choose what lifestyles to lead. In particular, some of the participants were opposed to certain support group messages that expected or even demanded of them to completely abandon their previous lifestyles in order to fit into the biomedical model of adherence - e.g. not imbibing or using traditional medicines. These behaviours, as I observed earlier in the thesis, are tied to identity of being a man and some of the participants felt that abandoning them would impact on their sense of manhood.

The interesting observation that I will pursue in this chapter is that these doubts and 'resistances' are not openly communicated in support groups where HIV positive men normally meet with other ARV users to share their experiences concerning treatment. In support groups, men portray a complete conformity and satisfaction with the support group messages to change and abandon their previous lifestyles. While they enter such spaces and discussions with praise for ARVs, they remain mute about their 'violation' or dislike of certain treatment rules. This gives the impression to an observer that support groups are succeeding in converting patients, and that participants are completely content with treatment. Yet, there is a 'darker side' of treatment experiences that is not revealed. I will therefore refer to these support group narratives as *performance narratives,* to indicate their tendency to depart from what people normally do in actual life, and the fact that they are carefully 'staged' to communicate a message of conformity with the dominant discourse rather than an honest account of what people do.

This chapter critically examines the operations of support groups to find out why it is difficult for ARV users to speak openly about their negative experiences with treatment. Here, it exposes the power and authority that are invested in these groups to define what it means to be HIV positive; what rights and privileges clients are entitled to and their limits to them; and what is an acceptable narrative on experiences of using treatment. Support group facilitators do not pay equal attention to the different experiences of using

ARVs. Instead they privilege narratives of clients who praise ARVs and then suppress 'deviant' narratives that communicate a negative side of treatment. Hence, in my view, they cannot be unquestioningly characterized as a site for empowerment; instead they can be disempowering because of the tendency to promote a one -sided perspective about ARVs, instead of allowing patients to explore various perspectives based on their divergent experiences and belief systems. This argument is limited to the observations that I made at the Rixile support groups, though it might be applicable to other contexts in South Africa.

The chapter has four sections. Section one investigates the concerns that men normally have about using ARVs and how they may impact negatively on their lives: how do men generally feel about ARVs; how do ARVs challenge their manhood lives? In section two I will provide a brief description of support groups to show how, when dealing with ARV users the facilitators try to 'convert' patients by marginalizing their health beliefs and forcefully imposing a biomedical model on them – this latter framework promotes particular 'versions' of acceptable health conduct for someone with HIV. I attend to strategies involved in achieving this, as well as what possible sanctions (mainly symbolic) for 'deviants' entail. In section three I will analyse men`s perspectives and experiences of using ARVs, as well as their adherence behaviour. This will then be contrasted, in section four, with a focus on how men talk about ARVs as being both 'magical' and a 'burden', thus indicating their ambivalence towards them. This is where the notion of *performance narratives* will be clearly illustrated.

Men and ARVs

The threat posed by ARVs to men's lives is reflected in two separate conversations that I had with two men during fieldwork, as well as in ongoing discussions with HIV positive participants. The first man is Lolo, my friend from Kildare. Lolo and I had a close relationship and we shared much about my research topic during my stay in the village. In one of those conversations we were sitting outside his house in the evening with his

friend, chatting informally about life, when Lolo suddenly changed the topic and asked me direct questions about ARVs.

He asked me whether ARVs work or not, and what lifestyle changes someone who uses them may have to adopt. I told him what I normally hear in support groups: 'Well, they normally say you must eat healthily, stop smoking, stop drinking...'. I was about to say 'use condoms' when he interrupted me and said: 'Stop drinking! Now how am I going to live among other men if I don't drink?'. I told him 'These ARVs don't mix with alcohol; doctors say they might actually be counterproductive if you do so...'. Lolo kept quiet for a while, and then looked at me and said:

> No, they are not for me then. If I have to stop drinking, then I don't need them. *Amanye ama auty a busy ayarhasa and mina ngihleli nje ngibukele!* (Other guys are busy drinking and I'm just watching!) No, these ARVs are not for me Sakhumzi. *Kungcono ngife* (I would rather die) (Informal conversation Lolo, 5 May 2006).

The next conversation was with a man that I met briefly at Rixile clinic on my first week of fieldwork. Kgabo came to the clinic to collect his HIV results and he was sent to support groups to wait for them. As it was too hot inside he went to sit outside and I joined him. We had a conversation on why he was at the clinic and then I asked what he thinks about ARVs. Kgabo said in principle he supports ARVs, but he has a problem with the fact that they must not be combined with traditional medicines. He said traditional medicines are an essential way of maintaining good health and as a man he needs them in order to stay healthy, to protect himself against evil spirits and to remove bad luck:

> Kgabo: You see, everyone needs to cleanse himself every now and then to remove *ukungcola* (dirt). Now if you use these ARVs you cannot do that. You wake up in the morning you swallow them; in the evening you swallow them. Everyday! Now what happens is that these ARVs pack up inside your stomach, now you need to remove them by cleansing yourself by vomiting and spading, otherwise the dirt in one's stomach eats away their energy, hence they (ARV users) are weak; you get sick. That's why some people die from these ARVs...You need to cleanse yourself to remove *isimnyama* (bad luck)

SM: But you can always remove *isimnyama* by adding traditional medicine into your water and then wash. Or you can steam, can't you?'

Kgabo: No it doesn't work like that. The dirt is inside; otherwise why, given the fact that we wash everyday, we still have *isimnyama*'?... You see, if I didn't cleanse myself for a long time and I walk through this hospital to that gate, no one will bother to even look at me. But if I cleanse myself you will see- people will greet '*Aye, Aye* – Hello, Hello' (Informal conversation Kgabo, 22 February 2006).

These conversations reveal much about the perceived threats that ARVs may pose to men`s lives. Both drinking and the use of traditional medicines are regarded as essential activities in performances of manhood in Bushbuckridge (see chapter 5), but commitment to ARVs means that men must refrain from these activities. Lolo and Kgabo`s doubts about ARVs is therefore not based on rejection of the drug itself, but on the fact that commitment to these drugs might be disruptive to their lives as men and also impact on their health behaviour. As we have seen in earlier discussions, health is perceived by most people to be more than the absence of a disease in a person's body, or having the disease under control – through using chronic medications. To be healthy means that one is free from both physical illnesses as well as being protected from evil spirits. This is achieved through using traditional and other spiritual medicines. It is in this context that Kgabo finds ARVs limited because they address one aspect of health (HIV health) while the leaving out other dimensions deemed important in local definitions of health and wellness.

As someone who was close to Lolo I can attest to the sorts of disruptions that commitment to ARVs would bring to his life as a man. Lolo's social network was composed of men who drank regularly every weekend; we attended football matches together, carrying alcohol and also socialized through drinking at my place of residence. His concerns are therefore understandable given how much he invested in drinking as part of his lifestyle and masculine identity. Lolo said he does not respect someone who does not drink alcohol someone like that is regarded by Lolo as being less of a man (see chapter 4);. As for Kgabo, his views echo those of other men who felt that life without traditional medicines is meaningless. As I showed earlier in this thesis traditional

medicine is seen by most men as being more than just a treatment method; it is part of what defines someone as a cultural being and a 'real' African man.

These above are not the only concerns raised by men about ARVs and how they may impact negatively on their lives. Other problems related to such requirements as using condoms, eating 'healthy' food, being a 'disciplined' patient, and attending regular medical check-ups. For example, in one of the support groups that I attended a facilitator encouraged all patients to always carry their medicines with them, saying: '…because you never know when you might need them. You might visit a place and then end up sleeping…'. For most men this advice was seen as being impractical and not fitting in properly with their lifestyles. A male focus group participant therefore responded to a facilitator`s advice by asking: Now how are we going to carry these things? Because we men are unlike women; we don't always carry purses?'. There was no definite answer from the facilitator, except that she acknowledged the difficulty of implementing this advice for men (Informal observations support groups, March 2006).

When one of my participants, Mathe, was about to start treatment his main worry was that he had to adopt a healthy diet as part of his new lifestyle. This advice came from his friend and fellow ARV user, Xola, during one morning when we were sitting outside the clinic chatting informally while they were waiting to see a doctor. Mathe approached both of us and wanted to know what lifestyle changes he should adopt as someone who will soon be starting with ARVs. In response Xola answered him: 'It will be helpful if you could reduce on meat or stop it completely, particularly beef. *Angithi* this beef can even cause gout...This meat is just not good for you *Sbari*...and you must eat lots of veggies ('*boroko*')'. Mathe looked perplexed by the idea of having to reduce on meat, and then he protested 'Are you telling me that I must now stop eating meat, and then eat *boroko*! No, no, no...I grew up eating meat and pap all my life and now I must stop! And this *boroko*, I never ate *boroko* from childhood; this stuff is for women' (Informal conversation Mathe and Xola, 6 December 2006).

I am sharing these stories to illustrate the kinds of anxieties that men normally have about ARVs and how they might impact on their lives. These accounts show us that men do not enter a treatment programme as blank slates upon which treatment information is passively imparted. Instead, when men enter these treatment programmes they already embody certain belief about health, food, body and manhood, and these beliefs impact on their reception of certain ARV massages. Secondly, ARVs are not seen by men as the sole means of managing health for an HIV positive person. Kgabo feels that, in order to be completely healthy, a man must pay attention to other aspects of his health, i.e. other than HIV health. I have argued that support groups are a site in which these pre-illness beliefs are challenged and then changed and a new biomedical discourse is imparted on patients in order to facilitate adherence. I now pay a closer attention to the operations of these groups in order to elaborate on this observation.

Philani Support Groups

The Philani support groups were designed primarily as a support, education and treatment information centre for PLWHA (see chapter 1). Unlike other groups of PLWHA, where people normally attend out of choice, these groups are compulsory. Every client that uses Rixile services must attend support groups every time they visit the clinic to receive their services – normally once every month. During their attendance of support groups patients receive education about their condition, ARVs, and how to live a productive life under HIV. These lessons are provided by support group facilitators who have received formal training on HIV issues. Some of the facilitators are HIV positive.

Support group discussions begin early, at about 8:30 in the morning when most of the clients have already registered and staff are still busy sorting out their files. They are of mixed gender and age, with both older men and younger women sitting next to each other and engaging in intense and personal exchanges of information and experiences about HIV, problems with sex and relationships, contraceptives, condoms, bodily pains, disclosure, traditional medicines, and other topics of interest and relevance to their situation. Thereafter, while discussions are still in progress, participants are called one-

by-one to see a doctor, leaving the rest of the group talking. At about 10:30am serious discussions have died down and people can either remain in the support group room or sit outside and socialize while waiting for their names to be called for consultation.

Among its clients, the Philani support groups are popularly referred to as a 'class' (*klasini*). The term 'class' says much about the operations of support groups and the kinds of positions that are occupied by the various actors. First there is a facilitator who may be likened to a 'teacher'. Her role is to educate, guide discussions, and also give messages of support and expert advice to clients. As a 'teacher' the facilitator has expertise about HIV, ARVs, and other issues pertaining to living with HIV; therefore she has some power over other actors. The second role players are normally referred to as 'expert clients' (Kyakuwa 2009. These are patients who are long-time users of ARVs and support groups. Some have received minimal training as support group co-facilitators and peer counsellors. They have no specific role in support groups except that they are as motivators to new clients. Sometimes the expert clients act as co-facilitators - either in conjunction with the main facilitator or on their own. Often they use their own experiences of being HIV positive as a strategy to motivate and counsel others.

Then there are patients. In support groups, patients are treated in a manner that is equivalent to being 'students'. When they enter support groups for the first time they are approached in a way reminiscent of their first day in class. The assumption is that they do not know anything about HIV and AIDS, or that whatever knowledge they have, is probably misleading and in need of correction and enrichment. The facilitators and expert clients then spend much of their time giving new clients the 'correct facts' about HIV, ARVs, AIDS, in order to educate them about their condition.

A significant part of this education process involves debunking certain 'myths' and 'misconceptions' that new clients might have about HIV and AIDS, and which originate from their respective communities. For example, some new clients come into support groups believing that they are bewitched or are suffering from *tindzaka* or *mafulara*. Others are sceptical of ARVs and believe strongly in using traditional medicines. In

support groups these belief systems are condemned, and a new biomedical approach is imposed on patients regarding how to interpret illness symptoms and to manage their health. A few examples will illustrate this point.

In one of the support groups that I attended, Ms Mathebula, a 30-something year-old client was seeking advice on how to treat the problem of '*nyongo*' (excess of gastric juice, I think). She said that in the past (before testing positive) she would normally treat it by cleaning herself with traditional medicines through vomiting. Now, as an ARV user, she wanted to know if she could still use the same method. In response to this question the expert client advised all participants to refrain from using 'untested medicines', saying:

> These things are not measured...I have used these things myself in the past. They don't work...I used these traditional medicines for six months. I would always go to this man; he gives me a five litre bottle. I drink it and then I have diarrhoea for the whole day. And when I finish it I go back to him; he gives me another five litre...Until I felt 'No man, this thing is not helping; I'm losing more weight here'...I tell you, these people are liars; they are only interested in your money. Once they are finished with you they send you to the hospital, saying 'go there and get some water (drip); you have run out of water.

In the case of Ms Mathebula, the expert patient advised her to cure *nyongo* by drinking soda water. When another client in the same group sought suggestions about stomach constipations she was experiencing, the expert client advised her to drink warm water rather than traditional medicines (Focus group observations, 17 August 2006).

In another support group a female client entered the support group for the first time after receiving her HIV results the previous day. On her arrival she was welcomed by the facilitator, telling her: 'You have come to the right place; here it is home. Now that you are here, you will live'. During the course of discussions the new client looked anxious and uncomfortable. This prompted the facilitator to ask if she wanted to say something, and the former replied 'I hear that some people die from using these drugs; is that true?'.

One of the experts was sitting next to the facilitator and she stood up immediately to answer the question, saying:

> If they were toxic then it means we could all be dead by now; but look we are still healthy and we will still live for a long time. Those that say ARVs are toxic simply want an excuse for not using them. And those that died, maybe they didn't follow the correct instructions. If you follow the correct instructions you will live, just like us... (Focus group observations, October 2006).

Similar processes of trying to change people`s beliefs occurred in relation to perceptions of HIV and AIDS. Most clients enter support groups holding certain community perceptions about HIV as a 'deadly' and shameful disease. Support group facilitators and expert clients worked hard to change these perceptions and presented a picture of AIDS as 'just another disease', 'just flu'. Participants were advised not to view themselves as sick and close to death, but to think of themselves as having just contracted a virus, or flu. As a virus, therefore, AIDS must not be feared, and PLWHA must not view themselves as different from other people because of being infected with or 'having' the virus. In fact PLWHA must be proud of themselves because, unlike other people in the community, they know their HIV statuses and can therefore make informed health decisions. This conversation between one client and a facilitator illustrates this point.

Mrs. Khoza came to the support groups one day in a depressed mood. She said she had been betrayed by her boss to whom she disclosed her results:

> What happened is that she disclosed my HIV status to other people in the office; she did that in the boardroom during the meeting. Now everybody at work knows that I`m HIV positive. And I can see that they know, because if sometimes I go into the kitchen, maybe they were talking but they suddenly keep quite. You can see that they were talking about me....

The facilitator responded by saying she must not be bothered, HIV is nothing to be ashamed of:

> Next time you see them doing that you must confront them. You must tell them 'I see you have been talking about me...Yes I do have HIV; how many of you know their HIV statuses here?' You will see they will never do that again (Support group observations, 2 August 2006).

The above narratives give evidence to the point I made earlier that these support groups attempt to be a 'conversion centre' for HIV positive patients. Patients enter support groups holding certain beliefs and these must be changed – overnight - in order to facilitate treatment adherence and gain unconditional acceptance into the group as a credible and trusted member. Thus these groups have power to define – and impose - what it means to be HIV positive, as well as telling patients how to live their lives under HIV. There is no room for debates or expression of different worldviews. The latter might be interpreted as a sign of lack of commitment to ARVs and may invite hostile response from the facilitators, as seen above (I am nonetheless not aware of someone who was 'disqualified' from using ARVs because of their failure to adhere to these required behavioural changes).

Men in support groups

In dealing with men, support groups make an extra effort of ensuring that their beliefs about manhood and health are also transformed in order to facilitate acceptance of ARVs and treatment adherence. Most men who enter support groups hold certain socially dominant beliefs about masculinity that construct manhood in terms of being dominant, in control, promiscuous, drinking, and others (though some of these beliefs have already been destabilized by being sick). Therefore, like Lolo and Lucky, most men view support groups messages about adherence as posing a serious threat to their lives.

The main problem that new male clients had was with being mixed with women and then expected to publicly share their problems. As shown earlier in the thesis, this was not typical of how men deal with problems; most men preferred to conceal their problems rather than to share them with others, whether through public or private disclosure. This

problem was communicated to me by Khaya, one of my participants. We were driving towards Thulamahashe one afternoon after his visit to the clinic, conversing about his experience of the clinic services. I asked him why men are normally quiet in these groups. He answered:

> *Angithi indoda ikhalela ngaphakathi* (a man doesn't cry out openly). Now in these support groups men and women are mixed together and they must share. Now that is not acceptable to men, because men are not used to that. Men are not used to talking things in front of women. Men sit together and talk and women sit together and talk. That's why in these support groups men don't talk. Even if you point them and say 'say something', they just look at you...(Informal conversation Khaya, 20 April 2006).

As a regular attendant in support groups I can also attest to the above observation made by Khaya. A new male client typically sits on the back row, firstly to avoid being identified by others who might know him and secondly, to avoid being asked to participate. In support groups someone is likely to meet a family member, a friend or ex-partner who is either HIV positive or accompanying a patient. Therefore men are careful not to be 'found out'. Some of them are embarrassed by their physical appearance, as I have shown earlier in this thesis.

A part of the support group 'initiation' of men into treatment is meant to deal with these anxieties. It was felt that - unless men change their constructions of masculinity, health beliefs and what it means to be sick – they would not embrace support groups and adhere to treatment. Supports groups therefore became a site where social conceptions of masculinity are challenged and contested, and new ways of being a man are imparted to clients in an effort to facilitate their acceptance of ARVs.

I observed two key ways in which this process was achieved. First, when new male clients enter support groups for the first time they normally receive special attention from facilitators. This attention is not meant to denigrate or label them negatively for being sick, as men would expect from wider society and/or the local community; rather it is meant to affirm them as having made the 'right decision'. Support group facilitators

would halt discussions and then start praising men for coming to the hospital. During one of the sessions that I attended I was a recipient of such praises: I was sitting next to another man in a group session that was dominated by women. After long discussions about disclosure, during which all the men remained quiet; one of the female participants -who had mistaken me for a client - turned to us and said 'You know, it's good to see men here. Men don't want to come to these places. So, you guys have made the right choice. Now you know your statuses, you will not die like other men do'. She then looked at me and asked 'have you disclosed?'. It was then that I told her I am an observer. Other participants burst out laughing, as they already knew me. The aforementioned woman came from another clinic (Focus group observations, 27 January 2007).

More occasions like this happened, in which men were praised for their 'brave' decisions to use the hospital. For most men this took away the embarrassment that normally follows from being sick in the presence of women. Most importantly, tribute gave men a positive self-image and a new feeling of being powerful and respected despite being sick. The fact that these commendations came from women added a new dimension – it enabled these men to no longer perceive women as a fearsome factor in relation to their lives as sick people. This then enabled them to later build stronger ties with women, including emotional and romantic ties with certain women that they met in support groups (see chapter 8).

Male expert clients also played their part in ensuring that new members 'feel at home'. Often they sat in front and then participated actively in discussions; at other times they shared personal stories of how they felt on their first day in support group. For new clients this resulted in 'normalization' of their presence at the clinic. It made them to feel that being sick is 'just normal' rather than a shameful aberration from 'real' manhood. This was expressed by Thabang, a male expert client when he said:

> Yhaa, when they see me here in front for the first time they get shocked. But later as they get used to seeing us talking they start to feel 'No man, other men are open about this

(HIV status); why should I hide it?' (Informal conversation Thabang, 13 March 2006).

Secondly, support groups try to transform men`s notion of masculinity by stigmatizing certain lifestyles that are normally celebrated in the community and are seen as good markers of 'real' manhood – like drinking, smoking and having multiple partners. These lifestyles were marked out as the worst forms of transgressions by someone who is using ARVs, and were associated with treatment failure. Drinking, for example, was associated with forgetting pills because one might fall sleep from drunkenness and wake up past his treatment time. Or he might completely forget his medicine while drinking in a shebeen. Alcohol itself was said to be 'toxic' if it is mixed with ARVs. Having multiple partners was associated with re-infection and drug resistance because a man might have sex with other HIV positive women who refuse condom use. He will then contract another strain of the HIV virus that might be difficult to treat. Men who violated these rules were treated unsympathetically in support group.

In one of the support groups that I attended I witnessed an occasion where a man, who said he was still drinking, was treated harshly by other clients. Senzo, whom I was recruiting into the study at a time, said he does not drink regularly or heavily '…but there will be this day; this day when I feel like 'No, today I really need it, I can't live without it...Just one'; if I take just one beer, you will see me walking by myself to the pot. I don't wait until you dish…' (Laughter).

His confession was met with a barrage of disapproval from other men who warned him against dangers of drinking. One of those criticisms came directly from a male facilitator who used a Xhosa phrase '*Isiqhelo siyayoyi`s ingqondo* (if you do something once, you will do it again, and again)'. Another man added 'The doctor advised me to think of stopping alcohol, and smoking. So he told me if I don't stop I might have problems with my medications…So from that time onwards I decided the best way for myself would be to just stop completely…I advise you to do the same my friend!'. Senzo was quiet when

such censure was aimed at him, and then he responded by saying 'No, I will try; I will try' (Focus group observations, 12 September 2006).

These discussions give further evidence to the observation that support groups are not entirely an empowering environment for ARV users. Instead, they impose from above what kinds of lifestyles and identities someone is allowed to embrace as a user of ARVs. Here, the identity of being a man – in a 'traditionalist' way - is constructed as a danger to men`s health, and a new discourse is imposed on new patients on what it means to be a man. This new identity is supposed to guide their everyday lives, including the various health choices that they make.

I am not completely rejecting the view that certain 'new', 'converted' subjects are somehow being produced in these support networks[22]. My concern, however, is with the manner in which they are fashioned, as well as the various strategies used to produce them. What I have shared in this section indicates a coercive, non-negotiable, top-down approach on what it means to be an HIV positive man. This is imposed willy-nilly on patients, irrespective of what their own belief systems are. The idea is that, for patients to successfully adhere to treatment, they must embrace one, uniform identity, defined mainly by their rejection of local cultural notions and practices, including the latter's health messages. Instead they must completely accept biomedicine as a sole way of managing their condition. As long as patients still embrace other identities and share in their community`s definitions of health, manhood, etc, they will have problems with adherence.

There is an interesting paradox here, where on the one hand PLWHA are encouraged to resist stigma by viewing themselves as not different from other people in the community; or even better than them because they know their HIV status and are choosing healthy and responsible lifestyles. On the other hand, to be HIV positive is presented as a 'special' status, thereby enabling PLWHA to lay claim on certain government resources

[22] As we will see in the next chapter, people are to a certain extent engaging with life differently than before.

that may be out of reach for a 'normal' person - like support grants and food parcels. Thus the identity of being HIV positive is not stable; it shifts based on what is at stake at a time and it can be deployed strategically to achieve certain individual needs.

My argument is that the tendency of support groups to forcefully impose one meaning of being HIV positive, rather than acknowledge the diverse experiences of patients and constant shifts in this identity, results in a tendency by patients to *perform* their complete allegiance to this identity while they are at the hospital. Yet, in private, they express unresolved issues with it. Before I elaborate on this argument I want to first share people`s experiences with ARVs and what their attitudes are towards adherence.

Experiences of using ARV

A significant part of my interviews with men involved the request to them to share their experiences with ARVs: Did ARVs make any difference in their lives? What are the common side effects? How do they deal with adherence demands? The dominant response given by men was that ARVs had a positive impact on their lives. Men described how they felt and looked before starting ARVs and then compared it to the way they felt while using them. In the majority of cases, they said treatment improved their conditions from near death to being able to live 'normal' lives again.

Of the 25 participants who shared their experiences of using ARVs, only one person reported completely negative experiences. He said ARVs made him sick and stiffened his body; as a result he stopped using them. A number of side effects were reported, such as stiff legs, stomach pains, skin rash, and 'drunkenness' (dizziness). In most cases these side effects were brushed aside as temporary and 'normal' phases in the treatment process. Participants were told during counselling and in support groups to expect them, as they are a sign of the body's attempt to restore itself after a long illness.

Zita is one of the longest serving clients of Rixile clinic. He began to use the clinic services in 2000. He fell sick from HIV in 1997 while he was still working at a

supermarket in Acornhoek. At that time, he was staying with his girlfriend who is a nurse at Tintswalo hospital. Zita shared with me a painful story about his struggles with HIV. He said when he was sick he struggled to do physical activities; he was dependent on other people to cook and fetch water from the tap, clean the house and to do his shopping. Because of his illness, he was also abandoned by his partner. He ended up living alone in a small one-room house in Acornhoek:

> Hey, Sakhumzi, it was tough man. You see that tree in front of my house? I was always sleeping there, under that tree. Every day I wake up in the morning and just sleep there for the whole day. Now there are these women that sell some staff here in Acornhoek (hawkers); they always go past my house and they saw me everyday lying there. Now, one day they stopped and asked 'Why are you always sleeping here?' I said 'I'm sick; I can't do anything for myself'. So they started helping me. They would always stop and maybe fetch water for me. Or sometimes they prepare something to eat, you see. Because I stayed alone...my wife abandoned me...

Zita entered an ARV programme in 2000. He said, since he started using ARVs, his situation improved dramatically. I asked him to describe how he felt before and after taking ARVs:

> Ey, when I started I was in a bad state. Even if I can show you my photos you might think I`m dead, that I'm already in the mortuary, that I`m not alive. You find that I was always sleeping, was struggling to even go to Spar (which is less than a km from his house). Even the manager at Spar could see 'Ey this man is struggling'. Now this day I went to Spar, and as I was walking out of the shop this manager came to me and patted me on my shoulders. I looked and realized it was him, and he said 'No I will take you with my car. I can see you are feeling a lot of pain. Put your staff into my car and I'll take you there'. That's how bad things were.
>
> But this treatment *Iyasisita kakhulu* (it helps us a great deal). It helps, and it also gives you energy, and you also sleep well. It's OK; it's nice if you use it properly. It makes you sleep whenever you want to sleep, and you also eat a lot! You eat more than those that don't use treatment. And this treatment gives you lots of weight because it encourages you to eat all the time; all the time you must eat. Mhmmm...When I wake up in the

> morning I feel I have some energy, you see. I also feel I can even play soccer again, you see (Interview Zita, 26 June 2006).

