Non-adherence to antiretroviral treatment in Maquassi Hills, North West Province: A Social Work perspective

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DECLARATION

I, Sheldon Nevondwe, hereby declare that the dissertation entitled “**Non-adherence to antiretroviral treatment in Maquassi Hills, North-West Province: A Social Work perspective”** submitted for the degree Master of Social Work at the North-West University, Mafikeng Campus, is my own original work. I further declare that all the sources that I have used, quoted or referred to have been duly acknowledged by means of complete references.

Sheldon Nevondwe

Signature:________________________ Date:_______________________________

ABSTRACT

HIV and AIDS continue to be a major public health issue worldwide. The HIV and AIDS epidemic is equally a major threat to social and economic development globally and in South Africa. Although antiretroviral (ARV) medication has brought hope, high adherence levels are required to ensure treatment success. While there is no cure for the disease, people are living longer with all the accompanying support they receive from health care, which include adhering maximally to antiretroviral treatment (ART). This study examined non-adherence to antiretroviral treatment in MaquassiHills, North-West Province, and looked at it from a social work perspective.

The main problem in this study is that access to ART does not necessarily mean adherence to the ARV regimen, with the main question being : “of those people initiating ART in the North West Province – Maquassi Hills district in particular, how many adhere maximally (about 95%) to the regimen. The research problem pointed towards relevant literature in order to review aspects such as: the phenomena of adherence and non-adherence to ART, the rate of ART globally and in South Africa, the goals of ART medication, ART monitoring tools, barriers and facilitators of adherence to ART, and strategies that could enhance adherence to ART. The study was undertaken from a social work perspective due to its relevance in the health care. Two theoretical perspectives, the Health Belief Model (HBM) and the Strength-based perspective, provided frameworks for the research.

Qualitative research was used, specifically eliciting data through in-depth interviews, focus group discussions and key-informant interviews, where a total of 28 participants were purposefully selected. Descriptive stories and content analysis were used to analyse the data. It emerged that barriers encountered by sampled patients on ART were related to patient, stigma, and health-care including systems factors. Food insecurity, pill-burden, lack of income due to unemployment, discrimination from employers, side effects, stigma from former intimate partners, having to walk long distances when collecting ARV medication, long waiting times at the clinics, few counseling rooms impeding privacy and shortages of staff (hindering on the quality of counseling received) pose as barriers to ART adherence in the demarcated area of study. Patient-centred policies and practices are recommended as a way of addressing the identified barriers to ART.

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DEDICATION

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Indeed, "...*each problem has hidden in it, an opportunity so powerful, that it literally dwarfs the problem, and also, the greatest success stories were created by people who recognised this very problem and turned it into an opportunity."* **Anon**

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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodefiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral (drug)
AZT	Zidovudine (also known as ZDV)
CASWE	Canadian Association for Social Work Education
CD4	T-lymphocyte cell bearing CD4 receptor
CHBCWs	Community Home Based Care Workers
CHC	Community Health Centre
EFV	Efavirenz (
FDC	Fixed Dose Combination
FTC	Emtricitabine
HAART	Highly Active Antiretroviral Therapy against HIV/AIDS
HCW-MC	Health care worker- member checking
HCWs	Health care workers
HIV	Human Immunodeficiency Virus
IFSW	International Federation of Social Workers
NDoH	National Department of Health
PHC	Primary Health Care facility
PLWHA	People living with HIV/AIDS
P-MC	Patient-member checking
PMTCT	Prevention from Mother to Child Transmission
TDF	Tenofovir (
UNAIDS	United Nations Programme on HIV/AIDS
UTT	Universal Test and Treat
WHO	World Health Organization

CHAPTER 1

BACKGROUND TO THE STUDY

1.1 INTRODUCTION

HIV and AIDS continue to be major public health issues worldwide. This epidemic is equally a major threat to social and economic development globally and in South Africa. It severely impacts upon the developmental gains made since 1994 with the onset of a South African democratic government, especially with regards the improvement of quality of life and services to families and children. The social impact of the HIV and AIDS epidemic presently manifests in protracted illnesses and death among the economically active section of the population, which further deepens poverty and hardship.

As a way of illustration, worldwide 2.1 million people were newly infected with HIV in 2015, bringing the total number of people who had become infected with the HI virus since the start of the epidemic to 78 million globally. Of these numbers, 35 million people are reported to have died from AIDS-related illnesses, accounting for 36.7 million people who were living with HIV globally in 2015. Within the Eastern and Southern Africa region by 2015, about 960 000 new HIV infections were recorded which brought the total number of people living with HIV to 19 million people. Of these numbers, women accounted for more than half the total number of people living with HIV. This region also reported a total of 470 000 people who have died of AIDS-related causes in 2015 (UNAIDS FACT SHEET, 2016: 1-2).

In South Africa, the total number of people living with HIV and AIDS (PLWHA) increased from about “4 million in 2002 to 5, 26 million by 2013. For 2013 an estimated 10% of the total population was HIV positive, with about 17, 4% of these being women against 15.9 % comprising HIV positive adults (men and women) within the age range 15-49” (Statistics South Africa, 2013: 4).

The statistics provided above of people living with HIV show the progression of the virus generally and specifically wherein Eastern and Southern Africa on the global level have taken a lead, including a high rate in South Africa, with women more infected with HIV compared to their male counterparts.

As pointed out by World Health Organisation – WHO (2003: 3) “people may live with HIV for a long time before the actual diagnosis with sometimes very few or no noticeable change in their health condition”. However, once they are diagnosed, it is essential to start antiretroviral therapy (ART) in order to slow the progression of the disease. This can be a challenging time, especially with the realisation that ARV drugs have to be taken daily for life. This situation could also serve as a startling reminder to the person diagnosed, that they are now living with a chronic and incurable disease. For ART to be effective, patients must adhere optimally to the regimen. This means that those infected and prescribed the ARV drugs must take their medicine ideally at the prescribed time at least 95% of the time. Such a high degree of commitment implies that someone should be mentally fit before beginning with the ARV treatment (World Health Organisation, 2003: 3).

Among the various professions, social work is concerned with “helping individuals, families, groups and communities to enhance their individual and collective social functioning. The profession aims at enabling people to develop their skills and innate abilities to use their own resources and those of the community in order to address problems” – thus placing the profession in the strategic position of dealing with those infected and affected with the HI virus (Canadian Association for Social Work Education – CASWE, 2013: 1). Social workers have long provided important direction, care, and participation in mobilising responses to dealing with HIV and AIDS. They offer various services that include: counseling, material and moral support, prevention, early intervention, rehabilitative services, and other related care and treatment interventions necessary to promote the well-being of the individual living with HIV and AIDS. Social workers are also guided in their intervention by social work principles such as self-determination, respect for the dignity and consideration of the worth of people, including advocating for their social justice (International Federation of Social Workers - IFSW (2012: 1).

Much as there is no cure for this disease, people manage to lead productive lives with all the support they receive from health care workers (HCWs). Some of the challenges confronting these health care providers in their intervention include dealing with the continued stigma of HIV and AIDS and dealing with the psychosocial effects experienced by people living with the disease – often manifesting in non-adherence to ART (Schultz, 2014:1)

The report on HIV/AIDS in South Africa (2010: 2), estimated that:

Of the 5,700,000 South Africans who were diagnosed with illnesses related to HIV and AIDS in 2010, just fewer than 12% of these were treated for advanced HIV and AIDS related illnesses and were on ART. By 2010, nearly 1 million or about 2% of all infected adults in South Africa were receiving ART, with 38% of these being children. During that year again, some 280,000 South Africans are reported to have died of HIV and AIDS related diseases, either because of the advancement of the disease and or their non-adherence to ART – the area of concern in this study.

Some of the reasons that account for the initial low levels of ART among those that were ready for treatment and possibly died in great numbers in the South African situation might have stemmed from the post-apartheid era AIDS policy in the country which was then, as Mbali (2004: 1) puts it: "characterised by conflict between the government, civil society and the medical profession. At the heart of this conflict was the argument over the then South African President Thabo Mbeki's denial of the causal links between HIV and AIDS, and claims that anti-retroviral (ARV) drugs were ineffective and lethally toxic in the face of scientific evidence to the contrary"

The other reason behind non-adherence in most cases seemed more than medical. For instance, a person cannot accept the treatment until he or she accepts the manifestation of the disease, especially in the face of stigma related to the virus and discrimination against those infected and affected by HIV and AIDS. It is therefore imperative to study the barriers to ART. In order to undertake this mammoth task, consideration has to be made of the role of the social work profession in providing social support and meeting the human needs and rights through its holistic approach. Social work also does facilitate screening and counselling for those living with HIV and placed on ART, among some of its intervention mechanisms (Seema-Rani, 20013: 70), In this study ART adherence means “taking the prescribed regimen of drugs in the right doses, at the same time, every day for a lifetime, following dietary prescriptions” (Skhosana, Sruthers, Gray & McIntyre, 2006: 17). Non-adherence to ART, on the other hand, is equally equated to aspects such as “not taking the medication at all, taking the medication at the wrong time, taking the wrong dose and or terminating the medication without consulting the health care provider” (Kagee, 2008: 414). For the purposes of this study, the WHO Guidelines (2013: 1) are used considering a combination of clinical and social factors which can include financial resource capacity, acceptability to people living with HIV (non-stigmatization) and understanding the local context. This viewpoint is upheld against the meaningful contribution that social work as a field of practice can have in the possible therapeutic impact of HIV and AIDS intervention roles. Also, in this study the terms “patient” and “people” are used interchangeably.

Based on this background, this study examined the non-adherence to ART in Maquassi Hills, North West Province, South Africa.

1.2 STATEMENT OF THE PROBLEM

According to the National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa (2008: 3) the North West province within the years 2002 to 2008 recorded an average of 11% HIV prevalence rate, the fourth highest within all the provinces in South Africa. Following this prevalence rate, the number of people who needed ART in the North West province increased from 83,770 to 95 080 in 2010 (National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa (2011: 44)

The gap between those in need of ART and those taking up treatment serves as an indication of the impact that HIV has in the province. The main problem in this study is the fact that access to ART does not constitute adherence to the ARV regimen, with the main question being: “of those people accessing ART in the North West Province – Maquassi Hills district in particular - how many adhere maximally (about 95%) to the regimen. According to Goudge and Ngoma (2011: 52) ART requires life-long adherence in order to be effective, and to also prevent the development of resistant strains that ultimately culminate in death. It is important to appreciate barriers that impede adherence to ART considering behavioural, structural, psycho-socio-economic, and contextual risk factors – going beyond what most of the research studies already conducted have concentrated on in their different research projects in the South African situation - which mainly targeted attitudes and beliefs related to adherence. Effective forms of interventions require a holistic understanding of the social processes and cultural aspects that create adherence differentials (Goudge & Ngoma, 2011: 53).

1.3 RESEARCH QUESTIONS

Given the research problem, the following research questions gave direction to the investigations:

- What is the phenomena and rate of adherence and non-adherence to ART?
- What are the barriers to ART adherence?
- What strategies are deployed in South Africa to address the problem of non-adherence to ART?
- How could global strategies be contextualised in order to enhance maximum adherence to ART in the demarcated area of the North-West province?
- What role can social work as a profession play in addressing non-adherence to ART?

1.4 RESEARCH AIM AND OBJECTIVES

The aim of this research was to examine non-adherence to antiretroviral treatment in the Maquassi Hills, so that guidelines for an integrated strategy and programme that addresses the problem of defaulting in the demarcated area of the North West Province could be recommended. The aim of the research was achieved through the following objectives, which were:

- To determine the phenomena and rate of adherence and non-adherence to ART.
- To examine barriers to ART adherence.
- To examine strategies that are deployed in South Africa in order to address the problem of non-adherence to ART?

- To contextualise global strategies in order to enhance maximum adherence to ART in the demarcated area of the North West Province.
- To analyse the role that social work as a profession can play in addressing the problem of non-adherence to ART.

1.5 SIGNIFICANCE OF THE STUDY

The significance of the study connotes its importance and contribution to practice and the disciplinary body of knowledge (Punch, 2004: 76). This study bears significance in terms of policy, research and practice.

1.5.1 In terms of policy:

The outcomes of the research contribute at policy formation and implementation levels to the broader clarification on non-adherence to ART with possibilities of urging for patient-centred intervention programmes that address the problem holistically.

1.5.2 In terms of research

Theoretically the study has possibilities of contributing to research regarding factors facilitating and or barriers to ART adherence, considering the views of selected participants in the Maquassi Hills – the demarcated area of study.

1.5.3 In terms of practice

Social service practitioners in the health field are provided with current and articulated challenges that contribute to people's non-adherence to ART – for an inclusive and more sensitive intervention mechanism.

1.6 CONCEPT CLARIFICATIONS

1.6.1 HIV and AIDS

Lahey (2001:261) defines HIV (Human Immunodeficiency Virus) as “a virus that destroys the immune system in the human body”. AIDS, on the other hand, is an acronym for Acquired Immune Deficiency Syndrome (Van Dyk, 2004:4). In the context of this study HIV is referred to as a virus that is acquired. This means that the virus enters the body from outside through multiple ways. In this study, the presentation of the terms “HIV and AIDS” separately over and above the familiar presentation of “HIV/AIDS” is used deliberately to indicate that though the two terms are mutually interdependent, they are fundamentally different, meaning that a person who is infected with the HI virus may not necessarily present with AIDS.

1.6.2 Antiretroviral therapy (ART)

Antiretroviral therapy refers to “the use of a combination of three or more ARV drugs used to achieve viral suppression”. – It is a lifelong process. Synonymous terms are: combination of ART and highly active ART which equals to HAART” (WHO Guidelines, 2013: 15). For the purpose of this study, this definition applies.

1.6.3 Adherence to ART

Adherence is defined as “the act of sticking to something”. In the context of treatment with medications, adherence means a more inclusive process of the patient and the health provider. The patient plays a more active role in their treatment and makes a commitment to follow the prescribed regimen as best as possible (Training Guide on Adherence to Antiretroviral Therapy in Adults, 2004:16). For the purpose of this study, adherence to ARV is pegged at 95% adherence rate.

1.6.4 Non-Adherence to ART

Non-adherence to ART “varies from missing one dose of a medication to missing a single dose of all three or four medications to missing multiple doses or all doses a day, week or in a month” (Training Guide on Adherence to Antiretroviral Therapy in Adults, 2004: 17). In the context of this study, non-adherence to ART entails not sticking to one’s medication as prescribed by a medical practitioner. At the same time this entails not observing provided instructions regarding dietary or fluid intake or not taking medications at prescribed times given.

1.6.5 Social work

The social work profession promotes social change, problem solving in the relationships of people, including the empowering and liberation of people, so that they should grow in terms of their well-being. The profession of social work uses theories of human behaviour and social systems. It also intervenes at the points where people are expected to have an interaction with their social and physical environments. Principles of human rights and social justice become pertinent in this field of practice and serving mainly as points of departure (International Federation of Social Workers (IFSW), 2012:1). In the case of this study, the social work is considered from the point of offering specialised services in the health field, specifically dealing with those affected and infected with HIV and being on ART.

1.7 ASSUMPTIONS OF THE STUDY

This research study rests on the following assumptions:

- Inadequate information on how the ARV drugs function is significantly related to the rate and nature of non-adherence to ART.
- There are relations between motivation (intrinsic as well as external) and adherence to ART medication.
- The stigma associated with HIV infection significantly relates to non-adherence to ART medication.

1.8 STRUCTURE OF THE DISSERTATION

CHAPTER 1: BACKGROUND TO THE STUDY. This chapter provides background information about the study.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORKS. In this chapter concentration has mainly been on reviewing topics related to non-adherence to ART. This was followed by a discussion on the theoretical frameworks that informed this study.

CHAPTER 3: RESEARCH METHODOLOGY: The chapter explains the research methodology utilised in this research study and provides justification for the use of such methods.

CHAPTER 4: DATA PRESENTATION, ANALYSIS AND INTERPRETATION OF RESEARCH FINDINGS. The chapter consists of a presentation of the data collated, the analysis thereof and its interpretation.

CHAPTER 5: DISCUSSION OF THE FINDINGS, RECOMMENDATIONS AND CONCLUSION. The chapter provides a discussion of the research findings, followed by recommendations for practice, policy and further research, culminating in a rounded conclusion of the entire study.

1.9 SUMMARY

This chapter briefly highlighted the background of the research, the statement of the problem, research questions and the aim and objectives of the study. The significance of the study was indicated, with clear concepts clarified. Assumptions of the research study were specified and a brief explanation of the research methodology used in this study was provided. Thereafter, the structure of the report was stated. The chapter ended with a summary of the spectrum covered in this research.

CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 INTRODUCTION

In general, the literature review provides important information regarding what has been done and what needs to be done in relation to a specific research problem (Fain, 2009:53). At the end point of the research process, findings that are established are gainfully connected to preceding literature and facilitate the identification of gaps that need to be closed. This process aims at refining and redefining the research questions through the findings of other researchers (De Vos and Fouché, 2001:66). In this study, literature review is linked to the specific objectives of the study as outlined chapter 1. Literature in this study was reviewed using books, articles, research reports, and journal articles. Different data bases were also sourced. Both local and international materials addressing the question on adherence and non- adherence to ART were also reviewed.

Through this literature review, a limited number of themes that are significant to non-adherence to antiretroviral treatment in the demarcated area of study were reviewed. Amongst these are the following: the phenomenon of adherence and non-adherence to ART, the rate of ART intake globally and in South Africa, the goals of ART medication, ART monitoring tools, barriers and facilitators of adherence to ART, strategies that can enhance adherence to ART. Since the study was undertaken from a social work perspective, the role of social work in HIV and AIDS was generally reviewed with specific reference to ART adherence as well. Thereafter two theoretical perspectives underpinned this study and they are the Health Belief Model (HBM) and the strength-based perspective.

2.2 THE PHENOMENA OF ADHERENCE AND NON-ADHERENCE TO ART

2.2 1 The meaning of adherence to medication generally

The term adherence generally can be seen as “the act of sticking to something”. In the context of treatment with medications, adherence is a joint process and effort involving the patient and the health care provider. This process is differentiated from ‘compliance’ – which in a way does entail “the act of conforming, yielding or following (blindly)” (Training Guide on Adherence for Antiretroviral Therapy in Adults, 2004: 17). The explanation provided here implies that in adherence to treatment medication, the patient is expected to play a more active role in their treatment, followed by a commitment to follow the prescribed rules provided by the health care worker as best as possible in order to acquire the desired results. In conforming to treatment, the implication is lack of patient participation and commitment with a paternalistic element on the part of the health provider. This can further mean the presence of unequal power relations between the service provider and the consumer of services which has the possibilities of impeding treatment to medication adherence.

The question is: how big is the problem of lack of adherence to medication generally? On this score Barber, Ntilivamunda, Babatunde, and Khan (2015: 3) noted that globally about 20-30% prescriptions are never fully adhered to. In the United States of America for instance, approximately 50-75% of cases of medication have been reported as not continued by patients as prescribed. World-wide chronic non-communicable diseases rates of medication adherence tend to drop after the first 6 months, based on high costs. The results have been higher morbidity and mortality outcomes, and development of drug resistance (Barber et al, 2015: 3).

2.2.2 The meaning of adherence to ART

WHO Guidelines (2013: 176) indicate adherence to ART as the actual way in which a person’s behaviour taking ARVs, following an eating plan and at the same time undergoing some lifestyle changes corresponds with provided and agreed upon recommendations from a HCW. For ART, a high level of sustained adherence (95%) is necessary in order to:

> “Suppress viral replication and improve immunological and clinical outcomes, decrease the risk of developing ARV drug resistance, and reduce the risk of transmitting HIV” (WHO Guidelines, 2013: 176).

Yet Schonneson, Diamong, Ross, Williams, & Bratt (2006: 409) looked at adherence for ART from a perspective which includes dose, schedule, and dietary adherence. To these researchers, “dose adherence refers to the quantity and proportion of doses taken (correctly). Schedule adherence refers to doses taken at the prescribed time and dietary adherence refers to doses taken correctly with the prescribed types of food”. The question posed then is whether adherence at 95% is possible, considering especially the combination of dose, schedule and dietary requirements. From the stated question, researchers Orrell, Bangberg, Badri & Wood (2003: 137), in their study reported 93, 5% adherence rate as measured by clinic-based pill count. Similarly Dagnew (2009: 143) from a study undertaken in Ethiopia, found 19, 8% adherence level at the rate of <95%, while 80, 2% took their ART medications for 30 days preceding the study. This possibility exceeded expectations given that Ethiopia is a relatively poor country where the reasons for non-adherence can be expected to be largely diet related. This demonstrates the importance of motivation and high levels of will-power which can supersede all other factors.

For ART adherence a combination of factors does play a role. For instance, Volberding, Sande, Lange, Greene & Gallant (2012:60) found that high motivation, positive coping styles and high levels of interpersonal support were positively associated with greater adherence. Enriquez and McKinsey (2011:47), however, identified for ART adherence “a sense of self-respect, feeling positive about the ARV drugs, having a strong will to live, acceptance of the HIV diagnosis, understanding the importance of ART adherence, making use of reminder tools, having an ARV regimen that fits into one’s daily schedule, one daily dosing of ARV medication, perception of a positive health care provider–patient relationship, and having social support”. Research conducted by Acton (2013:545) revealed also that the use of mobile phone reminders, involvement of relatives and HIV self- management training programmes does have the potential to improve ART adherence.

The explanations above clearly indicate the importance of both internal and external factors working in concert. With internal factors the patient or person on ART has to take full responsibility which can manifest in self- motivation and preparedness. Externally, a support base is significant.

Adherence to ART does have value to its response to the HIV and AIDS epidemic. In order to achieve the goals of zero new HIV infections and discrimination, as well as zero AIDS-related deaths, everyone elligible for HIV treatment has to have access to this kind of therapy, including having access to HIV prevention services as well. ART serves as an essential treatment mechanism and an essential part of an efficient, sustainable response to the HIV and AIDS epidemic (UNAIDS, 2015: 2).

2.2 3 The meaning of non-adherence to ART

Non-adherence, according to Hiko, Jemal, Sadhakar, Kleric and Degene (2012:4), is defined as:

"Missing from one dose to multiple doses of the prescribed drug, not observing the required time span, not observing food restrictions, not taking the correct quantity of drug and patients taking their medication less than 95% adherence level".

Poindexter (2010:20) agrees with the earlier definition of non-adherence to ART. This writer posits that poor adherence is a widespread problem. Non-adherence to ART can also be equated to aspects such as "not taking the medication at all, taking the medication at the wrong time, taking the wrong dose and or terminating the medication without consulting the health care provider" (Kagee, 2008: 414).

From Seema-Rani (2013: 71) the following points clearly define non-adherence to ART:

- Periodic under dosing which involves failing to take the correct amount of drugs regularly.
- Chronic over dosing - which is about taking the drugs more often than prescribed.
- Abrupt over dosing - Neglecting to take the medication properly for a long time and then suddenly over dosing before one goes for a check-up. .
- Drug Holidays – Stopping to take all medications all of a sudden for either days or even weeks - a situation sometimes caused by "pill fatigue".
- Random administration can include taking the drugs whenever the thought occurs.

As observed above, very high levels of adherence are expected in order to attain the full desired benefits of ART.

