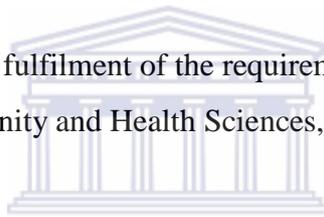


**UNIVERSITY OF THE WESTERN CAPE**  
**Faculty of Community and Health Sciences**

**BARRIERS TO ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG  
ADULT PATIENTS IN A RURAL HOSPITAL IN THE EASTERN  
CAPE**

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A mini-thesis submitted in partial fulfilment of the requirements for the degree of Masters in Public Health, Faculty of Community and Health Sciences, University of the Western Cape.



**UNIVERSITY of the  
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**Supervisor: Prof Brian Van Wyk**

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**KEYWORDS:**

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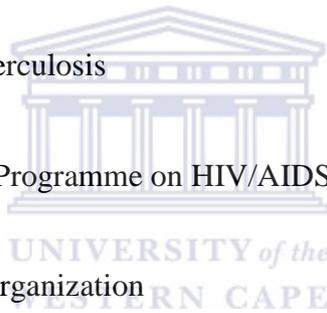
Health workers

Rural



## **ABBREVIATION**

ART	Antiretroviral Therapy
HAART	Highly Active Antiretroviral Therapy
KI	Key informant
NGOs	Non-governmental Organizations
OI	Opportunistic Infections
PLWHA	People Living With HIV/AIDS
PTB	Pulmonary Tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS
WHO	World Health Organization



## **ABSTRACT**

### **BACKGROUND**

Antiretroviral therapy (ART) improves the quality of lives of people living with HIV/AIDS by suppressing HIV replication and improving the patient's immunity. An improved immunity will help prevent patients from contracting opportunistic infections. Adherence to ART is vital to obtain good clinical outcome for patients. Defaulting ART leads to increase in viral load, decreased host immunity, development of HIV drug resistant strains, exposure to opportunistic infections and ultimately death. HIV positive patients who are on ART face many challenges in adhering to their medications, these challenges act as barriers to their adherence to treatment. This study explores the barriers that adult patients in a hospital in Eastern Cape of South Africa face while on treatment. These barriers include individual factors, socio-economic factors, health service factors, medical regimen factors.

### **METHODOLOGY**

An exploratory, qualitative study was conducted. In-depth interviews were done with 16 adult patients on ART in Emplisweni hospital in the Eastern Cape Province of South Africa. Two key informant interviews will also be conducted with health workers in the ART clinic. Data was analysed using thematic analysis.

### **RESULTS**

This study found individual, socio-economic, health service and medical regimen factors that are barriers to ART adherence in Empilisweni hospital ART clinic. Illiteracy, beliefs about HIV/AIDS, poverty and unemployment were identified as major barriers to ART adherence among participants. Other reasons given by participants for not adhering to ART included mental health state, substance abuse, quality of health service, poor health worker-patient relationship, pill burden, side effects and dietary restrictions.

### **CONCLUSION**

Adherence to ART is important for people living with HIV/AIDS (PLWHA) to remain healthy while on treatment. The problems faced by PLWHA while on ART will be overcome if barriers to ART adherence are addressed by the national government. Strategies and

programs that improve adherence among PLWHA on ART should be a priority for the government. Reporting and monitoring of ART defaulters should be done through an effective recording and reporting system in all ART clinics.

### **ETHICS STATEMENT**

Permission to conduct the research was obtained from the Joe Gqabi district health department and Empilisweni district hospital management in the Eastern Cape. Participation in the study was voluntary. Indirect benefits of the study were explained to participants prior to obtaining written consent. Anonymity of participants and confidentiality of information was strictly adhered to.



## **Declaration**

I, **Kenechukwu Okechukwu Akusoba**, hereby declare that this study is a true reflection of my own research, and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted for a degree examination at any other institution of higher education.

**Signed**



**Akusoba K.O**

**Date: 19 December 2012**



## **Acknowledgements**

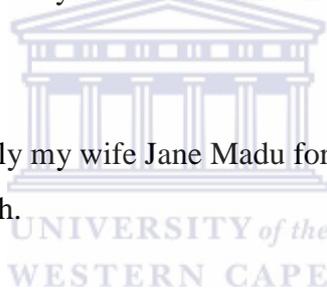
I would like to express my profound gratitude to God almighty who made kept me strong and health through this research; to him I give all honour and glory.

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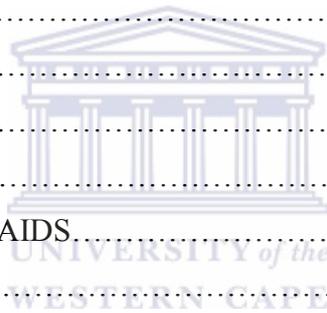
I finally thank my family especially my wife Jane Madu for taking care of the family while I took time to complete this research.



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# CHAPTER 1

## INTRODUCTION

### 1.1 HIV/AIDS in South Africa

The 2011 UNAIDS World AIDS Day report highlighted that South Africa is one of the African countries hardest hit by the HIV/AIDS pandemic (UNAIDS, 2011). A recent study by Statistics South Africa (2011) shows that the number of persons living with HIV/AIDS in South Africa increased to 5.38 million in 2011, which is an estimated 10.6% of the population. The number of new HIV infections for 2011 among the population aged 15 years and older was estimated at 316,000, with about 1.5 million adults receiving ART in 2010. Eastern Cape Province has the third highest new infections of HIV in South Africa, behind Kwazulu-Natal and Gauteng. Eastern Cape has an estimated 46,400 adult HIV new infections in 2009 with an incidence rate of 1.6 (UNAIDS 2009).

### 1.2 Antiretroviral therapy

UNAIDS/ WHO (2010) estimates that while about 34 million people are currently living with HIV/AIDS, AIDS related deaths decreased from 2.2 million in 2006/7 to 1.8 million in 2010. This decrease is due to better access to highly active antiretroviral therapy (HAART). HAART is a combination of at least three different antiretroviral drugs. Appropriate use of ART has improved the health of many HIV positive individuals who otherwise may have died. Notably, the efficacy of any treatment depends on sustained high levels of adherence to ART (Deeks *et al.*, 1997).

Even though more people are now having better access to ART (UNAIDS, 2010), Chesney (2000) suggests that access to medication does not guarantee adherence, as there are other challenges individuals may face in taking ART. Adherence is the key to the effectiveness of the antiretroviral therapy as it ensures that the viral load in a patient is kept at undetectable levels (Bangsberg *et al.*, 2001).

In South Africa, the national ART program was launched in April 2004. By the end of 2009, WHO (2010) report that 971,556 people in South Africa were receiving ART, and the provision of ART has resulted in an estimated 700,000 life-years gained. From 2008 to 2009,

the proportion of HIV positive children on ART increased by about 30% and the proportion of adults on ART increased by approximately 26% (USAID, 2010).

### **Problem statement**

Adherence to ART is a major predictor to the success of HIV/AIDS treatment as research has shown that patients who adhere to treatment tend to have better clinical outcome. In Empilisweni hospital ART clinic in Eastern Cape, hospital statistics shows that by 2011, 33% of patients who started on ART have defaulted on their treatment. The reasons for defaulting treatment in different communities are not known, but this situation raises concerns about adherence. Sufficient knowledge is needed to understand the challenges the patients face in taking their ART, as better understanding of the barriers that lead non adherence will assist in finding ways to improve adherence to ART.

### **1.4 Outline of the thesis**

Chapter 1 introduces the study and includes the formulation of the problem statement and study rationale.

Chapter 2 focuses on the review of the relevant literature on treatment adherence

Chapter 3 explains the research methodology, which includes; the aim and objectives, the research design, the study population, sampling, data collection, data analysis, credibility and trustworthiness.

Chapter 4 presents the study results.

Chapter 5 discusses the study findings.

Chapter 6 presents recommendations and conclusions.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter reviews the literature on adherence and the factors that affect adherence. The factors that affect adherence that are discussed in this chapter are individual factors, socio-economic factors, health service factors, medical regimen factors.