Kenneth started using ARVs in May 2006. When I visited Kenneth's home, his partner described the former's condition as it was before he started to take treatment. She said Kenneth was sick and that he was dependent on her for everything he needed:

> He was unable to do anything; we had to carry him to go to the toilet and then remove his pants, then wait for him to finish and then bring him back. We had to feed him; he couldn't even feed himself or put his clothes on...it was really a terrible situation...if it wasn't for these ARVs I`m sure he could have died.

Kenneth was sitting next to his partner, smiling, when she made these revelations. He added:

> Ey it was tough, Broer! It was really tough I thought I was going (dying). You see, I`m not used to being sick, so I think that's why I became like that...it`s just not being used to being sick. And the other thing is that I didn't know what I was sick from, so I used lots of traditional medicines for up to 6 months. And by that I mean everyday; there was no day that passed without using them. But they never worked... (Informal conversation Kenneth and Joyce, 7 August 2006).

Kenneth is one of the clients that I met and befriended before he started treatment, therefore I was able to observe his progress over a long time. When I first saw him sometime in May 2006 he was physically weak and shy. He struggled to walk, and during our first interview (4 July 2006) he took breaks to catch his breath and he was constantly coughing. It seemed as if he was in pain but was hiding it and presenting a strong front. At our second interview, six months later, he seemed to be quite a different person. He had gained weight as well as self esteem. On this day, as I entered the support group room to look for him, I found him standing in front of the group welcoming new clients. He told them about his own previous struggles with HIV and of the benefits of ARVs.

We then went outside to start our interview. He shared with me the significant changes that occurred in his life since he started treatment:

> Ken: In the beginning they caused me rash, and also this pain I told you about. I felt like I was having sores inside my stomach. I would feel as if I'm hungry! And it's hot inside here (pointing at the stomach). But things are improving a bit.
>
> Sak: You know some people experience some problems, like you mentioned, you see. Some have sexual problems, some the drugs get them drunk; you see…do you experience any of those problems?
>
> Ken: Yhaa, for example when I started taking TB treatment, yhaa, I had about a month and some two weeks; you find that I could feel nothing (sexually). But then I went to the support group and they told me 'Ay this does happen. You will get alright as time goes on'. So I just feel those changes. But since I started using these pills I never felt drunk or what (Interview Kenneth, 14 February 2007).

Two things came out from these testimonies. Firstly, ARVs are experienced as having been effective in alleviating certain physical discomforts that were felt before using them. Secondly, side effects are perceived as having had no impact on whether or not these men continued with treatment. These were seen as temporary phases in an otherwise positive experience with treatment. These experiences reflect those of the majority of participants. Out of 25 men only one reported completely negative experiences with using ARVs. Bob said ARVs gave him stiff legs and also affected his overall bodily movements. As a result he decided to stop using them.

I met Bob for the first time in August 2006, a month after he started treatment. He was in a celebratory mood, talking positively about treatment, saying '...I'm fine; I think with these ARVs my life will get back on track'. A month later, when I called him to arrange for an informal conversation, his mother answered his phone and told me Bob had been arrested for rape. This kept him in prison for three months. While in jail Bob was still committed to ARVs – he disclosed his HIV status to the police officers and for a period of three months they escorted him to the hospital to collect his medication. Due to lack of evidence Bob was eventually released in November 2007. A month later he called me

and we arranged to have an interview in the following year. In our interview Bob told me he had discontinued his treatment. The main reason was that he was experiencing bad side effects:

Bob: *Ushukuthi* they told me I'm HIV positive, and they gave me a referral letter to Rixile. Then they gave me pills there, but I really didn't understand them; even today. And by the time I was on treatment I couldn't even work. I can give you an example of a brick; I couldn't lift a brick.

SM: By the time you were on treatment?

Bob: Yhaa; I couldn't lift it. Just a brick! No…These pills, I don't understand them…they made me, like, my joints were stiff. This whole section (moving his hand through from left leg to left shoulder) would be just stiff. Sometimes I would get a cramp the whole of this side; this side would be just stiff. And sometimes I would, you see, maybe I'm trying to walk there; I would go 1, 2,. 3 steps and then I sit down, tired. But now I can see a difference. My foot wouldn't do like this (forcefully bending his foot); now I can even do like this; like this, you see.

SM: So you are saying the pills actually made you worse?

Bob: Yes, and I was always sleeping, all the time.

SM: So what has helped you? What are you using?

Bob: They got me some *umuthi* (traditional medicines), and I drank it. Because I don't have a chance for the pills and they don't care about me (the clinic staff). Even if you request them they will tell you 'my programme is so-and-so, and today I must do so-and-so'. So it's just the same because they don't give me transport money to come and collect the pills; they don't give me money. It's my health (*impilo yami),* but they are not helping me, and they are not helping me. So I just stopped. Because I don't get time and my main problem is money; and they won't give me money here; they won't. They instruct you to come at a certain date, but where are you going to get money. They tell you 'we give pension to people that are sick in this and that way', but the very same people that register pension will give it to their relatives, you see. If they give you soon then you are close to dying, you see. I can say 90% of people that come to Rixile don't get the pension (Interview Bob, 2 February 2007).

It is unclear from the above testimony why Bob stopped treatment, as he is citing several factors. Firstly, he feels that the side effects have worsened his condition; secondly he says he is not supported by the clinic staff; and then he protests against an unfair distribution of government grants. Interestingly, other men had similar problems, yet they did not discontinue treatment. I then spoke to his mother and uncle to find out if Bob gave them any specific reasons for rejecting ARVs. His mother said Bob was upset about not receiving a government grant. This might have led him to decide to stop treatment as a form of protest; alternatively he discontinued in order become sick and get government grant:

> Well from what he was when he had TB, he had improved a great deal. Bob was thin, this thin (lifting a finger). But since he started these ARVs he regained his weight. His CD4 count was 58 and he weighed only 60…so I saw a great improvement. But he started complaining that his fingers couldn't close, that his legs were stiff...you never know if these things were true or not... he once talked about the grant, that there are people that are getting grants at the clinic. Maybe he wants a grant. If he wants grant that means he wants to get sick, because you can only get a grant when you are sick (Interview Ms Mali, 20 February 2007).

Bob's uncle had a more sympathetic response towards his decision to not take ARVs any longer. He said Bob's difficulties with ARVs started when he was in prison. He said Bob was not properly cared for by the prison authorities:

> Well, in fact that's where this whole problem started. These police didn't care much, because he stayed for 3 months there, 3 or 4. Now I took his medicines to the police and told them he needs to take them every day. But they don't give him every day; sometimes they give him at 7, sometimes at 9. Now by the time he came back he had some sores on his body…he had sores here, all over here…I told them they are ARVs! (Informal conversation Bob`s uncle, 20 February 2007).

The claim that ARV users, like Bob, wanted a government grant was a recurring theme in support groups. Facilitators pointed out certain clients who were said to 'tinker' with their ARV routine in order to remain sick and still access the grant. According to the government protocol, the grant is a temporary measure given to someone whose health condition is bad – it is given at a doctor`s recommendation. It might not be entirely true that Bob was motivated to end his treatment a result of his need to get a grant, but it does seem from his complaints that he felt uncared for by the state. Perhaps then, his decision to stop treatment is a protest against an indifferent state; unfortunately it had health complications for him.

For three months after the interview I kept in contact with Bob to find out how he was doing without ARVs. A week before I ended my fieldwork I was driving towards Cottondale clinic and I saw him walking down the road and gave him a lift. He looked weak and pale and told me he had been having diarrhoea. I asked him why he does not return to the clinic to resume treatment. He responded that 'I want to go, but I'm scared that the nurses will shout at me. I mean I haven't been there for five months now. They will shout at me'. The following day I visited his mother and raised my concerns about Bob`s state of health. She pleaded with me to speak with the health workers and persuade them to welcome Bob back and give him medicines. However, despite my efforts and subsequent assurance from the nurses that he would be welcomed, Bob still did not return.

The experiences of using ARVs have been documented worldwide and evidence points to the power of these drugs to improve health condition of the users. Here my decision to share only two cases is due to limited space rather than lack of further narratives about the effectiveness of ARVs. There is however a danger that in focusing too much on the positive side of ARVs we may either ignore or treat the negative experiences of other users such as those shared by Bob as insignificant or as exceptions. Research conducted with ARV users indicates that his experiences are not unique. Some of the users of ARVs are reportedly not content with personal outcomes of treatment (Persson and Newman 2006). Drugs, while being effective in improving the health of a person with HIV–

measured mainly by reduction in viral load and increase in CD4 counts - can produce outcomes that are unacceptable to a person' overall health and well-being. These outcomes may then discourage him or her from continuing with ARVs despite experiencing an overall improvement in HIV health. This seems to be the case with Bob, whose HIV related health improved from using ARVs; yet he had other difficulties that rendered the experience of using ARVs unpleasant, leading to a decision to discontinue treatment.

Adherence behaviour

Adherence is a cornerstone of the success of ARV treatment. Patients must use treatment everyday indefinitely and failure to do so may have serious health consequences - like drug resistance and treatment failure. In Philani support groups adherence was defined as taking medicines every day at the same time without a stop. Patients who missed medication time with even a few minutes were described as setting themselves up for failure. For example, in responding to a patient who said he often misses his treatment time by 'maybe 10 – 20 minutes' the facilitator said: '…ten minutes will build into 30 minutes, and then an hour and then a day, and in the end you will forget completely…'. [23]. Patients were advised to choose a time that would suit them and to also have a treatment support person who will remind them, or use other reminders - such as a clock or TV programmes.

The majority of participants said they are adhering to treatment according to these requirements. Of all 25 men, only two men said they did not use treatment as prescribed. One of them (Bob) ceased treatment. Most of them experienced side effects, such as 'drunkenness' 'stiff legs', skin rash, eye sight, and other problems, but these did not result in a decision to stop treatment. Sipho shared his experiences with one of these side effects:

[23] In my conversation with a doctor he said these rules are relaxed in a one-to-one counseling between patients and health providers '...in one to one interactions we relax the rules a little bit where necessary. Like if you miss your treatment for a couple of minutes that shouldn't pose a problem, but you don't want to communicate that to them' (in a public forum) (Informal conversation, medical doctor, 26 November 2006).

> When I started with these pills I used to feel drunk. As they say there, you must drink it before you sleep. But I was not going to sleep yet. Now *kwaye kwanzima* (it was tough). I took these pills and was supposed to go to the kitchen; Ey! It was as if I had drunk alcohol [laughter from both]. It was tough, man. Until I got used to them. Now I no longer get drunk (Interview Sipho, 23 April 2006).

Partners and family members played an important role in enabling men to adhere to treatment. Since most men had disclosed to at least one person, they used that person – and many more in the case of men who disclosed to more people – as a treatment supporter. Sabu said as soon as he disclosed to his new partner, who was HIV negative, he assigned her a role as his treatment supporter:

> *Ushukuthi* I told her 'baby if you truly love me you must remind me every now and then to take my medication. Now everyday at around closer to 7pm, I receive an SMS from her 'Sabu, have you taken your medication?' (Interview Sabu, 11 October 2006).

Other men, whose partners were also HIV positive and using treatment, decided to set the same treatment time as their partners. Sipho said he and his wife settled for seven (am and pm); this is even known to their children: 'They know, if its seven pm they come running "Papa, its seven"; and if I'm not home – maybe I'm next door - my wife sends them to call me' (Interview Sipho, 23 April 2006).

Meanings of adherence

Adherence is often viewed from the perspective of a doctor - as following his 'orders'[24]. My findings, however, suggest that most people followed their prescribed regimen because they assigned certain subjective meanings to their adherence behaviour. They were not merely following the doctor`s rules but had set themselves personal goals that needed for them to remain healthy in order to achieve these aims. The main motivational

[24] Despite a now famous conceptual move from 'compliance' to 'adherence' to indicate the active role of a patient, this is still the case.

factor for adhering was that ARVs gave them a second chance in life, following their near death experience from AIDS. This second chance enabled them to play meaningful roles as fathers and lovers. ARVs also enabled these men to regain their sense of manhood.

For Mathe the decision to stay on treatment was linked to his role as a father of five children. Mathe lost his wife from an undisclosed sickness in 2004. When he became sick himself, he first turned to traditional medicines. In the end he underwent an HIV test and subsequently enrolled for treatment in September 2006. He said the death of his wife motivated him to stay on treatment; he wanted to live for his children:

> *Ushukuthi* since their mother passed away I became both a mother and a father to them, and I receive lots of love from them. Even this woman I told you about, the one I am in a relationship with, she is not as closer to them as I am. They are always with me and they don't want to separate from me – wherever I am they are following me (Interview Mathe, 4 February 2007).

For Mathe, staying on treatment gives positive meaning to his fatherhood responsibilities. During fieldwork Mathe was unemployed, so he was not providing material support to his children. He said his mere presence amongst them was what he could offer to make them happy. The manner in which Mathe embraced ARVs exceeded the expectations of health professionals. In one of my visits to his home I asked him how he feels about having to daily use medicines for the rest of his life. He said this does not bother him; in fact he is enjoying them:

> You see these pills Sakhumzi; these pills are magical! You see in the beginning I didn't really like them. The idea that I must take them for all my life didn't settle down well with me. But you see, after about 3 months or so I began to love them. You see now, if I don't take these pills I can feel my body isn't right; I feel thirsty. Then I know it`s time for my pills. And immediately after I take them I feel 'yhaa; I'm now alright...I can now go on with a day'. And I tell you Sakhumzi, lots of these people at Philani love them; they love their taste; they say they are sweet (Laughing) (Informal conversation Mathe, 16 March 2007).

Here Mathe constructs ‘these pills’ in a way that seems to redefine who he is - in a positive way: without using them his body ‘isn`t right’. This indicates how he has embraced the pharmaceuticals as an extension of who he is. Indeed much of the resistance observed in relation to non-adherent behaviour stems from the fact that some people cannot ‘connect’ with their medicines. Instead they perceive them as an ‘outside’ and invasive, a constant reminder of their condition as HIV suffers (Pawluch, Cain et al. 2000). The authors describe a situation where patients completely reject ARVs because the medication interferes not only with their lives but also with their own definition of who they are. In this narrative shared above we see a different see a case of a person who attaches a positive meaning to his use of ARVs; this enables him to adhere.

Mathe described himself as a compliant patient. He said since he started using ARVs in late 2006, he only missed his treatment once. This happened when he was in Moria to attend a church ‘conference’. He said he has no plans of discontinuing his ARVs: ‘The only time I will stop is when maybe they say they have run out of stock at the clinic. That’s the only time I will stop, but while they still have them I will still continue using them’ (Interview Mathe, 20 February 2007).

It is therefore not surprising that Mathe uses the word ‘magical’ to describe ARVs. Magic is also associated with power that is beyond human control and here Mathe seem to assign this power to ARVs (despite being manufactured by humans). The notion of ARV as somehow having supernatural or miraculous properties indicates the faith that he has in them. It also shows how he endows them with power to transform in a ‘magical’ way. Mathe probably gave up in life (this part is unclear) due to being ill, but the ‘magic’ of ARVs brought him back into life. This explains why, despite experiencing difficulties, such as side effects, he has no intentions to discontinue. He adheres for his own sake and that of his children.

Sam assigned similar meanings to using ARVs, saying they enabled him to take care of his 10 year-old son. Sam and his son lived together in a small three-roomed house. The

mother of his son left him for another man after Sam disclosed to her. Sam received a government support grant and he used it to start a small business. When the grant was withdrawn his business was already stable and during fieldwork he lived entirely on it. Sam described himself as an adherent person, saying ARVs contributed greatly to the improvement of his health:

> These pills don't restore you completely; but they make you much better than your previous state. You find that sometimes you couldn't even walk or wash yourself; now you are able to walk, to sweep the house. You can even walk to Acornhoek (3km from his home). Yes it's still hard because you are still sick, but it's not as hard as it was during that time. I can even run as far as kwaZita (about 1.5km from his house) and not feel anything. Even food; you can eat well; drink water properly…they do work.

Sam keeps himself busy all the time. Besides having a business he has a big garden where he produces fruits and vegetables for commercial use. From observing him over a long period of time I saw someone who had passion for life and who wanted to live longer. I therefore asked him what motivates him to live and to adhere to treatment:

> You see *mnganam* (my friend); this a*uty* (boy) is still young. And I'm the only parent. Now if I die who will look after him? My family has deserted me because of this virus. Now this child will be discriminated. I can't allow that *Mnganam*. At least let me live for as long as these pills allow me, you see...let me live for as long as they allow me...

Sam said the fact that ARVs involve a lifelong treatment schedule does not bother him; nor does he feel personally inconvenienced by the strict regimen:

> Well, I am not bothered by that. I know I must always be going to the clinic every now and then. But I guess I'm used to it, and they do help a lot there at the clinic….like sometimes I don't eat well and they give advice...If that's how they are made to work (lifetime) then we have to accept it (Interview Sam, 27 August 2006).

Sam and Mathe are the only two participants who raised their responsibilities of fatherhood as the main incentive for staying on treatment. In the case of most of the participants it seemed as if their motivations were more individualistic and were directed mainly at restoring their bodies to health. This, in turn, would make it possible to regain dignity and respect. Their bodies, as I showed in earlier chapters, were seriously affected by the experience of being ill. This is because most people became weak and were unable to take care of themselves. Some men lost complete control of their bodies – including control of certain bodily excretions – and these were experienced as embarrassing and demeaning moments. Hence when I asked them 'what motivates you to stay on treatment?', The dominant answer I received was 'I don't want to go back to where I was before'.

Other men decided to stay on treatment to enable them to 'get back' at people who had made fun of them and labelled them as 'dead' while they were sick. Kenneth explained 'Yhaa, even when they look at me now they don't believe. Even if I tell them I have HIV they still don't believe…' (Interview Kenneth, 14 February 2007).

The main limit of these findings is that I did not follow men for a longer period of time to observe the length of adherence. Research shows that once patients overcome the shock from being seriously ill they are likely to develop resistance to certain treatment messages and may try out other therapies. Patients also start to pay attention to other previously insignificant outcomes of treatment in their lives. These include issues such as the way in which their regimens restrict them from doing certain things, or cause certain physical discomforts or bodily changes (Persson 2004). Most participants in this study had been using ARVs for over a year; only two had been using them for more than five years. There were indications from some of my participants - though a small minority - that they were already having some discontent with certain treatment rules from the clinic. However the overall commitment to ARVs was not affected. In the next section I focus on the contradicting experiences with ARVs.

Treatment narratives: facts or '*performances*'?

The main purpose of discussions in this section is to critically examine the above treatment experiences, especially as they are shared in support groups with other PLWHA. I want to particularly highlight – and later explain - the discrepancy that exists between how patients talked about treatment in support groups and how they talked about them in private or with me as a researcher. It has been noted that, in sharing their treatment experiences, patients may be more concerned with safeguarding their moral integrity and the need to project a positive image of themselves, rather than with being completely open about their (negative) experiences. To illustrate this difference Cornwel, cited in West (1990, p. 1229), makes a distinction between 'private' and 'public' narrative accounts. The latter refers to 'sets of meaning', which affirm or reproduce the moral order or dominant ideology, and are in essence 'ought' type expressions of an acceptable kind'. These differ from private accounts, which may '…reveal the deviant or darker side of things and typically occurs between confidants who share, or are granted access to, that reality'.

The notion of an actor as a '*performe*r', as conceived by Goffman (1967), has been drawn upon to make sense of this gap (Riesman 1990). Goffman constructs a theory of social practice that portrays the actor as an active definer of how others should perceive or judge him. Actors are fully aware of the norms and standards of a society in which they live and what constitutes morally 'good' conduct. Therefore they may deliberately frame their behaviour in order to conform to these norms and standards. In the end, according to this perspective, what we see in everyday life may be a carefully managed or 'staged' front, but it does not always reflect an actor`s true/inner feelings.

My use of the concept *performance narratives* to describe the ways in which patients talked about ARVs in support groups – as opposed to how they talk about them in private - is inspired mainly by this perspective from Goffman, but I will also draw from my own fieldwork to reflect on its analytical limits. It is not my intention to argue that what is observed in support groups is merely a 'staged front' and that the genuine experiences of

using ARVs are those that are shared with me as a researcher. As we have seen above, most men benefited considerably from using ARVs and some of them attach personal meanings to their adherence behaviour. Testimonies that they give about the positive impact of ARVs in their lives in support groups are accordingly authentic to a large extent.

It is, however my contention that men have other stories to tell about treatment outside the support groups. In this regard, some participants contradicted the image that they portrayed about themselves in support groups. There were men who drank and used traditional medicines; some were critical of ARVs and opined that they are ineffective or a 'burden'. One participant wanted to stop treatment. These stories somehow destabilize the positive picture about ARVs that we normally witness in support groups. The narratives also go against the grain of current scholarly perspectives on support groups successfully producing new, responsibilised, converted, subjects. Instead they invite us to pay closer attention to the ambivalence that people have towards their commitment to ARVs. They show that ARVs do not have a one-sided impact on users; instead they are simultaneously liked and disliked; accepted and rejected, depending on what a user wants to achieve at that time and how they may interfere with his present plans.

A possible way to begin this discussion is to cite two separate interviews that I conducted with two men who use ARVs. Vusi is one of my participants whom I knew as being loyal to the clinic. Since I met him in April 2006 Vusi never missed an appointment date. When he visits the clinic he would send me a message to signal his presence and that we can meet and talk. Vusi is shy in public and he hardly speaks in support groups. But when he is asked by facilitators to say something about his experience of treatment he normally gives a brief precise answer 'No, *sisi, mapilisi ahikhome kahle; akunankinga* (the pills are keeping me well; no problem)'. This response indicates his complete satisfaction with ARVs and it does not give a hint on whether or not he has issues with the medicines.

One afternoon in February 2007, I visited Vusi at his house. He told me the 'other' side of his experience with ARVs that he never shared in support groups. First he confided

that he once missed his medication for four days because he had no money to go the hospital. Then he said that he does not adhere to treatment and that he does not believe he has HIV. He drinks occasionally and also uses traditional medicines. This revelation came about ten months after I met him:

SM: And how are the pills keeping you?

Vusi: I never experienced any problems, but I did develop a skin problem on the early days, but after that things got just fine. I used to drink some pills and I brought them to the doctor, but he told me 'No, from now onwards you must only drink these ones; stop drinking those ones'. And since then I have stuck with these ones; until today I don't have a problem and I`m not sick. I feel nothing wrong with me

SM: And how did you feel during the time you were not taking them, how was your body?

Vusi: I was just fine; I was just fine. There were no changes in my body...The thing is I actually don't believe I`m sick; I don't believe I have HIV, but they told me that. So I accepted it because they told me, but I`m not really sure; I`m not sure.

SM: Why don't you believe?

Vusi: I don't believe; well they told me I`m sick, but I don't believe it. *Angithi* I used traditional medicine, that's why I don't believe it. I don't feel any changes in me: I run, I exercise and I do hard work. I have strength – if there is a funeral I go there and work, pick up some concrete bricks, you see. I'm not weak. But I will not stop these pills because next time if I get sick they will blame it on that; they will say I have stopped medication.

SM: But do you think you can live without them?

Vusi: Yhaa, I can live, because nothing happened during those four days. I just told them 'I had a problem with money'; that's all...The same goes with TB – they gave me TB treatment, but I was not coughing. They said I have TB but I never even smoked, so I wondered 'where did I get this TB?', because I never smoked in my life. But they insisted I have TB and they gave me this TB treatment. But to tell you the truth I never finished that treatment, I didn't drink those pills. I only drank them while I was at the hospital and a little bit here at home. I have to tell you the truth *mos*! (Interview Vusi, 28 February 2007).

Vusi`s disbelief was strengthened by the fact that his wife was HIV negative. She tested twice in two different clinics and both results came back negative. Vusi has a one-year old child with another woman whom he said is also negative:

> Yhaa, my wife is negative, and I have children too. Just now I have a small child. If I do have it (HIV) the child should have had it as well, you see. I mean I slept with my wife all the time without using condoms. I would come from work in the army and then sleep with her and I was sleeping with other women there. If I have it she must be having it too (Interview Vusi, 28 February 2007).

The second conversation was with Thandi, another man who was a committed user of Rixile services. I met him for the first time in May 2007 and we immediately became friends. He kept me informed whenever he visits the clinic and we would meet and chat informally about his life. Thandi, together with another man who works for a local AIDS NGO, was actively involved in an unsuccessful attempt to form a male-only support group at Cottondale clinic. During the few meetings that he managed to organize he was active in motivating other men. He advised them on how to use treatment correctly and how to manage their health under HIV: i.e. by avoiding traditional medicines, eating healthily, etc. In these meetings, and in mixed support groups, Thandi never criticized ARVs, nor did he share a side of him that departed from the biomedical approach adopted in support groups.

In February 2007, after knowing Thandi for seven months, I conducted a second interview with him. During our interview Thandi told me he does not believe in ARVs. He questioned some aspects of ARVs: the fact that it is a lifelong treatment rather than a cure, and some demands on adherence and lifestyle changes. The extract below is taken from our interview:

> Thandi: You need medicine that will kill the virus and then remove it. But these ARVs don't do that. If they were a treatment, as they call it, they should kill it and then remove it from the body. They should remove it, Sakhumzi...But I tell

you, if these people are really serious about fighting this disease they can find a cure.

SM: Yhaa; but *angithi* you are now using the ARVs...

Thandi: Can I tell you something: You need to be stupid sometimes if you want to live; then your stupidity will help you live longer. They do tell you that these ARVs don't cure AIDS. Why then do we stick to them? Because we have accepted to being stupid. It's just similar to ZCC person who keeps telling himself that his tea works. He is stupid; it's just a normal tea, but it works for him. Why? Because he has accepted being stupid. So that's why I say for the sake of your own life you should just accept being stupid. There is no difference (between using and not using ARVs).

SM: But I'm sure there is a difference.

Thandi: Yhaa there is. You have accepted your dependence on them... that's why I say I accepted my stupidity; that 'my life will be dependent on these pills'. But if I had another option I would use it.