2.3 THE RATE OF ART INTAKE GLOBALLY AND IN SOUTH AFRICA

2.3.1 Global intake of ART

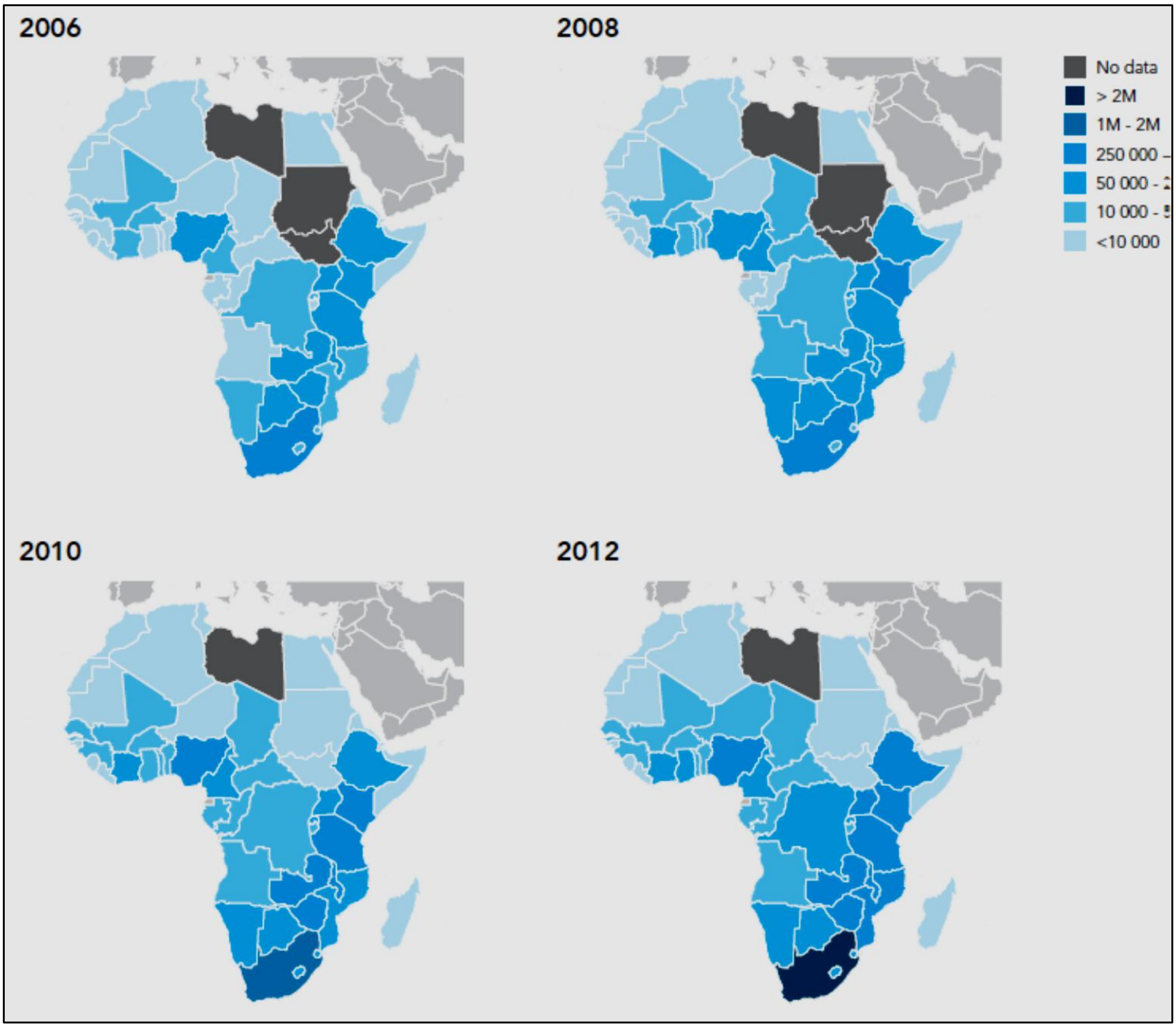
As of December 2012, an estimated 9.7 million people in the so called low- and middle-income countries were receiving antiretroviral therapy - an increase of about 1.6 million compared to what was the case in 2011.With the situation in high-income countries, approximately 875 000 people were reported as accessing ART, and by December of that year (2012) the number of those receiving ARVs went up to 10.6 million people (UNAIDS Rreport on the Global AIDS Epidemic, 2013: 46). The figures stated above clearly show how HIV infection knows no neither boundaries nor economic status. Both the so called low and middle income countries are casualties of the epidemic.

The UNAIDS (2015: 3) report indicates that Africa leads the world in increasing access to ART among those in need of the medication, with a total of about 7.6 million people recorded across the continent as having been initiated on ART as of December 2012 (See Figure 1). Countries in Western and Central Africa also witnessed an increase in the number of people receiving treatment, although at a slower pace. About 10 countries (Botswana, Cape Verde, Eritrea, Kenya, Namibia, Rwanda, South Africa, Swaziland, Zambia and Zimbabwe) are reported to have reached about 80% of adults eligible for ART, under the 2010 WHO guidelines (UNAIDS, 2015: 4).

From Figure 1 below it is increasingly clear that there has been progress in the intake of ART on the African continent from 2006 through to 2012. Many are still in need of the medication, especially considering the staggeringly high numbers of people who become infected almost daily. As an illustration, according to UNAIDS FACT SHEET (2016: 1) worldwide, 2.1 million people became newly infected with HIV in 2015, down from 2.2 million in 2010. The gains in treatment nevertheless are largely responsible for a 26% decline in AIDS-related deaths reported globally since

2010, from an estimated 1.5 million in 2010 to 1.1 million in 2015. The reduction in deaths since 2010 is said to have been greater among adult women (33% decrease) compared with adult men (15% decrease) – a point which somewhat reflects higher treatment coverage among women than men (Global Aids Update, 2015: 4). It must be indicated, however, that there is still need for governments in different countries of the world to invest in prevention programmes in order to combat new HIV infections.

Figure 1: Number of people receiving ART in Africa (2006-2012)



Source: UNAIDS Report (2015)

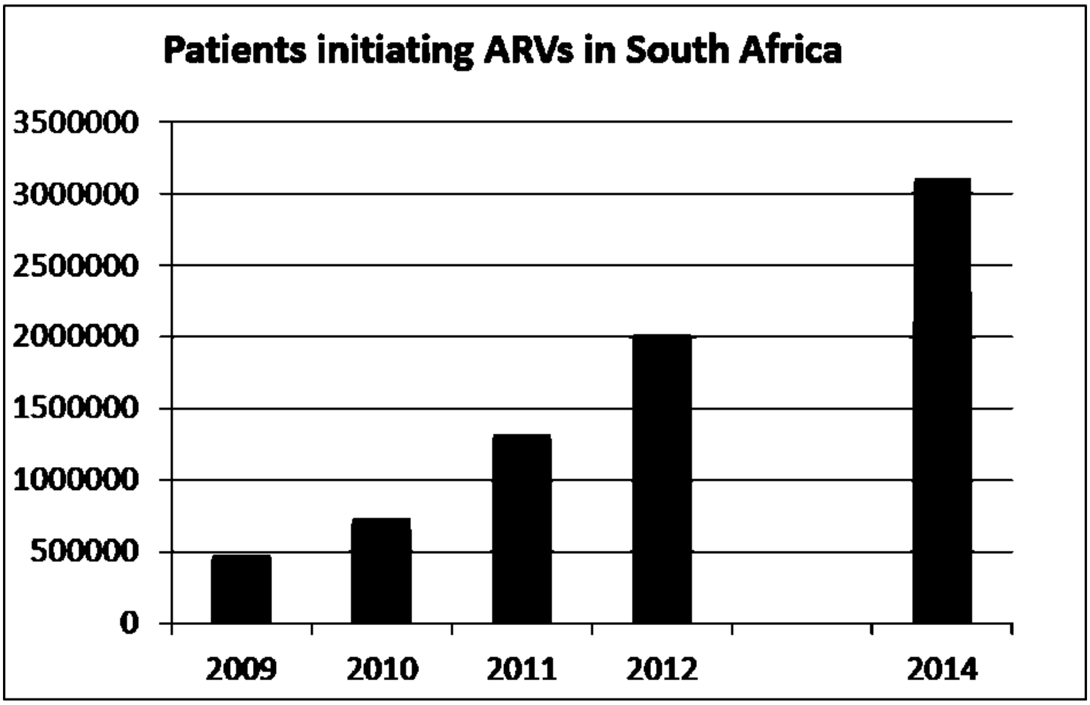
2.3.2 South African intake of ART

South Africa has been experiencing some of the highest increases in treatment access in the world, with a scale-up of treatment services of up to 75% between 2009 and 2011 (Statistics South Africa, 2011: 2). In October 2011 South Africa reached the target of universal access to treatment as the total number of people receiving treatment reached 2 million. The huge scale-up of treatment in South Africa has been especially impressive considering that some of the country's leaders at one time had doubts about the effectiveness of ART, a situation which manifested in an initial delay and slow pace of delivering a public ARV programme (Statistics South Africa, 2011: 2).

Van Dyk (2011: 2) asserts that these years of denial came to a virtual end in 2003 when the South African Government finally approved a national programme to make ARVs publicly available to all HIV infected people who qualified for treatment - following pressure from mainly the Treatment Action Campaign (TAC). Even in 2004, the distribution of antiretroviral drugs was relatively slow, with only around 28% of people in need receiving treatment at the end of 2007. This slow provision of treatment could still be linked to unconventional views about HIV and AIDS (Masokoane, 2009: 13).

Van Dyk (2011: 3) observes on this aspect, "unfortunately the damage done by the government's inaction was irreparable and many believed that the national rollout was too little too late." Phenomenal growth of people initiating ARVs in South Africa has also been reported for the period up to 2014 (See Figure 2).

Figure 2: Patients initiating ART in South Africa



Source: Barber et al (2015)

Figure 2 above clearly shows a staggering increase in the number of those initiating ARVs in South Africa from 2009 and reaching a 3.5 million mark in 2014. The high numbers of those initiating ART demonstrate the commitment on the part of the South African government and on the health of people, especially against the knowledge of the high costs of the medication.

The next question is: what are the numbers of those receiving ART in South Africa by province, and the number of people receiving ART in South Africa by gender? The paragraphs that follow are an attempt in answering these questions. Table 1 shows people receiving ART in South Africa by province:

Table 1: Patients/People receiving ART in South Africa by province

	2004	2005	2006	2007	2008	2009	2010	2011
Eastern Cape	5, 300	12, 600	26, 000	43, 000	65, 000	98, 000	137, 000	187, 000
Free State	2 200	4 900	10 000	18 000	29 000	47 000	66 000	91 000
Gauteng	13800	30 800	62 000	95 000	145 000	219 000	280 000	439 000
KZN	12800	30 000	67 000	110 000	174 000	282 000	409 000	558 000
Limpopo	2 000	4 800	12 000	21 000	36 000	60 000	101 000	124 000
Mpumalanga	3 300	5 800	12 000	24 000	38 000	61 000	96 000	142 000
Northern. Cape	400	1 500	3 000	7 000	9 000	13 000	16000	19 000
North West	2 700	8 800	21 000	34 000	48 000	70 000	96000	126 000
Western Cape	5 000	11 400	21 000	31 000	45000	64000	85000	107 000

Source: Johnson (2012)

As Table 1 shows there is a marked increase in terms of ART coverage provincially in South Africa. What is evident also, is the unequal ART coverage in the different provinces. Two provinces that stand out with regard to ART initiation are Kwa-Zulu Natal and Gauteng. It is not clear whether this scenario points to an advancement of medical facilities responsible for dispensing such or, to a commitment on the part of health personnel providing such. Johnson (2012: 3) on this score provides a version of probabilities that “this could possibly be due to individuals with advanced HIV migrating to urban areas because of the perceived superiority of health services in the major urban centres.” The two highly covered provinces are chronologically followed by: Eastern Cape, Mpumalanga, with the North West province – the demarcated area of study taking fifth place in terms of ART coverage. The three lower provinces in terms of ART coverage are: Western Cape, Limpopo and Northern Cape.

Table 2 shows the number of people receiving ART in South Africa in terms of gender:

Table 2: Number of patients/people receiving ART in South Africa by gender

Gender	2004	2005	2006	2007	2008	2009	2010	2011
Women	25 000	63 000	138 000	228 000	354 000	553 000	777 000	1 090 000
Men	17 000	37 000	75 000	120 000	183 000	283 000	396 000	551 000

Source: Johnson (2012)

As can be noted from Table 2 there are substantial differences between men and women with regard to the rate of ART initiation. The low rate of initiation in men relative to women may point to information that most women compared to some men do access and utilise medical facilities. This scenario may serve as a reflection of "gender differences in health-seeking behaviours and perceptions that men who seek help are weak" (Johnson, 2012: 4).

Table 3 shows the number of people receiving ART in South Africa by providing sectors.

Table 3: Number of patients/people receiving ART in South Africa by providing sectors

Providing sector	2004	2005	2006	2007	2008	2009	2010	2011
Public sector	9 600	60 000	163 000	290 000	470 000	748 000	1 073 000	1 528 000
Private sector	34 000	43 800	57 000	68 000	86 000	117 000	154 000	190 000

Source: Johnson (2012)

Table 3 shows that in 2004 the private sector was the biggest provider of ART but has since been overtaken by the public sector. A possible explanation can be that the private sector has been more discreet, organised, though expensive. The public sector dispenses this medication free of charge – which makes it more accessible and affordable.

Not only is it important for people to take ARVs, but to remain on ART and adhere maximally to the regimen. As an established fact already, this form of medication does not cure HIV but bears some goals which are looked at next.

2.4 THE GOALS OF ART MEDICATION

As posited clearly by UNAIDS (2015: 2), the following serve as advantages for initiating ART to:

> ART intake is said to have prevented millions of people in the world from dying from 1995 until 2012. Sub-Saharan Africa had most lives saved through medication; ART can reduce the risk of HIV transmission if adhered to maximally; ART can reduce AIDS-related illnesses among PLWHA.

After showing the high rate of eligible people accessing ART in the world and in South Africa in particular, with the goals of ART medication pointed out, the question that needs to be answered next is: How can adherence be assessed and monitored?

2.5 ART MONITORING TOOLS

According to the Guidelines for the Use of Antiretroviral Agents in HIV-1-infected Adults and Adolescents (2014: K3), there is no hard and fast rule in regard to the assessment of adherence, but there are many validated tools and strategies to choose from. In the case of this research two practical monitoring tools are considered, viz: the patient’s self-report of adherence and the clinical/pharmacy records and pill counts. Although patient self-report of adherence predictably overestimates adherence by as much as 20% (Guidelines for the Use of Antiretroviral Agents in HIV-1-infected Adults and Adolescents, 2014: K3), this measurement still remains the most useful tool. Clinical and pharmacy records and pill counts is an addition to simply asking the patient about adherence. A brief explanation of these two monitoring tools is provided below:

1. **Patient's self-report of adherence**

In this monitoring tool, patients are asked to report their own adherence in a self-report. The monitoring does seem to have a history of predictably overestimating adherence, though remaining the most useful tool and the easiest to use in a clinical setting. Accuracy in this tool can be maximized by:

- Approaching the patient in a non-judgmental way- by listening to their version of the story
- Asking about missed doses, and
- Using prompts to help a person recall (Training Guide on Adherence for Antiretroviral Therapy in Adults, 2004: 20).

In the context of this study, the patient self-report of adherence was used to ascertain adherence and or non-adherence to ART.

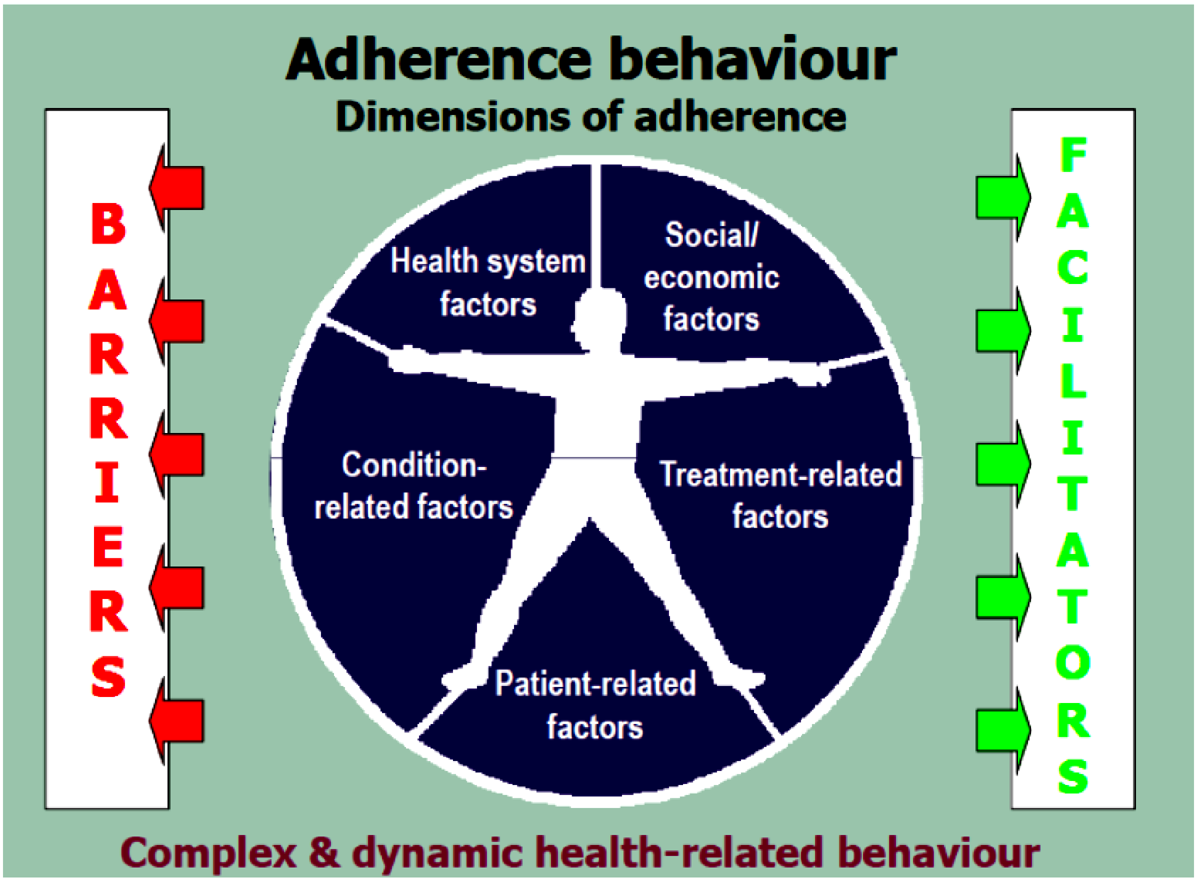
2. **Clinical/pharmacy records and pill counts**

This monitoring tool serves as an addition to simply asking the patient about their adherence. Ideally HCWs are supposed to conduct pill counts during scheduled clinic visits of a patient. The main disadvantage of this monitoring tool is that a patient can actually interfere with the unused pills by getting rid of them – dumping them just before the actual visit to a health facility. This mode of monitoring tends to rely heavily on a patient's reliability and honesty by presenting their actual count of medication at the time of their visits. Ideally unannounced pill counts may be more accurate, which suggest visiting patients at their homes – a non-probability since the exercise is resource-intensive and there may be issues of confidentiality and stigma in the community (Training Guide on Adherence for Antiretroviral Therapy in Adults, 2004: 21).

2.6 BARRIERS AND FACILITATORS OF ADHERENCE TO ART

Barriers of non-adherence to ART generally can be associated with the inability to take antiretroviral treatment consistently (Enriquez & McKinsey, 2011:47). In order to draw a comprehensive picture of the barriers and facilitators to ART adherence the WHO (2015: 5) dimension is used in this study, where these factors are discussed under: Patient-related factors, Treatment-related factors, Social/economic factors, Health system factors, and Condition-related factors (See Figure 3).

Figure 3: Barriers and facilitators of adherence to ART



Source: WHO (2015)

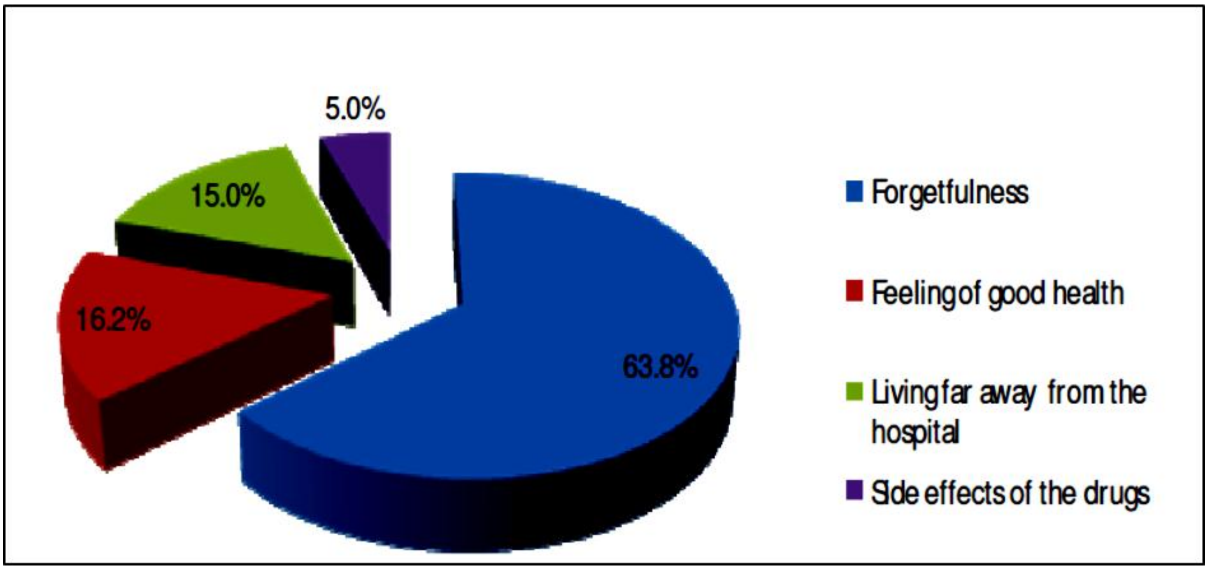
2.6.1 Patient-related factors

Patient factors, also termed the individual factors, can include socio-demographic factors such as:

Gender, marital status, religion, age, employment status, income, education level, as well as psychosocial factors, such as substance abuse, mental ill-health/health, level of social support and or lack thereof, and acceptance of one's health status (Training Guide on Adherence for Antiretroviral Therapy in Adults, 2004: 19).

WHO (2013: 178) further expands the individual factors to also include "forgetting doses, being away from home; changes in daily routines, other illnesses; and a lack of interest or desire to take the medicines". A study by Igwegbe, Ugboaja, and Nwajiaku (2010: 241-243) in Nigeria found the reasons for non-adherence to ART to be mainly centred on individual factors, which also included aspects of socio-economic factors. For instance, to these authors non-adherence was found to be linked to forgetfulness (63, 8%) which led to the participants in the study missing the drug (ART). The other reasons mentioned included feeling healthy (16, 2%) and living far away from the hospital. According to this study, patients living far from the hospital indicated that they had missed their drug doses based on the fact that they missed clinic attendance mainly on account that they were unable to afford the high costs of transportation. About 5% of participants cited side effects of the drugs as another reason that led to their non-adherence to ART (See figure 4).

Figure 4: Reasons for non-adherence among HIV positive pregnant mothers at PMTCT clinic in Nigeria (N=80)



Source: Igwegbe et al (2010)

In a study by Jean-Baptiste (2008: 16) of patients who missed ARV doses within the past four or 30 days of conducting that research, about 26.5% fell into this category. The top three reasons provided for missing doses were: forgetting (30%), being away from home (25%), and being busy with other things (11%). Surprisingly, less commonly mentioned reasons were that the patient ran out of pills (8%), felt sick or ill

(7%), or had a change in daily routine (5%). Equally, the most common reason mentioned by the study participants in Abdissa's (2013: 100) study on reasons for missing their HIV medications in the past one month was forgetfulness (35.1%). This was followed by being busy with other things (17.5%), running out of pills (10.5%), feeling depressed (8.8%) and not wanting others to see them taking their medications (8.8%).

A study undertaken by Menamo (2014:51-54) in Ethiopia which investigated demographics of participants in relation to their non-adherence to ART revealed that among the male respondents studied, 87 % of them adhered to antiretroviral treatment while only 80.7% female respondents adhered to the ARV regimen. However, no significant relationship existed between the gender of respondents and non-adherence to ART. That study further indicated that a significant number of respondents who adhered to antiretroviral treatment were identified in the age group of 25-34 years, followed by those aged 35-44 years. The trend showed that adherence to ART decreased with older ages – implying that older adults are to be prioritized. However, no significant association was reported within the different age brackets of non-adherence to ART based on the $p>0.05\%$.

Menamo's study (2014:52) revealed in both bivariate and multivariate analysis that there was a significant relationship between non-adherence to ART and the religious status of respondents. Both Protestant and Catholic religion followers were not likely adherents compared to their Orthodox ($p<0.05$) counterparts. This might have been informed by their belief that their fate is in God's hands and with praying healing is probable. With regard to poor literacy, that study found an association of low levels of understanding of medical instructions and non-adherence to ART. On the other hand, higher levels of education revealed an increase in the patient's adherence to ART. A good level of understanding about HIV and AIDS awareness of the consequences of non-adherence are associated with higher educational levels.

In the South Africa context, Barber et al (2015: 7) found that patient-related factors that posed as barriers to ART also included forgetfulness to come to health care, life stress, hopelessness and negative feelings, including dependency on others financially. Facilitating functions, according to Barber et al (2015: 7) can include helping the patients to monitor their drug and alcohol use, attend psychiatric consultations, participate in psychotherapy and telephone counselling. Self-management of disease and treatment can also enhance adherence to ART. Cash grants have been provided upon meeting the minimum requirements in South Africa as part of creating an enabling situation. Also, a patient's knowledge of their medication regimen coupled with their understanding of the relationship between non-adherence and build-up of resistance to ART can equally predict better adherence. A patient's belief and confidence in therapy also does influence adherence to medication generally and to ART specifically (Training Guide on Adherence for Antiretroviral Therapy in Adults (2004: 19).

2.6.2 Treatment-related factors

Factors may include adverse events; the complexity of dosing regimens; the pill burden (always having to take medication at a said time); and dietary restrictions (expected to take medication with food and sometimes having to cut on certain restricted type of food) (WHO, 2013: 178). In the South African situation treatment-related factors also encompassed the following factors: severe-lifestyle changes and lack of clear instructions about how to take the medications (ARVs) (Barber et al (2015: 7). The most significant challenge with regard to treatment is also that of the limited and often inadequate supply of antiretroviral drugs at several ARV facilities. In the South African situation this is referred to as drug 'stock-outs' and has a detrimental effect on the ARV rollout programme. As an illustration, in November 2008 ARV shortages in one of the provinces (Free State) resulted in approximately 30 patients dying daily, as reported by the Southern African HIV Clinicians Society based on reported stock-outs of ARVs. During that period the Province's Department of Health placed a moratorium on the enrolment of new patients in the ARV programme (Vawda & Variawa, 2012: 495).

