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Adult men's experiences of long term HIV care and treatment services in Johannesburg, South Africa

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Adult men's experiences of long term HIV care and treatment services in Johannesburg, South Africa

Submitted by

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This report has been submitted to the School of Public Health in the Faculty of Health Sciences of the University of the Witwatersrand. The report is in partial fulfilment of the requirements for the degree of Master of Public Health in the field of Social Behaviour Change and Communication (MPH).

Date: 19 June 2017

DECLARATION

I, **Bright Phiri,** declare that this research work titled **Adult men's experiences of long term HIV care and treatment services in Johannesburg, South Africa** is my own original work and that I have properly acknowledged in this report any portions of work done by other people.

The report is being submitted in partial fulfilment of the requirements for the degree of Master of Public Health, in the field of Social and Behaviour Change Communication (MPH-SBCC). The report has never been submitted for any other degree or examination either at the the University of the Witwatersrand or any other university.

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Signature:.....

Date:.....

ABSTRACT

Background

Extant research in South Africa and elsewhere has shown that men tend to shy away from health care services. For men living with HIV, this may lead to poor ART adherence. Literature on men and masculinities suggests that social definitions of what it means to be a 'man' affect and influence men's decisions to either seek or not seek health care. Some authors have argued that these definitions of manhood often discourage men from using public health facilities. Another body of scholarship suggests that South African men's poor health seeking behaviours and adherence to ART is also influenced partly by their experience with the healthcare system and the attitude of healthcare providers.

Aim

This study explored health seeking behaviours of men living with HIV with a focus on their long-term experiences with HIV care and treatment services, as well as their experiences with the new single, fixed-dose combination tablet and how it influences adherence to ART in South Africa.

Methods

This study used an exploratory qualitative study design, using in-depth interviews (IDIs) to collect data. The IDIs were conducted with 14 adult HIV positive men living who had been on ART for five or more years and were receiving care and treatment at Stretford Community Health Centre (CHC) in Orange Farm, Johannesburg.

Findings

The men shared in-depth individual experiences of what it means to live with HIV and subsequently being on treatment for a long time (five or more years). They gave insights on the psychosocial challenges that they have endured living with HIV. Furthermore, they shared their subsequent resolve to live healthy lifestyles despite the challenges they have encountered related to living with HIV. Regarding health care systems, the men were generally impressed with the services received at the health facility. Further, all but one man, were not bothered about the gender of the nurse attending to them at the health facility. The experiences of the men collectively, reflect and provide some insights of how self-determination can transcend societal definitions of what it means to be a man, and how notions of masculinities may influence how men cope and adjust to living with HIV, and their adherence to ART over a long period of time.

Conclusions

This study concludes that men are capable of modifying their masculine positions to cope with life-long adherence to HIV treatment regimens. The men's self-determination to adjust from destructive notions of masculinities in order to accommodate treatment is an area for further research to inform men's programming. Social support systems are key to men's ART adherence programmes. Stigma and discrimination remains a challenge within communities, and as such community sensitisation programmes should be strengthened to combat the vice. Programmes targeting men should promote behaviours perceived to be beneficial in prolonging men's lives.

The introduction of the fixed dose combination pill provides a great opportunity to strengthen men's abilities to consistently adhere to ART as it was taken once a day.

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And a big thank you to my research assistant, Vhuti, and all the participants who willingly took time off their schedules to come and share their experiences with me. Certainly, without this collaboration the study would not have taken off. Finally, I treasure my fond memories of MPH class and lecturers of 2014/15.
I thank you all.

DEDICATION

For my extended absences from home when my attention was needed the most, I sincerely dedicate this accomplishment to my family: Muluti, for keeping me company late in the night during my writing process; my children, for all your love and giving daddy space, to do the research and finalise the report. I love you all.
God bless.

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LIST OF ACRONYMS

ADR	Adverse drug reactions
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CHC	Community Health Centre
CDC	Centres for Disease Control and Prevention
FDC	Fixed Dose Combination
HIV	human immunodeficiency virus
HBM	Health Belief Model
HTC	HIV Testing and Counselling
HREC	Human Research Ethics Committee
IDIs	In-depth interviews
NDoH	National Department of Health
NGO	Non- governmental Organisation
NSP	South African National Strategic Plan on HIV and AIDS, TB and STIs
PLHIV	People living with HIV
SANAC	South African National AIDS Council
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on HIV and AIDS
WHO	World Health Organisation

CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.1 Introduction

Men are documented to have a tendency of shying away from primary health care services. This may lead men living with HIV to have poor ART adherence. Social definitions of what it means to be a 'man' affect and influence men's decisions to either seek or not seek health care. These definitions of manhood often discourage men from using public health facilities (1). Strong empirical evidence suggests that South African men's poor health seeking behaviours (2-4) and adherence to ART is also influenced partly by social stigma and discrimination and men's experience with the healthcare system (5).

This study explored adult men's health seeking behaviours with a focus on their long-term experiences with HIV care and treatment services in South Africa. The study further explored men's experiences with the single fixed-dose combination (FDC) tablet and its influence on ART adherence.

1.2 Background

The HIV and AIDS epidemic is a global phenomenon. By the end of 2015, approximately 36.7 million people were living with HIV (PLHIV) globally (6). Eastern and Southern Africa accounted for 19 million PLHIV representing approximately 52% of the global estimates during the same period (6).

The Joint United Nations Programme on HIV and AIDS (UNAIDS) estimated 7 million people were living with HIV in South Africa by end of 2015 (6). Factors that drive the HIV epidemic in South Africa are both social and structural including the type of locality such as informal settlements in urban areas. The South African National AIDS Council (SANAC) notes that socio-structural factors, such as poverty, gender inequalities, and human rights abuse drive the HIV epidemic (7). This view is informed by national surveys. For instance, Shisana and colleagues found evidence that linked locality type to HIV prevalence where they concluded that there is higher vulnerability to HIV for people living in urban informal settlements (4, 8-10).

With widespread availability of antiretroviral treatment (ART), there have been positive developments in the response to HIV and AIDS. The latest UNAIDS data, reveal progressive developments wherein an estimated 18.2 million PLHIV globally were enrolled on ART by 2016 (p.1) (6).

In Eastern and Southern Africa, UNAIDS estimates that the number of people on treatment has more than 'doubled since 2010, reaching nearly 10.3 million' (6). South Africa has recorded the largest ART programme with an estimated 3.4 million people enrolled (11). The regional estimates were complemented by a 36% reduction in AIDS-related deaths in this region during the same period (6).

However, despite the increased access to treatment services globally, men have been known to be less likely than women to seek and receive ART (12, 13). Men's health seeking behaviours and service use is influenced by varied documented facilitators and barriers such as 'socioeconomic status, educational level, sexual orientation, racism, lack of awareness of the need for primary care, religious beliefs, family support systems, peer influence, and some constructions of masculinity' (14-21). International studies have shown that notions of masculinity found to be barriers to men's health seeking behaviours in relation to ART and HIV care in general include men's social role beliefs that they are immune and immortal, the challenges they have on surrendering control and a conviction that men should not ask for help. These notions thus imply that 'men are not interested in disease prevention (p. 47) (16).

South Africa scholars found similar notions of masculinities that limit health seeking behaviours of men (19-21). Scholars claim that men interpreted an HIV positive diagnosis as a defeat, associate it with failure as a man, and perceive it as a demonstration of loss of control over their lives and an inability to perform expected masculine roles (21). The research implies that men's convictions about what it means to be a man become challenged when they are infected with HIV. This study focused on men being on ART for a long-term. The long-term treatment impacts on the men's health seeking behaviours and also on their notions of who they are as men.

The introduction in South Africa of the FDC pill for ART in 2014 added a need to understand whether this led to improvements in men's adherence to ART as well as broader psychosocial factors related to men's health seeking behaviours (15).

CHAPTER TWO: LITERATURE REVIEW

2. Literature Review

2.1 HIV prevalence in South Africa

By 2016, South Africa had an estimated 7 million PLHIV and this amounted to 12.7% of the entire population living with HIV (11). For the 15-49 years age group, UNAIDS estimated the HIV prevalence in the country to be 19.2% in 2015 which is among the highest in the Southern African region (6). The high prevalence may be as a result of the positive impact of the ART programme that has seen PLHIV on ART living longer (22). South Africa's HIV prevalence varies according to provinces with KwaZulu-Natal having the highest prevalence at approximately 40% (22).

2.2 Antiretroviral Therapy (ART)

Increasing evidence suggests that effective ART can control the multiplication of the HIV in the body thereby resulting in suppressed viral load and enable PLHIV to live healthy and productive lives (23). In addition, enrolment onto ART demonstrates health seeking behaviour among those infected with HIV. The World Health Organization (WHO) reports that the number of people accessing ART has been increasing rapidly over the years from just over 400 000 in 2003 to approximately 11.7 million by end of 2013 in low and middle-income countries (23). By June 2014, an estimated 13.6 million PLHIV had access to ART globally (23). Sub-Saharan Africa had a bigger share of this increase rising from 100 000 people on ART in 2003 to approximately 9.1 million people in 2013 (23). By June 2016, it was estimated that globally, 18.2 million PLHIV were accessing ART (6).

2.2.1 ART in South Africa

According to the National Department of Health's (NDoH) 2015/16 annual report, South Africa has the largest ART programme in the world with approximately 3.4 million PLHIV enrolled and receiving ART by March 2016 (11). South Africa's achievements in expanding ART can be credited to political will and that led to policy shifts on ART eligibility in alignment to new evidence and WHO recommendations. South Africa introduced free ARVs in the public sector in 2004 (24, 25). Prior to this, the government had been compelled by the courts in late 2001 to introduce and develop a comprehensive programme to prevent mother to child transmission (26). Following this, the South African government further adopted new policies and approaches for the prevention of mother to child transmission and treatment of their children. These policies including the HIV and TB treatment plan were meant to reduce the disease burden (26). In 2009, the government announced that ART was to be initiated to infants, pregnant women and people with tuberculosis (TB) - who had CD4 counts less than

or equal to 350/µl (5), from a previous CD4 count of 200/µl since 2004 (26).This policy shift occasioned 2.6 million PLHIV commencing ART by mid-2014 (27).

Further government enhancements in the management of HIV were shown through the development of a five year National Strategic Plan on HIV and AIDS, TB and STIs (NSP) 2012 – 2016. The NSP aimed to ensure that at least 80% of all people in need of ART were able to get it, and that 70% of them recovered and remained on treatment three years after initiation of ART(7). With this goal, there has been a great increase in the number of patients initiated on ART in the country (24).

In 2013, the South African government introduced the FDC pill, comprising three drugs used in the first-line regimen – Tenofovir (TDF), Emtricitabine/Lamuvidine (FTC/3TC) and Efavirenz (EFV) (27). This change was followed by an upward adjustment to the initiation of ART from CD4 count of ≤350/µl to ≤500/µl in 2014 (27). These changes in the administration of ART were intended to improve enrolment into ART, adherence, retention and ultimately reduce ill health and deaths caused by HIV and AIDS (27).

In 2015, the WHO issued ART guidelines which required that all PLHIV needed to be initiated on ART immediately after testing positive regardless of their CD4 count (28). Consistent with this, the South African government committed to rollout the WHO's Test and Treat recommendations from 2016 (29). These efforts would enable the expansion of ART eligibility and enrolment to a wider scope with the government planning to implement a gradual process starting with high risk groups such as sex workers (29).

Research has shown that in spite of the large ART programme, South Africa has a major problem of retaining people on ART (30). Problems related to retention are not unique to South Africa. UNAIDS data from 18 other countries shows declines over time in retention of PLHIV in HIV care, reporting retention rates at 12 and 60 months to be 86% and 72%, respectively (31). Retention in HIV care problems have been attributed to a variety of factors including adverse drug reactions, poor adherence, and other psychosocial issues (32).

SANAC suggested that 'high dosages of HIV treatment, taking too many pills and associated side-effects are major setbacks to ART adherence (33). The WHO also allude to the 'complexity of dosing regimens and the pill burden', including side-effects as affecting ART adherence (34). A systematic review of studies amplify these challenges point out that un-simplified dosing of medications can be a barrier to adherence (35). To assure retention in

ART programmes, there is need to link patients to care mechanism where they would receive important support services (36).

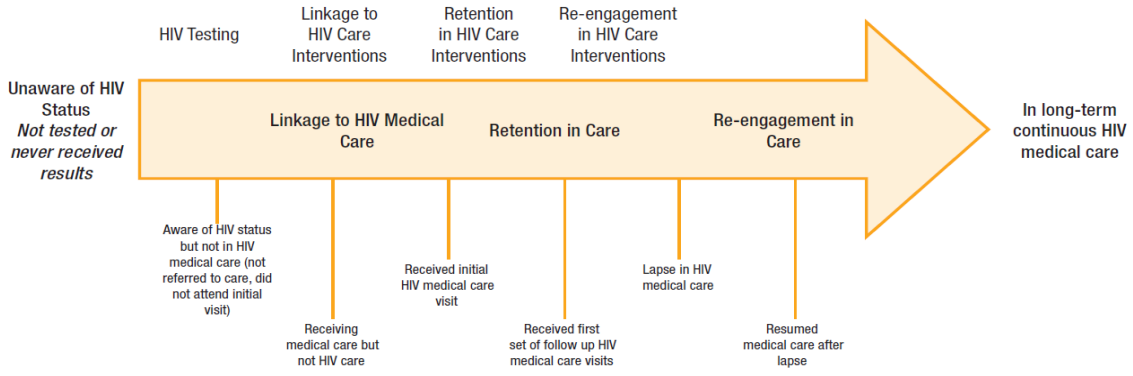
2.2.2 Linkages to care mechanisms

It is important to ensure that linkages to care mechanisms exist when people undergo HIV Testing and Counselling (HTC) and find out their positive HIV status. People often become devastated with such results and therefore need care and support services to cope with their new serostatus (36). The linkage to support systems should commence immediately after diagnosis through the counselling processes. The ideal care mechanism should be holistic involving *clinical, psychological, social, and preventive care services offered either at clinical or home-based setting (36).*

People who are on ART need to be enrolled in a continuum of HIV care. WHO broadly defines HIV care continuum as 'the continuum between identification of PLHIV and initiation and maintenance of treatment. This process begins with a 'positive HIV test, an assessment for ART eligibility, followed by initiation of ART and continuation of lifelong ART' (37) (p60).

In line with this, the NDoH developed guidelines with regards the continuum of care as shown in figure 1 below.

