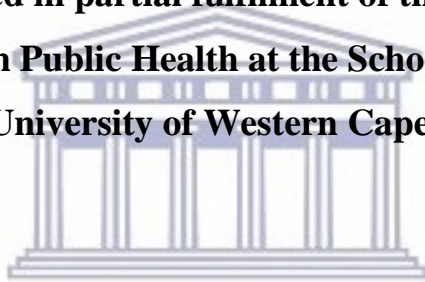


**Exploration of factors that influence poor adherence to  
antiretroviral therapy amongst patients at Pule Sefatsa primary  
health care clinic in Mangaung district, South Africa.**

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**A mini-thesis submitted in partial fulfilment of the requirement for the  
degree of Masters in Public Health at the School of Public Health,  
University of Western Cape**



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## **KEYWORDS**

Adherence

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HIV

AIDS

Nurse

Health



UNIVERSITY *of the*  
WESTERN CAPE

## ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
HIV	Human Immunodeficiency Virus
DHIS	District Health Information System
PLWHA	People Living with HIV/AIDS
WHO	World Health Organization
UNAIDS	The Joint United Nations Programme on HIV and AIDS
DoH	Department of Health
NIMART	Nurse-initiated management of antiretroviral therapy
CD4	Cluster of differentiation 4
TIER.NET	Three Interlinked Electronic Register for HIV & TB
FGD	Focus Group Discussion



## ABSTRACT

**Background:** Over the past decade, South Africa has scaled-up its antiretroviral treatment (ART) programme in an effort to control the HIV epidemic. Interventions to support the rollout of ART include task shifting ART initiation to nurses at primary health care level and ensuring HIV adherence counselling at every visit by lay counsellors. Furthermore, community-based outreach teams work at the community level to follow up on patients and ensure that patients remain in care and are adhering to ART. Despite all these efforts, poor adherence to ART remains a pertinent problem. In 2016, the national adherence to ART rate among adult patients was estimated at 35% compared to 39% in Pule Sefatsa clinic in Mangaung district, Free-state Province.

**Aim:** The aim of the study was to explore the factors that influence poor adherence to ART among patients receiving ART at Pule Sefatsa primary health care clinic in Mangaung district, South Africa.

**Methodology:** A descriptive qualitative research approach was used. Two focus group discussions were conducted with health workers and community caregivers and 16 in-depth interviews were conducted with ART patients who are in care and those who had defaulted on their treatment. Audio recorded data obtained from these sources were transcribed verbatim and prepared for analysis. Thematic analysis was used for data analysis and the results were classified under various categories.

**Findings:** Adherence to ART in Pule Sefatsa clinic was found to be influenced by medical related factors, socio-economic factors, health system factors and individual factors. The medical-related factor was the side effects of the medication. The socio-economic factors were stigma and discrimination, lack of family support, poverty and food insecurity. Health system factors that hindered adherence to ART were medication stock-outs, long waiting times and poor service delivery. The final group of barriers to ART adherence was related to the individuals using ART and these include patients forgetting to take treatment and feeling depressed.

**Conclusions:** Poor adherence to ART is shaped by a collection of factors of individual, medical, socio-economic and health system nature. The findings of the study propose that poor

ART adherence is related to limited health system resources, weak social support and uneasy socio- economic status. Therefore, it is crucial for HIV programs and interventions to focus on addressing these factors to improve the adherence levels and therefore prolong life expectancy for ART patients.



## DECLARATION

I declare that this thesis entitled “*Exploration of factors that influence poor adherence to antiretroviral therapy amongst patients at Pule Sefatsa primary health care clinic in Mangaung district, South Africa*” is my own work. It has not been submitted for any degree or examination in any other university. All references used and quoted have been acknowledged.



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## CHAPTER ONE – INTRODUCTION

### 1.1 Background

There were approximately 36.7 million people living with HIV/AIDS worldwide in 2016 (UNAIDS, 2016). Within the same year, there were about one million deaths from AIDS-related illnesses contributing to the total 35 million AIDS-related deaths since the start of the epidemic (UNAIDS, 2016). Sub-Saharan Africa has the majority of people living with HIV/AIDS (PLWHA) with an estimate of 25.6 million people accounting for 66% of new HIV infections (WHO, 2016). The HIV epidemic has been in South Africa since the early 1980s (Kanabus, 2016). In 2017, 7.1 million people were reported to be living with HIV in South Africa (UNAIDS, 2017). This represents 11.5% of the general population of the country and is the highest number reported in the world (Kanabus, 2016). HIV/AIDS has contributed to an estimated 30.5% of deaths in South Africa in 2015.

The South African Department of Health established the antiretroviral treatment (ART) programme in response to the escalating HIV epidemic (Department of Health, 2012). Some achievements of this programme include initiating PLWHA on ART at the primary health care level and initiating patients on ART irrespective of their CD4 cell count and/or WHO staging (Rhodes *et al.*, 2017). According to the UNAIDS (2017), South Africa currently runs the largest ART programme worldwide with 56% of adults and 55% of children initiated on ART in 2016. Following these successes, the next mission of the South African health system is ensuring that these patients remain in care and adhere to their treatment to achieve good patient outcomes.

The South African health system has set goals based on the 90-90-90 strategy for 2020 that is; 90% of all people living with HIV knowing their status, 90% of all HIV diagnosed people receiving sustained ART and 90% people on ART achieving viral load suppression (UNAIDS, 2014). In accordance with these goals, 85.5% of HIV positive adults have been diagnosed, 56.9% of HIV diagnosed patients are on ART and 78.4% adults on ART were virally suppressed by 2016 in South Africa (Johnson *et al.*, 2017). These figures indicate that while South Africa is on track to diagnosing 90% of PLWHA, challenges remain in reaching targets on ART initiation and viral suppression.

## **The notion of adherence to antiretroviral treatment**

Adherence is defined as the degree to which patients take their treatment according to the prescribed programme, otherwise described as compliance (WHO, 2010). Adherence to ART plays a major role in viral load suppression and in reducing drug resistance for HIV positive patients.

Although significant efforts have been made to initiate and sustain HIV patients on ART in South Africa, there is a challenge with non-adherence among patients on ART (Mukumbang *et al.*, 2016). For instance, a study conducted in Pretoria showed a 63% of non-adherence to ART among patients attending a clinic (Adefolalu *et al.*, 2014). Poor adherence to ART has been found to lead to low levels of CD4 cell count, inadequate virologic response leading to viral rebound, the development of HIV drug-resistance leading to treatment failure and increased HIV mortality rates (Centre for Disease Control and Prevention, 2015).

For the HIV treatment programme to be successful, it is essential to address the issue of poor adherence to ART amongst patients. Adherence to treatment for HIV patients is critical because the ART formulary has a biological threshold for the development of drug resistance amongst HIV positive patients (Etienne *et al.*, 2010). According to Reda and Bladgilign (2012), ensuring adherence to ART treatment needs a clear understanding of multiple barriers that are faced by patients to develop relevant and evidence-based interventions to overcome stated barriers.

### **1.2 Problem Statement**

The ART programme in Pule Sefatsa clinic was rolled out in 2003. Since its inception, it has been observed that 39% of the patients on ART are not adherent to treatment (DHIS, 2016). The current non-adherence rate at the facility is higher than the 35% non-adherence rate reported at the national level in South Africa (DoH, 2016). Despite this high non-adherence rate to ART, no formal study has been done to date at Pule Sefatsa clinic to explore the reasons for the high non-adherence rates.

### **1.3 Aims and Objectives**

The aim of the study was to explore the factors that influence the lack of adherence to antiretroviral therapy among adult patients at Pule Sefatsa primary health care clinic.

The objectives of the proposed study were:

- To explore individual (patient-related) factors that influence lack of antiretroviral therapy adherence.
- To explore medication-related factors that influence patients' lack of adherence to antiretroviral therapy.
- To explore socio-economic factors that influence lack of antiretroviral therapy adherence.
- To explore health systems factors that influence lack of antiretroviral therapy adherence.
- To explore social-cultural factors that influence patients' lack of adherence to antiretroviral therapy.

### **1.4 Structure of the thesis**

This thesis is organised into six chapters. Chapter one provides the background of the study, problem statement of the study, study aims, and objectives. Chapter two focuses on the literature reviewed across sub-Saharan countries on factors influencing poor ART adherence. Chapter three outlines the methodology followed by the various methods employed while conducting the study. This chapter elaborates on the study design, study setting, study population, sample, data collection, data analysis, and steps followed to ensure trustworthiness. Chapter four presents key findings of the study that is, themes and sub-themes on factors influencing poor ART adherence. Chapter five discusses study findings with highlights to the existing literature. Chapter six draws a conclusion and provides recommendations based on the findings.

## CHAPTER TWO - LITERATURE REVIEW

### 2.1 Introduction

Adherence to ART is influenced by a range of factors, which are extensive and complicated. This chapter reviews the literature on the factors influencing ART adherence with a particular focus on sub-Saharan countries.

According to WHO (2003), non-adherence can be defined as patients taking the wrong dose, patients forgetting to take treatment completely or patients prematurely terminating the treatment. To achieve long-lasting viral load suppression rate, HIV positive patients need to maintain high adherence rates – taking a sufficient amount of prescribed medications (average of 75%), which leads to sustainable suppressed viral load. There are several challenges encountered by patients when it comes to adherence. Predictors of non-adherence have been classified under regimen characteristics, patient factors, health system factors and social-cultural factors (WHO, 2003). Table 1 below further classifies potential predictors of poor adherence (Mukumbang *et al.*, 2017).

Table 1: Classification of potential predictors to ART non-adherence

Category	Barriers
Individual- Factors	<ul style="list-style-type: none"> <li>• Age (being younger)</li> <li>• Depression (Mental health)</li> <li>• Forgetfulness</li> <li>• Substance abuse</li> <li>• Poor self-efficacy</li> <li>• Low Health Literacy</li> <li>• Perceived wellness</li> </ul>
Medication-Related Factors	<ul style="list-style-type: none"> <li>• Medication side effects</li> <li>• Medication dosing (Complex regimen)</li> <li>• Treatment fatigue</li> </ul>
Health System Factors	<ul style="list-style-type: none"> <li>• Access to ART (Medication stock outs)</li> <li>• Relationship with health care providers</li> <li>• Staff shortages</li> <li>• Long waiting times</li> <li>• Poor services delivery</li> </ul>
Socio-economic Factors	<ul style="list-style-type: none"> <li>• Poverty</li> <li>• Lack of family support</li> <li>• Food insecurity</li> <li>• Stigma and discrimination</li> <li>• Transportation challenges</li> </ul>
Socio-cultural Factors	<ul style="list-style-type: none"> <li>• Alternative treatment</li> <li>• Male dominance and gender-based violence</li> <li>• Religious beliefs</li> </ul>



## 2.2 Individual factors

Individuals often chose not to take ART treatment because perceived needs for medical care are outweighed by multiple barriers to adherence and competing priorities, for instance, long distance from the facility and high transport costs (Layer *et al.*, 2014). Common reasons for missing one or more pills are due to forgetfulness, conflicting work schedule and travelling (Bijker *et al.*, 2017). Some of the reasons why patients miss their treatment or are non-adherent is because of competing demands on their time for instance, caring for a sick family member in a distant location, travelling for work or attending a funeral in another town (Ware *et al.*, 2013).