Barber et al (2015: 7) mentions the simplification of regimens; education on use of HAART, and assessment and management of side-effects as a facilitating aspect of ART, while Vawda & Variawa (2012: 508) suggest that health care workers (HCWs) are to be affirmed firstly as the backbone of the ARV rollout programme. As a result of their affirmed position, their complaints and grievances need to be urgently addressed. Also, an efficient monitoring and evaluation of all ARV rollout facilities should be undertaken periodically, in order to identify the deficiencies and institute remedial measures. The involvement of HCWs in the decision-making process, as well as setting time limits for the completion of specific interventions, has possibilities of contributing to a more transparent process and better outcomes.

2.6.3 Socio-economic factors

A study undertaken in Zambia by Sanjoba, Frich and Fretheim (2012: 140) reported stigma and discrimination, disclosure of one's status as HIV positive, concerns about confidentiality, use of alternative treatments and lack of food as barriers to adherence. Patients and HCWs mentioned specifically that stigma and discrimination related to being HIV positive were still present in their communities and within families, despite the positive visible benefits of ART. That study further revealed the use of alternative treatments as another barrier to adherence. In support to the barrier of stigma, the study by Semakula (2010: 64) undertaken in South Africa equally revealed that several of its respondents intimated that they withdrew from social activities and that it was uncomfortable for them to fulfil their appointments on the days they were supposed to visit the wellness clinic to get treatment due to fear of being seen by someone they know.

Kagee, Remien, Berkman, Hoffman, Campos, and Swartz (2011: 2-3) divided in their study the most salient social barriers into: poverty-related factors, problems with access to transport and food insecurity. Additionally, the issue of gender inequality as a structural factor was also included based on the fact that each of the highlighted factors has possibilities of influencing men differently from women. Some of these aspects are briefly explained below:

- **Poverty-related structural barriers:** Resources both material and non-material may be absent or minimal in order to help a person acquire basic necessities such as food – thus hampering ART intake;

- **Problems with access to transport:** A substantial number of patients may have to walk under sometimes difficult situations in order to collect their medication. Based on the absence of funds to pay for transport ART collection can be hampered;

- **Food insecurity:** In this case this can be about not being able to adhere to certain prescribed dietary requirements.

The main facilitating factors, in contrast to the barriers to ART adherence mentioned here, are reported to be: self-disclosure, and support groups. Several patients and HCWs interviewed also mentioned self-disclosure as a critical facilitator, usually linked to the support they received from their families (Sanjoba, et al, 2014: 141). Bringing services to the doorsteps of the patients by expanding the existing facilities may improve patients' adherence to therapy as well (Igwegbe et al, 2010: 241).

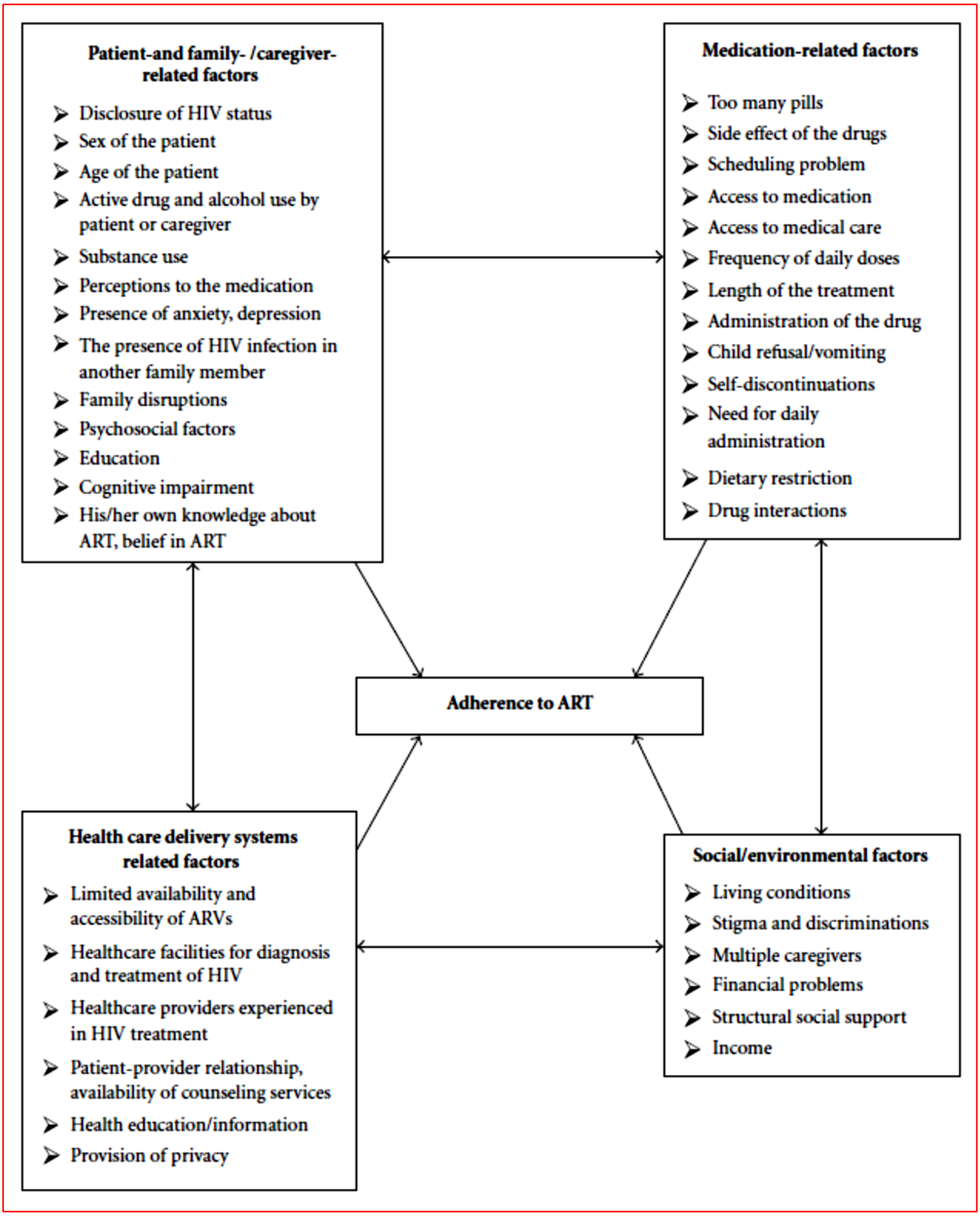
2.6.4 Health system factors

These require people with HIV to visit health services frequently to receive care and obtain refills; travelling long distances to reach health services; and bearing the direct and indirect costs of care (WHO, 2013: 178). Lack of clear instructions from HCWs, poor implementation of educational interventions and long waiting times at clinics can also be some of the health system factors to ART non-adherence (Barber, et al, 2015: 7). On the other hand, a friendly and supportive HCW, convenient appointment times as well as privacy at a health care centre can facilitate adherence (Adherence to Antiretroviral Therapy in Adults Guide for Trainers, 2004:19).

2.6.5 Condition-related factors

May include patients who do not seem to understand the relationship between adherence and viral load, In this case education on use of medicines, screening for co-morbidities; attention to mental ill-health, as well as abuse of substances become vital ways of facilitating adherence (Barber, et al, 2015: 7). Additional barriers to ART adherence are presented by Ayalu and Sibhatu (2012:4) in summary form diagrammatically (See Table 4 below)

Table 4: Identified barriers to ART adherence by Ayalu and Sibhatu (2012)



Patient-and family- /caregiver-related factors

- Disclosure of HIV status
- Sex of the patient
- Age of the patient
- Active drug and alcohol use by patient or caregiver
- Substance use
- Perceptions to the medication
- Presence of anxiety, depression
- The presence of HIV infection in another family member
- Family disruptions
- Psychosocial factors
- Education
- Cognitive impairment
- His/her own knowledge about ART, belief in ART

Medication-related factors

- Too many pills
- Side effect of the drugs
- Scheduling problem
- Access to medication
- Access to medical care
- Frequency of daily doses
- Length of the treatment
- Administration of the drug
- Child refusal/vomiting
- Self-discontinuations
- Need for daily administration
- Dietary restriction
- Drug interactions

Adherence to ART

Health care delivery systems related factors

- Limited availability and accessibility of ARVs
- Healthcare facilities for diagnosis and treatment of HIV
- Healthcare providers experienced in HIV treatment
- Patient-provider relationship, availability of counseling services
- Health education/information
- Provision of privacy

Social/environmental factors

- Living conditions
- Stigma and discriminations
- Multiple caregivers
- Financial problems
- Structural social support
- Income

What one can draw from the barriers to ART reviewed above is that, much as they appear similar, their aetiologies are different based on their context and different dynamics inherent in people/patients from different settings. Facilitators recommended can be contextualised in order to address the question on relevance for a particular setting.

2.7 STRATEGIES THAT CAN ENHANCE ADHERENCE TO ART

Globally and in South Africa, some people who are diagnosed with HIV do not ultimately receive the quality of services they need, while some on the other hand who access such services are not retained in care as demonstrated in the subsections above. There is no single strategy that can be recommended for enhancing ART adherence that can be applied universally in every clinical setting.

2.7.1 Re-designing the health care services

The following are some proven strategies recommended by UNAIDS (2015:8) for governments in different countries, and can also be adapted for the South African situation:

- The re-designing of health care services in line with the expressed, identified, felt and comparative needs of people. This can help people be motivated and retained in therapy;
- Speeding-up the decentralization of HIV services, with the main aim of bringing them closer to people in a more relevant manner;
- Building the capacity of health and community systems by periodically training HCWs on current issues pertaining to HIV and ART, including taking steps in ensuring the availability of essential HIV testing, and laboratory services at designated ART dispensing settings;
- Enforcing strong anti-discrimination provisions, and ensuring that PLWHA have access to legal services that might assist in trying to address stigma-related barriers;
- Strengthening the commodity procurement and supply management processes in order to prevent problems of stock-outs and prioritize local drug production as per the regional AIDS Plan 2013–2016 of the Economic Community of African States (ECOWAS).

Application of these strategies calls for commitment – both morally and financially from the government in all countries.

2.7.2 Proven guidelines for individual clinicians

Consistent with the idea of enhancing adherence to ART, Enriquez and McKinsey (2011: 48) equally provide some proven guidelines for consideration by individual clinicians, and they are:

- Readiness-assessment strategy to make sure that ART “naive” patients are provided with relevant information that can help in addressing anticipated barriers before they impede treatment. Also, should treatment failure occur a new regimen be prescribed;
- Barriers to adherence should be identified before they manifest;
- Social support networks should be further enhanced through stakeholder identification and involvement – in order to provide an enabling environment free from stress for those initiating ART;
- Actively involving the patients to list their barriers to adherence in rank order and for them to suggest possible ways on how best these can be addressed.
- If possible, moving towards prescribing once-daily regimens is recommended to prevent pill burden problems;
- Identifying and attempting to address problems related to the abuse of substances before ART is initiated;
- Ensuring mental health immediately before ART provision,

As a way of showing commitment to not only initiating people on ART, the South African government equally is constantly in search for workable solutions that can help in retaining those on ART in the programme. One such strategy has been the introduction of the Fixed-dose combination antiretroviral programme

2.7.3 Fixed-dose combination antiretrovirals

According to Moodley (2015: 1) Fixed-dose combination (FDC) antiretroviral drugs (ARVs) have been rolled-out in South Africa since April 2013 as a first line treatment of HIV-positive patients. FDC is a single tablet which contains a combination of the three: Tenofovir (TDF), emtricitabine (FTC) and efavirenz (EFV) (See Annexure 1). The main difference therefore between FDC and the current ART regimen is that the patients have to take one pill once a day instead of three or more pills multiple times a day. The decision to change over to FDC was based on some marked benefits, and the hope that adherence to ARVs would improve. Some of the benefits of FDC to patients include:

> "FDC it is proven is more effective compared to the current ARV regimen; It is more convenient in terms of having fewer side effects; It requires fewer laboratory tests to measure CD 4 Count; It does reduce the problem of pill burden especially for patients who present other chronic illnesses; and it can also be easily remembered since it is only one pill" (Moodley, 2015: 1; Health 24, 2013: 1).

The benefits of the changeover to FDC for HCWs would also be the following:

> "FDC is easier to order, store and manage; Training demands are lesser for HCWs who are forever expected to undergo rigorous training as a way of keeping abreast with recent ART information demands; Relationships between patients and HCWs may also improve with a regimen dispensed that is not complex to explain, and manage" (Moodley, 2015: 1).

As in Health 24 (2013: 1) some people are excluded from taking the FDC based on their complicated presenting health conditions. For instance, persons who have failed their first ARV regimen are not to take FDCs. In addition, those who have problems with their kidneys or people with severe psychiatric conditions are not to take the FDC. The National Department of health (NDoH) in South Africa announced that the roll-out was to be phased in according to priority groups such as:

- All new patients: Including adults, adolescents and pregnant women are eligible.
- All pregnant HIV positive women, regardless of their CD4 Count. They are to start with FDC from the 14th week of pregnancy, and going into their breastfeeding period, with possibilities of continuing on this medication for life. The probabilities are that this drug intake may even reduce mother-to-child transmission during the breast feeding period.

- All patients presenting with side effects due to toxicity from the currently taken ARVs (from stavudine as an example).
- Patients who are currently presenting with Tuberculosis (TB) comorbidity for example;
- Patients who present comorbidities as a result of their other chronic illnesses that can include for example hypertension, diabetes mellitus, etc (Moodley, 2015: 2).

The rationale provided by NDoH on why not all people currently on HIV treatment would benefit from FDC immediately, is at this juncture to avoid stock outs. Under the 2013/4 tender, it is indicated the manufacturer could supply NDoH with approximately 30 million units in phases. The promise is that as more FDC ARVs become available, other patients would then be phased in (Moodley, 2015: 2).

From this subsection on recommended strategies for ART adherence, it is evident that there is a need to re-design of the health care system in order to make it more accessible, to improve the quality of services dispensed and the quantity of services rendered as well. A need is also identified for the treatment team to also adopt treatment techniques that benefit the patient more in terms of initiating them to ART, identifying facilitators to ART adherence and potential barriers that should also be addressed with the active involvement of the patient/person in question. With individual clinicians they are expected to undergo a holistic assessment to ensure readiness for adherence.

On the other hand, the implication for the FDC initiative to successfully function in South Africa is that government cannot do this alone. Concerted effort on the part of NDoH, including HCWS – nurses, doctors and clinicians shall be essential in their adherence and dedication to the new set of guidelines to make sure that the country and settings do not overextend themselves beyond the set goals. Also, there is a need on the ground to equally mobilise civil society, traditional and community leadership, the faith-based sector and people living with HIV to spread the word so that people should take advantage of the services.

Since FDC initiative is still new and its effectiveness therefore cannot as yet be evaluated. What is important though that shows commitment on the part of the South African government is coming with ways of addressing barriers to ART adherence.

2.8 SOCIAL WORK IN HEALTH CARE

The role of social workers in health care generally varies, depending on the setting in which they work. In general, the social worker assesses for psychosocial issues and tangible needs that could affect the individual's ability to engage in services and manage treatment. The social worker's role may initially be to help the individual access treatment and later, in managing and staying on treatment (Poindexter, 2010:105). In working with individuals, groups, families, organisations and communities on the management of HIV and helping people in their adherence to ART, a social worker is expected to be knowledgeable and skilful in filling a variety of roles. The following are some of the identified roles as explained clearly in Zastrow (2014: 74-75):

2.8.1 Social work roles

2.8.1.1 Enabler: In this role the social worker is expected to help individuals, groups or communities to identify and articulate their needs, clarify and identify their problems as well. Also, people are expected to explore resolution strategies, and then select and apply a strategy that is most suitable to their needs and potential. The enabler role is the most frequently used in counselling individuals, groups and families when initiating ARVs.

2.8.1.2 Advocate: This role is actively directive in the sense that social workers provide leadership for arguing the correctness of the clients' need for help, especially when having to challenge an issue connected to a particular institution's decision not to provide expected services.

2.8.1.3 Empowerer: This role is about helping people to actually increase their personal, interpersonal, socioeconomic and political strength. Social workers as empowerers ought to create an enabling environment within which people can own and control their problem-solving process and make choices responsibly which can include taking their ART medication responsibly.

2.8.1.4 Activist: An activist seeks basic institutional change. Often the objective involves a shift in power and resources to a disadvantaged group. An activist is concerned with social injustice, inequity and deprivation. Tactics involve conflict, confrontation, and negotiation. Social action is concerned with changing the social environment in which people who are living with HIV are stigmatised and discriminated against.

2.8.1.5 Mediator: Mediators intervene in disputes between parties to help them find compromise, reconcile differences or reach mutually satisfactory agreements. Social workers use their value orientations and unique skills in many forms of mediation between opposing parties, which can involve an HIV positive couple who continue blaming each other. As a mediator a social worker ensures that they understand the positions of both parties. The worker in this case clarifies positions, recognises miscommunication and helps the parties present their cases clearly.

2.8.1.6 Negotiator: A negotiator brings together those who are in conflict over one or more issues, and then helps them to reconcile their differences. Somewhat like mediation, negotiation involves finding a common ground that both sides can live with. Unlike a mediator, a negotiator usually is allied to one of the sides involved.

2.8.1.7 Educator: Educators give information to clients. In the case of this study it can be providing people with information on the advantages of adhering maximally to ART and then teaching them adaptive skills. To be an effective educator, the worker must first be knowledgeable about the subject matter – which in the case of this study is ART. In addition, the worker must be a good communicator so that information is conveyed clearly and is readily understood by the receiver.

Social workers, according to DuBois and Miley (2010: 136), also have the responsibility for ensuring in their service delivery social justice, which is about ensuring people's human rights, and their rights to social welfare. These categories of rights are briefly discussed below:

2.8.2 Social work and social justice

2.8.2.1 Human Rights

In the South African situation section 7(1) of the Constitution of the Republic of South Africa (Act 108 of 1996) - chapter 2 addresses the Bill of Rights. Much as the state is expected to promote these human rights, social workers equally have the duty to respect, protect, and promote these rights, which include:

- The right to equality: No person may be unfairly discriminated against on grounds of race, gender, sexual orientation, etc.
- The right to human dignity: Everyone including people living with HIV and AIDS (PLWHA) have the right to have their dignity respected and protected.
- The right to life: Everyone has the right to life – which in the case of the present study can include eligible people initiating ART and being retained in this therapy.
- The right to freedom and security: Everyone has the right not to be subjected to medical or scientific experiments without their informed consent.
- The right to health care: Everyone has the right to health care services

2.8.2.2 The Rights to Welfare

The following are key principles for a developmental approach underpinning the delivery of social welfare services in South Africa. These principles are to be observed and complied with by social workers, and they include:

- **Participation which is about the active involvement of people in their own problem-solving process.** It is about working with people on ART over and above working for them.
- **Self-reliance on own capacities and initiatives:** In this case people initiating ART have to come to the realisation that they have innate

inherent strengths and to have the ability to also realise such strengths in others – thus having to connect with others and with their environment in ways that can enhance their individual and collective efforts towards their well-being;

- **Empowerment should be about retaining lost power over the disease:** In this case, it should be about ownership and control of processes around them. It should also be about people on ART taking informed decisions that affect their lives;
- **Universal access of services:** Social services should be made available to all those in need of such, such as: the poor, the disabled, including those with a different sexual orientation.
- **Equitable distribution of resources based on need, and geographical situation:** This means that people on ART should be individualised;
- **Transparency on how the medication works:** This should entail being provided with information about the side effects of the medication;
- **Appropriateness of ART disbursement:** Service providers should be knowledgeable about the patient's social, economic, cultural and political conditions. Sensitivity to these aspects is key for providers of ART services;
- **Accountability towards legislation, policy and regulations relating to ART:** There should be ethical compliance on the part of the service provider;
- **Accessibility to ART services:** Services to people on ART should be within reach in terms of geographical factors, time of operation, and language used (Integrated Service Delivery Model (ISDM), 2005: 11).

In order to skilfully execute the roles already alluded to, ensuring the patients' human and social rights, the following according to Poindexter (2010: 105) are essential skills that can bring all these other responsibilities together, and they are briefly explained below:

2.8.3 Social work skills

- **Empathy**

It is the ability to connect and engage with an individual patient, with the main aim of building trust, even in brief situations with them. HIV stigma is often embedded on top of stereotypes such as associating the virus with promiscuity and or unfaithfulness. As a result of such issues empathy becomes essential.

- **Knowledge of the disease or condition affecting the people served**

In no way does this presuppose extensive medical expertise pertaining to the HI virus. Reference is instead directed to knowledge of the psychosocial understanding of the symptoms, cause of the condition and typical treatment interventions and effects. In the case of a person newly diagnosed with HIV for instance, common questions that could be posed during post counselling sessions for example include: “How do I stay motivated on treatment”?; “What will happen if I do not adhere to the ART regimen?” and many more.

- **An ability to work independently**

The social worker, through training, has the ability to work with the medical team to stay informed, communicate and coordinate the service delivery process as well as problem-solving. Much as the social worker in medical care becomes part of the medical team, ethically he/she is expected to execute his/her part of the treatment plan and intervention independently and confidentially.

- **Organizational management**

The social worker is often required to help manage multiple levels of needs such as: the health and socio-economic needs (Poindexter, 2010: 106-106)

From this subsection, one can deduce that indeed the core business of social work as a profession ideally is to enhance the social functioning of people. All the roles referred to, including adherence to human rights and welfare rights, create an enabling environment in which people can participate actively in their problem-solving process. Emphasis is on people, with their active involvement. In the context of this study HIV treatment should be patient-centred, and holistic. This subsection has also showed that for all the tasks to be professionally carried out, a social worker has to be: empathetic, knowledgeable about HIV and AIDS, including on the clinical functioning of ART, able to work independently, with organisational management skills.

2.9 THEORETICAL FRAMEWORKS

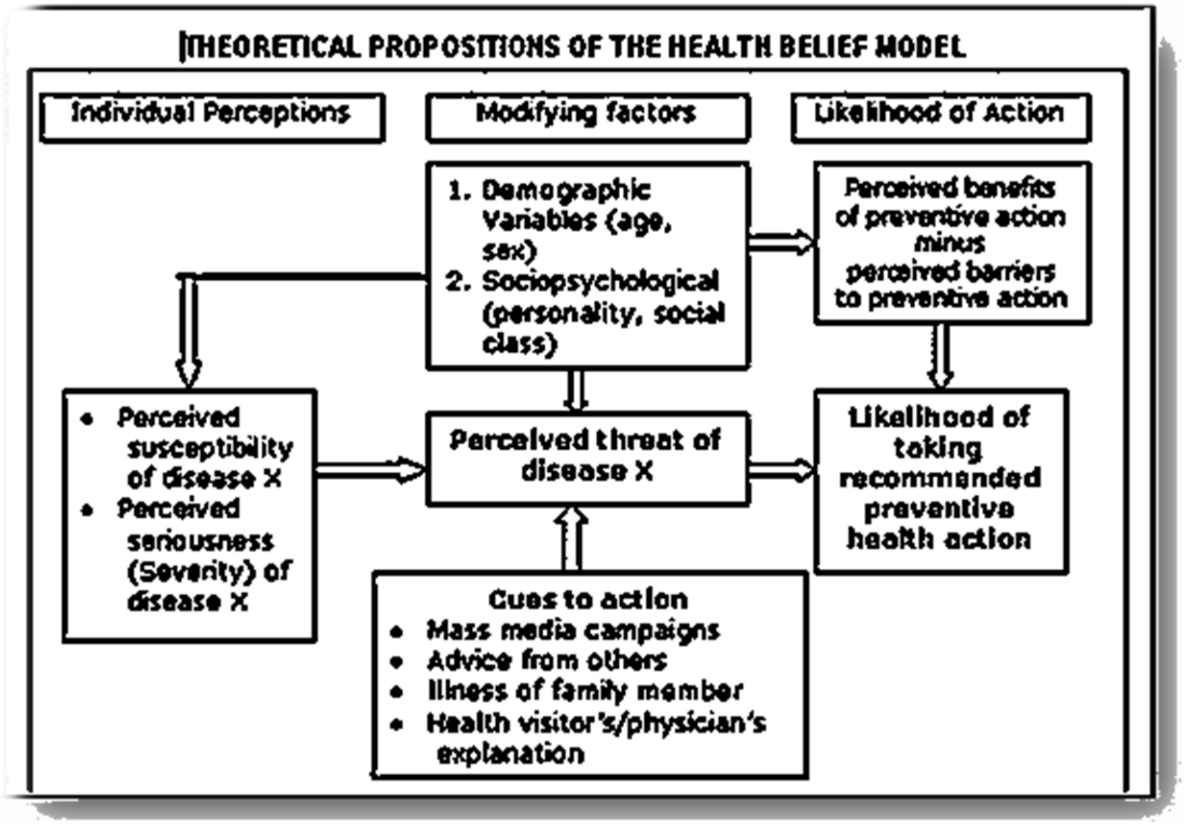
The Health Belief model (HBM) and the strength-based perspective are theoretical frameworks underpinning this study, and are discussed next:

2.9.1 Health Belief Model

HBM attempts to explain and predict health behaviour. This is done by focusing on the perception of risk of an individual person including his/her reaction towards that risky behaviour. The rationale for using HBM in this research study is to understand the behaviour of individuals through examining of their perceptions and attitudes towards HIV and AIDS that they are living with together with the possible negative outcomes of not maximally adhering to ART. Once risks are perceived and predicted, preventive action can be perceived with the likelihood of leading to perceived health benefits.