Figure 1. The Continuum of care approach



Source: NDoH, 2015 National consolidated guidelines for the Prevention of Mother-To-Child Transmission of HIV and the management of HIV in children, adolescents and adults

The processes in the continuum of care figure above is akin to a model already suggested in research at the time of conducting this study. McNairy and Elsadr proposed an "HIV care continuum'' (38) in which 'linkage from testing to enrolment in care, determination of ART eligibility, ART initiation, and adherence to medications would contribute to viral load

suppression' (p1) (38). The assumptions being made here are that when people are supported in their treatment processes, there is likelihood for them to adhere to the medications. The care continuum described above is important to this study as it facilitates the comprehension of the men's adherence to ART considering they have been in care for five or more years.

2.2.3 Non-adherence to ART and its effects

Studies have shown that in Sub-Saharan Africa, high rates of attrition (39, 40), and interrupted treatment (41) contribute to poor health outcomes for PLHIV. Whereas use of Traditional Complementary and Alternative Medicine (TCAM) by HIV patients was not the focus of this study, it is worth noting that some PLHIV tend to use traditional therapies. Literatures suggest that people tend to use TCAM alongside ART. However, as patients remain on ART over a period of time, herbal therapies tend to decline as patients adherence to ART improves (42, 43).

There are also other contextual barriers to art adherence such as need for food before taking medications and access to clinics (44, 45). Kagee and colleagues found that in resource constrained contexts, ART adherence can be impacted upon by poverty-related barriers such as food insecurity as well as other competing demands such as transport needs to go to the health facility, the role of disability grants and poor social support (44).

Similarly, Hardon and co-authors' findings in Botswana, Uganda, and Tanzania reveal that despite PLHIV wanting to adhere to ART, they are faced with numerous challenges among them transport costs and hunger. Many patients could not afford ART related transport costs to go for refills. In addition lack of food has been cited as a potential challenge especially in the initial stages of treatment, noting how that some patients could only afford to take medicines once a day as that was the only time they could afford food (45).

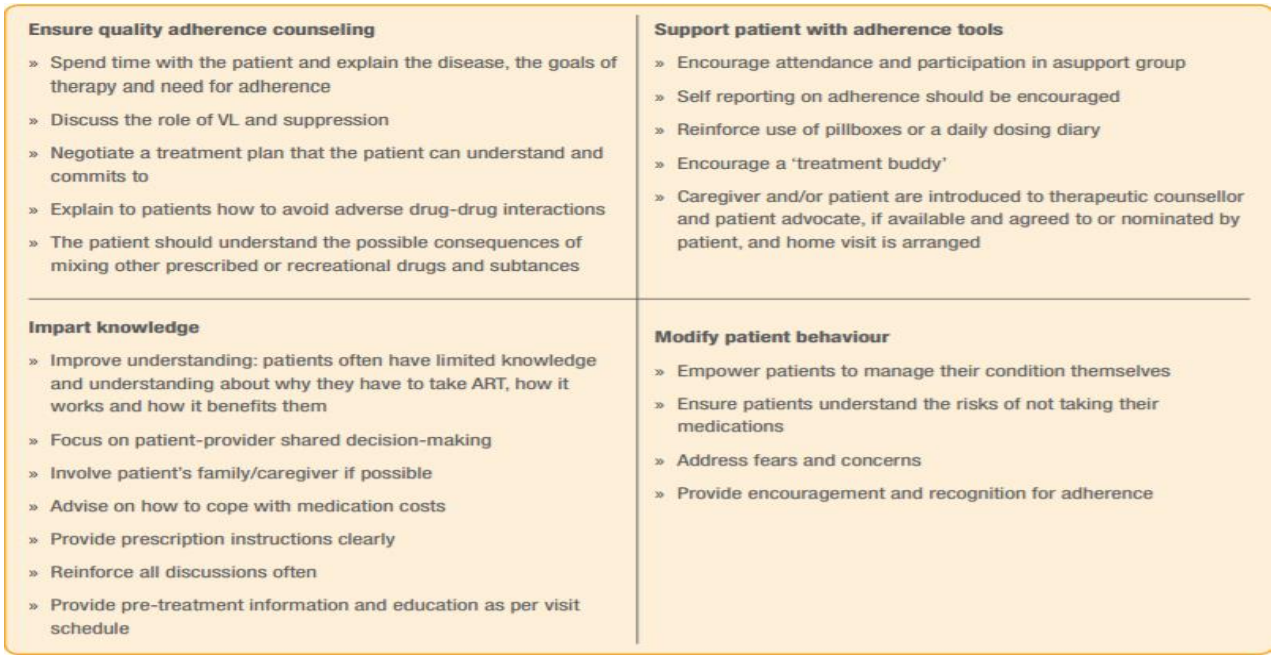
Failure to adhere to ART treatment regimens may result in drug resistance and or adverse drug reactions (ADR) (32). The management of causality and of side effects of individual case interventions at facility level have for a long time remained significantly weak in ensuring quality of care for improved patient outcomes in the South African health system especially the ART programme (46). Among other reasons, this may be due to inadequate training of public healthcare providers in recognising and reporting adverse drug reactions coupled with other psychosocial factors such as stigma and discrimination (46).

Skinner and Mfecane found that stigma *drives HIV out of the public sight* thereby complicating prevention and treatment work. (47). Indeed, where stigma is rife, people

diagnosed HIV positive will not easily disclose their status to anyone, thereby making it difficult for intervention programmes to succeed. Adherence to ART requires consistent monitoring (32), and is most likely to be achieved with the social support from immediate family , partners and community members (30). The environment should be supportive to allow PLHIV to freely disclose their status for treatment purposes. The NDoH has provided guidance on strategies to use in the promotion of ART adherence.

The NDoH emphasise that adherence is influenced by many dynamic factors and therefore strategies to deal with this challenge need to be flexible to respond to the changing needs of ART adherence (5). Box 1 below is illustrative of the government proposed adherence strategies.

Box 1: Strategies to improve ART Adherence.



Ensure quality adherence counseling

- Spend time with the patient and explain the disease, the goals of therapy and need for adherence
- Discuss the role of VL and suppression
- Negotiate a treatment plan that the patient can understand and commits to
- Explain to patients how to avoid adverse drug-drug interactions
- The patient should understand the possible consequences of mixing other prescribed or recreational drugs and subtances

Support patient with adherence tools

- Encourage attendance and participation in asupport group
- Self reporting on adherence should be encouraged
- Reinforce use of pillboxes or a daily dosing diary
- Encourage a 'treatment buddy'
- Caregiver and/or patient are introduced to therapeutic counsellor and patient advocate, if available and agreed to or nominated by patient, and home visit is arranged

Impart knowledge

- Improve understanding: patients often have limited knowledge and understanding about why they have to take ART, how it works and how it benefits them
- Focus on patient-provider shared decision-making
- Involve patient's family/caregiver if possible
- Advise on how to cope with medication costs
- Provide prescription instructions clearly
- Reinforce all discussions often
- Provide pre-treatment information and education as per visit schedule

Modify patient behaviour

- Empower patients to manage their condition themselves
- Ensure patients understand the risks of not taking their medications
- Address fears and concerns
- Provide encouragement and recognition for adherence

Source: NDoH, 2015: National consolidated guidelines for the Prevention of Mother-To-Child Transmission of HIV and the management of HIV in children, adolescents and adults

2.3 Men and health seeking behaviour

The WHO argue that for HIV programming to be effective, gender differences must always be taken into account and addressed (48). While statistics show that women are disproportionately affected by HIV accounting for almost 58% of the total number of people living with HIV in sub-Saharan Africa (6, 48), in contrast men are likewise unduly affected by negative health outcomes (49, 50) as they seldom seek health care compared to women. A growing number of studies show that men compared to women are less likely to seek healthcare when they fall ill (2-4, 51). Furthermore, studies have shown that men are less likely to get tested for HIV, to enrol, and adhere to ART services (52-54).

As literature indicates a low acceptance of HIV testing by men, this affirms the assertion that men do not usually access nor use health services as much as women do (55). Some studies have found that men have a high likelihood to die of AIDS related illnesses than women because they present late at health facilities when the virus had advanced to AIDS and only then are they initiated on ART(56, 57). Additionally, more research have shown that men even when on ART, are still more likely to die than women because they are often lost in the continuum of care (13, 50, 58). Badri, Lawn, & Wood, 2006 argue that the effectiveness of ART treatment is compromised when initiated in the later stages of AIDS related illnesses (59). In order for HIV treatment to effectively work, one has to consistently adhere to the regime. Yet, research has found that men unlike women have a higher likelihood of defaulting their ART during the HIV continuum of care (55, 60).

An analysis of access to ART in South Africa found that while the number of adults commencing ART in 2010/11 was 1.56 times than those who had become ART-eligible in the same year, the ratio was substantially higher in women than in men (24). The study attributes the low rate of ART initiation in men relative to women to a reflection of gender differences in health-seeking behaviour and perceptions that men who seek care are weak (24, 61). Like elsewhere, men in Sub-Saharan Africa have been found to have a disproportionately higher dropout rate from HIV related services than women (62).

Studies have found men to be more vulnerable than their female counterparts to higher morbidity and mortality as a result of their delayed and poor health seeking behaviour (63). Findings by Moodley 2013 indicate that most men still feared the idea of being diagnosed with HIV despite ART being available for free in most public health facilities in South Africa. (63). Moodley found numerous reasons for men's fear to seek health care some which were the fear of imminent death, stigma, and also the fear of being rejected by society. She also found that men did not seek health care because they perceived health facilities are predominantly female spaces (63). Similarly, other research found uneasiness and a feeling of alienation among men when they are at clinic settings supposedly caused by the presence of so many women who to the contrary traversed the health facilities with ease (64).

In recent studies in South Africa, Fleming and colleagues (2016) and Dworkin and others (2015) postulate that gender transformative interventions may assist in addressing men's obstacles to care and treatment. Such interventions seek to promote gender equity while challenging masculine norms (51, 65).

To further understand dynamics of health seeking behaviours of men in this study, it may require drawing from some behavioural frameworks such as the theory of planned action, the Health belief model (HBM), theory of reasoned action and many others. While there are many such frameworks, this report will draw upon the HBM(66, 67) to examine how HIV positive men managed to stay on ART for such a long time despite their exposure to stigma and discrimination.

2.4 Masculinities and health in SA

Critical men's studies both in South Africa and elsewhere have shown that the harmful hegemonic notions of masculinity play a significant role in men's health seeking behaviour (17, 68). Extant literature suggests that there is a close relationship between the concept of hegemonic masculinity and men acting in ways that are perceived to be tough, being dominant and in control of their circumstances (69-72). In line with this, some authors have argued that the discourse that men have to be and are in control, strong, resilient, disease free, highly sexual and economically productive negatively affects their health and health-seeking practices (73-75). develop men's health centres where men would feel comfortable to go and seek In this case, literature points to the perception about masculinity and strength not being associated with illness. Davies and colleagues provide evidence that because males are socialised to be independent and not show vulnerability, they rarely utilise health facilities. The study suggests the need to help (76).

Studies have documented various reasons for men's lack of health seeking behaviours (19-21). Among them is the notion of hegemonic masculinity, which affects men's identities of what it means to be a man. Hegemonic masculinity prescribes attributes of what the ideal man should be and also what kind of behaviours, attitudes and beliefs are expected of such a man (77). These prescribed attributes include displaying abilities of physical strength and bravery (78). In this regard, men who aspire to hegemonic masculinity view the health seeking attribute as falling outside the prescriptions of being a man. Health seeking would be perceived as a sign of weakness – characteristic not synonymous with the image of an ideal man. Therefore, to avoid displaying what society would term feminine behaviours, men care less about their health in conformity with the society's view of men being more resilient than women (17). Attempts to consolidate these ideal men images or identities has shaped some men in ways that lead to poor health seeking behaviours(79).

Some societal expectations of a man providing for their families regardless of whether they are working or not and that the men have to be in control over many things sometimes leave

men feeling lacking of those masculine attributes (74). However, other authors such as Connell and co-authors (2005) argued on the dynamism of masculinities, that masculinities are not static but are constantly being reconstructed as circumstances of men evolve (71). Read collectively, the various studies underscore the influence that some 'harmful masculine norms' have on how men would seek care and treatment(51).

2.5 Psychosocial issues impacting on PLHIV

Today, HIV is considered as a chronic disease and PLHIV on ART live longer, healthy and productive lives. This, however, sometimes comes at a price as PLHIV are faced with psychosocial challenges such as stigma and discrimination (80-82). Research has shown that such challenges faced by PLHIV complicate efforts towards prevention and treatment outcomes (47, 80). In other research, psychosocial challenges have led to mental illness such as depression and anxiety among PLHIV (81, 82). Psychosocial issues such as stigma and discrimination impact negatively on PLHIV especially when it comes to deciding whether or not to disclose their status which in turn may impact on their adherence routine to ART.

2.6 Problem Statement

Due to medical advances, access to and the effectiveness of ART, HIV is now considered a chronic disease. For the desired treatment outcomes to be realised, patients on ART need to strictly adhere to the drug regimens and be continuously linked to care services (1). Adherence includes 'patients taking treatment as prescribed, keeping to appointments for test results, referrals and appearing for further clinical investigations'(27). However, men in particular are documented to have a tendency of shying away from primary health care services which may lead to men having poor ART adherence. Social definitions of what it means to be a 'man' affect and influence men's decisions to either seek or not seek health care (1).

Strong empirical evidence suggests that South African men's poor health seeking behaviours (2-4) and adherence to ART is also influenced partly by the men's interactions with the healthcare system and the attitude of healthcare providers (27) as well as stigma and discrimination experienced within the communities, families and the work place (47, 83).

2.7 Broad Justification of the study

Whilst there have been numerous studies conducted in South Africa exploring men's health seeking behaviours (2-4), there is dearth of studies that have specifically looked at men's experiences on long-term HIV care and treatment services. Several studies have looked at how well patients on ART have adhered to their daily medication schedules, but little

attention has been paid to finding out how long people stay on medication (especially men) to avert illness or indeed death (39). Being on long-term treatment means that one has been adhering to ART over a period of time. Literature indicate that many of the people that start HIV treatment programs in Africa no longer receive treatment after two years for various reasons (39). Long term treatment is relative, however, for purposes of this research, I have taken five years on treatment as long period on ART.

Furthermore, to my knowledge, this is the first qualitative study to explore experiences of men with the FDC pill and how it influences their adherence to ART in South Africa. Findings of this study may contribute and expand the knowledge on men's experiences of long-term HIV care and treatment services and provide insights into ways to enhance ART adherence. Additionally, the findings of this study may inform future research into programming for men living with HIV and their health seeking behaviours.

2.8 Research question

What are the HIV care and treatment services related experiences of adult men who have been on ART for five or more years in Johannesburg?

2.9 Study aims and objectives

This study aimed to explore adult men's experiences of long term HIV care and treatment services at Stretford Community Health Centre in Orange Farm, Johannesburg.

