

**THE IMPACT OF HAART ON SEXUALITY AND MEDICINE
TAKING BEHAVIOURS AMONG PEOPLE LIVING WITH
HIV/AIDS IN GRAHAMSTOWN**

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Abstract

Introduction: Adherence to Highly Active Antiretroviral Therapy (HAART) is critical for optimal therapeutic outcomes. A possible factor in adherence is the impact of HAART on sexual functioning.

Methods: A mixed methods approach was used. A cohort of 14 people living with HIV/AIDS (PLWHA) in Grahamstown was identified. Two semi-structured interviews and two structured questionnaires were administered. In-depth interviews were conducted with two HIV counsellors in so as to obtain a different perspective on the topics. The theoretical framework used three health behaviour models: the Health Belief Model, Leventhal's Common-Sense Model of self regulation and the Transtheoretical model.

Results: The participants were between 27 and 49 years old and had been on HAART for between 9 months and 10 years. Six participants were support staff members from Rhodes University and eight from the Raphael Centre – a local NGO which assists PLWHA.

In most of the participants HAART was associated with increased libido and improved sexual functioning (sexual activity and sexual enjoyment). The use of alcohol increased risky sexual behaviour. Issues of adherence were seemingly not directly affected by the effects of HAART on sexuality. PLWHA, especially women, face challenges related to their sexuality, some of which are not directly related to their illness and treatment. The fear of transmitting drug resistant HIV or getting re-infected, stigma, disclosure issues, difficulties negotiating for safe sex among women, HAART-related lipodystrophic changes that affect one's sense of self and unmet reproductive needs are some of the problems that were reported. The men's dislike for condoms was overt and blatant.

Discussion: Being diagnosed with HIV and reaching a point where treatment is required are life-changing events. Making decisions about one's life (including adherence to HAART, alcohol use and knowingly partaking in risky sexual encounters) become all the more significant in the context of AIDS. Intentional non-adherence is informed by the individual's assessment of the costs and benefits of taking treatment. Cultural influences, gendered power relations and misconceptions strongly influence sexual behaviours.

Conclusion: The general lack of attention among health care providers concerning issues related to PLWHA's sexuality and reproductive issues needs to be addressed. Insights from

the theoretical models should be integrated with empirical findings in designing adherence interventions.

Dedicated to:

Christina and Ernest Chizanga

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If I have seen further than others, it is by standing upon the shoulders of giants.
- Sir Isaac Newton

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The family - that dear octopus from whose tentacles we never quite escape,
nor, in our inmost hearts, ever quite wish to. - Dodie Smith

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Abbreviations

3TC	Lamivudine
AIDS	Acquired Immunodeficiency Syndrome
BMQ	Beliefs about Medicine Questionnaire
CSM-SR	Common Sense Model of Self Regulation
d4T	Stavudine
HAART	Highly Active Antiretroviral Therapy
HBM	Health Belief Model
HCP	Health Care Provider(s)
HEAIDS	Higher Education HIV/AIDS Program (South Africa)
HIV	Human Immunodeficiency Virus
HR-QoL	Health-related Quality of Life
MCC	Medicines Control Council (of South Africa)
MSM	Men who have sex with men
NCD	Necessity-Concerns Differential
NRS-S	Numerical Rating Scale on Sexuality
PLWHA	People Living with HIV/AIDS
STI	Sexually Transmitted Infections
TCAM	Traditional, Complementary and Alternative Medicines
TTM	Transtheoretical Model
VCT	Voluntary Counselling and Testing (for HIV/AIDS)
WHO	World Health Organization

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1.0 Introduction

This study considered the effect of antiretroviral medicines on aspects of sexuality in people living with HIV and AIDS (PLWHA) on antiretroviral therapy and issues of medicine taking in these people.

Research on issues of sexuality among PLWHA has largely focussed on prevention especially on reducing risky sexual behaviours.[1] Despite the fact that a World Health organization (WHO) report[2] recognises the sexual and reproductive rights of PLWHA as fundamental, a paucity of published studies focusing on the impact of Highly Active Antiretroviral Therapy (HAART) on PLWHA's sexuality especially in the South African context are available. This study was intended amongst other things, to deepen understandings of how people on HAART experience their sexuality, to integrate the findings with existing knowledge, to inform risk reduction programmes and to ensure that they enjoy healthy sexual lives.

South Africa is one the Sub-Saharan countries at the epicentre of the HIV/AIDS pandemic. As access to lifesaving antiretroviral medicines increases, concerns over the sustainability of long-term adherence to treatment have emerged.[3]

This chapter states the research problem being investigated, the purposes of the study and defines the important terms that were used in the dissertation. An overview of the structure of the dissertation is also provided.

1.1 Statement of problem

Sexuality is an intrinsic part of a person's wellbeing. Knowledge gaps exist on our understanding of issues of sexuality outside the risky behaviours paradigm among PLWHA on HAART in South Africa. A bidirectional relationship between PLWHA sexual dysfunction and adherence to HAART underscore the need for this study.[4]

An exponential increase in the number of South African PLWHA on antiretroviral therapy occurred after the government unveiled its 'Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa'.[5] As access to HAART improves, concerns have arisen over issues of non-adherence and potential drug resistance. Suboptimal adherence to HAART causes drug resistant virus to emerge. Risky sexual behaviours among PLWHA on HAART could potentially result in the transmission of the drug resistant virus creating another epidemiological nightmare. The sheer scale of less than optimal adherence (<95 %) to antiretroviral therapy among PLWHA in Southern Africa¹ is a major health concern. Nachega and colleagues[6] assessed adherence by pharmacy refills at 6, 12 and 24 months after initiation of HAART in a cohort of adolescents (age 11–19 years; n=154) and adults (n=7,622) who were clients of 'Aid for AIDS', a private-sector disease-management program in southern Africa. The proportion of PLWHA who achieved 100% adherence at each time-point was low (adolescents: 20.7% at 6 months, 14.3% at 12 months, 6.6% at 24 months; adults: 40.5%, 27.9%, and 20.6% at each time point, respectively; $p < 0.01$). Although evidence from a systematic review of adherence studies show that adherence in resource-limited settings is equal or superior to that in resource-rich settings,[7] it is critical to understand causes of non-adherence especially where health resources are scarce

Despite substantial attention to adherence issues in recent years, gaps still exist in our understanding of medicine taking behaviours and the effectiveness of multifaceted interventions aimed at promoting adherence among PLWHA on HAART.[8] This suggests that gaps exist in our present understanding of medicine taking behaviours among PLWHA

¹ Reported adherence rates vary depending on how it is measured, over what period of time and the sociodemographic characteristics of the sample.

on HAART. Although the prevalence and determinants of non-adherence are well documented, there are not many published qualitative studies exploring PLWHA's personal experiences of taking HAART in the South African context.

The South African government's previous denialist response to the HIV/AIDS pandemic makes it even more important to understand how PLWHA perceive and take antiretroviral medicines, including the factors that influence the uptake of and adherence to HAART. The term "AIDS denialism" is often used to describe former President Thabo Mbeki's government's response to the HIV pandemic[9, 10]. The HIV discourse was characterised by discord concerning the link between HIV and AIDS, and surrounding the merits of HAART. Antagonism between the government and HIV/AIDS activist groups persisted until the commencement of the public antiretroviral programme. Furthermore, conspiracy theories about the origin of HIV[11, 12] and the notion that "pharmaceutical imperialism"[13] is behind antiretroviral medicines 'roll-out' still circulate in some quarters.

Traditional medicines, complementary and alternative therapies (TCAMs) use among PLWHA in South Africa is common[14] and the government previously actively promoted their use alongside HAART.[15] Since the beliefs that inform the use of traditional medications are different from those underpinning the biomedical approach, an understanding of the meanings people assign to TCAM use and how this impacts on adherence to HAART is vital in efforts to bridge this paradigmatic divide.

Being almost six years after the government started providing fully subsidised² HAART, and as efforts to further scale-up access to HAART are in progress under a plan called the 'HIV & AIDS and STI Strategic Plan for South Africa 2007-2011', a study exploring some of these knowledge gaps is therefore timely. A patient-friendly approach which allowed participants to describe their own experiences of taking

² Subsidised or 'free' HAART means that the medicines are procured by the government and provided to patients through public hospitals/clinics without them paying for the medicines upfront.

antiretroviral therapy as a conduit to understanding the myriad biosocial factors influencing medicine taking was used in this study.

1.2 Aims of this study

The aims of this study were to explore:

- a) the impact of HAART on participants' experience of their sexuality and related issues;
- b) medicine taking behaviours among PLWHA on HAART. The hopes, fears, personal beliefs and decision making process that led the study participants to adopt HAART, and their day-to-day experiences of taking these medicines;
- c) participants' use of prescription and non-prescription medicines, and non-biomedical healing systems such as TCAMs; the reasons and meanings that they assign to their use, and their impact on adherence to HAART.

1.3 Clarification of Terminology

Pharmaceutical care is defined as “the direct and responsible provision of medication-related care for the purposes of achieving definite outcomes that improve a patient’s quality of life.”[16] Accordingly, a pharmaceutical care practitioner works *with* and *for* the patients, “takes *responsibility* for optimising the entire patient’s drug therapy, regardless of the source (prescription, non-prescription and TCAMs)” with the ultimate goal of achieving optimal therapeutic outcomes.[17] An understanding of the manner in which patients make decisions related to the use of their medicines and how they take them in real life or their **medicine taking behaviours** is critical for the provision of pharmaceutical care since adherence to treatment regimen constitutes part of the vital link to successful therapeutic outcomes. Examples of medicine taking behaviours include: whether the patient takes the medication as prescribed, adjusting doses to accommodate ones’ daily schedule,

unilaterally discontinuing medication, forgetting to take medicine on time and timely refilling of their prescription. Medicine taking behaviours can be intentional or unintentional.

The patient centred approach acknowledges the central role of the patient in self-managing his/her illnesses. The patient's expectations, hopes, concerns, lifestyle, preferences, attitudes, personal beliefs, cultural predispositions and religious influences shape their medication taking behaviours.[17, 18] A concept called the patient's medication experience[17] has been used to describe the patient's unique personal experiences, past and present, of using medicines. Cipolle[17] defines the patient's medication experience as:

The patient's medication experience is the sum of all events a patient has in their lifetime that involve drug therapy. This is the patients experience with medications. This lived experience shapes the patients attitudes, beliefs, and preferences about drug therapy. It is these characteristics that principally determine a patient's medication taking behaviour.

TCAMs are an integral component of many patients' medication experiences. The term **traditional medicines** is used in this study to denote "the sum total of knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures that are used to maintain health, as well as to prevent, diagnose, improve or treat physical and mental illnesses."[19] **Complementary and alternative therapies**, whilst similar to traditional medicines in many respects, are distinctively "not part of the country's own tradition." [19] Complementary therapies are used concurrently with conventional medicines whereas alternative therapies are used to substitute for standard care. TCAMs include herbal remedies; dietary supplements; spiritual practices such as prayer, meditation; acupuncture; exercise; reflexology; healing touch; and yoga among others.

Highly Active Antiretroviral Therapy refers to a combination of anti-HIV medicines (usually ≥ 3) used to manage AIDS. Components of HAART are however marketed as single entities or as co-formulations.

The World Health Organization,[20] uses the term **sexuality** in some of its reports in reference to:

...a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

Human sexuality is a broad, complex, widely contested concept, which includes: sexual functioning, risky sexual behaviours, disclosure of HIV status to sexual partner(s), and sexual self concept. **Sexual functioning** describes issues related to sexual dysfunction (such as impotence in men, decreased libido)[21] and sexual enjoyment and satisfaction. **Risky sexual behaviours** refer to “continued sexual-transmission risk behaviour, substance use during sex, and disinhibition.”[21] **Sexual self concept** describes an individual’s perception of self. This may be affected by HAART in terms of body image, and emotions related to sexuality.

The act of making known one’s HIV status known to another person is referred to as **disclosure**.

1.4 Significance of this Study

It is hoped that findings from this study will shed light on how PLWHA make decisions regarding treatment uptake and adherence to HAART. Unlike most published studies on adherence behaviours which use quantitative methodology, this study used the mixed methods approach. This enables the strengths of both methods to be drawn on while partially offsetting weaknesses inherent in using monomethods.

There is a paucity of published literature on sexuality in PLWHA on HAART and related adherence issues from South Africa, and Grahamstown in particular (the area in which this

study was carried out). The study explores the impact of cultural, historical, political and socioeconomic factors which influence the sexuality, health seeking behaviours, and medication experiences of PLWHA.

Seeing that access to HAART in South Africa is set to expand by twofold in 2011,[22] findings from this study might help in filling some knowledge gaps and assist health care providers in formulating effective campaigns to facilitate treatment uptake and promote adherence. For persons who are already on HAART, the study may help shed light on some of the challenges they face with regards to their sexual and reproductive lives.

1.5 Delimitations and Limitations

The study was limited to the experiences of a small group of fourteen HIV-infected individuals on HAART drawn from Rhodes University's support staff members and members of a local community-based non-governmental organisation called the Raphael centre. In addition, two HIV counsellors were interviewed to obtain a different perspective on the research topic.

1.6 Structure of this thesis

Following this chapter, **chapter 2** consists of a review of the pertinent literature. Brief historical insights into the socio-political discourse pertaining to HIV/AIDS and HAART in South Africa in the 1990s until 2004 are provided. Medicine taking behaviours among PLWHA on HAART, and the impact of anti-HIV medications on sexuality is reviewed. In terms of structure, the review of literature on medicine taking behaviours is presented before that of the impact of HAART on sexuality.

Chapter 3 describes three theoretical models commonly used in explaining and predicting health-related behaviours – the Health Belief model (HBM), the Common Sense Model of Self regulation (CSM-SR) and the Transtheoretical model (TTM).

Chapter 4 details the methodology that was employed in this study. Descriptions of the sampling design, data collection and management processes, data analysis, issues of rigour and ethical considerations are provided.

In **chapter 5**, the qualitative findings and quantitative results are presented.

In **Chapter 6** the study findings are discussed using insights from theoretical frameworks and existing literature.

Chapter 7 contains a summary of the whole study, conclusions and recommendations, and reflections on the research process.

CHAPTER 2: LITERATURE REVIEW

2.0 Introduction

Acquired Immunodeficiency Syndrome (AIDS) is a chronic disease characterised by Human Immunodeficiency virus (HIV) induced progressive depletion of immunocompetent CD4+ T cells, increased vulnerability to opportunistic infections and death. HAART has proven therapeutic success in significantly suppressing viral replication, improving immune system function, decreasing susceptibility to life-threatening opportunistic infections, and is associated with the general improvement in physical functioning among people living with HIV/AIDS.[23] HAART use is associated with sexual dysfunction and this indirectly affects PLWHAs health-related quality of life (HR-QoL) and by extension, their adherence.[24]

In this section, issues of adherence are first presented followed by the factors associated with sexuality and HAART.

A considerable decrease in HIV-related morbidity and mortality and an improvement in PLWHAs quality of life is directly attributable to HAART.[25] However, therapeutic success is partly dependent upon early diagnosis of the illness, timely initiation of treatment and on strict adherence (ideally >95 percent) to treatment.[26] As with most chronic diseases that can be managed using pharmacotherapy, medicine taking behaviours such as being adherent to treatment, are an important link between medications and optimal therapeutic outcomes. With HAART, near-perfect adherence is indispensable for maximal and durable suppression of viral replication, which is critical to prevent the emergence of drug-resistant viral strains that might render some antiretroviral drugs, or in some cases the entire drug class, sub-optimally efficacious or ineffective.[27] Concerns about drug resistance are centred on three themes.[28-30]

Firstly, non-adherence to HAART has been identified as one of the most important impediments to successful therapeutic outcomes.[3] As noted earlier, non-adherence leads

to a waste of scarce medicines and the chance to successfully manage the disease may be lost. In addition, the hazard of drug resistance looms large. For this reason, ensuring that the patient adheres to the treatment plan is one of the key goals of pharmaceutical care.

Secondly, concerns have emerged over the widespread concurrent use of HAART with TCAMs, nutritional supplements, prescription and non-prescription medicines.[31] Drug-drug/food-drug/herb-drug interactions involving hepatic enzyme inhibition may result in increased serum drug levels and this might increase incidences of adverse drug events, which in turn, discourage adherence.[32] In cases of hepatic enzyme induction, suboptimal drug levels might promote the emergence of drug resistant virus and suboptimal therapeutic outcomes. Evidently, both these scenarios may cause suboptimal therapeutic outcomes. Drug-drug interactions were not the subject of interest in this study, however, the impact of using these additional therapies³ on the participants' adherence behaviours was. A synthesis of seven studies on the impact of TCAM use on adherence to HAART found mixed results.[33] Considering that TCAMs use is embedded in indigenous cultural beliefs among black South Africans,[34] and that the government actively supported their use,[15] a study exploring the acceptability of biomedical treatments is necessary.

Third and last, concerns about drug resistance are centred on the possibility of some PLWHA who are on HAART engaging in risky sexual behaviours. In the context of a hyper-endemic, generalised epidemic, the spread of drug resistant viral strains within and outside the HIV-infected population might lead to more cases of drug resistance. This partly explains why issues of sexual behaviour among PLWHA on HAART are of great concern, especially as more people are enrolling on treatment world over.[35]

This chapter draws attention to existing literature on the medicine taking behaviours, the use of additional therapies among PLWHA and how taking HAART impacts on their sexual lives.

³ Additional therapies refers to TCAMs, prescription and non-prescription medicines

2.1 The dual nature of antiretroviral medicines in South Africa - Healing and Harm

An estimated 5.7 million people were living with HIV/AIDS in South Africa as of December 2007.[36, 37] Of these, over 370 000 PLWHA were accessing antiretroviral medicines through the government-funded public antiretroviral program and plans are in progress to increase on this number substantially by 2011.[22] In addition, 100 000 PLWHA were already accessing antiretroviral medicines through the private sector.[36] According to the Global HIV/AIDS and STI Surveillance report,[36] in spite of the increasing availability of antiretroviral medicines through the public sector treatment program, only 27.4 percent of adult patients clinically eligible for HAART were receiving treatment by the end of year 2006.

About one in five adults in the age range 15-49 are HIV-infected in South Africa. Since this group, which accounts for 94% of the disease burden, is also the most sexually active,[22] it is important to consider issues concerning their sexual and reproductive rights. The advent of HAART means that they can live longer and some may want to engage in sexual relationships and to have children.

The above statistics also provide an overview of the mammoth challenges facing public health services in responding to the HIV pandemic. Where health resources are scarce, it is vital that they are used wisely. To prevent wastage through non-adherence, an understanding of how PLWHA perceive and actually take their medications is essential so that effective adherence interventions are designed and implemented.

Brief historical insights into South Africa's response to the HIV/AIDS epidemic are warranted in order to shed light on how historical antecedents have shaped people's representations of the disease and their perceptions of HAART. In the mid-1980s, South Africa recorded its first cases of HIV infection and like in many Western countries, it was largely a gay-man's disease.[38] This became a source of stigma for PLWHA[39] as in many South African communities, particularly Black communities, homosexuality is frowned upon.[40] Since then, HIV/AIDS has rapidly spread to the general population

becoming a predominantly heterosexual disease.[41] The disease continues to evoke stigma because it is associated with sexual practices such as promiscuity, homosexuality and with the use of illicit drugs.[42]

The advent of HAART gave hope to PLWHA. However, then President Thabo Mbeki's government was sceptical about the mainstream view concerning the causal link between HIV and AIDS, and he questioned the motive behind the existence of antiretroviral medicines. Instead, he advanced that poverty was the chief culprit. According to Sember [13], President Thabo Mbeki's stance was a way of "condemning pharmaceutical imperialism and medical experimentation" on African populations. President Mbeki is famously quoted saying:

I spent time trying to study it, to understand it. Your medical documents will say: Acquired Immune Deficiency Syndrome, that is AIDS, which means that you have got this challenge of immune deficiency. All right, what causes immune deficiency? HIV? All right, is that all that causes immune deficiency? And your medical textbooks would say no, there are other things that will cause acquired immune deficiency. There is also a genetic immune deficiency, a different phenomenon. There would be other things. So, I say, all right, in which case let us respond comprehensively to everything that will cause immune deficiency, including HIV...and the various tropical diseases, which because of poor health infrastructure, poor nutrition, general levels of poverty, don't get treated; syphilis, untreated or not properly treated (which as I hear is a big problem, when it is treated and the symptoms disappear, but, in fact, it is not cured and incubates there) that will impact on the immune system. So you have got to deal with these things.[43]

If you accept that there can be a variety of reasons, including poverty and the many diseases that afflict Africans, then you can have a more comprehensive treatment response.[44]

In 1997, then Minister of Health, Dr. Nkosazana Dlamini-Zuma⁴ allegedly endorsed conducting contentious clinical trials investigating the antiretroviral activity of dimethylformamide (or VirodeneTM), an industrial chemical used in dry cleaning which was purportedly viewed as a potential indigenous "cheap miracle cure" for HIV/AIDS.[45] However, the government distanced itself from the project in the midst of intense criticism

⁴ Dr. Nkosazana Dlamini-Zuma was Minister of Health from 1994 to 1999 under President Nelson Mandela. Thabo Mbeki was vice president then and he allegedly supported the clinical trials. Thabo Mbeki was president between 14 June 1999 – 24 September 2008

from the scientific community.[46] In 1999, President Mbeki expressed reservations about zidovudine use among PLWHA. He said:

...there also exists a large volume of scientific literature alleging that, among other things, the toxicity of this drug [zidovudine] is such that it is in fact a danger to health...[47]

He also stated:

If the scientists . . . say that the virus is part of the variety of things from which people acquire immune deficiency, I have no problem with that. But to say that this is the sole cause and therefore the only response to it is antiretroviral drugs, [then] we'll never be able to solve the AIDS problem.[44]

His unrelenting emphasis on multiple causes of immunodeficiency syndromes – HIV, tropical diseases, sexual transmitted infections and malnutrition - and convoluted answers to a seemingly straightforward question: Does HIV cause AIDS? - was a source of frustration for many HIV activists who interpreted his stance as an oblique attempt to undercut ‘mainstream’ views. As a result, he was (and still is) labeled an “AIDS denialist.”[9, 10] His stance on HIV/AIDS attracted widespread criticism, including from some prominent South African scientists such as Professor Makgoba⁵[48] who criticised Mbeki for attempting to “conflate causation with cofactors through a mixture of pseudoscientific statements” noting that such actions were “scientifically and politically dangerous in a society where denial, chauvinism, fear, and ignorance were rampant.”

Some prominent scientists, who were also branded as “AIDS dissidents”, urged against the use of zidovudine on the basis that it was toxic and some likened it to napalm,[49] a corrosive chemical used in warfare. There was speculation in some quarters that the antiretroviral medicines might be responsible for the deaths of HIV patients who were being initiated on them.[50]

⁵ Now Vice-Chancellor of the University of KwaZulu Natal, he was the former president of South Africa’s Medical Research Council (MRC) and has been a leading researcher in the field of AIDS vaccine development

In the midst of all this wrangling, President Mbeki appointed a presidential advisory panel comprising experts aligned to the mainstream paradigm and those opposed to orthodoxy to advise his presidency on national HIV policy.[51] However, attempts by the two factions to arrive at an acceptable compromise regarding the link between HIV and AIDS were futile.

Distrust for Western medicines and the belief that poverty was the chief culprit in the fight against AIDS seemingly stalled efforts to introduce antiretroviral medicines for the majority of AIDS patients in South Africa. The Pretoria High Court ruling in December 2001 and its subsequent endorsement by the Constitutional Court ruling in 2002 compelled the government to provide nevirapine to pregnant women to prevent intrapartum mother-to-child HIV transmission.[52] Adding to the uncertainty, in July 2003 the South African Medical Control Council (MCC) decided that they could no longer regard HIVNET012, the Ugandan study which formed the basis for Nevirapine's approval as a pivotal study.[53]

Amid intense pressure from AIDS activists, the South African Cabinet approved a programme for the Comprehensive Care, Treatment and Management of HIV and AIDS on 19 November, 2003,[5] paving the way for what is said to be the world's most ambitious public antiretroviral programme. Details of the plan were revealed on the 14th of April in 2004.

Controversies about HAART continued to surface even after the commencement of the public sector antiretroviral medicines program. For example, the former Minister of Health, Dr. Tshabalala-Msimang, drew widespread criticism from AIDS activists for promoting the use of garlic, olive oil, beetroot and lemon in HIV/AIDS patients. Some viewed her promotion of so-called alternatives as a covert attempt to undermine the central role of antiretroviral medicines in managing the disease.[54] According to Nicoli Nattrass,[49] after losing the battle to disallow the use of antiretroviral medicines, the government then resorted to supporting "alternative, scientifically untested remedies." A case in point was when the Minister allegedly failed to intervene when Matthias Rath conducted scientifically flawed "clinical trials" in which patients were given very high doses of vitamins to "cure" HIV.[49, 55]

South Africa's response to the HIV/AIDS pandemic also needs to be understood in the context of the socio-political history of a once deeply divided nation. HIV/AIDS became more overt in 1994 – especially as the focus on the struggle to end apartheid had just ended.[56] At a time when the majority of its people were still celebrating their newly found freedom, the emergence of HIV/AIDS served to awaken the deeply entrenched distrust for Western countries.[10] Antiretroviral medicines symbolised continued Western dominance. Steinberg[57] asserts that:

A new democracy is an era of resurging life. Sex is the most life giving of activities. That a new nation's citizens are dying from sex seems to be an attack both on ordinary people's and a nation's generative capacities, an insult too ghastly to stomach. AIDS has given rise to accusations, nowhere is this more evident than in the politics of South Africa's president, Thabo Mbeki, who questioned *with bitterness* whether the dying was caused by a sexually transmitted virus after all, and who asked caustically whether antiretroviral drugs were for the benefit of Africans or pharmaceutical companies. [emphasis in original]

Epprecht[58] notes this about Africa in general:

...[there is] a particularly dangerous idea that still circulates in some venues that there is no connection between HIV and AIDS, and that Western scientist and drug companies who make that connection are engaged in a conspiracy to exploit or even to wipe out Africans entirely...

The AIDS discourse in post apartheid South Africa is further complicated by cultural beliefs that assign blame for one's sickness to some "malicious, invisible supernatural force" or witchcraft[34] or discontented ancestral spirits.

Meanings people assign to specific diseases/illnesses and medicines are influenced by the political, historical and socio-cultural context.[59] President Mbeki's sceptical response to the HIV/AIDS pandemic, coupled with endemic myths and conspiracy theories that still circulate unchallenged in some communities about HIV/AIDS/HAART might negatively influence PLWHAs' perceptions and hence willingness to adopt and adhere to these life-saving medicines. An understanding of how these factors influence medicine taking

behaviours, which this thesis attempts to expand, might assist in developing effective culturally-sensitive adherence interventions.

2.2 Self-management of illness and medicine taking behaviours in patients on chronic medications

Like other chronic diseases, HIV/AIDS requires considerable patient self-management of their disease and medications. Self-care means that individuals take most of the responsibility for managing their health and make critical day-to-day decisions in implementing the recommended treatment plan.[60] Since taking HAART is to a large extent a self care activity undertaken by the patients for their own benefit, this means health care professionals have to work with patients in a collaborative manner to ensure good health outcomes. Working in collaboration means acknowledging the important role that the patient's ideas and personal beliefs about their illness play in influencing health-seeking and adherence behaviours, all of which are critical to achieving successful clinical outcomes.[61]. Cipolle et al.[17] refers to this as the "patient centred approach to self-management of illness": "it necessitates that the pharmaceutical care practitioner understands how the patient feels or perceives their medicines and how they actually take them." Patients on HAART are expected to take their medications in correct doses, on time, every day, and sometimes to adopt specific recommended lifestyle changes. Making such adjustments to one's lifestyle could be quite challenging.

As stated in Chapter 1 (page 4), the term medicine taking behaviours describes *the manner in which patients reach decisions about the use of their medicine and how they actually take them in their unique microcosms*. Medicine taking is an integral component of self care in PLWHA on HAART. Medicine taking behaviours are either intentional or unintentional. The former involves patients making conscious decisions to comply with or deviate from the health practitioners' directives. For example, a patient may choose to deliberately skip or delay taking some medication doses. Unintentional behaviours involve patients accidentally forgetting taking some doses as directed. Dowell and Hudson[62] identified three types of medication users namely: passive acceptors who faithfully comply with the physician's instructions without questions being asked, active acceptors who

demand a greater say in the way they take their medications and finally, complete rejecters who want nothing to do with the medicines. Although useful, this categorisation of patients is too simplistic since patient's behaviour may vary depending on their circumstances. The limited success of existing adherence interventions suggests that medicine taking involves much more than simply swallowing pills on time.

2.3 Shifting the Blame: From Compliance to Adherence and Concordance

In an attempt to improve on patients' medication taking, there has been a shift from focusing on patient compliance to adherence, and subsequently, to concordance.[63, 64] The terms compliance and adherence are often used interchangeably to describe the "extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider." [65] The terms "*non*/compliance" and "*non*/adherence" were generally deemed too authoritarian or prescriptive (i.e. patients should comply with/adhere to health practitioners' instructions) and for not sufficiently acknowledging the patient's role who makes critical day-to-day decisions and bears the responsibility of enacting the treatment plan.[66] As disease burden continues to shift from acute to chronic illnesses requiring sustained medication taking, and as the body of evidence accumulates showing the limitations of the adherence model, the "concordance movement" is gradually gaining momentum. It is intended to reflect the perceived shift in the patient's role from being passive recipient of medications and instructions to a new role in which they wield considerable say by being actively involved in deciding and implementing their treatment plans.

The concordance model acknowledges that patients are active participants in health decisions and they sometimes have their own ideas about their illness/medications. It places emphasis on "therapeutic alliance", [67] dialogue, and shared decision making between patients and the health professionals.[64] According to this model, patients have the right to *communicate* their health beliefs to health professionals who, in turn, have a *duty* to listen, then negotiate and attempt to formulate a workable solution for both parties.[64] Unlike the adherence model which blames patients for failing to take medications as prescribed, the

concordance model apportions responsibility to both parties. However, the concordance model seems unclear about how one deals with situations where the patient's and health care provider's positions are irreconcilable. Nonetheless, the concordance movement highlights increased recognition that with self-care, patients are ultimately solely responsible for taking their medications. Pharmacists are, however, well positioned to engage the patient in dialogue and hopefully through shared decision making and without undermining the prescriber's instructions, positively influence the patient's medicine taking behaviours and health outcomes.

In some quarters, the concordance model has been met with scepticism. For example, Segal[68] likens the model to the compliance model but with some "pandering" added to it. While the concordance model has received a lot of attention in Great Britain, other countries (e.g. USA and South Africa) have not yet adopted the model. In fact most published literature on medicine taking uses the adherence model. Its use in a key World Health Report on medicine taking attests its dominance.[3] In keeping with this trend terminology associated with the adherence model is used throughout this dissertation.

2.4 Adherence to HAART among PLWHA: A Balancing Act

The World Health Organization report[3] on adherence states that factors influencing medicine taking among people on chronic medications can be classified into five domains:

- Medication regimen-related factors
- Patient-related factors
- Disease-related factors
- Health care team/Health system-related factors
- Socioeconomic- related factors.

This classification was adopted in structuring the review of literature, below, on factors influencing medicine taking behaviours in PLWHA on HAART.

2.4.1 Medication Regimen Related Factors

For patients on chronic medications, adherence rates decrease with increasing regimen complexity.[69] Determinants of regimen complexity include: pill burden⁶, dosing schedule, dietary/water and lifestyle restrictions, prescribed dosage form, medication side effects, special requirements associated with medication use, medication storage requirements, routine laboratory tests associated with medication use and the ease with which a patient can obtain prescription refills.[70] These factors influence the individual's understanding of their medication regimen and hence, potential adherence.

Conn et al.[71] used the Medication Complexity Index[72] to examine the association between medication complexity and adherence in 178 older patients who had been recently discharged from hospital. Although increased regimen complexity was associated with lower rates of adherence to treatment, it was not statistically significant. Stone et al.[69] also examined the association between regimen complexity - dosing frequency and food-dosing requirements - and patient's adherence to HAART in 289 HIV-infected women. No association was found between self reported dosing instructions and skipped medication doses. However, when self reported dosing instructions were replaced with correct dosing instructions for each medication, the results showed that patients were approximately one and a half times more likely to skip taking medications that were supposed to be taken on an empty stomach or those requiring three or more doses per day. The discrepancy between "self reported dosing instructions" and the "correct dosing instructions" highlights that patients on more complex regimens have challenges in understanding the drug dosing requirements. Further analysis of the study results showed that 86% of patients taking the least complex regimens ($2 \leq$ medications minus food restrictions); 69% and 29% of patients on moderately complex regimens (≥ 3 medications minus food restrictions and ≤ 2 medications plus food restrictions respectively); and only 28 % of patients on the most complex regimens (≥ 3 medications plus food restriction) could recount correct medication dosing instructions.

⁶ Pill burden refers to the total daily number of tablets, capsules or other dosage forms one uses

Another study involving 299 PLWHA on HAART[70] found that the attributes of regimen complexity with the greatest impact on perceived ability to adhere to therapy were - in order of importance: pill burden, dosing frequency, adverse events, dietary restrictions, pill size, number of refills, number of copayments⁷, number of prescriptions, number of bottles and bedtime dosing. These findings showed that the various attributes of medication complexity are not equally important in influencing adherence behaviours. In South Africa, direct costs to PLWHA of purchasing antiretroviral medicines are unlikely to be a factor that might cause non-adherence since treatment can be accessed free of charge in designated public health care centres.

Initially, most antiretroviral medicines required multiple dosing per day. Co-formulations of 2-3 antiretroviral medicines – called fixed dose combinations - are now commonplace, especially in developing countries. The advent of highly potent, once-daily, fixed-dose combination pill with lower side effect potential such as Atripla[®] (combination of efavirenz, emtricitabine and tenofovir)[73] and Truvada[®] (emtricitabine and tenofovir),[74] was regarded as a major milestone towards improving long-term adherence to HAART.[75] A meta-analysis of eleven studies showed only modest ($\approx 1.0 - 4.8\%$) improvement in adherence rates in patients on once daily dosing compared to those with twice daily dosing of HAART. Stone et al.[70] found that patients preferred twice daily dosing to thrice a day dosing. Whether this apparent increase in adherence associated with decreased dosing frequency leads to better virological outcomes in the long-term remains unresolved, largely because of the relatively short follow-up periods in the studies. It is worth mentioning that once-daily fixed dose combinations pills are not common in the public sector in a resource limited setting such as South Africa.

Most Protease Inhibitor based regimens⁸ require at least twice-a-day dosing and some have dietary/water restrictions. Typical examples include: nonboosted indinavir which should be taken one hour before or two hours after meals with extra fluids (up to 1.5L per day) to

⁷ Copayment describes the amount of money patients on health insurance pay each time they access medical services

⁸ Exceptions include ritonavir boosted atazanavir or if atazanavir is administered concurrently with efavirenz/tenofovir; and ritonavir boosted fosamprenavir

avoid kidney stones; ritonavir-boosted saquinavir tablets and hard gel capsules which should be taken within two hours after food; and duranavir which should ideally be taken with food.[26] Food restrictions are not limited to protease inhibitors; patients should avoid high-fat meals when taking efavirenz. In resource poor settings, some of these seemingly straightforward requirements may not always be attainable.[76] For example, Kaletra[®] (lopinavir/ritonavir) soft gel capsules were reformulated into tablet form in an effort to eliminate the stringent storage requirements (refrigeration) that imposed a heavy burden on its users. Fezeon[®] (T20/enfuvirtide), although not widely used in resource-limited settings, requires refrigeration and is administered subcutaneously using bioinjectors.[26] Videx[®] non-EC (didanosine) tablets, the forerunner to Videx EC[®] is an example of antiretroviral medicine impacting negatively on patient's lifestyle. These chewable/dispersible buffed (non-EC) pills were unpalatable, fragile, and in some instance patients had to crush and dissolve them in a glassful of water before taking the mixture. This was a time consuming procedure which made it difficult for patients to take their medication privately. These examples illustrate some of the challenges that PLHWA may face in taking their medications.

Polypharmacy, the use of multiple medications (prescription, non-prescription, TCAMs, recreational drugs), is widespread among PLWHA[77] and the resulting high pill burden undermines adherence to HAART.[78] Furler et al.[77] studied the problem of polypharmacy⁹ in 144 PLWHA in Ontario, Canada. Using a combination of self-reports and medication chart reviews, they found that on average, patients used 20.7 (plus/minus 12.5) pills per day. Recurrent opportunistic infections in HIV sufferers often necessitates that they take additional medications. In some cases, they also use over-the-counter and TCAMs – a practice that increases the pill burden.

HAART side effects hinder adherence. In a study involving 686 PLWHA in Uganda, approximately one-seventh of patients discontinued antiretroviral treatment and a quarter modified their regimen at some point.[79] HAART side effects accounted for 21% of these

⁹ Polypharmacy refers to the prescription/dispensing of multiple medications for use by patients. Irrational polypharmacy is when use of multiple medications is not clinically warranted.

cases, and were surpassed only by exorbitant transport cost which was responsible for 43%. Other studies[80, 81] have shown that side effects are a major cause of discontinuation or non-adherence to treatment. An estimated 71% of PLWHA on HAART experience medication related side effects.[81] PLWHA who use triple therapy comprising of zidovudine, stavudine and efavirenz – a common regimen in South Africa - between 40 and 50% report experiencing medication related side effects. Common side effects are: cutaneous, haematological, neurologic, metabolic, gastrointestinal and hepatic abnormalities.[81]

2.4.2 Patient-related factors

2.4.2.1 Patients' knowledge and understanding of HIV/AIDS and HAART

Disease knowledge and understanding of treatment recommendations are critical for the self management of the illness. In conceptualising and understanding HIV/AIDS in everyday life, PLWHA sometimes use metaphors. The metaphor of dirt and the warfare metaphor are extensively documented in literature.[82, 83] The dirt metaphor frames HIV-infected people's blood as being unclean or polluted with dirt (i.e. the virus) whereas the warfare metaphor involves the use of militaristic terms. Sontag[83] urges against the use of metaphors because they are a source of stigma.

Low health literacy and poor knowledge about HIV/AIDS is associated with low adherence rates among PLWHA.[84]

Evidence of the impact of patients' expectations on adherence is mixed. Unrealistic or unmet expectations lead to patient dissatisfaction[85] and hence non-adherence. However, some studies [86] have found no association between the two variables. Jackson et al.[85] found that nearly all patients visiting a primary care facility had at least one expectation. These were related to their diagnosis (81%), probable duration of the symptoms (63%), the prescription (61%), concerns about diagnostic test (54%) and referrals (45%). Prognostic (54%) and diagnostic (33%) information were the most commonly unmet expectations.

2.4.2.2 Influence of personal beliefs on adherence

Necessity and concerns beliefs with respect to HAART may influence treatment uptake and adherence behaviours. Horne et al.[87] found that the necessity-concerns framework accurately predicted treatment uptake and adherence to HAART among 153 participants. Another study found PLWHA with higher necessity scores relative to concerns were more likely to have higher CD4+ counts compared to those with low scores.[88]

With regards to religious beliefs, Borrás et al.[89] found that they play an important role in influencing adherence in 103 schizophrenic patients. Over a third of the patients used religion to assign various meanings to their illness. For example, patients used phrases such as “illness is punishment from God for my sins”, “[its] devil’s work,” “[its] Gods work so I accept it with humility,” “[it was] sent by God to put me on the right path,” and “illness is a demon” to describe their illness. Patients who viewed their illness from a biomedical perspective were more likely to be adherent to treatment than those who based their decisions on religion. In South Africa’s black communities, beliefs about witchcraft and traditional healers are rooted in the traditional healing paradigm and this could potentially influence adherence behaviours.

2.4.2.3 Social Support

Social support refers to “those social interactions or relationships that provide individuals with actual assistance or that embed individuals within a social system believed to provide love, caring, or a sense of attachment to a valued group or dyad.”[90]

Supportive social interactions are essential for PLWHA to cope with the threat of AIDS and make critical adjustments leading to the adoption of and adherence to treatment. Support networks for PLWHA typically comprise family, friends, health care providers, members of support groups and peers.[91, 92] The various forms of social support are: instrumental (e.g. providing solutions to problems), appraisal/emotional (e.g. reinforcement and providing feedback), informational (e.g. providing pertinent information), and tangible/material support (e.g. goods, financial). Access to adequate social support is

thought to have a stress-buffering effect[90] enabling patients to better cope with life changing events such as HIV/AIDS.

Gonzalez and colleagues[91] found that adequate perceived social support and a positive state of mind were associated with increased adherence to HAART whereas depression had the opposite effect. Low self-efficacy beliefs, depression and feelings of hopelessness are thought to mediate non-adherence behaviours among people with inadequate social support.[93]

South Africa's PLWHA on the public sector ART program are encouraged to disclose their HIV status to at least one close friend. This person is known as the treatment supporter or buddy. According to Nachega et al.,[92] treatment supporters are normally "trusted confidantes" who have "moral authority" over the patient and they influence their health decisions and assist them to take their medication as prescribed. A cohesive family unit and living with another adult is associated with increased adherence.[94]

2.4.2.4 Psychiatric disorders

Although people with psychiatric disorders were excluded from this study, it is worth highlighting that approximately one-seventh of PLWHA on HAART suffer from cognitive and affective disorders such as depression, anxiety and stress, and dementia.[95] Neuropsychological compromise is associated with memory loss, diminished psychomotor and cognitive function[96] hence forgetfulness is a common cause of unintentional non-adherence among HAART users.[3]

2.4.2.5 Alcohol factors

Alcohol consumption undermines adherence to medications. For example, Samet et al.[97] found that patients who consume alcohol were three times more likely to be non-adherent compared to nonusers. Alcohol-dependent patients are more likely to skip doses, to forget, run out of pills and have irregular medication taking patterns.[98] Lowered perception of risk and forgetfulness are believed to be the mechanisms by which alcohol causes non-adherence.[97]

2.4.3 Disease condition- related factors

Adherence rates vary considerably across disease states depending on patients' perceived seriousness of their conditions. Adherence also varies depending on whether the condition is acute, sporadic or chronic, symptomatic or asymptomatic and whether the medication is prophylactic or curative.[99] HIV-infected patients are often initiated on HAART based on two laboratory markers - the CD4+ cell count and plasma viral load.[26]

Recurring opportunistic infections such as oropharyngeal and oesophageal candidiasis, and oral ulcers directly impede a patient's ability to swallow medications. Other HIV-related symptoms such as feeling fatigued/lethargic, severe diarrhoea, nausea and vomiting could negatively impact a patient's ability to implement the recommended treatment plan.