The model was initially developed in response to the failure of a free tuberculosis health screening programme, since then HBM has been adapted to explore a variety of long and short-term health behaviours including HIV and AIDS (Turner, Hunt, DiBrezzo & Jones.2004:30). According to Turner et al (2004:33) HBM, is spelled out in terms of the following four constructs perceived for their treatment and net benefits (See Figure 5):

Figure 5: Theoretical Proposition of the Health Belief Model



Source: http://currentnursing.com/nursing_theory/health-belief_model.html

2.9.1.1 Perceived risks

Personal risk is one of the aspects motivating people to adopt healthier behaviours. For instance, once there is perceived risk, there are greater probabilities and likelihood of avoiding such risky behaviours. In the case of this research study perceived risks should be the possibilities of drug resistance and even premature death resulting from the non-adherence to ART. It is only logical that when people believe that they are at risk for an illness or a disease, they will be more likely to do something to prevent it from negatively affecting them. The opposite in other situations can also be the case. When people believe they are not at risk, unhealthy behaviours tend to result. When the perception of risks is combined with the seriousness of the situation the result is perceived threat. If the perception of threat is to a serious health complication/ disease for which there is a real risk, behaviour often changes

2.9.1.2 Perceived severity

Perceived severity can also include the manifestation of the problem which can be very severe. In the case of this research study the prospect of deterioration in the health status of a PLWHA, with the possibility of the chronic situation of the illness and ultimately death is the perceived severity of the situation (Kagee, 2008: 420)..

2.9.1.3 Perceived benefits

The formed perceived benefits are a person’s opinion of the value or usefulness of a new behaviour in decreasing the risk of developing a complication to the present illness. In this study, the usefulness of a new behaviour can involve the usage of ART. People tend to adopt healthier behaviour when they believe the new behaviour will decrease their chances of developing chronicity to the already present illness. Perceived benefit can play an important role in the adoption of secondary prevention behaviour – such as complete adherence to the ARV regimen.

2.9.1.4 Perceived barriers

Since change is not something that comes easily to most people, the last challenge that HBM attempts to address is the issue of perceived barriers to change. This is an individual’s own evaluation of obstacles in the way of him or her adopting a new behaviour. Perceived barriers are the most significant in determining behaviour change. In the case of this study stigma may be the perceived barrier that can negatively affect adherence to ART. (Kagee, 2008: 420). Once barriers are articulated after being perceived, with the help of strategies for change, these can be mapped out (Turner et al, 2004:33-34).

2.9.2 Strength-based perspective

According to Barbra (2014:52) the strength-based perspective is a social work theoretical approach that honours and respects the potential of all people. This perspective assumes that all people and communities have strengths that can be used to deal with challenges that can include dealing and living with HIV and AIDS. A strong and faulty belief has it that if the presenting problem can be identified and understood, all what is needed is finding an expert with knowledge to analyse it then find a prescription that will fix it. However when people act as experts in resolving the problems of others by so doing “we deny those facing the problem the opportunity to participate, take control of the situation and learn from the situation” (Barbra, 2014:40).

The rationale for using the strength-based perspective in this research study is based on the fact and belief that PLWHA and those who are initiating ART have capacities and capabilities that can be used to ensure that they adhere maximally to the ARV regimen. The strength’s perspective can also be useful in stimulating their personal power.

According to Zastrow and Kirst-Ashman (2006:6-7) the following principles serve as the foundation for guiding and implementing strength-based perspective, and they are:

- **Every individual, group, family, and community has strengths:**

Every person, family, group, and community holds the key to their own transformation and meaningful change process. The strength-based perspective moves from the premise that, every human being has got strengths. . It is the role of counsellors in the case of this study to help those people/ patients to realise, know and use their strengths in order to address their personal health problems. Embracing strengths encourages seeing beyond the risk behaviours and characteristics of patients in high need communities to the potential of what can be achieved.

- **Trauma and abuse, illness and struggle may be injurious, but they may also be sources of challenge and opportunity:**

Having gone through the stages of learning about one’s HIV status is traumatic in itself. Living in a situation of not only taking ARVs but being open about one’s HIV status can serve as a source of having learned from one’s trauma, illness and struggles. People often grow from crisis they handled effectively. It allows one to see opportunities, hope, and solutions rather than just problems and hopelessness.

- **Assume that you do not know the upper limits of the capacity to grow and change, and take individual, group, and community aspirations seriously:**

People living with HIV and AIDS sometimes might not have a crystal ball to tell what opportunities and choices will confront them in life. It can be a social worker's role to assist them to identify their strengths so that they can see those opportunities as they occur and grasp them.

- **Every environment is full of resources and opportunities:**

Resources can provide great strengths. One of the social worker's major role is to link people with resources, in order to improve their lives. People living with HIV and AIDS who embrace a strengths-based perspective hold the belief that they have strengths, resources and the ability to recover from adversity as opposed to emphasising problems, vulnerabilities and deficits. This approach requires a collaborative partnership between service providers and people utilising such services, in order to assess for strengths, address problems and difficulties, and use optimally newly found strengths and resources that can be utilised in the future.

Practically the implication from the HBM is the importance of knowing and understanding the participants' perception of the severity of living with HIV and AIDS, and the risks accompanied by their non-adherence to the ARV regimen. Thereafter, participants' opinions on their perceived benefits will be looked into, including their perceived barriers which should be guarded against as these can interfere with their retention to therapy issues.

With the strength-based perspective, it is the practice that the practitioner should adopt and embrace. Everything that the practitioner does in her/his delivery of services ought to be informed by the principle of helping the client system discover, and explore his/her potentially inherent strengths.

2.10 SUMMARY

Through this literature review, a selected and limited number of topics that are central to the topic of non-adherence to antiretroviral treatment in the demarcated area of study were reviewed and comprised: The phenomenon of adherence and non-adherence to ART, the rate of ART globally and in South Africa, the goals of ART medication, Art monitoring tools, barriers and facilitators of adherence to ART, strategies that can enhance adherence to ART. Since the study was undertaken from a social work perspective, an overview of social work and its relevance in the health care system was given. Thereafter two theoretical perspectives underpinning this study: HBM and the strength-based perspective were also examined.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter, a detailed description is provided of how the research methodology unfolded and was applied in the study. It is essential for the researcher to not only know the research methods but also the methodology, pertaining to their particular research study. Novikov and Novikov (2013:1) explain methodology as “the theory of organization of an activity.” Further, Daniel and Sam (2011:41) define research methodology as “a way to systematically solve the research problem. It may be understood as a science of studying how research is done scientifically and study the various steps that are generally adopted by a researcher in analysing his or her research problem along with the logic behind them.” In other words, it can be deduced that research methodology is a systematic strategy used in order to achieve research goals.

3.2 RESEARCH METHOD

Basic research, whose primary motivation is to contribute to human knowledge and understanding relating to a particular phenomenon (Bless, Higson-Smith, & Kagee, 2006:44) is used in this study. This involved by gathering facts and information which highlighted issues around the existing body of knowledge on the non-adherence to ART to be challenged and new information explored, examined and developed for use by policy makers, researchers, and practitioners in the health and social field dealing with ART matters.

3.3 RESEARCH PARADIGM

The researcher used a qualitative research paradigm, which answered questions about the complex nature of the phenomena, with the main purpose of describing and understanding the phenomenon of non-adherence to ART from the participants’ point of view (Leedy & Ormrod.2005:94). Qualitative methods are also effective in identifying intangible factors such as: social norms, socio-economic status, gender roles, ethnicity, culture and religion (Denzin, & Lincoln, 2000:370). This research paradigm also “provides information about the human side of an issue, which is often found in contradictory behaviours, beliefs, opinions, emotions and relationships of individuals.” From yet another angle, “qualitative research can serve as an umbrella term covering different techniques which aims to describe, decode, and otherwise come to terms with the meaning, not the frequency of certain naturally occurring phenomena in the social world” (Sharan, 2009:13). From all the given definitions and explanations, it can be deduced that the qualitative research paradigm studies phenomena in their natural settings and habitat and attempts to make sense of or interpret phenomena in terms of the meanings people bring to it.

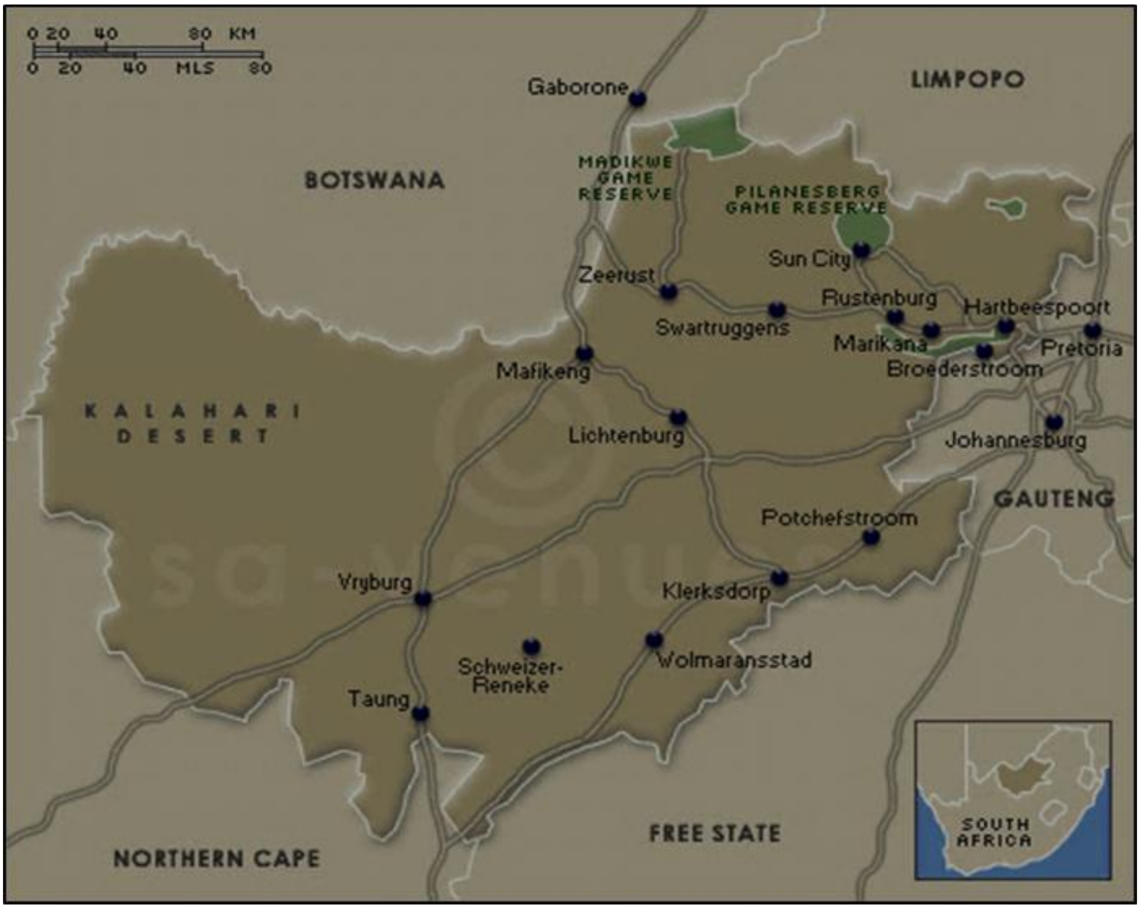
The rationale for using qualitative research in the current study was informed by the following advantages as highlighted by Diggs-Brown (2011:117):

i. Qualitative research is exploratory in nature. It is useful when the researcher does not have a thorough understanding of how the target audience relate to the issue or problem. In other words, this type of research paradigm enabled the researcher to gain insights into behaviour, attitudes, motives, and opinions of the targeted participants on non-adherence to ART.
ii. Qualitative research is designed to be in-depth and descriptive in nature – and in the case of this study, to provide in-depth and descriptive information on the reasons why some of the selected participants who are on ART do not adhere to their treatment maximally.
iii. Qualitative research is flexible. The design can be modified while the study is in progress because it builds upon what is being learnt and allows new questions to be raised. In fact, astute interviewers can follow-up right away if a new point or issue is presented during an interview.
iv. Qualitative research generally costs less and takes less time since a few people are selected as participants. In other words, depth is more imperative than width.

3.4 DEMARCATION OF THE FIELD OF STUDY

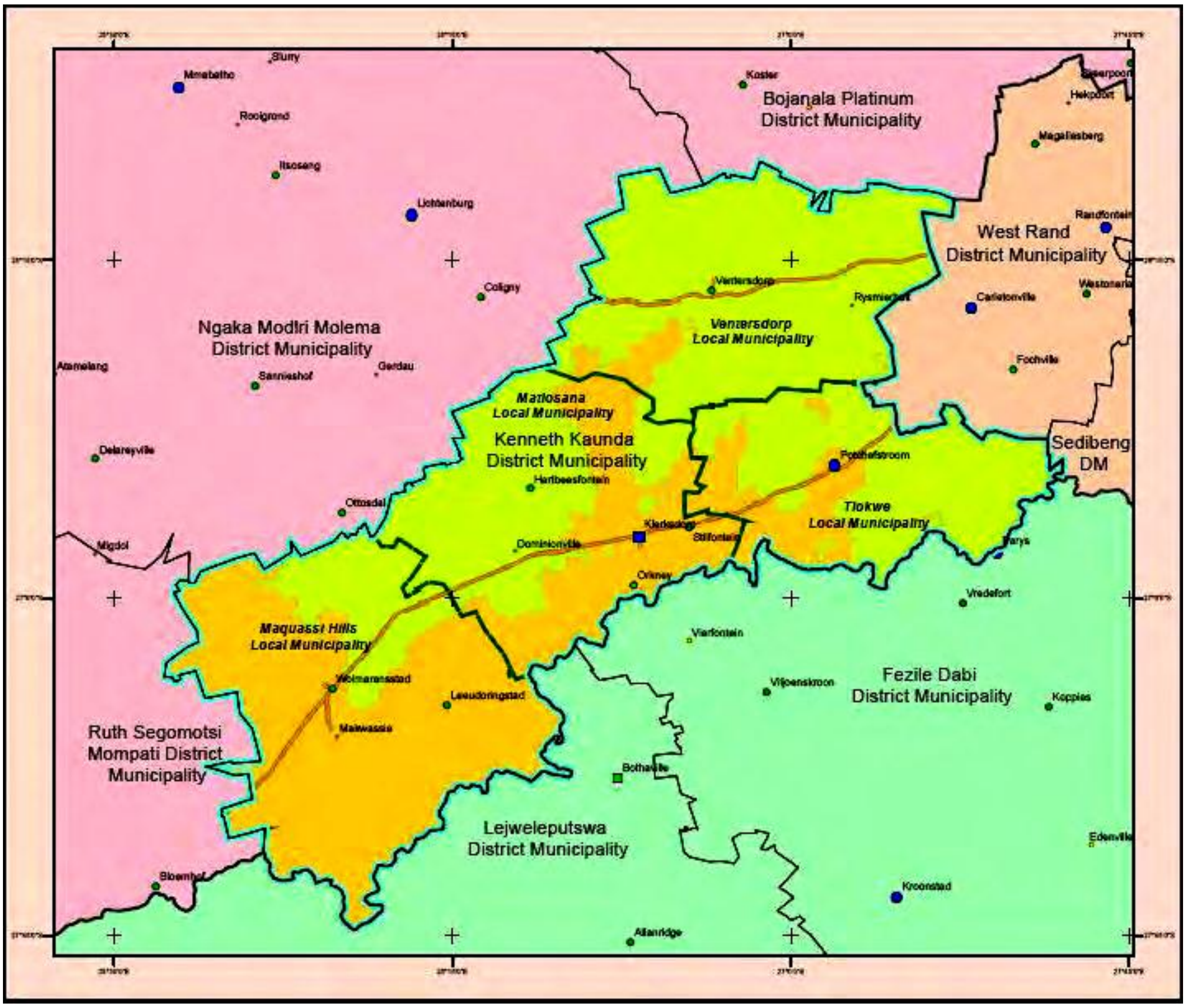
This study was conducted in the Maquassi Hills area which is situated in the North West Province of South Africa. The North West province (See Figure 6) is one of nine provinces in South Africa. The province lies on the border of Botswana, fringed by the Kalahari Desert in the west, Gauteng province to the east and the Free State to the south. The capital city of the North West Province is Mahikeng (previously Mafikeng). (The Local Government Handbook. 2014: 1). The North West province has four District Municipalities, namely Bojanala, Ngaka Modiri Molema, Dr Kenneth Kaunda and Dr Ruth Segomotsi Mompati. Maquassi Hills is found in the Dr. Kenneth Kaunda District (See figure 7). This district consists of four local municipalities: the cities of Tlokwe (Potchefstroom) and Matlosana and the towns of Maquassi Hills and Ventersdorp. Unemployment rate in the district was recorded in 2012 as being in the region of 30% (The Local Government Handbook, 2014: 1).

Figure 6: Map of the North West province



Source: www.sacarrental.com/north-westprovince-map.htm.

Figure 7: Map of Dr Kenneth Kaunda District Municipality showing Maquassi Hills



Source:http://www.kaundadistrct.gov.za/index.php/documents/doc_download/7-

According to the brief profile of the Maquassi-Hills local municipality (See Table 5) 89% of the area's population is black. With a total population of approximately 77, 974 people as at 2013. Maquassi-Hills is divided into 11 wards. Amidst the high unemployment rate in the district, the main economic sector is mining (22%). It is a region rich with diverse natural and cultural heritage (The Local Government Handbook, 2014: 1).

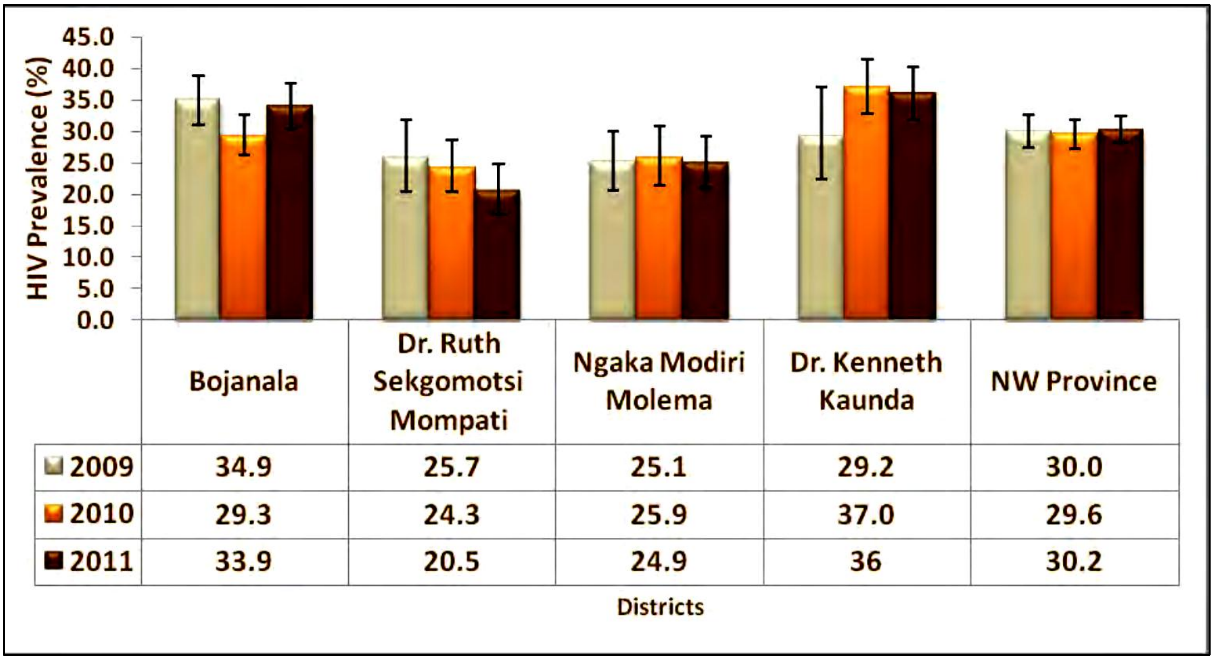
Table 5: Brief Profile of the Maquassi Hills Local Municipality

DISTRICT	Dr Kenneth Kaunda	
RACIAL COMPOSITION (2011)	Black African	89%
	Indian	8.2%
	Coloured	2.3%
	White	8.2%
POPULATION (2013)	Total	77,974
	Density	17km^2 (43/sq. mi)
AREA	4,643km^2 (1,793sq mi)	
SEAT	Wolmaranstad	
FIRST LANGUAGE (2011	Setswana	
GOVERNMENT TYPE	Municipal council	
WARDS	11	

Source: http://en.wikipedia.org/wiki/Maquassi_Hills_Local_Municipality

The rationale for the selection of this area is that Dr Kenneth Kaunda district - covering the Maquassi Hills Municipality (See Figure 8) recorded the highest prevalence of HIV and AIDS at 36% in 2011 compared to all the other districts in the North West province (National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa, 2011: 45). The question that needed to be asked and answered was: from the high prevalence rate of HIV and AIDS in the demarcated area, how many of these people have been on ART and of that number how many adhered maximally to the regimen, how many defaulted ncluding the reasons for non-adherence to ART.

Figure 8: HIV and AIDS prevalence trends in North West Province



	Bojanala	Dr. Ruth Sekgomotsi Mompati	Ngaka Modiri Molema	Dr. Kenneth Kaunda	NW Province
2009	34.9	25.7	25.1	29.2	30.0
2010	29.3	24.3	25.9	37.0	29.6
2011	33.9	20.5	24.9	36	30.2

Source: National Antenatal Survey Report, 2011

3.5 RESEARCH DESIGN

As posited by Habib, Pathik and Maryam (2014:16) a research design serves as “a map which identifies the means and methods to be pursued for collecting and analysing the data. It can also be defined as the systematic procedure which includes the designing, compiling, and analysing of information through the conceptual model, variables and construction of the interview schedules”. Kumar (2008:30) on the other hand defines a research design as “the basic plan which guides the data collection and analyses the phases of the project. It is the framework which specifies the type of information to be collected, the sources of data and the data collection procedure.” In other words, a research design is a plan for a particular study. It tries to communicate and interpret the intentions of the researcher, the purpose of study and its importance, together with a step-by-step way of conducting the study.

The researcher used a phenomenological research design, which Creswell (2007:57) regards as a study that describes the meaning of the lived experiences of a phenomenon for several individuals. Duke and Mallette (2011:138) regard the phenomenological approach as more concerned with coming to understand the world from the participant's perspective. This lens assumes that knowledge, beliefs, and values are socially constructed through social interaction and thus are constantly changing and evolving. In order to understand participants' perspectives from a phenomenological research design, the researcher must live in the world as a participant, interacting with group members while observing and interviewing them. Potter (2013, 42-43) further explains that the phenomenology approach is "the understanding of human behaviour from the actor's own frame of reference, and is also about how the world is experienced, and the reality of what people imagine it to be. It requires the researcher to get into the perspective of the actor (person being studied)". The rationale for using this type of research design in this study is that the object of interest and the people being studied should be interrogated and understood without any preconceived notions or a priori expectations pertaining to apparent reasons for their non-adherence to ART.

Phenomenology as a research approach therefore, does provide what Spielberg (2012:256) terms a "generic understanding" of the way in which the contents of people's consciousness takes shape of their experiences. In the context of this study, these have been the lived experiences of people on ART. This approach also aimed at describing what people's lived world consists of, or more specifically, what concepts and structures of experience provide form and meaning to it.

3.6 TARGET POPULATION

Holloway and Wheeler (2013:137) define a population as consisting of individuals from whom the researcher can gain access to and who have the appropriate knowledge and experience pertaining to the study theme. Ritchie, Lewis, Nicholls and Ormston (2013:64-65) look at a study population as involving the identification of those people who, by virtue of their relationship with the research questions, are able to provide the most relevant, comprehensive and rich information. From yet another angle, Polit and Beck (2010:306) describe a population as comprising the entire aggregation of elements or cases in which a researcher is interested. A target population "is accessible population that has the particular experience or knowledge of the phenomenon which the researcher is seeking to explore" (Holloway and Wheeler, 2013:137).

In study, the entire population of the demarcated area of study was made up of eight clinics – divided into: two Community Health Centres (CHCs), six Primary Health Care facilities (PHC) and one hospital within the Maquassi Hills sub-district, which offer ART among other services. These health facilities are: Leeudoringstad CHC; Tswelelang CHC; Kgakala PHC clinic; Tswelelang PHC clinic; Makwassie PHC clinic; Wolmaranstad PHC clinic; Segametsi PHC clinic ,Bophelo PHC clinic and Nic Bodenstein Hospital. A CHC delivers 24-hour care, from a fixed structure and provides a greater variety of health care services than an ordinary clinic. A PHC clinic offers first level contact and comprehensive services to individuals from the community. From a total of six thousand, six hundred and nine (6609) patients on ART as of January 2012 to date from the entire eight clinics and one hospital, a total number of six thousand, two hundred and ninety eight (6298) were recorded as adherents to the antiretroviral regimen as opposed to approximately three hundred and forty one (341) who were recorded as non-adherents of ART from their clinic records (Privately communicated with the hospital manager on 6 September 2015).