### 2.2.1 Age and Gender

Age and gender are associated with ART adherence as younger people and males are at greater risk of non-adherence (Bijker *et al.*, 2017). Younger age has been associated with non-adherence and this is a concern as the majority of HIV infections occur in the age group (Semvua *et al.*, 2017). In addition, a study done in South Africa showed that there is poor adherence amongst male patients and younger patients and this indicates that interventions should focus on male involvement approaches and youth friendly services within health care should be strengthened (Clouse *et al.*, 2013). However, Vreeman *et al.* (2013) found that, youth born with HIV and taking ART indicated that after disclosure from their caretakers, they were enabled to maintain their HIV treatment and conceal the diagnosis from other people. Apart from youth, being age 35 years or older and being a female-initiated on ART during pregnancy had an influence on adherence in that women were not adherent to treatment after giving birth (Tweya *et al.*, 2014).

A study done in South Africa has shown that women initiated on ART during pregnancy are more likely to default treatment during post-natal stage, this could be due to the fact that they no longer feel the need to be on ART since they have given birth and this means that HIV positive women are not adequately counselled on importance of adherence to lifelong treatment (Phillips *et al.*, 2014). However, a study done in Malawi suggested that pregnant women and those who have just given birth were not adherence to treatment either because they could not disclose their HIV status to their partners, they travelled away to relatives to give birth close to home or they experienced high transport costs (Tweya *et al.*, 2014).

### 2.2.2 Depression (Mental health)

A study conducted in sub-Saharan Africa indicates that the likelihood of achieving good adherence to ART is lower amongst patients with depressive symptoms compared to those without depression (Uthman *et al.*, 2014). This is because patients with depression develop negative thoughts and feelings of hopelessness, which discourage them to take medication. Furthermore, depression increases social isolation, which widens the gap between patients and their support networks (Memiah *et al.*, 2014). Patients who experience anxiety, insomnia, and confusion have lower adherence rates (Dakkak *et al.*, 2012). Moreover, ART patients exposed to potentially traumatic events and severity of depression symptoms have poor adherence to treatment (Whetten *et al.*, 2013). Depressions and isolation are often related to anger, confusion and patients often struggling to accept HIV status of their children but with family support, most patients tend to accept their status and move away from isolating themselves (Mutwa *et al.*, 2013).

### 2.2.3 Substance abuse

Alcohol consumption plays a unique role in ART adherence and independent of any other factors including structural, demographic and psychosocial factors (Morojele *et al.*, 2014). Alcohol and drug abuse is also a barrier to ART adherence (Gerbregabher *et al.*, 2017; WHO, 2003). For example, non-adherence may occur because the patient forgot to take their treatment due to drinking and can obstruct patients in reading instructions on how to take ART medication (Yaya *et al.*, 2014). Alcohol and substance abuse has been linked to non-adherence in that patients tend to forget to take treatment when they are taking alcohol (Wekesa, 2017). It has been discovered that acute effects of intoxication have negative impact on ART adherence that is, drug abuse results in psychosocial deficiency and psychiatric dysfunctions (Bhatti *et al.*, 2016). Alcohol is also known to be a proxy of self-control and thus, lead to poor adherence (Shumba *et al.*, 2013).

### 2.2.4 Low Health literacy

There is greater ART adherence amongst people with lower educational levels than those who are highly educated (Peltzer *et al.*, 2010). However, being knowledgeable about HIV and ART has significant improvements on adherence since patients are literate enough to read and get informed about the benefits of adherence to ART treatment (Molla *et al.*, 2018). Enhancing health literacy amongst ART patients improves ART adherence. Providing adherence



counselling to patients and also equipping them about issues of health through interpersonal communication and counselling provides enough knowledge to patients about health and therefore improves ART adherence (Tomori *et al.*, 2015). Another barrier to ART adherence is patients' belief about ART and this suggests that adherence enhancing interventions should target psychological factors such as self-efficacy and patients concerns about ART (Langebeek *et al.*, 2014). A study done in Ghana showed that non-adherence rate were higher in patients with inadequate knowledge about ART as compared to patients with adequate knowledge (Boateng *et al.*, 2013).

#### 2.2.5 Perceived wellness

A study conducted in Tanzania showed that patients who are visibly sick are more likely to seek ART services whereas healthy ART patients expressed reluctance to continue to take treatment with the belief that they do not need treatment (Layer *et al.*, 2014). Some of the reasons why healthier patients have poor adherence are that they might lack experience in taking medication frequently due to lack of interest in taking medication because they feel healthy and comfortable (Tegegne *et al.*, 2018). Patients stop taking their medication after noticing an increase in weight because they feel better and fit (Mukumbang *et al.*, 2017).

#### 2.2.6 Forgetfulness

In a study conducted in sub-Saharan Africa, it was also noted that forgetting to take one's medication is a barrier to ART adherence (Croome *et al.*, 2017). A study conducted by WHO (2003) also indicates that a patient's forgetfulness is a barrier to ART adherence. Both studies are coherent with the study conducted in Congo, which indicated that forgetfulness was stated as one of the most frequent reasons for missing treatment (Musumari *et al.*, 2014). Another study also suggest that patients forgetting their medication at home is barrier to treatment (Gare *et al.*, 2015). Patients forgetting to take treatment has shown to hinder ART adherence and use of personal mobile phone to set reminders can improve adherence (Safren *et al.*, 2014). Moreover, forgetting to take medication can be promoted by misplacing medication which also leads to missing treatment (Hodgson *et al.*, 2014).

### 2.3 Medication-related factors

In a study that included both sub-Saharan Africans and Asian participants showed that regimen

complexities and pill burden were some of the influencers of adherence (Bijker *et al.*, 2017). There is proof that simplified regimens with fewer pills and lower dose frequencies improve adherence (WHO, 2003). This notion is supported by a study conducted in South Africa, which showed that TB/HIV patients who were on dual therapy had low adherence levels (Naidoo *et al.*, 2013).

Side effects associated with the regimen can also decrease adherence levels and patients who experience more than two adverse reactions are likely not to continue with treatment. ART patients who have experienced side effects like nausea, skin rash, dizziness and hallucination tend to be 83% less likely to adhere to treatment (Wekesa, 2017). A study done in Malawi also showed that patients stopped treatment because they experienced nausea, dizziness, nightmares and hallucinations and this also made patients to question the efficacy of the treatment (Kim *et al.*, 2016). Another study suggests that HIV positive patients who have been on ART for two years or more were not adherent to treatment because of treatment fatigue since patients get tired of taking treatment on a daily basis (Gerbregabher *et al.*, 2017).

## **2.4 Health system factors**

Improved adherence may partially be attributed to the resource available within the health system, such as patient's access to an ART site, trained staff, low patient-staff ratios and the availability of patient monitoring strategies (Bijker *et al.*, 2017). A study done in sub-Saharan Africa in 2009 further indicates that community health worker programmes have positive effects on adherence and retention care for ART patients (Hermann *et al.*, 2009). In Zambia, the deployment of well-trained community health workers decreased lost to follow up rates from 15% to 0% (Hermann *et al.*, 2009). Accessibility and availability of health facilities plays a vital role in promoting ART adherence since patients get to have access to treatment at any time and in a conducive environment (Gerbregabher *et al.*, 2017).

### **2.4.1 Access to ART (Medication stock outs)**

Health system barriers affect adherence to ART, specifically inconsistent supply of medication to patients. For example, in sub-Saharan Africa, weak procurement and supply management systems often lead to drug stock-outs which can discourage patients to be adherent (Reda & Bladgilign, 2012). Patient's medication interruptions occur because of drug stock-out for

instance, there are times when patients are given two weeks supply instead of one month's supply (O'Laughlin *et al.*, 2018).

#### 2.4.2 Long waiting times

Patients waiting too long to see a nurse or a doctor cited this as a barrier to ART adherence in a study conducted in Durban (Drain *et al.*, 2013). The scale-up of ART has added workload to clinic staff and given the patients- health worker ratio, this has increased the time taken by ART patients in facilities by over seven hours waiting time, which is discouraging patients to adhere to monthly visits to clinics (Napua *et al.*, 2016). Some patients have stopped taking treatment because of dissatisfaction of health care services provided for instance, some patients noted that they were unhappy with long waiting time they are experiencing at the clinic (Ware *et al.*, 2013)

#### 2.4.3 Poor services delivery

Poor counselling and an inadequate health education at ART initiation can inhibit good adherence. This means that it is essential to provide adequate and timely adherence counselling at the initiation of patients on ART regimen (Scanlon & Vreeman, 2013). Insufficient provision of counselling and information on HIV to patients hinders adherence to ART since patients do not have enough information to accept their HIV status (Patel *et al.*, 2016). Poor adherence can be associated with the bad attitude that patients receive from the clinic staff. Patients feel ignored, undermined and offensively communicated to, this leads to poor ART adherence (Katz *et al.*, 2015). A good patient-nurse relationship can positively influence ART adherence because patients get motivated and comfortable to discuss most challenges they face with the healthcare worker (Mbirimtengerenji *et al.*, 2013)

### 2.5 Socio-economic factors

Psychosocial and lifestyle play essential roles in ART adherence in sub-Saharan Africa. Living with parents in a household influences ART adherence and this is because ART patients do not disclose HIV status to parents in fear of being rejected making it difficult to take medication amongst them (Gerbregabher *et al.*, 2017). According to WHO (2003), lack of social support and lower income can also affect adherence. Patients living alone were more adherent to treatment compared to patients living in a family setting (Gerbregabher *et al.*, 2017). Stigma and discrimination can enhance ART non-adherence because patients fear to disclose their HIV

status due to perceived unfair treatment by community members hence they opt not to take treatment and hide their HIV status (Nachega *et al.*, 2009 ; Reda, 2012). Another socio-economic barrier to ART was cited as migration in that, patients born in South Africa had higher adherence levels than foreign patients and this is due to patient migration that is, patients dropped medication because they were not given enough supply and had no access to health services (Clouse *et al.*, 2013).