SM: But how does it make you feel; I mean the fact that you must use these pills for the rest of your life?

Thandi: I'm not sure if I will use them throughout. But I think at one stage I will risk for a month or some weeks, to see what changes will take place.

SM: And why would you risk with your life? Because this is your life.

Thandi: Well, I may win; I may not win. I may win. I will not make a risk at a higher level; I will start very low, then I will see 'Hey it looks like I'm succeeding'. And I tell you, when I see you again next year I will give you a report back of what happened. I have started it already; I have started it already...I will risk, but will do that bit by bit. The minute I see 'OK this risk is working', then I will take it a step further.

SM: Is it because you don't like the pills?

Thandi: *Ayahlupha; ayahlupha* (they are a burden; they are a burden); they are too strict. Even with alcohol, Sakhumzi – if you drink alcohol today, tomorrow no one will come to you and say 'go and drink again'. You will go there by yourself; and once that happens you become *uMatywaleni vele* (an alcoholic). Now if I drink these pills every day I will become *uMapilisi* (*pill-aholic*) [laughter]. I know they help; all pills do help. But even with Panado you shouldn't take them

> for more than 10 days; but these ones are for life...These pills *ayinkathazo* (they are a burden) because if you miss them for whatever reason your sickness worsens and you are unable to cope again (Interview Thandi, 11 January 2007).

These two interviews are a good way to illustrate the ambivalence that most men had towards their commitment to ARVs. This ambivalence, as I have observed, is not expressed in support groups where men meet and socialize with other HIV positive people. Instead it is confided to a trusted observer, or among men who share similar frustrations with ARVs. The striking factor about these two men is that despite their strong criticisms of ARVs – and Vusi`s denial of his HIV positive diagnosis - they are still using them, every day.

Vusi`s story illustrates the attitude of acceptance and rejection that I have observed to characterize the reactions of most participants to treatment. On the one hand ARV treatment was accepted by most men because of the way in which it improved their physical conditions, thus enabling them to rebuild their lives, take care of family, and regain their self-confidence. On the other hand ARVs are detested because they impose constraints on the men in relation to the kind of lifestyles they should live – not drinking; not using traditional medicines, paying too much attention to health, strict medical checkups, and others. Some of the participants found these rules oppressive and as depriving them of freedom to pursue lifestyles outside of an HIV identity. Most importantly the medicines were emasculating - rather than empowering - because they reduced the men's authority and control over their lives.

Vusi told me he belongs to a group of male dancers who participate in a 'traditional' dance called '*Mshongolo'*. Every Sunday *Mshongolo* groups meet in a designated village where they dance and express their masculinity through public display of physical strength. These dances are physically demanding, and require endurance during long periods of physical activity. Alcohol is sold and most dancers drink after dancing. Vusi told me that being able to dance in these events is further evidence that he is HIV

negative: 'Yhaa, I go there and I dance like other men. I go up and then go down; up and down, and I feel nothing!' (Interview Vusi, 28 February 2007).

Initially I thought of Vusi`s claims that he is HIV negative – and his subsequent decision to join these Mshongolo dance groups – as a sign that he was in 'denial'. In time I began to consider it as his effort to regain control of his life. Vusi does not want to be tied down by the identity of being HIV positive; he feels that this identity imposes constraints on his life as a man. If he embraces it, it means that he must adjust his lifestyle accordingly and then refrain from other social activities that are labelled as 'risky' for someone with HIV. It is therefore better to claim that he is HIV negative; in that way he can live like other men - drinking, dancing, and using traditional medicines – without having to observe certain limits.

The tendency of HIV positive people to want to 'disengage' from their HIV identity has been noted elsewhere and its health implications have been explored (Squire 1999). Squire observed that carrying an AIDS identity can be experienced as a burden and that at certain times people want to 'get away from it' (Squire 1999, p. 119) and live other identities. There are scholars who argue that by 'disengaging' from his HIV identity, a person may experience some health relief (Squire 1999). It seems as if support groups have not recognized this reality; instead they want patients to wholeheartedly embrace their HIV identity as an all-encompassing and 'master' identity, guiding all aspects of their lives. Someone who departs from what support groups prescribe as an acceptable lifestyle for an HIV infected person is immediately labelled as a deviant or non-adherent patient.

By doing *mshongolo* and drinking, Vusi resists his subjection to this identity and its behavioural implications. We can also view it as a way in which Vusi distances himself from the HIV community to which he supposedly belongs. Probably Vusi only wants to think of his HIV identity when he takes treatment or visits the clinic, attends a support groups, or is having sex (where he must use condoms). Outside of these contexts he wants to live a 'normal' life. During our interview he told me 'I want to get a job; not just

a soft job but a tough job…yhaa…'. Most people who are HIV positive were discouraged from doing hard work because it may affect their health and some of my participants deliberately avoided hard jobs due to health concerns (see chapter 8).

In his account Thandi makes an interesting point that 'you need to be stupid sometimes if you want to live'. Much can be deduced from this statement but I want to focus on what it implies about manhood. I have shown in previous chapters how men construct 'real' manhood in terms of being dominant and in control. 'Real' men do not passively accept things, as women purportedly do. Here Thandi seems to suggest that, in order to embrace treatment, someone must dispense with these attributes and allow himself to be controlled by women. This sort of 'stupidity' must however not be kept to oneself; it must be performed in front of others who will applaud and support it. Here, support groups provide a good platform and audience for men to demonstrate their 'stupidity' by publicly praising ARVs. By implication, support groups celebrate men who are 'stupid' rather than perceive them as not 'real' men. Someone who enters support groups and then begins to question its tenets is not perceived in a good light.

Throughout our interviews, Thandi demonstrated total rejection of support group messages on regimen observance. First he questioned support group definitions of adherence, i.e. that someone must take treatment every day at the same time. He opines that this is unrealistic since 'You will never be strict, to be in time all the time. No, you will never'. Then he questioned the rationale for adherence, arguing that it is misleading:

> Sakhumzi, a day is 24 hours and half a day is 12 hours. If you miss by 3 hours it doesn't mean you haven't taken your medication on that day. But that's not what should be communicated to people, that 'you can miss by 2 hours; you can miss by 3 hours'. But a day is 24 hours; if you miss by 24 hours then there might be a problem. Even at work you don't always arrive at 7 if you have to start at 7. You do have an allowance of 20 or 30 minutes. You have an annual sick leave and you will get paid for that. Now you are telling me that all the time when they say 7 o'clock you are always on time? *Phela* even the clocks differ; mine is ahead by 5 minutes. So what I'm trying to say is that in this world you do have allowance; you do have allowance.

Then Thandi questioned fellow support group members who claimed to be adherent, saying they are merely 'putting on a front':

> No, they are telling lies. Sakhumzi they are telling lies. I tell you Sakhumzi; I used to work and I would switch on a clock to wake me up in the morning. But as soon as it rings I would wake up, switch it off and go back to bed. I wake up late and go to work having missed my bus. And sometimes my manager is even late. You will never…no one is an automatic (Interview Thandi, 11 January 2007).

As I have already indicated above, I was taken aback by such revelations by men like Thandi and Vusi. They contradicted the positive attitude towards ARVs that they displayed in support groups. Looking back at my previous encounters, however, reminded me that these men were not alone in having ambivalent feelings towards ARVs. For example Tito, who is respected support group member and an expert patient, expressed similar feelings during our earlier interview, saying:

> …wherever I go I must always carry these pills; when I visit I must always carry them with me. Let's say there is a night vigil and I must be carrying my pills. That's really what bothers me a lot; cause sometimes they give me stress – I will live on these pills until when!. (Interview Tito, 20 October 2007).

In our interview Sabu expressed similar concerns, focussing in how ARVs constrain him in terms of his lifestyle:

> I know I don't drink and I don't smoke or so. But I just want to know; really does this mean that I will never drink again in my entire life, *Joe*? I only have to drink these pills?…Even if maybe they invite me to an event or so?. I mean, really…!' (Interview Sabu, 27 July 2006).

I learned through formal interviews and other encounters that some men are patently violating certain treatment rules although they remain mute about these contraventions in

support groups. Interestingly, expert clients themselves also sometimes transgressed the 'rules'. These men are normally at the forefront in urging other people to change their lifestyles and to adopt a biomedical approach to health. Mostly they denigrate local cultural practices and present themselves as having been 'converted'. For example, they sit in the front row, closer to the facilitator and are very knowledgeable about HIV 'language' - ARVs, CD4 counts, viral load, etc. They offer 'expert' opinions on diet, drinking and how to cope with being HIV positive. I was therefore shocked when I learned during other encounters, outside the clinic space, that some of these men are not completely dedicated to these lifestyles, though still committed to treatment.

Kenneth was a respected member of support groups and a model for 'positive living'. He talked openly about his HIV status and was active in educating new clients on how to live healthily with HIV (non-smoking, non-drinking, safer sex, etc). One morning, a side of him that was unknown to us was shared by his partner, Joyce, who came into the support groups and then started crying. Kenneth and Joyce always attended support groups together, but on this day she came alone because Kenneth had other engagements. This gave her an opportunity to share with us her 'true' experiences with Kenneth. She said Kenneth refuses to use condoms:

> Like last night; he refused. I said why and he didn't give any answer; he just went on without using it…and he is such a control freak. Sometimes when the phone rings he comes and listens to what I say and then asks 'who is it? (Focus group observations, 6 July 2006).

Participants were shocked by this story because they knew Kenneth as an inspirational figure and their role model. I later interviewed Joyce and she said she suspects that Kenneth imbibes and that he has other girlfriends 'Like there are these friends of his; sometimes he leaves here without telling me and stays with them the whole night. And these guys drink. What is he doing with drinkers if he doesn't drink?' (Interview Joyce, 15 March 2007).

These narratives problematize the existing scholarly perspectives about commitment to ARVs as an empowering and identity-conversion experience. They show that ARVs are tolerable mainly for their health benefits, but they are not equally acceptable in relation to the constraining impact that they have in user`s social and personal lives. The final discussion in this chapter returns to support groups and attempts to explain why it is difficult for users to openly express their 'darker' experiences with ARVs: why do they choose the route of *performance narratives* rather than provide honest accounts about their experiences and attitudes towards ARVs?

Firstly, we must view these performances as a reflection of a patient's subject position in the health sector. I have shown above how patients are assigned a subject position of being 'students' while facilitators were equated to 'teachers' and 'experts'. This had a constraining impact in patients who found it difficult to raise questions about ARVs or challenge facilitators even for minor things, like side effects, because of their respect for 'authority'[25]. Most importantly it gave facilitators power to impose a biomedical approach 'from above' (Rose and Novas 2005, p. 447) without taking into account patient`s diverse experiences and needs. Mathews (2000) observed that when support group participants interact as equals they tend to arrive at a consensus about the definition of their situation, drawing from their varied belief systems, rather than having one perspective imposed from above. This was not the case in Philani support groups where one paradigm – biomedical – dominated the interpretation of events. Other explanatory models that patients brought into the groups were treated as unimportant and irrelevant for their condition and were, in most cases, stigmatized.

Secondly, *performance narratives* come from the fact that patients rely on the clinic as their main support base. The clinic provides both material and emotional support for them. Material support comes in the form of medicine, food parcels and government support grants. Emotional support is gained by being in the presence of others who have

[25] One would expect that as PLWHA themselves, facilitators would be more open to engagement and that the interaction would be more equal. But my experience of attending these support groups showed that this is not the case. Facilitators were accorded a courtesy status of being nurses and this status carries with it a superior social position in the study area. This explains why most patients could not challenge them.

the same health problem, HIV. People valued the support that they received from support groups and said it improved their well-being. Patients were therefore careful not to lose these support systems, hence, when they are invited to share their experiences of using ARVs they immediately 'produce' or performed positive accounts. Talking negatively about ARVs or the clinic, as well as confessing to be not adhering invited hostility, stigmatization and subsequent alienation from others. Someone who imbibed or used traditional medicines was treated badly - as an outsider who must be avoided. Gossip circulated about him and others were warned against the 'dangers' of associating with him. Most users felt that they could afford to lose these support systems. Hence, when giving their treatment testimonies, it was deemed safer to follow the 'correct script', rather than to reveal negative feelings towards the clinic and treatment.

Finally, most men decided to reproduce positive accounts about ARVs because they wanted to protect and motivate new clients. It was felt that the public criticism of ARVs, or of sharing of negative experiences, would give new patients mixed feelings about their participation in treatment. My interview with Thandi illustrates this point:

> SM: I mean you are arguing against their rules, that '7' must be '7' and you are saying 'No', why don't you challenge them there at the clinic?
>
> Thandi: I would challenge them, but you must remember that there are new people there who listen to them and follow their orders. So if you come out and challenge them, these new people will begin to think 'Ey this one (facilitator) is misleading us with this 'seven-to-seven' (Interview Thandi, 11 February 2007).

Conclusions

Scholarly perspectives on experiences of using ARVs highlight the power of these drugs to transform people`s subjectivities while giving new meanings to the notion of citizenship. My point of departure highlights the fact that this transformation is not unproblematic nor is there a smooth insertion of patients into these 'new' HIV identity - based subjectivities. I have shown that while most people are committed to treatment they

have difficulty in wholeheartedly embracing the HIV identity because it limits them from living other identities. Here, the local identity of being a man still informed how some participants wanted to live their lives. This was exemplified by the behaviour of men like Vusi and Sabu who still wanted to dance and drink and Thandi who still used traditional medicines.

We should also not underestimate how adherence to certain ARV demands can alienate someone from the community in which he lives. Refraining from traditional medicines can result in the alienation of a man from his family and peers because he may be perceived as rejecting his 'culture' (see chapter 4). Similarly, restrictions on using alcohol are imposed 'from above' without consideration what drinking means to certain individuals or to the role it plays at roles it played in their individual lives and in maintaining social relationships.

CHAPTER 8

LIVING WITH HIV AS A MAN: CHALLENGES AND CHANGES TO MASCULINITY

Tito: There is something that I have observed, that if you are HIV positive and using these drugs you sometimes struggle to have sex. You feel weak, and when you want to have sex you are just weak; your *madala* (penis) is always sleeping, and it wakes up maybe after a week. Cause these pills are meant to make this virus to sleep; now this *madala* will also sleep. Now these pills make it sleep so you lose appetite for women; so that even if you see a woman there you just don't have any feeling...that's why some men end up just staying alone or maybe a wife leaves him, because he can no longer engage in sex (*akasayi emacansini*). He drinks these medicines and just after drinking them he sleeps, as if he drank alcohol. But a woman is still strong, so she goes and gets a man outside, a man that doesn't know anything about her status, that doesn't drink pills. You find that he is strong! And she says *Hayi, akusindoda le, indoda nayi* (No, that one is not a man; this is a real man).

SM: I wonder how a man feels; I mean his sense of manhood, if he cannot have proper sex… [Interrupted]

Tito: No, *kufanele nje uzihlalele* (you just have to do without it); what are you going to do? *Angithi* you are taking your medications. What's more important, sex or your health? Health is most important; to live healthy without any pains is most important (Interview Tito, 20 October 2006).

Introduction

In this chapter my main aim is to look at the constructions and experiences of masculinity under the HIV identity: what does it mean to be a man and living with HIV? I have argued in previous chapters that the perceptions of masculinity have been profoundly impacted by experiences of being sick and using public health services; however, men are not adopting a drastic departure from their previous understandings of manhood. Instead they are redefining the terms of being a 'real' man, taking into accounts their needs to

receive help and treatment from the clinic and to live longer with HIV. There are also differences between men with respect to these changes, with certain men being more impacted than others, depending on how much they invested in hegemonic definitions of masculinity before they became ill.

In particular this chapter investigates challenges that these men experience in fulfilling certain expectations of manhood, and how they deal with these challenges. Previous research on men living with chronic illnesses indicates that due to being sick and using chronic medications certain men are unable to fulfil certain obligations as required of their gender; this may result in someone's identity as a man being questioned (Charmaz 1994; Chapple and Ziebland 2002); or it may prompt men to re-think their definitions of masculinity in order to accommodate a new diagnosis and treatment demands (Broom 2004; Olliff 2004; Emslie, Ridge et al. 2006; O'Brien, Hart et al. 2007). Manhood is indeed not the only identity that is threatened by being ill and using lifelong medications. Research work conducted with women who have chronic diseases shows that they too face identity and role dilemmas as carers, employees, mothers, as a result of having a chronic illness (Anderson and Bury 1988).

What is clear from most research work conducted with people living with chronic illnesses is that this experience is life-changing (Bury 1982; Anderson and Bury 1988; Charmaz 1994). The difficulty that the infected individuals face, however, is whether or not to embrace the changes or continue with life as before; and as noted by Charmaz (1988) both choices have consequences to his identity: to change may mean that someone admits to having 'failed' in playing the role expected of him/her; on the other hand to continue with life as before may have dire consequences for a person's health because his condition may get worse. What response then, do men in this study have with respect to challenges posed by HIV to their lives? How do they relate with the identity of being HIV positive men? Do they embrace or reject it; do they adjust life accordingly in order to accommodate this identity or do they continue with life as before? How do they deal with pressures from the society to 'live like a man?'

The above extract from Tito already provides a clue as to what sorts of challenges and changes men experienced and how they responded to them. As shown in chapter 5, Tito is one of the men who had multiple sexual partners before his health became compromised by AIDS. In our interviews he told me 'Yhaa, I had lots of them (women). Zulus, Sothos, Ndebele`s, Indians and even whites!'. Tito worked as a driver for an insurance company and he said this gave him 'easy' access to women. Now, as someone who is HIV positive and using ARVs, Tito reports a significant change in his sexual life. He has sexual difficulties and this makes him to rethink his commitment to sex as an important part of his manhood life. He is embracing the change, seeing health as being more important than sex.

Based on interviews with other men, it will be argued that most men are embracing changes imposed by HIV in their lives and that as a result they are redefining their manhood. However, we are not seeing a situation where men are completely rejecting their pre-illness definitions of manhood in favour of 'new' versions. Instead men are selective in what they reject or embrace from their previous lives, taking into account their health needs. Hence on the one hand, work is seen as being important both for someone's survival and social image; yet men are not willing to do 'hard' work due to health concerns. Sex is also seen in the same light; men feel strongly that they need to have a sexual partner both for emotional support, sexual fulfilment and social image; yet they are not willing to enter into 'risky' sexual liaisons in order to fulfil these needs. Instead, sexual partners are chosen carefully, based on whether or not they are perceived as posing a health risk.

In this chapter I will show that most men living with HIV still want to live according to their previous definitions of successful masculinity; however the means for achieving these ideals have changed. In particular, the notions of being powerful, in control, dignified and respected are still central to these men`s perceptions of masculinity. But instead of being pursued under the previous, socially sanctioned practices – like having multiple partners - these roles are now being pursued under a new discourse that I shall call 'responsible manhood' (see also chapter 6). Hence, in moving on with their lives

after testing positive, they are more cautious than before; they think and reflect before doing something and they put their health needs first ahead of needing to be appear manly.

The first section of this chapter is descriptive, detailing challenges and changes that have occurred in men`s lives as a result of having HIV, and how they respond to these changes, focusing on the provider role and sexual lives. In section two I look at how these challenges have prompted certain men to re-think their commitment to these roles as well as how this is seen to impact on their masculinities. Section three focuses on how these men live their 'changed' identities in everyday life and how they deal with challenges from other men and the community to 'live like a man'. In section four I reflect on the overall impact of being ill in the transformation of masculinities, and the role played by support groups in fostering changed identities.

HIV and problems of being an independent provider

Having an employment and providing independently for oneself was one of the key definers of successful masculinity for these men. Only three were not working before they became sick from HIV. Access to a paid job enabled men to afford 'masculine lifestyles', such as drinking, having multiple sexual partners and dressing nicely and decently. And, as I noted earlier, very few men were actively involved in bringing up their children though they were employed. One of the major setbacks that they experienced from HIV sickness was loss of employment. This happened in two ways.

Firstly, when these men became ill they were living away from their homes in places of work, like Johannesburg. Because of being sick they left their jobs and returned home to receive medical help and support. By the time they recovered they were already replaced because of long absences (some spent up to 8 months at the hospital). Secondly, jobs were lost as a result of a voluntary decision not to go back due to poor health. Participants felt that their previous jobs were demanding physically and that as sick people they could no longer cope with such jobs. Despite taking ARVs they felt that they lost vitality that is

required to do 'hard' work. The majority complained about feeling weak and 'stiff', and said minor physical tasks, like cleaning the yard, exhausted them. Of all 22 men that were working before they sickened, only one man kept his job. Unfortunately he later lost it due to reasons not related to being HIV positive. There was only one case where someone lost his job due to being HIV positive. Zita said he disclosed his HIV results immediately to his employer at supermarket where he worked and a few days later he was dismissed, ostensibly for 'absenteeism'.

Of the 25 men who took part in the study, only eight received a government support grant (a temporary measure of about R700 a month); four of them used the money to start small businesses and the remaining seventeen had no sources of income. The primary means of support for the latter group of men was family: 6 of them left their homes to live with their parents where they received financial support and food. Others remained in their homes, but their houses were located closer to parents and siblings who assisted them with food and money. The next discussions focus primarily on those men who had no sources of income. I document how life was for them and how unemployment and dependence impacted on their lives as men. Most importantly, I am interested in how their situation of being unemployed and dependent impacted on their sense of manhood.

Consider Mathe, whom I described earlier as a man who had a good, stable life before he became ill. Mathe owned a house in Bushbuckridge where he lived with his five children and a wife who was a nurse in Bushbuckridge. He was working at a retail store and earned enough to support his family. Mathe lost his job because of a long illness and is currently living with his parents; his wife passed away and some of his children are supported by his parents. During our interview he talked at great lengths about being unemployed and how he felt about being dependent on his parents. He said being unemployed and dependent was an insult to his manhood:

> I used to work in the past, my brother. And now I have to ask for just about everything I need – soap, food; I don't even have soap to wash my clothes or myself, even lotion. All these things I must ask for them! And sometimes I'm even ashamed to ask for these

things. And sometimes I just wake up and leave, go somewhere where it's quiet and pray (Interview Mathe, 20 February 2007).

Here Mathe reminisces about his previous life as a 'real' man and a provider for himself and his family. Being a provider, as I observed earlier in the thesis, is bound up with perceptions of being powerful and in control. In the case of Mathe, it further earned him great respect in the community (see chapter 3). Now as an unemployed person Mathe felt that he no longer receives the same respect, particularly from his family. This emerged in our conversation about his children and how he felt about his inability to provide for them:

SM: But, as their parent, how do you feel about the fact that you are not supporting them? How does it make you feel?

Mathe: *Ngiziswa kabuhlungu* – It gives me great pain, because I know I should be buying this and that…the thing is I am the last born at home - it's me and my bother. We used to be three but our sister passed away and now we are two. My brother moved out of home to build his own home. I had also moved out of home to my own place, but since the death of my wife I was forced to come back home together with these children, because I wouldn't manage to take care of these children, especially since some of them are still very young. So when I'm not home you find that some are not home or they do all these other things…And I'm also sick, so there is nothing I can do. All this gives me pain because I can't do anything about it. I just wish I could get a job, but every time I try to get a job I don't succeed (Interview Mathe, 20 February 2007).

This comment confirms what men who are sick may feel inadequate and unable to exert influence within the household. In his case this feeling is exacerbated by being unemployed and therefore unable to provide material things, which are a basis for gaining respect and recognition as a man. Mathe is an exception with respect to how being unemployed affected his perceptions of fatherhood. For most men the impact was felt at an individual level, in being unable to afford certain 'masculine lifestyles' that these men enjoyed before he became ill, as we will see later in the chapter.

In my interview with Mathe`s, brother, Mdu, he confirmed his account, saying since his Mathe became unemployed he became insecure:

> He always talks about finding a job. And if you say something to him that he doesn't like he will go on and say 'it's because I`m not working...I will also get a job one day'...he has become like that; even a small thing, if you do a small thing he will say 'I will get a job'....It's as if a job will fix everything for him.

Mdu said Mathe`s relationship with his children deteriorated since they moved in with his parents:

> He always shouts at them 'hey, this is my home; you must go to your mother's home if you want to rule yourselves'. Sometimes children are just children. So I tell him 'Brother, don't be like this to children; you will make them feel as if they are not welcome (Interview Mdu, 19 April 2007).

Like Mathe, Lizo also lost his job as a result of being sick from HIV. Lizo viewed work as an important aspect of his manhood identity and highlighted the importance of male peers' acknowledgement and respect for men's sense of masculinity. Such respect is clearly bound up with material success so that those who do not have their 'own things' are not respected, and therefore not 'man enough':

> They will not respect you; even if you are a grown-up. Even when calling you they will say '*Ekse, Ekse*!' But if you have your own things they will call you in a dignified manner; they will call you by your child's name if you have a child (Interview Lizo, 6 June 2006).

Lizo became ill in 2004 while working in Sabie, a small town near Bushbuckridge. He then resigned from his job and moved in with his mother. Since he recovered from being ill in 2006 he struggled to get a job. During the time of research he was supported by his

mother, a pensioner who also supported several other grandchildren. He said being supported by his mother is an affront to his manhood:

> Lizo: It's a concern for me, because at the moment I live with my mother. She gets pension, about R800. And she is also building a two-room house. And we stay with my nieces; our sister left, leaving her children behind. Now our mother is looking up at us as her male children, hoping that maybe we can do something to support her here-and-there. My elder brother has his own stand and my older brother too. So my sister left six children of her own; my mother only gets about R800 and she is also paying an instalment for a fridge – every month she pays in about R231. She must also buy food and soap and all that. That's what worries me most
>
> SM: It worries you *neh*!
>
> Lizo: I do get some temporal, small jobs sometimes; maybe get that R50 or so, just to be able to buy soap for myself. But this thing of always troubling my mother doesn't settle well with me; it really doesn't settle well; it's not right.
>
> SM: Especially as a man.
>
> Lizo: That's what worries me most…sometimes I need to buy a polish; sometimes I need to buy this, and that…I can't ask all of these from my mother (Interview Lizo, 6 June 2006).

The impact of being unemployed and dependent, on a man`s sense of manhood is evident from this extract. It seems that the dependence on a female had an added impact on the loss of manhood. For Lizo, a male child should ideally provide for his mothers rather than being dependent on her, and as we saw in Mathe`s accounts in previous chapters, this earns him respect from family and the community. Lizo was however not the only man who was dependent on his mother. Of all 25 men that were using ARVs only Mathe had a father who was actively involved in his life. Others lost their fathers through death or abandonment and were entirely dependent on women for material and emotional support.