#### **2.2 ART Review in South Africa**

A study by Statistics South Africa (2011) shows that the number of persons living with HIV/AIDS in South Africa increased to 5.38 million in 2011, which is an estimated 10.6% of the population. An estimated 16.6% of the adult population aged 15-49 years is HIV positive. The number of new infections for 2011 among the population aged 15 years and older is estimated at 316,900. An estimated 63,600 new infections will be among children aged 0-14 years.

HIV epidemic in South Africa varies considerable between provinces. Actuarial Society of South Africa (ASSA) model (2008) estimates the population of Eastern Cape in 2006 to be about 6.67million; with about 10% of the population above 2 years living with HIV/AIDS and 81,000 were newly infected in 2006. In 2005 about 58,000 people in the Eastern Cape were estimated to be sick with AIDS related illness, with an estimated 39,000 AIDS deaths in that year of 2006. According to the Eastern Cape Department of Health report (2006), HIV/AIDS accounted for 64% of all deaths in the age brand of 15-49 years.

The South African government approved plans to provide access to ART in November 2003, as part of the plan for Comprehensive Care and treatment for PLWHA. The government's 2003 plan aimed to have 381,177 people on governments funded ARVs by 2005-2006, only 85 000 people in the public sector were receiving treatment by September 2005 (SA, info.gov, 2005). According to the South African Journal of medicine (2012), extraordinary progress has been made since ART roll out in 2004. As at 2011, 1.79 million people have access to treatment, 85% received treatment in the public sector, while 11% through disease management programmes in the private sector, and 4% through community treatment

programmes run by NGOs. Two provinces; KwaZulu-Natal and Gauteng accounted for 56% of all those receiving ART in South Africa.

The Comprehensive Treatment Plan for the provision of ART started in May 2004 in the Eastern Cape. It is estimated that 8.3% (534 000) of the population of the province is HIV positive and that 10% (53 400) need ART. It is envisaged that each health district will have at least one ART service point and that within five years this service will be provided in each municipality. There are 34 hospitals, 1 prison hospital and 213 clinics implementing the programme, currently benefiting 25 525 clients. In terms of the EC Department of Health's phased approach, during the period from May 2004 to March 2005, a total of 2 750 patients were receiving ART, which was to be stepped up to 15 169 patients reached between April 2005 and March 2006. There are 920 public health facilities in the Eastern Cape, and it was planned that by March 2008 all facilities would be offering comprehensive VCT and PMTCT services, with 644 facilities (80%) offering ART.

### **2.3 Definition of adherence**

Osterberg and Blaschke (2005:1972-1974) define adherence to medication regimen as “*the extent to which patients take medication as prescribed by their health care provider*”.

Adherence to treatment is referred to as the ability to start, manage, and maintain a given medication regimen at the times, frequencies, and under specified conditions as prescribed by a health care provider (UNAIDS, 2008). This implies that the patient and health care provider enter a mutual agreement that the patient has to take his/her medications by following the exact instructions given i.e. time of the day, how many pills, how to take pills and when to stop the medication. Any default on the part of the patient to take these medications as per instructed by the health care provider is often regarded as poor or non-adherence to the treatment regimen. Non adherence may take different forms like not taking medications at all, taking medications at the wrong time, taking the wrong dose because of lack of understanding of treatment instructions and stopping medications prematurely without consulting the health worker (Miller, 1997).

## **2.4 Measurement for adherence to ART**

Measuring patient's adherence to treatment is usually done by different methods like pill count, biological assays, pharmacy refills, electronic monitoring and self-reports. According to Sodergard (2006), each method used in measuring adherence has its own advantages and disadvantages.

### **2.4.1 Pill counts**

This method is one of easiest ways of measuring adherence. According to Jani (2004), the actual pill containers are opened and viewed to count the pill remaining on the day of inspection, and compared to the number of pills expected to be remaining at the time of patients visit. This method is good for resource poor health facilities, pill count can be done in the health worker's office. This method does not take into account how and when the pills were taken, and can easily be manipulated by patients discarding some pills when returning for appointment.

### **2.4.2 Biological assays**

This uncommonly used method requires expertise by health professional and can therefore be expensive (Osterberg & Blaschke, 2005). Biological assays involve measuring the concentration of drug or compound in the body usually the blood or urine of the patient (Vik *et al.*, 2004). This means that the patient will be required to be in the health facility at a specified time after the medication has been taken so as to get the expected therapeutic blood level of the drug in a given time. Other drugs and substances like alcohol may cause drug interactions in the body and result in higher or lower levels of the measured drug in the blood or urine.

### **2.4.3 Pharmacy refills**

Pharmacy refill is used to measure adherence to medications when data provided from pharmacy records indicates dates on which medications were dispensed. This method is easy to use as it can identify patients that fail to return for their medications by checking dates. Fairley *et al.* (2005) concludes that using pharmacy refill method to measure adherence can be unreliable as they provide only indirect measure of drug consumed, over and under consumption of medications cannot easily be assessed.

#### **2.4.4 Self-report**

This method involves patients on medications reporting their adherence behaviour at each clinic appointment (Chesney *et al.*, 2001). Self-report is a cheap and flexible way of measuring adherence, collected data can also assist in determining reasons for non-adherence. The measurements used in self-report includes surveys, interviews and diaries (Sodergard, 2006).

#### **2.4.5 Medication event monitoring system (MEMS)**

This system uses special bottle caps containing computer chips that records the date and time of opening and closing the bottle. According to Bangsberg *et al.* (2001), MEMS provides reliable measurements for adherence and a researcher can easily download adherence information on a computer. The disadvantage of this system is that it is expensive and can only be used in health facilities that can afford them (Moulding, 2007).

### **2.5 Factors that affect adherence to ART**

Factors that affect patient's adherence to ART can be categorized as patient (or individual), health service, socio-economic, and medical regimen factors (USAID, 2007).

#### **2.6 Individual factors**

These are individual factors that may prevent a patient from adhering to his/her medications, and include illiteracy, mental health state and individual beliefs about HIV/AIDS.

##### **2.6.1 Illiteracy**

Higher literacy levels have a positive effect on ART adherence as patients can read and understand instructions, and participate fully in their management (Schuman *et al.*, 2001). Also Kalichman, Ramachandren and Catz (1999) concludes in their research that illiteracy and low level of education can also lead to inadequate understanding about the effectiveness of medications, resulting in reduced adherence to treatment. Patients who are not knowledgeable or educated enough may not fully understand the instructions given by their health care professionals as regards how to take their medications, and may also not grasp the consequences that may result from not adhering to their medication regimens. Moralez *et al.* (1998) proposes that low level of education may affect the patients understanding of the side

effects and advantages of taking ART, and this may lead to poor adherence as patients will be afraid to take medications when they experience reactions which they do not understand.

### **2.6.2 Mental health state**

The mental state of a patient who is on ART may affect his/her adherence to medications. Ostrop (2000) argues that confusion and poor mental state are barriers in achieving good adherence in patients on HAART, as one's state of mind will affect how he/she takes medications. Starace *et al.* (2002) suggests that depression and other psychiatric illness have been shown to be related to poor adherence to ART as well as having significant impact on the quality of life of PLWHA in both high income and resource limited countries. Depressed patients feel isolated or stressed about their status; this may result in their defaulting treatment or forgetting to take pills. Conditions like depression, anxiety disorder and stress will lead to sub-optimal adherence. Poor mental state of the patient on lifelong ART may cause forgetfulness or lead to treatment fatigue, and result in the patient skipping doses (Borgat *et al.*, 2000).

### **2.6.3 Individual beliefs about HIV/AIDS**

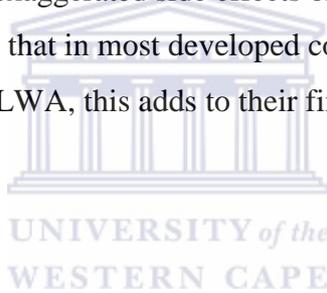
The beliefs a patient has about his illness may influence whether he/she will adhere to his/her medications. For example, Fomundam (2009) concludes that if a patient believes that HIV/AIDS is a curse from a family member or friend, such a patient will most likely default on treatment and seek an herbalist or traditional healer instead. There is also a belief in some African societies that those who are infected with HIV are bewitched, which may result to non-adherence (WHO, 2006). A study by Ware *et al.* (2009) concludes that cultural and social obstacles hinder treatment adherence as defaulters were convinced and believed that the cure from their illness will only come from traditional healers. This is true in Africa where patients have strong beliefs in traditional cure, even when medical treatment is free. Religious beliefs in some countries have resulted in patients abandoning medical treatment to seek spiritual healing of their illness. Spiritual healings and alleged seroconversions to HIV negative status by faith healers and miracle working pastors has led a lot of PLWHA on treatment abandon their treatment to await spiritual blood cleansing (Wanyama *et al.* 2007).