The study aim was achieved through the following specific objectives:

- To explore the experiences of living with HIV and being enrolled on ART for five or more years among adult men living in Orange Farm, Johannesburg
- To explore how adult men who have been on long term care have experienced HIV care and treatment services in Orange Farm, Johannesburg
- To explore the experiences of using the fixed-dose combination tablet among adult men who have been on long term HIV care in Orange Farm, Johannesburg

CHAPTER THREE

3. Research methods

3.1 Introduction

This chapter describes the research methodology used for the study. It further describes the context and setting in which the study was conducted, the study population, sampling methods, data collection including instruments used, and data management and analysis. The chapter also provides a discussion on the ethical considerations; and, last, describes my role and that of the research assistant in conducting the study.

3.2 Study design

An exploratory qualitative study design (84), using in-depth interviews (IDIs) was applied. The IDI is a qualitative research technique in which there is an in-depth conversation with the informant. As a data collection approach, it facilitated me to delve into social and personal experiences of the interviewees (p.16) (85).

This study design was found to be particularly useful in gaining insights into the men's experiences of potential changes brought about by their HIV positive status and subsequently being on HIV care and treatment for five or more years. Furthermore, this design enabled an in-depth exploration of the men's experiences of having switched from a three drug-regimen to the fixed-dose combination tablet, and whether such switch had any influence on the men's adherence to ART.

3.3 Study setting

The study was undertaken at Stretford Community Health Centre (CHC) in Orange Farm, south of Johannesburg, South Africa. Orange Farm is situated 50km south of Johannesburg and was established in the mid-1980s as a spill-over settlement from Soweto (86). The 2011 statistics south Africa census estimated that Orange Farm township had a population of 76 767 people and predominantly populated by black people estimated at 99.3% (87). Whereas there are other languages spoken in the area, isiZulu, Sesotho and isiXhosa dominate at 44.5%, 29.1% and 9.5% respectively (87).

The Orange Farm settlement faces multiple challenges including low levels of education among many adults, with 7% of the people aged 20+ having no schooling at all. A partial 3.8% having attained higher education and only 30.6 % with matric (87).

Unemployment is high among the estimated 67% working age group 15-64, with a high dependency ratio of almost 50%. Poverty and high prevalence of HIV and low quality basic infrastructural and social services are common in the area (87).

The Stretford CHC was opened in February 2006 and caters for the major part of the Orange Farm population as a primary health care provider. The clinic is a government public health facility that provides a range of care and treatment services, among them, HIV and TB related (88). The clinic encourages home-based care and community support groups for TB and HIV patients (88).

The choice of the study site (Stretford clinic) was motivated conveniently for ease of access because one of my supervisors had done research work and had developed good repport with management at the site. As a result, due to the sensitivity of the topic of my study, I needed to find a site that would easily provide me with access to willing participants. Further, the choice of Stretford clinic was also partly as a result that it was the main clinic in Orange farm with a large HIV ART treatment programme.

3.4 Study population

The study population comprised adult men aged 18 years or older living with HIV and having been on ART for five or more years at the time of conducting the interviews, and receiving HIV care at Stretford CHC in Orange Farm, Johannesburg.

3.5 Inclusion criteria

Research participants were recruited on the basis that they were adult men (irrespective of race or nationality), aged 18 years and above, HIV positive, attended and received HIV care and treatment services at Stretford CHC in Orange Farm. The men were also required to have been on ART for five or more years at the time of the interviews. Any man who fell outside of the selection criterion was not included in the study. This study did not use sexuality as an inclusion or exclusion criteria.

3.6 Sampling and Sample

A sample of 14 black African adult men living with HIV for five or more years and receiving care and treatment services at Stretford CHC in Orange farm was purposively selected to participate in the study. Purposive sampling is useful for samples that have already been predefined such as this one (89, 90).

The 2011 statistics South Africa census estimated that Orange Farm township had a population of 76 767 people and predominantly populated by black people estimated at 99.3% (72). It is this primary population of the study site that uses the services of the study clinic more often. It is therefore important to note that race or colour of skin was not part of the neither inclusion nor exclusion criteria for this study. During the participant recruitment process, only black people came forth to take part in the research.

The sampling process involved requesting, through the facility manager, a nurse/counsellor who worked at the HIV section of the clinic to assist with the identification and recruitment of possible participants. The nurse was required to share a study information sheet (see Appendix 2 with the would-be participants detailing the purpose of the study, procedures involved, rights of participants and the potential benefits and risks of participation.

With the aid of the computerised patient database, the nurse/counsellor checked for the names and history of male patients to select those who had been on ART for five or more years. A list of possible participants was generated from the database based on this criterion. The men were then individually contacted within two weeks by a nurse counsellor when they visited the health facility and asked whether or not they would be interested to participate in the research. Many of those spoken to were reportedly willing to take part in the research and gave their consent for me to contact them on the scheduled interview day.

With the assistance of the nurse, we contacted the prospective participants, explained the study in more detail and made appointments with those who expressed willingness to participate in the study. Initially, I intended to enrol a maximum of 20 adult men who met the study inclusion criteria; however, data collection was stopped at interview 14 as data saturation had been reached at this point.

3.7 Data collection

Data were collected through one-on-one IDIs using an interview guide (Appendix 3). A flexible interview schedule written in English steered the interviews which were conducted mainly in Sesotho and isiZulu. With the permission of the participants, interviews were recorded using an audio recorder with hand written field notes taken as supplementary record. Interviews were conducted by a research assistant and I was present in most interviews.

Appointments for interviews were arranged to coincide with the dates when the participants visited the clinic for any HIV related consultation. As noted by DiCicco-Bloom and Crabtree,

effective use of IDIs requires rapport building between the interviewer and interviewee. It involves building rapport and 'trust with the interviewee and the information being shred (DiCicco-Bloom and Crabtree, 2006). In this study, rapport was established with the individual participants through welcoming them into the interview room. Before beginning the interviews, we first had a casual talk with the participants after offering them some drinks as refreshment. This helped to create an environment that was conducive for the participants to relax and share their personal experiences. The interviews begun with providing information about the study. This was then followed by obtaining informed consent from the participants using consent forms (Appendix 4). Interviews lasted between 35 minutes to an hour.

As noted earlier, a maximum of 20 in-depth interviews were initially planned for this study, however, data collection was stopped after 14 interviews because responses from the participants became more or less similar with no new information being generated (91). In consultation with the supervisors, I determined and decided that since there was no further new information that was different from what the other participants had already shared, to cap the interviews at 14 (91).

A black African male research assistant was employed to assist me with conducting the interviews in local languages. The local language interviews in this case facilitated for interviewees to fully express their experiences in a language they were comfortable with. As the researcher, I am not conversant with the local languages spoken in the setting of this study. As such, I only fully interviewed one man who felt comfortable to be interviewed in English. For the other interviews, I sat in to ensure rigour and take responsibility for the acquisition and completeness of the data from the interviews. I was present in at least 70% of the interviews conducted by the research assistant. With my basic understanding of the languages, I was able to ensure, through the assistant, that questions were probed further to solicit in-depth responses.

The research assistant was experienced in conducting qualitative IDIs with adult men. Prior to conducting IDIs for this study, the research assistant had recently conducted IDIs with adult men on fatherhood for a study conducted by the South African Medical Research Council. That study had been led by my supervisors, who then recommended him for this task. I provided the research assistant further on-the-job training on qualitative in-depth interviewing skills and ethics.

In addition to collecting data meant to meet the objectives of the research as outlined above, I also collected information on social and demographic characteristics of the participants such as age, marital status and educational levels.

3.8 Scope of study

This qualitative study sought to explore and describe adult men's experiences of being on long term care for HIV and treatment services in Orange Farm, Johannesburg. The interview guide (Appendix3) sought to explicate men's physical, psychosocial, social and biological experiences of living with HIV for five or more years including ART adherence issues. Other areas of interest included men's experiences with health care services, men's experiences with switching to FDC ARV tablet, and how the notions of masculinity affected the participants' health seeking behaviours.

3.9 Data management and analysis

3.9.1 Data Management

I was responsible for the safe storage of data and other study material (e.g. signed consent forms) collected in this study. The recorded data, note books, and transcriptions, with all participants identifying information removed, were stored securely in a lockable cabinet at my home to avoid any kind of unauthorised access, loss or tampering of the data. Electronic data were also securely stored on my personal computer with restricted password access. All study material and data, in line with the University of the Witwatersrand's (Wits University) policy, will be kept for two years if the findings of the study are published and six years if not published and then be destroyed.

All the interviews were audio recorded while data on social and demographic variables were recorded in a book. The audio recordings for the local language interviews were later transcribed verbatim and translated into English by the research assistant. Some of the anonymised transcribed text was verified by an independent person (workmate) familiar with the languages to ensure that data logic matched and reflected the captured audio recorded data.

The use of the research assistant in both conducting the interviews and later transcribing them helped to a great extent in maintaining the participants' literal meanings of their experiences. In preparation for data analysis, all notes and transcripts were uploaded onto a computer software Max-QDA which supported electronic coding and analysis.

3.9.2 My position as a researcher in the study

I am a media and communications professional with over 15 years of development work focusing mainly on health promotion especially in the HIV and AIDS field. The choice of the research topic was influenced, to a large extent, by my health promotion background. Throughout my work, I have sought to explore any possibilities of strengthening men's dialogue on health seeking behaviours.

In addition to personal interest in men's health emanating from work experiences, there is literature that suggests that men's reluctance to seek health is largely influenced by the dominant notions of masculinities (17, 21, 70). This motivated the conceptualisation of this study with the aim of promoting men's health.

My interest in men's health may have latently influenced the interpretation of the data and engagement with research participants. This potential bias, however, was mitigated by the fact that the research assistant conducted almost all the interviews in the local languages of which I only have some basic understanding. Being of non-South African nationality presented a unique challenge as I was unable to personally conduct the interviews due to the cited language barrier. However, this was moderated by working closely with the research assistant during data collection. During the interviews, the research assistant, from time to time, checked with me whether the questions were adequately being addressed. Furthermore, my presence during the interviews was a demonstration of commitment and value I attached to the study; and allowed for the initiation of data analysis and refinement of questions during data collection to enable exploration of new avenues of questioning (92).

3.10 Data analysis

The data analysis process began with reading and re-reading of the transcripts. Thereafter, four randomly selected interviews were coded manually using word documents, and the inductive codes were counter checked by the supervisors. This was an important step in the coding process in an attempt to minimise possible biases when coding (93). This was an on-going consultative process, which enabled the development of a code book and the establishment of inter-coder reliability. The supervisors made suggestions for revisions which were subsequently made to the code book. Based on these initial codes, computer aided software Max-QDA was used to code the rest of the transcripts.

The coding was done both deductively and inductively and facilitated development of initial categories and themes for analysis. The brief deductive coding in line with the research question and the interview guide was meant to provide preliminary direction when delving

into the data. I then transitioned from the deductive approach to the inductive one as new codes started to emerge organically from the transcripts.

The data were analysed using a thematic content analysis approach (84). As a research method, thematic content analysis represents a systematic and objective means of describing phenomena (94). Thematic content analysis lays emphasis on the participants' perceptions, feelings and experiences as the paramount object of the study (95).

The analysis resulted in the emergence of eight main themes: the circumstances and context of HIV testing, men's reactions to HIV diagnosis, blaming discourse, psycho-social effects of living with HIV including HV status disclosure, motivation to live, pathways to coping and adjusting to living with HIV as well as exposure to ART regimes and adherence over time. These themes are explored in detail in the findings section.

3.11 Study limitations

The study has some limitations. Qualitative research is prone to certain inherent biases including social desirability bias. Social desirability bias is especially common in studies on sensitive issues such as living with HIV and ART adherence. The location of the data collection can also potentially influence social desirability. For example, as participants were recruited from a health centre, they may have not wanted to be perceived or known to be non-adherent to ART, and may have been reluctant to disclose candidly if they were non-adherent to ART.

Asking participants to look at their experiences retrospectively (over five or more years prior to the interviews) may have given rise to recall bias on the part of participants. Not all participants could vividly remember every detail what happened five years or more earlier.

Nevertheless, I anticipated these challenges and ensured that good rapport was established with the participants prior to interviewing them, and probing was done to assist participants to recall earlier experiences. Throughout the interview, the ultimate end-point was to encourage the participant, in their own words, to share as much information as possible. This meant urging participants to elaborate further on their responses.

My inability to fully converse in the local languages spoken by the participants was another limitation. For this reason, personal engagement with the participants was missed. This limitation was however, mitigated by being able to sit-in during most interviews, following the direction of the conversations, and at appropriate time, urging the research assistant to

probe further. For instance, it was easier to pick up the need for further probing whenever participants consistently gave short and brief answers to open ended questions posed by the research assistant. In addition, the research assistant was trained on how to encourage participants to explain and elaborate further any answers they would give to the questions in the interview guide.

Another potential limitation was about conducting the study in one clinic as comparing men's views and experiences in accessing health care in different clinics could have strengthened the findings of this study and enhanced their transferability to other similar settings elsewhere. Conducting the study in one clinic could have led to the researcher obtaining a relatively homogenous sample, which limits the transferability of the findings of this study to other clinics in Johannesburg or other settings in South Africa

Finally, the findings presented in this research report cannot be generalised to the entire Orange Farm community and to all male clients receiving ART from Stretford CHC or elsewhere. The sample size for this study was small and not statistically representative of the Orange Farm population or to all men living with HIV and on ART in Orange Farm (92). This is by no means suggesting that data collected through qualitative methods cannot be operationalized. To the contrary, qualitative data is highly regarded and useful in policy and programme implementation.

Further, the fact that this study was conducted just at one health facility could be a limitation and also time frames can be limitations as a comparison over different time frames could possibly yield different results

3.12 Ethical considerations

Ethics approval for the study was obtained from the University of Witwatersrand, Faculty of Health Sciences Human Research Ethics Committee (Medical) with a clearance certificate number M150743 (Appendix 8). The permission to conduct the study at Stretford CHC was acquired from the Gauteng Provincial Department of Health bearing reference number 2015-16/022 (Appendix 9). Further to this, the management at Stretford CHC also gave permission for me to undertake the research at their facility. This occurred after I and one of my supervisors approached them and explained the study aims, objectives and rationale, and the procedures to be followed in the study, and presented them with the approval and ethics clearance letters.

After the Stretford CHC management approved access to the facility I was assigned a nurse who worked in the HIV section of the clinic to help with the participant recruitment process. The nurse was informed about the study, the inclusion criterion was explained, and she was asked to assist with recruitment of study participants. A study information sheet detailing the purpose of the study, procedures involved, rights of participants and the potential benefits and risks of participation was given to the nurse to assist her in identifying potential participants.