2.4.4 Healthcare team/Health system- related factors

Patient and health care provider relationship: The patient and health care provider relationship and a patients' degree of satisfaction with health services influences their adherence to HAART.[100] Schneider et al.[101] investigated the impact of seven core aspects of doctor-patient relationship – general communication, HIV-specific information, participatory decision making, overall satisfaction, willingness to recommend the physician, physician trust, and adherence dialogue -- on patients' adherence rates to HAART. All these variables had a significant impact on adherence rates. When patients trust their doctors, feel valued and are confident that their privacy will be respected, they are more likely to adhere to therapy.[102] These issues are particularly relevant in the South African context where, because of the scale of the epidemic and widespread shortages of health care professionals in the public sector, fewer opportunities for forging good doctor-patient relationships may occur.

Inadequate provision of health education, lack of clear instructions about treatment plans, and reduced positive reinforcement from health care providers is associated with decreased adherence intentions.[3]

2.4.5 Socioeconomic Factors

A systematic review of 16 studies found that three key socioeconomic factors - income, education and occupation - were not consistently associated with adherence to HAART among PLWHA.[103] Half of the fourteen studies that examined the impact of income on adherence found a significant association between these two variables. The high cost of HAART and poor living conditions were associated with non-adherence. However, studies in Africa reveal a different picture. Although adherence rates in Africa are comparable to or even higher than in developed countries,[104] socioeconomic factors such as poverty[105] and high transport costs[106] impede adherence.

In South Africa PLWHA with CD4+ cell counts less than 200cell/ μ L qualify for a monthly disability grant. Phaswana-Mafuya et al.[107] explored the impact of the disability grant¹⁰ on the wellbeing of 607 PLWHA on HAART in the Eastern Cape of South Africa. Compared to recipients of the grants, non-recipients had lower CD4+ cell counts, lacked enough food and were more non-adherent. It was concluded that the government needs to consider giving the grant to all PLWHA, irrespective of their CD4+ cell count and that the application process should be expedited because PLWHA depended on the grant to meet their basic necessities. Nattrass[108] notes that “HAART offers patients a chance to restore their health, but it comes at the expense of losing the disability grant,” and that patients thus face “trade-offs between health (taking HAART) and income (keeping the disability grant).” She concludes by noting that the grant potentially undermines efforts to improve adherence to HAART especially when one takes into account the fact that economically disadvantaged individuals are more likely to be getting HAART through the public sector.

In his book *Three Letter Plague*, Steinberg[57] states that:

...if people are to administer their own lifelong treatment, they must have a lively relationship with their medicines, a relationship at once emotional and cognitive. They must know the name of each pill, its shape, its colour, its nickname, [and] all its potential side effects. They are stuck with these tablets for their lives. Their

¹⁰ Disability grant refers to a state-provided basic assistance given to AIDS patients (CD4+ cell count < 200cells/ μ L) on HAART. It is renewable every six months if the applicant still qualifies.

relation to them will at times be hateful and fraught and unhappy. The tablets will perhaps make them sick, fail to stop them from getting sick, and change the shape of their bodies. It is best to develop a language with which to speak to them.

Table 1 summarises some of the factors that were been identified in published literature which influence medicine taking behaviours.

TABLE 1: Summary of Factors Associated with Non-/Adherence to HAART among PLWHA

Medication-regimen-related factors	Patient-related factors
<ul style="list-style-type: none"> • Dose frequency of more than twice a day (-) • High Pill burden (-) • Complex treatment regimens (-) • Requirement for close monitoring(-) • Severe lifestyle alterations (-) • Medication related side effects(-) • Lack of clear instructions about how to take the medications (-) • Fewer dietary restrictions (+) • Problems fitting medication to individual's lifestyle (-) • Belief that medication is effective (+) 	<ul style="list-style-type: none"> • Active substance abuse (-) • Active depression (-) • Lower level of education and income (-) • Lack of self efficacy (-) • Lack of satisfactory change in health status (-) • Forgetfulness (-) • Life stress, hopelessness and negative feelings (-)
Health care providers/Health system-related factors	Medical Condition- related factors
<ul style="list-style-type: none"> • Lack of educational interventions (-) • Lack of trust relationship between patient and health care provider (-) • Good support from health care professionals (+) 	<ul style="list-style-type: none"> • Somatic symptoms of disease severe (+) • Patients understanding of the importance of adherence to successful clinical outcomes is adequate (+)
Socioeconomic related Factors	
<ul style="list-style-type: none"> • Women: stress of childcare (-) • Low income (-) • Young age (-) • Lack of social support(-) • Non-Caucasian (-) 	

Key: (-) = decreases adherence, (+) = increases adherence to medications.

Sources: References [3] and [109]

2.5 Uses of TCAMs among PLWHA

TCAMs: Babb et al. found that about 54.3% of PLWHA on HAART use TCAMs in South Africa.[110] The prevalence of TCAM use varies depending on the respondent's sociodemographic characteristics, cultural beliefs, how one defines TCAMs, and the period over which TCAM use is assessed. Peltzer et al.[14] studied the use of TCAMs in 618 treatment naïve PLWHA in three public hospitals in Kwa-Zulu Natal. Like Babb et al.,[110] they found that just over half of the respondents used TCAMs in the six months preceding the study. Commonly used TCAMs included herbal therapies (29.6%); religious healing (35.1%); physical/body-mind therapies that included exercise (4.6%), massage (1.1%), therapeutic touch (1.0%) and meditation (0.8%), micronutrients (42.3%) and over-the-counter medicines (5.1%). Reasons for their use were varied. Herbal medicines were used for pain relief, to boost the immune system and for stress relief. Spiritual practices or prayer were used for stress relief, to improve overall wellbeing and pain relief. Micronutrients (e.g. vitamins) were used for pain relief and immune supplementation whilst over-the-counter drugs were mostly used for pain relief.

Studies on TCAM use among PLWHA have found several unifying themes surrounding why they are commonly used. These are: the wish by users to regain personal control over their bodies, to improve their quality of life, and for longevity.[111] Specifically, TCAMs are used to alleviate HIV symptoms and to control HAART side effects. In South Africa's Eastern Cape Province, the most commonly purchased *amayeza* (*Muti*/TCAMs and non-prescription medicines) from traditional healing practitioners' stores were intended for "protection from evil spirits" (28%), dermatological complaints (17%), gastrointestinal and chest complaints (10%) and non-medical reasons such as attracting luck and love (4%).[112] Despite the paucity of scientific evidence supporting their effectiveness, most TCAM users report feeling better after using them.[113]

Indigenous traditional healing practices are entrenched in the cultural spheres of black people in South Africa. Cross generational knowledge transfer has perpetuated their continued existence over centuries.[19] In spite of the emergence of modern medicines, traditional medicines are still widely used in South Africa[14] and in most developing countries.[19] The World Health Organization attributes this to the fact that they are relatively inexpensive and widely available, and that their use is congruent with indigenous peoples' own belief systems.[19] Furthermore, ingrained suspicion and distrust of Western medicines which is evident in conspiracy theories[12] might persuade people to turn to TCAMs.

The biomedical model of disease causation is congruent with Western medical practices whilst traditional healing practices inform TCAM use. The former is highly structured, and places emphasis on “organ pathology to generate biological base”[114] and uses concrete evidence from randomised clinical trials as the basis for formulating standardised care for specific disease conditions. In contrast, the latter is rooted in folk culture/local customs, treatment is often not standardised and it claims to use a holistic approach to healing. The term ‘disease’ is associated with the biomedical model whilst the term ‘illness’ resonates with the traditional healing paradigm. The rather tenuous distinction between the two concepts is that while diseases are caused by pathogens or disruptions in physiological functioning of parts of the body, illnesses are mostly responses to a variety of conditions including diseases.

Concerns that TCAM use among PLWHA might undermine adherence to HAART[115] are reasonable in view of findings by Owen-Smith et al.[116] that TCAM use was associated with negative beliefs about orthodox medicines and TCAM users were approximately 1.7 times more likely to skip taking HAART. The fact that most PLWHA are hesitant to report TCAM use to their health care providers[117] means that little is known about these medications' impact on adherence behaviours.

Notwithstanding these concerns, there is a growing recognition of the important role of TCAMs in primary health care the world over and the South African government appears

to be moving towards establishing a statutory council to regulate traditional practitioners.[118] The South African Medical Research Council (MRC) has taken initial steps towards testing the safety and efficacy of TCAMs.[119] The lack of a robust regulatory framework for TCAMs is further complicated by widespread commercial advertising, the proliferation of adulterated products and the lack of credible, scientifically based information to consumers.

2.6 Prescription, Over-the-Counter medication use and Nutritional Interventions

Prescription medications (in addition to HAART) are commonly used by PLWHA to treat opportunistic infections. Evidence suggests that nearly all PLWHA on HAART also self medicate using over-the-counter medicines and in most cases, several products are used simultaneously. In spite of potential drug-drug interactions, few patients report non-prescription medication use to their physicians.[77] The resulting high pill burden and polypharmacy associated with the use of “additional therapies” might undermine adherence to HAART.

Nutritional interventions are used as adjuncts to antiretroviral therapy. Malnutrition is often mentioned as one factor associated with accelerated immune decline[120] and the South African government has integrated nutritional support for eligible HIV patients as part of the comprehensive approach to managing HIV/AIDS. Such interventions are useful in preventing HIV wasting.[121]

2.7 Issues of sexuality among people living with HIV/AIDS on HAART

There is a general lack of attention to issues of sexuality among PLWHA on HAART except in the risk behaviour paradigm. While the potential transmission of drug resistant HIV virus by PLWHA on HAART remains a serious public health concern, the impact of taking HAART on the sexual lives of PLWHA remains largely under-researched.[21] Most studies in this field focus on risky sexual behaviours and on sexual functioning, often ignoring issues to do with sexual adjustment in HAART patients. Kalichman[21] gives three reasons for the lack of research in this field: a) general “preconceived notions about the chronically ill” concerning issues of sexuality; b) the fear of stressing an ill person

about their sexual life; and c) priority is given to other issues (e.g. support, care) that are deemed more important. Kalichman further notes that the nature of HIV/AIDS, which unlike other chronic conditions is sexually transmitted and highly stigmatising, suggests that PLWHA face a unique set of challenges to sexual adjustment.

Aspects of one's sexuality such as sexual satisfaction have recently gained recognition as essential components of a patient's quality of life. Thus, health-related quality of life measures among PLWHA on antiretroviral therapy such as the Medical Outcome Study SF-36 form (MOS SF-36), the Multidimensional Quality of Life questionnaire for HIV/AIDS (MQoL-HIV) and the World Health Organization's Quality of Life Instrument for HIV (WHO QOL –HIV)[122, 123] include sexual functioning assessment questions. These quantitative instruments yield valuable numerical data but do not shed light on patients' personal experiences of sexual adjustment after discovering their HIV status and upon initiating HAART. As Ferrell and Coyle[124] note:

Sexuality goes beyond sexual intercourse. It may encompass physical touch of any kind, as well as experiences of warmth, tenderness, and the expression of love. Some patients may view sexual expression as an affirmation of life, or part of being human, a means to maintain role relationships or an expression of passion in life and for life itself. Some patients may view sexual expression as an essential aspect of being, while others see it as ancillary or unimportant. Some may enter into care with an established sexual life partner; some may lose their sexual partner during this period through separation, divorce or widowhood; and others begin relationships at this time. Some have several sexual partners; while others without a sexual partner may gain pleasure by erotic thoughts and masturbation. Understanding the various forms of sexual expression and pleasure is paramount to providing comprehensive care.

The fact that people on HAART are living longer and enjoy improved quality of life means that some might decide to engage in sexual relationships. As more PLWHA in South Africa are being initiated on HAART each year through the public antiretroviral program, concerns about risky sexual behaviours have emerged. Simbayi and colleagues[125] found that 85% of PLWHA on HAART continue to engage in “unsafe” sexual practices, hence there is potential for transmission of drug-resistant HIV viral strains. Wilson et al.[126] suggest that: improved physical functioning after initiating HAART motivates PLWHA to

reengage in sexual activity; misconceptions about the efficacy of HAART in preventing viral transmission (e.g. nevirapine use in preventing maternal-foetal transmission); and the perception that potent HAART lessens the consequences associated with HIV-infection; might contribute to increased risky sexual behaviours. Perceptions that new potent anti-HIV therapies lessen the health threat associated with HIV infection are not entirely unfounded.[127]

The impact of HAART on sexual functioning has been assessed in several studies but the mechanisms mediating these effects are still unclear. An estimated 25-62% of men on HAART have erectile dysfunction[128]; this is much higher compared to the general population.[129] The Schrooten et al.[130] study conducted in ten European countries, found the use of protease inhibitor-based regimens was significantly associated with more frequent reports of decreased sexual interest (40% vs 16%) and sexual potency (34% vs 12%) compared with a control group. Colson et al.[131] found increased rates of sexual dysfunction in males associated with the use of four protease inhibitors (indinavir, saquinavir, nelfinavir and ritonavir) and the prevalence of sexual dysfunction was highest with ritonavir based regimens. Lamba and his colleagues[132] established that the prevalence of low libido and erectile dysfunction among London's gay men was 2 and 10% in the control group; in contrast, decreased libido in 48% and erectile dysfunction in 25% were reported among patients on HAART. Wide variations in the reported prevalence of sexual dysfunction among PLWHA on HAART have been reported. Women on HAART have been found to suffer from decreased sexual enjoyment, libido and sexual potency.[133]

All antiretroviral drugs seem to be linked to sexual dysfunction to varying degrees. Hormonal-associated changes such as the relative elevation of serum oestradiol levels in men[132] and a decrease serum testosterone levels or hypogonadism and changes in the secretion of other hormones[134] have been advanced as possible causes of sexual dysfunction in men on HAART. Increased levels of tumour necrosis factor, interleukin-6 and hydrocorticosteroids stemming from the accumulation of fibroblast and macrophages in lipotrophic areas is thought to accelerate intracellular aromatisation of testosterone to

oestrogen resulting in sexual dysfunction.[135] Collazos et al.[136] found no hormonal association with sexual dysfunction.

Body image is an important aspect of sexuality. HAART-induced metabolic adverse events leading to changes in body shape are common among PLWHA. This phenomenon often results in patients developing negative perceptions about HAART and results in decreased adherence to medications.[137, 138] The term lipodystrophy refers to changes in body fat (or adipose tissue redistribution) that occur in roughly 25 to 34%[139] of people on prolonged HAART regimens that include stavudine, zidovudine, efavirenz and protease inhibitors as one of the drugs[140, 141]. Stavudine which is widely prescribed and is part of the first line therapy in South Africa, is associated with high rates of lipodystrophy.[141] Lipoatrophy or fat loss, occurs primarily at peripheral sites - the arms, legs and face (facial lipoatrophy) and gives the appearance of protruding cheekbones and sunken eyes; fat accumulation, on the other hand, occurs primarily in the stomach, breasts and the posterior neck (commonly known as a 'buffalo hump').[142] Blanch et al.[143] examined the impact of lipodystrophy in 84 PLWHA on antiretroviral therapy. Nearly one third of the respondents' way of dressing was influenced by the changes in body fat; half of the respondents had feelings of shame and about one forth reported disruptions in their sexual life. These undesirable cosmetic changes which occur more frequently with increased adherence could lead to non-adherence especially where patients keep their HIV status a secret. Low-self esteem, depression and withdrawal from social activities have been reported[144] in these patients. As patients attempt to mask/reverse these changes, they also sometimes resort to using CAMs.[145]

2.7.1 Alcohol Consumption and Sexual Behaviour

Alcohol consumption is a well documented risk factor for risky sexual behaviours in South Africa.[146] Multiple concurrent sexual partners, unprotected intercourse, sensation seeking, condom failure, high prevalence of untreated sexually transmitted diseases are associated with alcohol consumption in South Africa.[147, 148] Since the context in which alcohol consumption occurs is an important determinant of risky sexual behaviours[149] they might possibly be observable in *shebeens*/taverns where alcohol is socially consumed.

Potential mechanism by which alcohol consumption leads to increased risky sexual behaviours include increased sexual disinhibition, reduced perceptions of risk and consequences of unsafe sex practices.[150] Since alcohol consumption is associated with both nonadherence and increased risky sexual behaviours, the potential of transmitting HIV, including drug-resistant viral strains is also increased.

2.8 Conclusion

The literature on issues of sexuality among PLWHA on HAART and on medicine taking behaviours reveals that numerous diverse factors influence health behaviours. The complex nature of issues related to sexuality and medicine taking behaviours provides a compelling case for exploring and understanding the specific determinants/factors that apply to this setting.

CHAPTER 3: THEORETICAL FRAMEWORKS EXPLAINING THE HEALTH DECISION MAKING PROCESS

3.0. Introduction

Insights from three health behaviour models - the Health Belief Model (HBM), the Common Sense Model of Self regulation (CSM-SR) and the Transtheoretical Model (TTM) – provided the theoretical framework for this study. The models can be used to study, explain and understand the decision making processes that inform treatment uptake, medicine taking, and sexual behaviours.

3.1 The Health Belief Model

Developed in the 1950s by Hochbaum and his associates, the Health Belief Model[151, 152] has been extensively used to explain and predict individual health related behaviours. The HBM conceptual framework was originally designed to explain why people do not participate in prevention and screening programs but it has been extended to understanding other health behaviours. Components of the original HBM are:

TABLE 2: Constructs of the Original Health Belief Model

Construct of HBM	Brief Explanation
Perceived severity	An individual's assessment of potential medical, economic and social consequences of a disease.
Perceived susceptibility	An individual's assessment of his/her personal likelihood of contracting a disease. This term has been extended to include perceived re-susceptibility (see Figure 1) (the risk of getting re-infected with HIV). Jointly, the perceived susceptibility and perceived severity constitute a perceived health threat
Perceived benefits	An individuals assessment of the advantages or positive outcomes associated with adopting specific behaviours or following a particular course of action
Perceived barriers	This refers to impediments to adopting healthy behaviours. Barriers can be psychosocial, cultural, financial or physical.

According to the model, people assess both the health threat and the proposed course of action before making health decisions. Two constructs – perceived susceptibility and severity – describe a person’s assessment of the health threat whereas perceived benefits and barriers refer to a person’s assessment of the recommended behaviour. The former motivates individuals to act whereas the latter informs their choice on the appropriate behavioural response to enact. Attempts to improve the predictive validity of the HBM have resulted in multiple reformulations since its inception in the 1950s. The additional components that have since been added to the original model are shown below.

TABLE 3: Additional Components of the Health Belief Model

Components	Explanation
Demographic variables	Age, gender, education, marital status, religion
Sociopsychological variables	Social pressure, influence of peers, attitudes and cultural beliefs
Self efficacy Beliefs	Belief in ones ability to execute the necessary behaviour change.
Cues to action	Triggers or precipitating factors that prompt a person to act on desirable health related decisions.

A modified version of the HBM that describes sick role behaviours is shown in Figure 1 below.

As is the case with all values-expectancy theories, the HBM proposes that people’s health beliefs and actions are informed by the value that one assigns to illness threat reduction and the expectations that complying with the recommended health plan will reduce the threat. Before choosing a preferred course of action, individuals carry out an implicit cost-benefit analysis when making health related decisions. Where benefits outweigh the costs, individuals are more likely adopt that particular course of action and vice versa. Various

cues to action are thought to act as triggers for a person to execute the action plan. Cues to action are diverse and highly subjective; the nature and magnitude of a “trigger” needed to inspire action or to activate behaviours may vary depending on the individual’s motivation or cost-benefit evaluation. For highly motivated individuals, the presence of symptoms alone could be a sufficient trigger. Cues to action might be external factors (e.g. mass media, life events and talking to other people) or internal (e.g. somatic symptoms, reflection). The mass media play a central role of informing and education of the public.

Demographic factors and psychosocial variables influence the adoption of health behaviours through acting on one or some of the model’s constructs. Gordillo et al.[153] found that sociodemographic and psychological variables influence PLWHA’s degree of adherence to HAART. The HBM’s constructs do not equally influence health decisions. Perceived barriers have been found to be more consistent predictors of health behaviours than the other constructs.[151]

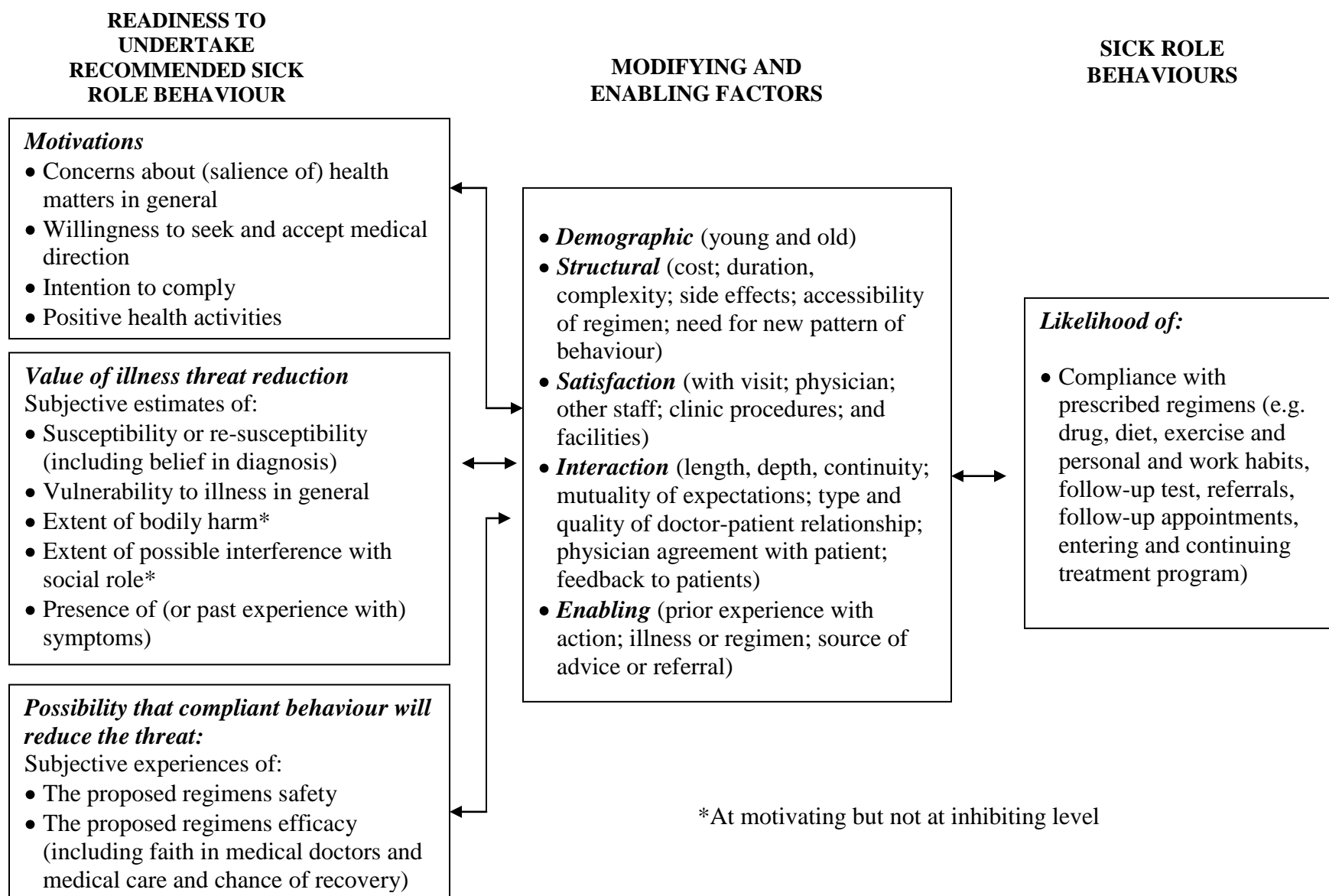


Figure 1: The Health Belief Model for Explaining and Predicting Sick Role Behaviours [154]

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Criticism of the HBM is centred around several issues. First, the lack of standardised questionnaires or measures of various constructs of the HBM makes it difficult to collate, analyse and compare results from different studies. Undertaking a comprehensive meta-analysis of HBM-based studies is therefore difficult. Rosenstock[155] noted that a significant proportion of questions used in some studies do not even measure the HBM constructs that they purport to measure. Secondly, there is a tendency by respondents to underestimate their susceptibility to diseases or health risks - a phenomenon sometimes referred to as “unrealistic optimism” or “optimistic bias.”[156] This is sometimes unaccounted for in studies that use the HBM. Third and last, although some of the constructs of the HBM can predict health behaviours independently, there is a general lack of understanding on how all the dimensions interrelate. This calls into doubt the notion of HBM being a comprehensive model. Harrison et al.’s[157] 1992 statement that “for the HBM to be validated as a model, studies must develop weights and interaction terms that show how its four dimensions work together” remains valid today.

3.2 Leventhal’s Common-Sense Model of Self regulation of Health and Illness

3.2.1 Brief Overview of the Core Tenets of Self-Regulation Models

Self regulation is defined as a “systematic process involving conscious effort to modulate thoughts, emotions and behaviours in order to achieve goals in a changing environment.”[158] It has been proposed as the mechanism through which human behaviour responses are modelled, controlled and altered. A person’s life’s experiences are believed to be organised into scripts or schema which in turn provide the framework for interpreting future events. These cognitive schemas are thought to guide our responses to everyday situations and they are believed to be mutable subject to the availability of important new information. Schemas are thus responsible for “construing and specifying goals.”[159] The underlying assumption with all self regulation approaches is that human behaviour is inherently goal-directed or purposeful; human beings are seen as active problem solvers. Volitional goal setting, self motivation and self monitoring underpin self regulation. Self monitoring involves the individual constantly

assessing his/her progress and attempting to correct the discrepancy between set goals and their current situation.

3.2.2 Description of Leventhal's Common-Sense Model of Self regulation of Illness Behaviours

Leventhal's common sense model of self regulation (CSM-SR)[160, 161] (also called the self regulation model of illness representation) proposes that health related behaviours are influenced by a person's beliefs, ideas and expectations concerning his/her illness. These cognitive representations of the health threat inform the nature of the coping strategies that they adopt. This model emerged from studies by Leventhal and associates[162] on the impact of fear messages and action plans on people's attitudes towards adopting recommended health behaviours. Although high fear messages were associated with better attitude changes than low-fear messages, neither of the two resulted in sustained attitude change. From these studies, they concluded that peoples' representations of the health threat *and* the available action plan determine their responses or coping strategies. The model has since been expanded to understand medicine taking in patients with chronic diseases.[163]

Individuals are construed as active problem solvers concerning their illness and it is assumed that they use their common sense understanding to assign meanings to symptoms and to make health decisions. The CSM-SR recognizes that people's ideas about their illness might not always be congruent with the tenets of the mainstream biomedical model. Instead, the model focuses on patient's subjective views and how they perceive and understand their illness.

Leventhal proposed a dual process model in which both cognitive and affective pathways mediate responses to illness in parallel to each other. Cognitive processes involve the application of one's knowledge and reasoning in devising mechanisms to cope with the health threat. Emotions such as fear, hope, doubts, and anger reflect on the individual's satisfaction with how well their actions are progressing towards attaining set goals. Hope signifies confidence that the planned action plan is feasible, sustainable and will result in the desired outcome. Strong self efficacy beliefs are associated with being hopeful.[164]

The process of self-regulation of health behaviours is divided into three stages (See Figure 2 on page 43):

- 1) **Representations of illness:** involves appraisal of the health threat
- 2) **Coping response/Action planning:** involves the adoption of appropriate coping strategies in response to the health threat
- 3) **Appraisal stage:** the individual's appraisal of the success of coping strategies in accomplishing the set goals.

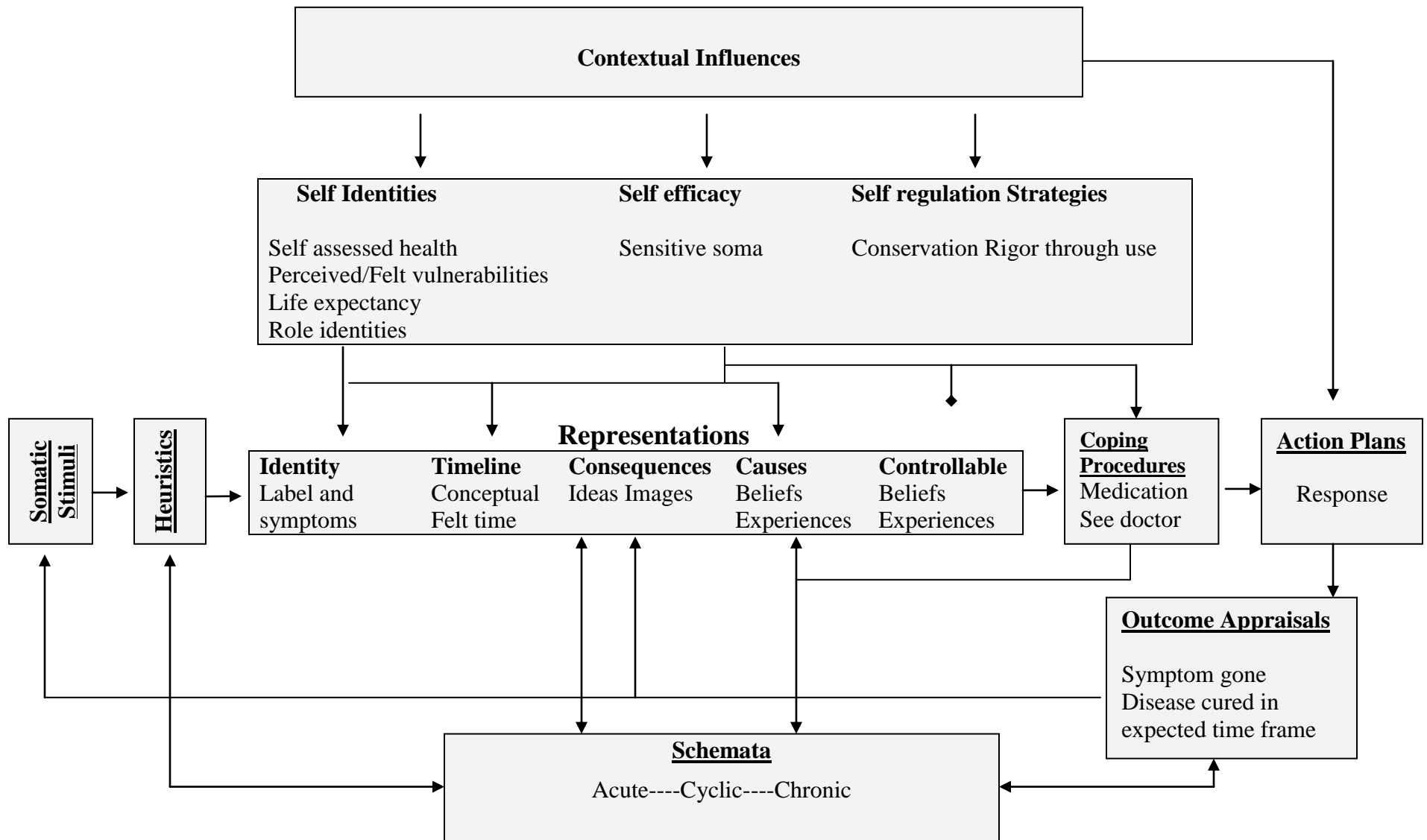


Figure 2: Leventhal's Common Sense Model of Self Regulation[163]

Stage 1: Appraisal of the health threat and goal setting

Initial stimuli (*either* internal stimuli; somatic pain, itching, oedema; *or* external stimuli; messages such as “you look thin!”, “your eyes look inflamed!” “your CD4+ cell count is very low”, “hair loss”) alerts individuals to the presence of a health threat. Individual’s cognitive representation of the health threat are then constructed based upon their past experiences with similar illnesses (pre-existing schema); their impression of somatic symptoms; information from the health care system, media, friends and significant others; personal experiences of seeing others with similar illness; cultural construction of the illness; and the perceived origins and cause of the illness. According to the CSM-SR, individuals consider the following five dimensions in assessing the health threat.[161]

TABLE 4: Component of Illness Representation

Component of illness representation	Brief explanation (including examples)
Identity of the illness	This refers to individual’s own evaluation of the symptoms that enables them to label the illness
Perceived cause of the illness	Individual’s ideas about the origin/cause of their illness. E.g., Pathogens? Spiritual? Stress? Witchcraft? Genetic? Malnutrition?
Timeline	Refers to the anticipated duration of the symptoms E.g., How long will the illness persist? Is it temporal or chronic?
Consequences of the illness	Individual’s perceptions or expectations of the outcome of the illness if allowed to continue without any intervention. E.g., Is it a serious condition? How is it going to affect my lifestyle?
Curability/Controllability of the illness	Concerns about whether the illness can be controlled or cured. E.g., How can I improve my prognosis and quality of life? Using medication? TCAMs? Dieting?

An example of how these five constructs influence illness representations is as follows. An individual might experience inflamed cervical lymph nodes, a persistent dry cough at night and flu-like symptoms. Based on these symptoms and existing information, one might decide to label this illness as HIV infection. By so doing, the person has implicitly

assigned the timeline (i.e. chronic) to the health threat and its consequences (imminent death if untreated). The individual might then formulate and implement a common sense plan such as eating a balanced diet, exercising, and avoiding stressful situations until such a time when he/she is initiated on HAART. While this is happening, a parallel emotional response to the HIV-diagnosis is in progress.

The Illness Perception Questionnaire (or variants of it)[165] which is based on the five constructs has been used to explore people's illness representations (including HIV/AIDS). Current evidence suggests that illness representations shape people's choice of coping procedure, including whether to adhere to treatment and lifestyle recommendations.[166] A study conducted across five countries by Reynolds et al.[166] explored the impact of PLWHA's perceptions about their illness on self care behaviours and quality of life outcomes. They found that quality of life outcomes were mediated via self care behaviours, which in turn were influenced by the respondents' perceptions of the seriousness, consequences and controllability of the disease.

Stage 2: Formulating and implementing coping strategy/action plan

The process by which illness representations foster the adoption of specific self-care behaviours is mediated through coping strategies. The term coping strategies is used here to describe people's responses to stressful situations and/or actions that they take to attain set goals. Although processes leading to the adoption of specific coping strategies are still poorly understood,[161] coping procedures have been delineated into two groups: problem-focused or emotion-focused coping. Maladaptive emotional coping strategies include denial, transferring blame for the illness to others, avoidance behaviours and depression whereas adaptive emotional responses include acceptance of one's circumstances and seeking emotional support from others. Examples of problem solving coping include seeking medical attention and adhering to treatment and lifestyle recommendations.

- ***Stage 3:*** Appraisal of the success of the action plan

At this stage, after implementing the action plan, the individual evaluates whether he/she has achieved the intended goals. Positive outcomes may reinforce performance of that action and negative outcomes might cause individuals to adjust their actions.

3.2.3 Extended self-regulation model and Horne's necessity-concerns framework

Horne's necessity-concerns framework[167] is an extension of Leventhal's self regulation model, and provides a simple quantitative instrument for assessing patient's beliefs which inform their adherence behaviours. According to Horne,[168] "adherence/non-adherence behaviours reflect patient's appraisal of their illness, and their concerns and beliefs about the necessity of treatment." Horne reduced patient's illness and treatment perceptions into two categories: beliefs about necessity and concerns about medicines.

Necessity beliefs are informed by a person's assessment of the seriousness and consequences of the illness. Thus the presence of symptoms might serve to reinforce one's necessity beliefs for medications. Low perceived necessity for HAART is associated with rejection of treatment, higher non-adherence levels in the long-term and poor clinical outcomes. Concerns create doubts about the need for medicines. The relative balance between necessity beliefs and concerns has been shown to predict adherence behaviours.[88]

3.3 The Transtheoretical Model (TTM)

The TTM integrates the core tenants of other psychosocial behavioural theories but unlike the HBM, it explicitly acknowledges the temporal nature of intentional behaviour change. It advances that change is not a once-off event but rather a process that occurs in six stages. Also known as the "Stages of Change" model, the TTM was originally developed by Prochaska and DiClemente[169] in an attempt to address the limited success of other behavioural interventions to the problem of addictive behaviours (alcohol and smoking). It has since been adopted and adapted to explaining various health behaviours including adherence behaviours. The four core domains of the TTM are:

stages of change, process of change, decisional balance, situational self efficacy beliefs and temptation. These are discussed in detail below.

3.3.1 Stages of Change

The TTM advances that behavioural change occurs over a protracted period of time in six sequential stages.[170] Self-change is thus not a spontaneous event but a process. Each stage reflects the individual's attitude, self efficacy beliefs and degree of motivation towards attaining behavioural change. According to the model, adherence interventions should be tailored based on the patient's needs and readiness to change. As such, it advocates for stage-matched interventions that recognise that different strategies and messages are needed to assist people in different stages of behavioural change.[170] Hence knowing the patients "stage of change" at any particular time cloud enable pharmaceutical care practitioners to provide suitably designed educational interventions.

The model also acknowledges that behaviour change is not a linear process as shown in Figure 3 (page 49). Recycling and relapse may occur at some stages. The six stages of change are labelled: pre-contemplation, contemplation, preparation, action, maintenance and termination. These are further considered using the context of adherence below.

Stage 1: Pre-contemplation During this first stage, the person seems indifferent to their situation. He/she is in a state of denial and is oblivious to the consequences of inaction. Also, the person has no intention of changing his/her behaviours in the foreseeable future. When applied to the issue of adherence to treatment, at this stage the person is unconcerned and uninterested in taking his/her medication. He/she tends to be "defensive", uncooperative and detached from the situation.[171] Because of this, the provision of information/adherence counselling at this stage has minimal to no impact at all.

Stage 2: Contemplation The contemplation stage is believed to occur several months after initiation of treatment and involves the patient at least thinking about adopting the desired action (i.e., becoming adherent). The person accepts that there is a problem, but is yet to fully understand the precise nature and consequences of the

problem.[171] At this juncture, an assessment of the pros and cons to behaviour change is ongoing. The patient is actively searching for information about his/her problem so educational interventions might be helpful.

Stage 3: Preparation When a person believes that the benefits of behaviour change outweigh the costs, he/she then prepares to take action within the next 30 days or so. For example, the person might purchase an alarm clock or devise a plan to help him/her to remember when it's time to take medications. Also, he/she might start experimenting to determine whether their intended course of action is doable. The preparation stage has not been verified by studies on adherence to medication.[171]

Stage 4: Action Actual implementation of the change plan occurs at this stage and some maladaptive behaviours are discarded. The period typically stretches for up to 6 months from the time one starts implementing the behaviour change plan. Since the change is still current, the person needs to develop ways of coping with temptations which might lure them into a backwards spiral.

Stage 5: Maintenance After six months of implementing the action plan, the person enters the maintenance phase. At this stage, he/she strives to integrate the behavioural transformation into daily activities, by so doing, durable change takes root and the risk of relapse is reduced.

- Indicates the applicable process of change

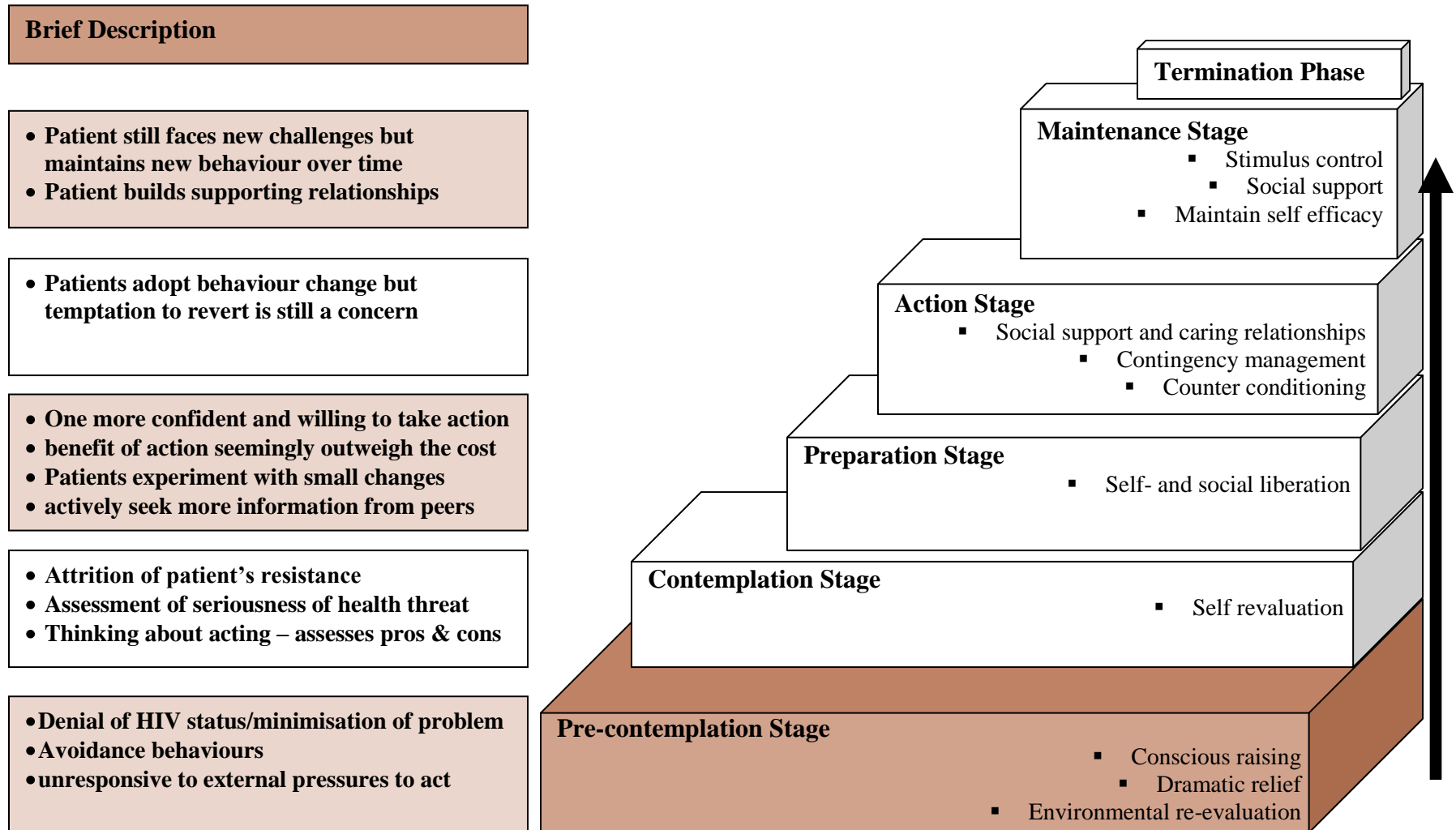


Figure 3: Illustration of the Transtheoretical Model

Stage 6: Termination At this stage, the individual is absolutely sure that they will not relapse to old behaviours.