## **2.7 SOCIO-ECONOMIC FACTORS**

This group of factors entails social and economic experiences and realities that help mould one's personality, attitudes and lifestyle. These factors include poverty and unemployment, substance abuse, stigma and discrimination, social support, and unplanned traveling.

### ***2.7.1 Poverty and unemployment***

Poverty and financial constraints on patients are a major factor affecting patient's adherence to medications. Grierson, Bartos, De Visser and Mc-Donald (2000) concludes that poverty is an increasing feature in the era of HIV infection, especially in the third world where many people are living below poverty line. Patients who are struggling to feed themselves or their family will find it an added burden to pay for transportation to the clinic or pay for medications in some cases. A study in Uganda found that poor patients on ART were afraid of taking ART on empty stomach; they prefer to defer taking their medication till they have money to feed because of fear of exaggerated side effects of the medications (Nakiyemba *et al.*, 2002). Katabira (2002) opines that in most developed countries there is no medical insurance or disability grant for PLWA, this adds to their financial situation and will affect the way they take their treatment.



### ***2.7.2 Substance abuse***

The life style pattern of a patient may affect how he/she takes medications. Alcoholism and substance abuse as a way of life are major culprits that affects adherence. Same *et al.* (2004) opine that alcoholics and substance abusers may forget to take their medications as they may be under the influence of certain substances as at the time they have to take their pills. A meta-analysis study in Botswana, nearly 40% of patients surveyed admitted to missing a dose because of alcohol consumption (Kip, Ehlers & Van der wal, 2009). Patients in Botswana who abuse alcohol as a way of relieving the stress associated with their illness end up not taking their medications when they are drunk or even in their sober state. Continuous effects of alcohol and other abused substance will later lead to behaviour disorder and memory loss.

### ***2.7.3 Stigma and Discrimination***

UNAIDS (2003) defines HIV/AIDS-related stigma as the process of devaluation of people living with or associated with HIV/AIDS, while discrimination is an unfair and unjust treatment of an individual based on his/her real or perceived HIV status.

Chinkanda and Mokgatle (2006) opines that in HIV/AIDS the nature of the disease i.e. the fact that one's physical appearance changes as the illness progresses may lead to stigma and discrimination. They concluded that stigmatization and discrimination associated with HIV/AIDS inflicts fear and prevents a great number of PLWA from seeking treatment or stop them from taking medications because of the shame associated with the disease. Another study done in Zambia by Murray *et al.* (2009) shows that fear of blame for bringing the HIV home was a major barrier to adherence among urban Zambian women. This study revealed the lack of encouragement and support to urban Zambian women living with HIV/AIDS resulted in self-blame by these women who default their treatment than to be blamed for bringing shame into the family. Crocker, Major and Steele (1998) opines that the core feature of stigma is that a stigmatized person has an attribute that conveys a devalued social identity within a particular context, and this devaluation leads to a variety of stressors which could be psychological and physiological. Stigmatized individuals may tend to isolate themselves, not disclosing their status and may not get support from their friends and family as regards his or her condition and this may lead to neglect in taking ART.

#### **2.7.4 Social Support**

Good social relationships are important for good ART adherence. Unsupportive social relationships, living alone and lack of support have been associated with an increase in poor adherence to ART (William & Friedland, 1997). Social support encourages PLWHA to disclose their status without fear of discrimination, and with the knowledge that people around him will be supportive of his illness. Abah *et al.* (2004) concludes that PLWHA who lack family support find it difficult to adhere to treatment as they are unloved and isolated.

#### **2.7.5 Unplanned traveling**

Patients on ART often face challenges such as unexpected travels to meet appointments or emergencies. Depending on the distance or duration of stay of these unexpected travels, ART taking may be interrupted by patients. According to WHO (2007), patients find it difficult to adhere to treatment schedules when they are away or in the presence of strangers. McAllister (2006) opines that patients who have unexpected trips find it difficult to keep appointments and adhering to treatment plan.

## **2.8 HEALTH SERVICE FACTORS**

Health service factors are factors that may affect how PLWA take their medications, and includes quality of health services and health worker-patient relationship.

### ***2.8.1 Quality of health services***

A report by WHO (2009) concludes that public health services are known to be overcrowded and slow in health service delivery. In some health facilities where ART is provided once a week this may compromise the quality of care offered to the patients as there will be limited time spent between the patients and health care workers. Compromising quality time spend between PLWA and the health workers may affect educating the patients about the medications which they are taking, and also counselling on adherence to ART. Kasyaba and Ndyabanawe (2009) opine in a study done in Uganda that waiting time for health services in an out-patient clinic is a proxy measure of quality care, and long waiting times result in client dissatisfaction and consequent missed appointments and disrupted adherence.

### ***2.8.2 Health worker-patient relationship***

A caring and supportive relationship between the patient and the health care provider is vital in overcoming barriers to adherence. Marelich, Roberts, Murphy and Callari (2002) propose that there is a growing recognition that a great deal of adherence hinges on the positive interactions between patients and their health care providers. Factors that ensure a good relationship between patient and provider include perceptions of provider competence, quality and clarity of communication, compassion, involving the patients as an active participant in treatment decisions and convenience of the regimen (Chesney, 2000). A study done by Hasker et al. (2010) shows that reasons for defaulting treatment by patients in some public hospitals has to do with the attitude of the health workers. The health worker attitudes which like scolding patients, lack of empathy, refusing to give defaulters their medications all affect adherence to treatment.

## **2.9 MEDICAL REGIMEN FACTORS**

These factors are related to the medications the patients on ART take, and include pill burden and drug complexity, side effects and adverse reactions, dietary restrictions.

### **2.9.1 Pill burden**

In recent years ART has been switched from single and dual therapy to taking three or more classes of ART in order to achieve suppression of the highly resistant HIV. WHO (2003) study concluded that the higher the pill burden the lower the adherence to ART. Also a study done by Weiser, Wolfe and Bangsberg (2003) found that 30% of the respondents believed that were made to swallow too many pills a day by their health care workers. The number of pills per dose or the number of doses per day eventually results to these patients skipping medications, as they get tired of the regimen.

### **2.9.2 Side effects and adverse reactions**

ART can cause devastating and fatal adverse reactions to some patients on HAART, while in some patients it may be a mild to moderate side effect to the medications. Rao *et al.* (2007) proposes that some of the side effects experienced by patients on ART include; rashes, nausea, vomiting, fatigue, hallucinations, tingling sensations etc. The anticipation and fear of side effects often prevents patients from adhering to medication.

A study by Weiser, Wolfe and Bangsberg (2003) establish that about half (51%) of the survey respondents reported experiencing one or more side effect to ART. Williams and Friedland (1997) proposes that the likelihood of a patient's adherence apart from polypharmacy and frequency of dosing will depend on the severity of the Side effects to medication. Carr and Garsia (1997) also opine that drug hypersensitivity is more common in patients with HIV/AIDS.

### **2.9.3 Dietary restrictions**

There are certain dietary restrictions that come with the taking of ART, so as to minimize side effects and also to ensure absorption. Some of these restrictions include taking some classes of ART on an empty stomach. Grierson *et al.* (2000) opines that these restrictions may make affect the patient's way of life especially where workmates, family or friends are involved and may result in patient skipping pills at certain times.

## **2.10 Summary**

This chapter has discussed the literatures on adherence and factors that lead to poor ART adherence. Literature review was done on individual factors that affect ART adherence, socio-economic, health service and medical regimen factors that all affect patient's adherence to treatment.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 Introduction**

This chapter describes the methodology used in this study. It details the aims and objectives of the study, the study setting, study design, sampling procedure, participant's characteristics, data collection and data analysis, credibility and trustworthiness of research, limitations and ethical considerations.

#### **3.2 Aim**

This study aims to explore the barriers to adherence to ART among adult patients in a hospital in the Eastern Cape.