Lizo said the main impact of being unemployed to his manhood was in sexual relationships. As an unemployed man he cannot attract women, nor does he have confidence to approach them and initiate a relationship:

SM: Don't you sometimes feel like being with a woman?

Lizo: [with a sigh]...Yhaa, definitely you do get feelings for a woman, but if you can see your condition is not right you better just stay on your own. The minute I bring a woman home I will add to my mother's burdens. And my mother is still struggling to cope with all these children at home. Now I'm unemployed and I bring a wife home – she will demand this and that; she wants soap, I go tell my mother; you see that? It would be adding stress to my mother, so I don't want to do that.

SM: So your main concerns is your mother; you don't want to trouble her.

Lizo: Yhaa, my mother; I would rather be the one struggling…but if I do get a temporary job or so I will find myself someone to do the washing for me (Interview Lizo, 6 June 2006).

Lastly, let us look at Magwa, another man who was negatively impacted by being sick and unemployed. A father of thirteen children from three different mothers, Magwa had a successful career in the mines where he held a supervisor position. He lost his job in 2000 before he became ill and has since remained unemployed. During fieldwork he was living alone in a government funded house (RDP) and was selling small packets of tobacco for a living. About six of his children live with his mother who is a pensioner; others live with their mothers in other parts of South Africa and Mozambique. I asked him to elaborate on his situation as an unemployed man:

Magwa: In total I had three wives, and from those two wives I have thirteen children. So my

mother does try here and there, you see. Now she doesn't buy anything for herself – whenever she gets paid she buys, like food for them. And even at school she pays school fees for them, you see. As for me, I can't even contribute a cent; where will I get it? I'm not working! Cause really I'm not skilled for any other work; you see. I don't know it…

SM: How does it make you feel personally, the fact that you are unable to support your
own children?

Magwa: It's painful, man. It doesn't make me feel good about myself. It doesn't make me feel good cause now….*ey*...*ey*…I can't explain to you…I really can't explain how it feels, really. I can't tell you…cause I used to have money, but now I can only manage to support myself only, I'm not in a position to support my own children, you see. Some are in Mozambique…yhaa… and others are here. And if you ask me what they eat there in Mozambique I wouldn't tell you, I don't know at all.

SM: But by the time you were working did you support them?

Magwa: Yhaa, a lot…a lot...even if you can go and speak to my mother right now, she will tell you of how well I treated them during my time...Yes I was playing a lot (with women), but not that they made me forget about home. Cause all of us (mine workers) had close links to our homes, you see – the first thing we would think about was home, and then we would go and play around with women; but the first thing that you think of when you get paid was home, you have to send money at home first, then you can think of women after that (Interview Magwa, 4 October 2006).

Magwa said the most stressful factor in being unemployed was dependence on other people for financial support. As a man who used to provide independently for himself, Magwa said he is not used to such life. As a result he feels insulted by having to ask from others:

> Some of my friends do help me a bit, you see; they help me a bit. At least I can get some food, you see. But the fact that for me to eat I must first wait for someone else, it's troubling (*iyahlupha)*. I'm not used to that, you see. Sometimes I go to bed having drank just tea, you see; sometimes I don't eat at all, you see. Sometimes I sleep without eating at all! I just get a piece of bread, and I take my pills, then I sleep, you see. I wake up in the morning, you see. Cause that's not what I'm used to, you see. Really I`m not used to asking, you see; cause that's not how I was raised up (Interview Magwa, 4 October 2006).

The three cases I have cited above illustrate experiences of living with HIV as a man and challenges experienced by men in playing a role of being a provider. All three men provided independently for themselves before they got ill, but as a result of having HIV they became dependent on others for financial and material support. This has impacted seriously on how they view their manhood as dependent men. The dependence seems to have impacted profoundly on their dignity and pride, as these seem to be achieved mainly by being able to provide for oneself.

These stories tell us much about the limits of medical interventions in people`s health needs: It is one thing to make medicines available and accessible to patients; it is another to make sure that people are supported beyond merely being kept alive through using these drugs. Most of my participants were indeed happy to be alive, but their needs went beyond being merely alive or healthy. It was important that as men they are seen as active providers for themselves and families, and failure to do that threatened their sense of manhood. I did not meet a man who was content with being unemployed as long as he is alive; or someone who cared less about getting a job.

When I compared men who received government grants to those who had no access to them there were significant differences in the quality of their lives. Men with grants had less to worry about as they could afford food; the grant restored their sense of manhood by enabling them support themselves and their families (those who lived with families). Others used the money to build new houses or renovate the existing ones, or start small businesses[26]. When I visited them in their homes, they were cheerful and offered me drinks and meals; some bought me drinks during their clinic visits. During a visit to one of my participants he offered to give me R20, saying '…you are a student. So when you come here to see us, if I do have some cents I can give and say "here are some cents, buy yourself something…"' (Informal conversation, 6 September 2006).

[26] See participant list

This differed from my visits and interactions with men who had no sources of income. Most of the time these men were withdrawn and when I visited them in their homes they seemed embarrassed by their living conditions and financial situation. Hence some would make apologetic statements such as 'Ey, we don't have a drink; next time when you come...'. It was clear that being unemployed, dependent and having nothing, had deeply affected their sense of pride and dignity. The government support grant can do much to alleviate this feeling of being emasculated if it is distributed widely among PLWHA. Currently the criteria for receiving grants is strictly medical (CD4 counts below 200; opportunistic infections, diarrhoea). Some of the men I met, for example, Magwa, had a CD4 counts above 200 and were not sick, but they were physically weak and could surely not perform demanding jobs.

During one of my visit to his home Magwa begged me to get him a grant at the clinic and when I came back saying he does not qualify because, according to the prescribed criteria he is 'healthy', he said 'Well, I don't know, because in support groups I see people who are fat and fit than me, but they are receiving grants…and you can see them talking loudly, you can see they are happy…' (Informal conversation Magwa, November 2006).

Magwa`s comments that grants recipients 'talk loudly' attests to a sense of confidence that they may have, compared to others who earn nothing. It seems from this comment that having access to money can improve a person' self-esteem in addition to improving his health. In a later section I will return to how being unemployed is viewed by men in relation to their definitions of masculinity, and how they are generally responding to challenges of being unemployed to their manhood. The next discussion deals with HIV and its impact on men`s sex lives.

HIV and sexual performance

Being in a sexual partnership was discussed in chapter three as having been one of the principal means for achieving manhood by most participants. Most of them had multiple

partners and this was perceived to enhance their standing among peers. Only two men said they practiced serial monogamy and they both belonged to ZCC church.

The experience of living with HIV affected men's sexual lives in two ways. First there was a group of men who lost their partners either through abandonment or death. Of 25 men that I interviewed, about seventeen men were in this category: five men were abandoned by their partners immediately after disclosing to her; four lost their partners through death and others separated for other reasons not revealed by participants. Secondly, HIV impacted on sexual activities of those men who were in sexual relationships (either with new or pre-HIV partners). Nine men remained with their partners post HIV diagnosis. Out of seventeen men who lost their pre-HIV partners, about six initiated new sexual relationships. The next discussion starts by looking at challenges of starting a new relationship for HIV positive men before I look at challenges experienced by men who are in sexual partnerships. It must be kept in mind that these challenges are not unique to HIV positive men, but as the discussion below will demonstrate, HIV adds it own dynamics with regards to how men respond to them.

The main challenge posed by HIV in initiating a new relationship was confidentiality. Men felt that if they start a new relationship they will be obliged to disclose to a new partner, who might in turn 'publicize' his HIV results. Men were particularly opposed to having sexual partnerships with HIV negative women because, unlike HIV positive women the former women cannot be completely trusted with confidentiality. It may happen that when a man discloses to her she goes and tells others, thus tarnishing his social image. Lizo cites lack of confidentiality as one of the reasons he decided to remain single:

> I would love to have one, but *kuyafana* (it won't help), because I will meet a girl and tell her 'look, I love you and I'm like this (HIV +)'. Now she will be shocked and then she will go and tell her friends that 'that guy approached me and then he told me he is like this and that'. Now they will also know my situation. So I decided it's better if I'm on my own and just forget about these things... (Interview Lizo, 6 June 2006).

Zita felt the same, saying 'So you find that I tell someone, but she can't keep it a secret and she goes on and tells someone else. You find that they have now publicized this, that I am HIV positive (Interview Zita, 26 June 2006).

I probed men further to find out if they were indeed obliged to disclose to a partner. I asked: 'What will happen if you simply use a condom without telling her'? Answers to this question took us deeply into how women were perceived in relation to condom use. Men felt that women generally do not like condoms (women said the same about men in support groups); a woman might accept condoms early in the relationship and then later she will demand unprotected sex because she wants a child or is 'tired' of condoms. For men, this would mean that they must explain fully the reasons for insisting on condoms. Zita, said the issue of condoms is one of the main reasons he is single. He has been without a partner since 2004 when his girlfriend abandoned him:

> …still now I don't have a 'wife', I stay alone. And I don't feel like staying with a woman. I want to stay alone because I know…because if I get a woman who doesn't have HIV there is no other way, I will infected her because there will come times when she refuses sex with a condom; she will want to know 'why do we have to use a condom? If we want to have children how are we going to do it?' Now I must tell her 'no we actually can't, because I have this kind of a disease'. So the way I see it this could trouble me; that's why I would rather be alone. I feel I'm OK being alone without a girlfriend (Interview Zita, 26 June 2006).

My interviews with men who had new partners revealed that these concerns about condom were grounded in reality. A number of men said they had encountered problems where a woman either refused condoms or abandoned him because he insisted on using condoms. Magwa said since he tested HIV positive he always insists on using condoms, without an explanation, saying 'I just put it on!'. Magwa initiated sexual relationships with four women since he tested positive; he said none of them stayed with him for more than a month 'because of these condoms'. It was clear from my interviews that condoms presented a serious dilemma to men's confidentiality. Condom use requires justification;

some of the men felt that if justifying condom use means that they must disclose they would rather remain single. I found this to be quite a significant finding because men are often portrayed as the problem in HIV prevention work because of their apparent rejection of condoms. In Bushbuckridge the dominant discourse about men who are HIV positive is that they willingly spread the virus to women through unsafe sex, using the adage: 'I do not want to die alone'. In the case of these participants they would rather be deprived of sex than have unprotected sexual intercourse.

The second dilemma faced by HIV positive single men was related to sexual performance. All of them doubted their sexual abilities, particularly their abilities to satisfy a prospective sexual partner. Part of this doubts had to do with the impact of using ARVs, where men experienced them as having reduced their sexual appetite. Others felt that as HIV positive men who are constantly sick they are not 'powerful' enough to please women. Women, particularly HIV negative women, were seen as demanding sexually, and as sick men they felt that they could not meet their demands. Zita said this is one of the reasons why he is single:

> …she will give me troubles because she will always demand sex, because she is healthy. And she will finish off all of my energy; she will make me work harder because she has more power than me. So you'll find that I fail and when I fail she will go and say '*Ey, la mfana akakhoni kwenza nicks* (Ey that man is unable to perform'). So I'm scared of that, you see. Now I want to get the one that's also sick (Interview Zita, 26 June 2006).

The quote from Zita illustrates the kinds of anxieties that HIV positive have in relation to their masculinities. Sex is one of those activities that men used to prove their masculinity and gain respect of men and women (see chapter 3 & 4). For Zita, sexual performance has meanings for his masculinity. He feels that as a man, he has an obligation to satisfy his partner, and that this affirms his manhood status. If he fails to do so his sexual partner would go on and publicize his 'failures', telling others that he is not a man because he cannot do what is expected of 'real' men - good sex. Being single therefore is a way in

which he protects himself from a potential humiliation that might occur as a result of his failure to perform.

During the course of fieldwork some of the participants formed new partnerships with women who were HIV negative. I then followed up with interviews to find out how they were doing sexually with their new partners: Is it the case that HIV negative women are too demanding sexually; or it is just a perception? Sabu shared some light on the topic. He found a new partner through his neighbour who is also HIV positive. His new partner already knew about his HIV status when they met, so he had no difficulties with disclosure. But he told me his partner is demanding sexually and tht he could not meet her demands:

> Sabu: Yhaa, I do have sex with her, maybe two rounds and I feel I have enough, you see. You know what, last week she asked me and said 'You know what Sabu, please do it again (*ngicela uzongiphinda*)', and I said 'No *ngiGrand* (I'm OK) (laughter) ; she said 'But I'm not satisfied'; I said 'No, mina *ngi sharp* (I'm OK)'. The thing is I wasn't feeling well, you see. Now whenever I pull over from her, my thing (penis) just sleeps, you see. And I take out this condom, you see. And you find that the same time that I'm pulling off, she calls me 'Hey, I still need more', you see. So that's the thing that worries me, that 'Ey this girl…she isn't getting satisfaction'. But I just can't change the circumstances, you see.
>
> SM: But at least she does understand your situation, of why things are like this.
>
> Sabu: Yhaa, I think she does; cause I tell her 'Ey girl, you mustn't expect me to be strong; I'm not strong', you see. I'm not as strong as I used to be; like when I was still a normal person, you see (Interview Sabu, 11 October 2006).

Koko shared similar experiences. His partner demanded 'too much' sex and Koko felt that as a sick man he cannot meet her sexual demands. In the end she left him and went to live with another man who later impregnated her. Koko said his partner left him because of his poor sexual performance:

Koko: When you are sick you don't think about sex, but maybe she did. I think that was also a cause; and she is still young, her blood is still hot. Now I'm sure she met a stronger person and obviously that rules me out because I'm not the same anymore (*angisafani nakuqala*)

SM: What do you mean you are not the same anymore?

Koko: Well, I'm sick now with TB, flu, HIV. I spend time thinking a lot and you end up not entertaining sex.

SM: So she demands you as well

Koko: Yhaa; sometimes you do have money and all these other things, but just one problem: sex… (Interview Koko, 22 February 2007).

The centrality of coital sex as constitutive of a sexual act is clear in these comments. Participants did not mention trying other means of 'pleasing' women such as oral sex, or anal sex as an alternative to penetrative sex (see Makhubele and Parker, 2008, for a qualitative study on anal sex as an alternative in South Africa). For them sex was defined in terms of penetration and this is how they evaluated their performances.

Other men resolved that they would only date HIV positive women. This option was felt to be 'safer' because, firstly, HIV positive women will not publicize his sexual 'failures'; secondly, she will be supportive of condoms and thirdly; she will be less demanding sexually. An HIV positive partner was constructed as an 'insider'; therefore she knows how it feels to be sick from the disease and what physical challenges it poses to someone. Lizo illustrates this point:

> We will be sensitive to each other; *angithi* we are both on treatment, so there will not be conflicts between the two of us. And we won't be scared of each other. The minute I take out my pills she does the same (Interview Lizo, 8 January 2007).

Of all the men who were single at the time of research (17), only one participant was opposed to the idea of dating another HIV positive person. Zola has been single since 2004. He said dating another sick person would cause problems when they are both sick:

Zola: Ideally as someone who is sick I would rather not date an HIV positive, because she is also sick. So now when it comes to doing domestic work she might not perform well, but the one that's not sick will be able to work because she is stronger…because what will happen when we are both sick? It means there is no one to help us. You'll find that she is sick and I`m also sick; now who will help us? But if I`m the only one sick then my partner can help me – if I say 'Ey I feel pain here' she will be able to help, you see; to provide some hot water, prepare some tea, you see.

SM: But some people fear that if a girl is not sick she will be demanding

Zola: Well, maybe if she doesn't understand she will be demanding, but if she understands she will not be demanding (Interview Zola, 26 November 2006).

The decision to date other HIV positive women turned support groups into a dating site. Of 17 men that were single during early research period, five of them initiated new sexual relationships with other HIV positive women that they met in support groups. Meeting someone in support groups was said to be easier since they all come to the clinic on the same date to collect their treatment. They are therefore familiar with each other and can easily initiate conversations and then start dating. Often these interactions are initiated by men, but in other cases women were active in seeking out partnerships with HIV positive men.

When I interviewed partners of my male participants they also supported the idea of dating within the group, saying men from 'outside' cannot be trusted. With another HIV positive person one is guaranteed of mutual understanding and support, as illustrated in this comment by one of the partners:

> Well, I met him at the support groups and I felt 'this one will not trouble me (*Lo ngekhe angihluphe)*. You know how men are out there- you say this and he says 'No; this!'. I didn't want to be stressed. I knew that since we are both in the same situation we would understand each other. I didn't want any situation that would worsen my condition. And look, we have been together for 3 years now and we are happy… He doesn't go up and down (with women). He is always here at home with me. In fact he is my friend – I don't

> have friends and he also doesn't have friends. So he is my only friend and I am his only friend (Informal conversation, March 2007).

I had a conversation with a support group facilitator to elicit her views about the trend of dating within a group, and whether she thinks it is a safer thing to do. She said ideally it should be discouraged:

> We don't really support it. I mean these people are sick from the same problem, and now if one starts to get sick and maybe dies, this one who is left behind is stressed. He starts to think 'Ey, I will go through the same thing myself. So we don't encourage it

She also pointed to the fact that some people might be lax with condoms since they are both HIV positive, resulting in re-infection and unplanned pregnancy. There were a few who got pregnant while using Rixile services and this upset some staff (Informal conversation health worker, 11 April 2007).

I have focused on the situations of men who were rendered single by HIV illness, and documented their dilemmas in starting new relationships. Some of the participants were able to keep their pre – HIV partners and we need to know what happened to their sexual lives.

In total there were six men who managed to keep their pre-HIV partners and five of them were married. The main problem cited by these men was decrease in their sexual performance and virility. From their comments it was not clear whether these problems started before or after starting with ARVs. What seemed to have happened is that the illness itself reduced sexual activities, and when men started treatment they were already less sexually active. Xola said before he became ill from HIV he had a 'healthy' sexual life with his wife. This has changed significantly in the years after his illness:

> Yhaa, there are changes. My work rate has gone down drastically; I easily get tired. Things are no longer the same. Like for example in the past *neh*, I would make sure that a week doesn't end without having sex. But now a month can pass; I don't stress about it; I

even sleep with her, just sleeping with her without doing anything with. Even if I do hard work, for example, my body gets tired, so I must sleep. I must sleep so that when I wake up in the morning I should have some energy. It's the same as what I do with a woman – like for example is I can tell you (I'm not being offensive neh; I'm just sharing with you) I used to do like one, two, three rounds; but one is enough for me now; one if enough for the whole month (Interview Xola, 4 July 2006).

Here Xola does not cite ARVs as having contributed to his problem of sexual underperformance. When I spoke to him in a follow up conversation he said his problem started before ARVs: 'I think since I got sick I just lost appetite for sex...'. Other men, however, attributed the problem directly to ARVs, saying they have reduced their sexual potency. Thabo said since he started with treatment his sexual life changed. He was living with his partner at a time of his HIV diagnosis:

Thabo: Well, of course you don't have the power. *Ungashaya one, hayi uzolala* (You just do one 'round' and you go sleep after that) [Laughing]. Just one…maybe you can do the second one in the early morning, say about 5am, but you are just forcing yourself.

SM: And how does that make you feel, I mean not having enough power?

Thabo: What can I say! I think it's these pills because in the past I would do five rounds, you see. But these days I only do one and then I sleep. The first one is just fine, and then I go to sleep and maybe at around 4/5 am it gets up again and maybe I can do the second one, but that's rare. And just twice a month is just fine for me; if I get it twice a month I just forget about women. Things have really changed from how they used to be, you see.

SM: And did this change happen after you started with treatment?

Thabo: Yes...yhaa, ey, because these days *ngiyafloppa, akusafani nakudala* (these days I'm failing; it's not the same as before)...yhaa, just one round and I can't go on anymore (Interview Thabo, 20 April 2007).

I was struck by what people like Thabo described because, according to medical expertise ARVs should improve rather than undermine sexual life. I therefore spoke to health

providers where I shared my findings. One of them, a doctor, attributed sexual difficulties to psychological states of patients:

> Well, the truth is that sexual performance does get affected when one is ill; but as one recovers and gains his usual self he should return to the normal state of his sexual life…that is why you will see that some of them, once they get better, they go on and have children. My view is that the problem is psychological…like the excitement around sex that normally happens to people goes down because of what they went through…people don't want to find themselves in the same situation again…(Informal conversation medical doctor, 22 November 2006).

There is no clear indication from the literature as to whether ARVs improve or undermine sexual life. Certainly experiences do differ, and perhaps the medical doctor is correct in attributing the problem to psychological states of patients. More research can shed further light on this issue.

The striking factor about men who had sexual difficulties is that they did not want to address the problem, whether through using traditional medicines - as most men in the community normally do - or telling a doctor. Jozi, one of them, said he would rather remain like that than tell a doctor:

> …because should I tell him he will give me more pills and that's something I don't like….say maybe he gives me these pills and now I start charging very fast; now I go around looking for women. That's` why I'm saying I'm OK like this. *Angithi* I`m sick; so *Kungcono ngizihlalele* (I would rather stay like this)' (Interview Jozi, 1 November 2006).

Sabu gave a similar response, saying:

> I won't tell myself I must go to the chemist and buy some pills so I can satisfy this woman, you see. How will I survive when these pills are not here; how will I survive? It's true they do sell these things that boost you, you know; you sleep with her for four

> rounds or so, you see. But the time you don't drink them you must know this person is going to leave you, you see. So, try and get her used to your situation, you see. If she truly loves me she will get used to it too; you see (Interview Sabu, 11 October 2006).

These two responses may hide something that I think is key to men`s reluctance to report their sexual difficulties: embarrassment. I became aware of this problem when I walked into the clinic one morning and a man that I had met briefly in support groups stopped me and said he needed to talk. We sat aside and he told me he has difficulties with sex. I asked if he would like to speak with any of the health providers and he replied 'maybe if it is a man, but I cannot tell women something like that'. I then referred him to Mr. Sibi, the only male support group facilitator at the clinic. I wondered how many other men are having the same problem but are embarrassed to talk or decided to live it as did Jozi and Sabu.

The above discussions have focused on the problems experienced by men living with HIV in terms of their roles as providers and sexual partners. It can be seen from these discussions that living with HIV changed these men`s lives in significant ways in terms of these two roles. The next section looks at how men are responding to these problems. Do they see these problems as challenging their masculinity or are they finding other ways of defining their manhood? What new ways of defining masculinity have emerged out of experiencing these difficulties?

Reconstructing masculinity

The central argument of this thesis is that the experience of being HIV positive did not result in complete rejection of the dominant social definitions of masculinity, though it resulted in significant transformations in men`s lives and their health behaviour. In fact I would argue further here that most men still measured their manhood on the basis of these socially dominant perspectives on what it means to be a 'real' man. This was particularly true with respect to the provider role and relationships, where most men felt

that their manhood is under threat for failing to provide independently for themselves or be in a sexual relationship.

What has changed however, is that in pursuing these goals, men are more cautious than before. Their main goal is health; hence jobs and sex are pursued only if they do not have a negative impact on health. We can refer to this approach to manhood 'responsible masculinity' to distinguish it from a previous masculinity where men did not take health into consideration when making decisions about a job or sex. Its key feature is ambiguity because on the one hand men want a job and a wife in order to reconstruct their positive manhood and improve their self image; on the other hand jobs and women are resisted by these men if they are perceived as a threat to their health or the confidentiality of HIV status.

Sipho has been unemployed since 2003 when he left his job in Johannesburg due to being ill. During fieldwork he was offered two jobs, first at a construction company and then at a security company, as a security guard. But he rejected both jobs saying they are a health risk:

> Sipho: The thing is I'm sick. I would do it if I was fresher. I mean every time I do hard work; if for example I work in the yard, say during the day; at night I can feel the body is sore. So you can imagine how it will feel if I do construction work...'.
>
> SM: But how does it make you feel now, the fact that now there are things you cannot do, like for example being unable to do some hard work; especially being a man…?
>
> Sipho: It happens that sometimes I work at home. Like sometimes I work in the garden – – do this and that, and that. But then I can't sleep at night. I get sick, coughing and this and that. Now how much more if I work for the whole day? I would definitely go back to where I was before and I don't want that (Interview Sipho, 23 May 2006).

His security job entailed that he works night shifts and also do night patrols. He worked for only three days and then resigned: '…the house was full of water; it was dirty, and the

clothes were dirty too, and old. I said 'No; I will not work under these conditions anymore'. *Phela mina* (the thing is) I'm sick; I can't be subjected to these conditions' (Informal conversation Sipho, 15 January 2007).

Sabu was in a similar dilemma. He lost his job at a supermarket in Johannesburg due to being ill, and during fieldwork he was unemployed and dependent on a government grant. As a young man (27 years old), Sabu felt that being dependent on a government grant was not ideal for him; instead he wanted a paid job. But his main problem was that his previous job was no longer suitable for him as a sick person:

> I worked with paint, but now the doctor told me to stay away from paints and dust because I have TB. Now how am I going to live? You mean I will be receiving this grant all my life now? I'm still young, *Joe* (Interview Sabu, 30 October 2006).

To an outside observer the decisions of these men to reject certain jobs could be interpreted as a sign of weakness or laziness. A 'real' man who is looking for a job and understands the importance of having a job for his manhood cannot be choosy (particularly since they are unskilled and uneducated). However, as men who are sick, Sabu and Sipho are more cautious and calculative in the kinds of jobs that they want. Health comes first and any job that is perceived as a health risks is rejected. This does not mean that men are content with being unemployed and dependent or that they no longer recognize job as a necessity; instead health has become a highest goal in their lives.

I found similar attitudes in relation to problems posed by HIV to men's sexual lives. Here, while men acknowledged a need to be in a sexual relationship, or to sexually satisfy a current partner, they were not willing to do so at the expense of their health. For them, health was important, ahead of being seen as socially fitting by having a sexual partner or multiple partners. Some men made a direct reference to health as the main reason for changing their sexual lifestyles. Zita said he chose to be single for health reasons:

Zita: So, the main thing is that I stay away from girls because really I don't like women. Cause I tell myself if I go after women this illness will come back to me again, because for now I'm much better. So, the minute I start dating women, taking them and sleeping with them…even if I use condoms…even if I use it, I would still be using my own energy. So this energy that I will be using, the one I get from these pills, from this treatment that I take, it will all go away. So I will be left powerless, you find that I have used all energy on these women.