3.3.2 Process of Change: Moving From One Stage to Another

Diclemente and Prochaska[169] use the term “process of change” to refer to “the engines that facilitate movement through the stages of change.” The term answers the question: How does change in behaviour occur? After extensive research into behavioural change, Prochaska identified ten processes that people use to bring about behaviour change.[172] Processes are classified into two distinct categories namely: the behaviour or experimental domains. See tables 5 and 6 below for details.

A. Behavioural Processes

TABLE 5: Behavioural Processes of Change

Process	Brief Description
Helping relationships	Establishing connections with other people that provide support for the behaviour change. PLWHA may choose to disclose their status enabling them to mobilise emotional and tangible support from friends and family.
Reinforcement management	Self motivation through self-rewards to encourage /reinforce adherence to medication. For example, one might decide to reward oneself with a special gift if one successfully adheres to medication at the end of each week.
Counter-conditioning	Denotes “substituting alternatives for problem behaviours.”[173] For example, instead of taking alcohol, one might engage in recreational sporting activities.
Social liberation	Understanding that one’s society does indeed support that particular behaviour (e.g. adherence to medications).
Stimulus control	Involves removing cues that promote non-adherence to medication and adding those that facilitate adherence. For example, one might decide to use reminders to complement one’s memory or join support groups.

B. Experimental Processes

TABLE 6: Experimental Processes of Change

Process	Brief Explanation
Consciousness raising	Individuals actively search for information with the aim of gaining more understanding of the nature and consequences of non-adherence. By so doing, they increase their level of awareness regarding the appropriate behaviour.
Dramatic relief	Experiencing negative emotional arousal (fear, uncertainty, anxiety) that accompanies non-adherence behaviours.
Self re-evaluation	Self-appraisal of one's progress towards becoming adherent
Environmental re-evaluation	Individuals' cognitive and affective assessment of the impact of good adherence to treatment on their immediate physical and social environment
Self-liberation	Showing commitment and will-power to achieving adherence. The person might do this by making public commitment, entering into a contract, keeping a diary or by making it their new year's resolution.

3.3.3 Decisional balance

Another cornerstone of the TTM is the proposition that an individual's health-related decision making is informed by decisional balance. Decisional balance is an assessment of the potential benefits (pros) and cost (cons) of changing one's behaviour. The decisional balance inventory[174] has been developed to assess people's evaluation of the pros and cons of behavioural change. The pros of change are the perceived benefits (desirable outcomes) of change whereas the cons are the costs (undesirable consequences) of changing one's behaviour. The net balance of pros and cons varies across stages. During the pre-contemplation stage, the cons significantly outweigh the pros; in the contemplation stage, the pros and cons are almost evenly balanced and in the subsequent stages, the pros outweigh the cons.

3.3.4 Self efficacy

Self efficacy refers to the perceived ability of an individual to implement the necessary behaviour change even in the face of competing challenges and barriers. Bandura[175] describes self efficacy beliefs as a "set of proximal determinants of how people behave,

their thought patterns, and the emotional reactions they experience in taxing situations.” People are motivated to assume behaviours which they believe can be executed successfully.[164] A person’s motivation and self efficacy beliefs vary depending on their stage of change.

3.5 Conclusion

In this chapter, three models that are widely used to explain and understand individual health decision making were examined. The individual’s disease knowledge, beliefs, attitudes, perceptions of necessity and concerns, decisional balance are believed to influence their health behaviours. The underlying assumption across all models is that the overriding goal in life is survival: people strive to avoid illness or at least minimise its impact on their lives. They are more likely to undertake a particular course of action if they believe they have reasonable chances of achieving this goal. From this perspective, patients are characterised as active problem solvers.

4.0 Introduction

The terms methodology and methods are often used interchangeably and thus incorrectly. Creswell and Tashikkori's[176] offer a precise description: a comprehensive methodology accounts for the “entire research process...[its] philosophical assumptions, data collection, analysis and interpretation of findings.” This research follows Creswell and Tashikkori's interpretation of the term methodology as encompassing the philosophical underpinnings of the research, as well as its design and the series of steps that the researcher takes in conducting a study. All of these are described here.

After reviewing the several research methodologies, the mixed methods approach was selected. In this chapter, the researcher explains and justifies the logic for adopting mixed methods to answer the research questions and how two seemingly incompatible paradigms – quantitative and qualitative – were integrated in a pragmatic way to understand the phenomenon under investigation.

4.1 Research Paradigms

Morgan[177] defines the term paradigms in four ways:

Paradigms are i) worldviews (all encompassing systems of beliefs and practices on the world); ii) they are epistemological stances (ontology, epistemology and methodology); iii) are exemplars (best or typical solutions to problems) or iv) are shared beliefs in a research field (shared beliefs about the nature of questions and answers among members of a specialty area)

Originally proposed by Thomas Kuhn[178] and redefined by others over the past four decades, the concept of paradigms advances that a system of shared beliefs within scientific disciplines guides scientific research. These shared beliefs or philosophical assumptions shape our thought patterns; how we define research problems, make observations and how we interpret them. Research paradigms differ in their

characterisation of the nature of reality (ontological assumptions) and how knowledge is acquired (epistemological assumptions). Axiological, rhetorical and methodological differences also exist between paradigms.[179]

Historically, two worldviews or paradigms - quantitative and qualitative paradigms - have dominated health behavioural research. The quantitative paradigm – also called the positivist, empirico-analytic or hypothetico-deductive approach – advances the notion of a singular, objective reality that exists independently of the researcher.[179] Measurements using structured instruments generate numerical data that can be statistically manipulated. In contrast, the qualitative paradigm advances that reality is subjective, socially constructed and that multiple realities exist based on peoples' varying interpretations of the world. Consequently, to understand reality, the qualitative researcher needs to make observations or at least engage in dialogue with the people who are being investigated, and ideally in their natural setting in order to understand how they make meaning.[179]

Quantitative studies use hypothetico-deductive logic in which numerical data gathered from a large sample size are statistically manipulated to test for causal-effect linkage or to test pre-existing hypothesis/theories. The aim is to generalise findings to some larger population. By so doing, quantitative studies decontextualise human behaviour. In contrast, all qualitative studies use people's personal narrative or texts as data to explore the meanings people attach to personal and social phenomena in order to increase our understating of them. Some qualitative studies use inductive reasoning (from data to theory) to generate theories, for instance Grounded Theory.[180] Most use a combination of inductive and deductive reasoning to move and arbitrate between theory and data.

The positivist approach enables researchers to quantify/measure and to explore statistical relationships whereas the naturalist approach enables researchers to explore the reasons (why?) and the mechanisms (how?) via which social phenomena occur. Quantitative approaches are criticised for decontextualising human behaviour: critics say human behaviours are inherently complex - both medically and behaviourally - and to

understand social phenomena, rich personal data are required.[181] Criticism of the qualitative approach stems from its inability to generalise findings because of non-random sampling techniques and small sample sizes, and because of concerns about validity and reliability.[179] These criticisms are discussed in more detail in below, but for now the following examples illustrate important differences between the two approaches or paradigms and also form a basis for arguing that using insights from qualitative as well as quantitative paradigms leads to a better understanding of the complex social and personal aspects that this study sets out to explore.

Keegan[182] used a *qualitative* approach to understand the impact of HAART on sexual functioning among PLWHA. Although the study yielded valuable insights, a shortcoming of the study is that the lack quantitative instruments made it difficult for the study to gauge changes in sexual functioning before and after the respondents were started on HAART.

In contrast, Lambert et al.[183] used *quantitative* research to survey factors affecting sexual relationships among women living with HIV/AIDS on HAART. They found that about a third of women diagnosed with HIV abstained from sex and that over half of those with sexual partners reported some sexual dysfunction. Coping strategies employed by the participants included decreased frequency of sex, avoidance of sex and non-communication. Avoidance behaviours and reduced condom use were associated with depression and anxiety. However, the quantitative results do not shed light on the reasons *why* some women adopted such behaviours. Another example is that of Eisele et al.[146]: they used a *quantitative* approach to explore sexual behaviours in PLWHA on HAART in Cape Town. The large study sample size meant that the results could be extrapolated to a larger population but the results provides little/no insights into some important questions: *Why* do PLWHA who are waiting to be initiated on, or who are already on HAART continue to engage in unprotected sexual intercourse? *How* do they feel about using condoms during sexual encounters? *How* has HAART impacted on their sexual functioning? To be fair, the abovementioned questions were not what they set out to answer, but they demonstrate limitations of utilising quantitative approaches in isolation.

At the core of the quantitative/qualitative divide there are disagreements over epistemological and ontological assumptions. Kuhnian postulates[178] advance that from a philosophical standpoint, paradigms are essentially incommensurable and thus mixing both research methodologies in a single study is inconceivable. But the aftermath of the “paradigm wars” has seen the coalescing of researchers dissatisfied with the constraints imposed by this philosophical divide and this gave rise to the mixed methods movement. The movement’s philosophical underpinnings are grounded in pragmatism and reject the “false dualism,” of “unproductive dichotomies” created by purist’s stances.[184] Zeller[185] notes that:

Qualitative and quantitative techniques differ dramatically in their purposes, goals, objectives, tactics, strategies, strengths and weaknesses. The original question that prompt the research and the new ones that emerge from its results require a blending of methods.

Johnson[186] et al. define mixed methods research as:

...the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference technique) for the broad purpose of breadth and depth of understanding and corroboration.

Or, alternatively, they define mixed methods research as:

...the use of data collection methods that collect both quantitative and qualitative data. Mixed methods research acknowledges that both methods have inherent biases and weaknesses; that using mixed method approach increases likelihood that the sum of the data collected will be richer, more meaningful, and ultimately more useful in answering the research questions

Over the last two decades, proponents of the mixed methods approach (e.g. Creswell, [187] Morgan,[177] Tashakkori,[188] and others) have elaborated on various facets of mixed methods research, such as the sampling logic, research design, as well as integration and analysis of both types of data. It should be noted that some inconsistencies still persist within this methodology.[184]

Pragmatism is the guiding philosophy for mixed methods research[189, 190] Its central tenet is a focus on ‘what works’ in answering the research question as opposed to concentrating on debates about the nature of reality and knowledge acquisition, which can easily become polarised and dogmatic. As Reason[191] put it:

The characteristic idea of philosophical pragmatism is that ideas and practices should be judged in terms of their usefulness, workability, and practicality and that these are the criterion for their truth, rightness and value. It is a perspective that stresses the priority of action over principle.

And, according to James:[192]

[Pragmatism]...turns away from abstraction and insufficiency, from verbal solutions, from bad a priori reason, from fixed principles, closed systems, and pretended absolutes and origins. ..It means the open air and possibilities of nature, as against dogma, artificiality, and the pretence of finality of truth.

By placing emphasis on the workability and usefulness of ideas – on what works best in understanding real life situations - pragmatists argue against philosophical imperialism. Morgan [177] notes that pragmatism focuses on “what difference it makes to believe in one thing versus another or to act one way rather than another.” Furthermore, he rejects situations where ontological assumptions inform epistemological issues which in turn dictate methodological issues. He argues that this “top-down” approach is “too simplistic,” and instead advocates that the connection between the methodology and epistemology need to take precedence. In other words, a researcher’s ontological and epistemological stances should not prevent him/her from employing the most appropriate data collection and analysis methods for answering research questions.[190] Thus pragmatism advocates for methodological pluralism and diversity.

In embracing methodological pluralism and diversity, the choice of a mixed-methods approach enabled this study’s researcher to formulate a flexible and pragmatic research design. This study aim was to understand the what as well as the why of participants’ perceptions and behaviours. Using mixed-methods enabled the researcher to obtain

quantitative measures of participants’ use of HAART and the impact of HAART on their sexual functioning whilst *qualitative interpretations* allowed for nuanced and more comprehensive insights into what motivates participants’ medicine taking behaviours, their personal experiences of medicines, and how HAART impacts on their sexuality.

When quantitative and qualitative approaches are combined, weaknesses inherent in each approach are partially counterbalanced and their complementary strengths can be harnessed to generate a more compelling account of the social phenomenon being investigated.[179] Secondly, the weaknesses inherent in one data collection technique were partially offset by using other techniques. In this study, the researcher sought to generate numbers as well as attribute meaning to the numbers. Thirdly - as discussed in more detail in “**Strategies for Validation**” (on page 75) - using multiple data sources or triangulation enhances the credibility of the final account.

4.2 The Triangulation-convergence model of a mixed-method design

The triangulation - convergence model for mixed methods study[187] (see Figure 4) was adopted for this study to guide data collection, analysis and the integration of findings.

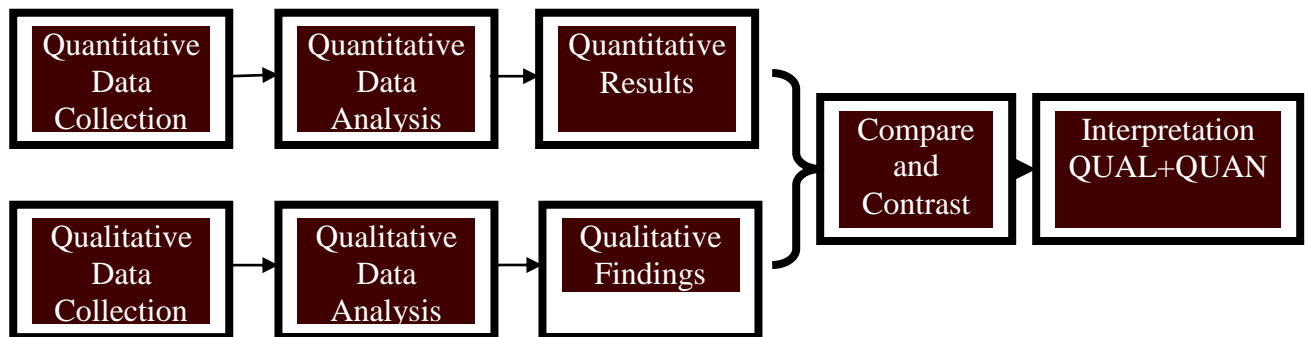


Figure 4: The triangulation Design – Convergence model[187]

In this study both qualitative and quantitative data were collected simultaneously. The quantitative phase was embedded within a predominantly qualitative study (QUAL+quant study design)[187] Quantitative instruments – modified Horne’s Beliefs about Medicines Questionnaire[167] and a self-designed numerical rating scale on sexuality (see appendices 2 and 5) – were used to assess participant’s use of HAART and their

perceptions of its impact on their sexuality. Qualitative techniques use were in-depth interviews, which enabled participants to describe their daily experiences of taking HAART using their own words, and document analysis[179] of participants medication records.

Figure 5 below provides a detailed outline of the research design adopted in this study.

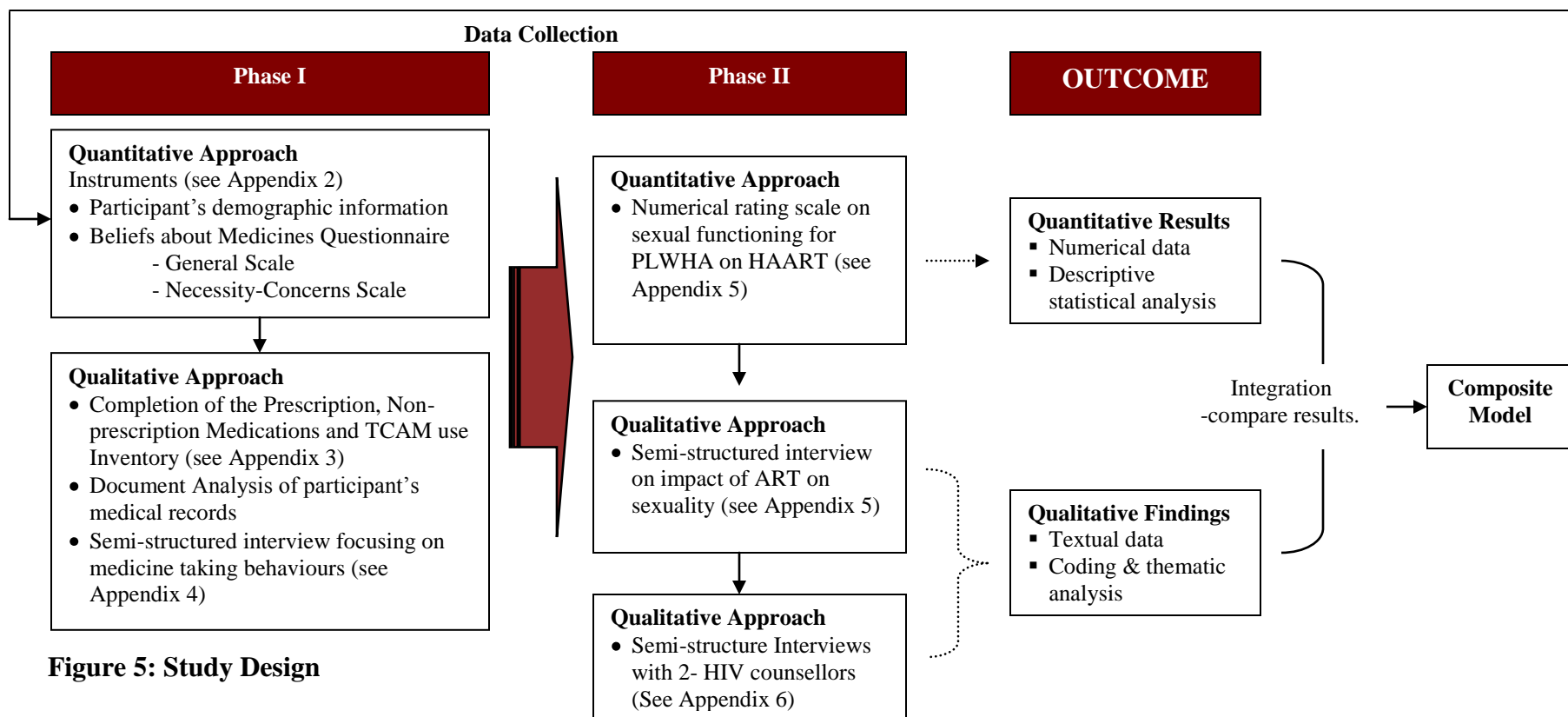
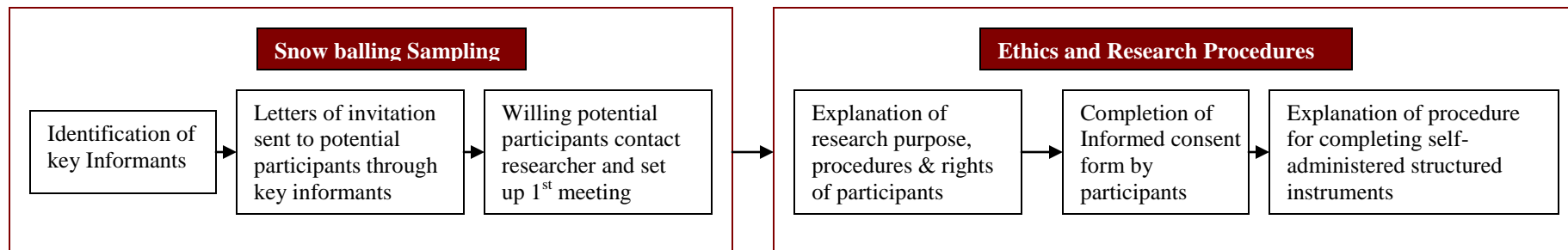


Figure 5: Study Design

4.3 Sampling Design

Sampling refers to the systematic process of selecting participants or items for inclusion into the study. Collins et al.[193] notes that important elements of a sampling design are the sampling unit, sampling scheme and the sample size. Sampling units are basic, indivisible elements of the study population subject to sample selection, in this case, individual PLWHA on HAART and individual HIV counsellors. The approach or strategy one uses to select the units is called the sampling scheme. The sample size is the number of sample units chosen for inclusion into the study.[193] These are described below.

Purposive sampling is a non-probability sampling technique in which the participants/sampling units are selected on purpose to achieve certain predefined goals.[193] From the outset, this study sought to focus on the medicines taking behaviours and experiences of sexuality among PLWHA who are Rhodes University community members: Initial liaison with campus-based HIV/AIDS advocacy groups indicated that PLWHA at Rhodes were generally hesitant to disclose their HIV status because of the high levels of stigma and secrecy associated with the illness. This made it difficult to enrol enough participants into the study. So sampling was extended to members of a nongovernmental organisation, the Raphael centre, located in the Grahamstown community.

Fortunately, the researcher was introduced by a colleague to a person in the Rhodes University community who is living with HIV and on HAART. She is referred to as the key informant throughout this thesis. She is a retired HIV counsellor, an HIV activist, openly living with HIV/AIDS, and had been taking HAART for just over ten years. She provided the critical link between the researcher and other PLWHA on HAART at Rhodes. Using the Raphael centre, the researcher was able to gain access to people on HAART in the Grahamstown community

The snowball sampling technique[194, 195] was then employed to select additional participants. Snowball sampling is traditionally reserved for sampling “rare” populations and involves one or more participants leading the researcher to additional participants.[194, 195] It was also appropriate because it was a relatively inexpensive way of generating a sample. Snowball sampling, however, suffers from the problems inherent in all non-probability sampling methods. Self selection by participants yields samples that are not representative of the general population and the small sample size means that results of the study are not generalisable. Because participants self select, a relatively homogenous sample was achieved. The merit of using snowballing sampling method is that it eliminates the researcher’s selection bias.[195]

Convenience sampling[193] was used to select two HIV counsellors working with PLWHA at Settlers Hospital. Convenience sampling occurs when individuals are selected based on whether they are readily available and are willing to participate in the study. Two HIV counsellors were included in order to obtain different perspectives on the phenomena under study.

In terms of size, 14 PLWHA on HAART were enrolled into the study. Six were from the Rhodes university community and eight were from Raphael centre, which serves (mostly disadvantaged) PLHWA.

4.3.1 Inclusion Criteria

The following criterion was used to determine the eligibility of prospective participants for inclusion in the study. Participants had to be:

- HIV-infected
- On HAART for at least 6 months preceding this study. Participants were asked to bring their medical records (commonly called *passport*) as proof.
- Between 18 and 60 years of age
- Able to provide written informed consent with minimal assistance for the researcher
- Able to communicate fluently in either isiXhosa or English. This was subject to my own assessment.

4.3.2 Exclusion Criteria

The following factors disqualified people from inclusion in the study:

- Prospective participants with illnesses that might potentially impede on their ability to contribute effectively to the study, for example, diarrheal diseases, cognitive impairment or active mental illness, malaise, or being bed ridden.
- Those who do not meet the inclusion criteria stated above.

4.4 Data Collection Tools

The tools described below were structured to address questions that were used to examine medicines taking behaviours. It is important to note that many of the advantages and limitations of the structured tools in terms of (quantitative) validity, reliability and generalisability are not relevant to this study in as far the small sample did not yield data suitable for complex statistical analyses. Rather, quantitative data yielded *counts* to aid (a) the generation of more simple descriptive statistics and (b) to allow more insightful interpretation of and comparison with qualitative data.

4.4.1 Structured Instruments

4.4.1.1 Demographic Data

Participant's demographic data such as age, marital status, monthly household income, education level, religious beliefs, and number of children were collected.

4.4.1.2 Beliefs about Medicines Questionnaire - General (BMQ-G) and the Necessity-Concerns Framework

Developed by Horne, the Beliefs about Medicines Questionnaire (BMQ)[87, 88](see Appendix 2) is a self report instrument that has been used extensively in health behavioural research to assess the influence of patients' personal beliefs, perceived personal necessity for treatment, and concerns about medication in relation to treatment. The BMQ is derived from an extension of Leventhal's common sense model of self regulation. The questionnaire consist of two sections: a) the *general scale* that is further subdivided into the general harm, general overuse and general benefits subscales, each with four items; b) the *necessity-concerns scale* that is subdivided into

the necessity scale and the concerns subscales, each with five items. Each item is rated on a five-point Likert scale which allows respondents to indicate their degree of agreement or disagreement with statement/items. Participant's responses are assigned the following numerical values: 1 = strongly disagree, 2 = disagree, 3 = uncertain, 4 = agree and 5 = for strongly agree.

Unlike the BMQ's general scale, which assesses patient's beliefs about medicines in general without making reference to specific medicines or disease/illness, the necessity-concerns scale focuses on specified medicines for a particular illness. It takes into account the fact that patients' perceptions about medicines are dynamic and vary depending on the nature of the illness and the extent to which different treatments affect the individual's lifestyle.

4.4.1.3 Prescription and Over-the-Counter Medicines, & TCAMs Use Inventory

Participants were asked to list all orthodox medicines (prescription and over-the-counter medicines), traditional medicines, complementary and alternative medicines that they had used in the six months preceding the study on the form shown in Appendix 3.

4.4.1.4 Numerical Rating Scale on Sexuality

In reviewing literature, it was evident that there is a general deficit of validated structured instruments to accurately assess sexual functioning among PLWHA on HAART. Aspects of human sexuality such as sexual enjoyment, libido, and sexual satisfaction are important determinants of patient's health-related quality of life (HR-QoL). Various HR-QoL measurement instruments among PLWHA such as World Health Organisation's HIV Quality of Life (WHO-QoL)[122, 123] and HIV/AIDS Targeted Quality of Life (HAT-QoL) instruments[196] have only recently incorporated these aspects, albeit tangentially.

After reviewing research from other fields of study (e.g. pain, mood disorders and depression) for clues on measuring subjective phenomena/experiences that require self

report, the researcher chose to use a self-rated numerical rating scale¹¹ to explore issues of sexual adjustment after being initiated on HAART. Participants were asked to rate certain aspects of sexual functioning before and after being initiated on HAART on a numerical scale, with zero being the lowest score and 10 being the maximum score. Self rated items included: general quality of life, sexual enjoyment, sexual libido, and sexual satisfaction.

The numerical rating scale was chosen because it offered several advantages. Because issues of sexuality tend to be private and sensitive in nature, the scale provided an unintrusive method for collecting data since it was self administered. Also, potentially difficult-to-understand quantitative terminology associated with structured questionnaires is avoided. As some study participants had low literacy levels, the use of numerical rating scale was meant to facilitate comprehension and compliance in the study. Furthermore, numerical rating scales are relatively easy to administer, can be administered verbally when necessary, and can be completed in a short space of time.[197]

It is worth mentioning that the modified Beliefs about Medicines Questionnaire and the numerical rating scale used in this study were not tested for internal consistency (degree of correlation between items and entire scale), validity (whether instrument measures the construct it is intended to measure) and reproducibility (ability to consistently produce similar score when used repeatedly) in the South African context. However, as stated before, complex statistical analysis and generalisation of the findings were not intended; the primary reason for using these instruments was to complement and add precision to the qualitative data obtained face-to-face in-depth interviews.

¹¹ Visual analogue scales are ‘quasi-dimensional ordinal scales’ on a 100mm horizontal line ‘whose ends are labelled as extremes.’[197] The scale is contains descriptive terms of distance (e.g. mild, moderate, and severe) are incorporated into the scale to provide guidance to respondents.

Numerical rating scales are similar to visual analogue scales except that they are graduated with numbers.

4.4.2 Semi structured Interviews

As mentioned earlier (page 54) interviews are common in qualitative research. They enabled the researcher to probe respondents' answers to questions and gave participants the opportunity to narrate their experiences of taking HAART in their own words thereby contextualising some of their decisions. In designing this study the researcher was acutely aware of the sensitive nature issues relating to sexual practices, which are considered taboo or private in many societies. Face-to-face in-depth interviews were thus chosen over focus group discussions because they offer more privacy. Most interview questions were open ended to avoid imposing predetermined responses and leading questions. Interview schedules (see Appendix 4-6) were used to guide the content and sequence of questioning. The interview style was conversational and questions were not limited to those in the interview schedules. If a participant said something particularly interesting, the researcher probed them on the issue to better understand the meanings of what they were saying[198] A follow-up interview was carried out for data that were collected using the quantitative tools (the BMQ and NRS-S) in order to (a) seek elaboration on and clarify quantitative data, and (b) to identify similarities and reconcile differences between quantitative responses and qualitative statements.

With the participants consent all in-depth interviews were digitally recorded and transcribed.

4.4.3 Document Analysis

PLWHA who access HAART through public sector keep detailed medication records in the form of booklets or diaries, know as the *passport*.¹² (See Appendix 12 for an example of the diary). In this study the *passport* was used for several purposes, namely; a) as verification that participants qualified for inclusion into the study; b) the

¹²Personal medication records or health passport contain a comprehensive record of the patient's medications (prescription and nonprescription medications, herbal products, and other dietary supplements).

diaries provided up-to-date, systematically recorded information and useful insights that were sometimes forgotten by participants during in-depth interviews; c) document analysis yielded important insights which were used to supplement data from in-depth interviews and structured questionnaires, and d) like the structured questionnaire instrument, document analysis is a relatively unobtrusive way of collecting data: researcher-participant contact is minimal and participants have more privacy. The following data were collected from passports:

- Self reported adherence to HAART. Since participants are required by their health care providers to maintain a diary of how they actually take HAART on a daily basis, reviewing these records provided insights into potential non-adherence behaviours. Time-between prescription refills were also examined as a rough estimate of participant's adherence levels.
- The diaries were also designed for patients to record the day-to-day challenges they face when taking HAART. Some (six) participants systematically recorded HAART-related adverse events for their doctors to when they presented at clinics for prescription refills.
- From the participants' personal medication records, it was possible to compile an inventory of all the prescription medicines and some of the non-prescription medicines that were prescribed for participants in the six months preceding the study.
- Reports of sexually transmitted infections were used as proxy indicators of risky sexual behaviours. This background data were useful when questioning participants on sex-related behaviours such as condom use.

As anticipated, several weaknesses associated with document analysis were encountered. Although all participants brought their medical records, some diary entries were incomplete and misleading.

4.5 Piloting the Data Collection Tools

Pretesting or piloting of data collection instruments is essential to conducting rigorous research.[199] Primary concerns that prompted the pretesting of both the structured questionnaires and the interview questions were related to possible negative emotional reactions to some culturally sensitive and intrusive questions especially sex-related ones. The content of some questions and the way in which they were asked could potentially lead to inhibition or premature termination of the interview. By having a one participant – the key informant - review the interview questions, the researcher was able to: a) identify respondent-related problems such as the ease of comprehension of questions and negative emotional responses induced by some sensitive questions e.g. sadness and embarrassment; b) assess interviewer-related factors such posture, gestures so that the ability to ask sensitive questions are tried out in real life situations; and c) process-related factors : because multiple data collection tools were used, pretesting enabled the researcher to gauge the optimal timing and sequencing of data collection.

Pretesting was done with one respondent - the key informant – who the researcher felt was ideally suited for this role because of her unique background – as pointed out earlier, she was living with HIV/AIDS, had been on HAART for over a decade and had experience working with PLWHA as a HIV counsellor for nearly six years. During this pilot phase, the researcher administered all questionnaires and carefully checked for visible signs of distress, anger or embarrassment. After the interviews the key informant was asked how she experienced research process, interview questions and questionnaires and how these could be improved.

A number of valuable insights emerged from the pretesting phase. First, the BMQ general items were apparently ‘too general or too broad’ thus she often felt compelled to qualify her answers. For example, the general harm item “People who take medicines should stop their treatment for a while every now and then” elicited mixed responses: “I agree” – based on the premise that some medicines are used only for short while with some disease conditions, but at the same time, “I disagree” because

with HAART stopping is simply not an option. Remedial action was twofold. Instead of allowing participants to self administer the questionnaire, the researcher resorted to taking an active but peripheral role in administering the questionnaire. The researcher explained in explicit terms the meaning of the each item where necessary and the conversation that ensued during the completion of the questionnaire was digitally recorded, transcribed and analysed qualitatively as if it was an in-depth interview. This meant that responses collected using the BMQ - a quantitative instrument, were complemented and qualified by participant's explanations. Minor changes in the phrasing and sequencing of interview questions focussing on the impact of HAART on sexuality were made. In order to establish rapport with the participants, initial questions needed to be general and more intimate questions such as those focusing on alternative sexual practices (e.g. oral sex, masturbation) were shifted to the end. (See Appendix 5A for the interview schedule).

4.6 Data Collection processes

Initial correspondence between potential participants and the researcher was through letters of invitation sent via the key informant. PLWHA interested in participating in the study completed a tear-off slip attached to the letters, giving their contact details and these were then returned to the researcher through the key informant.(See Appendix 7). Direct telephonic correspondence between the researcher and the potential participants followed and culminated in a meeting being scheduled at a mutually agreed venue. All participants chose to be interviewed in an office located in the Faculty of Pharmacy at Rhodes University. It is a quiet, secluded location that all participants found to be convenient and accessible.

During the first meeting with each participant, the purposes, procedures, and potential benefits of the study were explained to participants and they were assured that their personal data will remain confidential as outlined in the informed consent form. (See Appendix 8). Some participants were asked to assist in recruiting other participants until the desired sample size was reached.

All participants were asked to assign themselves a pseudonym at the start of the study. These were used throughout the data collection and in the write-up phases. All sensitive identifying information such as names of friends/people and places were changed to protect the identity of the participants. The data collection processes are outlined in Figure 5 (page 60).

4.6.1 PLWHA on HAART

Prior to the first interview and after providing informed consent, the researcher explained to individual participants the procedure for completing the “Prescription, Non-prescription Medications and TCAMs use Inventory” (see Appendix 3) which they were to complete at home. Participants were reminded to return the completed form and to bring their personal medication record to the second interview. They were also asked to bring samples of herbal medicines that they were using, if possible.

Participants attended two interview sessions on separate occasions. During the first interview, issues related to medicines taking behaviours were explored. Participants were given 10 to 15 minutes to familiarise themselves with the BMQ. Meanwhile, the researcher studied the completed “Additional medicines utilisation inventory” which they had completed at home. Afterwards, the participant’s choice of answers on the BMQ was discussed. Most participants took between 15 to 25 minutes to complete this BMQ. An in-depth interview was then carried out – normally lasting for between 30 to 50 minutes. Participants were asked about their use of additional therapies (TCAMs, prescription and non-prescription medicines) and the reasons for their use. Some interview questions were based on information obtained from their personal medication records, for instance, self-reported adherence levels and monthly prescription refills reflected on their passports.

The second interview was normally held on the following day except in one instance. Most participants were willing to leave their personal medication records with the researcher overnight enabling detailed notes to be taken. The session began with a brief revisit of participants’ medicine taking behaviours, during which the researcher sought

clarification/elaboration on various emerging themes. Afterwards, the researcher explained the concept behind the numerical rating scale on sexuality, which the participants then completed on their own. Using real-life examples (e.g. a teacher marking a student's composition out of a possible 10 marks), the researcher was able to explain how the numerical rating scale is functions. Thereafter, participants completed the scale. An in-depth interview was then conducted focusing on the impact of HAART on sexuality. Participants were asked about their experiences of living with HIV/AIDS in general, how they discovered their HIV status and how their perceptions about HAART have evolved over time. On average, this interview lasted for approximately one hour.

During the interviews, the researcher constantly referred to data obtained from other sources (such as questionnaires, documentary analysis, numerical rating scale on sexuality) and where tension or conflicting evidence emerged, clarification was sought. In other words, data collection was not a linear process, it was cyclical. For example, if the respondent claimed that he or she was 100% adherent, the researcher would verify this by checking the prescription refill dates and self reported adherence diaries. And participants' scores on the numerical rating scale informed interview questions on the impact of HAART on sexuality. As pointed out before, records of sexually transmitted infections were used as proxy indicators of possible risky sexual behaviour.

4.6.2 HIV Counsellors

HIV counsellors are responsible for counselling and educating PLWHA, readying them for HAART. Their clients periodically return for adherence counselling after being initiated on treatment. In general, study participants may sometimes conceal what is socially construed as deviant behaviours and over report "normal" behaviours because of "privacy needs, embarrassment and fears of reprisals." [199] It was expected that since the HIV counsellors work with PLWHA on HAART regularly and live in the same communities, they could provide useful insights on the research foci. The interviews focussed on their clients (not my participants) and so were meant to obtain a

different perspective on medicine taking behaviours, use of additional therapies among PLWHA and the impact of HAART on sexual functioning.

Two HIV counsellors from a major public hospital in Grahamstown called Settlers Hospital were asked to participate in the study. The interview schedule in Appendix 6 was used as a guide for the interview. Only one in-depth interview lasting for approximately one and half hours was conducted with each HIV counsellors to save them time away from work. Coincidentally, both HIV counsellors were HIV-infected and one was on HAART. Both were women and had worked with PLWHA for over two years. They were articulate in spoken English.

4.7 The Role of the Researcher

In qualitative inquiry, it is important to comment on the researcher's biases, *a priori* assumptions, values, and judgement since they inadvertently influence data collection procedures and the interpretation of the findings [179] In chapter 7 (page 130) an entire section titled "A journey of discovery: The Researcher's reflections on the research process" is devoted towards detailing the researcher's reflections on the research process.

4.8 Data Analysis

4.8.1 Analysis of Quantitative Results

Participants' demographic data, their scores from the BMQ and the numerical rating scales on sexuality were entered into a Microsoft Office Excel 2003[®] worksheet. Descriptive statistical analysis using frequencies/counts was then carried out.

Since the data were not suited to complex statistical analysis, the generalisability of findings was not the aim the study. Nonetheless, to more fully understand what the counts denoted, participant's total scores for each BMQ-general subscales were calculated. Their necessity/concerns about medicines scores were used to calculate the necessity-concerns differential (NCD). The NCD indicates the relative balance between the patient's concerns and beliefs about the necessity for medications. If one

assumes that the persons' total score on the necessity scale is N_a , and on the concerns scale is C_a , (see page 64 for scoring rules), then his/her necessity-concerns differential was calculated using the formula: $N_a/5 - C_a/5$, where the denominator indicates the number of items in that scale. Since the necessity scale had 5-items, the maximum score that can be obtained is 25 and the possible minimum is 5. The same applies to the concerns scores. This means that the value of the necessity-concerns differential scores range from -4 to +4.

If the NCD is negative, then the participant's concerns about HAART outweigh the perceived necessity for HAART, thus, according to the necessity-concerns framework, the person is most likely to be non-adherent to treatment. Conversely, if NCD is positive, then the person's perceived need for treatment outweighs their concerns, therefore, in theory, they are more likely to be adherent to treatment. The necessity-concerns framework implies that people perform an implicit cost-benefit analysis before settling for a certain course of action regarding taking their treatment. The cost being referred to here, includes the disruption of one's lifestyle as one attempts to accommodate medicines into a daily schedule, medicine related side effects and the actual cost of the medicines in monetary terms. The benefits include freedom from signs and symptoms or the discomforts associated with the illness.

Participants' scores from the numerical rating scale provided a rough estimate of changes in certain aspects of sexual functioning – participants' general quality of life, sexual satisfaction, sexual libido and sexual enjoyment – based on their own subjective assessment before and after starting on HAART.

4.8.2 Qualitative Data Analysis

As mentioned earlier, all interviews were audio-taped and transcribed verbatim. Qualitative data – interview transcripts, observation notes and evidence from document analysis - were analysed for patterns of experiences or recurring themes, using thematic analysis. According to Miles and Huberman,[200] the main task of qualitative analysis is:

...to explicate the ways people in particular settings come to understand, account for, take action and otherwise manage their day-to-day situations.

Thematic analysis - defined as “a process of encoding qualitative information” or “the method for identifying, analysing, and reporting patterns within data”[201] - is widely used to provide rich descriptions of social phenomena in numerous fields including psychology, nursing and behavioural health studies. The works of Miles and Huberman,[200] Boyatzis,[202] Braun and Clarke[201] and Blanche and Kelly[203] informed qualitative data analysis procedures in this study. Although not a linear process, as the description below shows, the analytical steps were as follows:

Stage 1: *Checking transcripts for errors.* Because the transcription of verbatim records to text was carried out by typist, there was a room for human errors. So, the first step involved cross-checking interview transcripts against original audiotapes for accuracy and making the necessary amendments.