The study participants were recruited from among all men living with HIV and receiving health care services at Stretford CHC. Those who met the study inclusion criteria, from the list generated from the data base, were informed about the study by the nurse during their scheduled clinic visits and invited to participate in the study. Interested prospective participants were requested to leave their names and contact details with the nurse so that I could contact them to arrange a day with them for the interviews.

All participants gave written informed consent prior to participating in the study. A participant information and consent document written in simple English was used during the recruitment of study participants. The research assistant interpreted the English forms in Sesotho or isiZulu, depending on the individual participant's language preference, prior to conducting the interviews. The research assistant, using the participant information sheet, explained the purpose of the research, procedures involved, possible risks and benefits and the rights of participants. Additionally, permissions to audio record the interviews were obtained from each consenting participant. I sat in the interviews, and observed the initial consent processes before the interviews took place.

I also assured participants, through the research assistant, of confidentiality and that the information obtained was to be used solely for research and academic purposes. Due to the sensitive nature of the study, all the interviews were conducted in the privacy of a boardroom at the clinic for enhanced confidentiality of participants' responses. Furthermore, in order to protect the identity of the participants, due to the sensitive nature of the information they shared, at data management phase and subsequently throughout the research report, participants' real names have been replaced by pseudonyms. This helps to ensure that participants will not be identifiable by anyone reading the research report. The filenames of audio recordings were saved using unique codes.

Participants were invited to ask any questions at any time during the research process, and were informed of their rights to withdraw from the research at any time, and that their

withdrawal would not affect the management of their health at the clinic or relationship with the clinic staff.

There were no incentives paid to the participants to take part in the study. However, the participants were reimbursed R100 each for their transportation to and from the venue of the interviews at Stretford clinic. The same amount also catered for the men's time attending the interviews.

3.13 Project management

Management of this study from initiation to completion was my responsibility, in consultation with my supervisors. I ensured that all tasks were completed timely, and any challenges encountered discussed and resolved with the supervisors.

A lack of funding for the study was the main challenge in conducting this study. This implied reliance on limited personal resources to finance all the logistics of the entire research process. Another challenge that caused the deferment in starting data collection was the delayed ethics approval from the Gauteng department of health. The process took longer than anticipated.

3.14 Study funding

The research budget was fully self-financed, including translations, transcription services and paying of the research assistant's salary.

3.15 Planned utilization and dissemination of results

The research report is to be submitted to the School of Public Health, University of the Witwatersrand (WITS) in partial fulfilment of my Master in Public Health (MPH) degree. Thereafter, the report will be shared with the management of Stretford CHC and the Wits library. Furthermore, the results will be written up and submitted to a peer-reviewed journal for possible publication. The results will also be submitted for presentation at conferences such as the Public Health Association of South Africa (PHASA).

CHAPTER FOUR:

4. Findings

4.1 Introduction

This chapter presents the findings of the study which are based on the data gathered through in-depth interviews with adult men living with HIV, and who had been on ART for five or more years. The main aim of the study was to explore adult men's experiences of long-term HIV care and treatment services. Men interviewed in the study were receiving care at Stretford Community Health Centre in Orange Farm, Johannesburg, South Africa. The findings section covers the socio-demographic characteristics of participants, the circumstances under which men tested for HIV and their reactions to a positive HIV test result, including blaming others for their HIV acquisition. Findings on the impact of living with HIV including the psychosocial effects, as well as findings on how HIV disclosure to family, friends and workmates facilitated support for men, will be presented. The section will also highlight the men's coping strategies, and finally a summary of the section will be provided.

4.2 Socio- Demographic characteristics of participants

All fourteen participants in this study were black African men aged between 37 and 56 years, with an average age of 45 years. The participants had been taking ART for a period ranging from six to 12 years.

Of the 14 participants in this study, only three were in formal employment while the rest were either self-employed or dependent on government social grants as a source of livelihood. The highest education level attained by the men was grade 10, and none had attained any tertiary education.

The majority of the participants had been married before. However, at the time of the interviews, only two were still married, nine were widowers but living with a new girlfriend/partner. Three participants described themselves as single despite having had on and off relationships with different women. On average, most of the participants reported having two to three children.

Below is table summarising the profiles of the participants.

Table 1 gives a snap shot of the characteristics of the participants

Pseudonym	Age in years	Education level	Marital status	Source of income	Years on ART
Dumiso	41	Completed lower secondary school	Widower/partner	Employed	12
Khumalo	49	No formal education	Partner	Self employed	9
Mpumelelo	53	Completed lower secondary school	Married	Employed	8
Philani	47	Not completed primary school	Partner	Social grant	7
Likhona	56	Completed Primary school	Widower/partner	Employed	8
Lungile	38	Completed primary school	Not married	Self employed	6
Kulekani	43	Completed primary school	Not married	Unemployed	7
Sipho	44	Completed primary school	Widower/partner	Unemployed	9
Nthemba	42	Completed lower secondary	Married	Self employed	7
Nkosinathi	44	Completed lower secondary	Widower/partner	Self employed	6
Bheka	38	Completed lower secondary	Married	Self employed	5
Phenethi	51	Not completed primary school	Married	Social grant	9
Pule	37	Completed primary school	Not married	Self employed	7
Thabo	45	No formal education	Partner	Self employed	6

4.3 Circumstances and context of HIV testing

All participants, except three, indicated that they got tested unintentionally as they became very sick and were admitted to hospital. This finding of delayed health seeking goes to confirm available literature that men have poor health seeking behaviours (2-4). Most of the participants said they were initially tested and diagnosed with Tuberculosis (TB), and that while they were hospitalised they were encouraged by a health care worker to test for HIV as well, that way finding out their HIV positive status. Two participants said they voluntarily went for testing as a result of the deaths of their spouses. One other participant, Mpumelelo, 53, said he went for testing after seeing his brother and aunt die from what he believed were AIDS related illnesses.

Notwithstanding, when asked to describe further the circumstances under which they tested for HIV, some men talked about having been motivated to test after reflecting on their past risky sexual behaviour, thereby appraising their chances of being infected with HIV as high. One participant specifically mentioned that he already suspected that he was HIV positive

even before he went for testing, and this was because of the death of his ex-girlfriend to what was suspected to be AIDS-related illness.

Likhona, 56, described how he was prompted to go for an HIV test after he had heard that his ex-girlfriend had died of AIDS. He then thought he too was infected because the breakup with the ex-girlfriend was recent. He posited:

> *"The girlfriend I was dating passed away and it was after we broke up and I heard rumours that she died because of AIDS and that made me realise that I should come and get tested." (Likhona)*

Prior to being tested, almost all participants admitted having had limited knowledge about HIV, and not imagining that they could ever be infected with HIV. However, after undergoing counselling, men reported that their knowledge about HIV increased.

4.4 Reactions to HIV diagnosis

The data suggest that participants reacted differently when they were diagnosed with HIV. Among the reactions reported were those of shock, disbelief, despair- leading to fear of death, and uncertainty as to what would become of their lives. These feelings reportedly intensified after men were informed that they would be on ART for the rest of their lives. While these reactions may not be unique to men alone, the extent as expressed by the participants lends credence to literature on some harmful notions of masculinities that advocate that men are meant to be strong and therefore cannot fall sick, in this case, that they cannot be infected by HIV (73-75) .

Fifty-three year-old *Mpumelelo,* explained his initial reaction to the test result in 2008:

> *"…It was a shock the first time I heard it [HIV diagnosis] because I thought that I was going to follow [die] like my brother, my sister's mother… but because of the support from the family they [family] took care of me…" (Mpumelelo)*

In similar lines Philani, 47, reported his reactions of fear and helplessness to the test results:
"… I was scared when I came to get my results and when I was told that I am HIV positive… I felt there is nothing I can do. (Philani)

Beyond the test results, the reactions intensified with the idea of taking treatment as a lifelong undertaking. Khumalo,49 had been one of those who became afraid of what taking the treatment meant for his life, this is what he had to say:

> *"...I was scared but they [counsellors] do give us classes about that [taking ARVs]. I was scared not knowing how the tablets would make me feel but I did come and fetch them…. It was very painful but at the end I was able to accept it." (Khumalo)*

Philani who had initially reacted with a sense of helplessness after hearing his test results, felt that he had to accept not only his positive status, but also the fact that he was to be on ART for life. In his own words:

> *"…I accepted because there was nothing I can do and I said it is ok I will take the tablets, only God knows." (Philani)*

Highlighting the benefit of counselling post HIV diagnosis, both Khumalo and Philani emphasise that they accepted their HIV status and developed willingness to start taking ART, as was advised during counselling sessions.

4.5 Blaming discourse

When asked to share how they got infected with HIV, the men described different experiences. Nearly all of them said they were unsure exactly how they got infected. Yet, there were men who blamed their female partners for their HIV infection. For example, Dumiso, 41, initially blamed his acquisition of HIV on his late wife. But, at the same time, he was doubtful as to whether his wife had in-fact infected him or whether it was him who infected her. A similar blaming discourse by men who are living with HIV has also been reported in other studies (83, 96). This blaming discourse is best illustrated in the extract below taken from Dumiso's interview:

> *"My brother I am not controversial I want to tell you, these women, this is where I got this virus from… My wife died knowing that she has given me the virus and never said anything…or should I say I am the one who gave her? I will never know but I don't care… Ultimately I know that I got it..."* (Dumiso)

Contrary to this, other men felt that there was no need to blame either party for contracting HIV as it was difficult to tell who could have infected the other, if no HIV test was done prior

to marriage. For example, Philani shared his life experiences with his partner after they both tested HIV positive. Neither blamed the other for the infection, he explained:

> *"…God is great because when we [he and wife] found out that we were at this stage [HIV positive] we started bonding like never before because it helped us so that we can survive because they [other people] thought maybe I will blame her or she blames me…" (Philani)*

4.6 Psychosocial effects of living with HIV, disclosure and support

Men described relatively similar experiences on the psychological effects of living with HIV. They described how initially they sometimes felt lonely, sad, depressed or resentful because of having tested HIV positive. The data analysis suggests that these negative feelings were also exacerbated by both the realization that they will be on life-long ART, and the stigma they encountered within the communities. These challenges, in turn, made some men to be reluctant to disclose their HIV status to anyone.

Furthermore, different patterns emerged from the data as to whom the men disclosed, and the processes of disclosing. Whereas some men said they disclosed their HIV positive status to their friends and family members, others said they only disclosed to selected colleagues and their intimate partners because of fear of stigmatization. For instance, Thabo, 45, said while he did not disclose to his parents, he informed his spouse about the test results. In his own words:

> *"Let me just say I was not ok with all that thinking [about] what will people say but when time went by I told myself that if I live by what will people say I will not live my life well. That is when I decided to do things which are good for me. My parents don't even know that I am sick; the only person who knows that I am sick is the lady I am staying with." (Thabo)*

Like Thabo, other men shared their reasons for their decisions to either disclose or not. The reasons ranged from fear of death, stigmatisation, to seeking social support. Nearly all the men interviewed had had AIDS-related deaths in their families. Most men had lost their wife or girlfriend, while others had lost close relatives, and with most of these deaths attributed to HIV and AIDS. Witnessing family members dying of an AIDS-related illness had some traumatic effect on the men, however this, somehow, spurred them to be bold and disclose their HIV status. The fear of dying indirectly worked positively for some men as they got

encouraged to disclose their HIV positive status and start ART. The following extract from Lungile, 38, is illustrative:

> *"I just told them [family] because I stay with my mother at home. I told my mother first and then she called my sisters that there is something I want to tell them. I disclosed everything and they were very supportive and they told me that I should accept and take my medication." (Lungile)*

The data suggest that the men chose to disclose their status mainly to people they felt they could trust and have open communication with, and draw moral support from. This is clearly illustrated in Kulekani's, 43, interview where he explained that he went with his sister to the clinic to fetch his HIV test results, and received immediate support from his sister when he disclosed his HIV positive status to her:

> *"…I was with my sister at the clinic but when they told me that I was HIV positive I was alone in the office. I said to her, I am positive. Through her support and also from the family they took care of me and told me that I am going to make it, I will get out of bed and walk again and go back to work." (Kulekani)*

While men like Kulekani reported positive outcomes from disclosing to their family members, some men reported that they were rejected by their families and communities after they disclosed or it was somehow known that they had HIV. For these men, the disclosure led to stigmatization and discrimination. While there was unanimity among the men on the importance of social support, some indicated that because of fear of stigma they did not disclose their HIV status to anyone hence unable to receive the needed social support.

Indeed, among those who disclosed, a number of men described how they faced stigma in different forms either at workplaces, within their communities or families. For instance, while Lungile got unwavering support from his mother, his siblings were not always supportive. He reported that they would, at times, say hurtful things to him. In his own words:

> *"They [siblings] would say bad things about me if we are having a fight or an argument and one would say 'leave me alone you who is HIV positive …get out of here you who have AIDS'. It hurts me a lot … These people disrespect you when they know that you are sick and when they do their things they put you aside." (Lungile)*

Dumiso, who in this sample had been on ART for the longest period noted how scary and difficult it had been for him to live openly with HIV, 12 years earlier. He described being discriminated against by his family members and said when that happened he felt isolated. He explained that:

> *"…by then [12 years ago] it was very scary and it was difficult to disclose your HIV status because people will say he is sick and there is no cure for that sickness. I had my own cup of tea, tea spoon and plate which were being used by me only." (Dumiso)*

Dumiso further described how he encountered stigma perpetuated by his friends in the community, noting that they belittled him instead of supporting him to live on. He posited:

> *"They [friends] said 'this one is dying' and by that they didn't motivate me or show some strength [did not encourage him] as friends and they didn't care so they were destroying me instead of building me you see."*

Similarly, in the extract to follow, Sipho,44, spoke of how some of his close friends disappointed him by spreading stigmatising rumours in the community about his late wife, he posited:

> *"…there was this man who passed away but stayed around where I live who was there at my wife's funeral and he heard the old man saying his daughter was killed by HIV and when we came back, he started telling everybody that Sipho's wife was killed by HIV and people started saying it means that he also has the HIV virus and by then I didn't know my status." (Sipho)*

4.7 Prioritising and valuing own life above all: Motivation to live

"*Impilo yam le*", "*Kebophelo baka bo*" [It's my life]! These words kept echoing in different forms throughout the interviews with the men. This conviction that "it's my life" became an important cornerstone to the men's long term adherence to ART. Noteworthy, coming out of the interviews was the determination by all the men to prioritise their lives, to live long despite the stigma they faced in their communities, and regardless of the side effects of the medicines they were taking. This is encapsulated in Dumiso' statement below expressing self-confidence to demand ART at the clinic:

"It is my right, it is my life and I have to know. Wanting them (ART) it is my right, I have to want my tablets and I have to get them and if you have a problem don't make it mine because I will go to the centre [clinic] manager and tell them that I have a problem, that department is refusing to give me medicine." (Dumiso)