The health facilities in 2013 were serviced by twenty nine (29) nurses and nine (9) doctors who were responsible for administering ART. Eight of these doctors are operating from the hospital, while one doctor is responsible for the clinics. One Social Worker and thirty-four counselors are responsible for counseling those initiating ART, including those already on ART. From the community, a total of eight (8) groups were offering home-based care (HBC) to people on ART.

The unit of analysis was all three provided categories:

- All patients on ART in the designated health facilities in Maquassi Hills, North West Province;
- All nurses and doctors from the designated health facilities responsible for administering ART, in Maquassi Hills;
- Social service providers responsible for counseling those going on ART, including those already on ART from the designated health facilities in Maquassi Hills.

3.7 SAMPLING

Sampling is the selection of cases from a wider population (Bloor & Wood, 2006:153). Its main purpose is to choose what, where, when and whom to interview (Sharan, 2009:77). In the case of the current study, large numbers of ART patients, nurses and doctors administering ART, social service providers responsible for counseling those on ART from different delivering sites, made it impossible for the entire population to be studied. This situation pointed to a need for a small portion of the population to be studied and sampled.

Since the study is qualitative non-probability sampling was used. In non-probability sampling the odds of selecting a particular individual is not known at all (Gravetter & Forzano 2003:118). The researcher used purposive sampling to identify participants for this study. This technique is also called judgmental sampling: It is based entirely on judgement of the researcher, in that "a sample constitute elements that contain the most characteristic, representative or typical attributes of the population that serve the purpose of the study best" (Silverman 2000:104). In the case of this present study, each member sampled complied with the following eligibility criteria:

3.7.1 The unit of analysis: Research participants

Participants were selected purposefully and the following inclusion criteria a obtained for HIV positive people on ART including service providers who were administering ART and those offering counseling services to those on ART.

3.7.1.1 Criteria for the selected people on ART

- **Age**

The target group comprised of people who are on ART and within the age ranges of 18 – 55 years. This is a period within which people a mostly sexually active.

- **Gender**

Both male and female respondents qualified for inclusion in this study. Both men and women are susceptible to HIV and AIDS, and both genders do qualify to be placed on ART – eliciting information from both genders can be termed inclusionary.

- **Geographical distribution**

Participants were those residing in the Maquassi Hills district.

- **Duration on ART**

Participants were to have been on ART for at least two years (and more) in order to have been able to provide first-hand experience and information of their challenges or lack thereof to the ART regimen.

- **Public disclosure of HIV status**

Only those participants who had publicly disclosed their HIV status qualified to be selected for participating in the study, as a way of respecting their status and also adhering to the principles of respect and confidentiality.

3.7.1.2 Criteria for the medical team (the HCWS)

- **Professional status**

The medical team comprised of a doctor, nurses, a social worker together with counselors – these are professionals who place patients on ART after thorough examination, administer ART and offer counseling services to those going on ART for the first time, and those already on ART who are experiencing multiple challenges which interfere with maximum adherence to the ARV regimen.

- **Professional experience**

The health professional participants were to have acquired three and more years of professional experience in the field of HIV and ART – which include working directly with people on ART. They had to serve mainly as key informants.

- **Gender**

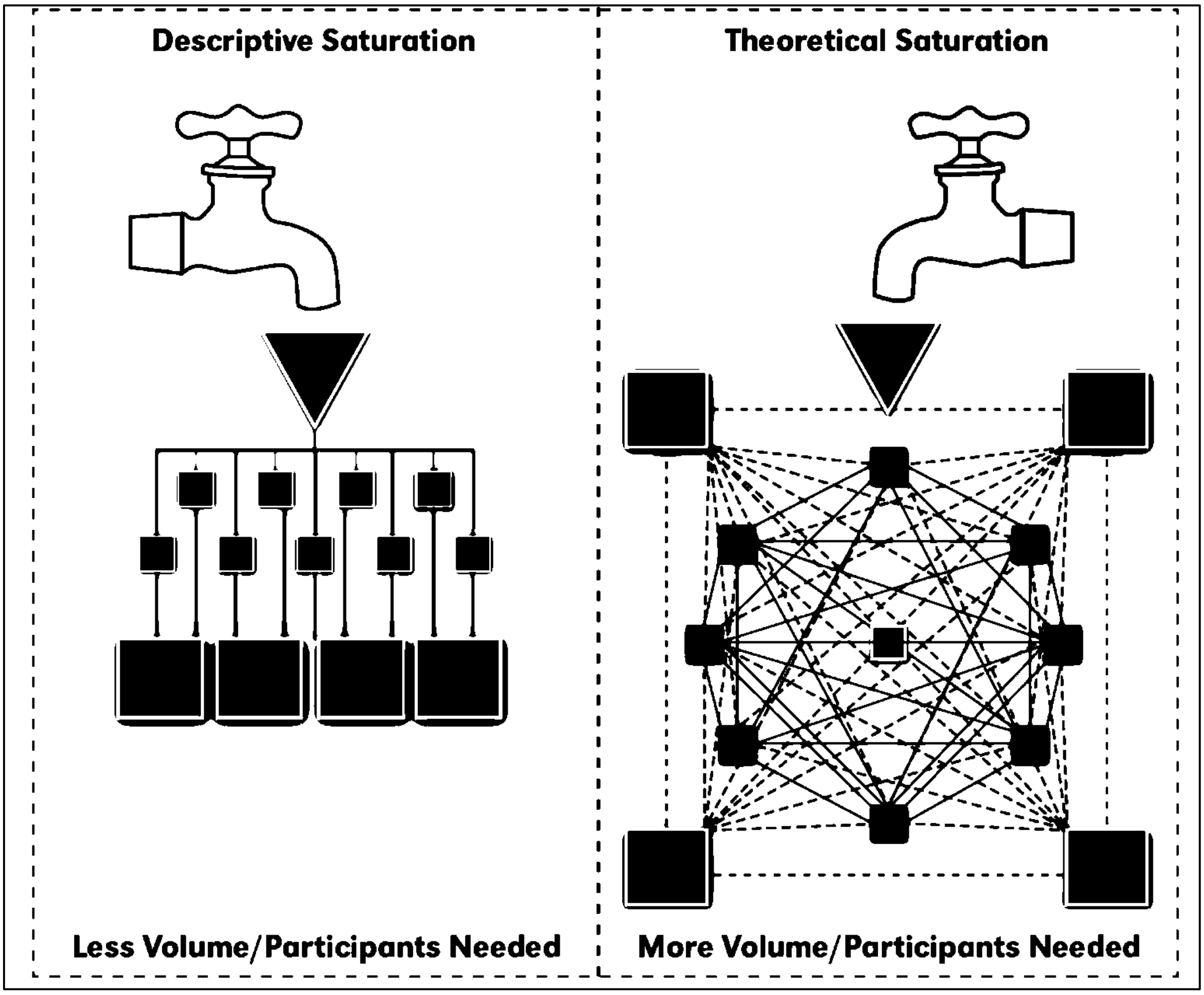
All the selected members of the medical team were either men or women. Both genders are involved in prescribing, dispensing, administering, and monitoring the intake of ART, and also dealing face to face with those not adhering to ART.

3.7.2 Sample size

As rightfully indicated by Hardon, Hodgkin and Fresle (2004: 64) there are no hard and fast rules for determining sample size in qualitative research. The number of participants selected in a qualitative study is purely dependent on what a researcher wants to know, the purpose of the study and practical factors. Since this study was qualitative in nature, the sample size was not determined at the very beginning, instead the principle of data saturation was applied in order to determine the final sample size. As posited by Hewitt-Taylor (2011: 71) saturation of data to researchers can mean “a convenient stopping point for their study. It occurs when the researcher notes that no new insights or leads are being offered, and no new theory is being generated.” However, the concept of ‘saturation’ can differ within different qualitative methodologies. Such differences can result in very significant variance of sample size (See figure 9).

As shown in Figure 9, at saturation the researcher finds that no new descriptive themes, sub-themes and categories are emerging from the analysis of data. This is opposed to theoretical saturation where the researcher not only ensures that the analysis describes the data, but equally explains how the various themes, sub-themes, categories, and concepts interconnect (Keen, 2013: 1). In the present study, theoretical saturation obtained in that the researcher stopped interviewing more participants once the same information was repeatedly provided with nothing new forthcoming from those interviewed. A total number of 28 participants were finally selected.

Figure 9: Descriptive and theoretical saturation



Source: Keen, 2013

From a total of eight (8) clinics offering ART services within the Maquassi Hills sub-district, 4 clinics were purposefully selected for the investigation. The selected clinics comprised of two (2) Community Health Centres (CHCs) and two (2) Primary Health Care facilities (PHC) including 1 hospital. The rationale for this selection was to ensure that information is obtained from all types of settings offering and dispensing ART in the demarcated area of study. From all settings a total of 28 participants participated. This number was made up of 12 in-depth interviewees with 10 participants comprised 1 focus group. A total of 6 key informant interviewees, from the settings were selected and comprised of: a doctor, 2 nurses, 1 social worker, and 2 counselors.

3.8 DATA COLLECTION

Data collection forms an important part of any research study because it does not only give a description of what data were collected and how this was done, but also constitutes the basic information from which conclusions are drawn pertaining to the aspects briefly discussed below:

3.8.1 Method of data collection

Interviewing is the predominant mode of collecting information in qualitative research. In the case of the present study semi-structured interviews were constructed. According to Galletta and Cross (2013:1-2) a semi-structured interview addresses specific dimensions of research questions while at the same time, leaving space for study participants to offer new meanings to the study or topic at hand.

In line with the views of Braun and Clarke (2013:24) the researcher in the current study had a list of open-ended questions, with scope for the participants to raise issues. Also, much as the interviewer was able to allow the conversation to flow freely, the researcher was equally able to steer it in such a way that specific questions could be introduced where such opportunities arose (Clark-Carter, 2004: 8).

Since the rules for interaction with people differ across cultural contexts, the following are some of the general issues that were considered before the interviewing process was undertaken, in line with the suggestions of Brikci and Green (2007: 15):

- Will eye contact be acceptable? – It was ascertained that people wanted eye contact as a way of showing them that the researcher was paying attention to what they were saying. This would be different from starring at a person.
- Is sitting in certain positions disrespectful (for example sitting with feet towards interviewees)? In order to provide the participants with space, too much closeness was avoided.

- Whether non-verbal cues will be appropriate – it was established that in certain instances nodding was deemed acceptable as a non-verbal cue to indicate understanding of what was said.

- If it was culturally acceptable, to give participants time to think – culturally this was deemed respecting their integrity as people who can make up their own minds.

- If it is vital that you check whether you have understood participants, instead of relying on one's own assumptions – the researcher in instances paraphrased what was said and asked further questions as a way of making sure that the essence of what was said was not lost.

The following interviewing skills highlighted in De Vos, Strydom, Fouché and Delport (2011:345) were also used during the process of interviewing the study participants as a way of enhancing the process:

- **Minimal verbal responses:** Verbal responses that correlates with occasional nodding and utterances for example "mm-mm, yes, I see" – were used to show participants that the researcher was listening to their stories attentively.

- **Paraphrasing:** This involves a verbal response in which the researcher will enhance meaning by re- stating the participant's words in another form with the same meaning. The interviewer may re-state the content of the communication in slightly different words. For instance, in the case of this study, simply repeating the participant's comments back to him or her helped in creating a sense of being understood and this in turn gave the participants confidence which enabled them to disclose more or to reveal more of their opinions and feelings.

- **Clarification:** This embraces a technique that is used to get clarity on unclear statements, for example – participants in some instances were asked to give more clarification of an issue they previously highlighted in order to get the real meaning on a response. Questions such as: “Could you tell me more about...” “You seem to be saying...” were posed to the participants.

- **Reflection:** This entailed looking back on something important that the person might have just said in order to get him or her to expand on that idea- questions such as: “So, you believe that taking ART consistently is useless” were asked. This gave the participants the opportunity to confirm, deny or clarify what they had said. In doing so, the participants were able to delve deeper into their own experiences and were able to give a fuller or more emotional description of their feelings.

- **Encouragement:** In this skill participants are encouraged to further open-up and to pursue an evident line of thought. Encouraging sentences such as: “I find that fascinating, tell me more about it” were used.

- **Probing:** Was used, in order to deepen responses earlier questions, with the main aim of increasing the richness of the data being obtained, and to give cues to the participant about the level of response desired. This skill was used with the aim of persuading the participants to give more information about the issue under discussion.

3.8.2 Data collection instruments

The following data collection instruments were used in this study:

3.8.2.1 Interview schedule

The aim of in-depth interview is to provide what all qualitative inquiries seek, that is, a deep understanding of what people are doing and thinking, and why (Roller and Lavrakas, 2015:50). The rationale for the use of an in-depth interview in this study was to gain “a rich, nuanced understanding of the thinking (motivation) that drives behaviour and attitude formation or otherwise leads to other consequences in the lives of the individual interviewee” (Roller & Lavrakas, 2015:51). The schedule was prepared in such a way that the same information would be obtained from each person. There were no predetermined responses and the interviewer was free to probe and explore within some of the predetermined areas of inquiry. In-depth interviews in this study were used to collect data from 12 patients on ART (See annexures 3 & 4).

The main question posed in the process of the in-depth interviews was: “Do you know how your ARV medication is supposed to be taken? Thereafter the following sub-questions were raised:

- What will you do if you miss a schedule dose of your ARVs?
- What are the possible side effects of your HIV medication?
- Are you concerned about being seen by others when you collect your ARVs?
- What type of support do you receive from your health care provider?
- What type of support do you receive from your significant others?
- Do you adhere maximally to the ARV regimen?

3.8.2.2 Focus group

A focus group is a form of qualitative research strategy in which a group of people are asked the same questions about their perceptions, opinions, beliefs and attitudes towards a product, service or concept. Questions are asked in an interactive group setting where participants are free to talk with other group members regarding their personal experiences. The purpose of using a focus group in this research study was to promote self-disclosure among participants. It was also to gain insight into what people in a group setting really think and feel and are experiencing in their personal lives regarding ART usage and or non-usage (Kruger & Casey 2007:7). The focus group was also used, moreover because in the present study multiple viewpoints or responses were needed on the specific topic at hand.

One focus group of 10 participants, comprising of individuals who had publicly disclosed their HIV status were selected and were conducted (See annexures 5 & 6).

The leading question posed to focus group discussants was: “What are your medication related challenges (in terms of taste, size of the pills and dietary restrictions for example)? Thereafter the following sub-questions were raised:

- What socio-economic challenges do you face (poverty, unemployment, lack of transport etc.)?
- What stigma and discrimination related challenges do you experience (fear of disclosing status to partner or family)?
- What health-care and Systems-related challenges (distance of setting, health care provider-patient relationship, waiting time, availability of counseling services, privacy at ART clinic, follow-up services)?
- How do you overcome all these challenges?
- How can adherence to ART be facilitated?

3.8.2.3 Key informant interviews

Interview guide was used as data collection instruments. Key informants are respected and knowledgeable people in this study who were used for a number of reasons: first, informants helped in providing valuable knowledge that led to a better understanding of the setting under study. In other words, they were able to facilitate entrance into an area of operation as well as into selected organisations. In addition, key informants as used in this study were also used to identify emerging themes in the interview process, based on their insight of the subject matter which is ART (Schurink, 2002: 285).

In the study, key informants were HCWS made up of a doctor, 2 nurses, a social worker and 2 counsellors – professionals directly working with people on ART. (See annexure 7).

The leading question posed to focus group discussants was: “What services do you offer to prepare patients medically and psycho-socially for ART”? Thereafter the following sub-questions were raised:

- How do you as a service provider ensure that patients as part of their enrolment into ART have treatment supporters?

- In your services delivery how is adherence to ART facilitated?
- Is there a way of monitoring those on ART who are maximally adhering to the ARV regimen and those who are none adherents to the ARV regimen?
- What follow-up services do you offer those who are non-adherent to ART?

3.8.3 Data analysis

Patton (2002:432) states that “qualitative analysis transforms data into findings. This involves reducing the volume of raw information, sifting significance from trivia, identifying similar patterns and constructing a framework for communicating the essence of what the data reveal”. Data analysis also entails the process of bringing order, structure and meaning to the mass of collected data. A thematic analysis was used. This type of analysis “looks across all the data to identify the common issues that recur, and identify the main themes that summarise all the views collected” (Brikci & Green, 2007: 23)

For the analysis of data in this study the approach by Hubberman and Miles (2004) was employed and consisted of the following three linked sub-processes as given by Poggenpoel (1998:340) (See figure 10:): data reduction or condensation, data display and conclusions drawing:

- **Data reduction**

With data reduction the universe of data is reduced in an anticipatory manner. In the case of this study, this was done in relation to research questions and discussion topics. Once the actual field notes were available, data summaries, through themes and narratives were used to further reduce and condense the data. In this study, themes were derived through the responses to questions from the interview schedules.

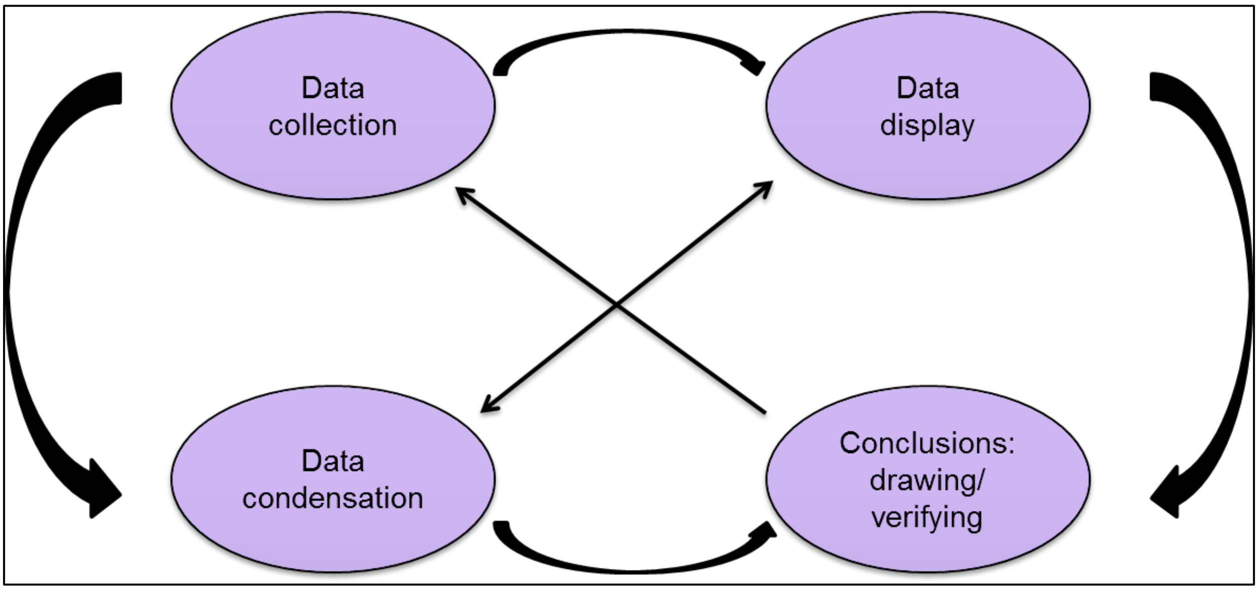
- **Data display**

Once stories were written with themes having emerged, the data was then displayed through sub-themes and categories for the researcher to draw conclusions.

- **Conclusion drawing and verification**

Interpretations and meanings were then drawn from the displayed data. The range of tactics used included noting of patterns with member literature checks – where data and findings are verified by what other researchers found from their studies (Maree & Van der Westhuizen, 2007:38).

Figure 10: Data analysis approach by Miles and Hubberman



Source: Miles & Hubberman (1984; 199)

3.9 TRUSTWORTHINESS

In quantitative research approaches for instance, the terms validity and reliability are used to describe the extent to which the results of a study measure what the study intended to measure in the first place, while qualitative research procedures on the other hand tend to reject the evaluative criteria of reliability and validity (Alias, (2012: 154), and uses trustworthiness instead. Lincoln and Guba (1985) in Alias (2012: 154) established criteria for establishing trustworthiness in qualitative research that are used in this research study, and they are: credibility, dependability, conformability, and transferability.

- **Credibility**

Credibility is related to whether the research findings capture what is really occurring in the context and whether the researcher learned what he or she intended to learn (Pitney, 2004: 26). In other words, this refers to the confidence in the truth of the data captured (Alias, 2012: 155). In this present study, several strategies to establish credibility, included: triangulation, and member checks. Triangulation involved collecting data from multiple and varying sources and using multiple data-collection strategies such as in-depth-interviews, focus groups, and key informant interviews. The idea of using triangulation was meant to help crosscheck information or findings to ensure that a full and accurate understanding of the phenomenon under study is obtained. Member checks involved providing the study's participants with the data or interpretations of the results so that they could verify their accuracy based on their experiences (Pitney, 2004: 26). On the question of member checks, four participants who were involved in in-depth interviews, focus group, and key informant interviews were provided with the derivative results in order to verify the truth.

- **Dependability**

Dependability refers to the stability of data over time and over conditions which can ensure replication and inquiry audit (Alias, 2012: 155). In this study this was achieved through the provision of specific methods such as: the use of multiple sources of data which could enhance the study's dependability by corroborating findings – thus strengthening the study's usefulness for other settings.

- **Conformability**

Here, the researcher tried to capture some elements of objectivity in the research study. The qualitative criterion in this study was derived from asking whether the data could help confirm the general findings and lead to the implications regarding policy, research and practice in terms of ART adherence (De Vos, 2009: 346-347).

- **Transferability**

External validity is traditionally related to the generalizability of a study's results, which is the extent to which the research findings from the data could be transferred to other settings or groups (Alias, 2012: 156). Because qualitative researchers are in most cases looking for depth rather than breadth of information, insight and understanding about specific context, qualitative researchers do not often concern themselves with generalizability. Qualitative researchers instead tend to use the term transferability (Pitney, 2004: 27). In order to address the question of transferability in this study a near detailed portrait of the demarcated area of study was conducted was provided on the non-adherence to ART of selected participants. The aim of this rich descriptive information was to give readers enough information about the context and participants, for them to judge the applicability of the findings to other settings. Analysing data from multiple settings such as: the hospital, clinics, and from the community and finding common themes among them can be suggestive to many readers that the findings are indeed applicable to their environment.

3.10 RESEARCHER'S ROLE IN THIS STUDY

In this study, the researcher, with the help of three community home-based care workers, located participants who were to be involved in this study. All the people sampled for the study were ultimately interviewed by the researcher solely. The researcher was also involved in recording the interview procedures and this process was enhanced with field notes. This process enabled the researcher to personally share at first hand in the experiences of participants during their answering moments.

3.11 PROCEDURES FOLLOWED IN EXECUTING THE RESEARCH PROCESS

Research procedure is about the sequence of the research activities followed when executing the research process (D'Cruz & Jones 2014:98). The following depicts the sequence of the research activities followed:

3.11.1 Preliminary visits to the selected sites

The researcher made preliminary visits to the selected sites. This was to acquaint the leaders including the Mayor of Maquassi Hills Municipality and the hospital and clinic managers from the provincial department of Health, including the people/patients on these sites with the purpose of the study and to secure their cooperation. Figure 11 shows diagrammatically how the researcher gained access to the study area, the gatekeepers and the research participants.

Figure 11: Diagrammatic presentation showing how access to the study area and to the participants was gained

STEP ONE: APPROVAL OF THE RESEARCH PROPOSAL

The researcher first presented the research proposal before the Faculty of Human and Social Sciences Higher Degrees Committee (HDC), for approval in terms of HDC's research requirements. Once this was approved the researcher was mandated to continue with the research process (See annexure 2).

⇩

STEP TWO: : ETHICS APPROVAL OF THE RESEARCH PROPOSAL

The approved research proposal was submitted to the North-West University (NWU) Ethics Committee for ethics approval. Ethics approval was granted subject to all declarations, undertakings and agreement incorporated and signed in the application form which included: expectations from the participants, their rights, and adherence to ethics by the researcher. Ethics approval provided the researcher with permission to make contact with the gate keepers

⇩

STEP THREE: APPROVAL FROM PROVINCIAL DEPARTMENT OF HEALTH (THE GATEKEEPER

An application letter was submitted to the Provincial Department of Health. This was followed by a presentation before an appointed panel. Approval from the Provincial Department of Health enabled the researcher to contact the hospital and earmarked clinics

⇩

STEP FOUR: GAINING ACCESS TO THE DEMARCATED COMMUNITY FROM THE MUNICIPAL MAYOR

A letter was written to the municipal mayor – Maquassi Hills, requesting to gain access to the community. Approval of access enabled the researcher access to the relevant local selected hospital, clinics, and ultimately to the selected participants.

3.11.2 Preparing research participants

Houtkoop-Steenstra (2000) in Nziyane (2010: 74) correctly asserts that research participants are social and emotional beings who cannot be forced to provide information that is required by the interviewer. It is therefore imperative that researchers should prepare participants in order to first establish a working relationship with them. Trust and respect are some of the important factors that should be considered when preparing participants for data collection.

The following sub-sections briefly explain how the preparation of participants unfolded.