Stage 2: This involved getting familiar with all interview transcripts by reading them several times. Afterwards, the researcher took time to reflect on their contents of the transcripts and write down initial insights. Interesting phrases and concepts were also noted.

Stage 3: Coding involves analysing for patterns and meanings or themes in the textual data and assigning a phrase or symbol to adequately describe phenomena.[202] The researcher chose to use highlighting in different colours to mark coding on the scripts.

A coding framework was generated inductively, from the data, as well as deductively, from information in the literature review and the three health behavioural theories (Health Belief model, Leventhal’s Common Sense Model of Self regulation, and the Transtheoretical model; see Chapter 3). Codes were compiled into a codebook to ensure that they were used consistently. As new perspectives emerged, codes were reviewed, altered, and merged.

Stage 4: *Searching for themes.* Codes were analysed for patterns and closely related codes were sorted into themes. Themes are defined as “a common thread” across an entire data set.[204] However, since simply searching for commonalities across the data set is often inadequate and important insights might be excluded[203] – the researcher was careful not to ignore data which at first glance appeared to be irrelevant. Also careful attention was paid to commonalities as well as differences between a participant’s accounts.

Stage 5: Qualitative findings and quantitative results were organised into a simple meta-matrix using Microsoft excel[®] software.

Stage 6: *Writing the final interpretive account.* When writing the final interpretive account, qualitative interpretations were brought together with quantitative measures. At this stage it was important to ensure that interpretations cohered and were true to the data and representative of participants’ lived experiences. Illustrative quotes were used to provide rich descriptions of the phenomena.

4.9 Strategies for Validating Findings

It is not reasonable to expect that quality assessment criteria and procedures specific to quantitative research will apply to qualitative research as the two traditions emerge out of very different ontologies and epistemologies. As noted earlier, quantitative research aims to *dis/prove* causality (cause-effect relationships) and the tendency is to experimentation in controlled conditions. On the other hand, qualitative research aims to *understand* social phenomena by allowing people to speak about their own reality.[179]

The following terms are used to assess the quality of quantitative research. The term “internal validity” refers to the extent to which the research measures what it claims to measure. Construct validity assess how well constructs/ideas/theories are operationalised to account for the actual reality. External validity refers to the extent to

which research findings/conclusions are generalisable or applicable to a larger population. Reliability refers to the consistency/repeatability of one's measurements using the same instrument.

In the qualitative paradigm there is an understanding that any examination and interpretation of phenomena is by nature subjective and thus the notion of one 'fixed truth' is questionable. Because the researcher is an essential instrument[179, 205] of interpretation much care must be taken to monitor subjectivity by interrogating interpretations. Lincoln and Guba[205] formulated four criteria for judging the quality of qualitative research namely: credibility, transferability, dependability and conformability. Others[206] have added: clarification and justification, procedural rigour, representativeness, interpretive rigor, reflexivity and evaluative rigour to this list.

In the following headings the qualitative as well as the corresponding quantitative, terminology for quality assurance criteria used in this research are shown.

4.9.1 Credibility/Internal Validity

According to Durrheim and Wessenaar,[207] a credible interpretative account ought to be "convincing and believable." The term credibility is used to refer to its trustworthiness, authenticity, soundness of the argument and whether the findings are plausible. Various strategies were employed to improve the credibility of this study's findings. Firstly, multiple data sources, methods and theories were used to decrease the bias inherent in using single data sources methods or theories. Secondly, because codes were generated both inductively and deductively, the researcher was thus able to search for rival explanations, divergent views and to generate alternative interpretations without being limited to predetermined themes/categories. These strategies are discussed in detail below.

a. Triangulation as a tool to enhance internal validity

According to Tritter,[181] the meaning of the term triangulation is twofold. Firstly, it refers to the “aggregation of data from different sources with the aim of validating a particular truth, account or finding.” Secondly triangulation results from the use multiple methods to explore and understand social phenomenon.

Triangulation of Methods: This is integral to a mixed-method approach. Accordingly document analysis, in-depth interviews and structured questionnaires were used in data collection. Different methods yield different data and this enabled the researcher to compare findings and juxtapose them in order to reach nuanced understandings of phenomena. This is achieved through strategically combining both qualitative and qualitative approaches in a way that exploits their individual strengths and partially offsets their inherent weaknesses; this also increases the number of different perspectives. A monomethod approach does not yield diverse range of views.

Triangulation of data sources: To a lesser extent the research drew on multiple data sources: there were 14 PLWHA on HAART and two HIV counsellors.

Theoretical triangulation: Multiple theoretical perspectives (health belief model, self regulation model and the transtheoretical model) were used to ensure that the most important questions were included in the study and thus a wide range of perceptions, attitudes and behaviours in relation to medicine taking and sexuality could be probed.

Negative case analysis. Deviant/ negative accounts were also examined and integrated into the overall interpretive account.

4.9.2 Transferability/External Validity or Generalisability

Generalisation of the findings in the quantitative sense of the concept is not intended in this study. In its place is the notion of transferability, which is used to refer to extent to which qualitative findings could be extrapolated to other settings/contexts different from the one in which the original study was undertaken. Ultimately, it is for readers to judge the transferability of the findings of qualitative study.

4.9.3 Dependability/Reliability

These are notions associated with repeatability/consistency or the ability to replicate the study. As described on page 66, interview schedules guided the interviews and while there was freedom to ask new questions or follow up on what participants said – which is essential in building a better understanding – all interviewees were asked the same essential questions. The questionnaires afforded consistency in this regard. Should anyone want to replicate the research, a rich description of the research method and templates of the data collection instruments are provided in this thesis.

In addition, an audit trail of consent forms, interviews transcripts, data analysis documents, communications with participants and observation notes were retained and checked by the research supervisors.

4.9.4 Conformability / Objectivity

Qualitative inquiry involves the interplay of the researcher's subjectivity and objectivity. Research findings ought to reflect the views of the study participants and not the preconceptions of the researcher. Since no observer is completely neutral;[179] the researcher's preconceptions, beliefs and values, opinions also inform their research choices/decisions, interpretations of data, meanings assigned to social phenomena and the study's conclusions. To lessen bias, qualitative researchers are encouraged to share their motivations, preconceptions and metapositions that could influence their choices regarding the research process. Kirtsi[208] defines reflexivity as “an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process.” She says:

Reflexivity starts by identifying preconceptions brought into the project by the researcher, representing previous personal and professional experiences, pre-study beliefs about how things are and what is to be investigated, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations related to education and interests.

Section 7.3 (page 130) presents some of these reflexions and assumptions.

4.10 Ethics

Ethical approval was granted by the Rhodes University's Faculty of Pharmacy's Ethics Committee prior to commencing this study.

Ethical issues in HIV/AIDS behavioural research present a unique set of challenges. For instance, the high levels of stigma associated with HIV/AIDS means that stringent measures are needed to safeguard the participants' personal information. With this in mind, ethical considerations took precedence in planning and carrying out the study.

Creswell[179] asserts that besides ontological and epistemological issues, researchers' values (ethical, aesthetics or religious) are inextricably linked to the process of knowledge acquisition, issues of truth, beliefs and justification. Thus, from this perspective, ethical issues can be viewed as an integral component of a robust research methodology and should be given due consideration at every stage of the research process. Alderson[209] warns against "adding a veneer of respect for rules" in a paragraph in a research write-up. Instead, they recommend that ethical considerations should be viewed as a fundamental component of the overall research process.

In this study, the snowballing sampling involved sending letters of invitation to potential participants through other participants for their consideration; their identity remained unknown to the researcher until they decided to participate in the study. That way, uninterested persons identity remained anonymous. Also, all participants chose pseudonyms at the enrolment phase. These were used as identifiers throughout the data collection phase to protect their participants' identities. Interviews were conducted in a mutually agreed upon venue and due consideration was given to issues of privacy, quietness and convenience in terms of accessibility.

Only information relevant to the study was solicited during interviews and efforts were made to minimise intrusion into the participants' private life. When undertaking

document analysis, only data relevant to the inquiry was recorded manually and only relevant sections of the *passport*) were photocopied when necessary. Digitally audio-recorded interviews were stored in password-protected folders in a personal computer and in back-up rewritable compact discs (RW-CD). This data was accessible to the researcher and his supervisors only.

Where interpreters were used, the participants' were made aware of their right to choose an interpreter. Interpreters and transcribers signed contracts with clauses to safeguard participants' information, right to privacy and to ensure confidentiality (See Appendices 10 and 11).

Whilst this study was physically non-invasive, due care was taken to ensure that the interview questions were at least sensitive to their cultural beliefs. Piloting the data collection instruments and interview questions aimed to lessen these problems. In-depth interviews can be psychologically intrusive, particularly in the case of this research where the topics and questions have the potential to evoke unpleasant memories from the participants. To reduce this, interview questions were worded and sequenced appropriately. Interviews were kept under 1½ hours in duration and only one interview was conducted per person per day.

Throughout this study, the researcher strove to adhere to the principle of justice that requires fair and equitable treatment of participants and, the principle of fidelity which obligates the researcher to be faithful to all agreements entered with the participants.

4.10.1 Informed Consent

Written informed consent was given by participants before the first interview.

One cornerstone that defines ethical research is informed consent which Dhali[210] defines as the “process of information sharing and decision making based on mutual respect and participation.” Pedroni and Pimple[211] use the term in reference to:

...practices and conventions that make it socially or legally acceptable to use a person as a research subjects, and includes the rules, regulations, and cultural and professional practices governing informed consent to research.

The second definition, while adequate for ethico-legal purposes, fails to acknowledge that informed consent does not end at the signing of a contract but that it is an ongoing process in which the rules of engagement are continually renegotiated between the two consenting parties. For instance, in spite having obtained written informed consent from the prospective participant prior to beginning the research, participants were asked for their permission to record the interviews at different times during the process.

Informed consent assumes that when a *reasonable* person is provided with *relevant* facts pertaining to a study, *cognisant* of the implications and consequences of their actions and in the *absence of coercion, deceit or misrepresentation* of facts, prospective participants will choose what's in their best interest.[210] The terms in italics highlight the key constructs of valid consent.

Firstly, prospective participants must be capable – physically and mentally - of understanding the information about the study in lay terms and must qualify under law to provide such consent. Cognitive impairment is common among PLWHA and is often associated diseases such as meningitis, AIDS dementia complex and other neuropsychological abnormalities.[212] As a consequence, the exclusion criteria in this study listed persons under 18 years of age (who cannot legally provide consent under the South African constitution)[213] and those who, in the researcher's judgement, may have been mentally and/or physically lacking the capacity to participate.

Secondly, prior to obtaining their informed consent, all prospective participants were made aware of the purpose of the study, the procedures, possible benefits, risks and discomforts, as well as issues to do with confidentiality.

Third and last, voluntarism or freedom from intimidation or coercion is the hallmark of informed consent. It does not, however, disallow persuasion [211] since the process of selecting ‘relevant’ information for inclusion in the consent form invariably involves some degree of persuasion. All participants in this study were given a honorarium amounting to R150 for participating in both interviews. This money served as encouragement to participate, as token of appreciation for their time and to help with transport or other incidental expenses that they may have incurred by participating in this study. Considering that monthly incomes of some six participants were less than R500, this honorarium could have been considered a significant incentive for people to participate in this study, but the researcher and his supervisors decided that participants should not bear monetary costs of the research. The study was also not made widely known and the chances of persons enrolling in order to obtain the honorarium were minimised.

Prior to giving written consent, all participants were made aware of their right to withdraw from the study at any point, emphasising that participation was voluntary.

Pedroni and Pimple[211] provide additional benefits of obtaining informed consent, namely: it boosts “public trust of the research community”: participants are more willing to communicate openly and comply with the research requests if they are well informed and participate willingly.

4.11 Conclusion

This chapter described in detail the methodology that was adopted for this study. The mixed methods approach was chosen because it was best suited to answer my research questions. Several strategies that were employed to address issues of research rigor and quality. Ethical considerations, which were given high prominence throughout the study, were described.

5.0 Introduction

In this chapter, the quantitative and qualitative findings are presented. First the participants are introduced. Next, themes related to impact of HAART on participants' sexuality are discussed. Following that are findings on the participants' experiences of taking HAART, non-prescription and additional prescription medicines, traditional, complementary, and alternative medicines.

5.1 Characteristics of Participants

The fourteen participants included eight females and six males. They were between the ages 30 to 50. Six (four males and two females) were Rhodes University's support staff members and eight (two males and six females) were members of a local non-governmental organisation called the Raphael Centre. Nine participants were employed on a full-time basis, three on a part-time basis and the remaining two were unemployed. Eight participants had monthly family incomes above R1500 whereas four participants had gross family incomes less than R500 a month. Eleven participants described themselves as devout Christians, two believed in African traditional religion and only one was non-religious. Most families included children. Two participants had no children. Table 7 below shows further information on the demographic characteristics of the participants.

Participants' CD4+ cell counts at the time of their HIV diagnosis ranged from 7 to 300cell/ μ L, and their current CD4+ cell counts ranged from 163 to 686 cells/ μ L. Participants had been on HAART for between 9 months to 10 years and the lag time between HIV-diagnosis and starting on HAART varied from several days up to six years.

TABLE 7: Brief Description of the Study Participants (in alphabetic order)**RHODES UNIVERSITY'S SUPPORT STAFF MEMBERS****Pseudonym Brief Description**

Diana	Diana is 35 years old and had nine years of formal education. She is single and has three children. Their gross family income is R2500. When she tested HIV seropositive in 2004, her CD4+ cell count was 23 cell/ μ L. She was then initiated on TB treatment for six months and on HAART in June 2005. She was later switched from stavudine to zidovudine because of side effects. She also suffers from chronic hypertension. She was involved in a serodiscordant relationship.
Jabulani	Jabulani is 34 years old and is a father to three children. He is currently cohabiting with his girlfriend who is HIV seronegative. Jabulani discovered that he was HIV-infected in 2007 and has been on HAART since January 2008. He has 12 years of formal education and earns about R2300 per month. He is also diabetic and takes oral antiglycemic drugs. He has had three sexual partners after his diagnosis but is currently in a monogamous relationship.
Ruth	She is aged 41, is currently single and has two children. She holds an information technology educational qualification and earns R4000 a month. She was diagnosed with HIV-infection in 1996 and her CD4+ cell count then was 300cell/ μ L. She was initiated on HAART in 1999 as part of an AIDS clinical trial. She later switched from stavudine to zidovudine because of concerns about lipodystrophy. Ruth has had two sexual partners following her HIV diagnosis.
Sinza	Sinza is 42 years old. He has one year of formal schooling, is employed on a full-time basis and earns about R1500 per month. He lives with his 4 years old child and his girlfriend. At the time of his diagnosis in September 2002, his CD4+ cell count was 97 cell/ μ L. He was then treated for TB before being initiated on HAART in June 2007. Although he had “too many” sexual partners before his HIV diagnosis, Sinza stated that he is now left with two partners – one of

whom has unknown HIV status.

Sizwe Sizwe is 48 years old; is employed and earns approximately R4000 a month. He currently cohabits with his girlfriend and has 3 children. He had 12 years of formal education. His CD4+ cell count was 43cell/ μ L at the time of his HIV diagnosis in December 2006 and it has since increased to 252cell/ μ L. He started taking HAART less than one month afterwards and has not disclosed his status to his family and friends. He was previously in a serodiscordant relationship. He also suffers from hypertension and gout.

Vusumuzi He is 38 years old and has two children. He has eight years of formal education and their gross family income is R2000. He lives with his girlfriend and their child is a year old. When he was diagnosed with HIV infection in August 2007, his CD4+ count was 178cell/ μ L. He was started on HAART in February 2008. His wife is also HIV-infected. He regularly takes alcohol and sometimes has unprotected sex with casual sex partners.

PARTICIPANTS FROM THE RAPHAEL CENTRE

Busisiwe Busisiwe is 39 years old and had ten years of formal education. She has two children and they all survive on government-sponsored monthly child support grant of R230. Busisiwe discovered that she was HIV-infected in November 2003 when she went to the hospital to give birth. She was started on HAART in August 2008 when her CD4+ cell count was 116 cell/ μ L. Her medication records indicated that she has had many illnesses since childhood including persistent chest pains, pneumonia, stomach aches and later, hypertension. She had three sexual partners after being diagnosed with HIV.

Elizabeth She is a 36 years old divorcee, lives with her two children and earns about R3700 per month. She has twelve years of formal education and is nonreligious. In 1999 when she found out about her HIV infection and was initiated on HAART in 2005 when her CD4+ cell count was 150cell/ μ L. She has had more than five sexual partners since her

diagnosis. She currently has two sexual partners and both are HIV seronegative.

Inid Inid is 50 year old divorcee. She had seven years of formal schooling, is employed full time and earns roughly R1000 a month. The youngest of her three children was adopted and is 2 years old. She discovered her HIV status in 1994 and was initiated on HAART in 1999. She was given the disability grant in the early stages of her illness. She switched from stavudine to zidovudine in 2006 because of lipodystrophy. She also suffers from hypertension.

James James is a 36 years old male, has one child and had eight years of formal education. He is unemployed and his family lives on less than R300 a month. When he was diagnosed with HIV-infection in May 2008, his CD4+ count was 7 cell/ μ L. He was then initiated on TB treatment and was later initiated on HAART in July 2008. He currently has two sexual partners.

Joyce Joyce is 36 years old divorcee, has three children, and now cohabits with her current partner who is not HIV-infected. She attained tertiary qualifications in computers and earns about R3500 per month. She discovered her HIV status in 1999 but began taking HAART in August 2005 when her CD4+ cell count was 85cell/ μ L. She was switched from stavudine to zidovudine because of lipodystrophy.

Mandla Mandla, aged 33, had one year of formal education and lives with his only child. He is employed on a part-time basis and has an estimated monthly income of R100. He discovered his HIV status in March 2006 and was immediately started on TB treatment for six months and on HAART thereafter. His CD4+cell count was 106 cell/ μ L at the time of diagnosis and is now 640 cell/ μ L. He switched from stavudine to zidovudine because of HAART-induced facial lipodystrophy.

Margret Margret is 30 years old, widowed and unemployed. She had nine years of formal education, her monthly gross family income is around R300 and she depends on her uncle for her groceries. When she found out

about her status in 2006, her CD4+ count was 75 cell/μL. She was initiated on HAART in November 2007. She has no children and although she desires to have some, she said her HIV status prevents her from doing so. She had two sexual partners since her HIV diagnosis and is currently in a monogamous relationship. Her current partner is HIV seronegative.

Nonzipho Nozipho is aged 31. She found out about her HIV status in 2003 when she went to the hospital to give birth. Her CD4+ count then was 198 cell/μL. She was initiated on TB treatment and later on, on HAART in May 2008. Her present partner is HIV negative.

HIV COUNSELLORS: Pseudonyms and additional information

Laura She has been an HIV counsellor at Settlers Hospital for four years. She is also HIV-infected and on HAART.

Susan Susan has been HIV-counsellor for seven years at the Settlers Hospital in Grahamstown and is HIV-infected but is not yet on HAART.

5.2 Impact of HAART on Sexuality

Participants' scores on the numerical rating scale on sexuality are shown below. Following that, themes that were identified from thematic analysis of qualitative data are explored in detail. The six themes are: perceived importance of sex in general, choosing a sexual partner, characterisation of sexual relationships after being initiated on HAART (including sexual functioning and risky sexual behaviours), issues of disclosure, alternative ways of fulfilling sexual needs, and reproductive issues. Table 8 below shows that all but one participant, Inid reported a general improvement of health-related quality of life after being initiated on HAART. Four women reported a decrease in sexual drive/libido, sexual satisfaction and sexual enjoyment after being initiated on HAART. In contrast, all male participants reported increased interest in sex. In general, findings indicate that participants' experiences of living with HIV illness, taking HAART and their sexuality are intertwined. The first three themes explore their views about sexuality in general and provide the backdrop against which the impact of HAART on their sexuality can be understood.

TABLE 8: Participants' Scores on the Numerical Rating Scale on Sexuality

Aspect Of Sexuality		Participants' Pseudonyms and Scores													
		Sinza	Diana	Vusumuzi	Ruth	Sizwe	Jabulani	Busisiwe	Mandla	Inid	Margret	Elizabeth	Joyce	Nozipho	James
Health-related Quality of Life	Before Starting on HAART	8	3	4	6	5	1	1	4	7	4	6	4	3	8
	After starting on HAART	9	10	9	10	8	10	10	9	7	8	10	9	8	10
Sexual Satisfaction	Before Starting on HAART	2	2	3	5	7	1	1	3	10	6	8	3	1	7
	After starting on HAART	8	10	10	9	8	8	8	8	5	5	4	9	6	8
Sexual Drive/Libido	Before Starting on HAART	2	1	7	4	5	2	2	4	8	7	4	2	5	10
	After starting on HAART	6	4	8	7	7	8	8	8	5	3	4	7	9	10
Sexual Enjoyment	Before Starting on HAART	2	1	2	8	7	1	1	4	10	9	8	3	2	5
	After starting on HAART	8	6	6	5	8	8	8	8	5	5	8	8	9	10

Discovering their HIV seropositive status and initiating HAART had a profound effect on the participants' sexuality. Participants described their initial emotional response as accompanied by feelings of anger, despair and for most women, feelings of betrayal and blame of their sexual partners: they claimed that they contracted HIV from their promiscuous male sexual partners. Abstinence from sexual activity was the most common immediate adaptive coping strategy that was employed by most female participants. The HIV diagnosis served to exacerbate pre-existing problems in sexual relationships such as distrust and violence. Most participants ended up breaking up or divorcing. In general, women reported re-engaging in sexual relationships after few months of abstaining. As Inid put it:

... I didn't want to have sex with him anymore after 1994. I didn't want to speak to him. He was also angry with me that I was also not speaking to him. When I looked at him, I would just get angry. That is why he decided to go and live with his other girlfriend...I was angry since I was diagnosed because I blamed him. (Inid)

Joyce stated that she continued enjoying a healthy sexual relationship with her ex-husband in spite of her feelings. Elizabeth stated that she preferred masturbating during this self-imposed abstinence phase.

Re-engaging in sexual relationships among the women seemed to mostly coincide with starting on HAART and/or their joining support groups. All male participants reported continuing with sexual relationships in the early stages of their illness or as soon as their regained physical strength because of HAART.

5.2.1 Perceived Importance of Sexual Intercourse

Mixed responses were obtained concerning the importance of sexual relationships. In general, sex was considered an important part of their life and was deemed healthy by all participants for various reasons. These included: for fulfilling one's bodily desires ("it is the desire of the body," (Nozipho)), to "release sperms", for pleasure/enjoyment, for stress relief, to show affection to their partners, to strengthen bonding within relationships and to foster a happy environment within the family. Participants had

diverse opinions about what happens if a person abstains from sexual intercourse for a prolonged period of time. Ten participants believed that “you go mad”, two said nothing happens. Two suggested that the person might commit rape; one male stated that women become “cheeky” and short tempered; two males said the “penis becomes sore” and one stated that women gain weight. For Elizabeth, sex provided an additional benefit of pain relief.

... I also had a certain pain by my waist but when I have sex that pain goes away. (Elizabeth)

Participants’ perceptions of sexual relationships were impacted on by the realities of living with HIV/AIDS. For James, Ruth and Vusumuzi, engaging in sexual intercourse was a painful reminder of the virus in their bodies.

...I used to have sex before. When I was with someone I would want sex. But now I just don't want. I was denying that I was positive....when I wanted to do sex there was that thing in my mind that I am HIV positive... (James)

Before [HIV diagnosis], when he initiated sex or touched me, I didn't have any problem. I just did it – my body would just become active. Now, there is this thing in my mind that I - eish - I am HIV positive... (Ruth)

All six male participants reported reducing the number of their sexual partners upon finding out that they were HIV infected. Some male participants were sometimes defensive and attempted to downplay their interest in sex (e.g. “it’s not as if I always want sex” (Sizwe)) during interviews.

5.2.2 Choosing a sexual partner

Thirteen participants said their HIV seropositive status was not a major concern in choosing their sexual partners. Generic attributes such as a caring, loving and understanding partner were the primary considerations among female participants. In addition, the partner’s acceptance of their HIV status was considered essential.

...I was angry before but when I got this guy [new boyfriend] my aim was just to get someone who understands my status whether they are positive or negative... (Joyce)

Elizabeth explained her preference for HIV seronegative sexual partners by saying that PLWHA are hesitant to use condoms. She thought that HIV-seronegative partners are more likely to practice safe sex.

....I want to live my life. Because [of my HIV status]...I should use a condom. I didn't want a partner who was HIV positive because they didn't want to use a condom unlike maybe one who is negative they will be scared and use condoms. (Elizabeth)

She also expressed her preference for casual sexual relationships because she wants to avoid becoming emotionally attached to the person.

...I don't feel interested in men. Sometimes I choose to date married people because they don't have a lot of time for me. I prefer casual partners. I get bored by seeing someone a lot. He must be far from me. ...At times feel like I need a man but when I get him I just want him for one night. The next day I feel like I don't need him -- for something like three more months (Elizabeth)

5.2.3 Characterization of Sexual relationship after starting HAART

5.2.3.1 Sexual functioning

All but one (Inid) participants reported a general improvement in their health related quality of life when this was measured using a self rated numerical rating scale (NRS-S). (See table 8) Three participants reported a decrease in sexual satisfaction after being initiated on HAART. With regards to sex drive/libido, when compared with the pre-HAART initiation stage; two participants indicated that it remained the same; two reported a decrease in libido and the remaining ten indicated that it actually increased. Ten participants reported enjoying sexual intercourse more after being initiated on HAART. (See table 8). Improved sexual functioning among participants was attributed to an improvement in physical functioning, the absence of debilitating opportunistic infections and a general improvement in their health.

...before I was on ARVs, when I was next to my sexual partner I didn't have any feelings. But after I started taking ARVs, I developed strong feelings for him... Before that my body was always sore when my boyfriend touched me

but after taking treatment I didn't have any of those problems anymore. I am enjoying sex together with my partner ...My body is strong now. (Nozipho)

...after I used ARVs, I started getting energetic and feeling much stronger. Sometimes I want sex more...I want to have it more than twice a week (Sizwe)

...I use to have frequent opportunistic infections - TB and vagina thrush. After I started ARV drugs I stopped having them (Joyce)

Ruth and Joyce said that a persistent "itchy" vaginal infection that had occurred each time with sex vanished after she started taking HAART. Vusumuzi described his frustration with "failing to perform" sexually before he was commenced on HAART because he was not physically fit. For him, performing satisfactorily was a way of affirming his manhood. James, Vusumuzi and Sizwe also reported experiencing erectile dysfunction before being initiated on HAART.

...before I started taking ARVs I could not perform...I was getting tired quickly...(Vusumuzi)

...I didn't have the drive that I have now...I was always tired. Sometimes when I wanted to have sex and am really on it, and when I was just about to do it, the penis died [loses erection]. (Sizwe)

...before ARV drugs, everything was falling apart, I was trying to have sex and it [*pointing to his genitals*] wouldn't wake up, but after ARV drugs everything was fine, my sex life was very good, it was waking up. (James)

Participants' scores on the NRS-S sometimes appeared at variance with their narrative accounts. For example, although Jabulani's score on the NRS-S seem to indicate a marked increase in sexual drive/libido after he was initiated on HAART, some of his statements during the interview appear to contradict this. He said:

...I started using a condom after I started taking ARVs ...before I started taking ARVs I did enjoy sex very well, and then after taking them I am less interested [and]...she is less interested if I want to do sex. (Jabulani)

Jabulani's reasons for decreased interest in sexual activity are twofold: first the thought of using a condom seemed unattractive and secondly, his sexual partner had become

less receptive to his sexual advances. Similar contradictions were seen with other participants' accounts.

NRS-S scores indicate that diminished sexual functioning might be gender related since all three cases (Inid, Margret and Elizabeth) were reported by women. They all indicated that sex was no longer a priority for them. Inid wanted to focus on raising her children whereas Margret and Elizabeth wanted to focus on their health.

...Before I started taking ARVs I used to love sex but once I was told that I am HIV positive sex was no longer a priority. (Margaret)

Although Joyce said she initially enjoyed sex with her ex-husband, she said the general body fatigue and “feeling bored” have resulted in her losing interest in sexual activities with her ‘new’ boyfriend. Joyce said:

...My sexual drive is down. I am always feeling so exhausted when I come from work. I just sleep like child and wake up to take my pills at 7pm...At times you feel tired and bored when someone is touching you. (Joyce)

The ten participants who reported an improvement in sexual functioning indicated that several factors impacted negatively on their sexuality. One of these is the constant fear of potentially transmitting HIV to their sexual partner during sex. This was particularly of concern among the six participants who were/had been in serodiscordant relationships. Diminished interest in sex was sometimes attributed to the inconvenience of having to use condoms or to sexual partners' who had become less interested in sex.

...I used to wear two condoms because I wanted to protect my partner (James)

...there is fear because I don't trust condoms. They might break so when I have sex I check all the time that they did not break because I fear infecting my partner. Sometimes I don't think about it but afterwards that's when my senses comes back and I check. (Sizwe)

5.2.3.2 Risky sexual behaviours

i. Participants' Understanding of Consequences of Unprotected Sexual Practices

All participants were aware of the consequences of unprotected sex, to them personally and to their sexual partners. However, most of their explanations were vague and showed incomplete understanding. They explained how, when taking HAART, using condom is crucial but they struggled to link notions of transmitting drug resistant virus to their partners or the possibility of re-infection with more resistant viral strains.

...she wanted to refuse using a condom. I said to her you are HIV positive and I am positive so we will have infection. Because we have infection, maybe your blood is not as strong as mine. Maybe my soldiers are strong and yours are weak. Your soldiers will kill mine and I end up sick. (James)

...I heard that if you sleep with a man who is not on ARVs and you are on them, he will absorb and suck them [ARVs] from me - it's like the issue of defaulting. He will be absorbing them from me so when he starts ARVs he can react to them. (Joyce)

Margret said her CD4+ cell count decreased from 150 to 128cell/ μ L when she was not using condoms and this motivated her to use them. Ruth explained how re-infection occurs by comparing her womb to a cup and male ejaculate to food. She said:

If you keep putting something in a cup, it will stay there. If you come again tomorrow and put a cool drink in that cup when there was coffee already there, imagine the colour of the juice that you will find. It will be a coffee/ tea/ some juices and whatever whatever... (Ruth)

In general, participants used militaristic terms (i.e. soldiers, fight, stronger, kill) to conceptualise what happens in their bodies during HIV infection.

Another consequence of unprotected sex that was mentioned by three women was the possibility of unwanted pregnancies. Although all participants said they used condoms as the primary means of preventing HIV transmission, some women (Elizabeth, Joyce and Busisiwe) also reported taking contraceptive pills as an additional precautionary measure to avoid unwanted pregnancies in case condoms broke during sex.

...when I used the condom the first two times it broke. So to be safe I decided to use other contraceptives [the pill] plus the condoms (Joyce)

Nine participants said oral sex was generally unhygienic and only two participants (Sinza and Elizabeth) reported ever practising it. Nozipho said this about oral sex.

...Your boyfriend puts his penis into your mouth, he might pour his sperms to my mouth and it is not healthy (Nozipho)

ii. Condom/Femidom Use

Five participants only began using condoms consistently after they were initiated on HAART; prior to that, after finding out their HIV status, they did not use any condoms or used them sporadically. Jabulani explained on the reasons for using condoms when taking HAART:

...If you are taking ARVs you are not allowed to have sex all the time. She [his partner] also doesn't like to have sex. Because ARVs *clean* the body, taking out *bacteria* that are not needed by your body, if I'm having sex I must use a condom so that she's not infected by me. Before taking ARVs we never used condoms and *I wonder why she's not infected!* I always motivate her to have an HIV test at all the time (Jabulani)

Upon starting taking HAART, twelve participants reported using condoms consistently to prevent re-infection or infecting their HIV-seronegative partners. Some participants' sexual partners resisted using condoms for various reasons.

...He didn't want to use it. He would say I was his wife and that he paid *ilobola*¹³ for me so he couldn't use a condom (Inid)

...I disclosed my status to that guy and he told me that he was also positive. He said that he saw no reason for us to use a condom. I was blind to the possibility of re-infection. He used condoms on and off. (Joyce)

...He didn't like condoms because he didn't see the need for a condom because most of his partners were HIV positive. He said if we are going to die we will die anyway... (Elizabeth)

¹³Although the meaning and function of the practice of *ilobola* is constantly changing, the term generally refers to the traditional payment made by the groom to the bride's family usually in the form of gifts, livestock or money. And although *ilobola* serves multiple functions, in this study it is viewed as the means of "transferring rights over women's productive and reproductive capacities" for her family to the husband's family.[245]

What was consistent in nearly all the relationships that were explored in this study was that men were generally the ones who initiated sexual intercourse.

Vusumuzi did not use condoms consistently because of alcohol related factors and sensation seeking behaviours. When asked why he felt it was necessary to use condoms when having sex with his wife who is also HIV-infected but not with casual sex partners who he meets at taverns, he said:

...the one at home is not fresh and the new one [referring to casual sex partners at taverns] is fresh than the one that stays with me... I want to know the corners of the vagina. All these girls from the location [township] maybe they have sex [with you only once] and only one round [once only]. If you don't perform well, she will tell the other girls that this boy is nonsense! He get tired quickly! She will call you a chicken! (Vusumuzi)

Although nearly all the study participants used condoms consistently, they were often used grudgingly because they said that condoms made sex less enjoyable. The common expression “you can't eat a sweet with paper” (James and Vusumuzi) was used by two participants or their partners to register their dissatisfaction with condoms.

..She doesn't eat a sweet in a paper...She said she can't feel it and it has no taste (Vusumuzi)

...at first I was reacting...I didn't want to use them when I started off...the problem was satisfaction.(James)

...the friction when you are not using condoms is not there. It is not the same when you start using condoms (Sizwe)

When the researcher asked Laura (HIV counsellor) how her clients respond to her advice to use condoms, she said:

...most clients just laugh and say who can eat wrapped sweets – it's not nice eating wrapped sweets. (Laura)

Nozipho reported using femidoms because unlike condom they did not cause inflammation and they were “very soft and strong.” She also said that femidoms were more acceptable to her partner and they had an added advantage that she could tell whether it is in place during sex.

Besides the lack of sexual satisfaction, participants also reported facing other challenges related to condoms use. These included: hypersensitivity reactions (rashes and itchiness) on genitals, stomach upsets and bothersome condom breakages.

iii. Fear of (re-)infecting one’s sexual partner

Five participants indicated that they still feared the possibility of transmitting HIV to their partners despite the use of condom. For example, Elizabeth was in a serodiscordant relationship and her partner proposed using two condoms for extra protection. She said she felt discriminated against.

...he was not comfortable and wanted to use two condoms. I said it was not fair, if he didn’t trust me he should find someone...He said he is scared to get HIV and I told him that if he use two the other condom will pull the other one and we will be using no condom.(Elizabeth)

James reported using two condoms to protect his partner. Sizwe and Inid lacked confidence and trust in condoms.

...there is always that fear because I don’t trust the condoms. They might break. So when I have sex I check all the time to make sure that it didn’t break because I fear infecting my partner. (Sizwe)

...during sex, I was thinking to myself what if the condom breaks. But that didn't happen. At first I wasn't sure if he could use a condom and because of that, I used to show him how to use it. I always want to check to make sure that the condom is used in the right way. I was worried but I noticed that he knew to use one. (Inid)

Coping strategies employed by the study participants in the face of these challenges included: abstaining or decreased frequency of sexual intercourse.

iv. Alcohol Consumption and Condom Use

Thirteen participants had either stopped taking alcohol or did so occasionally. Insights into the impact of habitual alcohol consumption on sexual behaviour emerged in only one case. Vusumuzi described instances of transactional sex where he exchanged beer for sex in communal beer-selling establishments known as taverns. Sexual intercourse occurs in cars or toilets and is rushed leaving no time to wear a condom.

...sometimes when you are coming from the *tavern*¹⁴ maybe there is a lady and she asks for a beer and she must pay for that beer so you have sex...maybe we just have sex on the toilet...sometimes when I am drunk I would forget to use the condom...(Vusumuzi)

However, not using a condom may not have simply been a matter of “forgetting” as Vusumuzi suggested. He also stated:

...Sometimes when you are coming from the tavern maybe there is a lady and she asks for a beer and you know she must pay for that beer so you have sex without a condom (Vusumuzi)

The researcher visited two township shebeens. Shebeens are people’s houses which have been converted into alcoholic beverages selling establishments. Most of the alcohol sold there was home brewed opaque beer made from millet. Patrons indicated that they preferred this beer primarily because it is cheaper than the one found in licensed establishments. Apart from alcohol consumption, transactional sex seems to occur quite frequently in the shebeens. Overcrowding and the lack of adequate public health facilities observed.

The two HIV counsellors concurred that alcohol consumption is associated with increased risky sexual behaviours among their clients.

Most men who pickup women from the tavern just go outside and have sex in their cars. One thing is for sure is that few of them remember to use condoms because they are so anxious to do it. (Laura)

¹⁴ A *tavern* (also known as *shebeens*) refers to unlicensed places which sell alcoholic beverages. Home brewed beer is also sold in these places.

5.2.4 Issues of Disclosure of HIV status

Sizwe had not disclosed his HIV status to his wife. Disclosure concerns were associated with the desire to avoid stigmatization. For example, Sizwe attributed nondisclosure to his family, including the wife, to perceived HIV-related stigma. He said he uses condoms consistently when having sex with his wife.

...They [family] don't know till this day that I am HIV positive. It's because the way they talk about people who are HIV positive is hurting, so they don't know (Sizwe)

Participants who were members of the Raphael Centre had publicly disclosed their HIV status. Because most of them met their sexual partners through support groups, issues of disclosure were not experienced as being problematic. Even among this group of PLWHA, they tended to disclose their HIV status selectively outside their support groups. Some kept their status a secret until the later stages of the relationship so as to avoid “scaring” away and being rejected by potential sexual partners as well as to ascertain the person's genuineness.

...I always prefer disclosing to people before we start anything. So when I disclosed to him before we got intimate he then said: “Ok, we would use a condom.” But before we even did anything he disappeared. I felt that I shouldn't disclose. If I love someone I must keep quiet. But as time went by I thought that if I love someone I should not kill them because I might infect the person with a virus. I don't know how a person will react. I might be killing them by infecting them. (Elizabeth)

Vusumuzi, on the other hand, disclosed his status to his long-term sexual partner but does not do so with casual sex partners. According to him, casual sexual partners seldom “ask” or simply “don't care” about it. He added that they sometimes scorn him when he tells them his HIV status.

...some of them ask and others don't care. Others already know. Some have HIV and they just want to spread it. When you tell them [about your HIV status], some say you are afraid of me [*meaning* you don't want to have sex with me] or you are lying. Why then are you are still working? If you had AIDS you will be so thin! (Vusumuzi)

Vusumuzi's quote reveals a misconception that was mentioned frequently throughout the interviews: that is, when one is HIV infected the person automatically become thin.

5.2.5 Reproductive Issues

Three participants (or their sexual partners) wanted to have children in the near future but felt constrained by their HIV status. Although Joyce had three children - all girls - she wanted to have a boy. Another participant, Jabulani, explained his predicament.

...she wants to have a child with me and I told her I would ask the doctor. I told her that we can't start having children now because they will die with AIDS and we will have wasted all our money preparing. (James)

And Inid said:

I also wanted to try and not re-infect someone, as much as I wanted to enjoy. I didn't want to kill anyone...I don't enjoy sex because the boyfriend I was involved with wanted a child and I also couldn't take a chance of infecting him. [I cannot] take the risk of not using protection so I wasn't happy because he would always talk about what he wants and I couldn't give him what he wanted. (Inid)

Besides the fear of transmitting HIV to their partners, the possibility of giving birth to an HIV-infected child and doubts about their future were some of the reasons participants gave for putting off having children (see James's quote above).

Laura described how HIV counsellors take advantage of HAART to advise couples trying to conceive to engage in unprotected sexual intercourse between a predetermined window period when the woman is at her most fertile and when both partners' viral loads are suitably low.

...[clients] are asked to go on a medical check up to see that the treatment that they are on is on the right track.... Then they can start having sex without a condom for two days [around the] time when the woman is ovulating. (Laura)

Inid resorted to adopting a child because of her advanced age in reproductive terms, 50, and her HIV status. Although Margret did not have any children of her own and desired to have some, she said her HIV status prevented her from having children.

5.2.6 Alternative ways of achieving sexual fulfilment

Two reported having oral sex and four reported using sole masturbation as a way of achieving sexual fulfilment. Apparently, sole masturbation was not congruent with indigenous cultural practices. For example, according to Joyce, her partner said:

...he said he is not an animal and he can't do those things. He refused masturbation (Joyce)

Laura, an HIV counsellor, noted that:

...using sex toys amongst the Blacks are never spoken about because in our culture we believe in doing the real thing. Masturbation! They will never say at all, it's a secret kept behind closed doors. (Laura)

Masturbation was said to be associated with homosexual tendencies by some and terms such as “*isitabane*” (Mandla) or “*moffie*” (meaning homosexual) were used to describe men who masturbate/sexually stimulate themselves by touching.

...I think they are just embarrassed that they are relieving themselves in that way. Like I said, in our culture we believe that people have sex the real way. There are stereotypes: if you do something that people are not used to then you are called names such as *moffie*. It means you are homosexual or you are someone who touches themselves when it should be done by someone else. (Laura)

5.3 Medicine Taking Behaviours among the study participants

5.3.1 Becoming Adherent is a Process

Using the transtheoretical model, three stages of taking antiretroviral medicines were identified. Stage 1 is the “Pre-HAART initiation stage”; stage 2 is the “Starting on HAART stage” and the third stage is the “Maintenance stage.” The process begins at diagnosis after which individuals go through a series of cognitive and emotional experiences (a gradual adjustment to a perceived life changing event). Ideally this leads to acceptance of their HIV status, the initiation of HAART and learning about self care activities that assist in coping with a chronic, stigmatising and ultimately fatal illness.