### 2.5.1 Poverty

Poverty is independently associated with poor adherence to ART treatment (Naidoo *et al.*, 2013). A study done in Zimbabwe indicates that patients who are unemployed were more likely to be non-adherent than those who are employed (Matare *et al.*, 2015). This could mean unemployed patients have food insecurity discouraging them to take their medication or that they do not have access to medication either because they live far from the health service point, which requires high transportation cost. A study conducted in Ethiopia, however, showed that income does not affect ART adherence and may be due to the fact ARV treatment had been given free of charge since 2005 (Mituku *et al.*, 2013). Employment facilitates ART adherence for instance, it has been cited that employed HIV patients were 27% more likely to adhere to treatment than those who are unemployed (Nachega *et al.*, 2014). This coherent with a study conducted in Ethiopia, which showed that unemployed patients are more adherent to ART (Tsega *et al.*, 2015)

### 2.5.2 Lack of family support (social support)

Barriers to ART adherence are promoted by lack of support from family members and at times patients fear to disclose their HIV status due to dependency on partners' financial resources, house hold conflict and low parental educational level (Scanlon & Vreeman, 2013). Patients described support from family members being critical for enabling them to overcome enactments of HIV-related stigma and other obstacles to care and successfully adhere to treatment (Katz *et al.*, 2013). However, family support alone does not ensure good adherence to ART because it has been observed that even a patient who has family support can have low adherence rate, therefore, patients also need support from friends, community and ART support groups (Mitiki *et al.*, 2013). According to Musheke *et al.* (2012), HIV positive patients may stop their treatment to preserve social support system, for instance, housewives or traders felt that they would lose their credibility in the society they serve if they disclosed their HIV status. People living with HIV usually hide or skip medication to avoid disclosing their HIV status to

friends or family members (Heestermans *et al.*, 2016).

### 2.5.3 Food insecurity

Access to quality food and consumption patterns such as, having less than three meals per day, discourage patients to take treatment (Berhe *et al.* 2013). In addition, Musumari *et al.* (2014) suggest that food supplementation improved ART adherence amongst food-insecure adults. This is congruent with a study conducted in Malawi, which showed that household and individual food insecurities influence ART adherence (Mckinney *et al.*, 2016). Patients being dependent on food supply from the clinic, left their medication with the nurses when they did not receive food ration from the clinic and some patients believe that they had to consume costly food items to take HIV medication (Bezabhe *et al.*, 2013). Lack of regular access to food and water is also cited as a barrier to ART (Hodgson *et al.*, 2014)

### 2.5.4 Stigma and discrimination

Patients who had difficulties in disclosing their HIV status were in fear of being stigmatised and this led to poor adherence and this means greater adherence can be experienced if patients can be given social support (Tenthani *et al.*, 2014). Morojele *et al.* (2014) elaborate that, both patients who have been stigmatised and those who have not disclosed their HIV status had lower ART adherence levels in a study conducted at Tshwane. Disclosing HIV status could be a benefit to patients because they will be given support to take treatment by their loved ones hence encouraging disclosure among patients on ART should be part of HIV management to reduce poor adherence and treatment failure (Matare *et al.*, 2015).

Patients have described avoiding to go to a clinic to obtain drugs because they did not want community members to see them and even family members could not go the clinic on their behalf because they also feared being labeled as HIV positive by community members (Mutua *et al.*, 2013). In a study done in sub-Saharan, women are more likely than men to cite fear of rejection, abandonment or violence from their partners because of their economic and social vulnerability and this promotes poor ART adherence (Bott & Obermeyer, 2013). A study done in Uganda also showed that ART patients avoid to visit the clinic out of fear of meeting familiar people who are perceived to spread the news about patients HIV status (Nabukeera-Barungi *et al.*, 2015). A study conducted in Uganda showed that most patients find it difficult to disclose



their HIV status at work as they fear negative attitude from colleagues which may affect their livelihood (Mbonye *et al.*, 2013)

#### 2.5.5 Transportation challenges

One of the economic constraints patients experience is a cost to transport to attend monthly check-ups (Hlarlaithe *et al.* 2014). Most patients in limited resource settings are located far from the health facility and need to take transport to clinics and this discourages patients to adherence to ART because they do not have the money to attend monthly visits. Siedner *et al.* (2013) identified that transportation challenges correlate with late presentation to clinic visits but there should also be consideration of varying climates, living standards, infrastructure conditions and topographies of the location.

Patients receiving free HIV services incur large private costs such as, transportation costs and lead to financial distress to patients, which makes them miss clinic visits (Chimbindi *et al.*, 2016). Common reasons for missing treatment are related to income and they comprise of failure to get transport to reach ART clinics, hence missing pharmacy refills (Shumba *et al.*, 2013). A multi-disciplinary study done in Sub-saharan Africa shows that transport cost hinder adherence in that patients who cannot afford to travel to facilities opt tend to be non-adherent (Wekesa, 2017). Another study suggests that patients do not adhere to treatment due to non-affordability of transport costs (Nachega *et al.*, 2014). Barrier to ART was due to affordability of transport costs to the clinic and patients had no option but to miss clinic visits because they did not have money to pay for taxi fares (Drain *et al.*, 2013).

## 2.6 Social-cultural factors

ART patients' barriers to adherence include patients' beliefs, attitudes, and behaviours towards the medication and medication taking. Pregnant women were also found to have a positive attitude towards taking treatment enforced by the need to protect their unborn babies from HIV (Mckinney *et al.*, 2016).

### 2.6.1 Male dominance and gender-based violence

Gender inequality influences ART adherence, for instance, women were shown to discontinue treatment because they were denied permission by their spouse or did not get required financial

support or social support to access services regularly (Lubega *et al.*, 2013). The other reason for refusing ART in women was fear of disclosing their HIV status to their partners because of unstable relationships, they were concerned about their partner's reaction (Kim *et al.*, 2016).

### 2.6.2 Religious beliefs

Consulting a traditional healer in relation to HIV treatment is related to poor adherence and in most cases, patients reported taking traditional medicine to cure HIV or opportunistic infections (Denison *et al.*, 2015). Religious rituals like fasting and holy water were found to promote poor adherence as patients do not take medication when fasting since they do not eat (Bezabhe *et al.*, 2013). Furthermore, patients who had holy water do not adhere to treatment since they believe that holy water will cure HIV. Patients can opt to stop treatment and resort to other methods with the belief that they will be healed. A study done in Malawi showed that some patients stopped treatment with the thought that God would be the one to heal them (Kim *et al.*, 2017).

### 2.6.3 Alternative treatment

In a study conducted in Tanzania, patients were attracted to the possibility of getting cured of HIV using traditional medication is so much that they would travel for long hours, incur significant costs and miss taking ART (Thielman *et al.*, 2015). Some HIV positive patients prefer to use herbal medicine as compared to ART with the belief that they will get cured (Patel *et al.*, 2016).

## 2.7 Summary

A synopsis of barriers to ART adherence was reviewed in this chapter, comparing factors from different studies done in sub-Saharan Africa from 2012 to 2018. Age, depression, substance abuse, low health literacy, and perceived wellness were viewed as individual factors related to poor adherence. Health systems factors discovered from previous studies were access to ART, long- waiting times and poor service delivery. Socio-economic factors revealed in other studies were poverty, lack of family support, food insecurity, stigma and discriminations, and transport challenges. Lastly, the studies reviewed showed be gender-based violence, cultural beliefs and patients using alternative medicine as social-cultural factors hindering ART adherence.

## **CHAPTER THREE - METHODOLOGY**

### **3.1 Introduction**

The chapter covers the study design used and provides the description of the study setting. The study population and the sampling technique used in the study are also described in this section. Furthermore, data collection procedures including tools used and methods of data collection have been covered in this chapter. Lastly, issues of trustworthiness and study limitations are described.

### **3.2 Description of the study setting**

The study was conducted in a provincial primary health care facility named Pule Sefatsa clinic, which is in the Botshabelo sub-district, Mangaung municipality. The clinic is one of the 41 public primary health care facilities in the Mangaung district and is situated at the U section in Botshabelo sub-district. The facility provides HIV and TB related treatment, care and support services. The Pule Sefatsa clinic is an accredited ART initiation and on-going treatment facility. There are three Nurse Initiated and Managed Anti-Retroviral Treatment (NIMART) nurses on site and one rotating doctor. The facility operates 24 hours a day, seven days a week and offers free of charge services. According to the District Health Information System (2016), 1,862 patients are registered for ART at the facility and the rate of ART non-adherence was at 39% as of September 2016.

### **3.3 Study design**

An exploratory qualitative research design was used. Malterud (2001) suggests that qualitative research explores meanings of social phenomena as experienced by individuals themselves, such as the various barriers to poor ART adherence. The researcher focuses on learning the significance that the participants hold about the problem or issue under consideration (Creswell, 2007). This study was focused on adherence to ART and the participants were selected because they could provide rich descriptions of the factors that influence adherence (Sofaer, 1999). Participants included both ART patients and health care workers as key informants. Having varying sample subsets provided the researcher with experiences and interpretation (perspectives) of events by actors with different stakes and roles in ART adherence (Sofaer, 1999). Therefore, a qualitative research study was done because it provides



a deeper understanding and explanations of factors that influence ART adherence in Pule Sefatsa clinic by exploring unique and unexpected events.

### **3.4 Study population**

The study population comprised of adults aged between 18 and 65 years old, living with HIV/AIDS and taking ART, both females and males attending the clinic at Pule Sefatsa primary health care facility from 2010 to 2016. This population included patients who had not collected their medication at the facility for more than 90 days and active patients who had once not adhered to treatment since ART initiation.

### **3.5 Sampling**

Purposive sampling was used to select participants that met the inclusion criteria (Blackstone, 2012). According to Marshall (1996), purposive sampling is the process whereby the researcher actively selects the most productive sample to answer the research question. The researcher and the facility administrator reviewed ART patients from the headcount register. Using the ART electronic register (TIER.NET), the researcher worked with the clinic's data-clerk to review the list of patients on ART who had defaulted and active patients who have once not adhered to treatment to identify the study participants. Sixteen patients who meet the criteria were selected in the facility. The list of participants was printed out and the researcher liaised with the NIMART nurses to recruit and interview the patients that met the inclusion criteria of the study.