3.11.2.1 Preparing selected in-depth interviewees and focus group discussants.

This type of study required data to be collected from participants who were on ART. Community home based care workers (CHBCWs) work directly with both patients who adhere to antiretroviral treatment and those who do not adhere to antiretroviral treatment. They do home visits to patients who default on antiretroviral treatment and assist them with adherence to their treatment. The researcher in the company of the CHBCWs visited the selected patients at their homes twice. During the first visit, the purpose of the research was clarified, the importance of participation in the study was also provided. Possible questions that would be asked were provided, and ethical principles that would guide the process were also highlighted. The researcher managed to build rapport with potential respondents and made appointments for the in-depth interviews which were conducted at their individual homes, in order to avoid travelling hustles. For the focus group comprising of different people from those who participated in in-depth interviews, a local school classroom which is centrally located was used over a week-end, away from distractions.

During the second visit the selected research participants were provided with consent forms in which they were required to indicate whether they were agreeing to participate in this study. This was free from coercion or pressure and gave individual members the opportunity to exercise their own free will. The researcher assured them that confidentiality and anonymity would be maintained and respected.

3.11.2.2 Preparing the selected key informants

This type of study required data to be collected from the HCWs. These included: a doctor, 2 nurses, and a social worker together with 2 counselors. The researcher was professionally known to the social worker and other members of the medical team as he had worked in this setting previously as a social worker. This to an extent facilitated trust and acceptance of the researcher by other members of the medical team. Since entry was through the hospital manager, he was engaged in discussions about the study through a face to face meeting. During this meeting the purpose of the research was clarified, the importance of the participation of the medical team in the study was also provided, possible questions that would be asked were provided, and ethical principles that would guide the process such as confidentiality and respect were once more highlighted.

3.11.3 Sequence followed in conducting the interviews

In-depth interviews were conducted first followed by focus group interviews. The key informants' interviews were conducted at the end, in order to link all the information from the three methods of data collection used.

3.11.4 Languages used in imparting information to selected participants

In-depth interviews and focus group discussions were conducted in the Setswana language (the home language of patients), to ensure easy communication between the researcher and the participants. The key informant interviews were conducted in the English language (all were comfortable with this language). Questions from the interview schedules and focus group discussions were initially written in English (See annexures 3 & 5), then translated from English into Setswana (See annexures 4 & 6), with the final responses translated back from Setswana to English.

3.11.5 Recording and transcribing of the data

Hand written notes and an audiotape was used. Prior permission to use an audio-tape sought and granted by NWU Ethics Committee, the relevant gatekeepers and by the participants in question. The main reason for recording the interviews was to ascertain the responses were recorded correctly. Transcribing (See table 6) and analysis of the data were done after the data collection process had been completed by the researcher. The information acquired was presented verbatim. In certain instances, explanations were provided supported by literature reviewed. Member checking was done to check whether the researcher captured the right information before analysis was completed.

Table 6: Transcription keys used

Description of activity	Symbols used and examples
Interruptions	Indicated by a hyphen (-) at the point of the interruption
Emphasis	Capital letters used to indicate emphasis. For example, “I am SCARED to share my HIV status with my family
Held sounds	Held sounds are repeated. If they emphasised they are capitalized. Such as in: “Ye-s-s-s-s” or I was “Very-y-y-y” disappointed
Pauses	Short pauses are shown by a series of dots (...). For instance three dots can be for one second. With longer pauses the term pause can be inserted in parentheses “(pause)”.
Laughing, coughing, etc.	Indicated in parentheses, for example, “(coughs)”, Used “(laughing)” to denote one person

Adapted from: Henning, 2004

3.12 ETHICAL CONSIDERATIONS

Ethical approval was obtained for the study - nr NWU –00244-14-A9 (See annexure 10), from the Ethics Committee of the North-West University. Ethical clearance was also obtained from provincial Department of Health (See annexure 11). The researcher’s code of conduct during the investigation was also guided by the following ethics: informed consent, avoidance of harm, debriefing of participants’, privacy and confidentiality.

3.12.1 Informed consent

According to Strydom (2011: 59) informed consent implies that all possible or adequate information on the goal of investigation, including the procedures which are to be followed during the investigation are communicated to the participants in order for them to make an informed consent. Obtaining informed consent implies that all possible information is provided pertaining to the goal of the investigation, the expected duration of the participant's involvement, the procedures which will be followed during the investigation, and the possible advantages of the study. In the study, participants were not coerced into participating. In this research project. Participation was voluntary. The briefing sessions were followed by the completion of a consent form, the conditions of which were binding to the researcher (See annexures 8 & 9).

3.12.2 Avoidance of harm

The fundamental ethical requirement of social research is that it must bring no harm to the participants (Babbie, 2007:27). Some things people do in life can possibly harm someone and therefore researchers should weigh the risks against the importance and possible benefits of the specific research project. The researcher has an ethical obligation to protect participants within all possible reasonable limits from any form of physical and emotional discomfort that may emerge from the research project (Creswell, 2003: 64). In order to avoid causing both physical and emotional harm to participants' sensitive topics have been avoided, and the physical venue where the interview took place was secure and safe. Participants were informed beforehand about the topics to be discussed. Such information offered the participants the opportunity to withdraw from the research project should they so wish.

3.12.3 Debriefing

Through the debriefing sessions all misinterpretations were clarified and results of the study were also made known to all the participants of the study, and permission for publication of the study was sought from the participants.

3.12.4 Privacy and confidentiality

According to Padgett (2008:67) qualitative researchers must provide absolute guarantees of confidentiality. Every individual has the right to privacy and it is his or her right to decide when, where, to whom, to what extent and under what circumstances his or her attitudes, beliefs and behaviour were to be revealed. Privacy also implies the element of personal privacy, while confidentiality ndicates the handling of information in a confidential manner. This means that every effort in this study was made to ensure that the identities of participants are not revealed or linked to the information they provide without their permission.

3.13 SUMMARY

The purpose of this chapter was to indicate and discuss the research methodology used in this research study in order to explore the problem of non-adherence to antiretroviral treatment in the demarcated area of study. As demonstrated in this chapter, all methods employed helped to realise the stated aim. Care was taken to choose the research methods and research designs that best responded to the research questions and objectives.

CHAPTER 4

PRESENTATION, INTERPRETATION AND ANALYSIS OF RESEARCH FINDINGS

4.1 INTRODUCTION

In this chapter data are presented, interpreted and analysed in order to come up with research findings. Data were obtained from 12 participants through in-depth interviews, 10 participants in a focus group, and 6 key informant interviews on non-adherence to ART in the demarcated area of study. The findings are analysed against the findings of other researchers and against the theoretical framework as handled in Chapter two of this study. This section of the study also provides meaning to the aim of this study which was stated in chapter one as being to: examine non-adherence to ART in the Maquassi Hills, so that guidelines are developed for an integrated strategy and programme in order to address the problem of defaulting in the demarcated area. This aim would be realised through the following objectives:

- To determine the phenomena of adherence and non-adherence to ART.
- To examine barriers to ART adherence.
- To examine strategies that are deployed in South Africa in order to address the problem of non-adherence to ART?
- To contextualise global strategies in order to enhance maximum adherence to ART in the demarcated area of the North West Province.
- To analyse the role that social work as a profession can play in addressing the problem of non-adherence to ART.

As indicated in Chapter three, data were analysed using the steps suggested by Miles and Hubberman which are: Data reduction, Data display and Conclusion drawing and Verification (Poggenpoel, 1998: 340). Six predetermined themes, with related sub-themes and categories emerged from this data analysis and these are set out in Table 7 below.

Table 7: Themes, sub-themes and categories which emerged from the data analysis process

THEME 1: BIOGRAPHICAL DATA OF PARTICIPANTS	
Sub-themes	Categories
Biographical data of In-depth interviewees and focus group discussants	1. Gender 2. Age 3. Marital status 4. Educational level of participants 5. Main source of income 6. Monthly income 7. Duration on ART 8. Place of medication collection 9. Means of transport used to collect medication 10. Distance travelled when collecting medication
Biographical data of key informants	1. Gender 2. Years of professional experience 3. Nature of operational setting 4. Nature of services offered 5. Area of functioning
THEME 2: ADHERENCE AND NON-ADHERENCE TO ART	
Sub-theme	Categories
Knowledge on adherence and non-adherence to ART	1. Direction of using ARV medication 2. Side effects
THEME 3: BARRIERS TO ART ADHERENCE	
Sub-themes	
• medication related challenges (taste, size of the pills, dietary restrictions) • socio-economic challenges (poverty, unemployment, lack of transport) • stigma and discrimination related challenges (fear of disclosing status to partner or family) • health-care and systems-related challenges (distance of setting, health care provider-patient relationship, waiting time, availability of counseling services, privacy at	

ART clinic, follow-up services)	
THEME 4: ART FACILITATING FACTORS	
Sub-themes:	Categories
• Support from families • Support from health care providers	1. Psychosocial support 2. Treatment support 3. Follow-up services
THEME 5: ART MONITORING TOOLS	
Sub-themes	
• CD 4 Cell Counts • Viral Load Counts • Pill Counts through Pharmacy records • Directly observed treatment (DOT)	
THEME 6: SERVICES PROVIDED TO ADDRESS THE PROBLEM OF NON-ADHERENCE TO ART	
Sub-themes	
• Preparation of patients medically and psycho-socially for ART • Enrolment and retention services	

The researcher first presents the demographic data of the participants (in-depth interviewees, focus group and key informant interviewees). Given the sensitive nature of the topic at hand, numbers and letters of the alphabet including pseudonyms were used in order to protect the participants' identities.

4.2 THEME 1: BIOGRAPHICAL DATA OF THE RESEARCH PARTICIPANTS

4.2.1 Sub-theme: Biographical data of in-depth interviewees and focus group discussants

The biographical data of in-depth interviewees and focus group discussants are briefly presented under the following sub-themes: Gender, age, marital status, highest level of education, employment status, main source of income, monthly income, duration on ART, medication collection point, mode of traveling used, and distance travelled when collecting ARVs (See tables 8 & 9).

Table 8: Summary of biographical data of in-depth interviewees

Participants	Gender	Age-Years	Marital status	Education	Employment status	Years on ART	Source of income	Monthly income	Place of collection	Means of transport	Travelling Distance
1	Female	46+	Single	Secondary	Unemployed	5+	Rely on family members	0-900	Clinic	Taxi	11-20 KM
2	Female	48	Divorce	Secondary	Informal employed	4	Own salary	0-900	Clinic	Taxi	11-20 KM
3	Female	36-45	Single	Primary	Informal employed	10	Social grant	1000-2500	Clinic	Walk	11-20 KM
4	Female	40	Single	Secondary	Unemployed	14	Social grant	0-900	Clinic	Walk	11-20 KM
5	Male	26-35	Single	No Schooling	Unemployed	2	Social Grant	1000-2500	Clinic	Walk	11-20 KM
6	Male	26-35	Single	Primary	Unemployed	4	Social Grant	1000-2500	Clinic	Walk	11-20 KM
7	Female	36-45	Married	Secondary	Formally employed	11	Social Grant	1000-2500	Clinic	Walk	11-20 KM
8	Male	36-45	Single	Secondary	Unemployed	5+	Social Grant	1000-2500	Clinic	Walk	0-10 KM
9	Male	36-45	Single	Secondary	Informally employment	2	Social Grant	1000-2500	clinic	Cycle	11-20 KM
10	Female	36-45	Single	No schooling	Informal employment	8	Own income	3600+	Clinic	Taxi	11-20 KM
11	Female	36-45	Widowed	No schooling	Unemployed	2	Social Grant	1000-2500	Clinic	Walk	11-20 KM
12	Female	36-45	Married	Primary	Unemployed	5+	Social grant	1000-2500	Clinic	Walk	11-20 KM

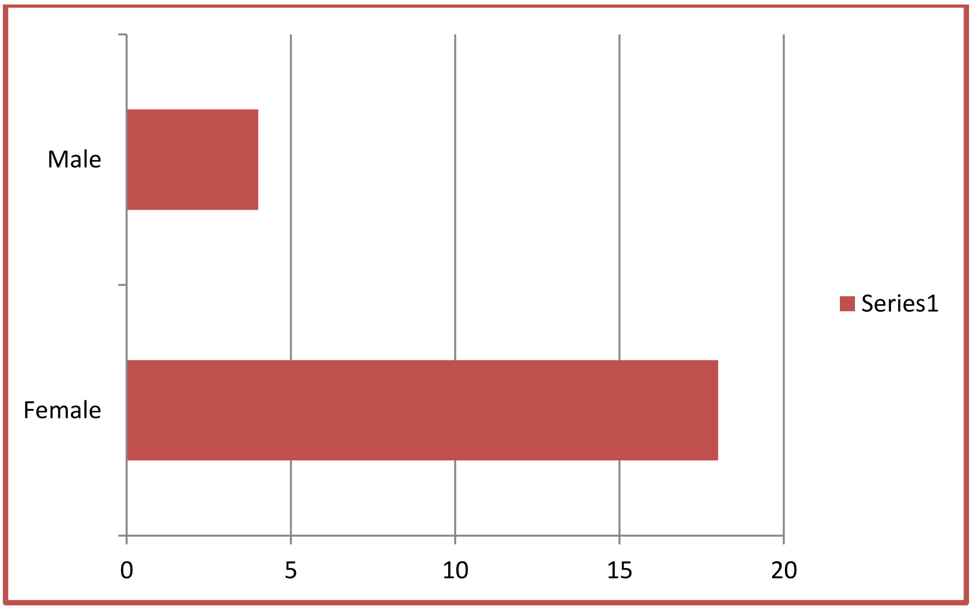
Table 9: Summary of biographical data of focus group discussants

Number of participants	Gender	Age - Years	Marital status	Education	Employment status	Duration on ART (Years)	Source of income	Monthly income	Collection of Medication	Means of transport	Travelling Distance
A	Female	36-45	Married	Secondary	Formally employed	11	Social Grant	1000-2500	Clinic	Walk	11-20 KM
B	Female	46+	Single	Secondary	Unemployed	14	Social Grant	1000-2500	Clinic	Walk	11-20 KM
C	Female	36-45	Single	No schooling	Unemployed	3	Social Grant	0-900	Clinic	Walk	11-20 KM
D	Female	36-45	Single	Secondary	Unemployed	9	Social Grant	1000-2500	Clinic	Walk	11-20 KM
E	Female	26-35	Married	Secondary	Unemployed	4	Combined income	2600-3500	Clinic	Walk	11-20 KM
F	Female	26-35	Married	Secondary	Unemployed	2	Social Grant	0-900	Clinic	Walk	11-20 KM
G	Female	26-35	Married	No schooling	Unemployed	2	Social Grant	1000-2500	Clinic	Walk	11-20 KM
H	Female	26-35	Married	Secondary	Unemployed	4	Combined income	2600-3500	Clinic	Walk	11-20 KM
I	Female	18-25	Single	Secondary	Informally employed	3	Own Salary	0-900	Clinic	Walk	11-20 KM
J	Female	26-35	Single	No schooling	Unemployed	2	Social Grant	1000-2500	Clinic	Walk	11-20 KM

4.2.1.1 Gender of participants

Figure 12 shows the gender of those who participated in the study

Figure 12: Gender of participants



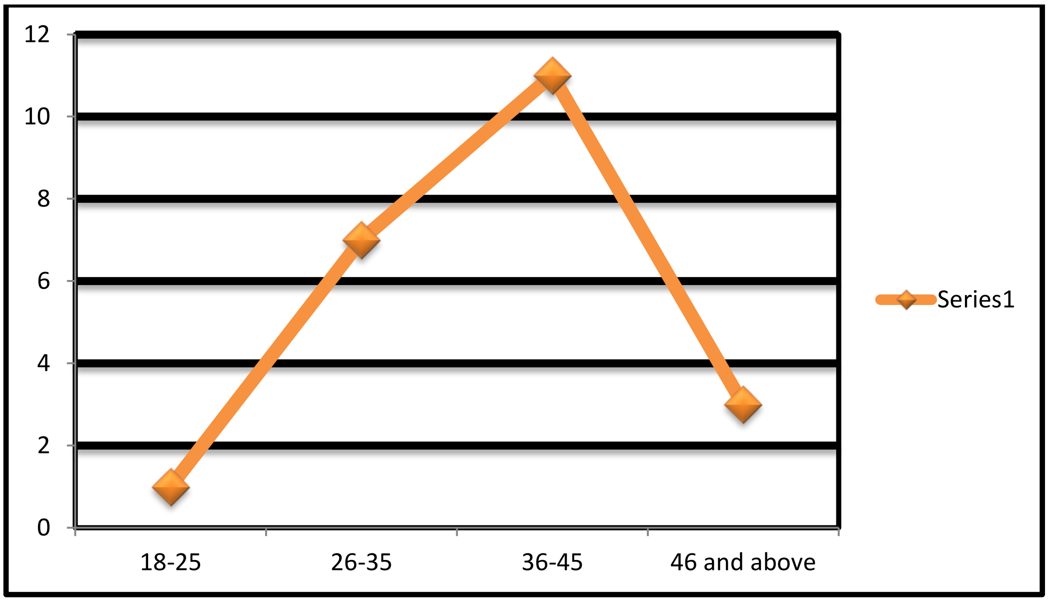
As depicted in Figure 12 above, a total of 18 of the participants were female while four were men. The inclusion of both genders was in line with sample requirements yet females far outnumbered males, to the extent that all focus group discussants were females. The implication that one can draw from this uneven distribution of genders is that HIV and AIDS affects men and women differently. For example the study undertaken by Turmen (2003: 411) showed that females can be more susceptible to HIV infection than males based on their physiological differences. In 2013 in South Africa also, a prevalence of 17.4 of women living with HIV compared to 15.9 adults (comprising of both men and women) within the age range of 15-49 years was recorded (Statistics South Africa, 2013). Such difference does point to a need for more gender specific prevention and treatment modalities.

Literature reviewed in Chapter 2 (UNAIDS FACT SHEET, 2016: 1) also showed the gender differences in how ART has been embraced. For instance, since 2010 world-wide a 26% decline in AIDS-related deaths from an estimated 1.5 million in 2010 to 1.1 million in 2015 were recorded. This reduction in deaths is said to have been greater among adult women (33% decrease) compared with adult men (15%

decrease) – a point which somewhat reflects higher treatment coverage among women than men (Global Aids Update, 2015: 4). Also, substantial differences between males and females initiating ART in South Africa were visible, suggesting that women do access and utilise medical facilities more than men. This situation equally confirms the faulty perceptions that men who seek help are “weak” (Johnson, 2012: 4).

4.2.1.2 Ages of participants

Figure 13: Age of participants



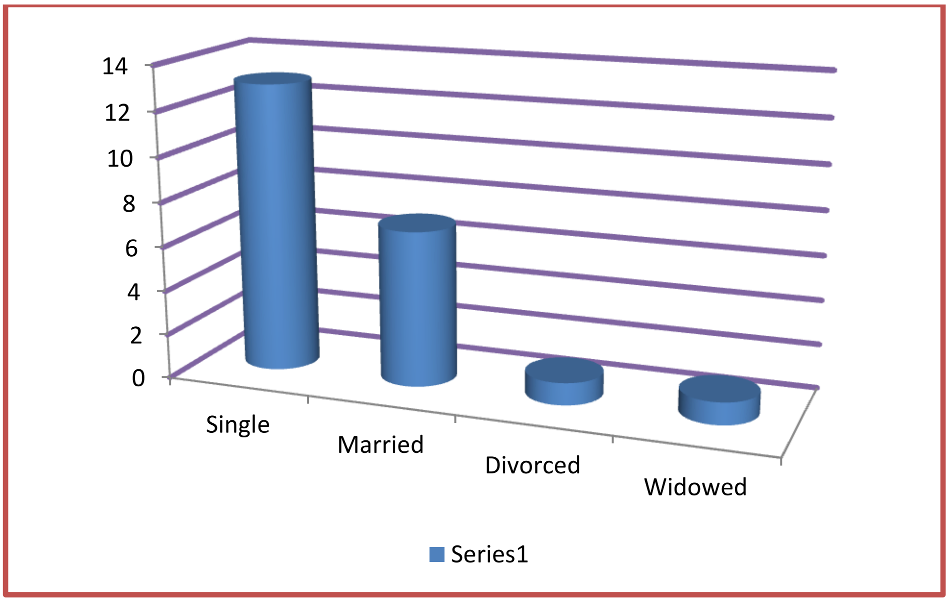
From Figure 13 it is evident that a substantial number of participants (10 from a total of 22) were within the age range 36-45 years, followed by those within the 26-35 years category (7). The two age groups depicted above clearly shows participants were in their productive and reproductive ages and stages. These age groups also depict people with established families (children). Chronological age however, does not in all cases connote growth in thinking and acting responsibly.

Kaguiri (2014: 46) showed that participants within a similar age range (35-44 years) were 3 times more likely to report maximum adherence to ART compared to those below 25 years. Increased medication adherence among these older adults was explained as part of a survivor effect for the sake of their dependent children.

4.2.1.3 Marital status of participants

The participants were asked to state their marital status during the interview. Figure 14 below shows that participants fell into the categories: widowed, divorced, married, or single. According to Figure 14, the majority of the participants (13 of 22 participants) were single – meaning that they had never been legally or customarily married. This number is followed by those who indicated that they were legally married (7 of 22 participants).

Figure 14: Marital status of participants



Such differences in marital status can point to the increasing vulnerability of women to HIV. For instance, the power imbalance that defines gender relations, sexual interactions, and marital status can affect women's access to and use of services and treatments (Gupta, 2000: 4). From personal experience, in many of the South African cultural practices, motherhood irrespective of marital status has been considered to be a feminine ideal. As such, in most casual relationships negotiating for safer sex has been near impossible, based on the need to satisfying cultural and personal (sometimes selfish) urges - those of procreation, predisposing such women to HIV and AIDS.

With those legally married, the Centre for Disease Control and Prevention (2005:1) also showed that some cultural traditions world-wide put women in the path of HIV and AIDS. For example in the South African situation, paying for “lobola” also termed “bride price” has been misused and relegated to an income generating venture by some families, from its initial role – that of being “a token of appreciation.” This has turned some married women into mere commodities who are expected to live up to the customary expectations regarding child rearing and other sexual activities without having a say in negotiating for safer sex.

4.2.1.4 Educational levels of participants

Wiseman and Glover (2012: 80-82) assert that formal education is one of the tools that can be used to transfer knowledge from one generation to the next. If used optimally, formal education also helps in building the capacity in people to effectively process and understand complex life risks they might be facing, together with ways on how to attain long-term preventive health strategies. On the other hand, Mishra (2005:75) found that the primary inherent value of formal education in this context is to enhance the skills required to understand HIV and AIDS education on offer and make sense of the many related messages from other sources that can enhance treatment adherence. Figure 15 shows the educational levels of participants.

Figure 15: Educational level of participants

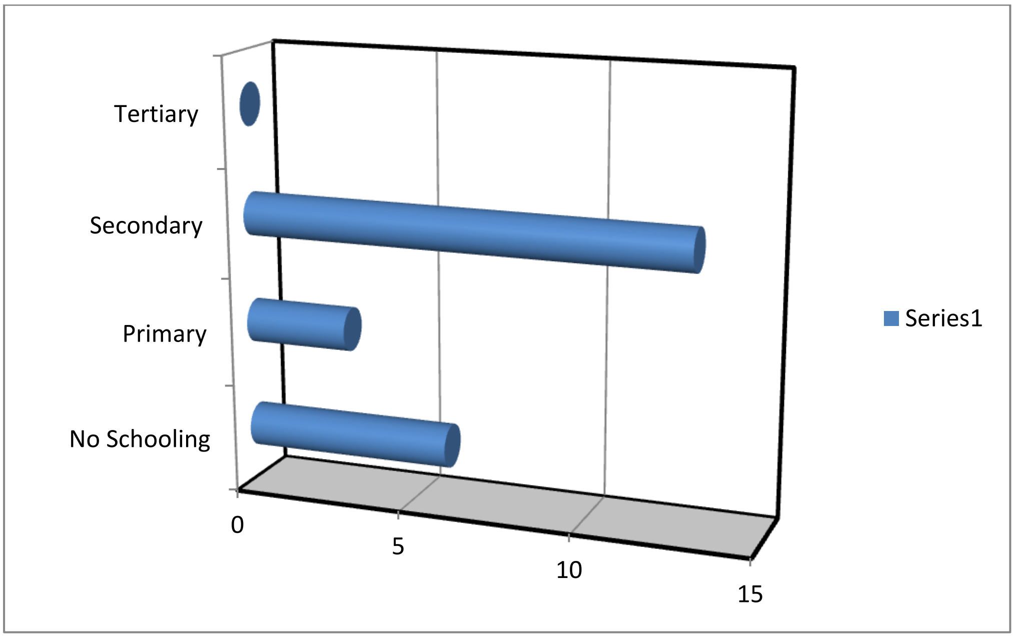


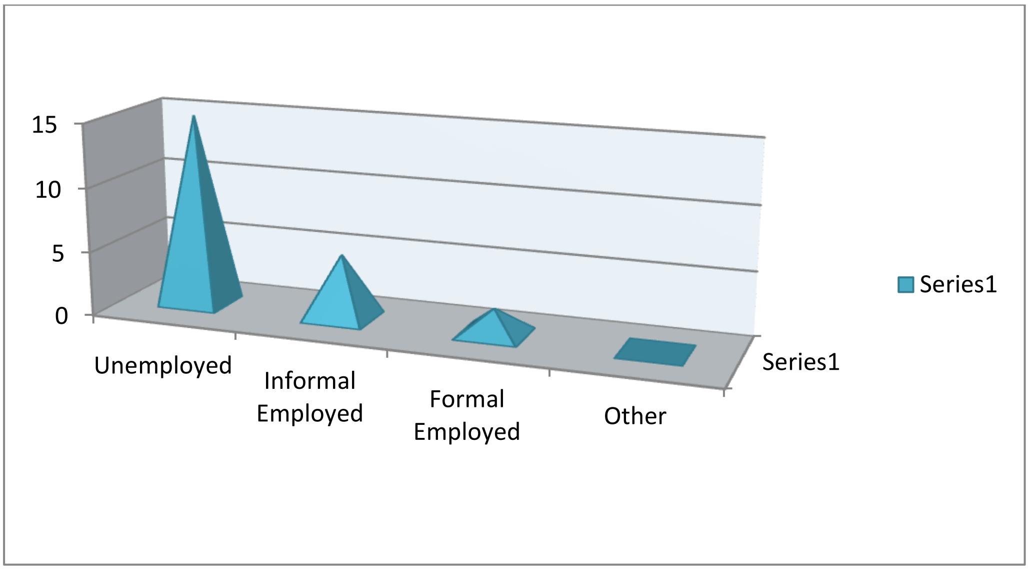
Figure 15 above indicates that 13 out of a total of 22 participants had attained secondary education - meaning that they had passed Grade 9. This level of education classifies them as functionally literate. They can read and write and follow instructions with understanding, and can be expected, based on their level of education, to make informed decisions. This group of participants is followed by 6 participants who do not have any schooling – they cannot read or write and rely in most cases on verbally provided information. In most such cases understanding of the relationship between adherence and viral load can be a challenge, suggesting the importance of specific and relevant education on the use of medicines and other drugs as ways of facilitating adherence (Barber, et al, 2015: 7).