Similarly, other men articulated a positive attitude towards life and noted that this contributed significantly towards their adherence to ART over a long period. They reported that they would sometimes request their friends to fetch ARVs for them at the clinic, if they had a competing commitment. Sipho's extract below is illustrative:

"…there is another one who stays at the same street and if I don't get a chance to go get my treatment I send him to the clinic to fetch my treatment and he is also HIV positive. In our street we are 5 or 6 with HIV. I don't care whether people know that I am HIV positive or not as long as I am taking my treatment and that's it." (Sipho)

For Dumiso, for him to fulfil his parenting role, as a single parent to his daughter, he first needed to priorities and take care of his own life by adhering to his treatment. He explained:

"That is when I put my foot down and said to myself I was brought up by a step mother and I don't want my baby to be brought up by a step mother. Her mother passed away and I told myself that I will see other ladies later but I should raise my daughter alone and she is 14 years old this year." (Dumiso)

4.7.1 Sickness and masculinities

The men in this study shared different experiences of living with HIV and accounts of enduring changes in their lifestyles. They described the challenges they encountered during the periods they were sick. They emphasised that, they were, in many instances, unable to carry out socially prescribed roles of men such as being strong and provide financially for their families. The inability by these men to carry out these roles affected their perceptions of their hegemonic position within their families. This sense of loss of power and control over their family and circumstances made them to feel unmanly, and be viewed as such by others in the community. Social expectations including the idea that a man should be independent and in control of his life and circumstances, challenged these men's masculinity when they were sick, as at times, they had to be cared for by others or depended on others for their living. For example, Khumalo, 40, noted during the interview that his life completely changed when he was sick. At the time when he was bedridden, he had to rely entirely on the support of his mother to take him to hospital and at times to fetch his medicines. He

further described how he felt disrespected and side-lined in the community because of his ill health. In his own words:

> *"My mother was the one who was bringing me on my wheelchair because I couldn't walk. Sometimes she used to go to fetch my medicine from the clinic…these people [community members] disrespect you when they know that you are sick and when they do their things they put you aside. In our location when they organise things for entertainment they don't tell me so I think it is because they know my status". (Khumalo)*

The discrimination he experienced from others in his community, which possibly emanated from a perception that he was infirm and weak and thus would not be able to fully participate in community activities, compounded with his dependence on his mother, seriously questioned his masculinity.

As is illustrated in-depth below, the men made decisions to adjust their lifestyles gradually shifting from activities they perceived were compromising and or harmful to their health.

4.7.2 Pathways to coping and adjusting to living with HIV

While it took the men varying timeframes to fully accept their HIV status, the readiness to and gradual acceptance of their HIV positive status seemed to have had positive psychological and health impacts on them. The acceptance of their status impelled them to adopt coping mechanisms in the wake of stigma and discrimination. Furthermore, to comply with the ART adherence requirements, the men had to adjust from their usual lifestyles perceived to symbolise the local hegemonic masculinity, characterised by having multiple girlfriends, partying with friends coupled with smoking and alcohol consumption. By implication, it can be argued that this was an important step in the men's pathway towards coping with their new life on ART.

Despite the challenges they faced, most men reported that they had to overcome the negative feelings and social and psychological effects of living with HIV to start living "positive lives". The acceptance of their HIV status, the passion to live a healthy life, and the desire to raise their children, stimulated them to start prioritising their lives above everything else. This caused them to consciously make adjustments to their lifestyles and adopt coping mechanism for survival.

A deeper analysis revealed mechanisms and factors that appeared to facilitate or hinder coping and adjustment to living with HIV for these men, and these included: social support systems, HIV support groups, workplace support, and lifestyle changes and challenges.

4.7.3 Social support systems

When the men were asked to share their experiences on whether and how social relationships and support systems have impacted their lives as men who live with HIV, they all acknowledged the importance of social support in their lives, describing how it enhanced ART adherence for them. The men reportedly received varied forms of support from members of their family and sometimes from their friends and workmates.

Khumalo, 40, recounted how his mother had been supportive especially at the time he was very sick. He explained:

> *"Since I was hospitalised my mother used to come visit me and she was the one who was comforting me and telling me that when I get discharged from hospital I should follow my treatment."*

Another participant Nthemba, 42, narrated how his whole family was supportive to the extent that his youngest eight-year-old son would remind him to take his medicines at a set time. On one particular evening, Nthemba took a nap and when Generations, a local soapie playing on SABC 1, started showing, the child remembered that it was time for the dad to take his medicines and reminded Nthemba to take his medication. While this may be an isolated case, it does illustrate the kind of support one would potentially receive once his HIV status is disclosed and communicated to family members. In his own words:

> *"… even the little one would tell me, 'dad its eight o'clock' or when Generations starts he would go fetch my tablet for me to drink." (Nthemba).*

Likhona, 56, described his current girlfriend, who is also HIV positive, as a pillar of support to his adherence to ART. He said their relationship was *"marvellous",* and that they always reminded each other to take medication, and would do so at the same time. He explained:

> *"…She told me that I can live a long life by taking my tablets and I can live more than ten years. (My) partner started drinking the tablets in 2005, so she is more experienced than me. She encourages me that we take the treatment together. We tell each other to eat and take the tablets. So our relationship is good." (Likhona)*

Similarly, Mpumelelo, 53, spoke of his experience of getting continued support from a nurse who was working at Stretford CHC. In his own words:

> *"She was working here as a TB sister, she was the one who would come to my place and tell me not to give up… and I ended up having hope that I have a long life ahead of me by the way she was telling me. She told me that I can live a long life by taking my tablets and I can live more than ten years." (Mpumelelo)*

4.7.4 HIV Support groups

Emphasising the importance of HIV support groups in linking and retaining men in care, several men said that once they were linked to an accessible health care system that also offered or encouraged participation in support groups; such linkage enhanced their drive and ability to continue seeking health care services. Some of the men who attended support groups reported that they felt empowered through the group. They said that being part of the support group made them know that they were not the only ones infected with HIV. This is best illustrated in Dumiso's extract to follow.

> *"… When we attend the clinic we get used to each other and become a family and we discuss about our lives and what we are doing and what problems do we have and some [people] are new and if they have side effects they first ask us and we discuss what's happening. It is another way of dealing with those tablets. We share everything and we know that we are in the same group having the same problem. We are part of the family and when we get to the clinic we smile because we are not sick as if we are dying." (Dumiso)*

In addition to this, some men reported that the clinic also provided supplementary food to the HIV support groups, such as vegetables. The provision of supplementary food for support group members by the clinic was seen by many men as a good incentive to go to the clinic. Dumiso explained:

> *"…When I came… (here), we were running a support group here at the same clinic. We had our own agricultural site in the clinic yard but it didn't make money… I was a pillar of strength in the same support group." (Dumiso)*

4.7.5 Workplace support

Support was also reportedly received from other institutions outside of the home and the clinic/support groups. Of all the three men who were in formal employment, when asked whether they had support from their workplaces, two said they had not disclosed their status at work, while Mpumelelo who had disclosed at his workplace received support from both the employers and his workmates. He was happy that his employers were readily able to accept a doctor's recommendation for him to do lighter work. Equally, he seemed comfortable with the support he was receiving from workmates. He stated that such a work environment was conducive for one to freely take treatment without worrying about stigmatisation.

> *"Where I work they never treated me like I was sick or something, they treated me like any other person but they didn't want me to work on heavy things. They always gave me something light to do because the doctor told them that I shouldn't work heavily and they were very supportive because they took me to their doctor to make sure that the clinic was telling the truth." (Mpumelelo)*

4.7.6 Lifestyle changes and challenges

The majority of men said it became inevitable for them to change their lifestyles in order to comply with treatment requirements. The men had to make deliberate and calculated lifestyle changes in order to take care of their health, in light of their HIV status and being on lifelong ART. These lifestyle changes translated into men drastically reducing their smoking and alcohol use, or quitting, in order to focus on taking their treatment correctly.

The data analysis suggests that these decisions were mainly influenced by the counselling classes that the men underwent at the clinic after testing positive. During interviews, some participants talked about harm reduction strategies such as reduction in alcohol and smoking strategies as having formed part of the on-going counselling sessions they attended at the clinic offered by health care workers. This was further enhanced through the support group meetings.

This was summed up by 44-year-old Nkosinathi, who said:

> *"I told myself that now that I am going to drink tablets for the rest of my life that means I can't drink tablets and use alcohol and I decided to quit alcohol and smoking. I used to drink and smoke but I have stopped everything and now I am concentrating on my life so I must take the tablets." (Nkhosinathi)*

Another man reportedly took steps to reduce his alcohol intake. Sipho, 44, stopped smoking and changed from drinking beer to one bottle of wine a month with the belief that this was less harmful to his health. He explained:

> *"…I quit smoking and drinking but I do drink red wine after a very long time, when we go to buy grocery I also buy a bottle of red wine even if it is these cheap wines as long as it is red." (Sipho)*

In another display of lifestyle change, Likhona reported how he had dramatically changed his lifestyle and reduced alcohol consumption to accommodate his now routine schedule of taking ART. In his own words:

> *"…I have made changes in my life, like beer and entertainment. I used to get paid and collect friends and go partying because I have a car. Now that I am sick I have to put all my friends behind me and face the challenges of my life...now I do drink alcohol but I don't drink too much… I only take two and it is enough then I go home and sleep so that I can give the tablet enough time to work." (Likhona)*

4.8 Heath seeking: Access to Health Care services

It should be noted that while men do seek health care from various spheres including traditional providers, men in this study were not asked to share their experiences with alternative sources of health care. Most men shared positive experiences with health care services, describing how these services impacted on their treatment and care outcomes. These men extolled the health facility staff as generally displaying a positive attitude towards the patients, and that the services rendered at the clinic were equally virtuous. Dumiso's extract is explanatory:

> *"…these women (nurses) are very good and they have improved in terms of rendering services because at first you could sit the whole day …but now, the service is so good … I can't change from this clinic." (Dumiso)*

The positive attitude of health care workers, described by some men, seem to have encouraged them to continue seeking care at the health facility; and this facilitates good linkage and retention in the HIV continuum of care.

On the other hand, Likhona, while acknowledging the good services rendered by the clinic overall, still expressed some reservations on bad attitudes of some nurses. He noted that

such bad attitudes are not good for patients. These sentiments implied that bad-health-care workers' attitudes could keep men away from the clinic which could in turn result in treatment non-adherence for them. He explained:

> *"…Some nurses are good because they know what they came here [clinic] for. But some of them are not good, when you ask for anything they are always in a bad mood and they will give you a bad answer. This is not good for patients." (Likhona)*

4.8.1 ART stock availability

In terms of medicine stock availability, all the men said there was never a time when they were returned home without being given their ART medication. Some alluded though to a time when there was delayed delivery of medicines to the clinic, but still the nursing staff managed to ration the available stock of medicines to ensure everyone got some replenishment. Instead of giving every patient their normal three months' supply, they were given a month's supply, until the situation normalised. Likhona, 43, and Kulekani,39, had this to say:

> *"…maybe there can only be a shortage because we used to get for three months and if there is a shortage they will give one pack each for one month." (Likhona)*

> *"…ever since I started taking treatment here I always get it, except I think it was the year 2007 or 2009 there was a strike for the nurses and that is when I turned at the gate but I still hard more tablets but it didn't affect me that much." (Kulekani)*

The predictable availability of stock at the clinic at all times appeared to have been an important factor in retaining these men in HIV continuum of care, for a long time. The mere fact that all the men attested to have never been returned home without medicines for the entire period they have been on ART emphasise the critical role played by ART availability in retaining patients, like these men, in care.

4.8.2 Health care facilities

The majority of men reported that other than the long waiting times when collecting patient cards, they were generally satisfied with the health care facilities. They lauded all other departments within the clinic (e.g. pharmacy) as being efficient in their work. Thirty-eight-year old Bheka said:

"…sometimes they used to tell us to go fetch the ARVs at the chemist but now they put them where they are working; if they don't have it they will go to the chemist and get them and give to you." (Bheka)

In an effort to curb stigma at one health facility, Bheka described how the clinic management decided to abandon the practice whereby HIV positive patients had their own section, separate from other general patients. He stated that this decision was welcomed by PLHIV at the clinic, noting that the previous arrangement was a source of stigmatisation for them. Bheka's extract below is illustrative:

"…When I started coming here to get my treatment there was separation, we who are coming for ARVs we had our own special place and the others who are just sick had their own place but now we are all at the same place and we have the same green cards. Back then everybody could see clearly that that one is HIV positive by going to our special place. I like it now." (Bheka)

Further analysis suggests that the practice of separating HIV patients from other patients at the clinic had a potential to keep men away from the clinic, resulting in them being lost in the treatment cascade and defaulting in their treatment.

Bheka, while acknowledging improved HIV care services at the clinic, still felt that some further improvements were still needed from a human resource perspective to increase the number of doctors at the facility. Concurring with Bheka, other men noted this as a general challenge with most local community health centres.

4.8.3 Health care facility: Male user friendliness

Almost all the men interviewed, except one, said that the health care facilities in which they received care were very user friendly and that they did not mind being attended to by female nurses, noting that the female nurses were merely doing their jobs.

"I feel open because I can talk to the doctor or a female nurse (sister). I can share with them because male nurses are hard to find in the clinic but nowadays I do see them a bit but this side more [nurses] are women." (Lungile)

The one man who said he felt uncomfortable to be attended to by female nurses wished the clinic could employ more male nurses who can attend to male patients. This discomfort can perhaps be explained from documented hegemonic notions of masculinity that emphasize

men's superiority to women, with implication that men don't want to be seen by women as vulnerable, unhealthy, and sick (21, 71). The extract from Bheka's interview below provides support to this literature.

> *"…I don't feel alright because this department is full of women, no men. So I would like it if the government could do something about this by bringing the male nurses because most of them are women and women are short tempered when you talk to them they get angry fast." (Bheka)*

Bheka's sentiments can be construed to be emphasising the need and importance of men friendly clinics or centres where men like Bheka would feel comfortable to seek health services.

4.8.4 Ill-health, ARV side effects & treatment adherence

The majority of men in this study reported having been sick, from time to time, prior to initiating ART, emphasising how ART had improved their health. However, some men reported experiencing adverse side effects such as dizziness, blackouts, and stomachs aches after commencement of ART. The side effects were mainly reported with the first regimen; and the men (12 of them) who were later switched to a fixed dose combination (FDC) did not report any adverse side effects.

Consistent adherence to ART is important in the management of HIV. In this research, most men signalled the importance of adhering to their ART, and cited various reasons for their motivation to adhere to it. For some, it was after seeing their HIV positive friends whose health had deteriorated because they did not adhere to their medication.