Inclusion criteria to choose a sample of ART patients was directed by the following

- Patients aged 18-65 years old of age
- Patients initiated on ART from 2010 to 2016
- Have defaulted from medication at one time in their treatment journey
- Have not made contact with the health care facility for the last 90 days

Table 2 below shows the characteristics of study participants

**Table 2: Characteristics of participants**

<b><u>Characteristics</u></b>	(n=16)
<b><u>Sex</u></b>	
Male	4
Female	12
<b><u>Age (in years)</u></b>	
25-35	3
36-45	7
46+	6
<b><u>Religion</u></b>	
Christianity	12
Traditional	2
No religion	2
<b><u>Marital status</u></b>	
Married	4
Single	1
Co-habiting	3
Separated	2
Widow/widower	2
In a relationship	4
<b><u>Education level</u></b>	
Primary	6
Secondary	6
High School	3
None	1
<b><u>Employment status</u></b>	
Employed	3
Unemployed	10
Self-employed	3
<b><u>Take alcohol</u></b>	
Yes	9
No	7
<b><u>Smoke</u></b>	
Yes	6
No	10

In addition to the ART patients, key informants were recruited to provide perceptions of the factors that influence ART based on their experience of working with patients on ART. The

first group of key informants was twenty community caregivers comprising of 15 female and five males working in different locations around Pule Sefatsa Clinic. The second group consisted of the three female NIMART trained nurses who manage ART patients at the facility on monthly basis. The NIMART nurses had five years and above experience in the current role and are residing in the Bloemfontein sub-district, which is approximately one hour away from Botshabelo sub-district.

### **3.6 Data collection**

In-depth interviews and focus group discussions (FGD) were used as data collection methods. According to Chaleunvong (2009), an interview is a data collection technique that involves oral questioning of participants. This technique allowed the researcher to explore the factors influencing adherence. Individual in-depth interviews were held with ART patients and this was the most appropriate method because the researcher was exploring factors influencing ART adherence. Interviews were held in a quiet room at the clinic where participants were comfortable to respond without restrictions. Semi-structured interview guides were used for both individual in-depth interviews and key informant interviews (Appendix D). The interviews were conducted in either English or Sesotho depending on the participant's preference and the researcher probed the participants on each question to obtain relevant responses.

According to Kitzinger (1995), FGD is a form of group interview based on communication amongst research participants to get data. FGD were held with key-informants at the facility and they were selected because of their knowledge and position in the community, which enabled them to give more detailed information and deeper perception on the subject matter (Marshall, 1996). For the FGDs, the discussions were held on the 29<sup>th</sup> and 30<sup>th</sup> January 2018 and time was arranged with the participants in collaboration with the facility manager.

#### *3.6.1 Individual interviews with patients*

Individual interviews were done with 16 participants who received ART at the Pule Sefatsa clinic. Each participant was interviewed in a private consulting room for them to feel comfortable to respond to questions being asked and to ensure confidentiality as this was a sensitive subject. The researcher used a tape recorder to record the interviews, a notepad to

note any gestures observed during the interview and a laptop to read all the questions. The participation information sheet was read by the researcher, giving detailed information about the study. The participants signed an informed consent after deciding to participate in the study. All interviews were conducted in Sesotho as participants felt that this was the most convenient language to use. The interviews were held from 30<sup>th</sup> January 2018 to 09<sup>th</sup> February 2018 and the interview sessions lasted between 10 to 25 minutes.

### *3.6.1 Focus group discussions with healthcare workers*

FGD were held with two groups. The first group was with twenty community care workers working in the community and the second group discussion was held with NIMART nurses based at the facility. The discussions were held at the clinic premises. FGD with nurses was conducted in English while FGD with community care workers was conducted in Sesotho as they felt they would express themselves better in Sesotho. The time taken to hold the FGD was 33 minutes with NIMART nurses and an hour with community healthcare workers.

## **3.7 Data analysis**

The framework approach was used to analyse data collected from ART patients and key informants. The researcher followed six steps listed below when analyzing the data (Gale *et al.*, 2013).

*Familiarisation:* The researcher reviewed all raw data gathered so as to familiarise herself with the data and this was done by listening to the tape recorders, which were used during the interviews, going through the transcripts and notes captured. Information gathered from interviews conducted in Sesotho was translated to English by the researcher who is fluent in both languages. Key themes and concepts were then noted for further exploration.

*Identifying a thematic framework:* The researcher identified the most suitable framework by reviewing past qualitative studies done which relate to poor ART adherence. The researcher outlined concerns, issues, and questions derived from the aims and objectives of the study as well as comments that were raised by the participants during the interview. The information was grouped into descriptive labels (medication-related, individual-related, socio-economic related, social-cultural related and health systems related factors) that were mended and

explored.

*Indexing:* Coding was applied for all transcriptions using descriptive labels for both focus group discussion data and individual interviews data. The codes made it easy to identify transcribed information.

*Charting:* The researcher grouped the data according to themes that were related to form charts. Themes were fitted into various descriptive labels of the thematic framework. Each chart entailed a different theme, which was summarised into data.

*Interpretation:* The researcher used the charts that were developed in the previous step to describe themes and found an association between them to have logical explanations of the patterns derived. The objectives of the study were also incorporated when interpreting the data.

### **3.8 Rigour**

To ensure rigour, the trustworthiness of the study was reviewed within a qualitative lens and paradigm assumptions, which are triangulation, member checking, researcher flexibility, audit trail, thick, rich description and peer debriefing (Creswell & Miller, 2000).

Triangulation process among various sources of information was done by the researcher to review themes and similar categories (Creswell & Miller, 2000). The researcher verified individual viewpoints from a range of participants, which includes Key informants and ART patients and assessed similarities in the data gathered. The researcher used different sources of data being informants and ART patients to search for concurrence.

To ensure honesty in participants, each participant approached was given an opportunity to refuse to engage in the research. Only participants who were genuinely interested in participating in the study were enrolled and the researcher developed a rapport to make participants comfortable and free to provide true, reflective information. The researcher encouraged the participants to provide answers on challenges they face in terms of adherence and participants were told that all answers are useful and that there is no right or wrong response. Participants were encouraged to be honest, contribute ideas and talk of their views and experiences without fear of not receiving services at the facility or being penalized (Shelton, 2004).

An audit trail is a process which allows the observer to trace the development of the research from the decisions made and procedures followed throughout the research (Shelton, 2004). The researcher used a notepad and a tape recorder to capture key steps followed and every decision made throughout the study and this helped to keep track of information for the future should the study be replicated. The transcripts, the literature reviewed and all other soft copies used in the study have been encrypted and are kept on researchers' Google drive. A notepad used to record gestures of participants, information of activities carried out during data collection has been kept by the researcher.

The researcher reflected their personal beliefs, values, and biases that might influence the inquiry of the study (Creswell & Miller, 2000). The researcher ensured that her beliefs on factors influencing poor ART adherence as monitoring and evaluation professional within the ART programme did not interrupt the research process. The researcher was aware of her role is a monitoring and evaluation officer supporting the ART programme at the facility. The researcher's own opinions towards factors influencing ART adherence were diarized during the study to ensure consciousness of how this might affect data collection and analysis.

### **3.9 Ethics consideration**

Ethics clearance was obtained from the Biomedical Research Ethics Committee (BMREC) of the University of Western Cape (Appendix C) and Permission to conduct the study was received from Free State Department of Health Research committee (Appendix B). A meeting was held with the Mangaung department of health district manager to ask for permission to conduct the study and it was obtained.

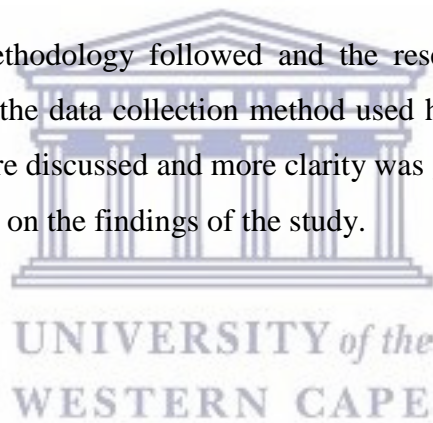
A participation sheet was read out to all participants and informed consent was obtained from the participants. The participants were assured that participating in the study was voluntary and no person would be penalized, loss their privilege, reprimanded or deprived of their rights for not participating. Information obtained during the interview and FGD were kept confidential. Information obtained from the participants was used only for the purpose of the research and all transcripts files and audio recordings were encrypted for security purposes. The personal data of the participants were protected by using codes instead of their actual names to protect the identification of participants and participants were informed about this.

A quiet, private room was arranged at the facility for the interviews to be held with the patients and a tape recorder and notepad were used to capture the data during the interview. All tools used to collect data that is, tape recorders, notepads and diaries were kept at the researcher's office in a lockable cupboard. Electronic files kept on a laptop were encrypted and only the researcher had access to the laptop.

The purpose of the study and the informed consent were clearly explained to study participants in order to get their permission to participate in the study. The interviews were conducted in both English and Sesotho languages, as this were the languages used by the population using the facility.

### **3.10 Summary**

This chapter outlined the methodology followed and the research design used. Issues of sampling technique used and the data collection method used have been discussed in detail. Strategies to ensure rigour were discussed and more clarity was given on ethics consideration. The following chapter focuses on the findings of the study.





## CHAPTER FOUR - RESULTS

### 4.1 Introduction

In this chapter, the results are presented. These results are based on the analysis of the data. These results are discussed as the main themes and sub-themes that emerged from data collected.

### 4.2 Summary of themes and sub-themes

The main barriers to adherence to ART in Pule Sefatsa clinic are presented in table 4.

**Table 4: Factors influencing poor ART adherence in Pule Sefatsa clinic.**

<b>THEMES</b>	<b>SUB-THEMES</b>
Medical related Factors	Side Effects
Socio-economic factors	Perceived Stigma and discrimination Perceived Lack of family support Poverty Food insecurity Work-related commitments
Health systems factors	Access to ART (Medication stock-outs) Long waiting times Staff shortage Poor service delivery
Individual factors	Forgetfulness Depression

### 4.3 Medical related factors

Medical-related factors acting as barriers to ART adherence include side effects experienced by patients due to the medication. Side effects emerged as the main theme from interviews.