SM: And the fact that you are a man and you don't have a girlfriend, how does it make you feel?

Zita: I'm just right – *ngikahle nje*. *Ushukuthi* I'm used to it now...someone can look at me - even a woman - and say 'Ey this one is not having sex, he's not a man' I just look at her and say 'well, she still has time, she can live her life the way she wants'. But I don't have time; I don't have time to play. Now I`m taking good care of myself, cause this sex is the cause of all these problems, we are where we are today because of sex (Interview Zita, 25 October 2006).

Kenneth said he no longer 'runs' after women because he is looking after his health:

> I can say I have changed a great deal because now I take good care of myself. Let's say for example I see a nice girl, I just appreciate her, but I don't have any intentions of doing anything. I tell myself that if I run after her I might just be inviting more of this problem. Because I will never know if she doesn't also have it. Because if she is sick and I'm also sick it will get worse (Interview Kenneth, 14 February 2007).

These comments reveal much about how sex is being redefined from the perspective of being HIV positive and sick. From being seen previously as something that gives pleasure and social recognition, sex is now recast as a potential danger to someone's health. Zita feels that he would rather be seen as not a 'man' than risk his own health in pursuit of social recognition as a 'real man' through sex.

When I talked to men who were in relationships I found them to have adopted similar attitudes towards sex. Most of them felt that sex was no longer an important aspect of their relationship. Sex must now take place when it suits them and it must not

compromise their health. Hence, in dealing with sexual matters these men were willing to trade a sexual partner for health if she is too demanding sexually. Tito said since he was diagnosed with HIV he puts his health first, ahead of sexually satisfying his partner:

> Even if your wife comes you for sex, just tell her 'I don't feel like it today; no I don't feel like it'...Even if she undresses, you just look at her, you don't bother. She says '*Ushukuthi awufuni nje ukuthi igazi lithi*? (Don't you want to just shake up your blood a little bit?)' I just tell her from the beginning that 'No; I don't feel like; I don't feel like'. She will understand, but if she doesn't understand, you tell her 'Ey lady; today it looks like you are causing me an additional stress. Cause one day you will be sick too and you will tell me the same thing; so how will you expect me to respond? Will you expect me to force you while you are feeling sick? You won't allow it, will you? Say maybe you have some pain in your body and I keep saying let's do it, let's do it; will you accept that? No you must feel for me as well; I will tell you when I'm in a good position to 'play' – I will tell you 'yhaa, today I'm OK, we can play' (Interview Tito, 20 October 2006).

This attitude was expressed in all interviews that I conducted about men`s sexual activities. Most men perceived their involvement in sex as fulfilling a biological need rather than a site for entertainment and performance. Hence Thabo commented 'I can stay up to two months without it, but when I feel like having it then I have it, just to get rid of this 'blood' (semen) and I'm OK after that'. The interesting thing here is that men still assigned importance to having a partner; however, partners were no longer pursued for sexual gains. Instead men wanted someone with whom they would be intimate and close. Thus when they talked about finding a new partner they meant finding someone 'who can do washing for me' 'whom I can share with' 'who will help me with treatment adherence'. Sex and sexual performance were secondary issues in initiation of a relationship.

This is a significant finding and it indicates how being HIV positive can shift men`s attention from being too focused on sex to focusing on building stable, intimate relationships. These types of relationships that men built are based more on mutual understanding and sharing of experiences, and they differed remarkably from pre-HIV

relationship where men were hardly intimate with their partners. Very often these men were not present at their homes and their interactions with partners were very brief. Now as people who are HIV positive, these men are able to cultivate close relationships. Most importantly they look for partners who can be companions, rather than merely sexual objects.

I interviewed some of these men`s partners and they confirmed these changes, saying that since their partners tested positive they have changed their approach towards them. They have become 'closer' and are willing to share. Nono said since her partner Sipho got sick he spends more time with her and they share 'everything':

> …because by the time we were living there (in Joburg) he was never at home. On weekdays he spent a lot of time with his brother and on weekends he is out drinking with friends. So I was alone most of the time. But now he is always here with me; even when we go to the clinic we always go together. He is now my only friend; I am his friend now (Interview Nono, 20 February 2007).

Another partner, Sindi, related a similar story about her husband, Vusi. She said Vusi used to come home late drunk and then make noise and other demands (probably sexual as well). He has since changed:

> Sindi: He is a nicer person now. He has also stopped drinking since he got sick, and if I can compare him to his pre-illness state I can say *ukahle* (he is better). He has changed from being a drinker who used to drink and then come back home to shout and all that. He has improved a lot from that.
>
> SM: What would he shout about?
>
> Sindi: I don't understand why, but he really used to be on our case
>
> SM: How did you feel about all that shouting?
>
> Sindi: Well, I taught myself not to take him seriously; I just ignored him, I didn't want to stress myself. But there are times when I just couldn't take it and I would feel 'Ey, I would rather go back home', but things have gotten better now (Interview Sindi, 28 February 2007).

These results show the shifts that have occurred in men`s lives as a consequence of being HIV positive. These shifts however do not indicate a wholesome rejection of hegemonic masculinity. Instead they are characterized by an incessant tension between continuity and change; a desire to continue fulfilling certain expectations of manhood and a desire to take care of his health through rejection of the same behaviour that qualifies someone as a 'real' man. For example the fact that some men still perceived women as 'someone to do washing for me' indicates that not much has changed on how gender roles are defined. Women are still regarded as the ones to do the bulk of domestic work, while men still perceived themselves predominantly as breadwinners who work outside home. Or the fact that coital sex is still assigned more importance than other forms (such as oral sex) shows how much these men`s perceptions of sexuality have not changed. But at the same time, being able to relate to a partners as a 'friends' marks a significant departure from their previous lives and is a sign of change and willingness to enter into a new forms of gender relationships that depart from their previous lives.

I then asked men to describe for themselves how they would like to be perceived in relation to their previous lives and other men in the community. Do they think they have changed? Do they see themselves as pursuing new forms of manhood; or am I reading too much into their health-conscious behaviour, which might be simply a matter of responding to treatment demands than a deliberate effort to be a different man? Most men viewed themselves as having 'changed' and 'different' from their previous lives and other men in the community. Mainly they focused on their sexual behaviour as a main site of difference.

For example, the fact that these men have one partner was cited as something unusual and an indicator of change and difference. The decisions to be stable were therefore cited as a sign of being responsible and caring:

> Sipho: Men don't want to die alone; they want to go down with more other people. But when you look at us (men using Rixile services) you'll realise that we are not the same as those men. You find that you live your life alone; you

don't chase after women (*awugijimi-gijimi*). That's the kind of life we should live; we shouldn't be running up and down. Your life must be stable (*kufanale siphile impilo eyi-one*). Things will be OK if we do that. Like me, I'm always at home, you see. Like, girls, I don't do that anymore. I tell you 'No, I have my own wife, I don't run after women', you see

SM: When did this attitude develop in you? Is this something that started since you realized you live with HIV, or you had changed already before you discovered?

Sipho: Since I tested. I realized that 'now I have tested and I am like this; now I need to keep my life stable', you see (Interview Sipho, 23 May 2006).

HIV disclosure and use of condoms were also cited as other sites of difference and change. As I showed in earlier chapters, most participants detested condoms before they became ill and they described other men in the community as being equally opposed to condoms. It is also unusual for a man to be open about his HIV status, due to shame and fear of rejection. Sabu said his decision to use condoms and disclose to his sexual partners was a deliberate effort from his part to depart from these practices and try and protect others rather than expose them to HIV. Sabu met two women after testing positive and he disclosed to both of them. The first woman turned him down after he disclosed to her; the second one agreed to go out with him.

Sabu said he was dejected when the first woman turned him down, but was happy about his decision to disclose to her: 'She said "I cannot sleep with you. It's fine, I can sleep with you and use a condom, but I don't trust a condom; it might just break, and now I become positive". I said "well, at least I told you; if I didn't tell you it would mean I don't love you"'. I then asked what motivates him to protect others and he replied:

> That's the way that I decided to handle myself after discovering my status. I told myself that *mangingamoshi umphakathi* (I don't want to destroy the nation). I know other men like to say 'I don't want to die alone'. But he doesn't know that he is also killing himself in the process. Maybe he could have lived longer. But I don't want that… (Interview Sabu, 27 June 2006).

The statement from Sabu that 'I don't want to destroy the nation' is a powerful one and it indicates a major shift in how he perceives his role as a man as well as his notion of being a good citizen, from previously being concerned with himself as an individual to reflecting on how his actions would impact on lives of others and ultimately, the nation itself. Sabu sees himself as a 'protector' rather than a 'destroyer' of the nation, through his 'responsible' sexual behaviour.

Magwa focused on his health behaviour and safer sex behaviour in particular, as a main site of difference from his previous lifestyle and other men in the community. He said the fact that he is not having regular sex does not lower his manhood. In fact he thinks he is better than other men in the community who are still living 'risky' lifestyles (such as excessive drinking or having unprotected sex):

> No, I don't think that's the right way to live (having multiple partnering); cause today you sleep with this one and tomorrow it's another one. Now you also find yourself getting some illnesses, you see. Now all these illnesses come to you, you see. So I hear some people sometimes saying 'Ey you must shake up your body sometimes'. I do it sometimes when that time comes, and put on this condom, you see. Sometimes I finish up to 3 months, you see, without making contact with a woman, you see (Interview Magwa, 2 November 2006).

Lizo felt the same as Magwa. For him, not having a sexual relationship does not lower his status. Instead, Lizo feels that he is in a better position compared to other men because he knows his HIV status:

> I can say now *ngiphila ngcono* (I live a better life), cause I know my status. Some just live but they don't know their statuses. Today he is sleeping with this one and tomorrow he is with another one. You might find that he has this disease and he is spreading it all over. But I know my own status. Yhaa… (Interview Lizo, 8 January 2007).

All of these participants are positioning themselves as different from other men in the community whom they perceive as acting irresponsibly towards HIV, due mainly to their sexual conduct and decisions to test and disclose. Interestingly none of them said they are proud of being unemployed or embraced unemployment as a good marker of their 'responsible' manhood. It seemed as if having a job was perceived as a 'non-negotiable' aspect in definitions of masculinity, and out of all other things that men changed, its loss was experienced as more stressful and undermining. This is understandable, given how a job was seen by most of these men as a useful tool to construct positive manhood and also gain access to other important markers of masculinity, like respect, control, and household authority.

It was left to family members and partners to continue to dissuade men from finding a job, citing their unstable health as a main reason. Mdu said his brother Mathe always insists on finding a job, but he continues to discourage him because of his poor health:

> He says 'I will go find a job; I am feeling better now and I will get a job', you see. So I tell him 'do you really think you can work?', he says 'Yes I have to, because I have nothing – I don't have clothes, I don't have soap, I have no money; I have nothing'. But I really don't think he can work; he is too weak for work. Unless maybe it can be a job where he sits down and writes or so. But not a hard job; I think he is weak for that. So I advised him 'Hey Broer. If you do get some money, maybe a grant or so, I would advise you to start some form of business; maybe you sell some stuff at home'. Because he can't work (Interview Mdu, 19 April 2007).

Female partners also said they were active in discouraging their male partners from finding a job, citing their poor health. These women recognized the pressure that their partners had in finding a job, but they insisted in telling them that they are not strong enough. In my interview with Nono she focused on Sipho`s health and said it is fragile; hence she does not encourage him to find a job. She said she is not bothered by his unemployment 'Well, about that I'm not really bothered. *Angithi* I can see that *akazenzi, uyagula* (it` s not his fault he is sick) (Interview Nono, 20 February 2007).

Joyce said the same about Kenneth. Her partner was unable to continue with business as a hawker due to being sick and they relied on his family for support. I asked her to describe how she felt about Kenneth when he was unemployed:

> Joyce: I accepted it because I could see the situation; I couldn't blame him because I could see he was sick. I wouldn't complain that 'now I don't have money; I don't have this and that!'
>
> SM: Did you ever think of going back home?
>
> Joyce: No, I never thought of that. I only wanted him to get well so I could remain with him. Because he doesn't have a father and a mother. He doesn't have someone that can help him, bath him, take him to the toilet, you see. So, I had to do all these things by myself; I had to help him, you see (Interview Joyce, 15 March 2007).

Kenneth confirmed Joyce`s account saying 'She also understood, she could see the situation. She knew if I was working I would have met her needs. That's why sometimes she would ask for money from her own father because she could see my situation. She never got upset with me because of that situation' (Interview Kenneth, 14 February 2007).

It seems as if the pressure that men imposed on themselves to find a job was not equally imposed by their family members and partners. These findings echo those from other studies of men with chronic illnesses (O`Brien, Hart et al. 2007). The participants in the cited study felt compelled to find a job in order to restore their 'lost' manhood. However they were constantly discouraged by other people from doing physical work due to their poor health. There is a likelihood here that by being dissuaded by their family members and partners from doing hard work, men`s feelings of being emasculated from being unemployed might somehow dissipate. Gender is normally conceptualized as a relational issue and here women play a vital role in redefinition of these men`s masculinities as sick and unemployed men.

Living 'new' masculinities in everyday life

Masculinities are both constructed and lived (Moore 1994). Hence it is not enough for a man to claim that he has changed; he must live his changed identity in the presence of others in the society. Studies have shown how difficult it is for men to adopt new lifestyles because of social pressures to conform to what other men do. Men who decide to change may be labelled as 'deviants' if their new identities are perceived as an opposition or affront to the socially dominant versions (Sideris 2005).

I asked participants to describe how they live their 'new' identities in everyday life: of being HIV positive men, caring, non-drinkers, monogamous/single; and how they deal with pressures from the society to still 'live like a man': drink, have multiple partners, work, etc. The common strategy used by most men to cope with these new changes was to reduce their interaction with the other community members. Before they got ill most of them mingled freely with other men in shebeens and other socializing places, and had many friends. Since being initiated into treatment this has changed. Most of them abandoned pre-HIV friends and formed new friendships either with other HIV positive men that they met at Rixile clinic or other men in the community whom they considered sympathetic to their situation.

These strategies were employed, first and foremost, as a means of 'information control' (Goffman 1968). It was felt that friends are too curious and demanding, therefore it is safer to reduce contact with them in order protect the privacy of HIV information. When someone is in regular contact with other men he risks being 'discovered' through conversations or other identifiers, such as someone seeing his ARV[27].

Jozi said since testing positive he drastically reduced interaction with friends:

[27] It must be kept in mind that there are a few people who were open about their HIV situation to their peers, so this observation does not apply to them.

> The problem is they will be asking too many questions, so I just distance myself from them. He will be curious 'why are you doing this; why are you doing that and not that?' Now I must explain myself to him (Interview Jozi, 1 November 2006).

Men not only avoided pre-HIV friends, but labelled them as 'bad influence'. It was felt that friends are only interested in one's money or in offering him alcohol; they have no interest in his health, as put here by Sipho:

> I don't socialize with them any longer; I`m always with my wife. Someone calls and says *'ey woza siphuze* (ey come let's have a drink) and I say 'no I don't drink. I don't want'. Where I now stay I don't have friends. I don't want friend because I can see that *abangani bakufaka ngentloko* (friends just mislead you) (Interview Sipho, 22 May 2006).

Younger men faced more pressure from friends to justify their changed lifestyles and to live like others. For example, Koko said he is constantly pressured by his friends to explain his decision to remain single. Koko was popular with women before he got sick; now his friends wondered why he no longer likes women. Koko said he first gave them misleading answers and when they persisted he distanced himself from them:

> SM: And *angithi* you used to be popular with women; now what do your friends say when they see you being alone, without a girlfriend?
>
> Koko: They do ask me 'why are you all by yourself'. I tell them 'women are troublesome. Today they say this and tomorrow they say something else; I would rather stay alone because then I can live a stress-free life'.
>
> SM: But do they still treat you with respect as a man? Because you told me that you guys used compete (for women) and all that.
>
> Koko: Well I don't socialize a lot these days since I opened my Tuck shop. I just stay indoors and in the evening and watch some movies or TV. For example I like watching 'Shift' because they talk about HIV; for example they talked about women and HIV one day (Interview Koko, 6 March 2007).

The pressure to conform not only came from male peers. Koko said that as a young man who has a business he gets attention from women who challenge him. But he still refuses, and when he does that they label him badly:

> SM: And don't you sometimes get girls that challenge you?
>
> Koko: Yhaa they do come and maybe buy a 10 cent chewing gum, and then they ask for something else; maybe she smiles or so. But I tell her 'I don't do any credit here'. Then she says 'you think you are better' '(*uyaxhoma*)', but I tell her 'I'm not worried; I'm trying to make money here. I also want to succeed, and you won't help me get there'. So she just laughs and says 'you are stingy' (Interview Koko, 6 March 2007).

Mathe said he faces similar pressures from women. As a man who was popular with women, he said he is still lusted by certain women, including his previous girlfriends. Mathe says he uses an excuse of having 'grown up' to discourage them:

> Even now I can tell you these women still love me a lot, the thing is I used to treat them very well. I don't know, maybe they used to love what I used to give them [laughing], so they still want it. But I tell them 'No, I am now a grown up man; I have a wife and children'. They say 'Yhaa we can see you are a father now; you go to church as well' (Interview Mathe, 20 February 2007).

Not all social spaces were seen as demanding and needing to be avoided. The church is one social space where men felt at ease with their changed lifestyles. As I have shown in chapter three, churches are opposed to drinking and having multiple partners. In church a good man is someone who exercises sexual restraint and has one sexual partner at a time. And most importantly, a 'real' man must look after his family. Most men found these 'alternative' definitions of manhood to be resonant with their present lives as people with HIV. Of 25 men that I interviewed, about twenty of them were going to church as an alternative lifestyle. Only three of them were committed to church before they became ill.

In most cases men joined spiritual churches such as ZCC. It was felt that these churches provide a workable compromise between demands imposed by an identity of being a man and those imposed by being an ARV user. For example, some of the churches are not completely opposed to practicing certain African rituals, like worshipping ancestors, preparing traditional alcohol, and others[28]. Men who joined these Zionist churches could therefore live 'African' identities while avoiding those activities that may risk their health, like drinking. Being a Christian could also be used as good excuse for not drinking or having one partner, thus reducing pressure to conform to what other men do. Most importantly it took away a focus from being ill as the main reason for change of lifestyle.

Finally some points must be made about support groups and their contribution in enabling men to change and adopt these new approaches to life. These groups appeared to locate the participants within a new discourse on matters of HIV and sexuality, as well as providing them with a new audience with which to negotiate their performances of reconstructed masculinity. In support groups, multiple partnering was discouraged and stigmatised as being indicative of irresponsible behaviour by someone living with HIV. Any man who had multiple partners was chastised rather than being celebrated as 'successful'. The support group therefore played a re-socializing role in terms of how masculinities were constructed and lived. It furthermore facilitated a confidence in participants to resist conforming to social expectations of hegemonic masculinity in favour of choosing to be more accountable to fellow support group members. Since support group members discouraged multiple partnering, participants appeared able to refrain from their old sexual practices while still reconstructing their masculinity and identity in a positive way.

By adopting 'responsible' lifestyles (such as controlled, safe sexuality), these men appeared to gain respect from other men to whom they disclosed their status. It was in these support groups that the 'problem' of constrained family roles and the de-emphasis

[28] In August 2006 I visited Sipho and he told me they were preparing traditional medicines for his church. The church would congregate at his place for the whole night and then drink alcohol in the morning. Neighbours were also invited.

of sex as a marker of masculinity were 'normalised'. In some ways then, the changes adopted by these men are endorsed, sanctioned and supported by other marginalised men, rather than men that represent hegemonic masculinity as a lived practice. For me as an observer this was the major role played by support groups in enabling men to change and adhere to treatment, despite its limitations that I pointed out earlier in the previous chapter.

Conclusion

This chapter has focused on the experiences of having HIV on men`s roles as providers and in their sexual performances. I have shown that HIV illness made it difficult for men to provide independently for themselves and that this has a serious impact on their masculinities. Men particularly felt emasculated by being dependent on other people for their living, especially women. Sexual lives are also significantly impacted by HIV, resulting in some of the participants being abandoned by their sexual partners and some deciding to refrain from having sexual relationships because of lack of sexual strength and a need to protect their health and dignity. Most men still aspire to have sexual partners; however concerns that they might fail to sexually satisfy her remain strong and they pose a significant barrier to their efforts to have sexual relationships.

The notion that 'masculinities are changing' is gaining momentum in South African research with men. This chapter has focussed on changes that are precipitated by an HIV illness. It shows that men who are using ARVs do not completely abandon their beliefs about hegemonic masculinity as a marker of their own manhood. However, they are selective and reflective in adopting certain lifestyles than before. Their main concern was to find a job in order to be independent and provide for themselves and their families. However, a need to remain healthy constrained men in terms of the choices that they made about work.

CHAPTER 9

CONCLUSIONS

Discussions

This study has investigated how notions of masculinity shape the experience of living with HIV in Bushbuckridge, and vice versa. I tackled this question through ethnographic research with one particular group of men in the study area: those who elected to test and then disclose their HIV status, and go onto ARV treatment for a sustained period. This group is not the mainstream of men in the area, the majority of whom are more reluctant to confront their illness in these ways. The study, then, in no way speaks to the dominant experiences by men of HIV in the Bushbuckridge area. Yet the numbers of men who choose the route I have studied are not insignificant, and their choices offer welcome hope for health educators and others committed to combating the epidemic.

This choice of focus in itself contributes to the novelty of this thesis and its argument. Most research deals with men as resisters of HIV messages and perpetrators of the epidemic, due mainly to their tendency to subscribe to certain social constructions of masculinity that perpetuate risky sexual conduct. With its focus on men who are already HIV positive and using ARVs, this study sets a new trend for engaging with men as equally impacted by the HIV virus. This opens pathways for investigating problems that they may encounter with HIV; their experiences with the health system in general; their various strategies for testing, disclosing and managing their HIV condition.

The central argument in this thesis has been that it is impossible to understand how the men studied deal with their HIV status without exploring how it affects, and is affected by, their sense of themselves as men. In many parts of the world dominant discourses on masculinity construct men as strong, powerful, dominant, stoical and therefore not needing help. Bushbuckridge is no exception. These constructions impact on use of health services as most men would not want to be judged as weak if they use health services.

Two key points of departure were made in this thesis that build on the existing work on men and HIV. First, rather than look at men as resisters of medicines this thesis focused on men as users of medicines, ARVs. Secondly, rather than limit the enquiry to the study of masculinity as a barrier to accessing health services, this thesis looked at how masculinity itself may be transformed by experiences of living with a chronic disease and using lifelong medicines. This has enabled this study to show how men reconstruct their lives following long and painful experiences of being ill from HIV.

Data shared with respect to these two focus areas shows clearly that living with HIV is a difficult situation for a man. From the onset of a disease men are faced with difficult decisions to make, such as whether or not to seek help, where and with whom. These decisions, I have argued, are not made in a vacuum, but are highly mediated by pre-existing views about manhood, culture, HIV stigma, perceptions of treatments, and other belief systems. Thus when someone becomes ill he draws from various meanings offered by these discourses to decide on how to respond to a physical discomfort. Overall these results have given us a deeper insight into the lives of men who are sick and using chronic medications, which have predominantly been explored from the perspectives of women. The significance of these results for studies of masculinities, ARVs, and HIV stigma are vast, and they are briefly outlined below.

Men, masculinities and HIV

What struck me the most during my fieldwork was the resilience that my participants had in adhering to dominant social definitions of manhood even when were faced with a prospect of losing their lives from a persistent HIV illness. It seems as if certain men had already come to terms with dying from an unknown disease than live with HIV because of how a positive diagnosis would impact negatively on their manhood lives. I have shared stories of men who were forced by their parents to test, or who turned back at clinic gates because they could not face the reality that they might be HIV positive. Having HIV, I have argued, undermines men`s power and dominance because of how an

HIV positive person is seen in the society as an outcast and 'already dead'. This was one of the main reasons why men resisted an HIV test.

Most studies that deal with men and their health behaviour singled out masculinity as a sole mediator of their health decisions. This study has extended the analysis by focussing on health beliefs of men as another factor that needs to be considered when theorizing about their health. Men live in a community and the latter holds certain belief systems about health, life, death, etc, and these beliefs impact heavily on their health decisions. The widely-held adage that 'real men don't get sick' or that 'real men don't use the hospital', therefore, does not have a universal meaning. In my study this view is constructed in a context where the use of western medicines is seen as more emasculating compared to use of traditional medicines. This is due to the fact that the use of western medicines is seen as sign of being weak and pliable (almost converted) while the use of traditional medicines indicates someone`s adherence to his culture or 'roots' - as one participants commented. Most importantly, sticking with traditional medicines at all costs may become a measure of someone`s resilience as a 'real' man, as well as a measure of his resistance towards western influence. For these reasons, masculinity alone is not sufficient to theorise about men`s health decisions. It must be viewed in the context of other belief systems about health and medicines that men hold.

Men who use health services are often perceived by observers as having changed or resisting the dominant social definitions of masculinity. These definitions normally dictate that real men don't seek help; otherwise they are perceived as emasculated. In this study I dealt with men who are seeking medical help, yet I am reluctant to label them as 'resistant' or 'changed'. This is due to the fact that resistance and change are complex issues; they are imbued with contradictions and ambivalences. For example, how do I make sense of men who are content with accompanying their partners to the clinic, yet not completely content with being in support groups with women; they want their own support groups where they can freely share their health dilemmas with other men, without being heard by women. Or men who tell me that they want new partners 'so they can do washing for me', yet they claim to have changed and want to be recognised as 'different'

from other men in the community? Or men who still see work as a principal way of measuring their manhood and are upset about loss of respect in their households due to being unemployed, yet they are content with their dependence on women health workers and their partners for emotional support? How do I situate these men in relation to various academic discourses about manhood – such as resistant, hegemonic, marginal, alternative, and others?

These findings, and further questions that they generate, support the research work on men that deals with resistances and transformation, as indicated earlier in the thesis. For example, in Sideri`s (2005) study, she shows how men are willing to share decision-making power, yet have doubts about relinquishing the dominant household head position. In Lindeggar and Maxwell (2007), participants are opposed to the use of violence and rape, as is commonly practiced by other men in their society (according to these participants), yet they still see themselves as being entitled to gender dominance. Walker (2005) shows how men who want to change from being violent must negotiate these changes in relation to other demands from a society - including women partners - to be seen as masculine through use of violence. These studies present masculine transformation as a difficult and fragile situation; most importantly it is difficult to measure 'change', given how certain men, such as those cited in these studies, have ambivalence towards it.