Based on their diverse experiences, men stated that defaulting on medication would have brought dire consequences to their health. Thirty-seven-year-old Pule, who had been on ART for seven years, explained how a person who quits taking treatment would develop resistance and may end up dying. He further described how he feels ART had become a part of his daily life.

> *"…this treatment is playing a big role in our body as much as controlling our lives because I can now say it is a natural source now in my body because I take it as my friend, where ever I go I carry it. It is like a cell phone on another hand because you can't go anywhere without your cell phone because you know you will need it anywhere anytime." (Pule)*

Similarly, fifty-one-year-old Phenethi explained how from 2007 he had been adhering to his treatment. In his own words:

> *"…it is a huge experience because you are a person who is now living on a tablet and in fact I can say this pill is controlling your life and you know that your life is based on God and this tablet." (Phenethi).*

Also, Bheka shared how he valued taking his medication without worrying about what people would say. He posited:

> *"…now I take the ARVs just like a pain killer. I am no longer scared of anyone, when I come to the clinic to get my treatment I do so without thinking of what other people will say. I no longer have a problem with anyone. If I don't drink it, I feel like I had killed someone." (Bheka)*

All the men reported that they underwent the pre and post-test counselling sessions in basic HIV, which also emphasised the importance of adhering to medicines. With this counselling, men's knowledge about HIV, AIDS, and ART improved. For example, one participant, *Khumalo,* affirmed that, after he was diagnosed with HIV, he was advised to attend counselling classes to learn more about HIV and how to deal with the condition. He explained:

> *"They told me that I should attend the counselling classes and that they would teach me how to deal with this [HIV] and I will be well again. In the classes, we were being taught about HIV."* (Khumalo)

Further, the realisation and knowledge gained from counselling classes that one can actually die of AIDS somehow motivated the men to continue to adhere to treatment. Bheka explained this further:

> *"…This disease kills if you don't follow the rules which you are told. You are not allowed to skip a day without taking your medication. You don't have to wait to get so sick then think of taking the ARVs. You must take your ARVs at a specific time. Even if you skip a day without taking the ARVs you must make sure that you take them the following day." (Bheka)*

Likewise, Dumiso emphasised the significance of the information he obtained from the counselling process. He reported how the nurses informed him of the need to adhere to prescribed time schedules for taking his treatment. As evident in his extract below, Dumiso adhered to the advice he was given. In his own words:

> *"They gave me the ARVs and they told me that it is a life time thing and I should take them my whole life without skipping and I should keep track of the time and that is when I will see the changes and up until today as I am talking to you now I have seen the changes due to ARVs, they are good to me." (Dumiso)*

Similarly, Thabo, who had once defaulted on taking his ART, reported on the side effects he experienced during the period he defaulted, which led him to be enrolled on a different ART regimen. This experience had made him appreciate the importance of adhering to treatment.

> *"I used to work at night and when I was working I could feel very hot and my temperature was very high after two hours of taking the tablets. So I was thinking it was the tablets which made me feel like that. [but now] as I am speaking to you I am ok and I have no stress. I have changed my dosage, I used to take Regimen 1 and then I defaulted for some time and that is when they changed me to Regimen 2 …I am ok and thanks to the support from the pills I am taking…" (Thabo)*

Some men explained how they shared their ARVs with other family members who were also on ART in order to not miss taking the treatment. This sharing of ARVs in this context underscores the importance the men attached to ART adherence. Dumiso posited:

> *"if I go to Soweto and I have forgotten my tablets for sure I will get tablets from my brothers at home even if they come to my place they do get the tablets from me because if you look at our tablets, they give me 28 tablets which is equivalent to 28 days." (Dumiso).*

Also, Bheka accentuated the importance of adhering to ART irrespective of where he is:

> *"…I don't skip taking my medication even if I am in my car I make sure that I have water in the car." (Bheka)*

Such bold determination on having to adhere to ART at all costs signals the men's confidence on the treatment they are taking in helping them to remain healthy. It indicates, to

some extent, the success of counselling programmes that emphasise the need to adhere to treatment to avoid side effects or development of drug resistance in their bodies.

4.9 Exposure to ART regimens and adherence over time

All the men reported that they were first initiated on first line regimen where they took two or three tablets a day at different time sets. At the time of the interviews, all but two men had switched to the FDC tablet. Patients on the FCD tablet only take one tablet a day. The men who were on the FCD tablet expounded the benefits of being switched to the fixed dose tablet. Many of them spoke about improved adherence with a single tablet because they take it once a day which lessened chances of defaulting, as was the case when they were taking three tablets a day at different times. This reported benefit is reflected in the extracts below.

> *"...this time around we no longer take three tablets, we take one a day. When I was taking those two tablets I was always dizzy after taking the tablets but now I am used to this one tablet… so the difference is that three is too much and if you take them without eating then you will feel dizzy and be very weak and feel like sleeping." (Likhona)*

> *"…one dosage is very good because you take it once unlike those other ones, they were too much and I used to take them in the morning and in the evening." (Kulekani).*

Another men, Thabo, explained how he had progressed from taking six tablets a day to just a single one. For Thabo, he saw being switched to one tablet as a relief from the burden of consuming many tablets, and having to strictly take them at specific times of the day. In his own words:

> *"I was taking 6 tablets, 3 in the morning at 9am and 3 in the evening at 9 pm but now I am taking only 1 tablet at 9pm."*

The data presented above clearly show how determined the men were to stay alive by adhering to their prescribed medical regimens. Furthermore, it highlight the critical role social support from families, other HIV positive men in the support groups, workmates, and others in the community played in enhancing ART adherence for men in this study. Last, these data demonstrate how the FDC tablet taken once a day seems to have helped the men in this study to improve their adherence to treatment.

4.10 Chapter summary

In this chapter, findings on men's experiences of what it means to live with HIV and subsequently being on treatment for a long time (five or more years) were presented. These findings gave insights on the psycho-social challenges men endured brought about by their living with HIV. Perhaps more importantly, these findings showed how men resolved to live and enjoy life despite the psycho-social challenges they had encountered. Though shared individually, these men's experiences put collectively, give important insights of how self-determination can transcend societal definitions of what it means to be a man, and how notions of masculinities may influence men's experiences of living with HIV, how men cope and adjust to living with HIV, and highlight the psycho-social factors that enhance adherence to ART over a long period of time.

CHAPTER FIVE

5. Discussions and Conclusions

5.1 Introduction

This chapter discusses the findings in the context of existing literature, and attempts to interpret the findings and their relevance and implications for linking and retaining HIV positive men in the HIV continuum of care in South Africa. The conclusion is later made based on the key points of discussion, and recommendations are suggested for programmes on how to retain men who are living with HIV in care. Areas for future research on this topic are suggested.

5.2 Social demographic context of participants

All the participants in this study were residing in the Orange Farm vicinity at the time of the study. Orange Farm, as a location, appears to be a relevant site for HIV research as the Stretford CHC which caters for this community has a dedicated HIV section with high volume of HIV patients. The study participants were black African adult men who had been living with HIV and on ART for a long time, thus providing a good sample to learn about the effects of long-term use of ART. Most men in the sample were partnered, and some had lost their partners to AIDS. The socioeconomic conditions of the men were rather poor as most had lower levels of education, and very few were formally employed. Studies suggest that there are connections between high risk of HIV infection and lower levels of education (97, 98), and another body of research has shown that living in informal settlements in urban areas is associated with higher risk of contracting HIV ((9, 10). However, since this was a qualitative study, conclusions about the association between the men's educational status and their HIV status cannot be drawn.

5.3 Reactions to HIV diagnosis

Findings suggest that men in this sample reacted differently to a positive HIV diagnosis. At the time of testing their initial reaction included shock, disbelief, despair and a sense of uncertainty about their future. Comparable initial reactions to a positive HIV diagnosis are reported by Sieff and colleagues (99). These authors suggested that initial negative reactions dissipate after a while. My study has also shown similar results in which the majority of men gradually transitioned from their initial negative reactions to accepting their positive HIV status and started taking ART, and made strong claims of adherence to the treatment. This acceptance of status also led some men to disclose their status to carefully selected people. This transitioning process did not occur in a vacuum, rather, it was

influenced by a number of factors, including support from friends and family, counselling sessions and the conviction about the value of one's life. Equally important in this transitioning period was the men's abilities to adjust their lifestyles and adopt healthy lifestyles such as reduction in alcohol intake and health seeking as demonstrated by their regular visitation to health facility to collect their medicine refills. The men's coping and adjusting process is akin to what Connell and co-authors (2005) argued on the dynamism of masculinities, that masculinities are not static but are constantly being reconstructed as circumstances of men evolve.

While in the present study the men's initial reaction could be paralleled with Sikweyiya and colleagues' argument that having HIV could be self-interpreted by the man as losing his masculinity and control of his life and circumstances (21), men in this study appear to have managed to overcome this sense of loss. Instead they used their HIV positive diagnosis as an avenue and opportunity to reconstruct new masculinities (71) that suited their need to adhere to ART.

5.4 Blaming discourse

The findings of this study point to a blaming discourse on acquisition of HIV. Although the blaming discourse was not inquired in the interviews, it featured in the men's accounts. It was interesting to note in the data how the blaming discourse tended to be gendered where men did not want to take responsibility for being infected with HIV, rather accused their female partners as being responsible for their infection.

This finding is consistent with Shisana and Simbayi's view that from a cultural perspective men often do not get blamed for HIV transmission (10), rather such blame is often extended to women. Further to this, some men in this study held a strong view that their female partners were generally secretive about their HIV positive status, an indication that the female partners may have been the ones who infected them with HIV. Existing literature suggest that, in the context of HIV, the blaming discourse affects women's disclosure of their HIV positive status to male partners. For instance, Mamam and colleagues found women to be reluctant to disclose their status for fear of men's negative reactions to the disclosure such as possible violence, stigma and discrimination (100). Similarly, Medley and colleagues found a number of barriers to disclosure by women, among them fears of being accused of infidelity, violence, and rejection by family (96).

5.5 Psychosocial effects of living with HIV and implications for disclosure and social support

It has been shown in this study that negative psychosocial factors can adversely affect men who live with HIV, and their ability to disclose their positive serostatus or obtain social support. The findings presented clearly demonstrated that the majority of men expressed emotions that are consistent with depressive symptoms measured in the Beck Depression Inventory scale (101) namely, feelings of loneliness or sadness immediately following their diagnosis. These depressive symptoms have been shown in studies to have implications for treatment outcomes as evidenced by findings of a systematic review by Nakimuli-Mpungu and co-authors which showed that achieving adherence among people with depression was 55% lower than those without (102).

Mounting evidence suggests that HIV-related stigma, be it internal or external, exacerbates the psychosocial problems associated with having a positive HIV diagnosis (103). A study in South Africa suggested that self-stigma can lead to depression which would in turn compromise treatment outcomes (83). In addition, Skinner and Mfecane found that stigma '*drives HIV out of the public sight'* meaning that people who live with HIV would not disclose their status for fear of being stigmatised and thereby complicating prevention and treatment work (47). Fleming and co-authors (2016) argue that the possible combination of notions of masculinities and stigma hinders men from seeking care and treatment. They further postulate that men's fears of being perceived to be weak if found to be HIV positive were based on conflicts with the ideals of men being tough and strong (51). In line with these views, my study found that stigma encountered by men in their communities made it difficult for some of them to disclose their HIV status to anyone (104). This finding reflects that of other studies which have shown that due to fear of negative consequences, men often do not disclose their HIV status (21). By extension, the failure by some men to disclose their HIV status to anyone deprives them of the much needed social support.

Indeed, it has been shown in this study that some men were stigmatized and discriminated against by family members and others in their community after disclosing their HIV positive status to them, or were known or suspected to be HIV positive. This finding reflects those of many other studies conducted in various settings in Africa, which found that many of their participants were subjected to some form of discrimination upon disclosing their HIV positive status (83, 105). A further contribution of this study to existing literature is the confirmation that stigma can be mitigated by adequate social support (106), as it has been shown that family support from the men's immediate family - mothers or siblings impacted positively on their lives in terms of adherence to ART. This is paralleled by other research on the

importance of social support systems to combat stigma and discrimination so as to improve positive health outcomes for PLHIV (30, 107-109).

5.6 Prioritising and valuing own life above all: Motivation to live

The findings presented in this study have shown that almost all the men in the study sample reached a stage in their lives where they prioritised and valued their lives, as evidenced by their consistent claim that “Impilo yam le”, “Kebophelo baka bo” (it’s is my life), which demonstrated a strong will to continue living a productive life despite their positive HIV serostatus and challenges they encountered. The determination by these men to value their lives (43, 110), their conviction that “it’s my life”, and trust on the effectiveness of ART in improving health outcomes, appear to be an important cornerstone to their long-term adherence to ART. This finding can be likened to a Zimbabwean study in which Campbell and colleagues argued that treatment enables those on ART to gain confidence and rebuild their perceived lost social value (111). The idea of trying to regain the perceived lost social value gives impetus to men to regain their old-self and become productive members of their communities (112). Furthermore, this is parallel to Viitanen and Colvin’s (2015) postulation that men tend to ‘reframe health-seeking behaviour as a means to reclaiming independence and self-reliance’,(113). By extension, men’s determination to live a productive life by adhering to ART may be viewed as their own perspective of redefining masculinities. This is shown in the men’s adaptation of those masculine notions that are in keeping with the men’s positive serostatus (113). The sheer determination to live–on as a driving force to adhere to ART, is however subject for future exploration.

It has also been shown in this study that the men had at one point in time witnessed either a close friend or family member dying of AIDS-related illnesses. The men’s resolve to adhere to treatment may have partially been due to fear of dying, and this may have impelled them to adhere to ART as the key mechanism for survival (112).

Findings of this study have shown that most men came to know about their HIV positive status when they were already very sick, especially with TB, and being hospitalised. This finding is analogous to those of other studies in South Africa and elsewhere which documented cases of co-infections of TB and HIV (114-117). As shown in the previous chapter, only two of the 14 men voluntarily undertook an HIV test following deaths of their spouses, while the rest of the men were tested involuntarily. This is consistent with Courtenay’s (2000) argument that men are less likely to visit health care facilities compared to women (18). Other studies such as Galdas and colleagues also found evidence of poor health seeking by men in the USA and UK (118). This trend by men is further comparable to

studies in South Africa and Zimbabwe as demonstrated by Sikweyiya and colleagues and Skovdal and co-authors who argue that hegemonic masculinities which require that men should be seen to be in control, strong, resilient, and disease free tend to negatively influence men's health seeking behaviour (18, 19, 21, 118-120).

5.7 Pathways: Coping and adjusting to living with HIV

Accounts given by men in this study on how they accepted that they were sick, and prioritized their health more than anything else are in sharp contrast with the societal ideals that men have to be seen to be strong and in control (18, 73). By implication, when a man is seen visiting or frequenting a health facility for a health-related problem, he could be viewed as weak and diseased, attributes that are inconsistent with those of a "real man" in this setting (21).