#### 4.3.1 Side effects

Poor adherence was due to side effects experienced by ART patients. Most patients revealed that after taking ART, they felt sleepy, had terrifying nightmares and were hallucinating. Patients also reported body transformations like gaining weight due to ART treatment.

*“The medication used to make me feel sleepy when I first started using them. They used to also give me nightmares, in the beginning, and I would dream about traditional healers and witchcraft sometimes and stuff like that.”* (41 years old female).

*“I used to have terrible nightmares so much that sometimes I would wake up in the middle of the night. I would wake up to confirm if these things I was seeing were indeed happening.”* (60-year-old female).

*“I experienced changes in my body. I used to have a proportionate body but after taking medication, my breasts became bigger and the lower part of my body became smaller...”* (40-year-old female).

#### 4.4 Socio-economic factors

Socio-economic factors identified from the data analysis are poverty, lack of family support, work-related commitments, food insecurity, stigma, and discrimination.

##### 4.4.1 Perceived Lack of family support

Lack of family support emerged as a sub-theme and patients indicated that their family members did not become supportive after they disclosed their HIV status. Most patients have faced rejection from their spouses and other family members, for instance, siblings, and children. Some patients reported being rejected by their parents. However, most patients know the importance of disclosing their status to members and spouse to illuminate new infections.

*“My spouse knows (I am HIV positive) but he has not yet accepted it. After I told him about my status, he just kept quiet and just looked at me. Even*

*currently as I take my medication he still does and says nothing.” (45-year-old female).*

*“My husband told me that he could not live with a sick wife (HIV positive) because we could not have sexual intercourse anymore. That’s when he left me and we have not communicated since then.” (52-year-old female).*

*“I think my partner got scared when I first told him (I am HIV positive) and then after that he just kept quiet. But after that never talks about my status and he has not tested for HIV yet” (47-year-old female).*

#### *4.4.2 Perceived Stigma and discrimination*

Adherence to ART was influenced by HIV related stigma and discrimination. Patients indicated that they do not disclose their HIV status to work colleagues, some community members, and family members for fear of being stigmatized or being rejected. They have revealed that some people in the society do not talk to them and they distance themselves from the ART patients after knowing about their HIV status.

*“He (husband) came with me to the clinic only once, you know how men are and when he heard that his results were different from mine that was the last time he went to the clinic. But when it comes to the community, they will always have something to say behind my back of course.” (38 year old female)*

*At work, I have not yet informed my manager about my (HIV) status because I do not want him to treat me differently from other colleagues.” (40-year-old female).*

*“I haven’t told my colleagues (about HIV status) because I think they will discriminate against me and it is not a single person. I don’t work under one person and I haven’t felt like telling them about my situation. Even when I need a day off I just tell them that I am going to the clinic.” (28-year-old male).*

*“Some people in the society have changed towards you. For instance, when you are greeting them or talking to them you will find that they are a bit hesitant to talk to you but then I just ignore them.”* (38-year-old female).

*“At first, that’s when people used to harass those who had HIV by distancing themselves. Some of my friends distanced themselves from me and now we are no longer friends.”* (41-year-old female).

*“The other thing I am still ashamed of is telling my three children about my situation because I am afraid they won’t be able to accept my (HIV) status.”* (47-year-old female).

#### 4.4.3 Poverty

Participants also indicated that poverty hindered ART adherence. Some patients indicated that being breadwinners in their families has put a lot of strain on them and the responsibilities they have to carry sometimes discourage them to take medication.

*“Others (ART patients) are defaulting because they want to stay receiving the social grant because when they are adhering they are going to be healthy like.”* (Female healthcare worker- nurse)

*“I spend most of my time here at the clinic and that makes it difficult for me since I also have to be at work. That is, the amount of time I spend here makes it difficult for me to go back to work on the same day of collection of medication. It is a complicated issue because I have to take my treatment and I also have to keep my job so that I can support my children and myself financially. But this makes me miss my treatment appointments from time to time since I have to check how many off-days are available...”* (43-year-old male)

*“.....again, last year was a problem because I had a job and asking for an off day every time to spend a full day here did not sit well with my employers. I mean they know that you will be off on a particular day every month and*

*that is some of the challenges. ’’ (40 year old female)*

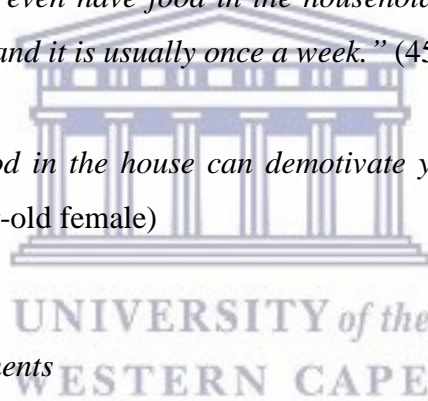
#### 4.4.4 Food insecurity

Food insecurity is one of the barriers to ART adherence. Patients revealed that not having food in the house prompted them to miss the treatment. Some patients indicated that they sometimes ask neighbours for food to take medication with but if they are not given any, they do not take treatment.

*“What demotivates me from taking my medication is lack of food in the household. You will find sometimes I do not have food in the house and then I do not take the pills due to that.” (34-year-old female)*

*“Sometimes I do not even have food in the household to help me take my medication properly and it is usually once a week.” (45-year-old female)*

*“The shortage of food in the house can demotivate you from taking your medication” (31-year-old female)*



#### 4.4.5. Work-related commitments

Work-related commitments are one of the barriers to ART adherence in Pule Sefatsa clinic. Patients revealed that they value their work more than taking treatment and since going to the clinic takes the full day, they choose to go to work. Their salaries are cut for the day off they spent at the clinic and this is challenging since they need the money as well.

*“Sometimes I do miss my clinic appointments due to the thought of the time I will have to spend here. For example, let’s say my off day (from work) starts from tomorrow (Thursday), and on Saturday I have to be back at work, that would have made it hard for me to come to the clinic because that would mean I would have to spend my entire Friday here at the clinic and have to be back at work on Saturday.” (41-year-old female)*

*“...And that (long waiting times) becomes a greater problem when you are*

*working because you did not go to work because you have to collect treatment. In addition, sometimes you are told to come the following day, but how do you do that when you had to ask for a leave at work? ” (28-year-old male)*

#### **4.5 Health system factors**

The way services were rendered and organised affected patient’s adherence to ART. This includes access to ART, staff shortage, long waiting times and poor service delivery. Sub-themes revealed by most patients were long waiting times, drug stock-outs and poor service delivery.

##### *4.5.1 Poor service delivery*

Several patients were not adherent to ART because they reported receiving poor services from the Pule Sefasa clinic. Reported unsatisfactory services received by patients include pharmacy closing at 4:00 PM, which makes it difficult for patients seen by the clinicians after 4:00 PM to receive their medication. This requires patients to come the following day. Some patient’s individual clinical stationery have been misplaced at the clinics and they were not given any services.

*“They (Health care workers) close the pharmacy at 4:00 pm, and sometimes I leave the clinic at around 5:00 pm and you will find that I do not receive my pills for about a week due to that time mismatch. They will tell you to come to collect the pills the following day....” (34-year-old female)*

*“Sometimes you even find that after all that waiting, your file (clinical stationery) is missing, hence you leave the clinic with no treatment.” (60-year-old female)*

*“My problem is when I get here after 6 months and they take my blood and say that I should wait for the results. Afterwards, I was told that the results are not yet out and what am I expected to be taking (treatment) during that time? They will tell me to come the following week and the following week*

*they (results) will still not be there. Then that made me stop taking my treatment because I felt that it was pointless to visit the clinic over and over without getting any services.” (40-year-old male)*

*“...test and treat (test for HIV and provide ART) and remember we are not having those we are helping with DRT (Drug Readiness Training). They (Patients) will be tested, come into our system and our clinic is overcrowded so we are trying to counsel them but the time is too limited hence we tend to push numbers and not provide quality services” (Female healthcare worker-nurses)*

#### 4.5.2 Long waiting times

ART patients and community care workers indicated that long waiting times is a barrier to ART adherence. Patients revealed that they arrive at the facility around 7:00 AM and leave around 6:00 PM. They spend the entire day at the facility and this limits them from conducting crucial activities such as going to work. One patient suggested that the facility should move all stable patients to fast-lanes as this is going to save time for both patients and clinicians.

*“The time we spend here is too long and that is demotivating honestly. We take too long here and every month you must be here. They should at least give us three months because when we get here the sister barely asks anything, all she does is writing. Then what is the use of coming here every day because all they do is write.” (26-year-old female)*

*“The thing that irritates at this clinic is the long hours we spend here especially because I come here during my off-days from work. You just can't have a rest from work since you spend the entire day here.” (47-year-old female)*

*“I got here at 7: AM and I will leave at around..., it all depends on what they have to do to me, sometimes I leave at around 3: PM, and sometimes at 4:00 PM. Sometimes as a person, I get tired of the waiting, and they (health*

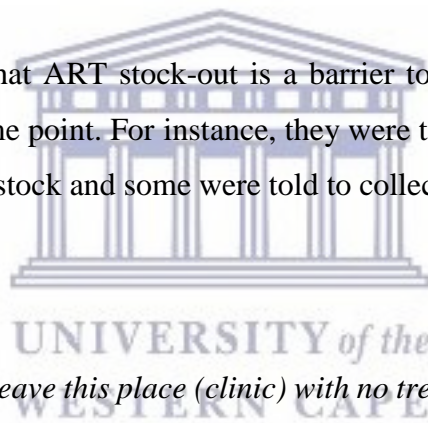


workers) do not explain what is going on here in the clinic. I am not complaining that much but it would be great if we were informed as to what is going on in the clinic.” (40-year-old female)

“The most irritating factor of this clinic is the amount of time you spend here waiting to be served. The waiting time is demotivating. Before coming to the clinic all you think about the day before is the amount of time you are going to spend here. You have to make sure when you come here that at least you have food that you will eat during the day since you are going to spend a lot of time here. For instance, I got here at around 6:00 AM and I am going to leave at around 4 pm when the clinic closes... (43-year-old male)

#### 4.5.3 Medication stock-outs

Some participants specified that ART stock-out is a barrier to adherence. They reported to having a limited supply at some point. For instance, they were told to collect medication after a week since ART was out of stock and some were told to collect medication on the following days



“...Yes, sometimes I leave this place (clinic) with no treatment. They will tell me to come back the following week. If I still have pills then I will continue taking those but if I do not have them then I just stay waiting.” (60-year-old female)

“I have experienced a day when the clinic ran out of ARVs and we were told to come to get them the following day.” (41-year-old female)

#### 4.5.4 Shortage of staff

Participants indicated that the shortage of staff was a barrier to ART adherence. Staff shortage in the facility prolongs the waiting times because the nurse to patient ratio is too high in the facility.