Participants' narratives showed a gradual shift in personal beliefs and attitudes towards HIV and HAART over time as they became more knowledgeable and experienced at taking it.

5.3.1.1 The Pre-HAART initiation Stage

The pre-HAART initiation stage is the period between the participants discovering their HIV seropositive status up to starting on HAART. All the participants indicated that finding out that they were HIV-infected was a traumatic experience and a life changing event. For some, the discovery was merely a confirmation of a pre-existing suspicion that they were HIV infected. Four participants reported self medicating using immune boosters, vitamins and herbal remedies from traditional healers before going for an HIV test. For example, James (who is unemployed and with a family living on less than R300 a month) spent R1600 over three months seeking assistance from traditional healers before deciding to go to the clinic.

Respondent: I had used a lot of medicine, healers, and what and what, until I saw the doctor who said I had this problem [HIV]. I started to drink then the doctors said I was messing up everything.

Interviewer: You saw traditional healers before you went to see doctors...?

Respondent: Us as Black people, we believe that this thing [is] because so and so doesn't like me, but I found out from my friend that I was wasting a lot of money and he said that we should go to the hospital. After three days in the hospital it helped...(James)

Twelve found out about their HIV status when they sought care at the hospital for persistent illnesses which seemed unresponsive to non-prescription medication and/or TCAMs. Busisiwe discovered her HIV status when she presented to hospital to give birth. All but one participant sought medical intervention when their CD4+ cell count was less than 200cell/ μ L. See Table 7 (page 84) above for details.

Themes that were identified at this stage included i) acceptance of one's HIV status, ii) disease knowledge and personal beliefs about HIV/AIDS and HAART, iii) motivation

for taking HAART, and iv) the effect of participants' past experiences of taking medications on their perceptions about HAART.

i. Acceptance of one's HIV status

The acceptance by participants' of their HIV seropositive status was a critical step towards their accepting antiretroviral therapy. All but one participant were encouraged, coaxed or forced to seek care from medical doctors and/or traditional healers, by close family members or friends out of concerns for the their deteriorating health. The exception was Sizwe who keeps his status a secret and sought medical care without encouragement or coercion by others.

All the participants reported some or all of the following after discovering their HIV status: feeling angry, hopelessness, regret, self-blame, self-distancing and denial. The diversity of narratives about coming to terms with being HIV infected indicates the uniqueness of each individual in coping with life changing events.

James became very ill, was diagnosed with HIV-infection and sought help from relatives who took him to the clinic. When the doctors recommended HAART he readily accepted. Joyce discovered that she was HIV-infected in 1999 and for six years she avoided having her CD4+ T cell count taken. After discovering her HIV status, she befriended an HIV caregiver who routinely gave her various vitamin pills. Later, she trained as an HIV counsellor and started helping patients at a local clinic.

...In 2005 there was a sister who was opening up files for clients. She said to us don't forget that as much as you a counsellor you are a patient. She then asked me to go for a CD4+ count. I was even fat and struggling to lose weight.... I then got my CD4+ count. This lady then wrote down CD4+ count = 85. I was even shocked and I thought that is full blown AIDS...I went to sisters' room and said my CD4+ count is low. She said: "I can see you are fresh and can do everything but I am afraid you have to start on these ARVs." (Joyce)

Unlike Joyce, other participants reported that were so very ill at the time of their HIV diagnosis that the urgent need for treatment overwhelmed other concerns.

ii. Disease Knowledge and Beliefs about HIV/AIDS and Medicines in General

All participants seemed aware of the existence of HIV/AIDS before their diagnosis and they generally knew that it transmitted through unprotected sexual intercourse. HIV infection was perceived to be a result of being promiscuous and immoral behaviours. Participants associated the disease with imminent death. None of them was aware that the disease could be managed using HAART. Most of the participants' initial illness perceptions about HIV/AIDS seem to have been shaped by information acquired through 'word-of-mouth' or hearsay and to a less extent, from mass media.

The table below (Table 9) shows participants scores on the BMQ general and the specific necessity-concerns questionnaires. Five participants disagreed with the statement that medicines are generally harmful whereas the remaining nine perceived medications as being generally harmful. Participant's scores on the BMQ (see page 104) indicate that nine participants believed that doctors generally over-prescribe medicines. Despite this, all participants' scores on the BMQs' general benefit scale indicate medicines were generally perceived to be beneficial. All participants reported having misgivings about taking medicines for any ailment in general.

I was scared at first because I am not a person that likes to take medications even if I am sick. Since I am a person who doesn't believe in medication even if I have a headache I won't take a pain tablet quickly. So I was thinking that I would take this medication for life and I was thinking and thinking and confused what would happen to my body. (Ruth)

After learning about HAART, two participants (Ruth and Sizwe) said that they initially expected that it would "cure" or "get rid of" the virus. Others hoped that the treatment would "help" them to recover from their illness.

I did not know that I would take those for life. I thought that I could take them for a while then stop. And later on, I found it was for life. At first I was not happy but because I wanted to be healthy I thought it would be fine and I should just take them. (Sizwe)

I didn't have any knowledge about the ARVs and HIV. My expectations were just to get cured but they told me that there was no cure for the virus so my

expectations were now not to get sick and to live a longer life...I didn't have a clear explanation about HIV, everything was new to me and I was just doing everything they asked me to. I would agree because I wanted to get rid of it.
(Ruth)

Both Sizwe and Ruth had similar expectations regarding HAART: Sizwe, however, expressed his disappointment over the fact that he was not informed early on that he would be taking HAART for life. All other twelve participants mentioned that they were informed that they would take HAART for life before being initiated on treatment.

TABLE 9: Participants' Scores on the Beliefs about Medicines Questionnaire (BMQ)

General Scale	Sinza	Diana	Vusumuzi	Ruth	Sizwe	Jabulani	Busisiwe	Mandla	Inid	Margret	Elizabeth	Joyce	Nonzipho	James
General Harm Scale (4-items)	7	6	10	8	9	8	8	9	10	9	12	11	14	8
General Overuse Scale (4-items)	7	9	11	11	10	9	13	12	10	13	17	12	12	15
General Benefit Scale (4-items)	12	20	16	16	19	15	18	13	16	11	18	14	16	17
Specific Necessity- Concerns Scale														
Necessity Scale (5-items)	19	25	21	20	25	19	22	25	25	22	22	20	22	22
Concerns Scale (5-items)	12	9	14	9	5	9	10	7	8	15	16	14	10	12
Necessity-Concerns Differential (NCD)	+1.4	+3.2	+1.4	+2.2	+4.0	+2.0	+2.4	+3.6	+3.4	+1.4	+1.2	+1.2	+2.4	+2.0

Participants actively sought to understand their disease and medications outside and beyond the information provided at clinics. Other sources of information about HIV/AIDS and HAART included: friends, other PLWHA, support groups, books and mass media (radio, television). Ruth, a Rhodes University employee, said that she used the internet. Participants sought information about medication related side effects, alternative therapies and prognosis.

iii. Participants' Motivations for accepting HAART

Participants' illness perceptions appeared to have a major impact on their health seeking behaviours. Common HIV-related symptoms that prompted some participants to seek medical attention included: perceived significant weight loss, wasting, persistent coughing associated with tuberculosis, herpes zoster infection, persistent diarrhoea, neuropsychiatric symptoms ("going mad" (James)), feeling lethargic, and inability to perform regular day-to-day activities. Equally important were superficial manifestations of HIV symptoms such as looking "thin" which they believed would rouse suspicion amongst their friends and peers leading to stigmatisation.

The perceived serious consequences of HIV/AIDS, in particular, inevitable death was participants' main motivation for accepting that they need to take HAART. Nozipho's statement below illustrates the desperate circumstances that led most participants to adopt HAART.

...I thought they [referring to HAART] would give me life because my state then... [she shakes her head as if to say things were very bad]. I had to have faith. If it wasn't for faith I would not have gone to the doctor. I was going to die because I couldn't talk. I was weak and I couldn't talk. They would just look at me and pass by as though I didn't exist so I stood up even though I couldn't eat. (Nozipho)

Participants hoped to live longer and healthy lives by taking HAART. In comparison to other chronic conditions, the health threat presented by HIV-infection was perceived to be more grim or serious. Nine participants had co-morbid chronic illnesses for

which some used chronic medications. These included: persistent back pain, gout, hypertension and diabetes. Busisiwe, who also takes antihypertensive medication said:

Sometimes I forget taking high blood pressure treatment for two days but HIV medication is different because I must take you're the pills everyday...If I don't, I will get AIDS and after that I will die so...There are machines to monitor your high blood pressure levels and it's not more dangerous than being HIV positive. (Busisiwe)

Sizwe said he stopped taking his gout prophylactic medications after his gout started getting better.

iv. The effect of participants' past experiences of taking medications on their perceptions of HAART

Participants past experiences with medications (besides HAART) influenced their perceptions about HAART. Nine participants had taken tuberculosis treatment immediately after their HIV diagnosis and prior to taking HAART. The anti-TB treatment regimen, known as the Directly Observed Treatment, Short-course (DOTS), was considered very demanding because they had to go to the clinic on a daily basis to take treatment under observation. The anti-TB treatment was described as "bitter", "[pills were] too big" and "stressful" in terms of side effects and time demands. Taking DOTS seemed to have aided individuals to develop the requisite cognitive and problem solving skills required for taking chronic medications.

TB medications were bad. I would mix them with sugar and water because they were so big. ...It got me used to taking drugs. When I started off I took bigger doses. So when I took ARVs, it was like a chocolate to me. (Joyce)

I think the reason why I got used to them [antiretroviral medicines] was that because before I used ARVs ...the doctor said I should take TB tablets because I was coughing. The tablets were so big but I had to take them anyway. Because I was so used to taking tablets, I didn't make any difficult changes when I started taking ARVs. (Sizwe)

Eleven participants reported taking cotrimoxazole prophylaxis to prevent the opportunistic infection *Pneumocystis jirovecii* pneumonia at some point after their HIV diagnosis. All participants reported being prescribed daily vitamin pills prior to being initiated on HAART and being monitored for HAART adherence. However, the duration during which participants were monitored varied considerably, ranging from less than four weeks to several years for some depending on their CD4+ cell count. (See table 7 for details).

5.3.1.2 Stage 2: Starting on HAART

This stage refers to the period when the participants were initiated on HAART and the first few months after that. Participants' accounts give a sense that taking HAART was a way of reasserting control over their bodies. Themes that were identified as belonging to this stage included: i) confluence of doubts about HAART and hope, ii) integrating medicine taking into one's lifestyle and iii) "It's hard" - barriers to adhering to HAART. In the initial stages, all participants reported struggling to varying degrees in taking their medications as prescribed. Although the challenges that they faced varied from person-to-person and were diverse, they were categorised as: medication-related side effects; forgetfulness; balancing privacy needs and adhering to HAART; and the difficult tasks of integrating medications into their daily lives. In spite of these challenges, all participants reported taking their medications diligently and expressed strong commitment to adhering to the recommended treatment plan.

i. Confluence of Doubts about HAART and Hope

Participants' accounts revealed a mixture of misgivings and hope in deciding to accept HAART. However, urgent concerns about their poor state of health and fatal nature of HIV illness took precedence and often overwhelmed such doubts. Their doubts were primarily related to the long-term effectiveness of HAART, having to take medication for life, rumours that HAART causes death and the harmful side effects of HAART. Ruth said:

I didn't feel comfortable at first because I started doubting if I should take the medication or not because they would not reach my expectations of curing it. I just continued in the hope that it would help me at a later stage somewhere

somehow. There were people that I knew already that were on ARV drugs and they died so I thought I would die also because there is no cure for this. (Ruth)

Besides Ruth, four other participants (James, Inid, Elizabeth and Nozipho) expressed similar concerns that HAART, and not their illness, might be the cause of the unexplained deaths. James said:

...the doctor told me that I will take them for life but at first I was not happy to hear that because I thought treatment would take only six months. They told me that my life will depend on ARVs. What made me afraid is that people were talking too much about these tablets. Around the community I used to hear that people *died* through using these tablets...[some] say they are scared about them and I tell them that those pills are not killers but actually help. They say if you take [have sex with] small children around the age of 15 you become better, but I say you will make them sick and you get more worse and die. (James)

Susan, an HIV counsellor for seven years, mentioned that concerns about people dying shortly after being initiated on HAART are common.

...My clients say that if they take ARVs they will die very soon. They say they knew someone who took ARVs for a short while and died so they don't want to take the ARVs. Some say they knew somebody who took ARV drugs, stopped for a while and when they were started again they died. So they say that they don't want to take ARVs for the whole year. (Susan-HIV Counsellor)

Busisiwe said she heard that when a person takes HAART, he/she goes mad. But seeing her peers coping well whilst on HAART helped her to overcome her doubts.

...I doubted because some people say when you take ARVs you go mad... [but I saw] that few people at Raphael Centre were taking ARVs and they looked ok so I didn't have any doubts now for taking ARVs.(Busisiwe)

The “instant” (James) improvement in one's health after being initiated on HAART helped to ease some participants' initial doubts.

Hope/Optimism: another side of overcoming doubts

For all the participants, HAART symbolised hope and longevity and was generally viewed as life saving. However, differences between women's and men's motivations were identified. For most women, HAART rekindled the prospect of seeing their children grow-up. As such, taking HAART was a very meaningful encounter.

... I don't mind [other people knowing that I am on HAART] because I have other important reasons to take ARVs. I have children and I want to see my children growing up well. I want to live a long life. If you use ARVs they boost your system so that you can survive for a long time. (Busisiwe)

Male participants appeared more concerned about regaining their physical fitness, resuming their traditional societal roles (e.g. work) and going out with friends. For example, James and Mandla said:

...When I was sick, instead of loving the friends I had to take care of my body, so my friends would leave me. So when I was in hospital I was free, I had no friends except this HIV. (James)

...I was a soccer player before I got sick. After taking the ARVs I go back to the field and do sport because I'm strong again. (Mandla)

Participants appeared to have become progressively more optimistic about their future prospects as they became more experienced with HAART. Besides seeing progressive improvement in their own health, another source of hope for participants was seeing other PLWHA, their peers, coping well with treatment.

...I had a friend who was very sick and he took those ARV drugs. He was sick more than me and I saw him get better so I was encouraged. He told me to go and get help. (James)

None of the participant's account was solely optimistic about HAART: hope and doubt coexisted.

ii. Integrating Medications into lifestyle

Upon being initiated on HAART, participants were immediately confronted with the reality of having to integrate taking medicines into their daily routines. They all

described their first months of taking HAART as particularly challenging because they would sometimes forget to take their medications on time.

The first time it made my life very uncomfortable because I would forget the time to take the medicine and I had no one to remind me to take the medication. But as time went, I became comfortable and wherever I am I take my medication. (Ruth)

Sometimes I felt if I could just get an injection for like a whole month it would be much better because at times children disturb me or I forget to take the ARVs. I realise later that it is been an hour and I haven't taken my ARVs, so you then take it late. (Elizabeth)

Taking HAART needed getting used to. Participants also reported reconfiguring their lives in order to accommodate HAART. The unrelenting nature of the disease was a problem for some participants. Elizabeth (see quote above) made clear her preference for “monthly injection” over having to take HAART on a daily basis.

Analysis of data suggests that becoming adherent goes beyond the physical act of swallowing pills as prescribed: it is also an emotional encounter for the individuals. Affective factors such as anger, mood, anxiety, feeling optimistic, and “feeling like stopping” were found to be an integral components of medicine taking. Pill fatigue ensured over time as individuals contemplated their decision to take HAART.

It is very stressful because at times I feel like stopping for three months then starting again but I know that I can't do that which is why I said I wish is was an injection for one month and then forget about the pills next month. (Elizabeth)

However, it is important to note that non-adherence was mostly due to forgetfulness or non-intentional and that for the most part in this stage, participants were generally committed to taking their medications despite numerous medication side effects. Over time, participants developed diverse coping strategies to help them remember to take their medication on time. (See section 5.3.1.3 page 119).

Another lifestyle adjustment that was reported by the participants was restricting alcohol consumption. Most participants reported adjusting or completely stopping consuming alcohol after being initiated on HAART because of concerns that this might worsen their condition. Further discussion on participants' lifestyle adjustments with regards to alcohol consumption are found under the subheading, "Alcohol Factors" on page 127.

Nearly all participants reported making some adjustments in their day-to-day schedules in order to accommodate HAART. Everyday activities such as visiting friends, conference attendance, breakfast time, and suppertime, and taking children to school were organised taking into consideration medication dosing times.

...I have changed my timetable to 7am [from 6am] because I have the little one [son] that I am also giving the ARVs. (Diana)

Four participants (Vusumuzi, Nozipho, Diana and Jabulani) still had problems stating the correct generic names of their medications. They all correctly recalled the dosing instructions. Jabulani said:

The colour makes it easy. The other one is brown other one has two colours, two are white and other one is also white with a line in the middle, one is yellow and the other one is white and oval shape. The brown and two white ones and the one with two colours I take in the morning 5am. I also take them in the evening including the yellow, oval shape one at 7pm. (Jabulani)

No clear association between the numbers of years of formal education and their ability to recall the names of their medication was seen. Jabulani had received twelve years of formal education, which was more than what other participants had had. In Vusumuzi, Diana and Nozipho's case, low literacy levels might be a factor. All these participants required the services of an interpreter during the interviews.

Besides their generic names, participants sometimes called antiretroviral tablets *amandongomani* (meaning peanuts) because the way that they are taken resembles eating peanuts.

iii. “It’s Hard” – Barriers to Adherence to HAART

a. HAART-related Side effects

Medication side effects were identified as a major impediment to adherence to HAART. All participants but one reported experiencing at least one side effect in the first few weeks after being initiated on treatment. Common ones included: central nervous system disturbances (nightmares, hallucinations and headaches), rashes, general body itchiness, xerostomia, anorexia, vomiting and fatigue. (see Table 10, page 115 for details)

Neuropsychological symptoms associated with efavirenz were reported by most participants in the early stages of taking HAART but these seemed to disappear after a few weeks. These included: feeling drowsy, vivid dreams and hallucinations.

...It was hard then after two weeks I become fine... I used to see things when I was sleeping. I was seeing things that no one could see even at night time because of the treatment. I used to see as if I’m dying and seeing birds coming straight to me. (Sinza)

With the exception of one participant, Vusumuzi, all participants informed their health care provider about medication side effects which resulted in some being prescribed additional medications.

Table 10 below provides a detailed summary of some of the medication side effects that were reported by the study participants.

TABLE 10: HAART-related Side Effects That Were Mentioned By Study Participants

Medication Side Effect	Participants who reported the medication side effect	Illustrative Quotes
<p>Neuropsychiatric Symptoms</p> <ul style="list-style-type: none"> • Vivid dreams • Hallucinations • Headache 	Inid, James, Nozipho, Vusumuzi, Busisiwe, Ruth, Joyce, Sinza, Jabulani, Margret	<p>..I used to feel ok but the tablets that I took in the evenings would make me drowsy every time...(Sizwe)</p> <p>..I used to see things when I was sleeping. I was seeing things that no one else could see... I was not in my right senses. I was scared of those visions but I carried on [taking my] treatment until I was okay. I used to dream that I was dying and I was seeing birds coming straight at me. (Sinza)</p>
Peripheral Neuropathy	Inid, Nozipho, James, Sinza, Jabulani	...[my feet] were painful as if I was wounded... it was hard to stand ... There was a pricking sensation on my legs and I would cry: Ooh my legs! It was as if there were nails under my feet. It was hard to go the toilet [which] is located outside the house... (Nozipho)
Rashes	Margret, Ruth	...I developed a fine rash ...(Margret and Ruth)
Generalised body itchiness	James , Jabulani	...my body was itching then I told the doctor...(Jabulani)
Lipodystrophy	Mandla, Ruth, Diana, Joyce	<p>...[the doctor] noticed that my face becoming skinny..[and he] discovered that D4T was the cause... (Mandla)</p> <p>...I develop a big tummy and big breasts but my legs remain thin (Ruth)</p>
Tiredness	Elizabeth, Ruth, Busisiwe	... I would even sleep when talking to a person after taking them and feel tired couldn't do anything (Ruth)
Anorexia	Vusumuzi	...I was dizzy and I didn't want to eat. I was walking like I had no balance.(Vusa)

b. Stigma: A double edged sword

Participants' narratives revealed that HIV-related stigma is a double-edged sword. The desire to appear "normal"/healthy and to avoid being stigmatised was mentioned by four participants (James, Inid, Joyce, and Busisiwe) as one of the motivating factors for initiating taking and adhering to their HAART regimen.

...ARVs are treating me well and I look good. People do not see that I am HIV positive because of them. (Busisiwe)

On the downside, stigma also discourages adherence to HAART. According to Laura (an HIV counsellor) the fact that HAART is taken at approximately the same time on a daily basis creates a pattern leads to the patient's close friends, workmates and family to question the purpose of the medications. She added that this was particularly applicable to clients like Sizwe who chooses to keep their HIV status a secret.

Diana only disclosed her HIV status to her mother and not her three children (the eldest is 18) because she feared being stigmatised. She however takes her pills in their presence and tells them that they are for hypertension, since her mother (the children's grandmother) takes antihypertensive medication.

...I say [to my children that] they [the pills] are for hypertension. I live with my grandmother who has hypertension so she takes her medication on a daily basis. She knows my status. I don't have hypertension myself. (Diana)

The following quotes from Sizwe illustrate the impact of stigma on disclosure and on medicine taking.

Interviewer: If someone were to ask you to describe in detail how it felt like taking ARV drugs in the first week, what would you tell him/her?

Sizwe: It was very difficult. Actually the first week was not a good week, but because I was sick I had to take them. Otherwise I didn't feel good taking them.

Interviewer: Why?

Sizwe: Because my family did not know about this, so now to take these drugs in front of your family...that I am positive...and taking these tablets, to them, it's a shock. They think that you're going to die so you feel safe but later you get used [to it].

Interviewer: You have not told your family that you are taking ARV drugs?

Sizwe: They do not know till this day that I am HIV positive because the way they talk about people who are positive is hurting, so they do not know.

Contrast this with Mandla and James's situations both of whom live openly with their HIV status. Mandla begins work as early as 06h00 and works till late into the night at a job involves working with the public throughout the day. He said that he often takes his medications in public and was not embarrassed by it because he has disclosed his status. James said that his workmates scorn at him when he takes his medication and although that makes him angry, it does not deter him.

...[ARVs are] like my son...I take my son with me even if they [workmates] are laughing. They do not know that they are HIV-positive until they get tested.
(James)

c. Experimenting With HAART

Instances where participants experimented with HAART by independently adjusting and skipping some doses were reported. By making these adjustments, participants sought to minimise the negative impact of HAART on their lifestyle and to avoid medication side effects. For example, Sizwe took part in an important traditional ceremony in which drinking traditional beer is an important ritual. He explained that he skipped a few doses of HAART because he had been advised by his health care provider not mix alcohol with HAART.

I was told at the clinic that I cannot mix alcohol with medicine...To tell the truth, I didn't see anything wrong: I just skipped the two days then I started [taking them] again... Nothing happened to me! I did not get sick or anything.
(Sizwe)

The link between participants misinterpreting their doctors' instructions and non-adherence is discussed in more detail under the section, "Trust Relationship between

Patient and Health care Providers” on page 124. Some participants (Joyce, Mandla) experimented with taking alcohol and HAART concurrently at one point. Joyce reported feeling drowsy after taking alcohol and HAART concomitantly.

Another form of experimenting involved participants modifying medication dosing schedules to fit into their daily schedules. Ruth, for example, deliberately shifted the time of her evening efavirenz dose from 19h00 to 21h00 so as to lessen the drowsiness associated with the drug. She said efavirenz made her feel fatigued and unable to “do anything.” Nozipho reported unilaterally stopping taking efavirenz for two days early on in her treatment in an attempt to evade medication side effects.

d. (Mis)Information

Participants were specifically asked whether they had heard reports that HAART is “poisonous” or “toxic.” Six participants said that they had heard about it albeit from different sources.

I attended a workshop in EL and the doctor said that you should not use the ARV drugs but use herbs and multivitamins because ARV drugs are *toxic*. It affected me a lot because I was worried about those people who are still on the program of getting ARVs...ARVs helped my life...maybe those in the process of getting ARV medicine would stop taking them. (Ruth)

Other participants said that they heard similar information on the radio and through friends. Despite this, all participants said that this did not adversely influence their decision to take HAART although Ruth (see quote above) was worried that it might discourage HAART uptake by others.

Another misconception was related to food requirements when taking HAART. All participants strongly believed that treatment must strictly not be taken on an empty stomach and this was said to be based on advice from health care professionals. This is despite the fact that the HAART regimens (comprising of a combination of stavudine or zidovudine, lamivudine and efavirenz) have no such food restrictions. Lack of food

was used as excuse for not adhering to treatment. This issue is described in more detail under the subheading “Hunger” (see page 125).

5.3.1.3 Stage 3: Maintenance Phase

After a few months of taking HAART, some participants appeared to have integrated medicine taking into their daily activities with varying degrees of success. For some, taking the pills had become habitual. Participants who had been on HAART for several years seemed at ease with taking medications on a daily basis compared with less experienced individuals. They were also more articulate on the subject of HIV/AIDS and HAART, acquiring a ‘mini-expert’ status in managing their disease. Themes that were identified for this stage included: i) adaptive coping strategies ii) social support iii) concerns about long-term effectiveness of HAART and side effects, and iv) self monitoring and self regulation.

i. Adaptive Coping Strategies

Use of Reminders

Participants employed various adaptive coping strategies to help them remember to take HAART on time. The four most common techniques were:

- (a) Using electronic personal reminder devices. Participants reported setting alarms on cellular phones and wrist watches. These devices were considered convenient since they carry them most of the time.
- (b) Being reminded by family members, friends and relatives. Children and telephonic reminders from friends played an important supportive role by helping them to remember to take their medications on time (See section on Social Support on page 120 for further discussion).
- (c) Synchronising medicine taking with their favourite television programmes. Soap Operas such as “The Bold and Beautiful” and “Generations” which are broadcast on local channels at 08h00 and 20h00 respectively were used as timekeepers. Whilst none of the male participants used this technique, four women, who said they were ardent followers of these daily programs, said this worked well for them.

(d) Synchronising medicine taking with their daily activities such as breakfast, supper, waking-up and going to work, participants were more or less able to integrate medicine taking into their lifestyle. This strategy was use by three men.

Participants also used a combination of abovementioned strategies. But some lacked specific strategies for taking their medication and relied instead relied on memory.

ii. Social Support

Eight participants from Raphael Centre and one from Rhodes University's support staff members (Ruth) belonged to a PLWHA support group. They generally meet on a monthly/fortnight basis. Gender seems to play an important role in influencing support group affiliation. Of the nine people who attended support groups seven were female. Typically, members shared information and provided emotional support to each other. Participants also reported forging lasting friendships. Besides encouraging each other, members were actively involved in solving each others' problems. Participants mentioned how through support groups, they came to accept their status and found reassurance, hope, dependable friends, meaning to life and also how through sharing their experiences of taking HAART, they came to identify with their medications. By learning about other peoples experiences of taking HAART, participants were more confident when taking HAART and were forewarned about what medication related side effects to expect. Mandla said that his support group helped him with "a lot with information" whilst Ruth said that she attended support groups in order to "just to talk about the pain."

Social support structures also included members of the participants' families. Thirteen participants had disclosed their status. They reported benefiting from emotional support, encouragement and being reminded to take HAART on time. Friends and health care professionals formed part of the participants' support structures. The later were particularly important in meeting participants' informational needs.

iii. Concerns about long-term effectiveness of HAART and side effects

During the maintenance stage, two long-term HAART related side effects – peripheral neuropathy and lipodystrophy – were mentioned as impediments to medicine taking. Five participants mentioned HAART-induced peripheral neuropathy as the reason for switching to zidovudine and four others did so because of the fat redistribution. (See table 10 above for quotes).

Of the four participants who were switched from stavudine to zidovudine because of lipodystrophic changes, three were women. The cosmetic changes that were mentioned include: enlarged breasts, abdominal visceral fat accumulation and fat wasting on the legs and face. Although they all said that these cosmetic alterations did not make them feel any less attractive or lessen their self-esteem, also it was clear that they wanted to avoid being stigmatised. These external manifestations of the side effects of HAART were, to some, a setback in their efforts to look as “normal” as possible.

...some of the side effects were bad dreams, big stomach and breasts. People even thought I was pregnant! The issue of the big stomach was about to worry me a bit. I told myself to choose to live or [choose] the figure. So I just thought let me go for as long as I know I have my children. (Joyce)

Other concerns that were expressed by the participants were centred around doubts regarding the long-term effectiveness of HAART. Elizabeth and James said:

I worry about ARVs because I don't know what is going to happen since I have been taking them for a long time. My aunt died and she was already on ARVs. Some say it was the treatment but I don't know how! Another lady who had been taking ARVs and working at the ARV dispensing site died last week. Now I don't know what killed her. She was taking ARVs for a long time. (Elizabeth)

A comparison of participants' CD4+ counts and NCD scores did not find a consistent pattern.

iv. Self Monitoring and self regulation

The term self monitoring refers to how participants regulated their medicine taking behaviours with the goal of achieving better health outcomes. Participants used biannual CD4+ cell count to assess if their medications were still working effectively. They were able to explain that the CD4+ cell count is an indicator of HIV progression and they demonstrated a limited understanding of how the human immunodeficiency virus destroys the body's immune cells or in their words, the body's "soldiers." Increased CD4+ cell count was interpreted as an indication that HAART was still effective and this was a source of optimism. Decreased CD4+ cell count, on the other hand, were a source of concern and unease.

Participants also reported monitoring their body weight as a way of assessing whether HAART was still effective. Weight loss was interpreted as a sign that HAART was not working optimally and vice versa. Women were particularly sensitive about their physical appearance, and cosmetic changes such as becoming "thin", rashes, and lipodystrophy caused distress. Elizabeth reported having headaches and other somatic symptoms when she skips taking HAART.

Although Grahamstown's public hospitals and clinics require PLWHA to maintain a diary (see Appendix 12) for purposes of monitoring their level of adherence to HAART, research findings show that these are neither dependable nor do they measure adherence levels precisely. The researcher found that the diaries were often either incomplete or were improperly completed. The diaries indicated that thirteen participants were 100% adherent to HAART but in-depth interviews revealed a different picture altogether. Four participants reported skipping taking their medications at some point. Sizwe did not keep a diary because he obtained his medications from private pharmacies.

5.3.2 Health Care System/Health care provider-related factors

i. Distance from health care facilities

Socioeconomic factors emerged as an important factor influencing medicine taking behaviours. A comparison of medicine taking behaviours between a Rhodes University's support staff members and members of Raphael centre yielded important insights into the impact of socioeconomic disparities. Whereas all Rhodes University support staff members were employed on a fulltime basis and had steady monthly incomes, five participants drawn from the Raphael centre were either unemployed or had part-time jobs and lacked a dependable source of income. Consequently, these members reported struggling to meet monthly transport cost to their health care facilities for prescription refills.

I was getting weak and the clinic is very far from where I stay. Sometimes I wake up at home going to the clinic for half past seven but I do fail to get there because I walk for a while and sitting down to rest. (James)

I did not finish TB treatment; I had no transport so I started ARVs when I was at Themba clinic. (Nozipho)

Their situation was exacerbated by the fact that their physical health was compromised making it difficult for some of them to walk long distances.

ii. Quality of health care service

Two participants who accessed HAART through public clinics/hospitals said the poor quality of service in these institutions was a major concern. James mentioned that separate sections are designated for PLWHA in hospitals and that this is a source of stigma. Similar concerns were echoed by Laura (HIV counsellor).

... When you come to a hospital, there are separate rooms where ARVs are taken. Now people will say that: "Oooh! I met Laura taking pills at that clinic so she has AIDS." Now the whole community knows. Clients feel embarrassed because there is a lot of stigma attached to HIV. (Laura)

Sizwe felt that the waiting times for prescription refills at the clinics were too long and an inconvenience, especially because he had to report to work. In spite of the more costly financial implications to him personally, he later joined a medical aid in order to

procure HAART through private pharmacies which, according to him, offer a better service.

...I used to get them [ARVs] from the hospital... I got medical aid because you sit there whole day in the hospital waiting for these medicine. I could not take that! (Sizwe)

iii. Trust relationship between participants and their health care providers

All but two participants said the caring, supportive and trusting relationship with their health care providers was one of the factors that enabled them to cope with their HIV diagnosis and that the constant encouragement also helps them to adhere to HAART. Ruth and Elizabeth reported becoming personal friends with the nurses and doctors over time. Ruth said:

...the first people that I trusted with my status were the nurses. They gave me support especially the sister in the TJ clinic where I was diagnosed. Up until now, she is still my contact. Whenever I have flu I call her! I ask her what I should do. She is like my mum she supported me and my kids. (Ruth)

In addition to forging helping relationships based on trust, participants also viewed health care providers as authority figures. As such, participants loyally adhered to the doctors dosing instructions. Although this loyalty enhanced adherence to medications, it also had some unintended effects.

Firstly, participants' accounts revealed that they are predominantly passive actors in the decision making process concerning their health and treatment plan. Participants seemed intimidated to ask questions and they seldom sought explanations for their doctors' decisions. For instance, the researcher asked some participants to explain why they took their medications in certain ways and typical answers were: "I just do as the doctor says" (Sizwe) or "the doctor is always right because he is more educated" (Vusumuzi)

...Doctors also told me to have food first, no further explanation and I know that doctors always right. (Sinza)

Secondly, some participants at times misinterpreted the doctors dosing instructions. For example, the doctor's instruction to take HAART after food or not to take HAART concurrently with alcohol were misinterpreted by some participants as meaning that they could skip taking their treatment when they are hungry or when taking alcohol. Sizwe said he skipped taking HAART for two days while attending a traditional ceremony where he took alcohol because he had been instructed not "mix alcohol with medicine." Vusumuzi also reported skipping taking HAART for three days in December because of similar reasons.

Interviewer: So, when you were taking beer how did you take your medicine?

Vusumuzi: I didn't take the tablets. I refused because I was using alcohol

Participants' accounts show that health care providers used both negative (e.g. "if you do not take your medicines you will die") and positive (e.g. "the bad dreams will stop after a week") reinforcement to motivate them to adhere to HAART.

5.3.3 Impact of Socioeconomic Factors

i. Hunger

For some unemployed participants, hunger was stated as a factor that affected their ability to take medicines as recommended. Because people with high CD4+ cell counts (> 200 cells / μ L of serum) are not eligible for nutritional support under from public hospitals, participants were faced with the dilemma of having to take medications on an empty stomach. Despite the fact that the HAART regimens that the participants were taking could be taken on an empty stomach, participants were resolute that their doctors instruct them to take the medications with food. However, some participants could not afford two regular meals everyday. According to some participants (Sinza, Mandla, Jabulani), taking HAART on an empty stomach causes gastric irritation and increased appetite and this is why food was necessary.

Always they say I'm fit for work but I am not working when you are taking ARVs you suppose to have food. I tried to get food parcel but I also reject me. When I go to social development they told me that my CD4+ count increased

so I don't qualify for social grant. Most people are defaulters because they want to qualify for social grant since they are not working.(Mandla)

If tablets are taken in empty stomach they will cause scratches in your intestines or a bad mark inside you. Maybe you will suffer from burning pains. (Jabulani)

Laura (HIV counsellor) said:

...they [clients] tell you that they didn't take treatment because they don't have food. (Laura)

ii. Choosing between Health and Income: The Paradox of the Disability Grant

Closely linked to issues of hunger, are issues relating to the disability grants. Since this monthly grants is issued to PLWHA on HAART with CD4+ cell counts below 200 cell/ μ L and it is subject to renewal after every six months provided that they still meet the eligibility criteria, Susan (HIV counsellor) noted that it provides a perverse incentive for PLWHA on HAART to become non-adherent.

...When you are taking ARVs and your CD4+ count is below 200 you are supposed to apply for the grant. After that when it goes up the grant is going to be taken away because your CD4+ count is high and you can work. Others stop taking ARVs because they do now want their grants to be taken from them. (Susan)

However, the issues seem very complex as highlighted by Mandla and Inid's stories below.

...My sister and my girlfriend support me. But they [the clinic] say I am fit for work but there is no work...It's a temporary grant, [whereas] treatment is for life. When I miss a dose my CD4+ count decrease and I ask for social grant and they give it to me for six months. But after sometime the CD4+ count will increase then they stop giving me the grant. As results there are people sometimes just became defaulters deliberately since they do not have the grant. Some people get help from support group to have something to eat. (Mandla)

...the disability grant being stopped did not affect my treatment but it did affect my family because I was using that money to support my children. (Inid)

Both Mandla and Inid did not have reliable sources of income and were concerned about the preconditions for receiving the grant. Bisiwe also reported surviving on a R230 child support grant with her two children. Margret reported living on R300 per month and depending on her uncle for groceries. Although in Inid's case, receipt/non receipt of the grant did not appear to influence her decision to adhere to HAART, Mandla believed that without the money, he could not feed himself and this would negatively impact on his medicine taking. Jabulani, who is employed by Rhodes University and earns R2300 per month, said that he would "not ignore" (meaning he would accept) the grant if offered.

Compared to participants drawn from the Raphael Centre, none of participants from Rhodes University's support staff members mentioned financial constraints, hunger and transport problems as a hindrance to becoming adherent.

iii. Alcohol Factors

Joyce, Sizwe and Margret said that they still drink alcohol occasionally and Vusumuzi said that he still drinks alcohol regularly. Most participants who used to take alcohol reported stopping taking alcohol after being diagnosed with HIV or in the early stages of taking HAART because of concerns about their health. Replacement conditioning was reported by some participants who substituted sports and going to church for alcohol intake.

..I used to drink alcohol after I started [taking] ARVs but the doctor told me that it was not good...so I decided to obey...It was not easy to stop alcohol and smoking. When I stopped, my supporter used to check on me... I used to hide the alcohol but then I thought that this is about my life so I totally stopped drinking and smoking. Now I am joining sport and going to church. (Mandla)

Mandla also noted that:

...alcohol was a problem because when I took it I used to forget taking my medication or I would come home late and miss taking my treatment on time. (Mandla)

Apart from concerns about his health, Mandla's statement above gives insights into other factors that contributed to his behaviour change. These include: his respect for the doctor's authority, the support from his treatment buddy, and replacing his alcohol intake with healthy social engagement. Joyce said that she reduced taking alcohol because it worsened the neuropsychiatric symptoms (i.e. dizziness and nightmares) associated with efavirenz.

The participants who still drink alcohol said it does not interfere with their ability to adhere to HAART. The two HIV counsellors had different views regarding the impact of alcohol on their clients' adherence levels. Susan believed that excessive alcohol consumption among PLWHA is widespread and poses a significant obstacle to ensuring optimal adherence to HAART. On the other hand, Laura believed this problem is fading and that most of her clients drink less alcohol once they are commenced on treatment. Both HIV counsellors believed that alcohol consumption is a coping mechanism used by their client in buffering illness-related stress.

It is very huge problem because I experienced myself an aunt who stopped taking ARVs because she loves taking alcohol. (Susan)

It [alcohol] used to be a problem but now it is ok. The moment someone is on treatment they are told about its effects and some start going low on alcohol. Usually, before they start treatment they want to drink and tell themselves that it is a way of forgetting about these things. (Laura)

Laura and Susan also said that there is a strong association among the excessive alcohol consumption and risky sexual behaviours.

5.4 Medicine Utilisation: Prescription, Non-prescription Medicines and TCAMs

5.4.1 Uses of Prescription Medicines and Non-prescription Medications among Participants

Self medication with over-the-counter medicines was widespread among the participants. On average, participants reported using 8.3 (range 5 to 17) different conventional medicines, including HAART in the six months preceding the study. See

Table 11 and 12 (page 130) for the summary. Through self medicating using over-the-counter medicines, participants sought to independently manage their health.

Using pharmacological classification, the most commonly used over-the-counter preparations by the participants were: oral antihistamines, topical corticosteroids, analgesics, antidiarrheal agents, immunomodulators, cough remedies, nasal decongestants, antianaemic drugs and antifungal preparations for oral thrush. (See tables 13 and 14). Participants used over-the-counter medications to treat what they perceived as minor ailments and to manage HAART related side effects. For instance, oral antihistamines and topical corticosteroids were used to treat allergic reactions such as body rashes and itching that are a common among HAART users - especially in the early stages when using nevirapine. Over-the-counter analgesics such as paracetamol, aspirin preparation and ibuprofen were frequently used to manage pain associated with peripheral neuropathy. Three participants reported using antidiarrheal medications (e.g. loperamide) and various electrolytes replacement mixtures.

Some of these non-prescription medicines were purchased from local shops called taverns. With the exception of immune boosters and multivitamins which were taken daily for months, most non-prescription medicines were mostly used intermittently on an 'as needs' basis for periods lasting no more than a few days.