#### **3.3 Objectives**

- 1) To explore the experiences of adult patients on ART.
- 2) To explore patient, socio-economic, health service and medical regimen factors that influence adherence behaviour.
- 3) To explore recommendations to improve adherence among patients.



#### **3.4 Study design**

An exploratory qualitative study design was used to explore the experiences of patients about being on ART. Exploratory studies can generate speculative insights into the barriers that lead to poor ART adherence, new questions can be induced during the interview and new hypothesis can be generated (Green & Britten, 1998). An exploratory study assisted this research by using an open and flexible approach to explore the barriers that lead to poor ART adherence among participants during the interview; these participants will explain their experience on the barriers that prevent them from taking their ART. Pope and Mays (1995) concludes that the goal of qualitative research is to develop concepts that will help us understand social phenomena in natural settings giving due emphasis to the meaning, experiences and views of all participants. In-depth interviews were used on participants, and this assisted the researcher to explore the lived experiences of participants and help gather rich data

### **3.5 Description of study setting**

This study was conducted in Empilisweni Hospital in Sterkspruit which is a rural hospital in Joe Qabi district in Eastern Cape, South Africa. Sterkspruit community is a poor community with many villages; many undocumented Lesotho nationals who speak the native language 'Qhosa' also reside there because of its proximity to the border. Lack of companies and government establishments have resulted to unemployment and poverty in the community. Empilisweni hospital has an ART clinic which was accredited in 2005. The clinic has 15 health workers which include 4 professional nurses, one pharmacist and a medical officer who is also the clinical manager of the hospital. At the time of this study the clinic moved to its new site donated by a non-governmental organisation (NGO). The ART clinic days are from Monday to Friday starting from 8h00 to 16h00. Empilisweni hospital ART clinic serves a catchment population of 90,000 from the 40 surrounding villages. In 2011 the clinic had 1,542 patients registered on ART; this includes 1,401 adults and 141 children.

### **3.6 Population and sampling**

The study population in this research were adult ART patients in Empilisweni hospital in Sterkspruit who were not adhering to ART. Adherence was measured by counting the remaining medications left in the pill box by the pharmacist or professional nurse to cross check whether the remaining pill correspond to the days the patient has been taking the medication. This pill counting usually takes place on a monthly basis when the patient comes for a new pack of monthly medication.

Two key informants were used in the research; the key informants which consisted of a pharmacist and a professional nurse were used to select participants. The key informants were selected based on their understanding about adherence, the length of time they have been on ART, the fact that they were not adhering to their medications and the fact that they can communicate effectively in Xhosa or English.

The sample size involved 16 participants who have defaulted on their treatment for more than 6 months according to the ART clinic records in Empilisweni hospital Sterkspruit. A sample size of 16 participants was within the financial and time budget for this research. The 16 participants selected for the study were believed to be large enough in ensuring that all

perceptions that were important for the research is uncovered, a larger sample size for this study would have led to the data becoming repetitive and eventually superfluous.

The sample consists of 8 adult male and 8 female participants to get an equal sex distribution.

The selection of participants was done to include the employed, self employed and unemployed patients, as this may assist in capturing a range of experiences and challenges.

### **3.7 Data collection**

Two key informant interviews were done with a pharmacist and a professional nurse working in the ART clinic. Chopra and Coveney (2003) proposes that key informants are one of the major source of information in the study setting because of their experience on research topic and understanding of the study setting.

These key informants explained their definition of poor adherence to ART in their setting, who and how they classify certain patients as poor adherers and some of the reasons these poor adherers give for not taking their ART. The key informants were interviewed separately at an arranged date and time convenient to them in a selected place in the hospital.

In-depth interviews were used for the collection of data for the study; the interviews were recorded on a camcorder. Liamputtong and Ezzy (2005) opines that in-depth interviews attempt to explore the complexity and in-process nature of meanings and interpretations that cannot be examined by the use of positivist methodologies, and appear to be like conversations between respondent and researcher, as compared to focus group discussion which attempts to understand and describe people's perception, interpretations and beliefs of a selected population to gain understanding of a particular issue from their own perspective. An in-depth interview assisted this study in having a face-to-face unstructured interview which was like a conversation with the participant. This assisted in exploring their experience on the barriers to adherence to ART. In-depth interview also gave this research the opportunity listening and allowing the participant to talk in a more naturalistic setting, some of the issues which the participant may not feel free to discuss in front of family or friends as in focus group discussion can be talked about freely by the participant because he/she is alone, relaxed and guaranteed confidentiality. Since in-depth interview is between the researcher and the participants, this type of data collection method assisted the study in exploring more complex issues and clarifies some questions for participants to understand.

### **3.8 Data analysis**

Green and Thorogood (2004) propose that data need to be broken down from field notes and interview transcripts into manageable units, and organise them in a systematic way. The aim is to discover patterns and trends, and ultimately something of value to tell others in a relatively unbiased way.

The researcher used the method of thematic analysis to analyse data and his involved several stages.

The initial stage of my data analysis involved listening to the audio tape several times after the in-depth interview and transcribing the interview verbatim and to make sure no information is lost. The second stage involved re-reading the transcripts until the researcher was familiar with them and new information maybe discovered while researcher was re-reading the transcripts. Important issues and concepts were identified, and then the content of the data was analysed to categorize the recurrent themes; this is the theme stage, a method of 'cut and paste' was used to classify more common themes. During the activity of developing themes the researcher also coded the data, this involved marking different sections of the data as being instances of, or relevant to one or more of the themes. After developing the themes and coding the data, researcher re-arranged them accordingly in a systematic and orderly way, so that events, barriers to adherence, experience etc. that were far away from one another were now brought close together. This allowed data to be compared with different sections of the text that belong together.

The final stage of data analysis was done by checking and interpretation of data, and this involved carefully going through the data and writing down the phenomena that have been studied using thematic categories from the analysis as sub-heading.

### **3.9 Credibility and trustworthiness**

Qualitative researchers, who frame their studies in an interpretative paradigm, think in terms of trustworthiness as opposed to the conventional positivistic criteria of internal and external validity, reliability and objectivity (Dinzin and Lincoln, 1994). One of the factors considered in establishing trustworthiness of findings from qualitative research is credibility. Marshal and Rossman (1995) opine that credibility refers to the process of demonstrating that inquiry was conducted in a manner that ensures accuracy of how subjects were identified and discussed. Credibility which also refers to the confidence one can have in the truth of the findings, can be established by various methods.

Data source triangulation was used to ensure credibility in the study. Data was triangulated with various forms of data from multiple sources in the research i.e. in-depth interviews, key informant interviews, document reviews and non-participant observation. Also thick rich descriptions were obtained in the study; this was achieved by listening to the recorded participant's interview under each theme and by providing detailed description of each participant's interview.

### **3.10 Limitations**

Sample size was a limitation, as 16 participants were selected for the study. Because of the small sample size, the results of the study cannot be generalized to the entire population of patients on ART in the Eastern province Cape of South Africa. Another limitation to the study includes threats to trustworthiness, and a major threat to trustworthiness could be respondents' biases. For instance, respondents may say what they think the researcher wants to hear and paint positive pictures of situations that are not altogether positive.

### **3.11 Ethical considerations**

The protocol was submitted to the University of Western Cape (UWC) Senate Research Committee for approval. Permission for research was also requested from the Ukhahlamba district department of Health and Empilisweni hospital in Eastern Cape.

Informed consent to participate in the research was obtained from each participants, this was done in English or Xhosa language. Participants were informed that they have the right to withdraw at any time during the interview without any consequences. Participants were assured that their refusal to be interviewed will not affect their future decision to participate in other research. No harm was done to any participant and those who are vulnerable were protected. All risks and benefits of the research were explained to each participant. Strict confidentiality, anonymity and privacy were maintained throughout the interviews.

Anonymity of each participant was maintained by not using names during data write-up. Tapes and transcripts used in research were kept locked in a secure place. Data for the research was only be accessed by the researcher and others directly involved in the analysis of the data. Participants were informed that they will be expected to sign that they give consent or thumb print if they can't write and were provided with an information sheet that was kept as their own copy.