However, ill-health among men in this study made them to change or adjust their lifestyles and adopt coping strategies to accommodate their treatment requirements (71). These changes were a shift from what was socially considered a common behaviour for "real men", including the need to demonstrate masculinity by drinking alcohol and engaging in excessive partying with friends, and risky sexual behaviours like having multiple concurrent sexual partners. Of interest to note, however, is the fact that most of the men did not completely stop drinking alcohol or smoking. They instead reduced these habits. This act of not completely stopping using these substances may symbolise, as Nkosi and co-authors argue, a level of complicity to the hegemonic masculinity circulating in this setting, as men in this study attempted to avoid being perceived by their friends as weak, and thus lose their access to the local form of hegemonic masculinity (121). This is also alluded to in Viitanen and Colvin's (2015) study that while avoiding some features of male identity that compromise their health, men still want to be seen to incorporate hegemonic ideals of being strong and in control of things (113).

The finding that some men were not concerned that they were known in their communities to be sick and receiving health care is inconsistent with the dominant ideals of hegemonic masculinity in South Africa. Extant literature on masculinities suggests that men do not want to be seen as sick, weak, and infirm (17, 21, 71, 120), yet men in this study clearly broke with this notion of masculinity, rather were determined to overcome their ill-health even if that would put their masculinity into question. The finding that the men in this study adjusted their life styles, with others disclosing their status to families, belonging to support groups and engaged in on-going counselling correlates with other research on the coping strategies used by people living with HIV in five African countries (122). Among the self-

taught strategies cited were 'changing behaviour, joining a support or social group, disclosing one's HIV status, getting counselling, helping others to cope with the illness, and educating others' (122).

In this study, as also shown above, the men either completely quit smoking or drinking beer or significantly cut down on these habits as a strategy to enhance their treatment adherence. This tallies well with health promotion messages that people on ART need to lessen consumption of alcohol in order to better adhere to their treatment regimen (123).

To support their coping and adjustment process, men underwent several counselling phases similar to those proposed by the NDoH guidelines and McNair and ElSadr's continuum of care framework (5, 38).The men in this study underwent different stages of on-going care at health facilities supported by families, communities and joining support groups. I posit that, the coping mechanisms adopted by the men in the study also depended on individual person's willingness and decision to accept the HIV positive diagnosis, accept to be counseled and to finally accept being on life-long treatment and adhere to it (38)

Another pathway to coping and adjusting to living with HIV was the men's reconfiguration of their masculinities. Findings in this study showed that men weighed the seriousness of HIV in relation to the importance of attaining the much valorised hegemonic masculinity in this setting, and survival became prime for them. As such, men chose to risk attaining the local version of hegemonic masculinity, and adjusted their lifestyles in order to live a healthy life. Furthermore, the fear of dying (124) appeared to have also prevailed over the men's desire to attain the hegemonic masculinity, thereby enabling them to adhere to their medications.

Moreover, social support did not only appear to be a critical pathway to coping and adjustment for men in this study, but was particularly important for their long term adherence to ART (125). It has been shown in this study that some men who disclosed their HIV positive serostatus to others received continued support from their families, communities and at workplaces (109, 125); and a deeper analysis suggested that this support was an important pathway to coping and adjusting to living with HIV for these men. The disclosure process appeared to have lessened feelings of stigma leading to these men being able to share their health challenges with others, and able to send friends to collect their medicines from the clinic. This finding provides support to mounting evidence which suggests that there tends to be improved ART adherence following disclosure of HIV status and subsequent social support networks (109, 126, 127).

5.8 Health seeking: Access to Health Care services

It has been demonstrated in the previous chapter that easy access to health care facilities is important for men's health seeking behaviours. In addition, the continuous availability of ART stock at the health facilities had a positive impact on men's willingness to visit health facilities to get their monthly ART supplies (128). Easy access to the health care facilities by men in this study appeared to have eliminated the structural and socio-economic barriers cited in other studies on ART adherence. Challenges such as long distances to health facilities which translate into high costs of transportation are barriers to ART adherence (112, 129-131). One can argue therefore that, easy access and predictable availability of ART can enhance long-term adherence to ART for men and their retention in care, as shown in this study. Notwithstanding this, men in this study mentioned several barriers to health seeking. Some of the barriers cited by men included the fact that their unemployed status posed a challenge to having enough food before taking medicines. As stated earlier, only three of the 14 participants were in steady formal employment at the time of the interviews.

Further, the men raised the issue of judgemental attitudes from health staff and being attended to by female nurses as another barrier. Literature suggests that these barriers influence how men access and remain linked in HIV care (19).

In this study, it has been shown that there were men, albeit few, who had reservations on being attended to by a female nurse. This finding is analogous to existing literature which suggests that men shun and may stay away from health care facilities because they do not want to be attended to by female nurses, some of whom they found to be rude or judgmental (19). While this may be the case, this finding cannot be emphasised in this study as most men were not bothered by being attended to by a female nurse. Rather, what can be accentuated is how the determination to live impelled the men to seek health care regardless of the gender of the person rendering it.

This study has shown that the men continuously realigned their masculine identities to meet their health needs and cope with their treatment. This finding is comparable to Nkosi and co-authors' argument that men who are living with HIV may engage in a process of constant shifts in masculine positions in order to be able to adhere to ART, while also publicly maintaining the attributes linked to hegemonic masculinities such as being strong and in control of their circumstances (121). I posit that by adhering to ART, men in this study, in line with Nkosi and co-authors' argument, repositioned themselves with their HIV status and maintained and expressed notions of being strong, resilient and not vulnerable by adhering to ART(121).

Connell's postulation for recognition of this dynamism with 'dominant forms of masculinities' being constantly influenced by 'subordinated' ones is informative in this case (71). The experiences of most men in this study of not caring about the gender of the nurse treating them, point to the embodiment of these 'subordinated' masculinities. Men were less bothered to be perceived as weak and or in loss of control as long as they could take their treatment and remain healthy. In quintessence, these men embodied the fluidity of masculinities. And this is in line with the argument that masculinities are fluid and dynamic (71), and are amenable to change to suit certain situations or conditions (132).

5.9 Exposure to ART regimens and adherence

To achieve successful viral load suppression, and for patients to accrue positive health outcomes, adherence to ART is very important (110, 133). With the introduction of a FDC pill for ART in South Africa, almost all men in this study were switched into the single tablet a day; and they reported that it improved their ART adherence, compared to the time they were taking several pills a day. This finding is in line with a mediline research in America indicating a decreased risk of non-compliance with the use of an FDC pill (134). Connor and colleagues' systematic review also reported improved adherence to medication with FDC (135). Equally, research in the US focusing on FDC tablets for communicable diseases, blood pressure lowering medications and diabetes has shown that switching patients from two tablets a day to a fixed dose single tablet a day significantly improved adherence and patient satisfaction with therapy (35). While this finding is essential, further targeted quantitative studies are needed to confirm this finding in South Africa.

5.10 Applying a theoretical framework

In an attempt to comprehend the narratives of the men in this study, I drew upon the Health Belief model (HBM) as a framework to assist in understanding how the men managed to stay on ART for such a long time despite the stigma and discrimination they reportedly encountered (66). The HBM constructs suggest that people's decisions to undertake any health related action is dependent on their belief that by taking such action they are likely to avoid a negative health condition and belief that they can successfully abide by recommended health actions (66, 67). While the HBM is applied often to primary preventive health promotion, it can also be applied to behaviours of people that may already be sick (136). In this case, men in this study had already been diagnosed with HIV, as such the HBM model is applied to help explain adherence issues with recommended treatment regimens (124, 136, 137).

The HBM is premised on four main constructs: perceived susceptibility, perceived severity, perceived barriers, and perceived benefits (66, 67). The constructs can be summed up as constituting perceived threats on one hand and perceived benefits on the hand. The individual person's decisions to relate to a given health situation is influenced by perceived threats and benefits of undertaking that action. Additional concepts of cues to action and self-efficacy provide further basis of understanding people's behaviours (67).

The HBM has been explored to help elucidate the experiences of the men interviewed in this study. The choice of the HBM was motivated by its reported wide usage as one of the behavioural frameworks that can assist in envisaging people's behaviours (57). In this study, principles of the HBM were applied retrospectively through the men's experiences in an attempt to understand men's beliefs and subsequent actions related to ART adherence. This is elaborated further below:

5.10.1 Perceived susceptibility:

Men in this study had already been diagnosed with HIV, consequently perceived susceptibility as a construct has been applied retrospectively to explain how men got to test and their reaction to positive HIV diagnoses. The findings suggest that the men's testing for HIV under duress, due to ill-health or death of a sexual partner to a suspected AIDS-related illness, and the subsequent reactions of shock and disbelief to their HIV positive diagnosis , illuminates, first, the fear and stigma associated with knowing one's status; and to some extent the idea that these men had appraised their chances of contracting HIV as very low. This has something to do with risk taking and interpretations of the gravity of those risks by men. (66). This can also be explained through beliefs that hegemonic notions of masculinity cannot be associated with illness in the first place (21, 71).

5.10.2 Perceived severity:

As the men gradually accepted their diagnosis, it appears that they started to realize the seriousness of being diagnosed with HIV, and the potential consequences if they did not adhere to the recommended medical regimen. Findings show that a number of men in this study had at one time been hospitalized and or had witnessed either family members or close friends dying from a HIV-related illness. These events seem to have further ingrained in their minds the seriousness of HIV and AIDS if one was not on treatment or defaulted his treatment. The severity of the problem seems to have been reinforced by the health care workers during counseling sessions. The men were able to recall counseling sessions where it was emphasized that consistent adherence to treatment was very important to avoid negative health outcomes, and they reportedly complied with the suggestions (66). However,

despite all the counseling, consistent compliance was found to be challenging by one of the men in the study who admitted having defaulted on his treatment. In this case, his perception of severity at the time of defaulting appeared to have been different to that of other men who self-reported to not have defaulted. However, by implication, when he fell ill again, and re-enrolled on ART, there may have been re-assessment of the severity of HIV and consequences of non-compliance with treatment requirements.

5.10.3 Perceived benefits:

Perceived benefits manifested themselves in the apparent determination men made to overcome the psycho-social barriers they faced, and lead a healthy lifestyle. The men adjusted their lifestyles to accommodate their new HIV status, and to adhere to ART. This perceived benefit coupled with social support systems proved attainable if men's reported submission to the health care providers' advice about how to take their medication and how they continued to exhibit positive health seeking practices (66).

Health care workers during counselling sessions reportedly motivated the men and accentuated to them the positive benefits of adhering to ART and maintaining a healthy lifestyle. This life style included stopping or minimising harmful practices as alcohol consumption and smoking. To be healthy was perceived to be a benefit by men. The importance of counselling is documented by other research work (138-141). It has been postulated that the more ART becomes available to more people, especially with the test and treat recommendations, the need to improve access to counselling services becomes even more important (141).

5.10.4 Perceived barriers:

Among the many perceived barriers to ART adherence, the men highlighted stigma and HIV status disclosure, medication side effects, patient relationship factors as barriers to ART adherence for them (142, 143). Poor social support systems were equally cited as having adversely affected the heath seeking behaviours of the men in this study (83, 109).

5.10.5 Self-Efficacy

Self-efficacy as a concept can be perceived to relate to abilities to execute specific actions in particular situations (144). In this study, men exhibited different self-efficacy actions ranging from disclosure and or a lack of it, to adherence to ART (145, 146). Disclosure of one's HIV status is not considering the prevailing stigmatization and discrimination of PLHIV in this setting, therefore, it can be argued that those men who disclosed their HIV status displayed self-efficacy. Also, it may be argued that those who chose not to disclose their HIV positive status but accessed health care still demonstrated their self – efficacy in a different way through help seeking from health facilities and adherence to treatment. The open

determination by the men to live health lives can also be read as an affirmation of the confidence they had to take care of themselves by adhering to treatment and adjusting their lifestyles.

5.11 Conclusions

The study presented evidence affirming that men are often reluctant to seek health care, and that they only do so when already very ill. Notwithstanding this, the study also confirmed that men are capable of coping and adjusting to living with HIV and adhering to life-long treatment. Linked to this is an interesting finding relating to the determination exhibited by all the men to live a healthy and productive life. The study showed how the men were able to adjust from their harmful lifestyle practices or harmful notions of masculinities after initiation of ART to a masculinity that allowed them to care for their health (121).

Using the health belief model, it has been shown in this study that men were largely driven to undertake actions that they perceived to be beneficial in prolonging their lives. Their long-term adherence to ART was meant to avoid negative consequences such as developing resistance to ARVs; side effects or death.

Evidence presented in this research report further indicate that men were largely not concerned about the gender of the nurse attending to them as long as they would obtain the care they needed. This emphasises the fact that these men were determined to improve their health even if that meant defying hegemonic norms of masculinities.

This study has made a very important finding related to the recently introduced FDC in South Africa. It was shown in this study that the FDC enhanced the men's abilities to consistently adhere to ART as it was taken once a day.

5.12 Recommendations

- Future interventions and programming for men living with HIV in South Africa should focus on individual men's inner determination to live a healthy and productive life, as this present a window of opportunity to intervene by assisting men to change risky behaviours. This can be done through enhancement of men's self-efficacy in health seeking behaviours. However, this requires further large scale investigation to inform future HIV programming for men. The focus on programming should highlight more the benefits that individual men would accrue from adhering to ART. Benefits such as involving men in HIV peer education activities reposition men as leaders, as strong and in control of their lives and circumstances, should be emphasised.

- Interventions in men's health seeking behaviours should scale up social support programmes such as sensitising communities to stop stigmatising PLHIV, and further strengthen collaboration between community-based support groups and health facilities to enhance men's linkage to and retention in the HIV continuum of care.
- Interventions in men's health seeking behaviours should scale up social support programmes to sensitise communities about the need to support PLHIV, and the effects of stigma on the lives of PLHIV. Furthermore, interventions need to strengthen collaboration between community-based support groups and health facilities to enhance men's linkage to and retention in the HIV continuum of care (106-109).
- The stigma reduction strategies are important mechanisms to support men's HIV positive status disclosures which translate to obtaining support from their partners, families and community, and enhance treatment adherence.
- Programmes targeted at men should also emphasise broadcasting positive inspiring public health messages for men to seek health and remain in care.
- Continuous HIV counselling is critical to ensure that men are linked and retained in the HIV continuum of care.
- Ensuring constant stock availability at the health facilities would encourage men to visit facilities for refills.
- Regular health care staff trainings to strengthen good work attitudes towards clients would encourage men to continue to visit the facility knowing they would be treated with dignity and respect.