*“...another thing is that, there is a shortage of staff in the clinic, as it is, there are only three nurses at the moment and they have to provide service to everyone here and the clinic is very full so what I am saying is the clinic is too small to cater for people residing in all the 6 sections”* (Male healthcare worker- community)

*“I think the shortage of staff really demotivated them (Patients) to visit the clinic. Sometimes they will just leave because they have been waiting for a very long time”* (Female healthcare worker- nurse)

#### **4.6 Individual factors**

ART adherence can be influenced by individual factors and this include age, depression, forgetfulness, substance abuse, poor self-efficacy, low health literacy, and perceived wellness. However, participants have revealed that only factors are barriers to adherence namely; forgetfulness and depression.

##### *4.6.1 Forgetfulness*

Forgetfulness was identified as one of the sub-themes and participants indicated that they usually forget to take their medication when attending ceremonies or when their daily mobile phone reminders were disabled.

*“I once forgot to take them when I was out on a party.”* (60-year-old female)

*“Apart from forgetting to take my medication every now and then, I haven't experienced any challenges related to taking this medication.”* (45-year-old female)

*“Sometimes you may find that I am not in the house at the time I am supposed to take my treatment hence I forget to take the treatment.”* (26-year-old female)



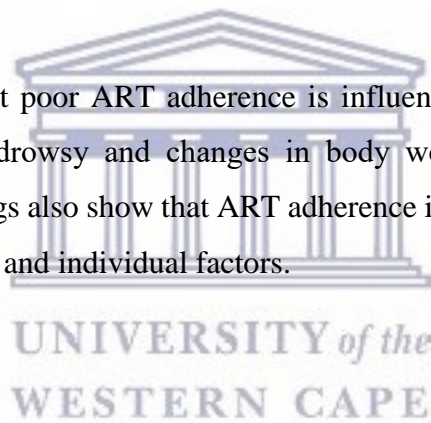
#### 4.6.2 Depression

Patients with depression develop negative thoughts and feelings of hopelessness, which discourage them to take medication. Furthermore, depression increases social isolation, which widens the gap between patients and support networks that would encourage adherence (Memiah *et al.*, 2014). This is what one participant has revealed they feel most of the time when they have to take treatment. The patients indicated that this feeling has discouraged her to take treatment.

*“Sometimes I just feel annoyed about everything. I feel like I could just live alone with nobody but myself, not even the children.”* (38-year-old female)

#### 4.7 Summary

The study results indicate that poor ART adherence is influenced by multiple factors. Side effects like patients feeling drowsy and changes in body weight have affected patient’s adherence to ART. The findings also show that ART adherence is hindered by socio-economic factors, health systems factors and individual factors.



## CHAPTER FIVE - DISCUSSION

### 5.1 Introduction

The purpose of the study was to explore the factors that influence poor adherence to ART among patients receiving care at Pule Sefatsa clinic. The key findings presented in chapter four are discussed in this chapter in light of the existing literature. The discussions in this chapter are categorised medical, socio-economic, health systems and individual factors.

### 5.2 Medical related factors

Medication-related factors found in the study are related to medication side effects experienced by ART patients consisting of weight gain, hallucinating and patients feeling drowsy after taking the treatment. The results of this study are similar to findings of Croome *et al.* (2017) and Fonsah *et al.* (2017). Patients feeling sick after taking treatment hindered their adherence to ART (Croome *et al.*, 2017). One of the factors that patients on ART face are the adverse drug reactions. ART patients have experienced gastrointestinal effects, central nervous system challenges, dermatological effects and metabolism challenges (Bhatti *et al.*, 2016).

The findings of this study revealed that patients were not adherent to treatment because they felt drowsy after taking ART. The results of this study are similar to those of Renju *et al.* (2017) where the side effects experienced by patients ranged from dizziness to headaches severe enough to prevent them from leaving the house or carrying for themselves. These side effects also prohibited some patients to attend clinic visits (Renju *et al.* 2017). More research should focus on examining the interplay between patient characteristics, such as ARV side effects and their impact on adherence. This can assist policy and guidelines to focus more on ART side effects and how they can be reduced (Al-Dakkak *et al.*, 2012).

### 5.3 Socio-economic factors

A number of socio-economic factors were found to hinder ART adherence amongst patients in Pule Sefatsa clinic and these included: stigma and discrimination, lack of family support, poverty, food insecurity, and work-related commitments.

#### 5.3.1 Stigma and discrimination

This study established that patients do not disclose their HIV status for fear of being

discriminated or rejected either at the workplace, by family members or by community members. The results of this study are comparable to the results of a study conducted in Uganda. Women who stayed with their husbands mentioned that they only take treatment when their husbands are away from home since they fear rejection from their spouses (Buregyeya *et al.*, 2017). A study conducted in Kenya also found that patients do not disclose their status to key people who can support them, either community or family member because patients pre-determine that people are not going to accept them hence they opt to default (Micheni *et al.*, 2017). Another study done in Uganda showed that HIV positive men on treatment feared that disclosing their HIV diagnosis to employers and work colleagues can limit job offers and affect any collaborative work that would be done in the workplace because of their HIV status (Sui *et al.*, 2012).

To eliminate stigma and discrimination, more interventions need to focus on intensifying health education campaigns that address stigma and discrimination (Eyassu *et al.*, 2016). Patients feel that they would rather miss follow-up visits required by ART clinics since they do not want to be harassed and discriminated by managers who also refuse to grant them time off-work for clinic attendance (Nachega *et al.*, 2014). Patients have reflected that they would rather risk having unprotected sex than to disclose their HIV status and they fear being rejected and stigmatized (Nabukeera-Barungi *et al.*, 2015). Patients experiencing stigma within communities have difficulty with ART adherence (Hodgson *et al.*, 2014)

### 5.3.2: Lack of family support (social support)

Some of the patients interviewed revealed that they did not get family support after disclosing their HIV status, that is, some of them were rejected. Other patients also indicated that they still could not disclose their HIV status to their children because they felt ashamed. The results of this study are similar to findings of a systematic review study done across sub-Saharan Africa. The main determinants found to hinder adherence were poor social support experienced by patients on treatment (Heestermans *et al.*, 2016). A study done by Afolabi *et al.* (2013), showed that family support is important in improving ART adherence, therefore, there is a need to educate family members on stigma reduction and how to care and support for their HIV positive relatives. In a study done Uganda, some healthcare workers acknowledged that they do not encourage discordant couples hence they had not been providing efficient counselling sessions and this has lead clients not to seek disclosure support (Inzaule *et al.*, 2016).

A study done in Sub-saharan Africa cited that social support obtained from partners, children, friends and family promotes ART adherence for instance, family members can remind the patient to take medication and they can also motivate the patients to take required diet when taking treatment (Wekesa, 2017). A study done in Malawi suggest otherwise, in that, partners support did not motivate patients to be adherent. The study suggest that some patients do not take medication even though they have full support from their spouse, for example, one women took the money her husband gave her for transport to the clinic and used it for other things (Kim *et al.*, 2016). Another study done in South Africa suggest that social support on its own does not promote ART adherence. This study suggest that better functioning families are more likely to enhance high levels of adherence to patients (Masquillier *et al.*, 2014). This is coherent with a study done in Uganda, which showed that disclosure to a friend of family member did not improve ART adherence (Shumba *et al.*, 2013).

### 5.3.3: Poverty and food insecurity

It has been found that inadequate basic needs like access to food, access to housing and transport demotivate patients from taking treatment (Cornelius *et al.*, 2018). Most of the patients interviewed were unemployed who do part-time jobs and some work as daily labourers and having to visit the facility for a full day becomes money lost to them. A study by Bezabhe *et al.* (2014) showed that patient's movement due to work, unavailability of nearby clinics and minimal income not sufficient to cover food costs hinder ART adherence.

The study revealed that not having enough food demotivates some ART patients to take their treatment. Hindrance to take treatment due to food insecurity was also indicated by Kalichman and Grebler (2010). According to Kalichman and Grebler (2010), patients did not adhere to treatment because they had no food to accompany their treatment. Similarly, lack of nutritional support has been identified as a reason for poor adherence that is, patients prefer not to take ART medication when there is no nutritious food to take the treatment with (Adejumo *et al.*, 2015). Food insecurity hinders ART adherence in that patients stop treatment when food is unavailable to avoid aggravated (gastrointestinal) side effects or because taking ART without treatment increased hunger (Heestermans *et al.*, 2016). A facility study done in Western Cape Province- South Africa showed that patients fail to take treatment at times because of poverty and unemployment that is, patients could not raise money for food and eat properly before

taking medication (Azia, Mukumbang & Van Wyk, 2016). This findings are similar to findings of a facility study done in the Eastern Cape Province – South Africa. The study showed that food security and poverty were barriers to ART because cost of buying food and transport costs promoted them to miss treatment (Kheswa, 2017).

#### 5.3.4 Work related commitments

The study revealed that patients miss taking the treatment because they have to go to work. The participants indicated that since going to the clinic takes the full day and this results in salaries cut for days missed at work, they opted not to go to the clinic. This finding is consistent with the findings from a study done by Mbonye *et al.*, (2013). A study conducted in Uganda also showed that employed patients struggle to juggle work routines and proper adherence (Mbonye *et al.*, 2013). Patients have also cited that being busy with work has hindered their ART intake, for instance, demanding work schedules make it challenging to take treatment (Gare *et al.*, 2015). Another study done in South Africa showed that patients had been deprived by their employers to visit the clinic therefore, they missed treatment (Kweshwa, 2017).

### 5.4 Health system factors

Patients revealed that health system-related challenges discouraged them from taking treatment and they pointed issues on access to ART, having to approximately full day at the facility before consultation and poor service delivery. According to Scanlon and Vreeman (2013), poor adherence is associated with cost of treatment, lack of integration of health services, long waiting times, inadequate laboratory resources and confidentiality of services.