## CHAPTER 4

### RESULTS

#### 4.1 MAIN THEMES

The discussion and analysis of the results from the interviews is grouped under the following main themes:

- Individual factors
- Socio-economic factors
- Health service factors
- Medical regimen factors

These main themes are classified with sub-themes and codes from key informant and participant's interview.



**TABLE 4.1: Themes, subthemes and codes**

<b>THEME</b>	<b>SUB-THEMES</b>	<b>CODES</b>
1. Individual factors	1.1 Illiteracy	<ul style="list-style-type: none"> <li>• Inability to read</li> <li>• Not able to understand instructions</li> </ul>
	1.2 Mental Health State	<ul style="list-style-type: none"> <li>• Depression</li> <li>• Forgetfulness</li> </ul>
	1.3 Individual Beliefs about HIV/AIDS	<ul style="list-style-type: none"> <li>• Traditional treatment alternatives</li> <li>• Cultural and spiritual beliefs</li> </ul>
2. Socio-economic factors	2.1 Poverty & unemployment	<ul style="list-style-type: none"> <li>• Lack of money</li> <li>• Transport cost</li> <li>• Lack of job opportunities</li> </ul>
	2.2 Substance abuse	<ul style="list-style-type: none"> <li>• Stress relief</li> <li>• Memory loss</li> </ul>
	2.3 Stigma & Discrimination	<ul style="list-style-type: none"> <li>• Non-disclosure of status</li> <li>• Lack of support</li> </ul>
3. Health service factors	3.1 Quality of Health service	<ul style="list-style-type: none"> <li>• Long waiting hours</li> </ul>
	3.2 Poor health worker-patient relationship	<ul style="list-style-type: none"> <li>• Lack of trust</li> <li>• Lack of empathy</li> </ul>
4. Medical regimen factors	4.1 Pill burden	<ul style="list-style-type: none"> <li>• Too much pills</li> </ul>
	4.2 Side effects & adverse reactions	<ul style="list-style-type: none"> <li>• Reacts to medications</li> </ul>
	4.3 Dietary restrictions	<ul style="list-style-type: none"> <li>• No food</li> </ul>

### 4.3 INDIVIDUAL FACTORS

In this study individual factors were reported to have affected participants adherence to ART, these individual factors includes: illiteracy, mental health state and individual beliefs.

#### **Illiteracy**

Illiteracy and poor education resulted in participants not being able to read and understand the instructions given to them on the importance of ART adherence, and on when and how the medications should be taken.

- ***Inability to read***

Some of the interviewed participants expressed that they find it difficult to read and understand how medications should be taken. Some also reported that they cannot read their clinic card to know when their next clinic appointment will be due

*“I forget every time how to read and interpret the instructions on my ART containers; I can’t even read my clinic card to understand my return date. I end up missing my appointments. I rely on my neighbour’s son to assist me in reading, but most time he is not around”.* (Male Patient 48 years)

*“...I did not attend any school and this makes it difficult for me to read the pamphlets they gave us in the clinic, even though they are written in qhosa language I still cannot read them. This affects my understanding of my illness and treatment”.* (Male Patient 42 years)

- ***Not able to understand instructions***

Participants also reported that they have difficulty in understanding the instructions given to them on the importance of adhering to ART and how to take ART.

*“...she (nurse) used very difficult English grammar to explain to me how to take my medications, I really didn’t understand most of the big words she used, and I was too ashamed to interrupt her and ask for explanation”.* (Female Patient 26 years)

## **Mental Health State**

The mental health state of patients may affect the way they perceive and take their medications. The mental state of the patient includes factors that may affect the patient's state of mind while on treatment, and may negatively affect how ART is taken.

- ***Depression***

Some participants reported that they feel isolated and unhappy because of their HIV positive status. The fear that they may die any time according to them stresses them and makes them depressed. Their depressed state prevents them from adhering to their medications.

*“.....I don't have anybody who understands how I feel and how I live; I stay alone without any relative. I am a loner, if only I have children of my own to support me with taking these pills.....”* (Female patient 51 years)

- ***Forgetfulness***

Three participants cited forgetfulness as the reason why they do not adhere to their medications. One of the participants has been counselled before on adherence because of skipped pills, but he still forgets some times to take his ART.

*“Eish my brother, taking these pills every day is not easy, now that I feel much better, I don't even remember I am living with HIV, in fact I don't have any symptoms again, and this makes me forget to taking my pill and going for monthly appointments”.*

(Male patient 52 years)

*“....I work in a very busy place that makes me forget about taking my pills, I don't even remember them when I get home tired. I try to make up by taking them when I am off work or on weekends”.* (Female patient 46 years)

## ***Individual Beliefs about HIV/AIDS***

Patient's beliefs about his/her illness or about the best treatment option will affect adherence to treatment. Patients will prefer to explore the treatment option which is believed will make him or her better.

- ***Traditional treatment alternatives***

Some interviewed participants expressed hope that herbs and mixture from traditional healers will cure their illness. This makes them abandon taken their ART to seek traditional medicine in the village.

*“.....I don't feel any better than I felt six months ago when I commenced on this white man's treatment (ART), I now take some herbs giving to me by traditional healers. I have decided to stop ART for now and continue on herbs.....”* (Male patient 50 years)

*“....nurse you know that this thing (HIV/AIDS) is a black sickness, I have gone to the best traditional healer in my village and he has given me some medicine to take, I am afraid this may react with the clinic medicine so I stopped taking them”.* (Male patient 36 years)

- ***Cultural and Spiritual beliefs***

Key informants and participants noted that the rural settings of the community affect their belief that cultural and spiritual treatment is the solution to their illness. Cultural beliefs participants have about their illness include beliefs in the ancestors or deceased family member to assist in the cure for their illness, while spiritual beliefs are religious beliefs that faith will heal their illness.

*“You know we are in a deeply remote area where people still strongly believe in culture and spiritual entities when they are sick. This seriously poses a challenge to us in the clinic especially when we initiate ART, some default based on their beliefs....”* (Pharmacist Key informant)

*“...we (family) believe that HIV/AIDS is a punishment from our ancestors for our sins, about six of our family members who disobeyed and took ART died while still on the treatment that was meant to treat them. I prefer now to seek traditional remedies for my ailment”.* (Male patient 49 years)

*“...I believe what my pastor said about my illness and treatment. FAITH will heal me; I have stopped taking those pills. It is written that for those who belief in Christ without doubt will experience his miracle....”* (Female patient 42 years)

#### 4.4 SOCIO-ECONOMIC FACTORS

These are social and economic factors that affect patient's adherence to ART. These factors include; poverty and unemployment, substance abuse, stigma and discrimination.

##### **Poverty and unemployment**

In this study poverty and unemployment was a major barrier to ART adherence in the community. Poverty and unemployment resulted in participants not having money while on ART treatment and this meant they could not take their medications regularly.

- ***Lack of money***

Most participants in the study reported that not having money made them not take their medications, as the needed money while on treatment to cater for food, shelter and other personal needs.

*“Eish, I cannot take these medicines on an empty stomach, I am sick and poor, I need money to buy food first, and Government has stopped my grant....”* (Male patient 52 years)

*“...how can they be asking me to remember to take my medications when I am thinking about when my next meal will come from? I only remember to take my pill when I am not hungry...”* (Male patient 38 years)

- ***Transport cost***

The long distance the community has to travel to get their medication means that they can only go by taxis, the high price of transport fare as a result of increased fuel cost and bad roads resulted in participants who could not afford the fares to skip appointments.

*“I cannot afford to pay R120 to attend the clinic, that amount is my feeding for one week. I have requested that the clinic send my pills through a friend every month and the refused, this made me stop taking my pills till I have a better arrangement”*  
(Female patient 45 years)

- ***Lack of job opportunities***

Some participants complained that the opportunities available for them to secure job is

limited, partly because they can't do strenuous jobs and also because there are no available jobs in the community. This results in participants wasting a lot of time searching for the participants, and affects who ART is taken.

*“...I have been searching for job for seven months now, every morning I leave my house and trek to town. This leaves me with no time and money, I have not been taking my pills regularly...”* (Male patient 42 years)

### **Substance use**

Three participants mentioned that they take alcohol and smoke cigarettes/marijuana as a way of relieving stress and escape their sorrows, but it also leads to loss of memory and adhering to ART.