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7. Appendices

Appendix 1. Plagiarism Declaration Report



PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS
SENATE PLAGIARISM POLICY: APPENDIX ONE

I **Bright Phiri** (Student number**: 427180**) am a student registered for the degree of **Master of Public Health** in the academic year 2017.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: **Bright Phiri** Date**: 28 March 2017.**

Appendix 2: Information Sheet

PARTICIPANT INFORMATION AND CONSENT DOCUMENT FOR ADULT MALES PARTICIPANTS IN A ONE-ON-ONE INDEPTH INTERVIEWS FOR A RESEARCH PROJECT

Self-introduction

Hello, my name is Bright Phiri, I am a student at the University of the Witwatersrand (Wits). I am studying towards a Masters in Public Health degree, and as part of the course requirement, I am conducting a study to understand adult men's experiences of long term HIV care and treatment services in Johannesburg, South Africa.

Invitation to participate

I am inviting you to be part of this study. This information leaflet will help you to decide whether you want to participate in this study or not. Before you agree to this, you should fully understand what is involved in this study. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the researcher.

What is involved in this study?

If you agree to participate in this study, you will be asked to have an interview with the researcher. The interview will be a conversation between you and the researcher where you will be asked to share your experiences of living with HIV, HIV care, and treatment services in Johannesburg. A total of 20 men will be interviewed in this study. You will be interviewed only once in this study, and the interview will take about an hour to complete. If you give permission, the interview will be audio (tape) recorded in order to record all the information you share during the interview.

Will any Procedures Result in Discomfort of Inconvenience?

Some of the questions asked in the interview may make you sad or uncomfortable. If this happens, please feel free not to answer any question that you are not comfortable with. And remember that you are still free to withdraw from the study at any time even during interview. There will be no negative consequences or criticism if you wish not to answer questions or withdraw from the study. Your withdrawal in this study will not affect your care at this clinic or your relationship with the clinic or the researchers. If during the course of the study you find information that disturbs you emotionally, please inform the researchers. With your consent, you will be referred to a professional counselor at the Stretford clinic.

Are there any Risks for me?

There is a risk that people who participate in this study may be known by others as people who are living with HIV and be stigmatized. However, we will try to minimize the risk of this happening by not telling anyone who is not involved in this study what the research is about. Also, we will conduct our interviews in a private place where only you and the researcher(s) will be present.

Possible Benefits of this study.

There are no direct benefits for you in participating in this study. But we hope that the information you will share with us will lead to future improvements in care for men living with HIV in South Africa.

Reimbursement

Your participation in this study is voluntary; and we will reimburse you for your time and taxi fare totaling R150 for purposes of participating in the study. We will also provide a drink and snack after the interview. You will be given the money at the end of the interview.

Confidentiality

The interview will be on a one-on-one basis with the researcher, except in instances where the researcher needs an interpreter, who will be the research assistant who is part of this study. The interviews will be held in a safe and quiet place where others will not have access during the interview. All the information that you share with the researcher will be kept confidential. Only study staff will be able to access the audio tapes as they will only be available to the researchers and will be kept safe and locked up and not shared with others. These tapes will be kept for two years, thereafter they will be destroyed.

Your name and other personal information **will not be** linked to your comments. We will ask you to pick a name other than your own to call you by. Therefore the information written into a report or reported to scientific journals will not include any personal information that can identify you or anyone else as a participant in this research.

Before we write the results of this study, we will ensure that your names and any other thing that would identify you as a participant in this study are removed. So the information that may be written into a report or reported to scientific journals will not include any personal information that can identify you as a participant in this research.

Has the study received ethical approval?

This study has been approved by the University of the Witwatersrand, Faculty of Health Sciences Human Research Ethics Committee (HREC). Additional to this, permission to

conduct this study at Stretford CHC has been granted by the Gauteng province Department of Health and Stretford CHC management. The ethics committee will continue to see if this study is being done in a safe way until the study is completed. I have a copy of the approval letter from the ethics committee that shows that the study was approved by them, and I can give it to you if you wish to have one.

Further information

If you require any further information or have any questions/complaints on the study please contact the HREC administrator or Chair.

Contact details of HREC administrator and chair – for reporting of complaints / problems.
Tel: 011-717-2700

Also, if you have other questions about this research, you are welcome to contact the researcher [Bright Phiri] at this number: 071 423 2949 or his study supervisors:

- Yandisa Sikweyiya, Tel: 012 339 8619; Email: yandisa.sikweyiya@mrc.ac.za
- Nwabisa Shai. Tel: 012 339 8529; Email: nwabisa.Shai@mrc.ac.za

Appendix 3. Interview guide

INTERVIEW GUIDE

Adult men's experiences of long term HIV care and treatment services in Johannesburg, South Africa

Date of interview: …….

Question 1: Demographic information

A Participant pseudo name

B Age

C Marital status

D Educational level

E Years on ARTs

- **Psychosocial**

Q2. In general, please share with me your experiences of living with HIV and being enrolled on ART for all these years

- Experience initial years
- Experience after long term
- Other general experiences

- **Health Care and treatment services**

Q3. Please explain your experiences with different health care services you have encountered as relates to your treatment and care

Probe on

- Clinic facilities
- ART stock availability
- Health care worker attitudes
- Health care facility male patient user friendliness

- **Exposure to different ART regimens**

Q4. Could you please explain to me your experiences with being exposed to different ARTs

- Explain the different ARTs regimens you been on
- Describe any side effects that you have experienced
- How has this affected your adherence

- **Ask about the single dosage (if on it, probe further the experiences compared to earlier regimens)**

➢ **Social Relationships**

Q5. Please describe your experiences in terms of being on ARTs and how it affects your relationship with

- your spouse,
- other family members
- and your friends in the community, at work etc

(probe further for the positives and negatives, adherence issues)

Q6. Any other additional experiences you would like to end with

Appendix 4: Consent Form

I agree to participate in the interview

Participant's name……..(Please print)

Participant's signature……Date……

PERSON OBTAINING CONSENT

I have fully explained everything about the research to the participant and am satisfied that the participant demonstrated understanding of the research and is giving consent voluntarily.

Researcher's name……(Please print)

Researcher's signature……..Date……

Appendix 5: Audio-recording Consent Form

The researcher has explained to me the reason for audio-recording the interview.
I know that I may choose whether to participate or not to participate in the interview and to be recorded.
I am aware that I may stop the interview at any point.
The researcher will take measures to ensure that the recording is kept confidential and safe.

I give consent for the interview to be audio recorded.

Interviewee:
Name: _____
Signature: _____
Date:_____

Researcher
Name: _____
Signature:_____
Date:_____

Appendix 6. Request for permission Letter

8 Evelyn Avenue
Bordeaux
2194
June 5, 2015

Attention: Stretford Clinic Manager
Orange Farm
Johannesburg

Dear Sir/Madam,

Request for permission to conduct a research study on the experiences of adult men who have been on ART for five or more years and receive care services at your clinic.

Reference is made to the above subject matter. I write to request for your permission to conduct an academic research at your institution. I am a Master of Public Health student at the School of Public Health, University of the Witwatersrand. In partial fulfilment of my studies, I am required to undertake a mini research study. I have chosen to conduct a study to explore adult men's experiences of long term HIV care and treatment services at your facility.

A total of 20 adult men who have been on ART for five or more years will be enrolled in this study. Due to the sensitivity of the topic, the study will be conducted privately using one-on-one in-depth interviews lasting approximately one hour. Confidentiality of all discussions is assured and will be maintained. Participation in the study will be voluntary and participants will be provided with all the necessary information for them to make an informed decision whether to participate in this study. When the study is completed, I will share the research report with the management of your facility.
Your positive consideration of this request is highly appreciated. I hope that the results of this study will contribute to knowledge on health programming for men on long term HIV care.
Yours sincerely,
Bright Phiri
Contact: Telephone number: 0714232949 or Brightphiri68@gmail.com

Appendix 7: Coding Book

Category	Code	Sub codes	Description	Theme
Marriage/partner relations	- Divorced - Widowed - Remarried - Living with partner/girl friend	- Inclination to date HIV positive women - Not easy to date negative person	- Participants marital or dating status during the time of ART	Marriage and dating relationships dynamics
Employment and income	- Sources of livelihood	- Social grants - Not working - Self employed - Working	- Participants sources of income and livelihood	Sources of livelihoods
Years since commencement of ART	- Range 6-12 years	- Was sick and commenced ART - After TB treatment started ART	- The number of years from the time participant began treatment - Five or more years in this research is being regarded as long term	Number of years on ART
Circumstances leading to testing	- Intentional testing - Unintentional testing	- Volunteered to get tested - Death of spouse - Was sick - Had TB	- What were the driving forces for participants to test for HIV	Circumstances & context of HIV testing
Reaction to diagnosis	- HIV status Results notification	- Shocked - Accepted - Difficulty to speak about - Surprised - God knows why me	- Participant's initial reaction to test results	Reactions to results of HIV diagnosis
Ill health	- Side effects - Unable to walk - Bedridden - hospitalised	- None - Got dark - Vomiting - Diarrhoea	- Participants state of bad health in the course of long term ART	Ill-health, ARV side effects & treatment adherence

Category	Code	Sub codes	Description	Theme
		- Nausea - Pimples		
Psychosocial impact of living with HIV and taking ART for a long time	- Psychosocial aspects of long term ART -	- Felt sad - Lonely/isolation - Depressed - It hurts - Hopelessness - Resentment - Gossip - workmates - Work conditions - Stigma - Loss of work - ART dependence	- Participants psychological lived experiences with taking ART for a long period - Participants social experiences of taking ART for a long time	Psychosocial impact of living and taking ART for a long time
Social support systems	- Source of support	- Family - Comforting - Will be okay - Friends - Work place - Support groups - You are not alone	- Participants sources of support for their continued adherence - Optimism about one's condition	Social Support systems
Health Care facilities and services	- Clinic facilities -	- Medicine availability - Health care worker attitudes - Gender and nurses - Gave us food - Support group - Counselling support	- Participants experiences with health care facilities as a factor for adherence	Heath seeking: Access to Health Care and treatment services
Acceptance of HIV status and determination to live	- Self-prioritising - Health prioritising - Self confidence	- It's my life - I didn't want to die - Seen others die - Tablets are my life - Medicine normal routine	- What motivated participants to remain on ART for a long time	Prioritising and valuing own life above all: Motivation to live

Category	Code	Sub codes	Description	Theme
		- I have accepted situation - Want to see a cure - Sharing medicines when away from home - I don't care what people say - Want to see my children grow up - Wanted to be a father - Only God knows		
Exposure to different ART regimens	- ART regimens - adherence	- Same regimen - Changed - Easy to adhere - Three times a day - Happy now - Once only - Child reminds me	- Exploring whether change in ART had effect on adherence	Exposure to different ART regimens and adherence issues over the years
ART and social relationships	- your spouse, - children - other family members - friends in the community, at work	- Accepted - Still love me - Gossip - Avoid friend - Not told them - Tested together - Don't want to test - Stigma - Strong together	- Describes how participants social relationships have been affected by long term ART	Social relationships & ART adherence
Masculinity and Context of changes	- Dependency on others - Need to change - Life style changes - Losing freedom - Cutting down on social life	- It hurts - On wheel chair - Couldn't walk - Bedridden - Determined to change - Send someone else	- Social definitions of being a man and changes that affect such definitions	Reconstructing new Masculinity?

Category	Code	Sub codes	Description	Theme
		for my medicine - I am stubborn - I am arrogant		
Substance use and treatment	- Adapting health life styles - Reductions in substance abuse - Seen others die for not changing life styles	- Reduced my beer intake levels - Quit drinking	- These codes explain changes in lifestyles for those who used to drink beers	Lifestyle changes and challenges
Stigma and discrimination	- Fear to disclose - scary - Friends - Community - Workplace - Health facility	- Mixing them with other patients - Colour of the cards - Community gossip - Supportive workplace - People disrespect you - Side-lined - Self-stigma - Denial - Isolation	- Codes here are demonstrative of sources of stigma and how participants dealt with such	Manifestations of stigma and discrimination
Disclosure process	- Family - Friends - Not disclosed (fear of stigma)	- Told my children - Told my wife - Told my mother - In community - Workmates	- This describes the disclosure process of participants and to whom disclosure was done	HIV status disclosure & processes

Discourse of blaming others	- source of illness
	  - TB
	  - Wife
	  - Multiple girlfriends
	  - Not sure
	  - Witchcraft
		- Spouse	- Describes whether or not participants blamed their HIV status on other people	Blaming discourse

Category	Code	Sub codes	Description	Theme
Dealing with Bereavements	- Death of family member - Wife died - Cousin died - My brother died - Girl fried died - Friend died		This code describes how the deaths of relatives/friends of participants inspired them to be more determined to adhere to ART to avoid dying	Bereavement in family

Appendix 8: Ethics approval Wits University

R14/49 Mr Bright Phiri

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150743

NAME: (Principal Investigator)	Mr Bright Phiri
DEPARTMENT:	Public Health Stretford Community Health Care Centre, Orange Farm
PROJECT TITLE:	Adult Men's Experiences Of HIV Care and Treatment Services in Johannesburg, South Africa
DATE CONSIDERED:	31/07/2015
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Yandiswa Sikweyiya
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	07/09/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 9. Ethics approval DoH

Form 2

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Joburg
a world class African city

JOHANNESBURG HEALTH DISTRICT

Enquiries:
Johannesburg.research@gmail.com
coralF@joburg.org.za

09/12/2015

Bright Phiri
University of the Witwatersrand
E-mail: brightphiri68@gmail.com

Reference no: 2015-16/022

Dear Bright Phiri,

Re: Study protocol: *Adult men's experiences of long term HIV care and treatment services in Johannesburg, South Africa.*

Your application the above approval project refers. The District Research Committee has reviewed your application. This letter serves as an in-principle approval to access the Districts Health facilities (mentioned below) for the above project, subject to following conditions:

- The facilities to be visited: Sub-district/ Region G (Stretford CHC).
- This facility will be visited from 14 December 2015 to 30 May 2016.
- You will report to the Facility managers of the Clinic before initiating the study.
- Participants' rights and confidentiality will be maintained all the time.
- No resources (Financial, material and human resources) from the above facilities will be used for the study. Neither the District nor the facility will incur any additional cost for this study.
- The study will comply with Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit a six-monthly progress report to the District Research Committee. Your supervisor and University of the Witwatersrand will ensure that these reports are being submitted timeously to the District Research Committee.
- The District must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.

We reserve our right to withdraw our approval, if you breach any of the conditions mentioned above.

Please feel free to contact us, if you have any further queries. On behalf of the District Research Committee, we would like to thank you for choosing our District to conduct such an important study.

Regards,

Ms M Morewane
Chief Director
Johannesburg Health district