TABLE 11: Utilisation of Prescription and Non-prescription Medicines, and Complementary and Alternative Therapies among Rhodes University Support Staff Members on HAART in the 6 Months Preceding the Study

Participants Pseudonym		Names of Medicines and Food Supplements Utilised by Participants in the 6 months preceding the Study			Total No. of Orthodox Medicines
		Prescription Medicines	O.T.C Medicines and Food Supplements	TCAMs	
Rhodes University Support Staff	Sinza	Stavudine*/ Lamivudine co-formulation, Efavirenz tablets Cotrimoxazole tablets	Paracetamol, Aspirin, Cough Mixture	-	6
	Diana	Zidovudine*, Stavudine/Lamivudine tabs, Efavirenz tablets, Hydrochlorothiazide tablets, Cotrimoxazole tablets	Vitamin EZ, Vitamin B Complex, Vicks rub, Paracetamol, Borstol Cough remedy	-	9
	Vusumuzi	Lamivudine/ Zidovudine tablets, Efavirenz, Clobetasole cream, Brompheniramine tablets,	Multivitamin tablets, Loperamide tablets, Paracetamol, Eye Gene, Vitamin B Complex tablets, Calamine lotion, Listerine Mouth wash, Benzyl benzoate, Folic acid tabs, Vitamin C tabs, Throat lozenges, stilpane® (analgesic)	Beetroot, Artemisia afra (<i>Umhlonyane</i>), Arcotis arctotoides (Ubushwa)	17
	Ruth	Zidovudine/ Lamivudine tablets, Efavirenz tablets, Amoxycillin capsules, Phenoxymethyl Penicillin tablets, Cotrimoxazole tablets	Chlorpheniramine tablets, Nasal drops, Garviscon, Paracetamol, Hydrocortisone cream, Gastrolyte, Vicks rub, aspirin, Nutri-cyrin	Fever tree leaves, Eucalyptus tree leaves, Traditional Herbal Mixture (name unknown)	14
	Sizwe	Zidovudine/ Lamivudine tabs, Efavirenz tabs, Betamethosone cream, ibuprofen, Cotrimoxazole tablets	-	-	5
	Jabulani	Zidovudine/ Stavudine*/ Lamivudine tablets, Efavirenz tablets, Amitriptyline, Diazepam, Ibuprofen	Paracetamol, Aspirin, Cough Mixture	-	8

* Indicates prior but not current use of the marked ARV

TABLE 12: Utilisation of Prescription and Non-prescription Medicines, and Complementary and Alternative Therapies among participants who are Clients of the Raphael Centre in the 6 Months Preceding the Study

Participants Pseudonym		Names of Medicines and Food Supplements Utilised by Participants in the 6 months preceding the Study			Total No. of Orthodox Medicines
		Prescription Medicines	Medicines& Nutritional Supplements	TCAMs	
Participants from local Raphael Centre	Busiswe	Stavudine /Lamivudine tablets, Efavirenz tablets, Cotrimoxazole tablets, Perindopril tablets, Hydrochlorothiazide tablets, Ibuprofen tablets, Diclofenac tablets, Amoxycillin Capsules, Nifedipine tablets, Penicillin tablets	Glycothymol gargle, Chlorpheniramine tablets, Iron supplements, Paracetamol tablets, Philani Porridge®	-	14
	Mandla	Stavudine*/ Zidovudine /Lamivudine tablets, Efavirenz tablets	Paracetamol, Multivitamins, Vitamin B complex	-	5
	Inid	Stavudine/Lamivudine tabs, Efavirenz tabs, Amitriptyline tablets, Hydrochlorothiazide tablets, Mist Morphine tablets	-	-	5
	Mar-gret	Stavudine/Lamivudine tabs, Efavirenz tabs, Ibuprofen tablets	Soluble aspirin, Paracetamol (Pain block) tablets	<i>Artemisia afra</i> (Umhlonyane)	5
	Elizabeth	Stavudine/ Lamivudine/Nevirapine tablets	Vitamin B complex tab, Multivitamin tabs, Magogotha Carniboost®	Ginger, Garlic, Green pepper, Cucumber	6
	Joyce	Stavudine tablets*, Zidovudine/Lamivudine tablets, Efavirenz tablets, Cotrimoxazole tablets, Hyoscine tablets, Ibuprofen tablets, Vitamin B injection	Paracetamol tablets, Multivitamin tablets	Unidentified Herb (Immune booster), Moducare Capsules	10
	Nonzip	Lamivudine/stavudine tablets, Efavirenz tablets, Cotrimoxazole tablets	Ferrous Sulphate tablets, Vitamin B complex tablets, Paracetamol tablet	Inongwe, Camphor, Rooiwortel (<i>Bulbine latifolia</i>)	
	James	Zidovudine/Stavudine*/Lamivudine tablets, Efavirenz tablets, Amitriptyline tablets, Cotrimoxazole tablets, Fluconazole Capsules, Amoxycillin Capsules, Ibuprofen tablets	Vitamin B6 tablets, Vitamin B complex tablets, Eletropack Powder, Energy porridge	<i>Hypoxis hemerocallidea</i> (African potato), Ingwe, <i>Artemisia afra</i> , Arnica message oil	10

* Indicates prior but not current use of the marked ARV (Stavudine)

TABLE 13: Participants' reasons for Using Non-prescription, Complementary and Alternative Medicines and Nutritional Supplements

Classes of Over-the-Counter Medicines	Reasons for Use	Examples of Medicines from this Class
Oral Antihistamines	<ul style="list-style-type: none"> ▪ To counter hypersensitivity reactions 	Chlorpheniramine tablets, Brompheniramine tablets
Topical corticosteroids	<ul style="list-style-type: none"> ▪ To alleviate allergies such as skin rash 	Hydrocortisone topical Cream, Betamethasone topical cream,
Analgesics	<ul style="list-style-type: none"> • For pain relief i.e. mostly associated peripheral neuropathy 	Paracetamol, Aspirin, Ibuprofen, Stilpane®
Antidiarrhoeal Medicines	<ul style="list-style-type: none"> ▪ To stop diarrhoea ▪ For electrolyte replacement 	Gastrolyte®, Loperamide, Eletropack Powder
Miscellaneous	<ul style="list-style-type: none"> • Relieve coughs, cold and flu • For nasal decongestion • Oral thrush • To cure body lice • Alleviate dizziness and bad dreams • Immune boosters 	Vicks rub, Borstol® Cough Mixture, Nasal Drops Listerine Mouth wash, Glycothymol gargle Benzyl Benzoate Lotion Ferrous Sulphate, Folic acid Magogotha Carniboost®

5.4.2 Participant's perspectives on Traditional, Complementary and Alternative Medications (TCAMs)

Additional therapies that were used by participants included: herbal remedies, exercise, spiritual interventions, nutritional supplements and body massage (See Table 14).

TABLE 14: Types of TCAMs that were used by the Study Participants

Class of TCAMs	Reasons for Use	Examples of TCAMs
a. Mind-Body Medicine		
Prayer	<ul style="list-style-type: none"> • For spiritual well being and hope • For stress reduction 	-
b. Manipulative and Body-Based Practices		
Massage	<ul style="list-style-type: none"> • To moisturise dry skin 	Arnica Massage Oil
c. Biologically Based Practices		
i. Herbal Remedies	<ul style="list-style-type: none"> • To relieve flu and coughs 	Eucalyptus tree leaves
	<ul style="list-style-type: none"> • To boost the immune system 	Mixture of life®, Irhawv, Hypoxis Hemerocallidea (indigenous names: Inongwe/African Potato), Moducare®
	<ul style="list-style-type: none"> • “To chase away bad dreams” 	Traditional Mixture (exact name unknown)
	<ul style="list-style-type: none"> • To treat coughs and chest pains 	Artemisia afra (Umhlonyane)
	<ul style="list-style-type: none"> • To relieve chest and ear pain 	Arcotis arctotoides (Ubushwa)
	<ul style="list-style-type: none"> • To alleviate oral thrush 	Ingwe
ii. Nutritional Supplements	<ul style="list-style-type: none"> ▪ To improve appetite 	Multivitamins, Vitamin B complex, Vitamin EZ, Garlic.
	<ul style="list-style-type: none"> ▪ To keep ones’ body healthy 	Beetroot, Philani porridge, Energy Porridge®, Garlic, Green pepper, Ginger

The following themes were associated with the use of additional therapies among the study participants.

i. Perceived cause of illness

Twelve participants reported using additional therapies (i.e. from belief systems outside the biomedical paradigm) at some point after their HIV diagnosis. Seven participants had used these therapies in the six months preceding this study. Their traditional healing system made use of indigenous traditional medicines that are given by traditional healers called *isangoma*¹⁵. These traditional practices are embedded in indigenous cultural practices. Participants reported consulting *isangoma* at the behest of other family members and paying between R50 and R1600 as consultation fees. Beliefs about the illness causation among the participants' relatives were linked to witchcraft or beliefs that certain family members did not wish them well.

...My mother took me to an *isangoma* who gave me things but they did not help-they thought it [HIV] was witchcraft. (Nozipho)

.. I am a Black woman. Sometimes people say that there is a *tokoloshi*¹⁶ behind me and if I drink certain [traditional] medicines the *tokoloshi* will run away. (Ruth)

Issues of TCAM use are complicated by the fact that traditional healing practices often involve cleansing the entire family of the "bad spirits." Ruth indicated that it was sometimes difficult for her to decline to use herbal medicines in spite of advice from her doctor to the contrary. She said:

...one [family] member had bad dreams so it [traditional medicine] was not for me. It was for another member of the family. When the *isangoma* came, he was trying to heal everybody. If he had healed one person [and left others] then those dreams would pass on to someone else within the family. (Ruth)

Five participants indicated that they stopped using TCAMs after being initiated on HAART on the advice of their doctors.

15 The following names were used by participants to refer to traditional healers: isiZulu: *isangoma* sing. / *izangama* pl. or isiXhosa: *amagqirha* pl.

16 A *tikoloshi* (isiXhosa) is a dwarf zombie used by witches to carry out mischievous and evil acts

ii. Meaning of TCAMs: Issues of Identity and Distrust of Orthodox Medicines

James viewed using traditional medicines as part of his Black identity and an affirmation of his cultural values. He noted that:

We as *Black people* we believe that this thing [HIV] comes because so and so doesn't like us. But I found out from my friend that I was wasting a lot of money and he convinced me that we should go to the hospital. (James)

ARVs help but as a *Black person* you don't want to use those drugs. You want to use the *natural* herbs as well. (James)

James statement statements appeared to contradict his earlier answer to the BMQ's general item No.4¹⁷ where he stated that natural medicines are not safer than orthodox medicines.

According to HIV counsellors a) "natural" herbs are more acceptable to some of their clients and b) unspoken suspicion and deep rooted distrust of medicines of western origin exist. This distrust seems rooted in the historical past of the country.

...To them they say it's natural. Anything that is grown from the ground is more natural. It's also cultural. The White men came and is trying to take it away - especially older people believe strongly in traditional medicines and say it is have always used and their fathers ..[who] never got sick. ... the older generation believe in traditional medication and [some] believe that the White men came to take their land and we can't use their stuff. [They] say that HIV came with the White men and it's his way of killing the Black men. So using the traditional medication is our Black man way of fighting the theories of the White men. It's not a vocal issue though because most traditional medicines are associated with witchcraft so they won't come out and say "I am going to such and such a traditional healer." (Laura)

..The minute they get it into their heads that pills are White men's pills they then stop taking medication and go to traditional healers to get their herbs. They come for the next treatment with half their pills unused and when they are sick too. (Laura)

¹⁷ BMQ Item 4 states that: "Natural herbal/traditional remedies are safer than medicines that I get from the clinic/hospital"

Although the following issue did not emerge in the researcher's discussion with the other participants, the HIV counsellors also mentioned that HAART, unlike most traditional herbal preparations, is not as bitter and this directly contradicts long-held beliefs by some Black people that medicines must be bitter for them to be effective.

...they look at the pills and compare them with a full cup full of bitter traditional medications and reason this pill will be slow to act so they opt for that bitter full cup which makes them sick... (Laura)

5.4.3 Uses of Complementary and Alternative Medicines

(See Tables 10 - 12)

a. To boost participants' immune system

Eleven participants reported ever using several herbal TCAMs before taking HAART to boost their immune system. Four participants had used immune boosters within six months preceding this study. Magogotha Carniboost[®], Mixture of life[®], Irhawv and *Hypoxis hemerocallidea* (African potato) were some of the products that were used for this purpose.

b. Managing perceived minor ailments

TCAMs, particularly herbal remedies were used for self-treatment of perceived minor ailments such as coughs, colds, oral thrush, as well as chest and ear pain.

c. Managing HAART-related side effects

Four participants reported using herbal TCAMs to manage HAART-related side effects. For example, Nozipho used *irooiwortel*¹⁸, an indigenous herb to control the dizziness associated with efavirenz use. James and Vusumuzi used the crushed *Hypoxis hemerocallidea* rootstock (commonly called African Potato) to treat cutaneous rashes, a fairly common hypersensitivity reaction associated with HAART use.

...ARVs work but they can put a rash on your body because they are trying to fight and chase away the virus. So when you are given these medicines you will have rash. They are working but they have other side effects. That's why with

¹⁸ irooiwortel is *Bulbine latifolia*.

African potato, when I put it on my face it is good. After I [use it to] wash my face, people see nothing. It makes my body clean... (James)

Nonzipho, who initially thought her “painful” legs were due to witchcraft, also used three herbal preparations to manage HAART-related peripheral neuropathy.

....I use *irooiwortel* but I got them from my mother who got them from someone else. My legs were painful and it was hard to walk. I would rub it onto my legs. They had to lift me up from the bed before I used *inongwe*¹⁹, *irooiwortel* and *camphor* for my legs.

Elizabeth used garlic to improve her appetite.

5.4.4 Sources of Information about TCAMs

Self medication using herbal TCAMs was commonly based on advice from family/friends/relatives, traditional healers and on participants’ own personal life experiences of using them. Traditional healers were said to seldom disclose the names and sources of their medicinal plants. James said the former Minister of Health (of South Africa), Dr. Manto Tshabalala-Msimang, was his source of information regarding African potato, beetroot and garlic use.

... I was using the African Potato that the Minister of health mentioned and also the beetroot. I heard it from the minister and then I ignored what the nurses where saying- “Don’t use those African herbs.” But then when I tried using it [African potato], it dried up. (James)

Vusumuzi also reported using African potato and beetroot based on advice from a friend. Advertisements from the mass media (e.g. radio and television) were another source of information about commercially-marketed TCAMs (such as Magogotha Carniboost, Moducare, Mixture of life and Arnica message oil). The major source of these medicines appears to be taverns.

¹⁹ Inongwe is *Hypoxis hemerocallidea*

5.4.5. Other TCAM Practices

a. Spirituality

Twelve participants were Christians and some made reference to God as their source of hope. Susan (HIV counsellor) narrated how, after discovering her illness and searching for a cure from multiple sources, she finally came to a realisation that she could only rely on God. She said:

... I didn't know that this thing [HIV] would stay in my body for a long time. I was very happy to go to isangomas so when that man [another traditional healer] didn't help me I left him and went out of Grahamstown to Umtata to find another sangoma who would help me. But the virus didn't leave my body. So then I realised that I can only rely on God. (Susan)

HIV diagnosis seemed to bring participants closer to their religion. Ruth and Elizabeth said that they were able to find new meaning and purpose to life through their religion after their HIV diagnosis. They reported valuing life more.

... I pray sometimes but not every day. I talk to God, just thanking him for my life. After discovering I am positive and to think I am still alive...(Elizabeth)

...Prayer is important to me, even when I am taking my medication. I know one day God will cure this. So one day I know I will get rid of the medication. I have that hope through my prayers and reading my bible. (Ruth)

Despite mentioning that his life and future depended on HAART, Sizwe also said:

...I know that I'm dependent on God, not on the drugs. It's only him who will make me live longer. So it helps because I know God is looking over me. (Sizwe)

Spirituality was used to understand and interpret their illness and the world around them. Some participants (e.g. Sizwe, Mandla) reported substituting going to church for alcohol consumption.

b. Body Massage

Mandla used arnica oil for body massage to help with relaxation and to soften his “dry and scaly” skin.

c. Physical Exercise

All participants used some form of exercise to stay healthy. Common form of physical exercise included walking to work and jogging. Besides the clear economic merits of walking to work, participants also mentioned stress relief as an additional benefit.

5.5 Conclusion

Participants had mixed views about various issues relating to their sexuality. Healthy sexual engagement was deemed as an important part of their quality of life by most participants. HAART use is associated with improved sexual functioning in most participants but evidence indicates that this might be gender dependent. Lowered sexual functioning seems to be associated with psychosocial causes such as the fear of transmitting HIV to their sexual partners, stigma associated with the disease and changing life priorities. Concerns about reproduction issues were raised by some participants. Cultural predispositions are sometimes used to justify risky sexual behaviours within sexual relationships. Gender issues and power dynamics also play an influential role.

The findings reveal that multiple internal and external factors, including participants’ knowledge and understanding of HIV and HAART, various cognitive and behaviour factors, and environmental factors such as stigma affect medicine taking in PLWHA on HAART. Becoming adherent to HAART is a dynamic process and is influenced by the interplay of individual, interpersonal, community-level and external factors. These factors include: individual’s perceptions of somatic symptoms, beliefs, expectations, perceived necessity and concerns about HAART, the perceived barriers to taking HAART and

affective factors. Participants' willingness, ability and commitment to taking HAART are important factors that influence medicine taking. Medication-related side effects and stigma were a source of ambivalence. No account of taking HAART was entirely optimistic. Hope/optimism about living longer is counterbalanced by reservations about the long-term effectiveness of HAART and worrying medication-related side effects.

Prescription medicines and non-prescription medicines were widely used among the participants. They were primarily used to treat minor illnesses and opportunistic infections, and to counter HAART induced side effects.

The use of complementary medicines and traditional medicines use were associated with strong cultural beliefs. Self medications using TCAMs and non-prescription medications allowed participants some degree of autonomy over their health. Religious beliefs and spirituality were important for coping with illness. Stress reduction and reduced worries about the long-term future prospects were some of the benefits associated with religion.

6.0 Introduction

In this chapter, research findings are discussed. Raw data – or quotes – are not repeated here as they have already been presented in full in the previous chapter. Following the same structure as Chapter 5, findings on the impact of HAART on sexuality are discussed first, followed by discussion on medicine taking behaviours.

6.1 Impact of HAART on Sexuality

In line with previous research,[4, 146, 214] the findings of this study revealed that PLWHA continued to engage in sexual relationships after being initiated on HAART as they believe that sexual activity is healthy and is an essential element of their wellbeing. However, myths such as “one goes mad”, “sperms accumulate in the brain” or man will “rape” women when they are deprived of or abstain from sexual activity highlight the complex and at times erroneous beliefs and misconceptions that not only inform sexual behaviours but seek to justify objectionable male behaviours such as rape. James’s statement (page 110) that some men think that HIV can be cured by engaging in sexual intercourse with “small children” echoes findings from previous studies[215]that showed that some South African men believe in the “rape myth.” These findings stress the need for educational interventions aimed at PLWHA that address these dangerous perceptions.

With regards to choosing sexual partners, contrary to what studies involving HIV-infected MSM have found,[216] serosorting²⁰ was not used by the study participants in choosing a sex partner. Most study participants had been involved in serodiscordant relationships at some point after being diagnosed with HIV-infection and all participants indicated that HIV status was not an important consideration when choosing a sexual

²⁰ Serosorting refers to a sexual harm reduction strategy of selecting sexual partners based on their HIV status. Whilst this practice is used by both HIV-seronegative and HIV-infected people as a risk reduction strategy, unprotected sex between two HIV-infected people carries the risk of re-infection with other viral strains or with resistant strains.

partner. In light of these findings, there is need to promote consistent condom use among PLWHA and in the general population.

Consistent with findings by Simbayi et al.[125] perceived HIV-related stigma was found to inhibit disclosure to prospective sexual partners and negative stereotypes associated with condom use made negotiating for safe sex very difficult with people with unknown HIV status. The decision making process informing disclosure appears to involve a covert cost/rewards analysis. By disclosing their status, participants risked being rejected, stigmatized or discriminated against. Thus nondisclosure serves a self-protective role as was seen in Sizwe's case. Conversely, the benefits of disclosing one's status included freedom from burdensome secret and increased access to social support resources. High perceived stigma partially explain why Vusumuzi and Diana selectively disclosed their HIV status, why Sizwe kept his status a secret and why some participants (e.g. Elizabeth) preferred casual sexual encounters. Keegan et al.,[217] also found that some PLWHA engage in casual sex as a way of avoiding disclosure. In addition to advising PLWHA on how to cope with issues of disclosure, educational interventions should aim to address the underlying cause of nondisclosure – the high levels of social stigma.

Sizwe's case (he had not disclosed his status to his wife) raises both moral and ethical questions. Although his doctor rightly keeps his HIV status confidential, one questions whether the wife deserves to be notified so that she can take appropriate self-protective measures such as insisting using condoms. This is of concern when viewed in the context of findings by Simbayi et al.[125] that in Cape Town, nondisclosure among PLWHA is associated with multiple partnerships and non-protected sex with nonconcordant partners. Since compelling doctors to notify patients' sexual partners might undermine their client's confidence in the system, undertaking public interventions that facilitate disclosure might be the best way to tackle this problem. HIV-related stigma needs be challenged and addressed through facilitating open dialogue within families, communities and in the public arena.

Conflicting evidence exists on the impact of HAART on sexual functioning.[4, 217, 218] Although improved HR-QoL, increased libido, sexual enjoyment and sexual activity were reported by most participants because of HAART, three women reported experiencing diminished sexual functioning. They attributed this decrease to psychosocial factors such as changes in priorities in life, depression and the fear of being re-infected. Keegan et al.[182] and Bova et al.[219] found that lowered libido among HIV-infected women is linked to their mental state, social circumstances, current health and time since diagnosis. Although no bidirectional relationship was found between sexual dysfunction and non-adherence among these three women, considering that diminished sexual functioning may be associated with non-adherence to HAART[4] and that participants rarely report issues relating to their sexuality to health care providers, it is reasonable to integrate adherence monitoring and sexual history taking as part of routine clinical assessment.

Lipodystrophic changes negatively affect PLWHAs' self-image[220] and that this may lead to non-adherence.[138] Several female participants reported feeling less attractive and having lowered self-esteem. Guaraldi et al.[221] found that men with fewer body changes were more sexually satisfied. None of the study participants mentioned that these morphological changes affected their sexual functioning. Nor did concerns about fat redistribution deter them from adhering to HAART. Despite this, some participants were concerned about these "visible markers of HIV disease"[144] because of fears of being stigmatised and the potential negative consequences on their social lives. Judging from participant's accounts, the current practice of substituting stavudine with zidovudine appears to be yielding good results in terms of alleviating stavudine-induced lipodysyrophy and peripheral neuropathy. These findings appear to support efforts by the World Health Organization to phase out stavudine in favour of alternative drugs such as tenofovir and zidovudine.[222]

In contrast to the perception that HAART, through disihibition or beliefs about its effect on reducing HIV transmission might encourage PLWHA to engage in risky sexual behaviours,[223] research findings showed that most participants fears of the risk of re-infection had a restraining effect. In addition, altruism was another motivator for adopting

safe sexual practices. The former is congruent with the propositions of the HBM that high perceived (re-)susceptibility to a disease encourages the adoption of healthy behaviours. Findings mirror those from a prospective study carried out in Kenya by Luchters et al.[214] in which HAART use was associated with decreased risky sexual behaviours. They, however, appear to contradict findings by Eisele et al.[146] who found widespread ongoing risky sexual behaviours among HAART users in Cape Town. The apparent contradiction might be a result of chance alone since this study's sample size was small and non-randomly selected.

Three constructs of the HBM - perceived susceptibility, perceived benefits and perceived barriers - may explain the decision making process that informed condom use among the study participants. The fear of re-infection (perceived re-susceptibility), the desire to maintain good health, and altruistic HIV prevention (by avoiding transmitting HIV to one's partner) (perceived benefits) were the primary motivating factors for using condoms. These were counterbalanced by several perceived barriers that included the reduced sensation/pleasure associated condom use, the risk of condom breakages, stigma associated with condom use and disclosure issues. The finding that cost/benefit appraisal plays an important role in health decision making is in line with the core tenets of all the three health behaviour models considered. Therefore interventions that promote condom use among PLWHA should, in addition to highlighting the risks associated with unprotected sex, attempt to address some of the barriers that hinder condom use.

Vusumuzi's selective non-use of condoms with casual sex partners, a practice that is widely regarded a high risk behaviour, appears irrational, and it appears to be at variance with the core assumptions underpinning the three behaviour models referred to. Preston-Whyte[224] explains that these inconsistencies in condom use by individuals can be attributed to situational selection. This means that the individual's cost/benefit evaluation that informs his/her decision fluctuates depending on the situation and time. In Vusumuzi's case, it was evident that with casual sex partners, the immediate benefit of sexual enjoyment with "fresh" women appears to supercede long-term concerns about HIV-transmission or re-infection. The cost/benefit appraisal appears to favour condom

use when he has sex with his wife; perhaps because of the degree of their emotional attachment, he is cautious about re-infecting his wife with the virus.

Tensions between adopting safe sex practices and sexual enjoyment were evident in some participants' accounts. Although all except one participant reported using condoms consistently, men appeared generally resistant to using them, especially in stable relationships. The metaphor "eating a sweet wrapped in plastic," was and is commonly used to convey displeasure with condom use because of the perceived decrease in sensation.[224] Considering that women often tend to take a subordinate role in heterosexual relationships and often find it difficult to negotiate condom use, they are particularly vulnerable to HIV re-infection. As was shown in Inid's case, cultural norms and beliefs such as *ilobola* appear to perpetuate male dominance and, by extension, risky sexual practices by disempowering women. One way of protecting women may be by promoting the use of femidoms. It was encouraging that the only participant who used femidoms, Nozipho, said that her partner found them more acceptable than the male condom. Further research into the use of femidoms in this context should be undertaken

Despite their knowledge about HIV transmission risks factors, worrying patterns of male participants' (four participants) involvement in multiple, and often long-term, concurrent sexual partnerships were identified.(see table 7) According to Maughan-Brown et al.,[225] this form of sexual partnering is common among black South Africans. Concurrent partnerships exponentially increase the risk of transmitting HIV or getting re-infected.[226] Cultural and peer group influences, and issues of masculinity appear to play an influential role in determining men's sexual behaviours. From the interviews, it seemed as if in isiXhosa culture, men are regarded as fearless and risk takers. This might partially explain why Vusumuzi had multiple sexual partners and why he deliberately sometimes does not use condoms so that he can perform well during sex. Interventions aimed at reducing risky sexual behaviours should aim to address the socio-cultural scripts that inform people's sexual behaviours. A limitation of the three health behaviour models is that they do not explicitly mention the role of cultural scripts. Components of ecological models could be integrated to assist in filling this void. Socio-ecological

models recognise that although individuals are responsible for making personal health and lifestyle choices, sociocultural (i.e. community norms and values, regulations and policies) and physical environmental (e.g. distance from health care centre) factors are key determinants of individual behaviour. What is needed then are multiple level interventions that deal with myriad individual, interpersonal, institutional and community-level factors, as well as public health policy deficiencies.

Alcohol consumption was found to be associated with increased risky sexual behaviours.[148] Besides the amount of alcohol that is consumed, the context in which it is taken played an important role in influencing risky sexual behaviours. Shebeens/taverns are well documented venues for high risk HIV transmission.[149, 227] Participants' narratives revealed that transactional sex - the exchange of sex for material gain – occurs in shebeens. Dunkle et al.[228] argues that these economic exchanges should be “viewed within a broader continuum of men's exercise of gendered power and control” and suggest that interventions to curtail transactional sex should also focus on issues of masculinity.

Although all the participants were of the general view that unprotected sex causes worsening of their health, their explanations as to how this occurs were vague and showed a lack of basic understating HIV/AIDS biology. Notions of a sexual partner “sucking” HAART during sex and the example given by Ruth where she likened her uterus to a cup where semen from repeated sexual intercourse continually accumulates illustrate this distorted view. None of the participants explicitly stated the possibility of acquiring or transmitting drug resistant viral strains during unprotected sex. The fact that most participants did not use condoms consistently prior to starting HAART suggests that the HIV-education/counselling that takes place in the early stages after the HIV diagnosis may have been inadequate or ineffective. Maughan-Brown et al.[225] also found that condom use among PLWHA increases considerably after they are started on HAART. They attributed the higher levels of condom use in the post-HAART initiation to more effective condom messaging compared to the pre-HAART initiation stage. The study findings indicated that health care providers seem to place more emphasis on condom use

after patients are started on HAART. Clearly this emphasis should be made as soon as possible after the patient is diagnosed with HIV because even before HAART, re-infection can occur.

Participants used metaphors to conceptualise HIV/AIDS and HAART. The metaphor of dirt which frames HIV-infected people's blood as being contaminated/ polluted with dirt (i.e. the virus) and HAART as an agent that cleans or cleanses the blood was used by some. Jabulani's statement that "ARVs clean" the body (see page 95) is an example of a person using the dirt metaphor. Another metaphor that was commonly used is the warfare metaphor. For instance, some participants called CD4+ cells "soldiers", the human immunodeficiency virus was depicted as an invisible enemy and the virus-immune system interaction as a "fight" or a war. Sontag[83] advocates the elimination of military metaphors because they perpetuate stereotypes, fear, phobias, stigma and discrimination by dividing PLWHA from the general population, and they serve to create distance between the person and the reality of living with the illness. Implicit in the participants' accounts were attributions of HIV/AIDS to promiscuity, indulgence and perversity. This explains the feelings of guilt, self-blame and shame that accompanied participants' HIV diagnosis. Annas[229] asserts that metaphors influence people's "construction of social and political reality" and reflect the society's attitude towards the illness. A possible step in eliminating the widespread HIV-related social stigma that was mentioned by the study participants might be by encouraging health care providers to replace these metaphors with more constructive and correct factual information.

With regards to reproductive issues, the findings indicated reproductive decisions are influenced by myriad health-related and non-health related factors. Similar to Cooper et al.'s[230] findings, social pressures to have a boy child, socioeconomic considerations and personal desire for parenthood were identified as some of the reasons for wanting to have children. Although in existing literature,[231] HIV- infection appears not to lessen one's desire for children, findings were mixed for this group of participants. Of the participants who had reproductive intentions, the fears about onward transmission of

HIV, doubts about the future prospects and the lack of adequate information are a major hindrance to achieving their dream of having children.

Although the discovery that they were HIV infected discouraged some participants from having children, HAART did not appear to alter their reproductive intentions. Although HIV counsellors said that reproductive options for PLWHA are available, it was not clear if they actually told PLWHA about them. Judging from the comments of (Joyce, Jabulani and Margret), who clearly were not aware of their options, PLWHA do not always think to ask. Cooper et al.[231] suggested that the reason why PLWHA do not ask about their reproductive options is because they anticipate negative reactions from health care providers. Cooper et al.[230] also found that stigma exist in communities that discourage HIV-infected couples from having children. As access to HAART improves and PLWHA live longer in South Africa, it is likely that some may opt to have children. It is therefore essential that people living with HIV/AIDS on HAART who want to have children are made aware of their right to bear children and of the various reproductive options available to them. Also policy makers should put in place a framework for addressing PLWHA's reproductive needs.

In summary: Key points relating to HAART and sexuality:

- a. Although all participants continued being sexually active after being initiated on HAART, four reported a decrease in their sex drive (libido), sexual enjoyment and sexual satisfaction and the remaining ten experienced the opposite effect.
- b. PLWHA's sexuality is interrelated with the process of coping with their illness. Numerous psychosocial factors that are independent of HAART influence their sexuality. These include: HIV-related stigma, issues of disclosure, fear of transmitting HIV or getting re-infected, partner's dislike for condoms, and gender and power inequalities within sexual relationships and cultural influences and reproductive concerns.

- c. The perceived risk of re-infection with drug resistant virus appeared to be a strong deterrent against engaging in risky sexual behaviours among the study participants.

6.2 Medicine taking behaviours

Findings on medicine taking behaviours among the study participants were mostly congruent with what has been published in literature on adherence. The study findings support the characterisation of adherence as a multifaceted and dynamic phenomenon.[232] The continual complex interplay of intrapersonal, interpersonal and contextual factors influenced participants' adherence behaviours, which furthermore evolved over time. Individual level factors included: illness perceptions; mood states, disease knowledge and personal beliefs about HAART. Interpersonal factors included: participants' relationship with their family, friends and their health care providers. External factors included: the broader social context (e.g. stigma), medication related factors (e.g. side effects), health care system-related factors and socioeconomic factors. Although multiple diverse determinants were identified, ultimately, the most important factors affecting treatment uptake and adherence behaviours seem to be related to the individual's illness and treatment perceptions, self motivation, as well as his or her level of commitment and ability to self manage treatment. Like the models suggests, the overarching goal for taking HAART was for longevity and to improve the quality of life.

Adherence to HAART was found to intersect with how well the individual copes with his/her illness. Adherence behaviours were categorised into three stages - the pre-HAART initiation stages- the starting on HAART stage and the maintenance. The TTMs' pre-contemplation and contemplation stages could be identified in the pre-HAART initiation stage whereas the preparation and action stages were identified in the starting on HAART stage. The maintenance stage, as in the TTM, described a period of relative stability in taking HAART. Findings showed that movement through these stages was often non-linear (i.e. not all participants appear to have gone through all the stages of change). The fact that none of the participants appeared to have experienced a relapse phase (regression from Action or Maintenance to an earlier stage/stopping HAART

completely) could be because of the life and death nature of HIV/AIDS. Several processes of change were identified from interview data. In the early stages of taking HAART, helping relationships appeared to help participants to move to the next stage whereas counter conditioning and self liberation were identified in the later stages of taking HAART.

As would be expected, the discovery that one is HIV-infected is a traumatic experience and negative emotional responses (e.g. anger, self blame) often accompanied the HIV diagnosis. The study findings showed that individual responses or stance to the illness have implications for the eventual coping strategy that are chosen. The first process that explains adherence behaviours is the acceptance or non-acceptance of one's HIV status. This stance appeared to influence treatment uptake and the participant's level of commitment to adhering to HAART. For example, Elizabeth, who was initially in denial, avoided having her CD4+ cell count taken for six years. Similar findings have been reported by Vervoort et al.[233] It is therefore essential for health care providers to facilitate the patients' acceptance of their status through offering *effective* counselling services and being empathic since this has a bearing on the patients' future adherence to treatment.

Elizabeth's case also highlights the importance of ascertaining the patients' readiness to commence taking treatment in line with the constructs of the HBM, TTM and CSM-SR. According to the TTM's 'stages of change' construct, a person is 'ready' when he/she is willing to adopt the recommended action. The HBM and CSM-SR are less clear on how to ascertain patients' readiness. Motivational interviewing may be used to ascertain readiness. Besides clinical and laboratory markers, focus should be put on assessing the patients' mental preparedness including his/her disease and treatment knowledge as well as whether he/she has adequate social support. Sizwe's case, where he was only told that he would take HAART for life after being initiated on treatment underscore the need for a systematic approach in educating patients about HIV/AIDS and HAART.

Rumours that still circulate in communities about HAART being toxic and causing death are of concern. While this has undertones of the former Minister of Health, Dr Tshabalala-Msimang's public objections to HAART, some participants said that they heard or saw some people die under suspicious circumstances after being initiated on HAART. This mutually reinforcing duo - misinformation and seeing/hearing of other PLWHA on HAART dying - appeared to bolster participants' doubts about HAART. HAART does have recognised side effects and may therefore to some degree be considered "toxic". Some people on HAART may die from complications of the disease process or because HAART was initiated too late. The participants' gave the impression that HAART's 'toxicity' is sometimes exaggerated in some social circles. As Susan pointed out, (page 110) negative perceptions about HAART fuel distrust and discourage treatment uptake and adherence to treatment. These misconceptions are however a symptom of a bigger problem that needs to be urgently addressed: the lack of reliable and accurate information which is compounded by the low-health literacy levels among Black communities. For example, some participants (e.g. Sizwe) could not distinguish between HIV and AIDS. Jabulani thought that HIV is a bacterium, and some (e.g. Ruth and Sizwe) initially believed that HAART "cures" AIDS. Low health literacy is associated with non-adherence.[234] Although Jabulani, who had problems with remembering the names of his medications, was able to identify his pills using their colours and surface morphology, potential problems could emerge if, for example, generic substitution is made. Health care providers should always explain verbally, and where possible, using the patient's mother language, all dosing instructions. The use of pictographic aids might also help to improve patients' understanding of their dosing instructions.

Participants' lack of knowledge about HAART before their HIV diagnosis is hardly surprising when viewed in the context of findings by Gebrekristos et al.[235] that the majority (74%) of patients attending a TB clinic in Durban in South Africa lacked any knowledge about HAART. The finding that none of the participants had gone for VCT before their HIV diagnosis was consistent with Mabunda's[236] findings that people in rural South Africa rarely use VCT service unless they had signs and symptoms suggesting possible HIV infection.

In line with the constructs of the health behaviour models, participants' health seeking and adherence behaviours were partly informed by their illness and treatment perceptions, their disease knowledge, and beliefs about HIV and HAART. Illness perceptions seemed to be primarily shaped by participants' experiences with HIV-related illnesses, seeing other people with HIV/AIDS, information from friends and to a lesser extent, information from key social actors and the mass media. HIV symptoms were an important cue to action. Since HIV-infection was considered by all participants as being synonymous with death, they were willing to take HAART despite the fact that HAART was a mystery to them. This illustrates the strong motivational effect of perceived severity of the disease and the perceived consequences of the health threat in influencing health seeking behaviours. High –perceived threat also explains why some participants' selectively adhered to HAART over other chronic medications such as antihypertensive, gout prevention and oral anti-diabetic medications. These findings support Leventhal et al.'s[163] conceptualisation of adherence as a self-regulatory process which is shaped by how a person makes sense of his/her illness and medications.

The participants' motivation for adhering to HAART was based on the belief that their actions would result in their illness being controlled. Excluding non-intentional incidents such as forgetfulness, non-adherence may be a consequence of the individual's rational appraisal of outcome expectations (pros and cons) of taking medications. Analysis of the multiple causes of intentional non-adherence that were identified (e.g. an attempt to avoid medication side effects, experimenting with medications, and for purposes of taking alcohol) indicates that non-adherence is not deviance behaviours but a conscious attempt by individuals to be in control of their lives and to minimise the impact of HAART on their lifestyle. Vervoort et al.[233] aptly refers to this as self-tailoring (which could be considered a form of agency). The participants' narratives showed that, as with sexual behaviours, assessing costs and benefits applies to adherence behaviours.

Taking other medication regimens such as DOTS and/or co-trimoxazole prophylaxis prior to being initiated on HAART seems to have helped participants to become

accustomed to taking medicines. Remiem et al.[232] and Vervoort et al.[233] found that adhering to HAART requires “getting used to” and involves the patient internalising medicine taking through repeated practice. From this perspective, medicine taking skills are learnt or acquired through experience. This view supports the current practice in clinics of starting newly diagnosed HIV patients on daily vitamin tablets to monitor their preparedness to adhere to HAART. However this practice can also be seen as patronising.

Although the findings could be interpreted as broadly congruent with the three models chosen, one conspicuous limitation was the models’ emphasis on individuals in explaining health decision making. Little attention was paid to the broader social contexts in which health behaviours such as medicine taking occur. Contrary to the assumption that individuals are the sole or main decision makers concerning their health, this study found that in most cases, influential family members often made critical decisions on behalf of the participants, especially in the early stages of the illness. Examples included: when and where to seek medical assistance as happened with James and Ruth; issues relating to TCAM use and HAART uptake as happened with Margret and Ruth; and actively monitoring that participants’ adherence to HAART as happened with Mandla, Elizabeth, Joyce and Nozipho. A family-oriented health behaviour change model that incorporates these key actors, or the addition to existing models of a scale designed to capture this information, may have been more useful.

The HBM can be criticised for being too simplistic and for failing to account for the dynamic nature of adherence behaviours. Also the definition of what constitutes barriers and benefits is too broad and subjective. For instance, whilst perceived stigma was a barrier to adherence for Sizwe, with some of other participants (e.g. Joyce and James), reduction of stigma through an improvement in general health was a motivating factor. The TTM gives an impression that adherence to HAART is a linear process when in actual fact participants sometimes vacillated between stages. Of the three models, the self-regulation model appeared to best explain medicine taking behaviours. In addition to accounting for the role of idiosyncratic beliefs, illness and treatment perceptions, the model explicitly describes the role of both cognitive and emotional aspects in coping with

illness. Unlike the TTM, the CSM-SR's feedback loop explains the important role of self appraisal /self-monitoring and accounts for the dynamic nature of adherence.

6.2.1 Facilitators of adherence

Adequate social support, in all its diverse forms, was a crucial facilitator promoting adherence to treatment. In an adherence study carried out in South Africa by Nachega et al,[92] family members, close friends, support groups and “treatment supporters” were identified as important actors in providing emotional, instrumental, tangible and informational support. Effective treatment supporters must have moral authority over the patient since this is congruent with the cultural norms of Black South Africans. Their suggestion that treatment supporters should be included in education sessions so as to “overcome the barrier of misinformation” seems appropriate for our study sub-population considering that non-adherence could sometimes be attributed to misinterpretation of the health care provider's instructions.

A caring, supportive and trusting relationship between health care providers and their patient positively influences medicine taking. With the exception of Mandla who changed clinics because of personal dissatisfaction with the quality of service, most participants said a friendly and trusting relationship with their health care providers was helpful in coping with their illness and encouraged them to adhere to HAART. Doctor-patient power relations appear to influence adherence behaviours. Doctors were viewed as authoritative figures and this had its merits and perils in relation to adherence to HAART. For instance, some participants said their health care providers instructed them to take HAART after food or not to mix alcohol with their medicines, which they interpreted as meaning that they may skip taking their treatment when they had not eaten or when they choose to take alcohol. This is despite the fact that, according to HIV treatment guidelines, all the HAART regimens used by the participants could be taken with or without food.²¹ It should be noted that the research was unable to establish whether the participants misinterpreted this or whether they were given unclear or incorrect information.

²¹ When taking efavirenz one must avoid fatty meals.