Perhaps a less explored, but important and relevant topic, is the issue of government support grants and their impact on health decisions – like testing, disclosure, and treatment adherence. In my informal conversations the government support grant was alluded to by certain people as constituting a powerful temptation to take an HIV test or (not) adhere to treatment. However, none of my participants mentioned it as having influenced them to test. For men who received the grant, it seemed to have contributed greatly to re-building their confidence and self esteem. It enabled them to play their socially defined roles as independent providers for themselves and their families. Further research is required on social grants and their impact on masculinity and other related health decisions.

Another issue that is less explored issue in this research is the role played by church in definitions and redefinitions of manhood. I was struck by a number of people who joined church as an alternative lifestyle after testing positive and entering treatment. Does this mean that the church legitimises another way of being a man that fits relatively comfortably and supportively with the experience of living with HIV? The church, as I have shown in the thesis, condemns drinking, having multiple partners, some of the key aspects in definitions of manhood in Bushbuckridge. In this respect it seems to fit comfortably with the notion of 'responsible manhood' that I argued most men pursued after testing positive and entering treatment. There are however, various denominations in Bushbuckridge, so a research study that attempts to explore the influence of religion on constructions of masculinity would need to take this into account. In my research most participants belonged to ZCC church and the kinds of masculinities that they embodied are constructed from its perspective.

ARVs and citizenship

Research on ARVs in South Africa is dominated by a medical focus on drug and their side effects, drug resistances, access, and other issues. The contribution of social science research is thus far limited to exploring treatment access, barriers, experiences of users and providers, and other issues. Elsewhere, research on ARVs has gone beyond merely exploring biomedical issues or access and barriers, to looking at how the use of ARVs gives new meanings to the notion of citizenship. Traditionally citizenship and citizen rights are defined by nationality, race and other markers (Rose and Novas 2005), but recent scholars have now began to pay attention to how consumption of certain pharmaceutical drugs or having certain health conditions can redefine someone`s identity, his relation to the state, as well as what rights he is entitled to as a 'citizen' (Petryna 2001; Biehl 2007; Inda 2005; Nguyen 2005). Here it has emerged clearly that using chronic pharmaceuticals drugs and belonging to treatment support networks is a life-changing experience; it recasts someone into new categories of citizenship as well as giving him/her new power to claim his/her entitlements to the state. Access to ARVs has

also been described as empowering, due to education that users receive from the HIV activist groups and other support networks, thus being able to stand up for these rights.

My findings partly support this literature due to their focus on how being HIV positive and belonging to a support group can reshape someone`s perceptions of his identity as a man. In support groups ARV users are encouraged to have a positive image of themselves as PLWHA and they are equipped with knowledge about their biological condition in order to help them cope with it (including coping with stigma associated with it). My critique of support group has focussed on its mode of operation, which I have shown, is coercive, top-down and non-negotiable. Support groups impose from above what it means to be HIV positive and they don't allow patient to share their 'alternative' belief about their condition, or treatment in the group. This has led me to question the claim that these groups are entirely empowering context.

This thesis has shared several stories of men who are content with using ARVs because they have improved their HIV health, but they are not equally content with their subjection to the HIV identity as an identity that they must embrace and live by. They view this identity as restrictive and somehow emasculating. Instead they want to live like other men in the society while still recognizing a need to exert certain limits in their behaviour as HIV positive men. It is therefore difficult to characterize these men according to certain terms used researchers to characterise users of pharmaceutical drugs, such as 'responsibilised citizens'; 'biological citizens'; 'health citizens'; 'therapeutic citizens', and others. These concepts tend to assume a static association with someone`s medical condition and complete embrace of its meaning, without considering the ambivalence and resistances that people demonstrate towards their condition.

To make this point clear, this thesis has engaged men outside the health centre where they normally share their experiences with treatment. Here it has emerged clearly that what we see in support groups as a complete embrace of ARVs does not always reflect participant`s true feelings about these drugs. Participants continue to question certain aspects of ARVs that they find disconcerting for their private lives. There are complaints

about unbearable side effects from ARVs; restrictive nature of ARV regimen, and other discomforting consequences.

In her account of HIV and its impact on identity, Squire (2004, p. 119) raises critical issues that I found relevant for my own analysis. She rejects the sociological view that HIV is a life changing or life-shaping condition. Instead she emphasises the fact that the HIV identities and communities are 'highly variable and conditional, operating strategically rather than as guiding principles of narratives and lives'. Her study documents situations of PLWHA who are embracing their identity, yet there are times that they want to 'disengage' or 'get away from it'. HIV is sometimes experienced as a burden and a constraint in their lives. They have other interests and these interests might not be equally shared by other PLWHA with whom they are supposedly a community. This leads her to reject the term 'citizens' to refer to them; instead she uses the term 'neighbors', noting '"citizen" still carries connotations of national unity and uniformity that neighors does not have. People in neighbourhood share some but not all interests' (Squire 1999, p. 115). There is a need to further interrogate the categorization of ARVs users as 'citizens' in South Africa, in order to highlight differences in interests and health beliefs that exist among them.

Health, body and stigma

Theories of the body have drawn attention to its importance in constructions of stigma and otherness in most communities. It is argued that the body is a marker of identity; that the societies rely on how the body looks to situate and position someone in a relevant social category (see chapter 2). Bodies that do not conform to an acceptable social ideal tend to be marginalised; or in worst cases they become ostracised and labelled as a threat to the society. A sick and weak body falls into the category of these socially undesired bodies.

There are two ways in which the body has been explored in this thesis; firstly as a source of embarrassment and shame for men who are sick and needing to test; secondly, as

means to reconstruct masculinity for men who have tested and are using ARVs. On the first part, this thesis has shared stories of men who were refusing to seek medical help because they were too embarrassed by their physical looks. This resulted in a situation where HIV testing was undertaken when someone was already too ill and had already exhausted other 'alternative' means of help – like traditional healers. The fear of stigma due to physical looks was linked to construction of masculinity whereby men who look healthy and strong tend to gain more respect and acceptance from the society compared to sick and weak men. Men therefore have more to lose in terms of their masculinity if they appeared sick in public.

Perhaps a more interesting account of the body and its impact on health decisions in this study is that which focuses on testing as a means of restoring a lost masculinity. Most men tested because they were feeling emasculated and alienated by being sick and wanted to restore their manhood, through using ARVs. I have shared stories of men who made direct reference to their physical looks as a main triggerer for testing. These men felt that they were no longer the same; they looked themselves into the mirror and felt estranged from their bodies. They felt socially marginalised. One person already labelled himself as *'inyamatane'* (an outcast) due to the way he looked physically. Once these men tested and received ARVs they focussed on reconstructing their bodies; mainly by adhering to treatment and making sure that 'I don't go back to where I was before'.

In her study based in India, Ecks (2005) made an observation that pharmaceutical drugs tend to be marketed as an effective tool to demarginalise someone. Here being sick is recognised as an alienating and marginalising experience. Access to drugs therefore brings someone 'back into the society'. Stories shared in this thesis echo a similar impact of ARVs on the lives of the users. It seems as if the recovery of the body was immediately associated with reincorporation into the society, where men were no longer seen as threats in their families and the society. I have shared stories of men who were utterly rejected by their families while they were still physically sick, but these rejections abated as soon as they recovered. Other men began to take active steps to challenge the

social categorisation of someone with HIV as 'already dead', relying on their own healthy physical looks to launch such challenges.

These men felt that they had nothing to hide; ARVs restored their bodies to a point at which they felt normal, or even better off compared to other community members. Thabang is a highly respected community member due to his openness about his HIV status; he is regarded as a role model and an AIDS ambassador. Kenneth discloses freely even to strangers and Duma urges his friends to test and uses his bodily looks to encourage them that HIV is just a 'normal' disease. These men have regained respect of the community; they are no longer marginalised because of their illness, instead their illness – and how they cope positively with it - is a new tool that they use to reconstruct their lives as respectable community members.

There is however, another side to using ARVs that cannot be overlooked when assessing their impact on users and whether or not they are demarginalised or dealienated by using them. Persson`s research work focuses on good and bad sides of ARVs and shows clearly that while ARVs may be effective in improving someone`s HIV health – for example making HIV undetectable - they may not be equally effective for his overall well-being and ability to function as an independent, autonomous and rational being (Persson 2004; Persson and Newman 2006). ARVs continue to produce physical and emotional outcomes that may render their restorative capacity questionable. Her work shares troubling stories of ARVs users whose immunity was improved by ARVs, yet the treatment continued to produce outcomes that undermined their rational selves and bodily integrities. There are participants who experienced mental instabilities as a product of their adherence to certain treatment prescriptions; others had bodily changes that rendered them more marginalised – than reincorporated - from the society. There are participants who thought of stopping ARVs or who resisted certain prescriptions because of their bad experiences with them. Thus the experience of using ARVs is not a completely pleasant one, despite their effectiveness in saving lives.

As I finished my fieldwork I could not help but be impressed by the restorative power of ARVs. ARVs, as I learned about them from accounts of my participants, saved these men from dying and enabled them to play meaningful roles as fathers, lovers, and friends. Thus, like Persson, I do not deny the merit or efficacy of these drugs. However, as I finish my thesis, I continue to be troubled by a tendency in the South African AIDS discourse to suppress any public criticisms of ARVs, and labelling those who question them as either dissidents or confused or confusing the public (Roberts 2007). This tendency, as I have shown, has already filtered into the support group networks of PLWHA, where there is only one acceptable way of talking about ARVs – praising them. Someone who enters the support groups and criticizes ARVs is immediately recast as either confusing other people or not committed to treatment. This makes it difficult to openly share experiences – good and bad - with treatment.

Like Persson`s participants, ARV users that I interviewed had lots of unresolved issues with treatment and how it impacted on their bodies, emotional well-being, as well as their gender health. There are men who could no longer work because according to their experiences, ARVs gave them 'stiff legs'; some could not perform well sexually; others complained about eye-sight, weight loss and numerous other difficulties. I worry that in privileging only the narratives that praise and support ARVs, we may leave these men`s needs unattended. HIV is both a medical and social problem and in measuring the efficacy of ARVs we need to pay attention to both aspects.

Lessons learned and policy recommendations

There are a number of lessons that I have learned from doing this research, which can be drawn upon to improve the provision of ARV services in South Africa. These are outlined below.

Knowledge of the social context – this emerged as a key finding in this study. In particular there is a need to know how the targeted population normally deals with health outside the HIV context. Most people believed in using traditional medicines when they

are sick and often they continued to use them in dealing with initial HIV symptoms, such as tiredness, cough, headaches and other symptoms. This had a consequence of delaying an HIV test, as most people thought they would get better or when they got worse they believed they were suffering from *tindzaka*, a disease syndrome that occurs as a result of violating sexual restrictions after death. Intervention programmes can therefore not simply impose ARVs 'from above'; they need to work with local communities to inform them about their role in relation to other treatment methods that people use. During my fieldwork there was a constant referral to western doctors as 'incompetent' in dealing with local ills; this points to a need for more collaborative work between western practitioners and local traditional healers.

Addressing HIV stigma. HIV stigma emerged in this study as being one of the critical barriers to testing and disclosing. Stigma manifests in how the society constructs someone with HIV as 'already dead' and an outcast. HIV testing is a first step towards gaining access to ARVs, yet in the study area it is often delayed due to fear of these negative judgements. Another significant factor in using ARVs is disclosure to partners, family members and friends. These people serve as treatment support partners who always remind someone about treatment. Results from this study have shown that due to fear of stigma most people are unwilling to disclose. There were cases of people who disclosed and were then immediately abandoned by partners and some family members. This indicates the importance of having a proper communication strategy about HIV to the broader community as well as equipping PLWHA with proper skills to disclose appropriately to partners; and also empowering them on how to deal with rejection.

There are good signs in this study that HIV disclosure is not always met with social rejection and abandonment, seen in men who are hailed as role models because of openly living with HIV. Most family members also embraced, rather than reject HIV positive men.

Addressing negative masculinity. The results highlighted the importance of focussing on masculinity as one of the key barriers to using HIV services by men. Throughout

fieldwork it was evident that men`s rejection of HIV messages – such as testing, adherence, disclosure – has nothing to do with their dislike of these messages, but how their involvement in these activities would impact negatively on their manhood. Manhood was constructed in terms of being strong, dominant, and in control, and involvement in these HIV activities was perceived as posing a threat to these ideals. The strength of this study is that it is based on men who have tested. I was therefore able to explore these barriers from actual experiences rather than from social discourses about men and their approach to health. Clearly then, any intervention that deals with men cannot treat them as neutral beings; it must consider their gender and how it is impacted negatively by using ARV services.

Community mobilisation and education. There were lots of confusions from the communities about ARVs – what they are; what their role is; why they don't cure, etc. These indicate that there was no community outreach programme to educate them about ARVs. These need to be organised in order to maximise the community use of ARVs. The community meetings can be used to update the community about the availability of ARVs for sick people and how far the programme has progressed. This will motivate others who are still reluctant to test and come forward because they know they can get help.

Transforming the health seeking cultures. Some efforts must be made to further engage the communities in terms of their health seeking cultures. These health behaviours do not occur in a vacuum but are informed by the existing social beliefs on causes of illnesses, diseases and deaths. I was particularly struck by the existence of a discourse that attributes what is biomedically understood as AIDS to local disease syndrome called *tindzaka*. Most people believed they had *tindzaka* and their families spent most of their money consulting traditional healers for help. This had consequences for economic stability of the family as all the money was used towards helping a sick person. While it is recognised that communities hold their own beliefs about diseases and that they cannot be changed overnight, it is important to address certain myths that render someone more vulnerable to AIDS due to late use of health services.

Support groups of PLWHA. A significant amount of data from this study was collected while attending support groups of PLWHA. These group meetings take place every day, with different people coming in for treatment each day. These groups are characterised by a top-down approach in which patients have no power to challenge the medical authority. This is seen in how someone who criticises ARVs or shares negative experiences may be labelled negatively and be singled out as 'confusing' others. Research has shown that when focus group discussions take place in a democratic environment there is room for patients to learn from each other`s experiences and then reach a consensus on the definition of their situation. This is particularly important in rural areas such as Bushbuckridge where people enter treatment with different health beliefs and must find ways of making sense of their dilemma. Imposing one perspective (medical) in this context is not useful because of how it alienates others who may not completely share the same worldview. Support groups must be open to talk about traditional medicines and other forms of treatment even if they contradict ARVs, because most people still use them.

Government support grants. The main problem faced by all participants was poverty and unemployment as a result of being sick. This was perceived as impacting severely on their self-esteem; however, it did not impact on adherence behaviour. The government currently provides grants to a few selected people who meet the criteria (CD4 lower than 200 and having other physical symptoms). It would be appropriate to reconsider the criteria for grants. Most of the participants who were receiving grants were able to buy food to support their medicine. This made a significant impact in their lives and instilled an overall positive attitude towards the clinic. People without grants were always complaining and often found themselves discouraged from using treatment, though none of them stopped it. They also had low self-esteem due to being poor.

Transforming the health system. The ARV programme in the study site is relatively new; therefore not much can be said about its impact in transforming the health systems. However there are already indications that ARV availability contributed to increase in the

use of HIV services – more people tested than before. Perhaps the most significant transformation that has occurred is in how PLWHA are beginning to play a positive role of encouraging other sick people to test and then access ARVs. Prior to availability of ARVs people were reluctant to approach others to test because they had nothing to offer them if they test positive. Most participants in the study and in support groups brought at least one person to the clinic whom they identified as being sick and then encouraged them to test. This is a good indication of how the availability of ARVs can change local health cultures where people are now more open about HIV their status. There is however still a problem of stigma that still needs to be addressed in order to encourage more people to be open.

Staff shortage. Staff often complained to me that they are overworked. The clinic opens for 4 days a week and it is always full. Patients start queuing up from as early as 4:30am and the last patients may leave as late as 6pm or later (they must also queue for pills at the dispensary).

REFERENCES

Abu-Lughold, L. (1991). Writing against culture. Recapturing anthropology: Work in the present. R. Fox. Santa Fe NM School of American Press

Ager, M. H. (1980). The Professional Stranger: An Informal Introduction to Ethnography Orlando Academic Press Inc.

Ahleberg, M. M., V. N. Kimani, et al. (1997). "The Mwomboko Research Project: The practice of male circumcision in Central Kenya and its implications for transmission and prevention of STD/HIV." African Sociological Review **1**(1): 66 - 81.

Airhihembuwa, C. O (1999)."Of Culture and Multiverse: Renouncing "the Universal Truth" in Health Journal of Health Education 5: 267 - 273.

Anderson, R. and M. Bury, Eds. (1988). Living with Chronic Illnesses London, UNWIN HYMAN.

Asencio, M. W. (1999). "Machos and Sluts: Gender, Sexuality, and Violence among a Cohort of Puerto Rican Adolescents" Medical Anthropology Quarterly **13** (1): 107 - 126

Atman, D. (1999). "Globalization, political economy, and HIV/AIDS." Theory and Society **28**: 559 - 584.

Auvert, B., D. Taljaard, et al. (2005). "Randomised, controlled intervention trial of male circumcision for reduction of HIV infection risk: the ANRS 1265 Trial. ." Plos Med **2**: e298.

Babbie, E. and J, Mouton (2001). The practice of social science research Stanford, California Stanford University Press

Bailey, R. C., S. Moses, et al. (2007). "Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial." Lancet **369**: 643 - 656

Becky, B. (2006). Article: Alternative masculinity and its effects on gender relations in the Subculture of skateboarding Journal of Sport Behavior http://www.highbeam.com/doc/1G1-18668787.html. Accessed 14 June 2010.

Biehl, J. (2007). Will to live: AIDS Therapies and Politics of survival Princeton and Oxford Princeton University Press

Bond, L., J. Lauby, et al. (2005). "HIV testing and the role of individual- and structural level barriers and facilitators " AIDS CARE **17** (2): 125 - 140

Bourdieu, P. and. Wacquant, L. J. D. (1992) An Invitation to Reflexive Sociology Chicago University of Chicago Press

Bourdieu, P. (2001). Masculine domination California Stanford University Press

Bourdieu, P. (2003). "Participant Objectivation " J. Roy. Anthrop. Inst **9**: 281.

Brennan, D. (2004). "Women Work, Men Sponge, and Everyone Gossips: Macho Men and Stigmatized/ing Women in a Sex Tourist Town." Anthropological Quarterly **77** (4): 705-733.

Broom, A. (2004). "Prostate Cancer and Masculinity in Australia " International Journal of Men`s Health **3**(2): 73 - 91.

Brown, J., J. Sorrell, et al. (2005). "An exploratory study of constructions of masculinity, sexuality and HIV/AIDS in Namibia, Southern Africa." Cult Health Sex **7**(6): 585-98.

Bujra. (2000). "Targeting men for change: AIDS discourse and activisim in Africa " Agenda **44**: 6 - 23

Bury, M. (1997). Health and Illness in a Changing Society. London Routledge

Business Trust. (2005). Bushbuckridge Nodal Economic Development Profile. Viewed 20 November, 2008. http://www.btrust.org.za/poverty/Bushbuckridge_narrative.pdf.

Caldwell, T., Caldwell, P et al. (1989). The Social Context of AIDS in sub-Sahara Africa Population and Development Review 15 (2): 185 - 233

Cameron, E. (2005). Witness to AIDS Cape Town Tafelberg

Campbell, C. (2001) Going underground and Going after Women: Masculinity and HIV Transmission among Black Workers on the Gold Mines Changing men in Southern Africa. R Morrell. Pietermaritzburg Zeb Books LTD 275 - 286

Cataldo, F. (2008). "New forms of citizenship and socio-political inclusion: accessing antiretroviral therapy in Rio de Janeiro *favela* " Sociology of Health & Illness **30**(6): 900 - 912.

Chapple, A. and S. Ziebland (2002). "Prostate Cancer: embodied experience and perceptions of masculinity " Sociology of Health & Illness **24** (6): 820 - 841.

Charmaz, K. (1994). "Identity Dilemmas of Chronically Ill Men " The Sociological Quarterly **35** (2): 269 - 288.

Civic, D. and D. Wilson (1996). "Dry sex in Zimbabwe and implications for condom use " Social Science and Medicine **42** (1): 91 - 98

Connell, R. (1995). Masculinities Cambridge Polity Press

Courtenay, W. H. (2000). "Constructions of masculinity and their influence on men's well being: A theory of gender and health." Social Science and Medicine **50**: 1385-1401.

Craddock, S. (2004). Beyond Epidemiology: Locating AIDS in Africa HIV and AIDS in Africa: Beyond Epidemiology E. Kalipen, S. Craddock and J. R. Ghosh. USA Blackwell Publishing 1 - 10

Crawford, R. (1994). "The boundaries of the self and the unhealthy other: reflections on health, culture and AIDS." Social Science and Medicine **38** 1347 - 1365.

Csordas, T. J. (1990). "Embodiment as a Paradigm in Anthropology." Ethos **18** (1): 5 - 57.

Cullinan, K. (2008). KZN Health minister mimics Manto and punts herbal remedies for Aids The Times Johannesburg. http://www.thetimes.co.za/News/Article.aspx?id= 89063 Viewed 23 November 2008

Davies, C. A. (1999). Reflexive Ethnography New York Routledge

Delius, P. and Glaser, C. (2002). "Sexual socialisation in South Africa: a historical perspective" African studies 61 (1): 27 - 54

DoH (2004). Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa. www.doh.gov.za

Donaldson, M. (1993). "What is hegemonic masculinity?" Theory and Society 22 (5): 643 - 567

Douglas, M. (1966). Purity and Danger London and New York Routledge

Ecks, S. (2005). "Pharmaceutical Citizenship: Antidepressant Marketing and the Promise of Demarginalisation in India " Anthropology and Medicine **12**(3): 239 - 254.

Emslie, C., D. Ridge, et al. (2006). "Men's accounts of depression: Reconstructing or resisting hegemonic masculinity?" Social Science and Medicine **62** (2246–2257).

Farmer, P. (1992). Infections and Inequalities: The modern Plagues. Berkeley Los Angeles University of California Press

Fassin, D. (2007). When Bodies Remember: The Experiences and Politics of AIDS in South Africa Berkeley, University of California Press

Feierman, S. (1985). "Struggles for Control: The Social Roots of Health and Healing in Modern Africa." African Studies Review **28** (2/3): 73 - 147

Fenstermaker, S., Ed. (2002). Doing Gender, Doing Difference: Inequality, Power and Institutional Change. USA, Routledge.

Gage, A. J. and D. Ali (2005). "Factors associated with self-reported HIV testing among men in Uganda." AIDS Care **17** (2): 153 - 165.

Gausset, Q. (2001). "AIDS and cultural practices in Africa: the case of the Tonga (Zambia)." Social Science and Medicine **52**: 509 - 518

Gevisser, M. (2008). The Dream Deferred Cape Town Jonathan Ball Publishers

Gibbs, L. (2005). "Application of Masculinity Theories in a Chronic Illness Context." International Journal of Men`s Health **23**: 287 - 300.

Gibson, B., N. L. Young, et al. (2007). "Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy " Social Science and Medicine **65** 505 - 517

Gibson, D. and M. R. Lindegaard (2007). South Africans boys with plans for the future: why a focus on dominant discourses tell us only part of the story. From Boys to men: Social constructions of masculinity in contemporary society T. Shefer, K. Ratele, A. Strebel, N. Shabalala and R. Buikema. Cape Town UCT Press 128 - 144.

Goffman, E. (1959). Presentation of Self in Everyday Life. USA, Pengium Books

Goffman, E. (1968). Stigma: Notes on the Management of Spoiled Identity London Pengium Books

Golooba - Mutebi, F. and Tollman, S. (2007). "Confronting HIV/AIDS in a South African village: The impact of health-seeking behaviour" Scandinavian Journal of Public Health 35 (3): 175 - 180

Gray, R. H., G. Kigozi, et al. (2007). "Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial." Lancet **369 257** - 266.

Green, G. and E. J. Sobo (2000). The endangered self: managing the social risks of HIV. London, Routledge.

Guttman, M. C. (1997). "Trafficking in Men: The Anthropology of Masculinity" Annual Review of Anthropology **26**: 385 - 409

Halperin, D. and D. Epstein (2007). "Why is HIV prevalence so severe in Southern Africa " The Southern African Journal of HIV Medicine 19 - 25.

Hollway, W., Ed. (1984). Gender difference and the production of subjectivity London Methue and Co.

HSRC (2002). South African National HIV Prevalence, Behavioural Risk and Mass Media Household Survey. Cape Town Human Sciences Research Council

HSRC (2009). South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2008: A turning tide among Teenagers Cape Town Human Sciences Research Council

Hunt, C. (1996). "Social vs Biology: Theories in the transmission of HIV in Africa." Social Science and Medicine **42**(9): 1283 - 1296

Hunter, M. (2002). "The Materiality of Everyday Sex: thinking beyond prostitution." African Studies **61**(1): 99 - 120.

Hunter, M. (2004). "Cultural politics and masculinities: multiple partners in historical perspective in KwaZulu-Natal " Culture, Health and Illness **7**(3): 209 - 223.

Hunter, M. (2006). Fathers without *amandla*: Zulu-speaking men and fatherhood Baba: men and fatherhood in South Africa R. a. Morrell. Cape Town HSRC Press 99-117.

IDP. (2008). Integrated Development Plan: Revision 2008. Bushbuckridge, South African Government. Accessed from the Bushbuckridge local municipality official.

Inda, J. X. (2005). Anthropologies of Modernity USA Blackwell Publishing

Iliffe, J. (2005). Honour in African History Cambridge University Press

Jensen, S. (2008). Gangs, Politics & Dignity in Cape Town Oxford James Curry

Jewkes, K. R., J. B. Levin, et al. (2003). "Gender inequalities, intimate partner violence and HIV preventive practices: findings of a South African cross-sectional study." Social Science and Medicine **56** 125–134.

Kahn, K., S. Tollman, et al. (2007). "Research into health, population and social transitions in rural South Africa: Data and methods of the Agincourt Health and Demographic Surveillance System." Scandinavian Journal of Public Health **35**(69): 8-20.

Kakoko, D. C., A. N. Astrøm, et al. (2006). "Predicting intended use of voluntary HIV counselling and testing services among Tanzanian teachers using the theory of planned behaviour." Social Science and Medicine **63** (991 - 999).