- ***Stress relief***

Some male participants during the interview explained that they abuse different substances like alcohol, cigarettes and marijuana as a way of easing the stress associated with being infected by HIV. These substances the report helps them sleep and prevent them from thinking too much about their condition.

*“Ooh bros, a man must drink. It is a way of life, I am addicted to this thing (alcohol), and I sleep well after I drink, this makes me forget about my stress, but I fall asleep after I drink and forget to take my ART”.* (Male patient 30 years)

- ***Memory loss***

One of the interviewed participants says he is permanently affected by memory loss because of the substance he uses, and this acts as a barrier to him adhering to his treatment.

*“Yes, I smoke marijuana well; it takes me to a different world where I forget my problems, at the same time it makes me forget taking my pills, even if I don't smoke I wouldn't remember to take my pills. I think my brain is permanently damaged...”*  
(Male patient 36 years)

## **Stigma and discrimination**

Stigma and discrimination experienced by PLWHA is a major barrier to ART adherence. The fear of disclosing HIV status and the shame of taking ART in front of relatives and friends has negatively affected adherence to ART.

- ***Non-disclosure of HIV status***

The fear of being stigmatized and discriminated on by participants resulted in their not disclosing their HIV status. This has led them to take their medications in secret and at times not taking their medications and skipping clinic appointments at all to hide their HIV positive status.

*“My sister, my boss does not like HIV positive people working with him, I have noticed how he reacted in the past when he discovered one of his workers was HIV positive. I do not want to disclose my status, now he gets suspicious any time I visit the hospital. I have stopped going for my appointments because I don’t want to be spotted”.* (Female patients 22 years)

- ***Lack of support***

Some participants have blamed the lack of support they get from their friends, partners, relatives and community as the reason why they experience stigmatization and discrimination.

*“I’m sure if they have support, somebody that will stand by their side now that they are on treatment they will not be ashamed of taking their medications”.* (Nurse Key informant)

*“...I became ashamed of myself when my partner left me as said he doesn’t want to be associated with my HIV positive status. I feel betrayed because if he can leave me what are people going to say. I have to hide my HIV status from everybody even if it means I have to stop taking my pill sometimes”.* (Female patient 36 years).

## 4.5 HEALTH SERVICE FACTORS

The health service factors that were barriers to participants taking their ART are quality of health service and poor health worker-patient relationship.

### Quality of health service

Two of the interviewed participants cited that the health service they get from Empilisweni hospital ART clinic is discouraging, as they have to spend long time in the clinic before they are attended to or before they get their medications. This they say makes them skip monthly appointments even when their medications has finished.

- **Long waiting times**

Some participants attributed their defaulting treatment the lengthy time they spend at the clinic to collect their medication.

*“I get to the clinic by 5am on my appointment days to collect my medications; surprisingly I have to wait till 4pm to get them, I don’t want to continue wasting my time in the clinic again”.* (Male Patient 30 years)

*“.....each time I came to the clinic I miss my taxi back home, the last taxi leaves by 17h00 and if I to board it then I have to trek many hours home, hiking is difficult because the road is bad and there are few people in my village that own a car...”.* (Female Patient 44years)

### Poor health worker-patient relationship

If the relationship between the health workers and their patient is not good enough for the patients this may become a barrier to their treatment, as they may not be attending monthly check up and appointments.

- **Health worker attitude**

Some defaulters to ART reported that the attitude of the clinic staffs resulted in their returning to the clinic. They explained that some clinic staff disrespects them by shouting, being arrogant and showing no signs of empathy to their situation.

*“Eish, those sisters in the clinic are very rude and arrogant, we argue every time I visit the clinic. I don’t want to ever go there again”.* (Male patient 52years)

- **Poor communication**

One of the participant reported that she struggles to communicate with the health workers, and this has left her frustrated and she stopped going to the clinic.

*“The foreign doctor doesn’t know how to explain and answer questions, each time I want to bring in my own opinion he dismisses me by laughing at me, I will only visit the clinic when he leaves”.* (Male patient 29 years)

#### **4.6 MEDICAL REGIMEN FACTORS**

These are factors that are related to the ART the patients take. They include pill burden, side effects and adverse reactions, dietary restrictions.

##### **Pill burden**

The amount of pills patients take make be a barrier to their continued taking of the pills. Taking too many pills may be tiring to patients on treatment.

- **Too much pills**

One of the interviewed participant in the research expressed that the number of drugs he took is much and this affected his adherence to ART.

*“Sister, these pills we are taking every day is too much, apart from the ART pills there are 8 other pills that I have to take as well. It means I have to take 15 pills a day, this is tiring for me to cope with”.* (Female patient 38 years)

##### **Side effects and adverse reactions**

Some participants said that they stopped taking their medications because they were reacting to them. Some of the reactions participants’ report they experience from ART include; skin rashes, nausea and vomiting, abdominal cramps and insomnia.

- **Reacts to medications**

To participants complained that they discontinued taking their medications because of the side effects and reactions the experience each time they take ART.

*“Each time I take those pills I feel like vomiting, I have tried my best but I just can’t be taking these pills because my body doesn’t agree with them”.* (Female patient 25 years)

*“...I nearly died when I was put on pulmonary tuberculosis (PTB) treatment while still on my ART. My eyes became yellow and I was unconscious. After I recovered I decided to stop these poisonous pills”.* (Male patient 42 years)

### **Dietary restrictions**

Participants who could not afford food or certain types of food may be forced to stop taking their pill because of the dietary restrictions.

- ***Lack of food***

One participant expressed some restrictions associated with ART and food as the cause of her defaulting ART.

*“I was advised on foods to take with my ART and also not to take them without eating. Since I don’t eat sometimes during the day I skip taking my medications to avoid any adverse reaction that may occur if I take them on an empty stomach”.*  
(Female patient, 38 years)

### **4.7 Summary**

This chapter highlighted the findings of the study. Four main themes and various sub-themes and codes were identified in this study as factors that contributed to barriers to ART adherence.

## **CHAPTER 5**

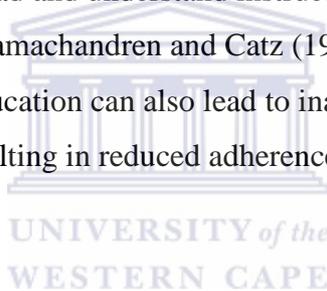
### **DISCUSSION**

#### **5.1 Introduction**

This chapter discusses the research findings with reference to the relevant literature. The discussion will be centred on the barriers to ART adherence as obtained in the research.

#### **5.2 Illiteracy**

This study identified that illiteracy in Sterkspruit community is a barrier to ART adherence among patients receiving ART from the clinic. Sterkspruit is a poor rural community where a high percentage of the population have no formal education. This affects the understanding of their illness and medication adherence. This research confirms findings in studies done by Marcus (2006) and Schuman *et al.* (2001) that higher literacy levels have a positive effect on ART adherence as patients can read and understand instructions, and participate fully in their management. Also Kalichman, Ramachandren and Catz (1999) conclude in their research that illiteracy and low level of education can also lead to inadequate understanding about the effectiveness of medications, resulting in reduced adherence to treatment.



#### **5.3 Mental health state**

The mental health states identified as barriers to ART adherence in the study are depression and forgetfulness. Some respondents explained that their taking ART depends on their state of mind. This is consistent with other studies done by Borgat *et al.* (2000), Amberbir *et al.* (2008) and Starace *et al.* (2002) suggest that depression and other psychiatric illness have been shown to be related to poor adherence to ART as well as having significant impact on the quality of life of PLWHA in both high income and resource limited countries. Depressed patients feel isolated or stressed about their status, this may result in them defaulting in their medications or forgetting to take them.

#### **5.4 Individual beliefs about HIV/AIDS**

Individual beliefs participants had about HIV/AIDS negatively affected their adherence to treatment. The rural setting of the community and lack of formal education resulted in participants still believing in traditional remedies and spiritual intervention to cure their ailment. Reports by participants showed that advice by friends and family members

influenced participants to stop ART and put their faith in traditional therapy and spiritual healing. A study by Ware *et al.* (2009) concludes that cultural and social obstacles hinder treatment adherence as defaulters were convinced that the cure for their illness will only come from traditional healers. Spiritual healings and alleged seroconversions from a HIV positive to HIV negative status by faith healers and miracle working pastors has lead a lot of PLWHA on treatment abandon their treatment to await spiritual blood cleansing (Wanyama *et al.* 2007).