#### 5.4.1: Access to ART (Medication stock-out)

The study revealed that patients' poor adherence is sometimes related to medication stock-out or patients given medication which does not last for the stipulated treatment period. Patients indicated that they are sometimes given medication for a few days and are told to collect their medication in subsequent days, which leads to increased transportation costs for clinic visits per month. These findings are similar to those of Paredes *et al.* (2013), which indicate that patients' adherence is hindered by medication stock-outs at facilities. There is a need to improve drug supply chain within the health sector so as to have drug formulation for the management of HIV and to minimize both individual and facility costs. According to Bekker *et al.* (2014),

drug-stocks can be costly to patients affecting adherence to medication and often burdening health staff.

#### 5.4.2: Long waiting times

It is apparent that patients are not comfortable with long waiting times. Almost all patients interviewed indicated that they normally wait for consultations with clinicians for at least five hours. One of the reasons for long waiting times was cited to be the shortage of staff at the facility. The findings of this study are similar to the findings of Ngarina *et al.* (2013). The study revealed that patient's adherence was affected by long waiting times at the facility (Ngarina *et al.*, 2013). To reduce the long waiting times of patients at facilities, difference adherence models could be implemented. According to Haberer *et al.* (2017), improvements in structural and logistical elements in the health system can improve the overall efficiency of crowded service delivery centres, for instance, implementation of differentiated ART delivery models such as fast lanes, adherence clubs and support groups for 'stable' patients. To ease the burden of patients, the facility can decant all stable patient to community-based organizations and adopt the community adherence club models.

#### 5.4.3: Poor service delivery

The study established that patient's adherence is hindered by poor services offered by the clinic. The findings reveal that some ART patients visited care facilities without getting any services due to the poor organisation of the health system. For instance, the patient's blood taken for test repeatedly with no results given to the patients and no further clinical management done. These events have led to patients not being monitored according to guidelines, so patients get discouraged to visit the facility and take medication. The findings of this study are similar to the findings of Colvin *et al.* (2013), who found that poor follow-up and tracking of patients, weak monitoring and communication systems demotivate the adherence of patients. Patients do not feel a sense of emergency or care from the clinics, hence they resort to giving up on treatment. Loss of clinical stationery by facility staff was one of the factors experienced by the patients. The study revealed that patients were not managed according to guidelines and were told that no services will be given to them unless the clinic finds their clinical stationery. This led to patients not given any ART services at the facility.



## 5.5 Individual factors

The findings of this study show that ART adherence is hindered by individual factors including patients forgetting to take treatment and depression.

### 5.5.1: Forgetfulness

The study revealed that patients forgetting to take their treatment affects adherence. Patients revealed that they forget to take treatment when they are going out with friends, or when they are attending traditional ceremonies and when their mobile reminders fail. The findings of this study are similar to findings by Goular *et al.* (2013) and Adejumo *et al.* (2015). According to Adejumo *et al.* (2015), the reasons why patients forget to take treatment are; patients not having acute illness and difficulty in organising medication intake schedule. Another systematic review study showed that ART patients forget to treatment due to being away from home and a change in routine and to overcome this challenge individuals should be given counselling on how to routinise medication taking in a way that fits daily activities (Shubber *et al.*, 2016). According to Tomori *et al.* (2015), patients' adherence can be improved by using mobile telephone short message service (SMS) consisting of medication reminders, motivational messages and addressing any issues experienced by patients. Another study by Tsega *et al.* (2015) showed that patients forgetting to take their medication hindered ART adherence.

### 5.5.2: Depression

The study results indicated that depression was another barrier to ART adherence. This is coherent with a study done by Abas *et al.* (2014), which reveals that depression may affect adherence due to constant negative thinking, deficits in concentration and problem solving brought by depressed mood swings. A study done by Memiah *et al.* (2014) indicates that depressed ART patients are prone not to take treatment consistently and the study also cites that feeling hopeless and discouraged promotes poor adherence. Therefore, interventions should focus on providing psychological and intense psychotherapy to ART patients (Chibanda *et al.*, 2014). In addition, more resource should be allocated to integrating mental health services with HIV care to enhance medication adherence (Whetten *et al.*, 2013).



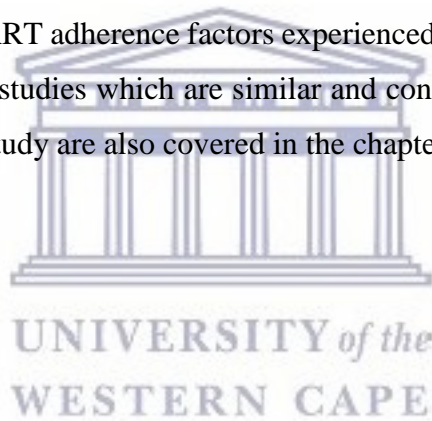
## **5.6 Limitations of the study**

The study is centred on HIV and adherence to medication and given the sensitivity of the topic, there was a possibility that participants may provide false responses to avoid being judged by the researcher. The researcher assured participants that confidentiality will be kept and factors discussed during the interviews will not be shared with facility staff.

The participant's data collection process to reach the desired patients was another challenge. Some of the patients did not adhere to their clinic visit dates and this prolonged the period of data collection process. The patients were reached because the researcher visited the facility for seven consecutive days so as to reach patients that have missed their appointment dates.

## **5.7 Summary**

This chapter was focused on ART adherence factors experienced by patients in Pule Sefatsa. It presents the findings of other studies which are similar and conflicting to the findings of this study. The limitations of the study are also covered in the chapter.



## CHAPTER SIX – CONCLUSION AND RECOMMENDATIONS

### 6.1 Introduction

The chapter covers the conclusion and recommendations of the study. It provides details on strategies and intervention that could be used to improve ART adherence at Pule Sefatsa clinic.

### 6.2 Recommendations

Collaborative work is required to address poor ART adherence in Pule Sefatsa. Therefore, the findings of the study can assist stakeholders and policymakers at district, provincial and national level to develop interventions and strategies for improving ART adherence in Pule Sefatsa clinic as well as other clinics in the Mangaung district.

#### *6.2.1 Recommendations regarding medication-related factors*

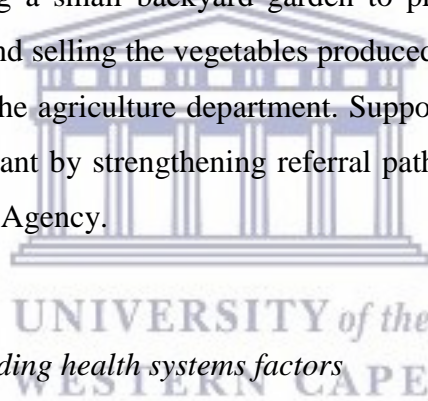
Medication-related factors revealed by ART patients included feeling drowsy, hallucinating, and changes in body weight. Drug readiness training for patients beginning ART treatment can assist patient to be more equipped about ART and HIV side effects. This is where patients who have been on treatment for a long time can share their life ART experiences with newly enrolled patients. Moreover, newly initiated patients should be linked to community caregivers from community-based organizations. The role of community caregivers would be to provide knowledge to ART patients and also link them to other HIV infected people within the same area and this will enable the patients to communicate about some of the complications they are experiencing and how they can handle them.

#### *6.2.2 Recommendations regarding socio-economic factors*

Stigma, discrimination, and lack of family support was cited to be hindering adherence to ART. Therefore, the involvement of different stakeholders within the community should be encouraged to address this challenge. For instance, faith-based organisations, traditional healers, the education sector and the nearest police station can be involved in stigma and discrimination awareness campaigns. These are organisations that are influential within the community and can assist in illuminating stigma and discrimination through road shows and awareness campaigns. Furthermore, patients revealed that they face stigma and discrimination

in their homes, at work and in their communities, therefore, interventions developed to decrease stigma and discrimination should focus on these points for maximum efficiency. Patients also revealed that they faced rejections by their partners after disclosing their HIV status and this discouraged them to take treatment, therefore it is essential to motivate couple HIV testing and counselling. This means partners can be well informed about HIV infection and treatment without passing any judgment and can, therefore, provide necessary support to their partners. Moreover, family-based testing and treatment intervention should be introduced in the ART programme. This will also allow family members to be educated about HIV and the importance of ART adherence.

Poverty and food insecurity were revealed to be barriers to ART treatment in the study. It is therefore important to involve multiple economic sectors to increase food security and illuminate poverty. To increase food security, patients can be involved in income generating activities, for instance, having a small backyard garden to produce nutritious foods to be consumed by the household and selling the vegetables produced from the garden and this can be done with guidance from the agriculture department. Support should be given to patients who qualify to get a social grant by strengthening referral pathways from the facility to the South African Social Security Agency.



### *6.2.3 Recommendations regarding health systems factors*

The study revealed various health systems issues as barriers to ART adherence. Patients and healthcare worker cited medication stock-out, long waiting times, staff shortage and poor service delivery as factors linked to poor ART adherence. To bridge medication stock-out gaps, the supply chain management system should be strengthened. The facility should place an order for medication using quality data indicating current patients on ART at the facility, estimates of new ART enrolments per month, order on time and strengthen the use pharmacy standard operating procedures by staff. Long waiting times by patients are due to staff to patients' ratio which is very high. To ease the burden of high volume patients utilising the facility ART services, there is a need to decant ART patients to differentiated ART delivery models. These models will accommodate stable patients with two consecutive viral loads suppressed, patients over eighteen years as per adherence club guidelines. There is a need to involve the clinic committee, ward councillor and carry a number of community dialogues when opening a new community adherence club. Furthermore, the facility can operationalise Centralised Chronic

Medicines Dispensing Distribution (CCMDD) model to ease the burden and this is where stable patients are given six months prescriptions to collect medication without consulting with a clinician unless they have complications.

Poor service delivery is one of the barriers to ART adherence amongst patients. The study revealed that misplacement of patient clinical stationery within the facility demotivated patients from visiting the clinic. Therefore, there is a need to adopt a filing system according to the District Health Information System (DHIS) policy. Clinical stationery should be filled according to patient folder numbers and clinical appointment dates for easy access. The study revealed that there is no procedure followed for monitoring blood. The study also revealed that patients felt discouraged to take treatment because their blood was taken for monitoring repeatedly without any issue of results. The facility staff should be encouraged to use blood results machine placed (PIMA) in the facility to monitor viral load. There should be a designated staff member to handle filling, recording and capturing of blood results on the clinical stationery.

#### *6.2.4 Recommendations regarding individual factors*

The study revealed that patients forgetting to take medication and feeling depressed hindered adherence to ART. With regard to patients forgetting to take medication, healthcare workers need to incorporate mechanisms to remember to take medication during adherence sessions. For instance, patients should be advised at convenient times to take medication and the use of gadgets as reminders. Mental health component should be incorporated into HIV management. For instance, HIV positive patients should also be screened for mental health in order to treat those that screen positive.