Kaminer, D. and J. Dixon (1995). "The reproduction of masculinity: discourse analysis of men`s drinking talk " South African Journal of Psychology **25** (2).

Kaufman, C. and S. E. Stavrou (2004). "'Bus fare please': the economics of sex and gifts among young people in urban South Africa." Culture, Health and Sexuality **6**(5): 377 - 391.

Kelly, M. and D. Field (1996). "Medical sociology, chronic illness and the body." Sociology of Health & Illness **18**(2): 241 - 257.

Kelly, M. P. (1991). "Coping with Ileostomy" Social Science and Medicine **33** (2): 15-125

Khunou, G. (2006). Maintenance and changing masculinities as a source of gender conflict in contemporary Johannesburg. Faculty of Humanities Johannesburg, University of Witwatersrand **PhD**.

Kimmel, M. and A. Aronson (2004). Men and masculinities: A social, cultural and historical encyclopaedia. Oxford: ABC-CLIO.

Kuate-Defo, B. (2004). "Young People`s Relationships with Sugar Daddies and Sugar Mummies: What do We Know and What do We Need to Know?" African Journal of Reproductive Health **8** (2): 13 - 37.

Kyakuwa, M. (2009). "More Hands in the Complex ART Delivery? Experiences from Experiences from the Expert Clients" African Sociological Review 13 (1): 143 – 167.

Leclerc-Madlala, S. (1997). "Infect one, infect all: Zulu responses to AIDS Epidemic in South Africa. Medical Anthropology Quarterly **21** (4): 363-380.

Leclerc-Madlala, S. (2002) "On The Virgin Cleansing Myth: Gendered Bodies, AIDSand Ethnomedicine" African Journal of AIDS Research **1**: 87-95

Leclerc-Madlala, S. (2001). "Silence, AIDS and Sexual Culture in Africa " Women`s International Network News **21** (1).

Leclerc-Madlala, S. (2002). "Transactional Sex and the Pursuit of Modernity." Social Dynamics **29**(2): 1 - 21.

Leclerc-Madlala, S. (2005) "Masculinity and HIV in KwaZul-Natal: *A treatise*." Viewed 19 November 2008. http://name.umdl.umich.edu/4761530.0010.015

Leclerc-Madlala, S. (2007). Intergenerational Relationships in the Context of HIV Prevention in Southern Africa. SAT/SAfAIDS Regional HIV Prevention Meeting. Livingstone, Zambia

Lindeggar, G. and J. Maxwell (2007). Teenage masculinity: the double find of conformity to hegemonic standards From Boys to Men: Social constructions of masculinity in contemporary society T. Shefer, K. Ratele, A. Strebel, N. Shabalala and R. Buikema. Cape Town UCT Press 94-111.

Long, C. (2009). Contradicting Maternity: HIV-positive motherhood in South Africa. Johannesburg, University of Witwatersrand

Lurie, M. N. and S. Rosenthal (2009). "Concurrent Partnerships as a Driver of the HIV Epidemic in Sub-Saharan Africa? The Evidence is Limited." AIDS Behaviour **DOI 10.1007/s10461-009-9583-5**.

Machel, J. Z. (2001). "Unsafe sexual behaviour among schoolgirls in Mozambique: a matter of gender and class" Reproductive Health Matters **9**(17): 82 - 90.

Mah, T. L. and D. Halperin (2008). "Concurrent Sexual Partnerships and the HIV Epidemics in Africa: Evidence to Move Forward." AIDS and Behaviour **DOI 10.1007/s10461-008-9433-x**.

Makhubele, B. and W. Parker (2008). Heterosexual anal sex amongst young adults in South Africa, Centre for AIDS Development, Research and Intervention.

Malungo, J. (2001). "Sexual cleansing (Kusalazya) and levirate marriage (Kunjilila mung`anda) in the era of AIDS: Changes in perceptions and practices in Zambia" Social Science and Medicine **52**: 371 - 382.

Makhubele, B. (1999). Perceptions of adolescents in Khayelitsha, Cape Town: On sexual and reproductive health Anthropology/Sociology Cape Town University of the Western Cape MA

Mathews, H. F. (2000). "Negotiating Cultural Consensus in a Breast Cancer Self-Help Group" Medical Anthropology Quarterly **14** (3): 394 - 413.

Matjilai, M. J., A. A. Hooseni, et al. (2008). STIs, HIV and AIDS and TB: Progress and Challenges. South African Health Review 2008. Durban, Health Systems Trust.

Mbali, M. (2003). HIV/AIDS policy-making in post-apartheid South Africa. The State of the Nation: South Africa 2003 - 2004 J. Daniel, A. Habib and R. Southhall. Cape Town HSRC Press 312 - 329.

Mc Grath, J. W., J. Pearson-Marks, et al. (1992). "Cultural Determinants of Sexual Behaviour for AIDS among Baganda Women." Medical Anthropology Quarterly **6**(2): 153 - 161.

Mc Gregor, L. (2005). Khabzela: The life and times of a South African Johannesburg Jacana Media

Mfecane, S. (2002). Xhosa constructions of masculinity and impact on the spread of HIV. Cape Town University of the Western Cape **MA**

Mfecane, S., H. Struthers, et al. (2005). The practice of masculinity in Soweto Shebeens Rethinking masculinities, violence and AIDS. D. H. Gibson, A. Amsterdam Het Spinhuis 88-109.

Mills, E. A. (2006). "From the Physical Self to the Social Body: Expressions and Effects of HIV-Related Stigma in South Africa " Journal of Community and Applied Social Psychology **16**: 498 - 503.

Moller-Leimkuhler, A. M. (2002). "Barriers to help-seeking by men: a review of socio-cultural and clinical literature with particular reference to depression." Journal of Affective Disorders **71** (1 - 9).

Moore, H. (1994). A Passion for difference: Essays in Anthropology and Gender Bloomington Indiana University Press

Morrell, R. (2003). "Silence, sexuality and HIV/AIDS in South African schools." Australian Educational Researcher **30** (1): 41 - 61.

Morrell, R. and L. Richter (2006). Introduction Baba: men and fatherhood in South Africa R. Morrell. Cape Town, HSRC Press 1-12.

Morris, M., A. Kurth, E. , et al. (2009). "Concurrent Partnerships and HIV Prevalence Disparities by Race: Linking Science and Public Health Practice." American Journal of Public Health **99**(6): 1023 - 1031.

Moynihan, C. (1998). "Theories of health care and research: Theories of masculinity." British Medical Journal **317**: 1072-1075.

Nettleton, S. (2006). The Sociology of Health and Illness Cambridge Polity Press.

Nettleton, S., J. Watson, et al., Eds. (1998). The body in everyday life. London Routledge.

Nguyen. V. (2005) Antiretroviral Globalisation, Biopolitics, and Therapeutic Citizenship Ong, R. and Coller, J. C. USA Blackwell 141 - 144

Nguyen, V., C. Y. Ako, et al. (2007). "Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment." 21 (31–35).

Niehaus, S. (2002). "Bodies, Heat and Taboos: Conceptualising Modern Personhood in the South African Lowveld." Ethnology **41** (3): 189 - 207

Niehaus, S. (2005). Masculine domination in sexual violence: Interpreting accounts of three cases of rape in Southern African lowveld Men behaving differently G. W. Reid and L. Walker. Cape Town Double Story Books 65-87.

Nye, R. (2005) "Locating masculinity: Some Recent work on Men" *Signs* 30 (3): 1937-1962.

O`Brien, R., G. Hart, et al. (2007). ""Standing Out from the Herd": Men Renegotiating Masculinity in Relation to Their Experiences of Illness " International Journal of Men`s Health **6**(3): 178 - 200.

Okwu, A. (1979). "Life, Death, Reincarnation and Traditional Healing in Africa " A Journal of Opinion **9**(3): 14 - 24.

Olliff, J. (2004). "Constructions of masculinity following prostatectomy - induced impotence." Social Science and Medicine.

Onwuanide, R. (1979). "Philosophy of African Medical Practice. ." Journal of Opinion **19** (3): 25 - 28.

Oppong, J. R. and E. Kalipen (2004). Perceptions and Misperceptions of AIDS in Africa HIV and AIDS in Africa: Beyond Epidemiology E. Kalipen, S. Craddock, J. R. Oppong and J. R. Ghosh. USA Blackwell Publishing

Parker, R. (2001). "Sexuality, culture and power in HIV/AIDS Research." Annual Review of Anthropology 30: 163 - 179

Parker, R. and R. Aggleton. (2003). "HIV and AIDS - related stigma and discrimination: a conceptual framework and implication for action." Social Science and Medicine **57**: 13 - 24.

Parker, W., Makhubele, B, et al. (2007) "Concurrent sexual partnering amongst young adults in South Africa. Challenges for HIV prevention". Johannesburg CADRE.

Paton, C. (1999). Inventing 'African AIDS'. Culture, Society and Sexuality: A Reader. R. Parker and R. Aggleton. London Routledge 387 - 404

Patman, R. (2001). 'The Beer Drinkers Say I had a Nice Prostitute, but the Church Goers Talk about Things Spiritual': Learning to be Men at a Teaches`s College in Zimbabwe R. Morrell. Pietermaritzburg. ZEB BOOKS LTD: 33-49

Pawluch, P., Cain, R, et al. (2000) "Lay constructions of HIV and complementary therapy use" Social Science and Medicine, **51**: 251 - 254.

Paxton, S. (2002). "The paradox of public HIV disclosure" AIDS CARE **14** (4): 559 - 567

Peacock, D., J. Redpath, et al. (2009). Literature Review on Men, Gender and Health in South Africa Johannesburg, Sonke Gender Justice.

Persson, A. (2004). "Incorporating Pharmakon: HIV, Medicine and Body Shape " Body and Society **10** (4): 45 - 67

Persson, A. and Newman, C. (2006). "Potency and vulnerability: Troubled 'selves' in the context of antiretroviral therapy" Social Science and Medicine **63:** 1585 - 1596

Petryana, A. (2003). "Science and Citizenship under Postsocialism" Social Research **70** (2): 551 - 578

Posel, D. (2004). Sex, Death and Embodiment Life and Death in a Time of AIDS: The Southern African Experience WISER

Posel, D. (2005). "Sex, Death and the Fate of the Nation: Reflections on the Politicization of Sexuality in Post - Apartheid South Africa" Journal of International African Institute 75 (2): 125 - 153

Posel, D., K. Kahn, et al. (2007). "Living with death in a time of AIDS: A rural South African case study " Scandinavian Journal of Public Health **000**(1 - 9).

Posel, D. (2007). A matter of life and death At RISK: Writing on and over the edge of South Africa L. Mc Gregor and S. Nuttal. Cape Town Jonathan Ball Publishers

Radar (2005). Report on HIV/AIDS, care and support services at Tintswalo hospital and Bohlabelo District Limpopo Province Bushbuckridge Rural AIDS & Development Action Research Programme

Ramphele, M. (2008). Laying Ghost to Rest Cape Town Tafelberg

Renold, E. (2004). "'Other' boys: negotiating non-hegemonic masculinities in the Primary School" Gender and Education 30 (2): 248- 266

Richter, L. and G. T. Mlambo (2005). "Perceptions of rural teenagers on rural pregnancy" Health SA Gesondheid **10** (2): 61 - 69

Ritchkin, E. (1995). Leadership and conflict in Bushbuckridge: Struggles to define moral economies within the context of rapidly transforming political economies (1978-1990). Anthropology Johannesburg University of Witwatersrand **PhD**.

Roberts, R. S. (2007). Fit to Govern: The Native Intelligence of Thabo Mbeki Johannesburg STE Publishers

Roberts, R. S. (2007). Notes on a theme: The AIDS -Drug Lobby and the Degradation of Public Discourse. Geosciences, University of Witwatersrand

Robins, S. (2009). From Revolution to Rights in South Africa: Social Movements NGOs and Popular Politics after Apartheid. James Curry: University of KwaZulu-Natal Press: 144 - 164

Robins, S. (2005). From "medical miracles" to normal (ised) medicines?: AIDS treatment, activism and citizenship in the UK and South Africa, Institute of Development Studies

Robins, S. (2005). Rights of passage from "near death" to "new life": AIDS activism and treatment in South Africa Sussex Institute of Development Studies 1 - 14

Robins, S. (2004). ""Long live Zackie, long live": AIDS activism, science and citizenship after apartheid" Journal of Southern African Studies **30** (3): 651 - 672

Rose, N. and C. Novas (2005). Biological Citizenship. Global Assemblages: Technology, Politics and Ethics as Anthropological Problems A. Ong and S. Cooler, J. Malden, Blackwell Publishing**:** 439 - 463

Saint - Aubin, A. F. (2005). Grammar of Black Masculinity: a body of science African Masculinities: men in Africa from late nineteenth century to the present L. M. Ougzane, R. KwaZulu- Natal University of KwaZulu-Natal Press 23 - 42

Sathiparsad, R (2007). Masculinities in the era of HIV/Aids: the perspective of rural male Zulu youth, From Boys to Men:Social constructions of masculinity in contemporary society T. Shefer, K. Ratele, A. Strebel, N. Shabalala and R. Buikema. Cape Town UCT Press: 181-194.

Scheper-Hughes, N. and Lock, M. (1985).The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology Medical Anthropology Quarterly **1** (1): 6 - 41

Selikow, T.-A., B. Zulu, et al. (2002). "The ingagara, the regte and the cherry: HIV/AIDS and youth culture in contemporary urban townships. ." Agenda **53**: 22-32.

Setel, P. (1999). A plague of paradoxes: AIDS, Culture and Demography in Northern Tanzania Chicago Chicago University Press

Shefer, T., K. Ratele, et al. (2005). A critical review of contemporary literature on men`s sexuality. Rethinking masculinities B. Gibson and A. Hardon. Amsterdam Spinhuis

Sideris, T. (2005). ""You have to change and you don't know how!" Contesting what it means to be a man in a rural area of South Africa " African Studies **1**: 29 - 49

Simbayi, L., S. Kalichman, et al. (2007). "Internalised Stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa." Social Science and Medicine.

Simpson, A. (2009). Boys to men in the shadow of AIDS: Masculinities and HIV Risk in Zambia. New York, Palgrave Macmillan.

Skinner, D. and S. Mfecane (2004). "Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa." Social Aspects of HIV/AIDS **1**(3): 157 - 164.

Squire. C. (1999). "Neighbours Who Might Become Friends": Selves, Genres, and Citizenship in Narratives of HIV Sociological Quarterly **40** (1): 109 - 137

Stadler, J. (1994). Generational relationships in a Lowveld Village: Questions of age, household, and tradition. Faculty of Arts Johannesburg, Witwatersrand University. **MA**.

Steinberg, J. (2008). Three-Letter Plague Johannesburg Jonathan Ball

Stone, G. P. (1962). Appearance and the Self Human Behaviour and Social Processes A, Rose. London Routledge & Kegan Paul

Tatyana, L. (2004). "Men in Crisis in Russia: The Role of Domestic Marginalisation " Gender and Society **18** (2): 189 - 206

Thornton, R. (2007). Unimagined Community: Sex, Networks and AIDS in Uganda and South Africa.

Tierney, W. (2002). "Get real: representing reality." Qualitative Studies in Education **15**(4): 385 - 398.

UNAIDS (2008) Status of the global HIV epidemic http://data.unaids.org/pub/GlobalReport/2008/jc1510_2008_global_report_pp29_62_en.pdf.Viewed 21 January 2010

USAID. (2008). "Addressing Multiple and Concurrent Sexual Partnerships in Generalised HIV Epidemics: Report on a Technical Consultation in Washington, DC, October 29-30, 2008, Convened by Pepfar General Population and Youth Technical Working Group and AIDSTAR-ONE" http://www.comminit/en/node/29806/2781 Viewed 27 November 2009

Vallaeys, C. (2003). "Awareness is not enough: Gender and HIV Pandemic in Africa " http//www.scu.edu/ethics/publications/submitted/vallaeys/gender.html Viewed 25 June 2005

Varga, C. and L. Makhubalo (1996). "Sexual non-negotiation." Agenda **28**: 31 - 38.

Walker, L. (2005). Negotiating boundaries of masculinity in post-apartheid South Africa Cape Town Double Story Books

Walker, L., G. Reid, et al. (2004). Waiting to happen: HIV in South Africa Colorado Lynne Reinner Publishers Inc.

White, S. (1997). "Men, masculinities, and politics of development" Gender and Development **5**(2): 14-22.

Whitehead, T. L. (1997). "Urban Low-Income African American Men, HIV/AIDS, and Gender Identity" Medical Anthropology Quarterly **11** (4): 411 - 447

Whiteside, A. and C. Sunter (2000). AIDS: The challenge for South Africa Capt Town Human & Rosseau

Williams, K. D. (2007). "Ostracism: The Kiss of Social Death " Social and Personality Psychology **1**(1): 233 - 247.

Whittaker, A. (1992). "Living with HIV: Resistance by Positive People." Medical Anthropology Quarterly **6**(4): 385 - 390

Wood, K. and R. Jewkes (2001). Dangerous Love: Reflections on Violence among Xhosa Township Youth Pietermaritzburg University of Natal Press

Zhou, Y. R. (2007). ""If you get AIDS...You have to endure it alone": Understanding the social constructions of HIV/AIDS in China " Social Science and Medicine **65**(2): 284 - 296

APPENDIXES

Appendix 1

Participant profile

This profile is a brief description of each participant and his situations before and after being diagnosed with HIV. Its main aim is to provide a reader with background information on all 25 men, that can be useful in understanding how being sick and using ARVs impacted on each of them. In addition, this participant profile provides a 'biography' of HIV for each person: when he got sick, how he tested and when he started treatment. The following information will be provided for each participant: age; work status (before and after illness); marriage or relationship status (before and after); situation with children; religious affiliations; education; alcohol use; family support; commitment to support groups; thoughts about masculinity; testing time; disclosure practices; sexual activity. The age of each participant is indicated in brackets.

Khaya (34)

Khaya is the first man that I approached to take part in my research. During the time of research he lived alone in a two-room house near Thulamahashe. Khaya is married with two children, but since he tested HIV positive his wife left him with both children and went to live with her family near Nelspruit. Originally from Mozambique, Khaya came to South Africa illegally in the 1985 to look for employment. He has spent much of his time in Bushbuckridge, though he had a short stint in Johannesburg where he worked for a construction company. He lost his job and then decided to return to Bushbuckridge and start work as a self-employed constructor. This was when he met his wife and then decided to stay permanently in Bushbuckridge. Khaya was diagnosed with HIV in 2003 following a long illness. He was sick for at least three years without testing and he consulted several traditional healers before finally deciding to test.

Khaya and I did not form a close relationship but in one interview that I conducted with him, I gathered the following about him: his highest education qualification is standard three; he left his parents 'at a very young age' and never saw them again. He had other sexual relationships outside marriage. He was a regular drinker and never went to church in his life. Khaya has no relatives in Bushbuckridge. He disclosed within a one month of receiving his HIV results and his wife left him immediately and did not test. He was not receiving a government grant during the time of research. He started using ARVs in 2005.

Kenneth (32)

Kenneth is the fourth child in a family of five children. Both his parents died. He has two children from different mothers and both of them are not living with him, but he is actively involved in their lives. He lives with his partner in a family house near Cottondale, together with his younger brother and his partner. Kenneth met his partner in Johannesburg at a train station where he used to work as a vendor, selling clothes and other staff. She had just lost her partner to AIDS but did not disclose this information to him when they met or that she was also HIV positive, until he got sick and tested. Their relationship was three years old in 2006 and Kenneth had plans to marry her.

Kenneth got sick in 2004 and started by using traditional medicines until he finally tested in March 2006. That was the time I met him at the clinic, looking weak and struggling to walk or talk. He started ARVs in May 2006 and soon he recovered, and by late February 2007 he was back doing his business as a train vendor, travelling every week between Mpumalanga and Johannesburg and coming back on weekends. I interacted with him closely for one year and we conducted two formal interviews (4 July 2006 & 7 February 2007).

I gathered the following about him: He had several women before, and disliked condoms. He was a regular drinker and smoker, and was a strong adherent to 'traditional' social beliefs about masculinity, saying that a man proves himself by having a job, a wife and a house. He disclosed immediately after receiving his results because he was urged by his

brother to test, who then wanted to know the results. He joined church as an alternative lifestyle after testing HIV positive.

Mathe (46)

Mathe lived with his parents and his three children in Buffelshoek. He has eight children aged between 14 and 23: four girls and three boys; five from a marriage and other three from an extra marital relationship. He is the last born in a family of three children. He is the only participants whose parents were both alive during research (his father died in August 2008). Both of them were earning pension grant and used it to support themselves, Mathe and some of his children. Mathe was the most educated of my participants, having passed matric. He was a teacher before and was married to a nurse who worked in Bushbuckridge; she has died in 2004 from an undisclosed illness.

I met Mathe in November 2006, just before he started treatment. He was looking weak at the time, but still friendly and cheerful. We spent a lot of time together during fieldwork. We conducted one formal interview and I continued visiting him at his place where we talked informally about his life. He described himself as a 'free man', always willing to talk about 'anything'. One of his favourite topics was women and sex.

Mathe got sick in 2004 and started by using traditional medicines; he tested in January 2006 and then entered ARV treatment programme in November 2006. After testing HIV positive he transformed his life, committing himself to church, stopping alcohol and traditional medicines, and committing to one woman. He disclosed to his family immediately after receiving his HIV results and to his new partner some months after starting their relationship, but not his children. He was not receiving grant during fieldwork.

Sabu (28)

Sabu is the last born in a family of six children, two boys and four girls. His mother died in 2003 and his father remarried to another woman and lives with her. During research

Sabu lived with his niece in a 3 bedroom house in Acornhoek. When I first saw Sabu in support groups he had a big sore on his forehead, which he covered with a cap. He looked embarrassed by it, avoiding eye contact and refusing to talk during discussions. Sabu and I formed a close friendship. We conducted two recorded interviews and numerous conversations about his life. What struck me most about him in these conversations was his openness and willingness to share even the most intimate aspects of his life. He referred to me as *Ta Khukza*, a sign of respect for an older brother.

From our numerous encounters I learned the following: he used to work in Benoni at a supermarket. He lost his job due to being ill, and then decided to come back to Bushbuckridge. He tested in 2005 following a two- year long illness. He was a drinker, a smoker, and had many girlfriends whom he met in shebeens. One of his ex-girlfriends died of AIDS while living with him and another one lives in Durban. He disclosed his HIV status to his siblings, but it was not well received as one of his sisters ordered her daughter to stop sharing food with him. Sabu had a girlfriend who was HIV negative and he disclosed to her. Their relationship did not last long as she left him for another man who later impregnated her.

Bob (31)

Bob is the first born in a family of four children. He has two children aged nine and eleven years. During research he lived with his mother in a four bedroom, fully furnished house in Cottondale (I emphasize this because it is the only home among my participant`s that was fully furnished). Closer to his mother`s house lives his uncle, an ex-policeman.

I met Bob for the first time on August 15 2006 at the Rixile and we interacted regularly since then. I gathered the following information about him: he left his home at a young age to look for work in the farms; he had several girlfriends and drank excessively. He used traditional medicines regularly and never favoured western medicines. Bob got sick in 2005 and started by using traditional medicines before going to a clinic for an HIV test after being ‘forced’ by his mother. He started treatment in August 2006, but by the end of

January 2007 he had already stopped, citing unbearable side effects. He did not receive a government support grant. He disclosed immediately to his family and his partner after receiving his results.

Koko (29)

Koko is the last born in a family of five children (three boys and two girls). During research Koko was living in a family house with his six year-old daughter. He was separated from his wife due to HIV (she abandoned him after disclosing to her). Koko was introduced to me by Khaya (P1), as 'another guy who wants to talk to you'. We then met regularly at the clinic and conducted two formal interviews. My interactions with him revealed the following: Koko left Bushbuckridge at the age of 18 to look for a job in Randburg, Johannesburg. His highest qualification is standard 8 (grade 6). He was involved with several women in Bushbuckridge and in Johannesburg. He said on average he would have four girlfriends at a time. He was a regular drinker and also smoked. He was also a strong believer in traditional medicines.

Koko became ill in February 2004 and started by using traditional medicines. In September 2005 when his illness persisted he decided to do an HIV test at the local clinic. At that time he was already weak and couldn't walk properly. He had lost lots of weight and had TB. He then enrolled for treatment in 2006 and had been using it until I left fieldwork. He was receiving government support grant and he used it to open a Spaza shop. He disclosed to one person in his family – his sister. He joined church as an alternative lifestyle.

Tinyiko (34)

Tinyiko lived in a one bedroom house with his partner who was also HIV positive. They have one child together and his partner has another child from a previous relationship. His wife is a traditional healer, but she said she uses only western medicines when dealing with her own health as someone living with HIV. Tinyiko tested in 2003 following a long illness. During research he was not yet taking ARVs.

Sizwe

Sizwe lives with his second wife and one child in a two bedroom house. His previous family (wife and 3 children) was all murdered by someone, a 'Mozambiquan', who accused him of cheating with his wife. Sizwe said the man had mistaken his household for his brother`s, and then one night he came and set it alight while his family was sleeping. He was working in Nelspruit at a time at a construction company.

He then discovered that he is HIV positive two years later after falling ill. His wife had been refusing to test despite knowing his HIV status. Sizwe and I didn't spend much time together during fieldwork. We conducted one interview and he was shy during our talk. But he revealed to me that he had several girlfriends before getting sick. He was working in Nelspruit as a sub-contractor. He said the main difficulty was to stop drinking. He still drank, though he said it was to relieve stress brought about by thinking about his family.

Magwa (50)

Magwa lived in a one bedroom RDP house in Acornhoek. His house was modest, with no furniture or proper equipments (stove, etc). He has thirteen children from three different mothers. During the time of research some of his children lived with his mother in Nelsrpuit. She was a pensioner and supported them and Magwa with her pension money. Magwa described himself as 'of mixed nationality'. His father is a Mozambiquan and his mother is SiSwati speaker from Nelspruit. He grew up in Mozambique, and left in 1975 to live with his mother in Mpumalanga. He later went to Johannesburg where he found a job in the mine. In 1998 he lost his job through retrenchment and was forced to return to Nelspruit and live with his mother and children. He ended up in Bushbuckridge after some struggles of trying to make a living and (at one stage he was arrested for a crime he never revealed to me).