### **5.5 Poverty and unemployment**

Lack of money and lack of job was identified in this research to be a major barrier in ART adherence. Sterkspruit is a poor community where majority of the population is unemployed. There is lack of government jobs in the community and this has had a negative effect on the lives of the population especially PLWHA. Financial constraints and unemployment has resulted in participants not having money for food and other personal needs. It also affected participants lacking money to pay for their transport fares to meet their monthly appointments at the clinic. This is in accordance with a cross-sectional study done in Malawi among patients on ART found that lack of resources and financial barriers accounted for two-third of the reasons for non-adherence to ART (Van Oosterhout *et al.*, 2005). Another study done in Uganda also found that poor patients on ART were afraid of taking ART on empty stomach, they prefer to defer taking their medication till they have money to feed because of fear of exaggerated side effects of the medications (Nakiyemba *et al.*, 2002).

### **5.6 Substance abuse**

This study also showed that participants who indulge alcohol and smoke marijuana default in taking their ART. Active alcohol or substance abuse makes it difficult for patients to adhere to treatment (Spire, Lucas & carrier, 2007). Their study showed that patients of different types of treatment are more likely to forget taking their medications because of the effect these substances have on the brain. A meta-analysis study in Botswana, nearly 40% of patients surveyed admitted to missing a dose because of alcohol consumption (Kip, Ehlers and Van der wal, 2009). Patients in Botswana who abuse alcohol as a way of relieving the stress associated with their illness end up not taking their medications when they are drunk or even in their sober state. Continuous effects of alcohol and other abused substance will later lead to behaviour disorder and memory loss.

### **5.7 Stigma and discrimination**

Stigma and discrimination is a major concern to the Sterkspruit community, as participants still fear disclosing their status to relatives and friends. The findings in this research shows that participants take their medications in secrecy to avoid been identified as PLWHA, this has resulted in their defaulting medications in situations that will reveal their status. This study is in accordance with a study done by Hardon *et al.* (2007) which identified non-disclosure of status as a result of discrimination to lead to irregular taking of medications as patients prefer to stop taking their medications instead of being associated with a HIV positive status. Another study done in Zambia by Murray *et al.* (2009) showed that fear of blame for bringing the HIV home was a major barrier to adherence among urban Zambian women. This study revealed the lack of encouragement and support to urban Zambian women living with HIV/AIDS resulted in self-blame by these women who default their treatment than to be blamed for bringing shame into the family.

### **5.8 Quality of health service**

Long waiting hours have been identified in this study to discourage participants from returning for their monthly medications. Not keeping monthly appointments means that participants will not have medications to take; this will lead to poor adherence to treatment. Empilisweni ART clinic has a large number of patients who depend on them for their medication, the clinic is also understaffed and these has resulted in delays for patients waiting to be reviewed or waiting to collect the monthly medication. This is in accordance to an earlier study done by Hardon *et al.* (2007) that in some countries the waiting time to renew a prescription in public health facilities can be an average of 5 hours, and these results in patients leaving the clinic without collecting their refills. In developing countries the story is very worrying as lengthy waits in few hospitals that do not have extended hours may also impede adherence (Grierson *et al.*, 2000). The health service system in South Africa is not as organised as in developed countries and this is a barrier to patients on medications returning for follow up appointments as they may not even be attended to before the end of working hours.

### **5.9 Poor health worker-patient relationship**

The relationship a patient has with his/her health worker is vital for good adherence to treatment. This study has identified that some interviewed participants miss their appointments because of the attitude of the health workers in the clinic. Some participants complained of the poor communication and bad treatment from health workers in the clinic, this resulted in participants avoiding going to the clinic to collect their medications. Not returning for monthly appointments because of the poor relationship between the health worker and participant's means that they will have no medication to take when their pills finish. A study done by Hasker et al. (2010) shows that reasons for defaulting treatment by patients in some public hospitals has to do with the attitude of the health workers. These health worker attitudes include scolding patients, lack of empathy, refusing to give defaulters their medications.

### **5.10 Pill burden**

In this study it is established that the burden of taking too many medications is a barrier to ART adherence. Some participants complained of the number of pills they have to take in a day. This becomes even more difficult for participants when they develop other opportunistic infections like pulmonary tuberculosis (PTB) resulting to additional pills to take. A study by Munro *et al.* (2007) confirms the findings of this study as their own study showed that the some patients on ART feel tired of taking their medications when they have to take many pills at once. The study also concludes that patients on combined treatment of ART and anti-PTB medications are even more likely to default treatment as the number of pills they take increases in number.

### **5.11 Side effects and adverse reactions**

The reactions to ART participants in this study experience while on treatment are a barrier to taking their medications. Participants reported vomiting, nausea, dizziness, insomnia etc. as some of the reactions which they have while on ART, and the only way they can avoid these reactions is to stop taking their medications. This is in accordance to a study done by Maskew *et al.* (2007) which observed that adherence to treatment is made difficult by multiple side effects associated with the drugs as well as the interactions with other chronic medications.

Their study also showed that poor adherence to ART is worse with certain class of ART especially protease inhibitor (PI) which have more severe side effects. This resulted in patients taking PI combined ART defaulting treatment to avoid experiencing its side effects



## CHAPTER 6

### CONCLUSIONS AND RECOMMENDATIONS

#### 6.1 Conclusions

A lot of research has been done on ART adherence worldwide, but the barriers to adherence vary in different regions. This study done in the Eastern Cape province of South Africa identified different barriers to ART adherence in Sterkspruit community. In-depth interview was done on key informants and selected participants, their experience on ART as well as barriers that prevent them from taking ART were discussed.

The Sterkspruit community is a poor community where most of the rural community are uneducated and unemployed. Illiteracy and poverty is a major barrier identified that prevent patients taking ART from defaulting. Financial constraints have also resulted in patients on treatment not affording transport fares, and not having enough money to feed themselves, this has resulted in poor adherence to treatment.

Stigma and discrimination in the community has resulted in patients on ART in the community taking their medications in secrecy to avoid being identified with a HIV positive status. Poor knowledge about HIV/AIDS has resulted in community members still having a negative view about PLWHA, and this has led to people in the community avoiding and blaming PLWHA. Participants in the study explained that they would rather not go for appointments or take their pill in the presence of others than to experience stigmatization.

Other findings in the study like patient's beliefs, mental health state substance abuse, quality of health service, poor relationship between the health worker and patient, pill burden, dietary restrictions and side effects of ART were also identified as barriers to ART adherence in this research

This study has shown that barriers that prevent patients receiving treatment from Empilisweni hospital ART clinic from adhering to their medications. The identified barriers that contribute to poor adherence in this research should assist in addressing intervention measures and effective strategies to maintain long-term adherence to ART and better quality of life for PLWHA who are on treatment.

## **6.2 RECOMMENDATIONS**

Recommendations from this study are based on findings that emerged during the research.

### **Creation of a provincial and national art adherence team**

Adherence to ART should be strengthened in the country by setting up a team that will be responsible for adherence and retention of care in different provinces. This team will be tasked with monthly visits in ART clinics and deal with issues of adherence and report their findings monthly to the national adherence committee for proper decisions to be taken on poor or non-adherence. Issues and findings on reasons for ART non-adherence from different ART clinics in different provinces will be reviewed in monthly meetings by this adherence team and recommendations that will improve adherence made.

### **Assessing and monitoring adherence**

Poor clinical environment and gaps in domains of health system have led to problem in identifying and monitoring of patients on ART. There should to be an effective and reliable patient tracking and tracing system in place in every ART clinic that will quickly identify and trace patients who have missed their clinic visits. This will involve upgrading already existing electronic medical records system in place, ensuring that the system does not break down, and a quick fixing team of technicians in place if the electronic system does beak down.

Ensuring that an electronic medical system is in all ART clinics with well-trained personnel's to operate them.

Use of latest technologies which include use of global positioning system (GPS) to locate patients home and determine if the patient has not migrated or died.

### **Health workers**

There should be committed health workers posted to work in the ART clinic. Health workers who are reported who are not dedicated to helping PLWHA should be posted to other hospital or clinic departments.