Menamo’s (2014:52) study found an association between low levels of understanding of medical instructions and non-adherence to ART. On the other hand, high levels of education have revealed an increase in the patient’s adherence to ART. A good level of understanding about HIV and AIDS and awareness of the consequences of non-adherence are often associated with adherence, which in turn is linked to higher literacy levels.

4.2.1.5. Employment status of participants

It was noted in Figure 16 that participants in this study were either employed (formally or informally) or unemployed. Employed people are considered as those engaged in market production activities such as working for a wage salary, commission, or payment in kind, including those running a business/project, or even those hired in this type of venture (Statistics South Africa, 2015: 2). . From this category those registered as workers were deemed formally employed, with unregistered workers termed “informal”. Whereas those people constituted as being unemployed people were the “proportion of the labour force that was trying to find work” (Statistics South Africa, 2015: 2).

Figure 16: Employment status of participants



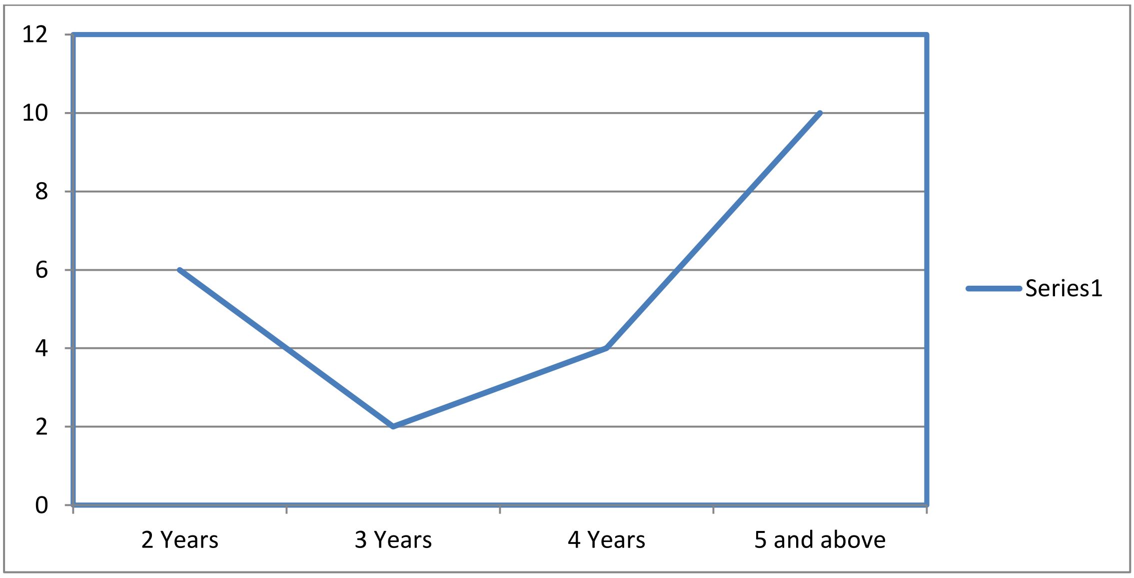
As shown in Figure 16 a total of 15 participants were unemployed, while 5 participants were informally employed. The next category was of those formally employed (2 participants). Unemployment appears to be a driver of poverty among the participants. Statistics South Africa (2015: 7) revealed that, based on the impact of global recession South Africa as a country recorded very high unemployment rates from 2008 (13.4) to 2015 (17.0). In the North West province the unemployment rate had risen sharply in 2014 (18.4), compared to in other years. The first casualties were the youth followed by women.

Haacker and Claeson (2009, 91-94) revealed in their study that much as every person can be negatively affected by unemployment, among people living with HIV and AIDS this effect has been high, especially in South Africa. This in turn has help increase the numbers depending on social grants, particularly on disability and care-dependency grants, which support far more than 10 million people in SA (Squire, 2007:17). Without work, buying healthy food to maintain immunity is difficult. As Kagee et al (2011: 2-3) in their study have shown from literature reviewed in Chapter 2 food insecurity may affect the regularity of ART doses, as some patients studied, indicated to have taken their medication only when they had food available.

4.2.1.6 Duration on ART

In response to the question: “for how long have you been on ART”? a total of 10 participants said that they had been taking the medication for 5 years and longer. This is followed by six who had been on ART for two years, and four who said they had been taking the medication for four years. Only two had been on ART for three years (See figure 17).

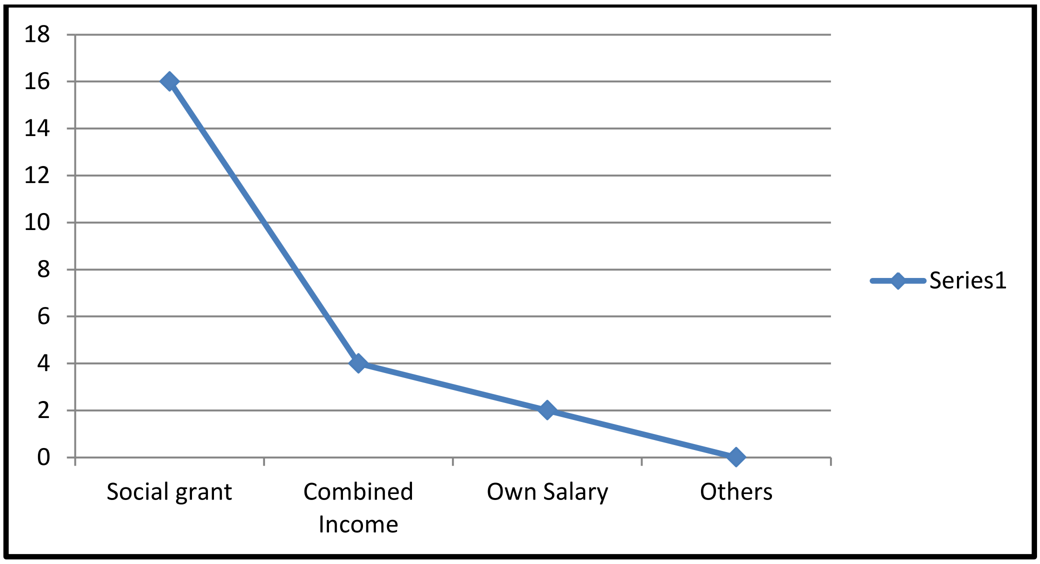
Figure 17: Duration of participants on ART



4.2.1.7 Main source of income

The majority of participants (16 of 22 participants) indicated that their main source of income is from social grants, followed by 4 participants who pointed to a combined salary – presumably theirs together with that of their intimate partner’s, with only 4 participants pointing to depending on own income (See figure 18).

Figure 18: Main source of income of the participants

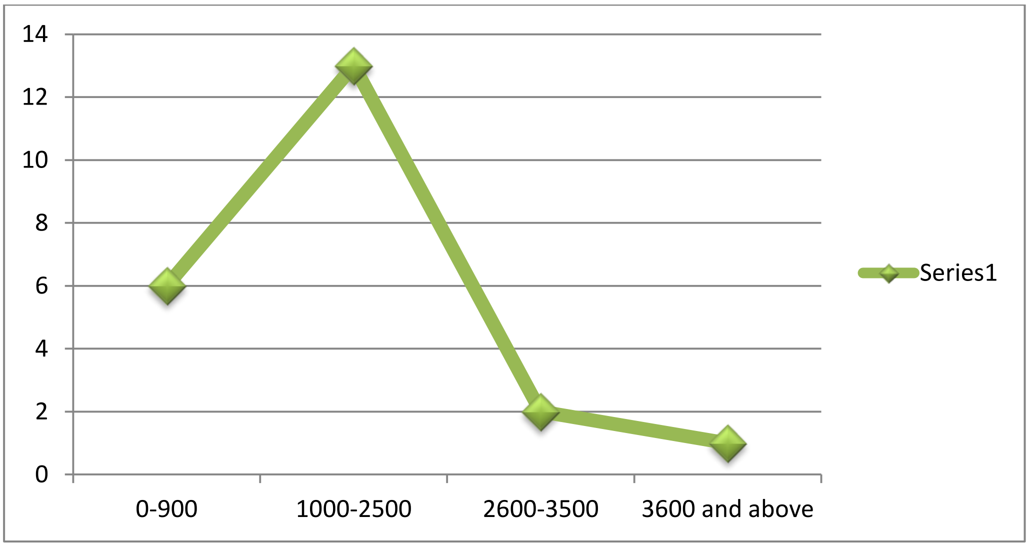


Reliance on state grants is confirmed by Kagee et al (2011: 4) in their study who found that some infected patients have been entitled to a monthly state-aided grant based on their illness which is related to their state of being incapacitated to engage in a paying job. Much as this state-aided grant is supposed to be serving as an aid in times of dire need, it was found by Kagee et al (2011: 4) that failure to adhering to ART can become one of the options patients used for fear of losing their grant once their CD4 Count increased.

4.2.1.8. Monthly income of participants

Figure 19 below shows that a substantial number of participants (13 out of 22) relied on a monthly income in the range of R1000-R2500, with 6 of the participants surviving on R900 and below. Only 3 participants depended on a combined salary (presumably their own combined with that of intimate partners) of 2600 and more. The implication that can be drawn is that most sampled participants (19 out of 22) could be termed relatively poor.

Figure 19 monthly incomes of participants



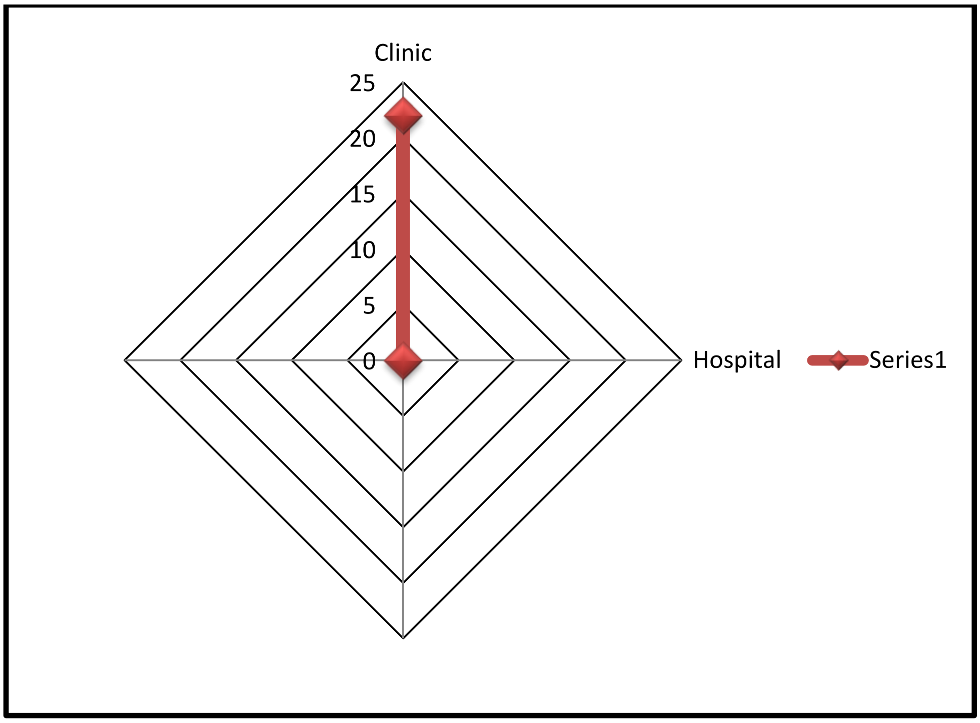
Ambrosino, Hefferman, and Shuttlesworth (2008: 171) confirm that “poverty generally means that household income is inadequate as judged by a specific standard.” The inadequacy can be measured against inadequate material and non-material resources. Following from this definition, the explanation of poverty is further expanded by Noble, Ratcliffe, and Wright (2004: 112) to encompass “the denial of opportunities and choices that are considered most basic to human development in order for those affected to lead a long, healthy, creative life and to enjoy a decent standard of living, freedom, dignity, self-esteem and respect from others.” The study by thes authors further expanded the expenditure bands showing that the monthly household expenditure in 1996 of R600 or less constituted those very poor; while the monthly expenditure of R600-R1000 constituted those that are poor.

Kagee et al (2011: 2) in their study as shown in Chapter 2 found poverty to be a structural barrier. The limited financial resources present in such families was directed elsewhere such as towards buying food stuffs and other basic necessities. As a result, funds for travel to a medical clinic that provides ART may not be available.

4.2.1.9 Collection of medication point

All 22 participants indicated to be using their state clinic as the collection point for their ART (See figure 20).

Figure 20: Collection of medication point

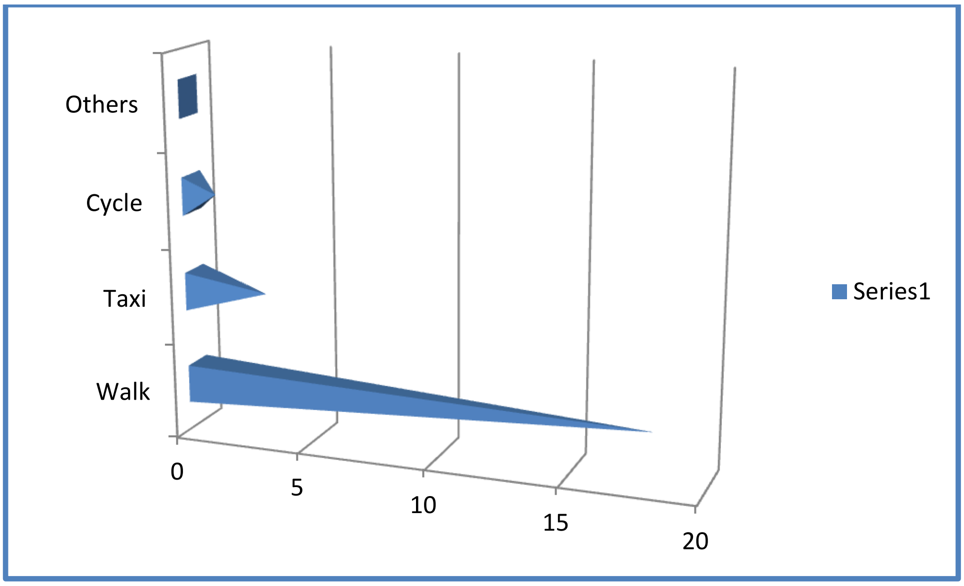


The study by Johnson (2012: 4) revealed that from 2004 in South Africa, the private sector was the biggest provider of ART, with the situation gradually changing from 2005 onwards, and a notable decline between the years 2006-2011. The public sector, which includes state hospitals and clinics, is recorded as the biggest provider of ART and was recorded to have provided over a total of 1 528 000 people with ART, as opposed to 1 900 000 people who received ART from the private sector. The greatest incentive in South African for preferring the public sector is because the medication is given out for free – making the services for ART in South Africa and in the demarcated area of study affordable and accessible.

4.2.1.10 Mode of transport used by participants

All the 22 sampled participants in this study indicated that they are required to travel a round trip of between 10-20 kilometres to collect their medication. The majority (18 of 22 participants) said that they were obliged to walk the indicated distance in order to collect their ARVs, 3 said they used taxis, with only 1 indicating to be regularly cycling to the clinic (See Figure 21).

Figure 21: Mode of transport used to collect medication



Much as the participants pointed out that they are used to walking the long distance as they use "short cuts," the apparent problem is on days that the weather is rough (example raining) and also when they are not feeling well.

4.2.2 Sub-theme: Profile of the key informants

The inclusion of service providers as key informants in this study was important, especially considering their relationship with patients/clientele. As pointed out in Abdissa (2013: 46) the interpersonal relationship of the service provider and consumer of those services (patient) plays a significant role in determining different patient outcomes including adherence or non-adherence to their treatment regimen. Cohesive partnerships and effective interpersonal communication, encouragement of participation of patients in their own care and trusting relationship - all serve as important components of effective patient-provider relationship. Such ideal interpersonal relationships can promote greater patient satisfaction with medical care, which in turn can foster higher levels of adherence.

Key informants were required to state their gender – this was important based on the fact that their patients are from both genders. The participants were also asked to provide their years of experience in offering their professional services in ART, together with the nature of settings they were operating from (See Table 10).

Table 10: Summary of biographical data of key informants

Key participant (Not their real names are used)	Gender	Years of experience	Types of setting	Team/Self	Area of function
Sister Naomi	Female	5+	PHC	Team	Nurse
Dr Tom	Male	4	PHC	Team	Doctor
Ms Mary	Female	3	Hospital	Team	Social Worker
Mr Ben	Male	4	Hospital	Team	Counsellor
Ms Ellen	Female	5+	CHC	Team	Counsellor
Sister Liz	Female	5+	CHC	Team	Nurse

In a practical setting health officials are the most significant individuals in the life of people living with HIV and AIDS. They have an influence in improving adherence to ART as well as motivating the defaulters in ART.

Sister Naomi: Is professionally an enrolled female nurse, with more than five years' experience in the nursing field and working in a PHC setting. She also renders services as a HCW.

Dr Tom: Is a male medical doctor who has been rendering medical services for four years. His services are presently rendered from a PHC setting, as a HCW.

Ms Mary: Is a trained female social worker with three years professional experience. She renders services related to ART and supportive services to the families of PLWHA from a hospital setting as part of the HCWs.

Mr Ben: Is a male counsellor with four years professional experience in rendering counselling services to those newly diagnosed with HIV and those initiating ART. He is based in a hospital setting as a HCW.

Ms Ellen: Is a female counsellor with more than five years work experience and she renders counselling services to those initiating ART. She also renders her professional services as part of the HCWs.

Sister Liz: Is an enrolled nurse with more than five years of experience in rendering services to PLWHA and in particular those initiating ART within a CHC setting as part of the HCWs.

The medical doctor further clarified his role as being that of a case management team leader, who has to take decisions regarding: initiation of ART, continuation of therapy, treatment failure, side effects, change of treatment regimen, and also responsible for the overall health status of the patient. The nurses explained their role as mainly initiating patients to ART, adherence counselling, treatment and management of side effects, and also for HIV testing services. They also work in close collaboration with the medical doctor. The counsellors said that they are responsible for adherence counselling of patients, and for providing the community members including the patients families with information pertaining to pre-ART, preparation for ART initiation, and about retention of patients on ART. The social worker pointed out her role as mainly that of liaising with all the team members in addressing the psychosocial problems that might impede ART initiation and retention.

The key informants - the doctor, nurses and the social worker – are all registered with their different professional bodies, and therefore bound by their Code of Ethics. Similarly the counsellors have undergone training and have taken an oath binding them to professional behaviours.

4.3 THEME 2: ADHERENCE AND NON ADHERENCE TO ART

This theme is divided into sub-themes: knowledge of adherence and non-adherence to ART, and also into the categories: direction of using ARV medication, missing the schedule dose of ARVs, and side effects of ARV medication. The presented data are then interpreted and analysed incorporating literature reviewed. As part of member checking 4 participants, comprising 2 patients on ART and 2 HCWs confirmed the discussed findings as either the truth of what is obtaining, and or indicated a discrepancy where there was no agreement. The patients and health care workers are identified by abbreviation: P – MC, and HCWs –MC.

4.3.1 Knowledge of adherence and non-adherence to ART

Much as participants expressed their different understandings of the meaning of adherence and non-adherence to ART, they all indicated to have been given information about how to take their HIV medication by health care providers at the time of ART initiation and during follow-up visits. It became clear that those with a longer duration on ART took this information a bit more serious in terms of usage, than the other participants, especially those with a shorter span (of less than 2 years) on ART. All participants confessed to not adhering maximally to their ARV regimen:

*“For me adhering maximally to the ARV regimen is to drink my medication daily at the same time” (***Participant 1).**

“*I understand adherence to ART as taking one’s medication daily with food and at the same time. We were taught that we should not panic when we occasionally forget to take our medication. The health care workers would say: ONCE YOU REMEMBER TAKE THE FORGOTTEN PILL, OR SKIP IT ALL TOGETHER – AS LONG AS THIS DOES NOT BECOME A DAILY PRACTICE”* **(Participant 3).**

“*With me much as I have learned about all other ways of ensuring adherence on ART, the only part that I think I stick to 100% is sleeping for long hours especially when I feel tired”* **(Participant 7).**

Two participants (Participants 8 & 10) indicated that adherence to ART does not only mean taking their medication at the same time daily, but also it is about sticking to required dietary instructions, which they constantly fail to adhere to.

‘*I fully understand from what we have been taught in our support groups that adherence to ART means taking my medication daily, at the same time and following the provided dietary instructions. I eat what is available and when food is also available”* (**Participant 8).**

One common element reiterated by all in the context of the in-depth interviewees was that much as they are not maximally adhering to ART, they all made it clear that they do not think of ever stopping taking their ARVs because they have seen its benefits on themselves and on others.

"*I am convinced that these ARVs work. In 2010 shortly after I was diagnosed with the HI virus I got SO-o-o-o-o sick, I even became confined for six months on a wheel chair. My health has now greatly improved after taking ARVs for more than 10 years" "* (**Participant 4**).

Dzinza (2007: 100) concurs with the emphasis placed by participants regarding respecting the time of treatment, eating well and sleeping properly as some aspects that are part of adherence to ART. However, the discrepancy was with participants not expressing that adherence to ART would also mean adhering to all procedures that accompany treatment – such as appointments, and continuously using safer sex in order to avoid extra infections with resistant strains.

UNAIDS (2015: 2) confirms the usefulness of ART as articulated by participants, that it saves lives – through the ART intake about 5.5 million HIV-related deaths globally were averted from 1995 until 2012; it reduces the risk of HIV transmission by up to 96% if adhered to maximally; it prevents other HIV-related illness; it also reduces the risk of tuberculosis infection among people living with HIV by 65%.

4.3.1.1 Directions for using ARV medication

All participants (in-depth interviewees) indicated to have been provided during pre and post counselling sessions on ART, with directions they needed to follow when using their ARV medication, such as: how much medication to take at a time, when to take the medication, how to take each pill with food, and even on how to keep the medication safe. In order to follow the provided directions practical helping tools they mentioned were provided to them included using either radio or favourite TV shows as reminders, use of mobile phones, involvement of relatives and or friends (a treatment buddy), and pill boxes serving as pill organizers.

"I understand how to take my medication; I drink my medication at 8 o'clock at night immediately when my favourite show "Generations" starts on TV" (**Participant 1).**

“With me my reminder is the soapy “Muvhango” – which starts at 9 o’clock every night” (**Participant 3).**

*“I use a 7-day pill box which I keep in my hand bag and re-fill after every eighth day. Wherever I go it is with me***” (Participant 11).**

*“My cell phone reminds me if it is about time to take my medication. The problem is when I am not home and when it is not charged I then forget to take my ARVs” (***Participant 10).**

Some of the participants (5.6 & 9) said that much as they know of all the directions to follow when they sleep out – either when attending a funeral or a wedding party, or even sometimes a family gathering, they fail to follow the provided guidelines based on the fact that they do not want other people who are not very intimate to them to know of their HIV status.

4.3.1.2 Side effects of ARV medication

In response to the question: “What are the possible side effects of your HIV medication?” There were mixed reactions in that 4 out of 12 participants indicated they experienced short term side effects that included: headaches, tiredness, nausea, dizziness, and an increase in appetite. The other 8 participants mentioned very long term side effects that they were encountering which involved bodily changes such as: having developed poor eye sight, hearing problems, a drastic loss of weight, having fat deposits around the tummy and neck area and developing more visible veins around their legs. These concerns were echoed as follows:

“*After using ARVs for a year I noticed that my curves were getting smaller with my tummy and neck area increasing in size – this causes a very uncomfortable feeling. A worrying fact is that people do notice these bodily changes and some of my friends make negative comments” (***Participant 2).**

*“When I take my medication sometimes I become VERY VERY nauseous, and feel like sleeping the whole day” (***Participant 11).**

“When you drink ARVs for longer periods as I have been on this medication for about 10 years, I have developed serious eye problems and my hearing is no more good” (**Participant 3**).