Magwa and I interacted regularly during fieldwork and we did two formal interviews. He told me the following: he had several girlfriends while working in the mines; he drank

(though mildly); he was a strong believer in traditional medicines; he believed in male gender dominance. Magwa got sick in 2003 and started by using traditional medicines. He then tested in 2004 and had already developed TB. He enrolled for ARVs towards the end of 2005. During fieldwork he had no girlfriend; he disclosed to his mother, and was not receiving a government grant despite being ill.

Tito (53)

Tito is the oldest of my participants and the most active in the clinic activities. He was married with two children, a boy and girl aged 20 and 26 years respectively. During research Tito was separated from his wife who lived in Johannesburg with their children. He was living with another woman whom he met in support groups, in a one bedroom RDP house in Acornhoek.

I met Tito on my first day of attending support groups and he showed an immediate interest in my research. We then interacted formally and informally throughout fieldwork and we did two recorded interviews. I learned the following about him: Tito used to work as a driver for an insurance company in Johannesburg; he belonged to ZCC church but drank excessively and had numerous girlfriends outside marriage. He was a 'traditionalist', believing in superiority of men over women. Tito got sick in 2003 and started by using traditional medicines and ZCC tea. This continued until the end of 2005 when he finally decided to do an HIV test, having already relocated to Bushbuckridge and leaving his family in Johannesburg. He had also made use of a private doctor while in Bushbuckridge. Tito disclosed to his ex-wife, who was already using ARVs when he fell sick but was 'hiding' them from him. The main change in his life was that he stopped alcohol and women (multiple partners). He also committed to church and was an active community HIV activist. He was receiving government grant.

Sam (36)

Sam is a single man living with his seven year-old son in a small one bedroom house near Cottondale. His partner left him for another man after he disclosed his HIV results to her.

I met Sam in April 2006 and we conducted one formal interview and several informal conversations. During these interactions I learned the following about him: he had several girlfriends whom he met mainly in drinking places. He said some of them died of AIDS. Sam was unemployed and relied on the earnings from his Spaza shop to make a living. The Spaza shop was opened with the grant money that he received which was subsequently withdrawn. Before then he was employed at a construction company, but since he got sick he left his job because 'it was just too difficult'. His parents both died and he said his mother might have died of AIDS.

Sam started feeling unwell in 2003, but 'I just ignored it; I thought you know *mos*, illnesses come and go, but I didn't really pay attention to it'. In 2005 he became too serious - sweating, coughing and throwing out lots of *isikhohlolo* (phlegm). That is when he decided to seek help, starting with traditional healers. He then proceeded to the hospital in September 2005 where he was diagnosed with HIV and then treated for TB. In 2006 he started treatment. The major changes that occurred in his life were drinking and women. He said 'I stopped everything – alcohol, smoking, and women'. During the course of my fieldwork he found a partner from support a group who was HIV positive, but they were not staying together. Sam said he was happy in the new relationship. He disclosed to his family hoping to get support, but they immediately abandoned him after disclosing to them.

Zita (33)

Zita lived alone in a one-room house in Acornhoek. He is a second child in a family of three children, two boys and one girl. He has an eight year-old daughter whom he was not staying with, but she visited him occasionally. He was unemployed, but had a small business in Acornhoek which was doing well. Like Sam, Zita started his business from savings of his government grant.

I met Zita in June 2006 and we immediately became friends. He struck me as a very talkative man, unashamed of his situation of living with HIV and generally open about

his sexual life. On the first day that I met him he told the whole support group that he hasn't had sex for the past two years and that he doesn't like women because they are unfaithful and do not like condoms.

Zita is one of the participants that I socialized with the most during fieldwork. I conducted three interviews with him and numerous informal conversations. From these encounters this is how I can describe him: From a young age (17) Zita left school to look for work. He was lucky to get a job at the local supermarket and this is where he worked until he was fired in 2003 due to absenteeism. At that time he had already tested and disclosed to his boss. He was a regular drinker and didn't go to church. He had a stable girlfriend that he lived with but said he also had other partners 'outside'. He described his relationship with his ex-partner as having been a close one; she asked him to move in with her and her mother and then bought him a car. Things went wrong when he got sick as she decided to abandon him.

Zita felt sick in 1994 and, like most men, ignored it saying 'maybe its ancestors'. He then became serious, resulting in his partner 'forcing' him out of the house. He tested in 2000 and then received a government support grant. He had been using ARVs for about 4 years when I met him. There were 3 major changes in Zita`s life: women; alcohol and church. He had not disclosed to his two siblings.

Joe (33)

Joe lived with his partner in a two bedroom house near Hlubukani, 30 km from Rixile clinic. He has one child from another woman that he described as his 'childhood girlfriend'. But he has no contact with them. When I met Joe in April 2006 he was employed in a construction company in Hoedspruit. But during the course of my fieldwork he lost his job for reasons not related to his HIV status. I met Joe in April 2006 and we formed a long close relationship throughout fieldwork. He described himself as a 'devoted' Christian (ZCC member) and said since childhood he has been going to church.

This has shaped his conception of life, relationships and masculinity in ways different from other men.

Joe became sick in 2004 and like most of other men, started by using traditional medicines. He then did his HIV test in January 2005 'though I was not too sick'. He disclosed to his family members two weeks after receiving his HIV results and his disclosure was met with 'overwhelming support'. Joe never drank alcohol in his life. There was no major change in his life after testing HIV positive except that he was using lifelong treatment. He was not receiving government grant.

Lizo (32)

Lizo lived in the family house with his mother and her eight grandchildren. He is the last born in a family of five children - two boys and three girls. He has a child but does not live with her. His partner abandoned him when he disclosed to her, and she took the child with her. Lizo was employed before in Hazyview, but lost his job because of being sick. I conducted two interviews with Lizo and also socialized with him regularly during his visits to the clinic. I learned the following about him: since childhood he has been a devoted ZCC member. Lizo is the only man in my study who never used traditional medicines; he never kept more than one partner at a time and he never drank alcohol.

Lizo got sick in 2005 and then did an HIV test a month later. He took the shortest time to test among my participants. He then started treatment in mid 2006. Lizo disclosed only to his mother, but not other siblings. His mother whom I also interviewed was supportive of him, though she had a burden of supporting other grand children, but always pleaded with me to find Lizo a job or a government grant. The major changes in his life were lost of his job and women. He was not receiving a government grant.

Thabang (34)

When I met Thabang in 2006 he was living with his mother and two siblings in a two bedroom house near Bushbuckridge. His younger brother was also HIV positive and a

Rixile client. Thabang is known informally as an 'AIDS Ambassador' in Bushbuckridge. He lives openly with HIV and discloses frequently in social gatherings and other encounters with people. He is devoted to HIV work and said he does it in order to save others, especially men, whom he once described as 'stubborn'.

I met Thabang in a support group in April 2006. He was active and talkative, advising people on living 'healthily' with HIV and openly sharing his own experiences with HIV. Thabang was physically disabled, so he never worked in his life; he received government grant. But his sexual history was not different from other men. He had several girlfriends at the same time and never bothered about condoms. Some of his ex-girlfriends are still alive and others have died. He was a drinker and never went to church.

Thabang got sick in 2000 and started by using traditional medicines. He described his situation as having been dire, saying 'I was using pampers; if you know pampers that they use for children…'. In 2002 he decided to do an HIV test at the hospital and was immediately referred to Rixile for support (no free treatment at a time). He attended a few HIV/TB trainings and then received ARVs offered privately at the clinic. The last time I saw him in 2007 he looked healthy and still active in doing community HIV outreach work. The main change in his life was reduction of women, safer sex and non-drinking.

Zola (31)

Zola lives with his parents in Buffelshoek. He has one child whom he was not living with. He was unemployed and struggled for a long time to receive government grant despite being ill. His family lives in a poor resourced household with no furniture or beds. On my first visit to the family Zola's mother talked about the hardship her family is facing: she is the only breadwinner and supports ten people from the R850 pension grant. These include her own children and grandchildren. One of her sons died two years ago and left two children under her care. She has been trying in vain to get a support grant for these children: 'they tell them "your grandmother is getting pension; what do you want

now?"'. Her husband, a Mozambique national, was struggling to get a South African ID, which will make him eligible for grants.

I met Zola in August 2007 and had one formal interview with him and several informal conversations held at his home and at the clinic. He described himself as having had a 'quiet' boyhood/manhood. He did not drink excessively as other men did; he had number of girlfriends, some of whom had died. During research Zola did not have a girlfriend. Zola remained sick throughout my fieldwork, despite using ARVs. I remember visiting him at his home and found him being carried to the toilet by his mother and niece because he could not walk. Zola got sick in 2006 and started by using traditional medicines. He was working in Palaborwa at a time for a construction company. He then returned to his home to receive help and support and then tested in 2007 and was immediately given ARVs. He disclosed to his parents, but not his nieces. He also joined church as a alternative lifestyle.

Vusi (36)

Vusi lives in his 3-room house with his 25 year-old wife and a six year-old daughter. He has other two children outside marriage, but hardly sees them. Vusi is the eight child in a family of nine children. He is an ex-soldier, having worked for the South African Defence Force for nearly ten years. His house is nicely decorated with his photos taken while in the military.

Vusi and I were close and we socialized regularly in his house and at the clinic. I conducted one interview with him; one with wife and one with his mother, and several informal conversations. I can briefly describe him in the following way: he tested in 2005 following a long illness which he initially addressed by consulting traditional healers. Vusi worked in Johannesburg at a time and he was forced to return home because of being ill. He spent several months at the hospital where he was treated for TB. His wife tested HIV negative. Vusi said during his time at the military he had several girlfriends despite being married; some lived in Bushbuckridge. He was a drinker and did not go to

church. His view was that a real man proves himself by being independent and having his own, separate from his parents. He worked hard to build his own household, but has been unemployed for a long time because of being sick. Vusi is the only man amongst my participants who said he was willing to do 'hard' work despite being HIV positive. At some point he doubted his HIV positive status, though he continued using ARVs. He disclosed to his family members and partner immediately after receiving his results and was discharged from hospital. He received government grant though he was not physically sick.

Lucky (32)

Lucky lives alone in a two bedroom RDP house. His wife whom he described as his 'first girlfriend', left him with their two children aged thirteen and nineteen, due to what Lucky described as a 'misunderstanding'. During fieldwork he was negotiating with his in-laws to try and get her back. He is the third child in a family of four (three boys and one girl). His highest education standard 8. Before getting ill, Lucky worked in Pietersburg. He is unemployed, having lost his job due to sickness, but he occasionally works as a bricklayer in the village.

I met Lucky towards the end of 2006 in a support group in Cottondale clinic. We interacted regularly and then conducted two recorded interviews and other informal conversations. Our interactions revealed the following about him: his father passed away while he was young and he was raised by his grandfather who also died some years ago. Lucky grew up being a soccer player and tried his best to get away from violence and other unruly behaviour led by his age mates. When he was doing standard 9 his girlfriend got pregnant and he was forced to leave school at the age of nineteen. This was the biggest disappointment in his life as he had planned to study further. He then left Bushbuckridge to join his brother who was working in Pietersburg where they worked together for the same company.

In 2004 Lucky got sick and decided to return home. He was taken to a traditional healer before finally doing an HIV test in 2006 and then started treatment in 2007. Lucky described himself as a family man. He was distraught by the absence of his children. His view was that real man proves himself by taking care of his family and being responsible. He drank, but said 'I was always in control'. He had girlfriends other than his wife, describing himself as 'I used to like women too much (*bengijima-gijima nabafati kakhulu)'*. The main change in his life was that he stopped drinking and women. He also stopped using traditional medicines. The last time I saw Lucky he was in good physical shape and looking for a job. Lucky has strong support from his family. He disclosed to his older brother whom he described as 'a nice guy', three days after receiving his HIV results. His brother sometimes escorts him to the hospital and I conducted an interview with him in March 2007.

Thabo (42)

Thabo lives with his mother near Cottondale; his father died and his siblings were living independently in their own households. He has two children from different mothers, but is in contact with none of them. Thabo worked in Pretoria before, but was unemployed during research. I did not have a close relationship with Thabo, but during my fieldwork I conducted one interview with him and several informal conversations. He told me the following: He described himself as having been a 'heavy' drinker; he had many girlfriends, some of whom died of AIDS. Thabo said he never used a condom before, even when a woman looked 'suspicious'.

Thabo got ill in the late 1990`s and started by consulting with western doctors in Pretoria where he worked, but when his illness persisted he decided to go back home in Bushbuckridge to receive help. He started by using traditional medicines before testing in 2005 and then enrolled for ARVs in 2006. The main change in his life was being unemployed and he also struggled with sexual performance. He found a girlfriend from support group whom he described as 'young…her blood is still blood hot'. Thabo was

active within his community, mobilizing other men to seek help and test. He disclosed to his mother; he was not receiving a government grant.

Sipho (34)

Sipho lives with his wife and two children (aged six and two) in a three room house near Acornhoek. He is the fourth child in a family of five, the last of boys. His father died of TB 'long ago', and his elder brother died of AIDS. He said his sister was also sick and he suspected that it she was HIV positive. His house is quite modest, with no furniture, except a table that serves as both a TV stand and a dining table. One of the decorations found in the house is a photo he took with his late brother while they were still in Johannesburg. Sipho always spoke fondly about his brother, saying he misses him. He regrets that he did not do enough to persuade him to test. Sipho and his brother worked together for the same company in Johannesburg before he got sick and decided to go back home in 2003. He was taken to the hospital where he did an HIV test. Before then his brother took him to several traditional healers in Johannesburg, including a certain '*umprofethi*' (prophet) who said he was bewitched.

I met Sipho in March 2006 and we interacted regularly during fieldwork and we conducted two interviews. He described himself as a 'family man' and said he is living mainly for his two 'young' children. Sipho said he was a drinker before and that '*bengijikeleza noo* cherry (I used to mess around with lots of women)'. He met his wife in Johannesburg and then decided to 'settle down' with her. He then reduced drinking and focused on making a family with her. When he got sick he decided to stop drinking. Sipho joined church as an alternative lifestyle since he became sick and used ARVs. He said the church has helped him settle down and accept his situation. He did not disclose to his siblings and he was receiving a government grant.

Duma (41)

Duma is of Mozambiquan origin. He came to South Africa in the late 70`s and considers himself a South African. He lives with his wife and three children (eleven, fifteen, and

nineteen years). His wife is also HIV positive. Duma was employed informally by 'a white' man in Hazyview before he decided to leave his employment to look for a job in Johannesburg. Duma said his previous employer was exploitative 'when I asked him why he didn't register me he said the union would question him about the money he was paying me; and then he would be forced to fire me. So, for the sake of my children I stayed because I didn't want to be unemployed'. Duma fell ill in 2001 while still looking for a job in Johannesburg. He started by consulting traditional healers until he decided to test in 2006. By that time he had already lost weight and had TB and skin rash. He started treatment in late 2006 and said he experienced no serious side effects.

I interviewed Duma once in August 2006 and also interacted with him regularly at his home and at the clinic. His house was modest, with no TV or furniture. He received government grant, but it was withdrawn once he got better. During research the entire family relied on two government grants given to their children (total R350). Duma said he badly wanted a job (he even begged me to find him one at the hospital), but he was also feeling physically weak 'You see I have lost so much weight; I used not to be like this…No *Mlungu* (white man) can employ me just to sit around; I don't have energy to work…'. Duma never drank alcohol or smoked. He belongs to ZCC church and said church plays an important part in his health. Even though he is committed to ARVs he thinks medicines cannot work without the assistance of a prayer: 'You see, as I leave here right now, I will pass by my priest and give these ARVs to him to pray at them. *Angithi impilo iya nge belief (health is about believing*…)'. Duma admitted that he had several girlfriends and he doesn't know who infected him with HIV. He has since stopped having girlfriends and focuses on his wife.

Thandi (38)

Thandi comes from a family of six children – five boys and one girl. His parents both died while he was still young and he was raised by his grandfather. During research he lived in Nelspruit with his uncle. He was married before, but his wife died from AIDS; his only child also died before reaching his first birthday. Thandi was bitter about the

death of his child, saying he was given traditional medicines instead of being taken to the hospital. His in-laws believed strongly in traditional medicines and his father-in-law was a traditional healer. When his wife got sick she was also treated with traditional medicines. Ironically, Thandi described his wife`s death, whom he was married to for a year, as having 'freed' him, saying: 'I'm now free…But of course you will not say that in front of other people, that I'm free now. But my heart has rested, it had rested, Sakhumzi'.

I met Thandi in August 2006 and we became close immediately. We interacted regularly at the clinic and in October we did a recorded interview. In January 2007 we conducted the second interview. Our interactions revealed the following about him: He was a drinker before, but said he only drank with a few friends. He was not too keen on women though he would be 'naughty' at times. Thandi left school in standard five because of being poor and he worked in Johannesburg for various construction companies before coming back to work in Nelspruit in the late 1980`s.

Thandi is the longest survivor of HIV amongst my participants; he tested positive in 1990. He did not disclose his HIV status to his wife and other girlfriends despite having sex with them 'I knew very well; but I didn't want to tell them what was killing me. I kept it my secrets…'. During fieldwork he had a girlfriend to whom he did not disclose, but said they are using condoms. He started using ARVs in 2004, first from a private funder and later benefiting from the free government-funded ARVs. Thandi is amongst two of my participants who were openly sceptical of ARVs, but they both remained on treatment. Thandi lived in Nelspruit but travelled every month to collect his medicines at Rixile, a testimony to his commitment. He was not receiving a government grant.

Xola (45)

Xola lives in a two bedroom house with his wife. He has two grown up children from a previous marriage and two grand children from one of them (a 24 year-old daughter). His father who was a soldier died 'long ago'. Xola followed on his footsteps when he decided

to join the South African army at the age of 20. He spent about 14 years living away from home doing peacekeeping work in places such as Democratic Republic of Congo (DRC). He was promoted to a position of a sergeant, but his mother had been pleading with him to leave military until he decided to resign in 1998.

I met Xola in June 2006 and we socialized regularly during research and conducted two recorded interviews. He discovered his HIV status in 2001 following a long illness that he addressed by using traditional healers. He told me his family spent up to R15, 000, 00 on traditional healers before he 'forced' them to take him to the hospital, saying: 'I would rather die at the hospital'. He disclosed to his partner and then urged her to test; she also tested positive. He has not disclosed to his family because he fears they don't have privacy.

Xola told me that as part of military 'culture' he was made to smoke drugs (including dagga) and he drank regularly. When I met him he still used some drugs and was struggling for a long time to stop them until he did so late 2006. He also stopped drinking and has never smoked in his life. He said the biggest change in his life was in sexual life. He lost sexual virility and said ARVs did not do much to restore him sexually. Xola has another girlfriend in addition to his wife, who is also HIV positive. He is the only man amongst my participants who kept more than one after testing positive. He was receiving a government grant.

Jozi (39)

Jozi lives alone in a one bedroom house. He has two children, a nineteen year-old boy and a nine year-old girl. His wife passed away in 2004 due to AIDS. He is unemployed and currently survives on government grant which he had been receiving for almost a year. His parents died 'some time ago' and he was raised by his aunt. His aunt told me: 'his father said "please look after my children". So I am doing that….'.

I met Jozi in June 2006 and, though we were not close, we spoke regularly during fieldwork. Jozi left school at the age of nineteen after impregnating a girl in his village. He then found a job at the 'Plaas' where he worked for four years before leaving and finding another job as a security guard in Nelspruit. He was then arrested for possessing an unlicensed firearm. He tested for the first time while in prison and the results came back positive but he ignored them because: 'that time people used to be hostile towards HIV positive people, so I just ignored them…'. In 2000 he got seriously sick and his family took him to a traditional healer. Jozi said he doesn't believe in traditional healers, but because he was sick he had no power to oppose them. In 2005 when his condition worsened his aunt advised him to do an HIV test. He enrolled for ARVs in 2006 after treating TB and other opportunistic infections.

Jozi described his pre-HIV lifestyle in ways similar to other men. He drank regularly and had many girlfriends: 'I was naughty with girlfriends. I was very naughty. And then I had a wife, but I continued being naughty'. He disclosed to his family (aunt, sister and a son) and was receiving good support from them. He was receiving a government grant.

Senzo (39)

Senzo lives in a one bedroom house with his partner who was also HIV positive. They have one child together and his partner has another child from a previous relationship. His wife is a traditional healer, but she said she uses only western medicines when dealing with her own health as someone living with HIV. Senzo tested in 2003 following a long illness. During research he was not yet taking ARVs.

Appendix 2.

Participant Information Sheet

My name is Sakhumzi Mfecane. I would like to invite you to participate in a study entitled Social Dimensions of AIDS treatment – exploring masculinity in the context of Antiretroviral Therapy (or AIDS treatment). The study forms part of my PhD studies at Wits University. It is also conducted within the Agincourt research programme which has received acceptance and trust within your area. The study is aimed at understanding how people in your area are responding to the AIDS treatment provided at the public health facilities by the government. It focuses specifically on men since very little is known about their health behaviour, particularly in relation to AIDS treatment.

My target participants include men (18 and above) living with HIV/AIDS that are on treatment; men living with HIV/AIDS that are not on treatment and general men in the community who either know or don't know their status. In addition I would also like to informally engage health providers, both traditional and professional and community leaders about their views on men's health behaviour. If you fall in any of these categories I would kindly invite you to participate in this project.

Your participation will entail being interviewed by me at a venue you deem private and suitable for sharing information. This can be your home, health facility where you seek/provide health services, socializing place, etc. The interview will last between one and one and half hours. It is however possible that I will interview you more than once.

The content of the interview will be shaped by your current status:
If you are a man living with HIV/AIDS, I will ask you to share your experiences of living with HIV/AIDS as a man; 2. Your experiences of seeking help at the health facilities (both traditional and professional); 3. Your views about appropriate treatment for AIDS; 4. The extent to which your HIV status affects your view of yourself as a man and other issues that you may find useful to share.

If you are an HIV positive men not on treatment, I will ask you your views and perceptions of appropriate treatment for AIDS; 2. Your coping strategies as someone living with HIV/AIDS; 3. How living with HIV/AIDS affects your view as a man and many other issues that you feel important to discuss.

If you are a general community member, you will be asked about 1. Your perceptions of AIDS; 2. What you consider as a suitable treatment for HIV/AIDS; 3. Your own conception of masculinity and 4. Your views about the ways men in general deal with health and illness.

If you are a health provider (traditional and professional) or a community leader I will ask you to share you experiences of providing health services to men and women in this community. 2. Experiences of providing health services to men in particular; 3. Challenges that you face in your line of work; 4 Your views about the best ways of encouraging men to utilise health facilities. The information provided will not be shared with your superiors; your superiors will also not react negatively either to your participation or your non-participation in this study.

Your decision to take part in the study is voluntary. You are free to choose whether you want to take part or not. Your refusal to participate will not negatively affect your relationship with me or the health services you receive at this clinic.

Interviews will be conducted at a private place where you feel safe and free to share your life experiences. They will last between one hour and one and half hours. It is possible that I can interview you more than once, but that will be determined by the amount and relevance of information you share with me on the first interview. In total I expect to conduct between 45-50 interviews with HIV infected men (on treatment and not on treatment); and also engage in a series of conversations with health providers (traditional and professional), community members and community leadership until I get enough information from them– these will be informal and can also take place more than once. Interviews will be tape recorded and tapes will be kept in a locked cabin that can only be

opened by me and WISER colleagues working on the Death in the Times of AIDS project under which this project falls. I will conduct interviews myself and also write them down (transcribe) to ensure confidentiality. Tapes will be stored for up to two years after the completion of a PhD project and will later be destroyed or recycled.

I will do my best to ensure confidentiality of the information you shared with me in the following ways: 1. By conducting all interviews myself and ensuring that they take place in a private place occupied by the two of us; 2. Information shared remains a private matter between you and me; 3. (In case you agree to record the interview) that all tapes are kept in a locked cabin where I (and colleagues at WISER) only have access; and that no one else other than myself and WISER colleagues listens to them; and that they are eventually destroyed when not needed; 4. In reporting information from this study, the information you provide will always be grouped with information from all study respondents so that you cannot be identified; 5. Your real name is not mentioned in the interview reports (transcripts) and the full study report; and 6.

There may not be personal benefits from participating in the study, but the information you share will help us better understand men's health behaviour, their concerns regarding the use of certain health facilities, their choices of treatment in general; the existing knowledge regarding AIDS treatment offered by the government. This information can be used to improve health services that target men. This way a community may benefit in a long term.
At present there is very little information about health behaviour of men, particularly with regards to AIDS treatment offered by the government. Your contribution can help us understand this aspect.

There may be risks from participating in this study. Health and illness, particularly HIV/AIDS related, is a sensitive topic; some people may experience negative emotional reactions due to sharing private and sensitive information. In case this happens I will provide the best support I could and be sensitive. I may also advise you to consult a

trained counsellor that can help you deal with such emotions. I will have a list of all supportive structures in your area where you can go for professional support.

You are under no obligation to take part in this study. You are also free to stop your participation anytime when you feel like doing so. In cases where we record the interview, you are free to stop the recording at any time and to also tell me to erase certain sections of the recorded information.

You may contact me, Sakhumzi Mfecane, at **0733853029** if you have any further questions about this study. The number is available for 24 hours a day.

Appendix 3

Informed consent for tape recording

Thank you for agreeing to participate in this study. Now I would like to make one more request before we can start the interview - that we record this interview. The purpose for recording is to ensure that I get an accurate account of the information you shared; this will assist in reporting and writing up the interview.

Again you are free to decide on whether you want this interview recorded or not.
Your refusal to record will not negatively affect your relationship with me or the health services you receive at this clinic. You are also free to request me to stop recording at any time; you can also ask me to switch off the tape for a while if you don't want certain information to be recorded. You can also ask me to erase some parts of the recorded information.

Would you like us to record the interview?

(If yes), proceed by asking the participant to sign
(If no), I respect your choice, we can now start…

I understand that the interview must be recorded to facilitate the writing and reporting of my responses during the interview. I have had all of the above information explained especially about how my confidentiality will be guaranteed and I understand the explanation. I can stop the recording at any time when I feel uncomfortable about it. I hereby agree to the recording of the interview.

_____

_____

Participant Name (printed) Date of Birth

_____ _____

_____

Signature of Participant Date

If verbal consent is provided, the interviewer must sign below in the presence of the participant.

_____

_____

(Signature of the interviewer certifying that informed consent has been given verbally by respondent) Date