An effective time management system should be in place for health workers to ensure they are not over-worked as a result of health worker shortage. The quality of healthcare may be affected if health workers are over-worked.

### **Psychologist and counsellors**

Counsellors and psychologist should be recruited to work or visit all ART clinics on weekly or daily basis. These professionals will address ART patient's social and psychological problems that result in defaulting ART.

### **Education and training**

Training of health workers is very important in addressing patient's barriers to their ART. These trainings may involve how to deal with factors that affect ART adherence and ways health workers on their own will assist in improving ART adherence in their clinic.

### ***Community and education***

Involving the community on issues of ART and adherence will improve health outcomes of PLWHA, and contribute to greater understanding of adherence benefits. Community involvement leads to stronger belief in the effectiveness of ART and reduces community stigmatization and discrimination. Community education and outreach may be in form of community seminars, drama and play, music sessions that will highlight adherence problems, issues of stigmatization and support for PLWHA.

### **Advertisement**

Different forms of advert that will attract attention of the community on ART adherence problems should be adopted. Adverts may be in form of radio and television programs on adherence. Other forms of advert may involve billboards and banners that highlight ART adherence.

### **Diet and nutrition**

Government should provide food security for PLWHA as a way of encouraging them to remain on their treatment. Government could assist in form of free food supplement supply to ART clinics for ART patients who keep their monthly appointments.

### **Disability grants**

Government should ensure that there is an effective disability grant system in place that will provide financial assistance for PLWHA irrespective of their clinical stage or CD4 count. This should be for PLWHA who are unemployed and poor and have no means of sustaining

themselves while on ART. This type of grant can be a temporary grant that can last till patients on ART are able to work.



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**PARTICIPANT INFORMATION SHEET**

**Dear Participant**

Thank you for giving me this opportunity to talk to you about this research. What follows is an explanation of the purpose of the research and an explanation of what will happen and what is expected of you if you agree to participate. The research is being conducted for a min-thesis which is a requirement for a Masters Degree in Public Health; which I'm pursuing with the University of the Western Cape. If there is anything that you don't understand or not clear about, please do not hesitate to ask me. My contact details and that of my supervisors are recorded at the end of this memo.

**TITLE OF RESEARCH**

Barriers to adherence to antiretroviral therapy among adult patients in a rural hospital in the Eastern Cape.

**PURPOSE AND CONTENT OF INTERVIEW**

The research will explore the barriers to antiretroviral drug adherence. It is hoped that with your participation, a better understanding of some barriers affecting HIV positive patients that receive ART from a particular hospital will be gained. I plan to do interviews with HIV

positive patients who are on ART, and this is the reason why you have been selected. By interviewing people like yourself I hope to gain better information about how you take your tablets and what makes it difficult or prevents you from taking your ART tablets. I will not ask many questions and it would be better if we have a conversation about your experiences in taking the ART drugs.

## **DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT**

### **INTERVIEW PROCESS**

An in-depth interview will be done and this will only take a short time. Notes will be taken and tape recording will be done. Recording will be done to enable all information to be captured even if it was missed when note taking.

### **CONFIDENTIALITY**

During the interview there will be no use of names. A code will be used instead of your name. The discussions between you and me will be confidential. I shall keep all records of your participation and our discussions including a signed consent which I will need to get from you once you accept to participate in this research study, under lock and key at all times and will destroy them probably a year after the research is completed. You will not be identified in the written reports as they contain no names.

### **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

Participation in this study is entirely voluntary, that is you may or may not want to participate. If you choose to participate, you may stop at any time. You may also choose not to answer particular questions in the study that you feel uncomfortable with. If there is anything that you would prefer not to discuss, please feel free to say so.

### **BENEFITS AND COSTS**

You may not get any direct benefit from this study. However the information we will learn from participants in this study will contribute towards identifying barriers to antiretroviral drug adherence in ART services which can guide on what targeted strategies can be implored to address the situation. Transport allowance and refreshments will be provided.

## **INFORMED CONSENT (AGREEMENT)**

Your signed consent (thumb print for those who cannot write) to participate and to be audio-recorded in this research is requested before I can proceed to interview you. I have included the consent form with this information sheet so that you can review the consent form and then decide whether you would like to participate in this study or not.

## **QUESTIONS**

Should you have further questions or wish to know more, I can be contacted as follows:

Akusoba Kenechukwu

Student No. 2816222

Cell No: 0769768475, 0833784773

E-mail: kakuzoba@yahoo.com

My supervisor's contact details are as follows:

Prof. Brian Van Wyk

University of the Western Cape

Private Bag X17, Bellville 7535, South Africa

Tel. +27 21 959 2872

Fax. +27 21 959 2175

Email: [bvanwyk@uwc.ac.za](mailto:bvanwyk@uwc.ac.za)





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**INFORMED CONSENT**

---

Thank you for agreeing to allow me to interview you. I am Akusoba Kenechukwu a student at the School of Public Health, University of the Western Cape. As part of my Masters in Public Health, I am required to do a research study. I will be exploring barriers that cause poor adherence of antiretroviral drugs. I am accountable to Dr. Brian Van Wyk who is contactable at Fax: +2721 959 2872, Tel. ...., email: [bvanwyk@uwc.ac.za](mailto:bvanwyk@uwc.ac.za) or at University of the Western Cape, Private Bag X17, Bellville 7535, South Africa.

**TITLE OF THE RESEARCH:**

**BARRIERS TO ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADULT PATIENTS IN A HOSPITAL IN THE EASTERN CAPE.**

As mentioned in the Participant Information Sheet: Participation in this research study is entirely voluntary, that is you may or may not want to participate. Refusal to participate or withdrawal from the study will not result in penalty or any loss of benefit to which you are otherwise entitled.

If you choose to participate you may stop at any time. You may also choose not to answer particular questions that are asked in the study. If there is anything that you prefer not to discuss please feel free to say so

The discussion and information collected in this study will be kept strictly confidential.

If you choose to participate in this study, your signed informed consent will be required before I proceed with the interview with you.

---

I have read/it has been read to me the information about this research study on the Participant's Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I voluntarily consent to be a participant and be audio-recorded in this research study and understand that I have the right to end the interview/recording at any time, and choose not to answer particular questions that are asked in the study.

My signature indicates that I'm willing to participate and be recorded in this research.

**Participants Name:** \_\_\_\_\_

**Participants Signature/Thumb print:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Interviewers Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

---

## **APPENDIX 3**

### **INTERVIEW GUIDE WITH ART PARTICIPANTS**

These questions are only the themes as in-depth interviewing will probe for more information to get a more detailed and rich information.

May you please tell me what you know about ART? (Probe for more specifics)

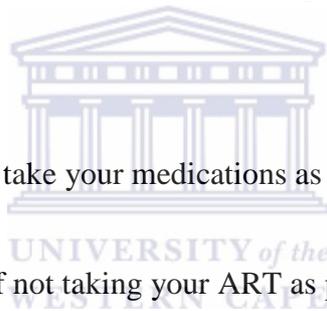
Tell me about your experience of being on ART?

Can you explain perceptions before you started ART and perceptions now that you are on ART?

What makes it difficult for you to take your medications as prescribed?

Do you know the consequences of not taking your ART as prescribed?

What are the things that could be done to improve on you taking ART as prescribed?





UNIVERSITY of the  
WESTERN CAPE

**OFFICE OF THE DEAN DEPARTMENT OF RESEARCH  
DEVELOPMENT**

04 September 2012

**To Whom It May Concern**

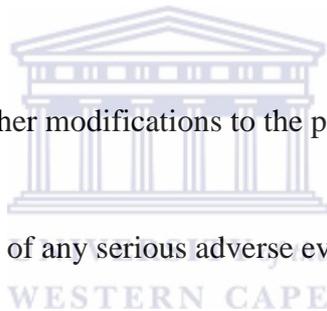
I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:  
Mr K Akusoba (School of Public Health)

Research Project: Exploratory study of the barriers to adherence to antiretroviral therapy among adult patients in Empilisweni Hospital in the Eastern Cape Province of South Africa

Registration no: 12/7/12

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

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



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

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T: +27 21 959 2988/2948. F: +27 21 959 3170  
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A place of quality,  
a place to grow, from hope  
to action through knowledge