Considering that the study participants seemed content with a submissive type patient-doctor relationship, the low health literacy and their apparent lack of confidence in asking their health care providers about their medicines raises doubts about whether the concordance model would be helpful in this setting. It would not only require a change of approach within the participants, but possibly also a re-training of the health care providers.

Electronic personal reminder devices such as alarms have traditionally been recommended by health care providers as a way to enhance adherence. Since the study findings showed that non-adherence due to forgetfulness seemed to be more prevalent in the earlier rather than later stages of taking HAART, in addition to meeting a patient's psychological needs in these early stages – health care professionals could encourage patients to use electronic reminder devices. As Wroe[237] points out, the use of electronic reminders decreases non-adherence due to forgetfulness (non-intentional) but not intentional non-adherence, which is more strongly associated with a decisional balance. It is therefore important a) to distinguish between intentional and non-intentional causes of non-adherence when formulating interventions and b) that the role of the treatment supporter should not be substituted by electronic devices since active monitoring of medicine taking may be necessary to detect and address causes of non-adherence. Electronic devices can also not provide the human contact of treatment supporters. Additional reminders identified in this study which were easily integrated into PLWHA's daily routines included synchronising HAART dosing times with daily activities (e.g. breakfast) and having family members reminding the person to take their medications. These adherence reminders are standard suggestions made by health care providers including HIV counsellors.

Mood appeared to play an important role in coping with HIV illness and in taking HAART. This supports Leventhal's dual process model in which cognitive and affective pathways influence health behaviours. A variety of emotional responses characterised the participants' responses to their illness. Emotions such as anger, "feeling bored," feeling

uninterested or happy accompanied HAART use. Although negative mood states such as low anger control is associated with increased non-adherence[238], this was not a feature of the participants in this study. Most participants indicated that being on HAART makes them feel happy; some said they felt what Halkitis et al.[239] call “a renewed sense of health and hope.” As happens with all people the participants’ emotions changed depending on situational variables. For instance, some participants felt “scared” when experiencing medication side effects and some felt “happy” when their CD4+ cell count improved. Interestingly, the names *inkobe* and *amandongomani*²² that were sometimes used by participants to refer to HAART not only reflects similarities between the physical characteristics of corn kernels, peanuts and pills, but the use of food metaphors may symbolise the life-sustaining nature of HAART. Religious faith and having hope emerged as major motivators for starting and continuing taking HAART. Psychological interventions and counselling might help PLWHA cope better with negative thoughts and emotions. Health care providers could monitor or ask patients about their feelings as a way of gauging how well they are coping with their illness and medications. This is a standard component of patient centeredness.

6.2.2 Barriers to adherence

Various impediments to medicine taking were reported. Chief among them were social stigma, HAART-related side effects, hunger, high transport cost, difficulties in integrating HAART into one’s lifestyle, alcohol consumption and psycho-emotional issues. Stigma can be a hindrance in adherence to HAART.[7] In this study, although most participants said stigma did not influence their medicine taking, some participants (e.g. Sizwe) were uncomfortable taking their medications in the presence of their family and/or workmates. Perceived stigma also hinders disclosure and this means that one cannot benefit from external social support. The fact that all Raphael Centre participants had disclosed their status could be due to the high emphasis placed at the Centre on the benefits of disclosure, as well as the presence of strong role models to counsel people on disclosure. Although the following example of the consequences of stigma has no direct implications for medicine taking among PLWHA, it is worth mentioning that at the time

²² *Inkobe* refers to boiled corn and *amandongomani* refers to peanuts

of conducting this study, there were attempts to by a neighbour to force the Raphael Centre to relocate from its current location in a low density suburb in Grahamstown. The enduring nature of stigma means that sustained educational interventions and campaigns should specifically address the multiple causes of stigma at all levels. Dispelling stigma at the family level may be accomplished by actively involving family members in the counselling process and in designing, implementing and monitoring the treatment plan. At a community level, encouraging PLWHA to live openly with their status and share their experiences, and where possible, to become counsellors/activists in their own right, might help change people's illness and treatment perceptions. From the participants' accounts, one can conclude that communication at the individual, community and societal levels is critical in reducing stigma.

This study also confirmed that the practice of separating HIV clinics from the rest of the hospital reinforces HIV-related stigma. Through fear of being identified, some participants reported being hesitant to enrol for treatment and to go for prescription refills. The long waiting times in public hospitals, the poor quality of service and the lack of privacy prompted Sizwe to switch to private pharmacies. This is of concern because most PLWHA on HAART who cannot afford to turn to private pharmacies, may find the public sector discouraging and default on their HAART. Although some of the problems (e.g. overcrowding, shortage of qualified health personal, poor service delivery)[240] that face South Africa's public hospitals are a consequence of the now obsolete apartheid system, imaginative and innovative health policies need to be implemented to ensure that hospitals are run efficiently and that the quality of services meets acceptable standards.

The most common medication-related factor identified as a barrier to adherence was HAART side effects. Side effects referred to by the participants included: vivid dreams and drowsiness associated with efavirenz, peripheral neuropathy and fat-redistribution/lipodystrophic changes associated with stavudine use. (See Table 10) While side effects may account for a large amount of non-adherence,[79, 80, 81] most study participants said they tolerated them because the perceived necessity for HAART overwhelmed concerns about side effects. Forewarning patients about potential HAART

side effects, how to detect and manage them, prior to starting on HAART are some of the strategies that could be used to help prepare patients in coping better. Another useful strategy is linking new patients to more experienced patients on HAART so that they can share their experiences and ideas about coping with problematic situations. Voluntary peer mentoring seemed to work well among the study participants drawn from the Raphael Centre. A comprehensive systematic review of 25 randomised clinical trials focusing on peer-based interventions in health behaviours, including adherence behaviours, supports the effectiveness of these strategies.[241]

Consistent with findings from other settings in Sub-Saharan Africa,[106] high transport costs and hunger were reported to be barriers to adherence. The unemployed participants were most affected by these. Financial constraints in the face of competing life demands (e.g. food, rent, children's school fees) mean that poor PLWHA may have to walk to clinics to collect their medicine on a monthly basis. As Mandla pointed out, the distance to the clinic is sometimes far and the high transport costs deter some PLWHA from going for prescription refills.

The provision of the disability grant by the South African government is meant to assist PLWHA with CD4+ count less than 200cell/ μ L to meet basic needs. But it seems to have had an unintended effect of undermining adherence. Because the grant has become a "lifeline"[107] for some, it can be seen as an incentive to skip taking treatment so that they can keep their CD4+ count below 200cell/ μ L, the upper limit required to qualify for the grant. If one considers the high unemployment rate (\approx 25-48%)[108] in South Africa, it helps explain why a person like Mandla found himself choosing between income (disability grant) and his health (adhering to HAART). In some parts of South Africa being diagnosed with HIV-infection has become cause for celebration. It is sometimes likened to "winning the lotto" because of the prospect of getting the monthly grant.[242] Whilst the intricate details surrounding the merits and disadvantages of retaining the grant in its current form are complex and beyond the scope of this study, it is evident that tackling HIV/AIDS will require bridging the increasing social and economic inequalities. From an adherence point of view, the current situation regarding the grant needs to be

revisited. At a minimum, the grant needs to be restructured so that the CD4+ count is not the sole consideration in awarding it.

The negative impact of alcohol use on adherence is congruent with the reviewed literature. Impaired perception, reduced executive function and forgetfulness are believed to cause non-adherence among PLWHA using alcohol.[97] In addition, the perception that alcohol should not be taken concurrently with HAART resulted in some participants skipping their medications. This shows a misunderstanding between the prescriber's intentions and the patient's interpretation of the instructions, perhaps due to poor counselling and/or language barriers. Considering that many different languages are used in South Africa, and the low health literacy that exist among Black communities, it might understandably be difficult for health care professional to explain in lay clear terms some of the biomedical terminology associated with HIV/AIDS and HAART. Efforts should be made to ensure that where necessary, translators who are proficient in local languages are used in order to avoid the misinterpretation of prescribers' intentions. It would help if patients were also given simple written instructions in their home language and if patients were "tested" to make sure they understand.

Most participants reported self-regulating their alcohol intake, or stopping completely, because of HAART. It is important for health care providers to: a) make certain that their instructions are not misconstrued by the patient as meaning that they can skip taking HAART in order to take alcohol and/or b) how to manage the use of alcohol in the context of tribal rituals, and c) if the patient finds it difficult to stop taking alcohol, guidance should be provided about taking it in moderation.

6.3 Medicine utilization: Prescription, non-prescription medicines and TCAMs

A review of the participants' health passports, which record their use of prescription, non-prescription and TCAMs in the six months preceding the study yielded several insights into why and how they use their medicines. Besides HAART, the participants commonly used prescription medicines were antibiotics used to treat and prevent opportunistic infections, various anti-allergy medications used to alleviate medication

side effects, and medications for co-morbid chronic diseases such as hypertension and diabetes. These findings concur with those of Peltzer et al.[14] who found that self medication using various non-prescription medicines and TCAMs (Table 11-12) is common practice among South Africans living with HIV/AIDS. This study's medicine utilisation review provided insights into the nature of everyday health challenges which sometimes go unreported, that PLWHA face. Chief among them are recurrent headaches and bodily pain, allergies, diarrhoea, coughs and general body weakness. Of concern, is that because some of the non-prescription medicines were bought from township shops/taverns (muthi stores) opportunities are missed for health professionals to screen for potential drug interactions with HAART. Possible reasons why taverns were preferred by the study participants could be because they are more accessible (i.e. close to their place of residence) and are perceived to be less expensive compared to community pharmacies.

With regards to TCAMs, the study findings are also consistent with what has been found by Peltzer et.al,[14] that these products are used prior to initiating HAART. Orally administered, scientifically untested herbal medicines to treat HIV symptoms, medication side effects and as immune boosters is of concerns because of potential herb-drug interactions. While vitamins were mostly dispensed by the clinics, herbal medicines were obtained from non-medical sources such as a friend, *isangoma*, and/or township *muthi* stores. Herbal remedies from traditional healers are part of Black culture and identity. Some remedies (e.g. African potato) have been shown to interact with some components of HAART *in vitro*. [243] As participants did not report their TCAM use to health care providers potential herb-drug interactions were not identified. It seems that by not disclosing their TCAMs use to their health care providers who are perceived as strongly discouraging their use, the participants were trying to avoid possibly being chastised. This is a logical consequence of the HIV counsellors indicating that their clients are strongly advised against using TCAMs, especially herbal remedies.

TCAM use among PLWHA on HAART highlights the uneasy intersection of different healing paradigms – traditional healing with biomedicine. TCAM use by some

participants was informed by beliefs about disease causation and doubts about HAART. Belief in traditional healing paradigm appears to be associated with TCAM use and consulting isangoma. Participants who strongly believed in God seemed to shun TCAMs and appeared more determined to adhere to HAART. Adherence interventions should therefore take into account the patient's religious beliefs.

TCAM use could be argued to be an essential component of some of the participants' medication experience and can potentially influence non-adherence to conventional medicines. Littlewood and Venable's[33] systematic review of seven studies on the impact of TCAM use on HAART adherence found two studies with an association between TCAM use and non-adherence while the remaining five studies found no difference in adherence between TCAM users and nonusers. Our findings are similar to Peltzer et al.'s[14] study in KwaZulu-Natal in which it was found that TCAMs were generally used to supplement, not to substitute for HAART. The participants' active engagement in making decisions about what other medications to take to support HAART – just in case – also indicates that they retained a sense of agency. However, the potential for serious interactions is increased. This problem is compounded by the widespread nondisclosure of TCAM use by patients on HAART. Health care providers should attempt to create an atmosphere conducive to open dialogue about their patients' TCAM use. The existence of aggressive commercial marketing of some of the TCAMs, which sometimes make therapeutic claims with questionable scientific basis, demonstrates the need for a comprehensive regulatory framework to protect the public who might have no means of verifying the authenticity of the medicine.

Although the politicisation of HIV/AIDS and HAART that characterised former President Thabo Mbeki's tenure seems to have not affected participants' decisions to take and to adhere to HAART, most of them reported having heard that HAART is “toxic” or “kills” or that they should use herbs and vitamins instead. Former Minister of Health, Dr. Manto Tshabalala-Msimang, who is famously known for calling HAART “poison”, and for promoting unproven alternative ‘treatments’ and nutritional interventions, was explicitly mentioned by Mandla as the reason why he started using non-biomedical

alternatives such as beetroot, garlic and African potato. Whilst Mills[244] assertion that medical pluralism is, to some degree, a consequence of political equivocation has merit, our findings indicate that cultural influences, doubts about the long-term effectiveness of HAART and a patient's desire to maximise health benefits by utilising both healing paradigms are primary drivers of TCAM use. Nevertheless, it is clear that information from key social actors (e.g. politicians) influences people's health seeking behaviours. Ruth, for example, felt that unnecessary confusion had been created among people who take HAART.

In summary: key points on HAART and adherence:

- Health seeking and adherence behaviours are shaped by the reciprocal interaction between a person's idiosyncratic beliefs and his or her actual experience with HIV-illnesses and medicines. Individuals weigh the pros and cons of various options available to them when making health decisions. Self monitoring enables individuals to assess progress in achieving their set goals and to adjust their actions if necessary.
- The influence of political equivocation by key political actors such as Dr Manto Tshabalala-Msimang and former President Mbeki on participants' decisions to accept HAART and to adhere to it appeared minimal. But rumours continue to be spread in wider communities, suggesting a need for HAART to be more positively promoted, along with the fact that HIV and AIDS is a manageable chronic condition, and treatment is more successful when people present early for testing and follow up instead of waiting until they are very sick. The study participants based decisions about treatment uptake primarily on their personal experiences of living with HIV-related illnesses, perceived necessity and concerns about HAART, and advice from family and friends. Subsequent adherence to treatment was determined by the participants' early experiences of taking HAART and each individual's appraisal of the benefits and costs of adhering to treatment.

- While state support for pseudoscience and political equivocation confused people, the findings suggest that bio-socioeconomic and health-care system factors such as stigma, medication side effects, the disability grant, high transport costs, improving doctor-patient communication and the quality of service at public hospitals are major barriers to adherence.
- Some of the major barriers (e.g. stigma, misconceptions and lack of information about HAART) to medicine taking appear to be shared among the community as a whole.

Limitations of the study: Several limitations of this study should be noted.

- The quantitative aspect of the Necessity-Concerns Differential (NCD) was not particularly meaningful with this small sample. In addition, problems with comprehension of some of the statements contained in the questionnaire were raised by some participants, further undermining its usefulness.
- Making comparisons between the University group and the Raphael Centre group was not useful because, contrary to the original assumption, the sociodemographic characteristics (e.g. level of income) of some of the participants from Raphael Centre group were comparable to the Rhodes University group. The issues that were raised by both groups were mostly similar.
- While a concerted effort was made to ensure consistency and credibility in data analysis, qualitative findings are intrinsically subject to different interpretations. As such, another person's interpretation of the qualitative data might not yield similar themes as the ones stated above.
- The theoretical frameworks used in this study emphasise individual behaviour change processes but pay little attention to the effect of sociocultural factors and the physical environment on behaviour.

- The small sample size and non-random sampling that were used in this study means that the findings cannot be generalised to some larger population.
- TCAM use was not documented by most participants. Interview data may not be accurate because of forgetfulness.

CHAPTER 7: CONCLUSIONS, RECOMMENDATIONS AND REFLECTIONS ON THE RESEARCH PROCESS

7.0 In conclusion

Although HAART use was associated with improved sexual libido, sexual enjoyment and sexual activity, findings suggest PLWHA, especially women, face challenges related to their sexuality, some of which are not directly related to their illness and treatment. The persistent fear of transmitting drug resistant HIV to one's sexual partner, being stigmatized, disclosure issues, difficulties in negotiating safe sex among women, HAART-related lipodystrophic changes that affect their sense of self and unmet reproductive needs are some of the problems participants mentioned facing. Cultural influences, gendered power relations, myths and misconceptions and men's dislike for condoms strongly influence sexual behaviours. Being on HAART did not appear to increase risky sexual behaviours. But for Vusumuzi, excessive alcohol clearly led to increased risky sexual behaviours. The perceived lack of attention among health care providers concerning issues related to PLWHA's sexuality and reproductive issues needs to be addressed.

Adherence is a multifaceted and dynamic phenomenon that is shaped by the continual interplay of individual, interpersonal and external factors. Both cognitive and affective factors such as PLWHA's illness perceptions, necessity and concerns beliefs, hope and a patient's "sense of" agency influence adherence.

South Africa's history of AIDS denial and the promotion of untested treatments by key political actors appears to have had a lingering impact on treatment uptake and adherence. Biosocioeconomic causes of non-adherence and improvements in the quality of healthcare delivery need attention. The lack of adequate knowledge about HIV/AIDS and HAART, the high levels of social stigma, HAART-side effects and issues related to poverty (hunger, high transport costs) are major barriers to adherence. Interventions to address stigma should incorporate community participation and promote open dialogue about HIV/AIDS between sexual partners and within families.

Multifaceted and pragmatic adherence interventions are needed that take into account: a) whether non-adherence is intentional or non-intentional b) each patient's unique life circumstances, personal beliefs, lifestyle preferences and cultural predispositions c) the historical, political and socioeconomic contexts in which medicines are taken d) other non-psychosocial causes of non-adherence such as medicine side effects. Despite their imperfections, insight from health behaviour models should be blended with empirical findings from local studies in designing effective adherence interventions.

The fact that traditional healers were the first people to be consulted by most study participants points towards a need to recognise the existence and important role of alternative healing systems used by PLWHA on HAART. Also, it highlights the need for a robust regulatory framework regulating the activities of traditional healers. In spite of the fact that most TCAMs are scientifically untested, some PLWHA may not necessarily consider this important since they have a lot of experience in using them. Furthermore traditional medicines are an integral part of the cultures and lifeworlds of many black South Africans. A cautious approach is needed among health care providers when discouraging their use so as not to alienate such patients as this may result in nondisclosure of their use. Because TCAMs are used to supplement HAART and not to replace them, the focus should be on encouraging disclosure by actively asking questions with the aim of screening for herb-drug interactions. A collaborative approach is more likely than a judgemental approach to enable people to talk about the traditional medicines they use. TCAM use did not seem to affect adherence to HAART in this study.

7.2 Recommendations

7.2.1 Recommendations for Health Care Professionals, Policy makers and Communication Interventions

- Although HAART appears to improve sexual functioning among PLWHA, they still face unique challenges relating to their sexuality. Because PLWHA seldom spontaneously inform their health care providers about these problems, there is a need to consider including sexual history as part of routine clinical evaluations of

PLWHA. The reduced self image effects of lipodystrophy and its impact on sexual functioning should be monitored.

- Interventions that promote condom use among PLWHA should, in addition to highlighting the risks associated with unprotected sex, attempt to address some of the barriers that hinder condom use. This might entail educating patients on how to use condoms correctly, and carrying out public campaigns re-branding condoms in a positive light.
- The tendency to make use of VCT services only once people have become ill should be reversed, and the possibilities of routine HIV testing (or ‘opt out’ testing) should be considered. It is nonetheless essential that communication messaging conveys that HIV is treatable and the sooner one’s status is known the better – in order to benefit from life-prolonging medicines.
- PLWHA on HAART who want to have children should be made aware of their right to bear children and of the various reproductive options available to them. Policy makers should put in place a framework for addressing PLWHA’s reproductive choices.
- Aggressive but well constructed prevention messaging and information about the dangers of multiple and concurrent partnerships should be developed.
- Involving men in changing male stereotypes and resisting peer pressure. Correct and consistent condom use needs to be promoted. Misconceptions such as the perception that using two condoms instead of one is more effective in preventing HIV transmission in serodiscordant couples needs to be addressed.
- All patients should be informed that ARVs are taken for life.

- Clearer, and non-conflicting information about HAART and alcohol consumption as well as taking HAART on ‘an empty stomach’ needs to be provided at the time of initiation of HAART and reinforced at follow-up consultations.
- Greater focus should be devoted to the following biopsychosocial factors that hinder adherence to HAART:
 - i. High levels of social stigma
 - ii. HAART-related side effects
 - iii. Socioeconomic factors (i.e. high transport cost, hunger, disability grant)
- In addition to dispelling misconceptions about HAART, health care providers must explain whenever possible using the patient’s mother language, all dosing instructions. The use of pictographic aids might help to improve patients’ understanding of the dosing instructions.
- Since TCAMs are primarily used to supplement HAART and not to replace it, it is important to encourage PLWHA to disclose their TCAM use and to screen for potential herb-drug interactions.
- In order to facilitate this disclosure health care providers should respect cultural differences of their patients and engage in open dialogue in a non-judgemental way for the benefit of the *patient* and his or her worldview and belief systems.

7.2.2 Recommendations for further research

The following areas were identified as needing further research:

- Qualitative as well as quantitative research – ideally mixed method studies - are needed to ascertain the influence of the disability grant on adherence behaviours among PLWHA on HAART in South Africa. This could inform policy makers on drivers and changes that need to be addressed.

- Further research is needed to explore how ideas in the transtheoretical model and self regulation model could be integrated in existing interventions aimed at improving adherence to HAART and reducing risky sexual behaviours.
- The impact of educational interventions, cultural influences and gendered inequalities on risky sexual behaviours (specifically, on the nature of sexual relationships and condom use) among PLWHA on HAART need further exploration.

7.3 A Journey of Discovery: Researcher's Reflections on the Research Process

“By three methods we may learn wisdom: first, by reflection, which is noblest; second, by imitation, which is easiest; and third, by experience, which is the most bitter. Study without reflection is a waste of time; reflection without study is dangerous” Confucius (551-479 BC)

This section is a reflection of my own experience of the research process. Unlike convention required in the previous chapters, I use the first person here.

Overall, the research process was fascinating and quite illuminating but it was also fraught with challenges and frustrations.

Choosing the research topic: Choosing a research topic was a daunting and lengthy process. It was even more challenging but in many ways exciting because as a foreign student studying at Rhodes University, the study gave me the opportunity to interact with the community, to learn about the local culture and how the health care system functions. With the assistance of my supervisors, we were able to formulate my research topic. At first, the topic seemed too broad and disjointed. After doing some background reading on the history of AIDS/HIV denialism in South Africa, I was convinced as regards to the topic's relevance.

Because of my previous exposure to quantitative research during my undergraduate studies, I initially structured the study along the lines of a quantitative survey involving the administration of questionnaires. Although I was initially apprehensive about idea of incorporating qualitative research, after consulting with supervisors and being made

aware of the difficulty of recruiting sufficiently large numbers of PLWHA to participate in the study given the short period of time over which the study had to be completed, I decided to conduct a mixed methods study which was predominantly qualitative. I reasoned that quantitative results could be used to enrich the qualitative findings although in hindsight, the questionnaires proved difficult to administer because some participants had low English literacy. Writing the research proposal proved challenging and time consuming but it afforded me the opportunity to refine, sharpen and clarify my ideas.

Conducting the actual research: After being granted ethical approval, I recruited the study participants. Initially, I sought to recruit only Rhodes University community members since my sponsors (HEAIDS)²³ were particularly interested in HIV/AIDS issues in tertiary educational institutions. It is worth mentioning that at about the time as this study, a large HIV-seroprevalence survey was being conducted by HEAIDS at Rhodes University as part of national study of tertiary educational institutions. The findings of the survey had, not been made public at the time of completing this research. In spite of spirited efforts, I managed to recruit only one participant who was a Rhodes University support staff member through a colleague/friend. She had publicly disclosed her status. I thus decided to use snowballing sampling technique and to expand my sampling population to include members of a local non-governmental organization that cares for PLWHA. A comparison of the antiretroviral experiences of the two cohorts was then envisaged. The two groups differed mainly in their socioeconomic characteristics and this comparison helped to shed insights into the impact of socioeconomic variables on adherence and sexual behaviours.

Deciding on the amount of honorarium (R150) that was given to participants presented a moral and ethical dilemma. Paying research participants often acts as inducement to participate in the study, however, if unchecked, undue inducement might undermine informed consent. The honorarium was significant for some participants when compared

²³HEAIDS is an acronym for Higher Education HIV/AIDS Program. It is a “nationally co-ordinated initiative to develop and strengthen the capacity of South Africa’s higher education sector to respond comprehensively to the challenges posed by the HIV/AIDS pandemic and to play a leadership role in the South African HIV/AIDS response.” See: <http://www.hesa.org.za/heads/index.php/who/overview->

to their self reported monthly family incomes. In deciding how much to pay each participants, consideration was given to: travel cost, time away from work and advice was sought from other researchers at Rhodes University on the 'standard' practice. It was also the amount recommended by the Clinical Trials Committee of the Medicines Control Council.

After making the above-mentioned adjustments, recruiting the required participants was relatively unproblematic. Obtaining informed consent from participants was trouble-free but conducting the actual interviews was quite challenging. Despite the fact that I had practiced asking the interview questions beforehand, feelings of embarrassment were sometimes experienced when asking questions focusing on the impact on HAART on sexuality among women participants. This was because as a man, in my culture, we hardly ever openly discuss issues related to sex especially with older women. These issues are considered taboo! I sensed that some women participants were also uncomfortable. Even more embarrassing where situations were I had to translate names of certain sexual acts into isiXhosa (e.g. masturbation, sexual intercourse, oral sex) to women participants who could not converse in English. Translated versions sounded offensive/vulgar.

Female participants were often very emotional when narrating their stories. Margret cried when I asked her how she discovered her HIV status. Although male participants were generally open during the discussions, Sizwe seemed suspicious of the tape recorder and because he had not disclosed his HIV status to anyone, he was concerned about privacy issues. In general, interviews where interpreters were employed tended to be less detailed and it was evident that their presence had an inhibitory effect on open discussion. This was worse during discussions on the impact of HAART on sexuality. I could understand isiXhosa so after a few interviews, I gained confidence about my isiXhosa speaking ability and began interviewing participants without the use of interpreters. All interviews progressed well.

Another dilemma worth mentioning was dealing with power relations with my participants. It was clear that some participants viewed me as someone with authority even though I had introduced myself as a postgraduate pharmacy student. In retrospect, I could have opted to carry out the interview in another location instead of my office.

Open ended interview questions allowed participants to express themselves ‘freely.’ Self administered structured questions were deemed too difficult to complete by some study participants. In hindsight, results from the BMQ were not as useful as was originally envisaged, because of the many practical challenges of administering the instrument to mostly semi-literate participants. The numerical rating scale on sexuality was deemed easy to complete by all participants.

An interesting finding that emerged from the study was that participants sometimes used traditional medicines because they are suspicious of HAART which they labelled as white mans’ medicine. According to HIV counsellors, their clients often keep their suspicions about the link between Western countries and HIV/AIDS a secret. This kind of information may not have emerged if I was a white person.

In many ways the research process proved to be a process of self discovery for me personally. My initial zeal to learn to do research was sometimes dampened by the practical challenges such as difficulties in recruiting enough participants, the language barrier during interviews, and the lengthy and tedious transcription process. The write-up phase was a challenging undertaking and involved a lot of introspection.

Visit to the Shebeens: My visit to two Shebeens with one of the study participants, Ruth, felt awkward. The patrons seemed well acquainted with each other and they could easily tell that I was an outsider. My inability to speak isiXhosa and the fact that I did not drink the home-brewed opaque beer (the only beer that was sold there) clearly made me a misfit. Ruth said that patrons preferred this type of beer because it was “very cheap” and more intoxicating compared to the one sold in licensed establishments. She also said that she knew some of the patrons who were on HAART. Because we did not disclose the

purpose of my visit, some patrons appeared curious and were inquisitive about what I did for a living. I indicated that I was a student at Rhodes University and Ruth's friend. Since my presence might have affected the behaviour of some patrons, the picture that I got about Shebeens might not be accurate. Future studies that chose to use participant observation as a data collection method should consider these issues.

In the midst of the loud music and dancing, we were able to briefly talk to the owner of the first shebeen. She described how her husband had lost his job and how they resorted to retailing beer to make ends meet.

Conclusion: I conclude by answering the question: How have my perceptions of PLWHA on HAART changed after this study? After listening to participants' stories, I now have a better understanding and appreciation of the numerous challenges that PLWHA face when taking HAART. Before, I tended to associate non-adherence with deviance but now I have a more positive view of PLWHA. The study has also increased my awareness of how the doctor's instructions can easily be misinterpreted and on the importance of good health care provider and patient communication.

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APPENDICES

APPENDIX 1

Demographic Data

Participant's Pseudonym: _____ Age _____ Gender (M/F) _____

Ethnicity: ☐ Caucasian ☐ Native African ☐ Asian Other (State) _____

Marital status: ☐ Married ☐ Widowed ☐ Single ☐ Divorced ☐ Cohabiting

Religion: ☐ Christian ☐ Islam ☐ African Tradition ☐ Other (state) _____

Residence area: ☐ Urban ☐ Peri-urban ☐ Rural

Employment: ☐ Unemployed ☐ Part-time ☐ Employed

Average Monthly family Income: R _____

Number of children: _____ Age of youngest child: _____

Level of education: _____

APPENDIX 2

Beliefs about Medicines Questionnaire

NB: ARVs stands for Antiretroviral Medicines

General Beliefs about Medicine Questions	Strongly Disagree	Disagree	Uncertain	Strongly Agree	Agree
General harm					
People who take medicines should stop their treatment for a while every now and then					
Most medicines are addictive					
Medicines do more harm than good					
Natural/traditional remedies are safer than medicines that I get from the clinic/hospital					
General overuse					
I think doctors prescribe too many medicines					
I think doctors rely too much on medicines to other alternative therapies					
If doctors had more time for their patients I think they would prescribe fewer medicines					
I like it when my doctor prescribes medicine(s) each time I visit him or her as opposed to advice on lifestyle changes only.					
General benefit					
Without medicines doctors would be less able to cure people					
Medicines help many people to live better lives					
Medicines help many people to live longer					
The benefits of medicines outweigh the risks in most cases					

Specific Necessity-Concerns Scale	Strongly disagree	Disagree	Uncertain	Strongly Agree	Agree
Necessity scale					
My health, at present, depends on my ARV medicines					
My life would be impossible without my ARVs					
Without my ARVs I would become very ill					
My health in the future will depend on my ARVs					
My ARVs protect me from becoming worse					
Concerns scale					
Having to take ARVs worries me					
I sometimes worry about the long-term effects of my ARVs					
My ARVs are a mystery to me					
My ARVs disrupt my life					
I sometimes worry about becoming over reliant on ARVs for my health					

APPENDIX 3

Prescription, Nonprescription Medicines and TCAMs Utilization Inventory

Participant's Pseudonym: _____

Date: ____/____/2009

Instructions

1. Please list all the medicines that you have been using for the past **SIX** months only and state the condition or reason for using each medicine.
 2. Please include traditional medicines, herbal remedies, food supplements and medicines that you buy, or that you get from the hospital, a clinic or the sanatorium (if you work at Rhodes).
 3. Please bring the list with you when coming for the second interview
-

NAME OF MEDICINE/SUPPLEMENTS	REASON FOR USE
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
11.	
12.	
13.	

APPENDIX 4

Interview Schedule

PLWHA Experiences of Taking HAART and Utilising Additional Therapies

Participant's Pseudonym _____ Date of Interview _____

Section A

Background Information

How do you obtain your antiretroviral medicines? Buy from Pharmacies ☐
Public ARV-roll-out program ☐
Other (State) _____

State other chronic conditions that you have (if any): _____

Are you taking medication for other chronic conditions? (Yes/No) _____

Section B

1. How would you describe your day-to-day experiences of taking antiretroviral medicines?
2. What were your concerns about antiretroviral medicines before you started taking them?
3. What did you hope the medicines would do for you?
4. How would you describe your experiences with antiretroviral medicines the first time that you started taking them?
5. How would you rate your quality of life, before and after starting on antiretroviral therapy?
6. Some people say antiretroviral medicines are "toxic" or they are "poisons." What is your opinion?
7. Do you have any other names that you use to remember your antiretroviral medicines? What are these names what do they mean?
8. What are some of the things you do to help you remember when to take your medicines on time?
9. *For those who use additional therapies:* What do these therapies do for you?
10. Do you take alcohol? Does being on antiretroviral medicines affect your decision to take alcohol?
11. That concludes my questions for you. Do you have any questions for me?

APPENDIX 5A

Interview Schedule: Impact of HAART on Sexuality

SECTION A

Background Information

Participant's Pseudonym: _____

Date of Interview _____

No of current sexual partners _____ No sexual partners after diagnosis: _____

Brief description of nature of sexual relationship (single, married, divorced, cohabitating, live separately, same sex, opposite sex, open/multiple partners, "one-night stands", party partners, etc.): _____

Frequency of sexual intercourse past month: _____

Condom Use: Never ____ Sometimes ____ Most of the time ____ Always ____

No of years since: HIV diagnosis: _____ Starting antiretroviral medicines: _____

Do you take alcohol? (Yes/No) _____

NB: If participant has more than one sexual partner, questions will be worded appropriately

1. How has being HIV positive and on antiretroviral treatment affected your sexual relationship with your partner?
2. Has this illness changed the way you feel about your partner? b. Has this illness changed the way your partner feels about you? If yes, ask in what way? etc
3. a. How important is sexual intimacy to you? b. How important, in your opinion, is sexual intimacy to your partner?
4. Some HIV positive people on antiretroviral viral medicines experience sex-related problems. Did you notice any change after starting on antiretroviral therapy?
5. Have you told your sex partner(s) about your status?
6. What are some of your considerations when choosing a sex partner in view of your HIV status and the antiretroviral medicines that you are using?
7. Do you think sex is necessary for good health? Explain.
8. What happens when a person (man /woman) does not have sex?
9. What are your experiences with condoms use during love-making with your partner?
10. Have you thought about any alternative ways for you and your partner to be sexually intimate?
11. Who usually initiates sexual intercourse in your relationships?

APPENDIX 5B

Instructions

The questions in this section begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please tell me which number between 0 and 10 is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

How would you rate the following aspects of your life, before and after you started taking antiretroviral medicines?

	Very bad										Excellent	
12. Quality of life in general	Before	0	1	2	3	4	5	6	7	8	9	10
	After	0	1	2	3	4	5	6	7	8	9	10

	Very low										Excellent	
13. Sexual Satisfaction	Before	0	1	2	3	4	5	6	7	8	9	10
	After	0	1	2	3	4	5	6	7	8	9	10

	Very low										Excellent	
14. Sexual Drive/Libido	Before	0	1	2	3	4	5	6	7	8	9	10
	After	0	1	2	3	4	5	6	7	8	9	10

	Very low										Excellent	
15. Sexual enjoyment	Before	0	1	2	3	4	5	6	7	8	9	10
	After	0	1	2	3	4	5	6	7	8	9	10

That concludes my questions for you. Do you have any questions for me? Thanks again for your participation in the research.

APPENDIX 6

HIV Counsellors' Interview Schedule

Patients' Experiences with Antiretroviral Medicines and Use of Additional Medicines

Note: Although the word “patients” is used in the interview, this does not imply that these persons are regarded as being sick or inferior. It is simply a descriptive term to indicate that they are on medication for a chronic illness.

HIV Counsellors' Pseudonym: _____ Date of Interview ____/____/2009

Years working with HIV-Infected patients: _____

1. When HIV infected patients first come for antiretroviral medicines, what concerns do they express about the medicines, if any? What do they hope to gain from using these medicines?
2. For those patients already on antiretroviral therapy, how do they describe their day-to-day experiences of using these drugs?
3. Some people say antiretroviral medicines are “toxic” or “poisons”. Do some of your patients raise this? If so, please could you indicate the words they use.
4. What are some of the things that patients do to remind themselves to take medicines on time?
5. Beside their names, what other names are given to antiretroviral medicines by your patients? Why do you think they call them that?
6. Do patients report use of additional therapies/medicines to you? What reasons do they give for using these other medicines? What meaning do they assign to their use? Or; what significance do they attach to their use?

APPENDIX 6 Cont'd

HIV Counsellors Interview Schedule

Impact of Antiretroviral Medicines on Patients' Sexuality

1. Do you talk about sex-related issues with HIV infected patients on antiretroviral therapy, or do you wait for them to raise issues of sexuality? What concerns do they have?
2. From your experience with HIV infected patients, especially for those on antiretroviral therapy, how important are issues of sexual relationships/intimacy to them?
3. Do you think that the frequency with which HIV-infected people on antiretroviral medicines have sex is different from their uninfected counterparts? Why?
4. Have your patients on antiretroviral treatment reported using condoms in their sexual relationships?
5. Are there any alternative forms of sexual intimacy, such as masturbation, that some of your patients report practicing?
6. Do some of your patients report taking alcohol? From your experiences with HIV-infected people on antiretroviral therapy, do you think that alcohol has an impact on the sexual behaviour of some patients? Please describe.

That concludes my questions for you. Do you have any questions for me? Thank you for your participation in this study.

APPENDIX 7

INVITATION LETTER TO PARTICIPATE IN THE STUDY

Dear Potential Participant

My name is Tongai Chizanga. I am a Masters student in the Faculty of Pharmacy at Rhodes University. I am planning to interview about 10 people on antiretroviral treatment from the Rhodes University - Grahamstown community. My study will explore people's perceptions about antiretroviral medicines, their day-to-day experiences of taking these medicines, their use of other medicines in addition to antiretroviral drugs and to assess the impact of antiretroviral medicines on their sex-lives.

This research is part of my studies towards a Master of Pharmacy degree. My supervisors are Prof Roy Jobson from the Faculty of Pharmacy and Dr Asta Rau from the Centre for Higher Education Research, Teaching and Learning. The study has been approved by the Faculty of Pharmacy's Ethics Committee, Rhodes University. I should like to talk to you about the above topics in a place of your choosing. The study will be confidential and your name would not be made public.

Should you agree to take part in the study, you will be asked to provide us with a list of medicines (see enclosed form) that you have used for the past 3 months.

If you agree, please complete the tear-off slip below and return it to me.

If you need further information, do not hesitate to contact me.

I hope that you will be able to take part in this study. Your assistance is greatly appreciated.

Yours sincerely,

Tongai Aldridge Chizanga

Tel: 0847985910

E-mail: tachizanga@gmail.com

I would / would not* like to take part in the study of perceptions about antiretroviral medicines, day-to-experiences with antiretroviral drugs and their impact on sexuality. (*delete as appropriate)

Your Name: Tel number:

Date:

Your Signature:

APPENDIX 8

PARTICIPANTS' INFORMED CONSENT FORM

Title of Research: A comparison of antiretroviral therapy experiences between a university's support staff cohort and members of a local non-governmental organisation: medicines-taking behaviours and sexuality

Researcher: **Tongai Aldridge Chizanga**
Faculty of Pharmacy
Rhodes University

Before agreeing to participate in this research study, it is important that you read the following explanation. This statement describes the purpose, procedures, possible benefits, risks and discomforts of the study. Also described are issues of confidentiality, as well as your right to withdraw from the study at any time. Tongai Aldridge Chizanga, a postgraduate student at the Faculty of Pharmacy, Rhodes University, will be conducting this study.

Purpose of the study

The purpose of the study is to examine your perceptions about antiretroviral medicines, your day-to-day experiences of using the medicines and your use of additional therapies, because you are a person living with HIV on antiretroviral therapy. The study will also explore the impact of antiretroviral medicines on your sexuality and sexual practices.

Explanation of Procedures

Participation in the study involves the completion of a short questionnaire and two interviews, which will last for approximately eighty minutes each. The interviews will be audiotaped by the researcher and later transcribed for the purpose of data analysis. The interviews will be conducted at a setting that is mutually agreeable to you and the researcher. A male or female interpreter will be made available to those who prefer to use isiXhosa. If you are unsure about the interpreter, you may choose to not have that interpreter.

Possible Benefits

The anticipated benefit of the study is to help improve health care professionals' understanding of how people perceive antiretroviral medicines and their experiences of using the medicines, and the medicines' impact on sexual functioning.

Risks and Discomforts

Potential risks or discomforts include possible emotional feelings of sadness or embarrassment when asked questions during the interview.

Confidentiality

The information gathered during this study will be treated as confidential and will be kept in a secure place until such a time as it can be destroyed in line with the Rhodes University's guidelines. Only the researcher and the Faculty of Pharmacy Ethics Committee or the Rhodes

University Ethical Standards Committee will have access to this information. A pseudonym (false name) will be given to each participant when they join the study, and no identifying names will be used on the audiotapes. The results of the research will be used as part of a master's thesis and may also be published in professional journals or presented at professional meetings.

The interpreter will have a contractual obligation not to disclose any information relating to the study to anyone except the researcher.

Withdrawal without Prejudice

Participation in this study is voluntary. You are free to discontinue participation in this study at any time without any consequences to you.

New Findings

Any significant new findings that develop during the course of the study, which may affect your willingness to continue in the research, will be provided by investigator.

Cost and/or Payment to Subject for Participation in Research

You will be given a honorarium of **R150** after completing the two interviews. This is to help you with transport and other costs involved in participating in the study. If you complete only one interview, only half the honorarium will be provided.

Questions

Any questions concerning the research project, participants can call Prof. Roy Jobson (supervisor for this study) on 046-603-8391. Questions regarding rights as a person in this research project should be directed to the Faculty of Pharmacy Ethics Committee Chairperson, on 046-603-8396.

Agreement

Writing your signature on this agreement indicates that you have read and understood the contents of the informed consent form above and that you agree to participate in this study.

Participant's name (Please print): _____

Participant's Signature: _____ Date ____/____/2009

Researcher's Signature: _____ Date ____/____/2009

APPENDIX 9

HIV COUNSELLORS' INFORMED CONSENT FORM

Title of Research: A comparison of antiretroviral therapy experiences between a university's support staff cohort and members of a local non-governmental organisation: medicines-taking behaviours and sexuality

Researcher: **Tongai Aldridge Chizanga**
Faculty of Pharmacy
Rhodes University

The information below describes the purpose, procedures, possible benefits, issues of confidentiality related to this study. Tongai Aldridge Chizanga, a postgraduate student at the Faculty of Pharmacy, Rhodes University, will be conducting this study.