### **6.3 Conclusion**

Poor adherence to ART is shaped by different dynamic, yet complex factors ranging from individual, medical, socio-economic and health system factors. The findings of the study propose that poor ART adherence is linked to limited health system resources, weak social support, and limiting socioeconomic status. Therefore, it is crucial for HIV programmes and interventions to put more focus on addressing these factors to increase adherence levels and therefore prolong the life expectancy for ART patients.

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## APPENDICES

### Appendix A: Mangaung Department of Health approval letter



TO:  
Local Area Manager: Mr K.P Koalepe  
Facility Manager: Ms M.G Masilo  
**BLOEMFONTEIN**  
**9301**

Dear Managers

**SUBJECT: PERMISSION FOR MS T JANKIE FROM THE SCHOOL OF PUBLIC HEALTH TO CONDUCT RESEARCH ON FACTORS THAT INFLUENCE ADHERENCE TO ART AMONGST PATIENTS AT PULE SEFATSA HEALTH CARE CLINIC IN MANGAUNG METRO**

The above mentioned subject and attached correspondence approved by the HOD bears reference.

Kindly note that permission is hereby granted for Ms T Jankies to conduct a research on the above mentioned matter at Pule Sefatsa Clinic.

Trust you will find the above in order

Your sincerely


  
**MS JN RAMAROU-MAKHOALI**  
**PHC MANAGER: MANGAUNG METRO**

**DATE: 16 JANUARY 2018**

Ms. N.J. Ramarou-Makhoali: PHC Manager  
Mangaung Metro (FSDOH)  
FSPC Building, Bloemfontein 9300  
Tel: (051) 487 2194, Email: [njramarou@health.gov.za](mailto:njramarou@health.gov.za)

[www.fs.gov.za](http://www.fs.gov.za)

## Appendix B: Free State Province Department of Health approval letter

 **health**  
Department of  
Health  
FREE STATE PROVINCE

07 November 2017

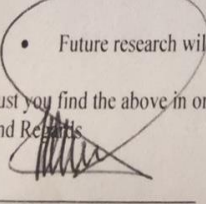
Ms. T Jankie  
School of Public Health  
Faculty of Community and Health Science  
UWC

**Dear Ms. T Jankie**

**Subject: Exploration of factors that influence adherence to ART amongst patients at Pule Sefatsa primary health care clinic in Mangaung district, South Africa.**

- Please ensure that you read the whole document. Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent form for each participant must be provided.
- Serious Adverse events to be reported to the Free State department of health and/ or termination of the study
- Ascertain that your data collection exercise neither interferes with the day to day running of Pule Sefatsa Clinic nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and please do not obtain information regarding the identity of the participants.
- **Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).**
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of Western Cape and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee the University of Western Cape and to Free State Department of Health.
- **Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to [sebeclats@fshealth.gov.za](mailto:sebeclats@fshealth.gov.za) before you commence with the study**
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution manager/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day
- Future research will only be granted permission if correct procedures are followed see <http://nhrd.hst.org.za>

Just you find the above in order.  
and Results



D Motau  
AD: HEALTH  
te: 8/11/2017



## Appendix C: University of Western Cape ethics approval letter



### OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535  
South Africa  
T: +27 21 959 2988/2948  
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18 October 2017

Ms T Jankie  
School of Public Health  
Faculty of Community and Health Sciences

**Ethics Reference Number:** BM17/8/12

**Project Title:** Exploration of factors that influence adherence to ART amongst patients at Pule Sefatsa Primary Healthcare Clinic in Mangaung District, South Africa.

**Approval Period:** 17 October 2017 to 17 October 2018

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

*Please remember to submit a progress report in good time for annual renewal.*

*The permission from the health facility/provincial health department must be submitted for record-keeping purposes.*

The Committee must be informed of any serious adverse event and/or termination of the study.

A handwritten signature in black ink, appearing to read 'Josias'.

*Ms Patricia Josias  
Research Ethics Committee Officer  
University of the Western Cape*

**PROVISIONAL REC NUMBER -130416-050**

## Appendix D: Interview for ART patients participants

### Interview guide

Exploration of factors that influence adherence to ART amongst patients at Pule Sefatsa primary health care clinic in Mangaung district, South Africa.

#### SOCIO-DEMOGRAPHICS (Tick where appropriate)

1. Sex:     Male     Female
2. Age in years \_\_\_\_\_
3. Religion:     Christianity     Traditional     Islam     No religion     other
4. Marital status:  Married     Single     Cohabiting     Separated     Divorced  
 Widow/Widower    In a relationship
5. Highest educational level attained:  Primary     Secondary     Tertiary    High school  
 None
6. Employment status:     Employed     Unemployed     Self-employed
7. Where do you live? \_\_\_\_\_
8. With whom do you live with?     Husband/wife     Partner     Family     Friends  
 Alone
9. When did you know you had HIV? \_\_\_\_\_
10. When did you start the HIV treatment? \_\_\_\_\_

#### Individual- factors

1. What helps you remember to take treatment?  
*Prompts: Are there times when you miss a dose or forgot to take a dose?*  
*Are there times when you do not feel like taking medication?*
2. What is most challenging in taking the treatment?
3. Do you take alcohol? \_\_\_\_\_
4. Do you smoke? \_\_\_\_\_
5. What were your perceptions about ART before you started treatment?  
*Prompts: How does treatment work? Does it cure HIV, Kill HIV, reduces HIV, makes your body strong? What would happen to you or the HIV virus if do not take the medicine regularly?*
6. What are your perceptions about ART now that you are on treatment?



*Prompts: How does treatment work? Does it cure HIV, Kill HIV, reduces HIV, makes your body strong? What would happen to you or the HIV virus if do not take the medicine regularly?*

7. Do you ever feel you are healthy enough not to take medication?

### **Medical -related factors**

8. How many ART tablets do you take per day?

*Prompts: Do you take fixed-dose combination? If yes, for how long have you been fixed-dose combination?*

9. Do you take any chronic treatment other than ARVs?

*Prompts: How many tablets per day?*

10. Have experienced any side effects since you started taking treatment?

### **Health System factors**

11. How do you find the service offered at the clinic?

*Prompts: What can be improved? Do you at times feel demotivated to go to the clinic because of services? Do you always have medication in stock?*

12. How is your relationship with a health care provider?

*Prompts: Do you see the same nurse in each visit/ familiar face?*

13. How long do you have to wait to see the health care provider?

*Prompts: what is the longest time you have waited? How did it make you feel?*

14. Are data clerks friendly?

*Prompts: have you experienced any mistreatment?*

### **Socio-economic factors**

15. What is your opinion about taking medication after meals or before meals?

*Prompts: Do you feel it is necessary to take medication with meals? Have you missed taking treatment with meals?*

16. What challenges have you faced since knowing your HIV status?

*Prompts: Do you feel ashamed of your HIV status? Has your companion's treatment changed since you disclosed your status?*

17. Have you told anyone about your HIV status?

*Prompts: What was their reaction (support, rejection)? How are they related to you?*

18. Do you need transport to reach the clinic?

*Prompts: How long does it take you to reach the clinic? How much money do you use for the bus fair? If you walk to the clinic, how long does it take you? Is it safe to walk?*

**Social-cultural factors**

19. Have you used alternative treatment for a cure?

*Prompts: Traditional medicine? Prayer? Fasting?*

**Thank you very much for your time and effort.**



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## Appendix E: Interview guide for NIMART nurses

### Interview guide

Exploration of factors that influence adherence to ART amongst patients at Pule Sefatsa primary health care clinic in Mangaung district, South Africa.

### Key informant Interview guide for the Nurses

I would like you to tell me a little bit about yourself and your work)

1. Can you please tell me about your role in the facility?
2. Can you tell me whether you work with ART patients if so, how long have you worked with them in this facility?
3. Where are you currently residing? (*Probe: how long do you take to get to work?*)
4. Can you give a description of your role in the community for ART patients? (*Probe: What service are you providing for Pule Sefatsa community? What are the key socio-economic status in the area e.g poverty, food security, stigma and discrimination, transport challenges?*)
5. Based on your experiences, what do you think about the general atmosphere at the health facilities for ART patients (*Do they have access to any information at any given time on the importance of ART adherence* )
6. Based on your interactions with ART patients would you say they are well informed about the importance of adherence?
7. According to you, what are perceptions of patients after initiation? (*Prompts: How does treatment work? Does it cure HIV, Kill HIV, reduces HIV, makes their body strong? What are your thoughts about patient's knowledge on adherence?*)
8. What would you say are the reasons for poor ART adherence in Pule Sefatsa (*Prompts: Individual factors (age, depression, forgetfulness, substance abuse, poor self-efficacy, perceived wellness), Medical-related factors(treatment fatigue, medical dosing, side effects), Health system factors (access to ART, relationship with health*

*providers, staff shortages, long waiting times, poor service delivery), Social-cultural factors( Male dominance, religious beliefs)?*

9. What would you think in your area of expertise will be a strategy to be used to reduce poor ART adherence in Pule Sefatsa Clinic?



## **Appendix F: Interview guide for community health care workers**

### **Interview guide**

Exploration of factors that influence adherence to ART amongst patients at Pule Sefatsa primary health care clinic in Mangaung district, South Africa.

### **Key informant Interview guide for the community health workers (CHW)**

I would like you to tell me a little bit about yourself and your work)

1. Can you please tell me about your role in the facility/community?
2. Can you tell me whether you work with ART patients if so, how long have you worked with them in this facility/community?
3. Can you give a description of your role in the community for ART patients? (*Probe: What service are you providing for Pule Sefatsa community? What are the key socio-economic status in the area?*)
4. Where are you currently residing? (*Probe: how long do you take to get to work?*)
5. Based on your experiences, what do you think about the general atmosphere at the health facilities for the ART (*Do they have access to any information at any given time on the importance of ART adherence* )
6. Based on your interactions with ART patients would you say they are well informed about the importance of adherence?

According to you, what are perceptions of patients after initiation? (*Prompts: How does treatment work? Does it cure HIV, Kill HIV, reduces HIV, makes your body strong? What would happen to you or the HIV virus if do not take the medicine regularly?*)

7. What would you say are the reasons for poor ART adherence in Pule Sefatsa?
8. What would you think in your area of expertise will be a strategy to be used to reduce poor ART adherence in Pule Sefatsa Clinic.