Purpose of the study

The purpose of the study is to examine patients' perceptions about antiretroviral medicines, their day-to-day experiences of using the medicines and the use of additional therapies in people living with HIV on antiretroviral therapy. It will also explore the impact of antiretroviral medicines on sexuality in HIV-infected patients. As HIV counsellors, you will be asked to describe your experiences and provide your personal perceptions' relating to the above topics, based on your experiences in working with people living with HIV/AIDS.

Explanation of Procedures

You will be asked to complete a one hour interview. The interviews will be audiotaped by the researcher and later transcribed for the purpose of data analysis. The interviews will be conducted at a setting that is mutually agreeable to you and the researcher. A male or female interpreter will be made available to if you prefer to use isiXhosa.

Possible Benefits

The anticipated benefit of the study is by way of improving health care professionals' understanding on how people perceive antiretroviral medicines and their experiences of using the drugs, and their impact on sexual functioning.

Confidentiality

The information gathered during this study will be treated as confidential and will be kept in a secure place until such a time as it can be destroyed in line with the Rhodes University's guidelines. Only the researcher and Rhodes University Institutional Review Board will have access to this information. The results of the research will be published in the form of a master's thesis and may be published in a professional journal or presented at professional meetings.

The interpreter will have a contractual obligation not to disclose any information relating to the study to anyone except to the researcher.

Withdrawal without Prejudice

Participation in this study is voluntary. You are free to discontinue participation in this study at any time.

Payment for Participation in the Research

You will be given a honorarium of R150 after completing the interview and you have an option of donating to a charity of your choice.

Questions

Any questions concerning the research project, participants can call Prof. Roy Jobson (supervisor for this study) on 046 603 8391. Questions regarding rights as a person in this research project should be directed to the Faculty of Pharmacy Ethics Committee Chairperson, on 046-603-8396.

Consent

To indicate that you have read and understood the contents of the informed consent form above and that you are willing to participate in this study, please complete the area below.

HIV Counsellor's Name (Please print): _____ Date: ____/____/2009

HIV Counsellor's Signature: _____

Researcher's Signature: _____ Date: ____/____/2009

APPENDIX 10

INTERPRETER'S CONTRACT

INTERPRETER'S NAME

Address: _____

Phone (Home): _____
Cell Phone: _____

Agreement

This contract is entered into between _____ (RESEARCHER throughout the rest of the document) and _____ (INTERPRETER throughout the rest of the document) to perform the jobs, duties and assignments described herein.

Contract Period: _____ through to _____

JOBS, DUTIES AND RESPONSIBILITIES OF THE INTERPRETER: The INTERPRETER will provide interpretation services in interviews that will be carried out as part of a research study when requested by the RESEARCHER. Dates and times of interviews will be arranged in consultation with the INTERPRETER.

The primary responsibility of the INTERPRETER is to facilitate the exchange of information between the RESEARCHER and the RESEARCH PARTICIPANTS, through verbal translation. The INTERPRETER is expected to be fluent in both isiXhosa and English.

STANDARDS OF CONDUCT: By signing this contract, the INTERPRETER agrees to conform to the following standards:

The INTERPRETER shall provide the most accurate interpretation possible.

The INTERPRETER shall receive assignments directly from the RESEARCHER only, and shall not act on request received from anyone else who is not part of the study.

The INTERPRETER shall maintain confidentiality about the identities of all the RESEARCH PARTICIPANTS as well as all the information provided. The INTERPRETER shall not discuss the content of any services provided under this contract with any person other than the RESEARCHER.

The INTERPRETER shall:

- Not disclose or divulge the confidential information or any part of it or extracts from it to any third party.
- Not record, copy or reproduce in any manner or form the confidential information or any part of it or any notes in any form which it makes of the confidential information without the prior written approval of the RESEARCHER.
- Continue to abide by the confidentiality rules after the conclusion of the study and information generated from the study shall remain confidential.

The INTERPRETER shall not offer personal advice, opinion, or counsel to the interviewee during the interview, unless with the consent of the RESEARCHER.

The INTERPRETER shall direct all questions or problems relating to work performed under this contract to the RESEARCHER for consideration.

If the research interviews are to take place in a venue to which transport is required, the RESEARCHER will be responsible for providing such transport.

FEE SCHEDULE: Payment for services will be made by the RESEARCHER (or his representative) to the INTERPRETER at a rate of R45.00 per hour of actual work performed. Only hours authorised by the RESEARCHER will be paid for.

I agree to provide the service and accept the conditions of this agreement as described above. I understand that this agreement becomes null and void upon written notice from either party, but agree that all confidential information will remain confidential and will not be disclosed to any other person.

(INTERPRETER'S SIGNATURE) DATE: _____

(RESEARCHER'S SIGNATURE) DATE: _____

WITNESS 1 DATE: _____

APPENDIX 11

TRANSCRIBER'S CONTRACT

TRANSCRIBER'S NAME

Address: _____

Phone (Home): _____
Cell Phone: _____

Agreement

This contract is entered into between _____ (RESEARCHER throughout the rest of the document) and _____ (TRANSCRIBER throughout the rest of the document) to perform the jobs, duties and assignments described herein.

Contract Period: 05/02/09 through to 05/02/09

JOBS, DUTIES AND RESPONSIBILITIES OF THE TRANSCRIBER: The TRANSCRIBER will provide transcribing services for interviews that were carried out as part of a research study when requested by the RESEARCHER. Dates and times relating to the transcribing services will be arranged in consultation with the TRANSCRIBER.

The TRANSCRIBER is expected to have good typing skills and to be fluent in English.

STANDARDS OF CONDUCT: By signing this contract, the TRANSCRIBER agrees to conform to the following standards:

The TRANSCRIBER shall provide the most accurate transcription services possible.
The TRANSCRIBER shall receive assignments directly from the RESEARCHER only, and shall not act on request received from anyone else who is not part of the study.

The TRANSCRIBER shall maintain confidentiality about the identities of all the RESEARCH PARTICIPANTS as well as all the information provided. The TRANSCRIBER shall not discuss the content of any services provided under this contract with any person other than the RESEARCHER.

The TRANSCRIBER shall:

- Not disclose or divulge the confidential information or any part of it or extracts from it to any third party.
- Not record, copy or reproduce in any manner or form the confidential information or any part of it or any notes in any form which it makes of the confidential information without the prior written approval of the RESEARCHER.
- Continue to abide by the confidentiality rules after the conclusion of the study and information generated from the study shall remain confidential.

The TRANSCRIBER shall direct all questions or problems relating to work performed under this contract to the RESEARCHER for consideration.

The TRANSCRIBER shall provide their own equipment (computers, head phones etc) necessary for the transcription.

FEE SCHEDULE: Payment for services will be made by the RESEARCHER (or his representative) to the TRANSCRIBER at a rate of **R250.00** per audio-hour of the interviews due for transcription. Only hours authorised by the RESEARCHER will be paid for.

I agree to provide the service and accept the conditions of this agreement as described above. I understand that this agreement becomes null and void upon written notice from either party, but agree that all confidential information will remain confidential and will not be disclosed to any other person.

(TRANSCRIBER'S SIGNATURE) DATE: _____

(RESEARCHER'S SIGNATURE) DATE: _____

DATE: _____

WITNESS

APPENDIX 12

COPY OF PARTICIPANTS' HEALTH PASSPORT

M. [REDACTED]

1. TICK EVERY TIME YOU TAKE YOUR MEDICATION.
2. WRITE DOWN ANY PROBLEMS, SIDE EFFECTS OR COMMENTS IN THE **NOTES** COLUMN.

	☀ MORNING ☀		*** EVENING ***			NOTES	
	D4T	3TC	D4T	3TC	EFV		
STRENGTH	30mg	150mg	30mg	150mg	600mg	TCA 3.12.08	
DOSE	1	1	1	1	1		
TIME	8am	8am	8pm	8pm	8pm		
ACTIVITY							
FORM	CAP	TAB	CAP	TAB	TAB		
DAY	DATE						
1	5/11/08	XXXXXXXXXXXXXXXXXX	8pm	8pm	8pm	Eyes problem	
2	6/11/08	8am	8am	8pm	8pm	8pm	They are sore and
3	7/11/08	8am	8am	8pm	8pm	8pm	sometimes they are
4	8/11/08	8am	8am	8pm	8pm	8pm	itching.
5	9/11/08	8am	8am	8pm	8pm	8pm	
6	10/11/08	8am	8am	8pm	8pm	8pm	
7	11/11/08	8am	8am	8pm	8pm	8pm	
8	12/11/08	8am	8am	8pm	8pm	8pm	
9	13/11/08	8am	8am	8pm	8pm	8pm	
10	14/11/08	8am	8am	8pm	8pm	8pm	
11	15/11/08	8am	8am	8pm	8pm	8pm	
12	16/11/08	8am	8am	8pm	8pm	8pm	
13	17/11/08	8am	8am	8pm	8pm	8pm	
14	18/11/08	8am	8am	8pm	8pm	8pm	
15	19/11/08	8am	8am	8pm	8pm	8pm	
16	20/11/08	8am	8am	8pm	8pm	8pm	
17	21/11/08	8am	8am	8pm	8pm	8pm	
18	22/11/08	8am	8am	8pm	8pm	8pm	
19	23/11/08	8am	8am	8pm	8pm	8pm	
20	24/11/08	8am	8am	8pm	8pm	8pm	
21	25/11/08	8am	8am	8pm	8pm	8pm	
22	26/11/08	8am	8am	8pm	8pm	8pm	
23	27/11/08	8am	8am	8pm	8pm	8pm	
24	28/11/08	8am	8am	8pm	8pm	8pm	
25	29/11/08	8am	8am	8pm	8pm	8pm	
26	30/11/08	8am	8am	8pm	8pm	8pm	
27	01/12/08	8am	8am	8pm	8pm	8pm	
28	02/12/08	8am	8am	8pm	8pm	8pm	
	03/12/08	8am	8am	XXXXXXXXXXXXXXXXXXXX			

APPENDIX 13

Respondent's Pseudonym: *Ruth* **Date:**
Interview: *1 of 2 (Medicine taking behaviours)*
Duration of Interview:

Notes

1. **Interviewer:** My name is Tongai Chizanga. I will be asking you about your experiences of living with HIV/AIDS and taking antiretroviral medicines and other additional therapies. The interview will be approximately one hour. With your permission, I will record whatever we discuss.
2. **Interviewer:** Besides HIV, do you have any other chronic conditions?
3. **Respondent:** No
4. **Interviewer:** When did you start taking ARV drugs?
5. **Respondent:** October 1999
6. **Interviewer:** And where do you get your ARV medicines?
7. **Respondent:** First time I got them from a doctor in Port Elizabeth - they were doing a research that time and it was at your own risk.
8. **Interviewer:** Can you name some of the ARV drugs you took in that time?
9. **Respondent:** In the first group aah ...in the beginning I was using the d4T, Efavirenz and 3TC
10. **Interviewer:** And this time you are using...
11. **Respondent:** Lamzid and Efavirenz. Lamzid is the combination of AZT and 3TC they changed because my body changed shape.
12. **Interviewer:** How serious were these changes?
13. **Respondent:** I develop a big tummy and big breasts but my legs remain thin. And I did report it to the doctor.
14. **Interviewer:** How can you describe your experiences of taking medicine in general?
15. **Respondent:** I feel very comfortable when I go to the pharmacy because when I tell them what I am experiencing I get sound advice, unlike going into a shop and buying medicine which I don't know whether it will suite me or not
16. **Interviewer:** How can you describe your day to day experiences of taking ARV medicines?
17. **Respondent:** The first time it made my life very uncomfortable because I would forget the time to take the medicine and I had no one to remind me to take the medication. But as time went on I got comfortable and wherever I am I take my medication.
18. **Interviewer:** What are some of the things you do to help you remember to take you medication?
19. **Respondent:** Since I have a cell-phone, I set a reminder so that whatever I am doing my cell-phone will ring and remind me. I then know that its medication time. I stop whatever I am doing and take my medication.
20. **Interviewer:** What were your expectations when you first started taking ARV drugs?
21. **Respondent:** Since I didn't have any knowledge about the ARVs and HIV my expectations were just to get cured but they told me that there was no cure for the virus so my expectations were now not to get sick and live a longer life.
22. **Interviewer:** How did it make you feel knowing that drugs you would be taking where not going to cure the virus?

23. **Respondent:** I didn't feel comfortable at first. I started doubting if I should take the medication or not because it would not reach my expectations of curing it. However, I just continued in the hope that it would help me at a later stage somehow somehow.
24. **Interviewer:** Did you have some doubts about the treatment?
25. **Respondent:** They were people that I knew already that were on ARV drugs and they died so I thought I would die also because there is no cure for this.
26. **Interviewer:** Now after taking ARV medicines for a long time have your perceptions/views changed?
27. **Respondent:** Yes it has changed a lot. I got more knowledge. I used to even read more books about the HIV virus; I wanted to know what would be going on in my body.
28. **Interviewer:** Who are some of the people that you consulted about your illness?
29. **Respondent:** The first people I did trust with my status are the nurses, and they gave me support especially the sister in the Tanji clinic where I was diagnosed. Up to now, she is still my contact even when I have a flu I just call her and I ask what I should do. She is like my mum she supported me and even my kids.
30. **Interviewer:** What would you say where most of the important concerns when you started taking ARV medicines?
31. **Respondent:** The most important thing to me is not to forget to take ARV drugs everyday. What is important to me is that I must know and understand that this treatment is for life and I must take it for life. I have understood that.
32. **Interviewer:** How did you come to know your HIV status?
33. **Respondent:** The reason why I came to know of my status is that I heard rumours that my ex boyfriend did have someone who was sick but I didn't know this lady. So I then met this lady. I spoke to him about the issue of getting HIV and I told him that I don't have many partners and that he had been sleeping around with many people. So I didn't think that I can also get HIV because my sexual partner had many partners. I then asked him if we would go for a test. I was just hoping that I would have negative results and he would be positive but unfortunately the both of us got the results that we were positive.
34. **Interviewer:** You said you were not sick before you were diagnosed; how long did you wait before starting on ARV medicines?
35. **Respondent:** I had been diagnosed in 1996 in February. Then I didn't have any problem until 1999. In 1999 I developed swollen glands behind my ears and then I went to the clinic. I didn't even know about the CD4 count then. The sisters then told me of this doctor in PE who was doing ARV trials. The sister then asked me if I was ready to go for the trial. I didn't have a clear knowledge of the ARV so I agreed. The doctor in PE then tested me on CD4 count, viral load, pregnancy test and all that stuff. I discovered that my CD4 count was above just 300 so I started taking the ARV drugs.
36. **Interviewer:** How did it make you feel knowing that you are taking medicines and yet you are not feeling sick?
37. **Respondent:** I didn't feel anything because I didn't have a clear explanation about HIV. Everything was new to me and I was just doing anything they asked me to: I would agree because I wanted to get rid of it.
38. **Interviewer:** Do you feel the ARV drugs helped you get *rid* of the virus?
39. **Respondent:** No because even now I know that I still have the virus. My CD4 count is up and my viral load down - my viral load is undetectable and my CD4 count now is 1300. I know that as time goes on my viral load will remain low if I continue like this. So I know these drugs will lower the virus in my body and not get rid of it so that I won't get sick.
40. **Interviewer:** How does it feel knowing you will take this treatment for life?

41. **Respondent:** I was scared at first because I am not a person who likes to take medicines even if I am sick. I don't believe in medicines; even if I have a headache I won't take a pain relief tablet that quickly. So I was thinking that I would take these medicines for life and I kept thinking and thinking and I was confused what would happen to my body.
42. **Interviewer:** If you were to meet someone who was HIV positive and wants to start taking ARVs and he/she says to you: Describe your experiences of taking ARV medicines, especially when you started them? What...
43. **Respondent:** ...When I started taking them I felt that maybe I would be cured of the virus. Another important experience is that I developed a fine rash and I called my doctor. he said, those are the side effects of the drugs, I should reduce the taking the D4T and take half of it and then I will see the difference after a week. He also said that I should get calamine lotion. The rash later disappeared.
44. **Interviewer:** Are there any other medication related side effects that you have experienced besides the rash?
45. **Respondent:** The drowsiness! I like to read. I realised that it was the efavirenz drug. I would even sleep when talking to a person after taking them and feel tired couldn't do anything.
46. **Interviewer:** So what did you do about it?
47. **Respondent:** I used to take it at 7pm so I changed the time from 7pm to 9pm.
48. **Interviewer:** And what were the results?
49. **Respondent:** At least I knew that I would be asleep by 10pm, so I started taking my pills [ARVs] at 9am and 9pm.
50. **Interviewer:** How about morning, did you feel tired?
51. **Respondent:** Yes sometimes I feel tired in the morning but then after a while I feel fine.
52. **Interviewer:** How has taking medicines changed your lifestyle?
53. **Respondent:** It has changed my lifestyle because now when I want to go out I have to always remember that I must not forget to take my medication with me. At night I must make sure I should be at home. After I take my drugs I cannot go to a party because I will fall asleep. I need to be a place to sleep after taking them.
54. **Interviewer:** Is the lifestyle change caused by the ARV medicines a big problem for you?
55. **Respondent:** It's not a big problem because I am not party person anymore. But it caused a problem because it meant I mustn't take my medication and go somewhere. Even when I want to watch a movie I know that I might fall asleep.
56. **Interviewer:** How do you cope then when there is an important event?
57. **Respondent:** Since there are these VCRs I would ask my brother to record for me because I know my status and they know the problems that I experience.
58. **Interviewer:** Your children, do they know about your HIV status?
59. **Respondent:** All my family knows about my status.
60. **Interviewer:** Do they help in any way by encouraging you to take your ARVs?
61. **Respondent:** Yes especially my children. If for example I am busy washing dishes and they see that its 9pm they remind me that its medication time. If they hear my alarm and I am in another room, they come and tell me that my alarm for taking medication is ringing. They keep reminding me; they even know which treatment I am supposed to take. My younger boy watches the HIV programs at school they taught how to live with those who are HIV positive. So when it comes on TV he will say look mum there are your ARVs, there is your D4T and even when I am with my friend who don't know my status, he is not afraid to remind me.
62. **Interviewer:** How does that make you feel?

63. **Respondent:** Since I disclosed [my status] in the first month, I didn't experience any problems. But there are HIV positive people who would come to for advice and I could see their facial expression that they think that maybe I might tell my kids about their status. My kids are very close to me. Sometimes the person wouldn't come again to my house because I also talk to my kids about HIV and I want them to know about HIV. I don't want them to get infected the way I did. I want them to know that there is HIV all over - in Zimbabwe, USA, etc - and that in their house there is someone with HIV.
64. **Interviewer:** Some say ARV drugs are toxic or poisonous; have you heard people saying that?
65. **Respondent:** Yes
66. **Interviewer:** Please explain more.
67. **Respondent:** I attended a workshop in East London and a doctor said that you must not use the ARV drugs but use the herbs and multivitamins because ARV drugs are toxic.
68. **Interviewer:** And how did that affect you?
69. **Respondent:** It affected me a lot because I was worried about those people who are still on the program of getting ARVs. I know that these ARV helped me to live longer. I started taking them when my CD4 count was 300 plus and now I heard that my CD4 count was like 700. Maybe those who are in the process of getting ARV medicines would stop taking them.
70. **Interviewer:** Do you think the description of ARV as toxic was inaccurate from your experiences?
71. **Respondent:** Yes, they are not toxic in anyway because I took them and didn't experience any problem. ... [Inaudible] that I can tell someone who never taken them because I am seeing 1, 2 and 3 things on me. I disagree about them being toxic.
72. **Interviewer:** Do you have any other names that you use to remember your ARV medicines? Are there any names that you call them with your children, for example?
73. **Respondent:** No, we just call them chronic medication because they are taken for life. My younger child asked why I call them chronic medication and I say its because I will take them for life.
74. **Interviewer:** Did you inform your children that they are called ARVs or chronic medications?
75. **Respondent:** I told my kids that ARV drugs are chronic medications because ARV drugs are chronic [drugs] and HIV is a chronic illness.
76. **Interviewer:** You said you had changes in your body; how did that make you feel?
77. **Respondent:** I feel very uncomfortable because by the time I discovered the changes I was already taking my medication. I asked the doctor in PE to transfer me to Settler's hospital because that time settlers now had an ARV site. So the doctor - who was a specialist - gave me my file to take to the doctor in Settlers Hospital. I now take my medication from Settlers. I discovered the changes in my body whilst taking medication in Grahamstown. I then went to the doctor and told him about it. I could see that my upper body is getting fat.
78. **Interviewer:** Your motivation: What keeps you going? What would you say are the major reasons why you keep taking these medications?
79. **Respondent:** What keeps me going (taking the medication) is because I feel that I am not sick whilst I am taking this medication. But some HIV positive people I see are skeletons, they are sick and so that gives me strength to keep on taking my medication. I just see many sick people even on the taxis and I assume that they are positive because I can see their health and I know maybe they didn't start [taking] their medication on time. Since I took the medication before I got sick I am motivated to keep on taking.

80. **Interviewer:** How has your life changed since you started taking ARV drugs in terms of your lifestyle?
81. **Respondent:** It did change a little bit. Firstly I should know what diet I must take; I must give myself a rest and I must not think too much because I will develop stress. That's what they told me. I should stick to my diet and so even if its food and I have been told not to eat I must not eat it.
82. **Interviewer:** And how does that make you feel?
83. **Respondent:** Firstly it was a problem because I wasn't staying alone. At that time it affected my life because I didn't have a job and at times the food cooked is what I am not supposed to eat. So at times, I would get something like 10 Rand then I buy something but most probably my kids won't eat and they didn't like it.
84. **Interviewer:** Can you give an example of the foods that you were told to avoid?
85. **Respondent:** Coffee because it has caffeine. I must not take refined sugar except brown sugar. I take brown rice but I must not take read meat.
86. **Interviewer:** Besides taking medication what other things do you do to keep healthy?
87. **Respondent:** Exercising and giving my brain a rest like taking a book to read especially when I am worried, then also sleep.
88. **Interviewer:** What does exercise do to your body?
89. **Respondent:** It keeps my body healthy. At 6 o'clock I would just run and if I tell myself that I would run for 2km. I just want to reach my goal. Early in the morning when I wake up on time I just run a set distance then go back to my house. I am lazy during the weekends so I clean the house wash clothes which are other forms of exercise.
90. **Interviewer:** Are there any other therapies that you use? - For example, herbal medicines, prayer and meditation.
91. **Respondent:** Herbal I use the gum tree and fever tree we mix their leaves if I have flu. I boil and put Vicks and inhale the steam. I also use prayer a lot because I am Christian and I feel very comfortable. At my church everyone knows about my status. When I meet with a member of my church or when I have a problem, I just explain it to them and ask for their prayers. Prayer is important to me. Even when I am taking my medication I know one day God will cure this so one day I know I will get rid of the medication. I have that hope through my prayers and reading my bible.
92. **Interviewer:** Before you started taking ARV drugs did you use any traditional medicines or herbs?
93. **Respondent:** Yes - traditional medicines. At my home there was an isangoma who came to visit. He gave us some bottles of leaves to mix. Traditional healers however did not even tell us about the name, type of medication or muti and what it was for. We were not sick though.
94. **Interviewer:** Why where those traditional medicines important to you?
95. **Respondent:** Because of the belief that I am a black woman. Sometimes they say that there is a tokoloshi behind me and if you drink certain medicines the tokoloshi will run away. It was for the belief otherwise nothing else.
96. **Respondent:** Did the medications help?
97. **Respondent:** No, I didn't see a difference when I drank the traditional medicines. I wasn't sick. It's unlike when one takes panado for a headache and wake up the next morning and they see headache is gone.
98. **Interviewer:** Do you take alcohol?
99. **Respondent:** No I never took alcohol in my life or tobacco.
100. **Interviewer:** Is there anything else you would want to tell me about your day to day experiences of taking ARV medicines?

101. **Respondent:** Yes, I can just about changing the lifestyle. My ARV changed my lifestyle, like today I don't have a boyfriend. The boyfriend I have didn't want to use a condom but at the clinic they told me that if I keep having sex without using a condom you will get re-infected - I would have more diseases on top of what I have. With my boyfriend, I would plead for him to use a condom but he refused. So I stopped the affair - I don't want to see any new illnesses on top of what I already have now. He ran away. The other night when we were having sex together I feel that there was something wrong happening. Although he had a condom before having sex, I heard a funny sound and felt that something was happening. I didn't even realise that he had burst the condom with a matchstick so that he could just give me everything. Then after he finished, there was no condom and there was a big hole on it. I realised from the sound before and the matchstick that was laying beside us that he had intentionally burst the condom. So there was no trust between us. I told him that he ruined our trust. Firstly, I plead with him to use condom so that we don't re-infect each other because I don't know his diseases and he doesn't know mine! Now, even worse, he burst the condom deliberately, so I didn't think I could trust him anymore.
102. **Interviewer:** What was his response to that?
103. **Respondent:** He said that he was sorry and I said that he didn't do it deliberately. He then said that he was not comfortable using a condom and then I told him to go to those women who don't like the condoms. He then said he would use a condom and I told him I was done with him because he wanted to destroy my life.
104. **Interviewer:** Is your partner on ARV drugs?
105. **Respondent:** He is not on ARV drugs; that's what makes me not to trust him anymore.
106. **Interviewer:** Do you think ARVs protect you from getting a new virus or disease?
107. **Respondent:** No they won't protect me from getting new virus if I am not using a condom. I will get a new virus; it will multiply more and more If I am careless with myself and if I am getting re-infected.
108. **Interviewer:** What kind of diet are you eating?
109. **Respondent:** Mostly its vegetables, clean purified water, green veggies and pumpkin is my favourite veggie.
110. **Interviewer:** With your ARV drugs do you ever worry that you are becoming too dependent on ARV drugs?
111. **Respondent:** No
112. **Interviewer:** You said you were taking herbal medications for fever the gum tree and maybe Vicks and immune boosters!
113. **Respondent:** Yes I used to get from the sanatorium there used to give us for free only those who are HIV positive here at Rhodes. Nutistririne and Mixture of Life - they are tablets just to boost the immune systems.
114. **Interviewer:** Are there herbs?
115. **Respondent:** They are herbs in tablet form and you can see plants outside these bottles.
116. **Interviewer:** You also use traditional mixture do you know the name?
117. **Respondent:** No but it was in September October last year because there was an isangoma at home I took it for 1-2 weeks and then I stopped then I realised that I should not be taking any traditional medicines that I do not know because I am using these ARV drugs.
118. **Interviewer:** Can you explain where you got the information that you are not supposed to use these traditional medications?
119. **Respondent:** Since I started these ARV the books I was reading and the doctor also said that if you want to use something herbal ask before you use because sometimes with

- these ARVs, I cant use them or mix them with any medication - if I go to a clinic I must explain to them my status first any medications that I am taking.
120. **Interviewer:** So you said the reason for using traditional medicines is for chasing bad dreams?
121. **Respondent:** Yes one member had bad dreams so it was not for me. It was for one member of the family. The isangoma came and was trying to heal everybody and if had healed one person then those dreams would go to someone. So I told my parents that I had to go to the doctor first because this medication would maybe lower my CD4 count.
122. **Interviewer:** Why are you using the fever tree leaves?
123. **Respondent:** You use those leaves if you have got flu, you feel better so I know that I don't drink it [the concoction] - I just cover it, and I sweat and I inhale the mist.
124. **Interviewer:** How about the gum tree leaves how do you take it?
125. **Respondent:** You boil the leaves and then you take them together with the fever tree, and then a little Vicks and then you inhale.
126. **Interviewer:** Besides taking medicines what else do you do to keep yourself healthy?
127. **Respondent:** The support group, just talking about the pain I am experiencing. I also exercise and eat healthy vegetables.
128. **Interviewer:** Are you taking any nutritional supplements?
129. **Respondent:** No, because that mixture of life and nutristine is part of a supplement but I used to take Vitamin B complex supplements before taking ARV drugs- that was before 1999. Vitamin A, Ferrous and also those white tablets called Cozol. Even after I started ARV drugs, I continued taking Cozol until my CD4 count went up. If I take Vitamin B complex, I wouldn't sleep because my body would be itchy so I am not taking Vitamin B complex tablets anymore. I checked from the internet for the side effects of Vitamin B complex and I found that if you take Vitamin B complex you can get that itchiness. So I told the sister that the calamine they were giving me wouldn't work because I was still taking Vitamin B complex so I stopped as they said.
130. **Interviewer:** We have come to the end of the interview. Thank you for participating in the study. Do you have any questions fro me?
-

Thank You!
The end

APPENDIX 13 Cont'd

Respondent's Pseudonym: Joyce

Interview No: 2 (Sexuality)

Duration of Interview:

Notes

1. **Interviewer:** You describe your quality of life as fair before ARVs and now it's excellent, why?
2. **Respondent:** Some of the things I couldn't do before I can do now. I have energy, wash my clothes, cook for myself, I don't feel that I am tired, I built my shack. But before ARVs I would feel that I am tired early in the morning when I am getting out of the bed.
3. **Interviewer:** How would you compare your quality of your life before you were diagnosed with HIV and now?
4. **Respondent:** It was like this I am back to normal.
5. **Interviewer:** Your sexual satisfaction before you started ARV drugs it was ok and now your sexual satisfaction is low what has changed
6. **Respondent:** I don't feel interested, sometimes I choose to have married people because that person doesn't have much time for me.
7. **Interviewer:** How about your HIV diagnosis
8. **Respondent:** Before that I was fine and I had the father of my children and we were staying together for eight years.
9. **Interviewer:** When were you diagnosed with HIV?
10. **Respondent:** 1999
11. **Interviewer:** And when did you start taking ARVs?
12. **Respondent:** June 2005
13. **Interviewer:** When did you separate with the father of your child?
14. **Respondent:** August 1997
15. **Interviewer:** Is he still alive?
16. **Respondent:** Ye, he is in PE and he is married now.
17. **Interviewer:** So you found out that you were HIV positive in 1999 and then you started ARV drugs in 2005 and you separated with your husband in 1997. How many sexual partners have you had since your HIV diagnosis?
18. **Respondent:** Maybe 5.
19. **Interviewer:** How about at present how many sexual partners do you have?
20. **Respondent:** 2
21. **Interviewer:** Are you married now?
22. **Respondent:** No I am single and I am not living with any of my sexual partners.
23. **Interviewer:** You have stated that your sexual drive hasn't changed at all since you started taking ARV drugs, why do you think this is the case?
24. **Respondent:** Most of the times I don't have sexual partners and the partners I am talking about, the other one is in Nigeria, I saw him twice this year the other one in Pedi but I am not sure if we will continue, we have been together for three months, but on Friday I told him that I don't want anymore. He has a bad attitude towards my kids, so I don't think I can keep him.
25. **Interviewer:** Your sexual drive is still low why this is the case?
26. **Respondent:** I at times have the feeling that I need a man but when I get that man, it's just for tonight and tomorrow I don't need him for three months - I am done. Maybe it's because of the father of my children because he was working in Jo'burg, and come down once in a while. I prefer casual partners. I get bored by seeing someone a lot; he must be far from me.

27. **Interviewer:** Why don't you want someone close to you?

28. **Respondent:** It's stressful

29. **Interviewer:** Why?

30. **Respondent:** If at times they drink or smoke and the they come back with short money, and worse they always go out and you don't know what is going on, what he is doing there or if he is going to come or not.

31. **Interviewer:** Your sexual enjoyment you said it was fairly good and still is fairly good

32. **Respondent:** I still enjoy sex when I get it but my desire for it lasts for a night or two days not for long.

33. **Interviewer:** In the past month how many times have you had sex - in December?

34. **Respondent:** It was one week because I told my partner that I was going to my parents' house.

35. **Interviewer:** Generally how many times do you have sex?

36. **Respondent:** Maybe once

37. **Interviewer:** Who initiates the sex when you have it?

38. **Respondent:** Sometimes I do if it's been long if he wants to do it he initiates bust mostly I don't want when he initiates

39. **Interviewer:** Your partner who is in Nigeria, does he know your status?

40. **Respondent:** Yes

41. **Interviewer:** And the partner whom you have now does he know your HIV status?

42. **Respondent:** Yes

43. **Interviewer:** Do you know their status?

44. **Respondent:** Yes, the one in Nigeria I met him and he was going to Raphael centre and he was getting tested and he is negative

45. **Interviewer:** How about the second one

46. **Respondent:** He didn't test but we were using condoms.

47. **Interviewer:** You mentioned that you had five men after your HIV diagnosis, let's start with number 1 - was he HIV negative or positive?

48. **Respondent:** He was negative and I already knew I was positive he accepted my status but didn't believe that I was positive.

49. **Interviewer:** For how long did you date?

50. **Respondent:** 3 years

51. **Interviewer:** When having sex did you use condoms?

52. **Respondent:** Sometimes

53. **Interviewer:** How did he feel about using condoms?

54. **Respondent:** He didn't like condoms because he didn't see the need for a condom because most of his partners had been HIV positive. He went for tests after we separated and he was HIV negative.

55. **Interviewer:** If there is no difference between using a condom or not why didn't he want to use the condom?

56. **Respondent:** I don't know I didn't have that mind before to ask him.

57. **Interviewer:** In your own opinion did you feel the difference when you used condoms?

58. **Respondent:** Yes because I had stomach upsets when I used condoms.

59. **Interviewer:** How about the quality of sex was it any different when you started using condoms?

60. **Respondent:** No it wasn't

61. **Interviewer:** With second men for how long did you date?

62. **Respondent:** It was only 6 months and then he died

63. **Interviewer:** What was his status?

64. **Respondent:** He was positive and had TB three times.

65. **Interviewer:** Was he on medication?
66. **Respondent:** Yes. TB treatment and he was drinking and [was also] smoking.
67. **Interviewer:** This man, did he know your HIV status?
68. **Respondent:** Yes
69. **Interviewer:** When you were having sex did you use condoms?
70. **Respondent:** No
71. **Interviewer:** Why not?
72. **Respondent:** He said that we were both HIV positive anyway he was forcing me to not use condoms, and I didn't say no.
73. **Interviewer:** Did you try using female condoms?
74. **Respondent:** I didn't know anything about female condoms then.
75. **Interviewer:** Did he mention any reasons for not using condoms?
76. **Respondent:** He said if we are going to die we will die anyway, no one will stay for long, a few months later he then died, maybe he felt it coming.
77. **Interviewer:** How did that make you feel?
78. **Respondent:** It was bad and I even lost more weight but I then told myself that I will not go down that same route. I want to live my life because maybe when I get another partner I should use a condom and I didn't want a partner who was HIV positive because they didn't want to use a condom unlike maybe one who is negative they will be scared and use condoms.
79. **Interviewer:** So you preferred one who was HIV negative to the one who is positive?
80. **Respondent:** I thought that people who are HIV negative are better than those who are HIV positive, but sometimes they are [discriminatory] like the first one. However he tried understanding me and he did because we approached the discriminatory matter, he was not comfortable and wanted to double the condoms (use two condoms) and I said it was not fair if he didn't trust me he can find someone.
81. **Interviewer:** Did he explain why he wanted to use two condoms?
82. **Respondent:** He said he is scared to get HIV and I told him that if he use two the other condom will pull the other one and we will be using no condom.
83. **Interviewer:** He scared.... he was scared?
84. **Respondent:** Yes
85. **Interviewer:** So did you have sex without a condom?
86. **Respondent:** No
87. **Interviewer:** How about yourself where you scared when having sex with him, where you scared that the condom would burst
88. **Respondent:** I thought about those things but I knew that when you use it correctly and none of those things will happen.
89. **Interviewer:** With you 3rd partner, was he HIV negative or positive?
90. **Respondent:** He was negative
91. **Respondent:** We didn't do anything because when I disclosed - I always prefer disclosing to people before we start anything, so when I disclosed to him before we got intimate he then said ok we would use a condom, but before we even did anything he disappeared.
92. **Interviewer:** How did that make you feel?
93. **Respondent:** I felt that I shouldn't disclose if I love someone I must keep quiet but as time went by I thought that if I love someone I should not kill them because if I am giving the person the virus. I don't know how that person will react and so I am killing them by infecting them.
94. **Interviewer:** Between 2004 and 2006 you didn't have a partner why was that so?

95. **Respondent:** I don't know. I just felt like not having anyone and I was scared that when I meet someone the next person will die and I will just stress myself.
96. **Interviewer:** So where did you meet the other partner who you are with now?
97. **Respondent:** It was like a joke, there was a child who came to the centre to ask to volunteer and while she was talking then the person I was with asked "where is your brother?" and then she said he is at home and "how old is he" and she said he is 25, I then asked "do you have another one?", and she said "yes", and "how old is he?" and she said "48.", then I said let me have his number. I called then I dropped the phone when he answered. The sister then told him everything. Then he called. Then I said I would call him back and never did. After 2 months he said you said you called me back and you never did and I said that you were rude on the phone. He then said my sister told me everything and I do love you even if I didn't see you. So I said we must exchange pictures. Then we started chatting over the phone, then he came to Grahamstown, then we met in town, October 2008, then he went back to Pedi.
98. The Nigerian man came in November and left in January, but I would only see him during my lunch time because I was busy, so nothing would happen.
99. **Interviewer:** And the guy from Pedi?
100. **Respondent:** Yes I met him October and we had sex and we used a condom all the time.
101. **Interviewer:** And your status, how did he come to know about it?
102. **Respondent:** I said when I call him to town that we have to talk about things before we start anything. He then said "things like what?", and I said "things like children, HIV status." I then told him that "I am HIV positive and I have two kids", because some people don't want people with kids. So he visited the next weekend and the next, then I asked him not to come every weekend because it's expensive, I didn't want to tell him the reason why. Then in November he came twice. In December he wanted to do a course, and then he noticed there was something wrong with me, and he said I was getting bored with him and I said yes I am bored and I do get bored and tired when someone stays too long. He then left. I told him that in the holiday in December I won't be here because I am going to my parents.
103. **Interviewer:** I would like to understand why you get bored when someone stays too long?
104. **Respondent:** Its nice during the day when you talk but at night its not. I don't want to have sex everyday and that is boring to me. He said that the relationship was still new and needed sex and I said that love is not about sex and alcohol.
105. **Interviewer:** You said you enjoyed sex?
106. **Respondent:** Yes I do when I get it I enjoy, but I don't want it everyday.
107. **Interviewer:** To you how important is sex in a relationship:
108. **Respondent:** It's not that important to me maybe because of the age
109. **Interviewer:** Has it always been this way or it was after you were diagnosed with HIV?
110. **Respondent:** Before I was diagnosed it was fine maybe it was because of the father of my kids: Because he had lost his job we stayed together so he started wanting sex everyday maybe that's why I was bored.
111. **Interviewer:** You and the father of your children were HIV positive?
112. **Respondent:** I don't know his status
113. **Interviewer:** Do you take alcohol?
114. **Respondent:** Not anymore
115. **Interviewer:** Why not?
116. **Respondent:** I don't know, I don't feel like I can take alcohol.
117. **Interviewer:** How important is sexual intimacy to your current partner, the Nigerian one?

118. **Respondent:** He is not interested because sometimes he will come in June and we meet once and we will have one round and he says no I don't want to get tired because I have to work. So I understand.
119. **Interviewer:** How about the young one from Pedi the one you don't want to live with?
120. **Respondent:** He is younger than me and he wants it everyday.
121. **Interviewer:** Some people on ARV drugs report low sex drive, or sexual enjoyment have you experienced these symptoms?
122. **Respondent:** I just get stressed, don't want to talk, and at times I just don't enjoy it.
123. **Interviewer:** In your own opinion what happens to a woman when they don't have sex?
124. **Respondent:** There is nothing happening, we just gain weight.
125. **Interviewer:** How about a man?
126. **Respondent:** They say it's not normal and not good, and you can't live for two weeks without sex. I don't know what happens to them.
127. **Interviewer:** Have any men told you that it's not good to go without sex?
128. **Respondent:** Yes this Nigerian man, he was here for two weeks, and then we met he said he wanted sex and I said you are from your wife, and he said it's too long for a men to go without sex for two weeks.
129. **Interviewer:** Did he explain why?
130. **Respondent:** No he didn't.
131. **Interviewer:** So you think men can't go without sex for a year?
132. **Respondent:** Yes I don't think they can; a woman can go without.
133. **Interviewer:** Do you think sex is important for good health?
134. **Respondent:** Yes I think it is. But to HIV people they must use a condom because there was one client who always had swollen feet, and then when he went to the doctor he said he must try and get sex and she was fine. I also had a certain pain by my waist but when I have sex that pain goes away.
135. **Interviewer:** And your stress, does it help in anyway
136. **Respondent:** Yes, you don't think about anything you just focus on sex and you sleep.
137. **Interviewer:** Then your experiences of using condoms, do you feel ok when you use a condom
138. **Respondent:** Yes I am fine now
139. **Interviewer:** Have you and your partner tried using alternative ways of being sexually intimate - for example masturbation?
140. **Respondent:** I use masturbation when I don't have partner.
141. **Interviewer:** How often do use masturbation?
142. **Respondent:** From 2004-2006 when I didn't have partner especially when I have the feeling of need. In June 1999-2000 November I also used masturbation then I didn't have a partner.
143. **Interviewer:** Did that give you the same satisfaction?
144. **Respondent:** Not that much but you feel that you are relieved because that thing just came out.
145. **Interviewer:** When you are having a partner do they practice masturbation?
146. **Respondent:** No
147. **Interviewer:** Have you tried oral sex with your partner?
148. **Respondent:** The one who didn't use condoms also used oral sex
149. **Interviewer:** In your own understanding is it safe sex?
150. **Respondent:** No, it's not really advised.

Thank You
The end