With me I am still experiencing more of these side effects. The medication makes me feel dizzy tired and lose appetite. The health care providers assured me that if I keep on with treatment I will be ok” (**Participant 7**).

What is evident from this finding is that with short term side effects these were expected. Whereas, with long term side effects no information participants said was provided and this does threaten adherence to ART.

The study by Urison (2012: 1) affirms the occurrence of both short term and long term side effects of being on ART. While ARVs are controlling the virus in the body they may also cause: anaemia (abnormality in red blood cells), diarrhoea, dizziness, fatigue, headaches, nausea and vomiting, pain and nerve problems, including the development of rashes, to mention only but a few.

With long term side effects of ART Urison (2012: 1) equally confirmed bodily changes that can include:

- **Lip dystrophy**–A problem in the way the body produces, uses, and stores fat;
- **Insulin Resistance**–A condition that can lead to abnormal sugar levels that can lead to diabetes;
- **Lipid abnormalities**–Increases in cholesterol levels;
- **Decrease in bone density; and**
- **Lactic acidosis**–A build-up of lactate which can cause problems ranging from muscle aches to liver failure.

4.4 THEME 3: BARRIERS TO ART ADHERENCE

Barriers to ART medication were explored. These barriers were regarding: the patient’s/people’s experience of taking the medication, socio-economic challenges, stigma and discrimination-related challenges, including health-care and systems-related challenges.

4.4.1 Medication-related challenges

All focus group discussants pointed out to dietary restrictions as one of their biggest challenge when having to take their treatment regularly, since they are not supposed ly not to take their treatment on an empty stomach. The food shortage was attributed to poverty which they indicated was aggravated by unemployment. Another challenge which was articulated was having to take too many pills at a time – termed "concoctions".

"Half of the time the only bit of food I have is for my two little children. As a result I skip my treatment until the time where there is enough food for all of us" (**Participant F).**

"I do not necessarily follow the diet of vegetables and fruits, as long as I take something to fill me up. The cheapest meal that at least I can afford is "jabula" – which I mix in a paste" **(Participant J).**

"I get nauseous when taking my ARVs on an empty stomach, and that makes me SO-o-o-o-o-o sad, when having to skip treatment. I get sad because I am aware that such actions do have a negative effect on my health. I cannot afford to die and leave my family behind "(sigh)" (**Participant A).**

"With me, we only have one meal late at night when all of my family members are home. As a result of this arrangement all my medications are taken during those times " **(Participant D).**

Another challenge articulated by some participants was taking many pills at a time. For example about 6 of 10 participants (**A, C, D, E F & G)** said that coupled with taking their ARVs, they are also taking treatment for Tuberculosis (TB) and for high blood pressure (BP) – colloquially termed as "high high" in the area of study.

*"The concoction of pills that I have to take day and night makes me very tired and this accounts for my regular vomiting. How I wish I could take only one pill. My whole body even just smells of these pills" (***Participant C**).

"With me my problem is once I forget to take one of my pills at a scheduled time, I double my intake the next time or sometimes drink these at very short intervals. This often leaves a very guilty and unpleasant feeling in my mouth and body" (**Participant E).**

Two other participants (**A & D**) openly confessed to also be using alternative medication derived from herbs that they get from the traditional healers they consult and over the counter medicines - often advertised as supplements and harmless..

"I have been taking herbs just to strengthen my immune system and for energy. I get these herbal products from one of the pharmacies, and require no prescription. The labels indicate that there are no harmful ingredients added". **(Participant D).**

"My traditional doctor has instructed me to take his herbs first thing in the morning on an empty stomach. In most cases I spend almost the whole day feeling like vomiting. But "(pause)" I guess I have no option" **(Participant A).**

4.4.2 Socio-economic challenges

Absence of steady and adequate income featured strongly as a barrier which was said to be preventing participants from meeting their daily dietary requirements such as buying of appropriate nutritious food and vegetables, together with paying for transport especially when having to collect their ARVs. A substantial number stated that they rely on a state grant – the disability grant which has to be renewed every six months.

Lack of structural support also featured strongly as another barrier in instances where participants based on their known HIV status are discriminated against in being considered for any type of employment. Some of the participants provided the following accounts.

*"I passed grade 8 but find it difficult to secure a job moreover because I am open with my HIV status and as a result have been relying mostly on the disability grant that is also not steady. It was stopped twice based on my improved viral load. Apart from struggling to buy fruit and vegetables, I sometimes wish to use any form of transport when having to collect my medication – having to travel for about 20kms is not easy especially when you feel dizzy and not well" (***Participant F).**

*"The possibilities of having the disability grant being stopped once your health improves does tempt me and some of my friends from not taking our ARVs regularly especially towards the review days of the grant. YES GETTING BETTER OFTEN MEANS THE POSSIBILITY OF LOSING YOUR ONLY SOURCE OF SUPPORT WHICH IS THE STATE GRANT" (***Participant G).**

"I was once in full-time employment, but was retrenched – I suspect that this was related to my HIV status – it makes me very sad and sometimes leaves me emotionally drained when thinking of that incident" (**Participant J).**

4.4.3 Stigma and discrimination-related challenges

There were mixed feelings regarding stigma and discrimination on the part of participants. Some indicated that they do not experience any form of discrimination especially at home because they have disclosed their HIV status. Others indicated to have experienced some form of discrimination from the hospital where they used to collect their medication.

"*At the hospital our files were different from other patients' who were not living with the HI virus. Once I observed this I was angry, until they corrected this practice*" (**Participant B**).

"*Not only was the file of a different colour, we had to use a different entrance and came on a set day and time of the week - everybody could see that we were different, which to some extent discouraged me from coming for my ARV supplies, until they changed the practice*" (**Participant C**).

Apart from the discrimination that participants said they encountered when applying for work especially when having to disclose on their curriculum vitae their HIV status, the church was another organisation where some indicated to be facing discrimination.

"*At the church that I used to be a member of they were very judgemental. They would assume from the remarks they made during some of their counselling* *sessions that the virus was acquired through my loose morals. That really put me off – I have since moved to another church which is more supportive and showing us the way with love”*. (**Participant A).**

4.4.4 Health care and systems-related challenges

Health care and systems-related challenges were those out of the control of patients/people who are using particular facilities which in this study were in-depth interviewees and focus group discussants. Barriers mentioned by participants included distance of the clinics from the communities, particularly given that the sampled patients used the clinics as their medication collection points (4.2.1.9). They all indicated they walked a round trip of 11-20 kilometres every time they had to go for ART (4.2.1.10). Long waiting times, few counselling rooms and space and shortage of staff also featured as barriers.

“I wake up at 5h00 in the morning but I will come back at 16h00, hungry and tired. I always do not look forward to the scheduled days” (**Participant A**).

“The nurses and doctors would take short tea breaks with us waiting very long hours after travelling long distances” (**Participant E**).

4.5 THEME 4: ART FACILITATING FACTORS

4.5.1 Support from families

All the participants (In-depth interviewees) said that because they had disclosed their HIV status to their families, they were receiving support from them. The type of support is financial, and moral in the form of encouragement to continue taking their medication regularly. Four of the single women (**Participants 1, 3, 4 & 10**) however indicated to be bothered by their former partners (the fathers to some of their children) who still blamed them for having infected them with the HI virus. They would want to restore the friendship with their former intimate partners for the sake of their children and for their own peace of mind.

“This pulls me down in most cases, especially because my ex uses my children against me” (**Participant 10**).

“*His family makes nasty comments whenever they meet me. What makes matters worse is that my former partner died six months back*” (**Partner 3**).

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4.5.2 Support from health care providers

All the participants acceded to the type of support they were receiving from the HCWs which included counselling sessions to try and address some of their medical and psycho-social problems, offering diet related information, and education on lifestyle changes. Individualising this support the participants indicated would make the exercise more worthwhile.

“*How I wish the HCWs could have been more in numbers, just to attend to our individual problems*” (**Participant 9**).

“I thank them for suggesting to me the “programme of down referral” which enabled me to collect my ARVs from the clinic, unlike before where I was collecting them from the hospital which is much further in distance. I am now able to walk to the clinic to take my treatment” (**Participant 11**).

4.6 THEME 5: ART monitoring tools

Key informants indicated that in their settings the ART monitoring tools used are: CD 4 Cell Counts, Viral Load Counts, Pill Count though pharmacy records, Directly Observed Treatment (DOT), and that after 2010 they moved to TIER NET System to capture all those patients who adhere and those do not adhere to ART. Home visits are also undertaken by social workers, DOTS support workers and Community Health Care workers/Care givers, tracing those who are non-adherent to ARV treatment, and constantly miss their scheduled appointments.

“*We perform a full blood count (FBC) when the patient is first diagnosed with HIV, when he/she starts with ART, and every year thereafter. FBC is used as a broad screening test to check for such disorders as anaemia, and many other pre-existing* *diseases that ought to be treated concurrently with the administration of ART*" (**Sister Liz).**

"*ARV treatment is recommended for all people living with HIV, however if a patient has chosen not to take treatment for the moment, looking at patient viral load and CD4 cell count can help predict a patient's immune system and monitor how the disease is progressing. Viral load testing can also provide important information such as measuring the actual amount of HI virus in the bloodstream. We use these tests to also to determine the need for therapy"* **(Sister Naomi).**

"Very recently the three integrated electronic register (TIER.Net) system is being used to monitor our patients. Department of Health nationally in 2010 adopted a three integrated electronic register approach for monitoring and evaluation of the antiretroviral treatment programme. TIER.Net has contributed to improved performances. It is used to monitor paper-based system making up TIER 1, an electronic version of paper register TIER 2, and full electronic medical record software TIER 3. TIER.Net is a user-friendly, menu-driven computer programme developed on the Microsoft.net platform". **(Dr Tom).**

Literature (Steel, Nwokike, & Josh, 2007: 6) confirms DOT as an ART monitoring tool that has the potential of being highly effective in settings of great deprivation as long as there is sustained commitment to uninterrupted care that is free to the patient. Contrary to its apparent advantages, it does have proven disadvantages those of: being expensive to administer, can stigmatise the monitored, and have no privacy.

On the other hand, the introduction of the tier-based system confirms how progressive South Africa is, in its periodic evaluation of monitoring tools. This tool is said to be based mainly on availability of resources at the time of implementation. As infrastructure improves a facility can then transition to the next tier – eventually with all three tiers implemented and complementing each other for more efficient results (Claudine, 2011: 7. The results envisaged are also for a non-invasive, easy to use, and sensitive to the peoples' needs and situations (Steel, Nwokike, and Josh, 2007: 5).

Much as it is all clear that current and modern monitoring tools are adopted in the different settings studied, the question of manageability remains fluid and tricky.

4.7 THEME: 6: Services provided to address the problem of non-adherence to ART

Such services are preparation of patients medically and psycho-socially, including on how patients are enrolled and retained on ART.

4.7.1 Preparation of patients medically and psycho-socially for ART

HCWs indicated that in an ideal situation they would be required to perform three sessions of preparatory counselling. In the first session ground work for adherence would be set, followed by more adherence counselling. With the last session assessing the patient's readiness and initiation of ART is done.

"I would during the counselling sessions learn about the patient's source of social support, socio-economic situation, and possible barriers anticipated when having to initiate ART" (**Ms Mary).**

*"We get a detailed medical history of a patient's health. This should include: prior use of ARVs and other medications, together with information on the patient's beliefs and attitudes about HIV and treatment". (***Ms Ellen).**

"*For patients who are pregnant or planning a pregnancy, additional counselling on prevention of mother to child transmission of HIV infection and services is made available".* **(Sister Naomi).**

The counselling sessions undertaken are apparently offered to groups of patients rather to individuals.

4.7.2 Enrolment and retention services of ART

As part of their enrolment and retention service related to ART, key informants provided different strategies that they follow such as: Requesting *naive* patients about to be initiated on ART to come with treatment supporters – termed a treatment "buddy" (this is a situation where mutual support can be provided by friends, someone in a similar situation, or with a similar encounter). Patients are also encouraged to disclose their status to family members or friends.

Treatment supporters also get counselling on ARV treatment so that they are able to give the patients the necessary support at home and monitor whether the patients take his/her medication properly. Another strategy used is to encourage the identified treatment supporters to accompany the patient to the clinic or hospital during certain check-up sessions and on some collection of medication days.
Some of the key informants expressed their views as follows:

“My task as a social worker is to make sure that all information that would have been provided by the doctors and nurses is well understood by the patient as part of preparation for initiation on art. This information is to guide in making informed choices. During this period also, counselling is provided on aspects such as: support for disclosure and partner notification. Based on a comprehensive investigation of the client’s/patients environmental circumstances, actions such as linking them with available resources are put in practice.” (**Ms Mary**).

“We also organise health talks in and outside the facility for members of the community and targeted members - those newly diagnosed with the HI virus, including those that are prepared for ART. Topics tackled are usually those dealing with: What ART adherence means and its importance, including also the importance of disclosure.” (**Ms Ellen**).

“At the facility from where we operate, three full adherence sessions are conducted on a weekly basis, with an additional one based on the need as articulated by the patients themselves.” (**Sister Naomi**).

These findings are supported by the National Consolidated Guidelines (NDoH South Africa (2015: 37) which also stressed the importance of discussing the patient’s willingness and readiness to start ART. The newly initiates are educated on the benefits of treatment and the possible side-effects. The nutritional status of the patient, co-morbidities and possible drug-interactions, together with any mental health and substance abuse issues are also to be considered. Risk reduction counselling and HIV prevention approaches ought also, to be emphasised including the practicing of safer sex, availability and use of condoms (especially during pregnancy), contraception and future fertility decision making processes.

4.8 DISCUSSION OF FINDINGS

The findings of this study are informed by in-depth interviews and focus group discussions with patients on ART and also by key informant interviews with HCWs who were in direct contact with those on ART. All participants were recruited from three types of facilities, namely a PHC, CHC, and a hospital. In terms of socio-demographic factors women featured in higher numbers compared to men. The patients were also predominantly single, unemployed and within the ages 26-45 years. Their main source of income was social grants – the disability grant in particular, and most were living on between R1000.00 – R2500.00 per month. All of them had acquired a secondary education and could be termed functionally literate. The selected patients had been on ART for 2 or more years, with their ARV collection point being the clinics, which were mostly within walking distances. With key informants male and female, with more than 3 years professional experience with their fields of practice as: medical, nursing, social work and counselling.

It emerged from the study that patients on ART were knowledgeable on the basics of what constituted adherence and non-adherence to ART. Not only were the patients on ART provided with knowledge about dose, time, and dietary adherence, emphasis was also placed on the dangers of skipping treatment which can result in drug resistance. They were also advised on how to practice safer sex, and were urged to encourage their partners to come for testing and to report side effects as soon as possible to the HCWs. Also, the amount of information provided to patients initiating ART is commonly correlated with their educational level.

It was clear interviewees did not stick 100% to schedule times and to dietary requirements. The HCW-MC during member checking negated this point and indicated that about 80% of patients on ART in the demarcated area of study and settings had made an attempt to “religiously” adhere to their ARV regimen. A study by Dagnew (2009) supported this finding on non-adherence irrespective of having been provided with relevant knowledge. That research found no significant differences in the HAART adherence behaviour of those who said that they knew how to take their HIV medication. This clearly demonstrates how education alone may not be sufficient to eliminate the obstacles that prevent optimal HAART adherence behaviour.

It emerged from this study that being on ART for more than two years was significantly associated with a relatively better level of adherence compared to having a shorter duration. The sporadic use of ART posed as a concern in this study given that poor adherence is associated with the development of drug resistance. The HCW-MC concurred with the observation that those on ART longer tended to be more adherent than those who had just started with ART. Before 2016, in South Africa, a patient was required to start with ART only when their CD 4 Count was < 250. As a result, they would develop opportunistic infections and got sick. After being initiated on ART their health would improve. Since 1st September 2016 the Universal Test and Treat (UTT) was introduced. Because patients do not immediately present with any symptoms (they appear healthy) they see no use therefore to adhere to ART.

This finding is in contrast to what Hansana, Sanchaisuriya, Durham, Sychareun, Chaleunvong, Boonyaleepun & Schelp (2013) found in their study that being on ART for 31-60 months was significantly associated with non-adherence. This could be a consequence of the assumption that the longer they are on treatment patients become complacent and found it harder to follow the strict regimen. Consistent with the views of Hansana et al (2013) regarding such differences in findings, caution is needed especially when comparing adherence levels and or issues across studies as sometimes the methods of measuring adherence, and settings can in a way influence findings. With the possibilities of developing drug resistance based on poor adherence to ART, literature reviewed in chapter 2 of this study (WHO Guidelines, 2013) supported the concern and indicated that, for ART, a high level of sustained adherence (95%) is necessary in order to suppress viral replication and improve immunological and clinical outcomes, decrease the risk of developing ARV drug resistance, and reduce the risk of transmitting HIV.

An interesting feature that emerged from this study is some interviewees who vowed never to stop taking their ARV medication. This is in line with the application of the HBM as dealt with Chapter 2 which is one of the theoretical frameworks underpinning this study. Participants **perceived the risks** in others and in themselves (of developing AIDS –related illnesses) – if they failed to take their ARVs altogether. **The perceived severity** they said included being wheel-chair bound and/or dying, with **perceived benefits** of staying on ART and gaining their health and love back from their families, as a result of adopting secondary prevention behaviour such as adhering to ART (Turner et al, 2004).

The study also revealed that some participants (in-depth interviewees) were knowledgeable about the directions they needed to follow when using their ARV medication, which included aspects such as: how much medication to take at a time, when to take the medication, how to take each pill with food, and even on how to keep the medication safe. Practical helping tools such as pill boxes, and TV programmes were provided to them in order to enhance application. The challenge noted to adapting this knowledge when in a different setting such as when sleeping-out (attending a party or a funeral). This finding is supported by Shigdel (2012) who found that both univariate and multivariate analysis of data in that study confirmed that having a reminder tool is a strong predictor of adherence.

Side effects were identified as a significant threat to good ART adherence, especially since long term bodily changes were not anticipated based on the information provided by HCWs. The HCW-MC concurred with this finding on side effects and indicated that it is important to encourage the patients through the periods of experiencing side effects, instead of pre-empting these before they occur. Once these are reported other medication can be co-prescribed to lessen the effects of side effects, and that a certain drug termed “D4T” has since been done away with because of its many side effects. For this reason Nsiba, Irunde, and Comoro (2010) noted that being informed about the side effects at the initiation of treatment, how to better manage side effects would be important information to communicate to patients

It emerged from this study that some churches (through their form of counselling) and some employer organisations (following the disclose of one's HIV status) were still stigmatising PLWHA.

In the current study medication and socio-economic related challenges to ART included food insecurity – where dietary instructions are not adhered to, moreover because participants reported high levels of unemployment, pill burden – which was associated with having to take many pills related to other illnesses, including the pill skipped earlier on. The HCW-MC added that most patients for quick recovery use remedies such as: “the African potatoe” – which tends to increase the CD4 Count without decreasing/suppressing the multiplication of the virus. A previous study (Nsiba et al, 2010) confirmed the issue of food insecurity in Tanzania as a serious problem that adversely affected adherence. Many patients from that study are reportedly complained that the costs of food precluded them from taking their medication as required. The study by Roura, Busza, Wringe, Mbata Urassa & Zaba (2009) also revealed ing that clinicians reported that patients were reluctant to take their medication on an empty stomach even though they had suggested to patients to take their medication regardless of this.

Health care and systems-related challenges experienced by patients on ART were associated with distance of the clinics from the communities because all the sampled patients used the clinics as their medication collection points, and had to walk a distances of between 11-20 kilometres every time they had to go for ART. Lengthy waiting times, limited numbers of counselling rooms, and space and shortage of staff also featured as barriers. The HCWs -MC negated the distance of between 11-20 kilometres that, it is shorter, and instead added the possibilities of “stock-outs” of ARVs that can disrupt ART intake. The finding on lengthy waiting times was corroborated by Vermeulen (2011) who found that, because large numbers of patients are now utilizing public healthcare resources, patients had to wait for extended periods of time before being attended to by doctors, nurses, and counsellors as well as having their prescriptions at the hospital pharmacy. This demand contributed to the lack of privacy when being attended to, as the overstretched capacity meant that multiple patients were attended to at the same time.

Facilitating factors identified by the sampled patients included: the willingness of some women (in-depth interviewees) to restore friendship and extend a hand of forgiveness with their former partners together with family members who still blamed them for infecting them with the HI virus, and the question of wanting to be treated on an individual basis by HCWS during ART sessions. The question of willingness to make peace in essence is consistent with the strength-based perspective as discussed in chapter 2 of this study. For instance, one of the principles t**rauma and abuse, illness and struggle may be injurious, but they may also be sources of challenge and opportunity** applies. Having been diagnosed with the HI virus, and having the prospects of being on ART for one’s whole life can be traumatic of its own. The strength-based perspective posits that people who have been victimised can be seen as active and developing individuals who through their personal problems do acquire skills that can assist them cope with future struggles. The women in question it seems have grown from their crisis which they handled effectively. Their problems do allow them to see opportunities, hope, and solutions rather than just problems and hopelessness.

It is clearly indicated in the findings of this study that ART monitoring tools used by HCWS to capture all patients who adhere and do not adhere to ART are CD 4 Cell Counts, Viral Load Counts, Pill Count though pharmacy records, Directly observed treatment (DOT) and the TIER NET System. HCW also trace those who are non-adherent to ARV treatment, and constantly miss their scheduled appointments. Much as it is all clear that current and modern monitoring tools are adopted in the different settings studied, the question of manageability remains a tricky issue. The HCW-MC confirmed that shortage of technical staff poses a problem. Ideally capturing of information from the test ought to be done on a daily basis, which is not possible due to shortage of staff.

A major enrolment and retention strategy to ART that HCWs are employing and appears to be effective is using “treatment buddies” – as part of treatment supporters. The P-MC confirmed the importance of treatment buddies but, indicated the idea was not readily practical in their situation. An earlier study by Hlophe (2010) confirmed the role played by treatment buddies in improving ART adherence. That study found that treatment buddies represented an important form of informal adherence and psycho-social support particularly in the early phases of ARV treatment, equally among married ART clients. Access to treatment buddies it is reported declined later in the treatment programme as clients health-related quality of life improved.

4.9 SUMMARY

In this chapter data were presented and interpreted. Thereafter, the research findings were analysed. Six predetermined themes, with related sub-themes and categories were identified from the analysed data. Narratives then emerged from these themes and were followed by a discussion of findings which were confirmed by literature reviewed.

CHAPTER 5

SUMMARY OF FINDINGS, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The study set out to examine non-adherence to ART in the demarcated area of Maquassi Hills so that guidelines for an integrated strategy and programme that could address the problem of defaulting in the the North West Province could be recommended. In this chapter findings are presented against the objectives of the study, with conclusions drawn, limitations presented against the strengths of this study and recommendations for further research made in the sector of ART.

5.2 DISCUSSION OF THE FINDINGS RELATED TO THE OBJECTIVES OF THE STUDY

5.2.1 The phenomena of adherence and non-adherence to ART.

The first objective sought to determine the phenomena of adherence and non-adherence to ART. This objective was realised in this research. Literature reviewed showed that adherence to ART encompasses a life style change which include: dose, schedule, and dietary adherence. Also, high motivation, positive coping styles and high levels of interpersonal support are all associated with adherence. A 95% adherence level was found (World Health Organisation, 2003: 3) as required in order to meet the desired goals of suppressing viral replication, decreasing the risks of developing drug resistance and also reducing the rate of transmitting HIV.

With regards non-adherence, literature reviewed showed that this is attributable to missing prescribed doses, non-observance of time intervals and dietary restrictions, as well as failure to adhere 95% to one’s ARV regimen. South Africa, in all African countries recorded very high treatment services of up to 75% and has attained universal access to treatment. It was clear that from the in-depth interviews that the measurement used for adherence and non-adherence included self-reported missed doses.

It can be concluded that adherence at 95% level is possible in all types of settings. What is required though is a broad knowledge of the functioning of the ART by both HCWs and people using these services, together with internal and external motivation support systems that are non-discriminatory.

5.2.2 The barriers to ART adherence.

The second objective sought to examine barriers to ART adherence. This objective was realised in this research. Literature reviewed (Enriquez & McKinsey, 2011) in Chapter 2 of this study explained barriers to ART adherence to the inability of patients on ART to being consistent with their ARV medication. These barriers were highlighted and examined under patient-related factors, treatment-related factors, socio-economic factors, health system factors, and condition-related factors. It emerged from this study that the barriers encountered by sampled patients on ART included those related to patient, socio-economic, stigma, and health-care and systems factors. Food insecurity, pill-burden, absence of a steady income as a result of unemployment, discrimination by employers, side effects, stigma from former intimate partners, having to walk long distances to collect ARV medication, long waiting times at the clinics, few counseling rooms which impeded privacy and shortages of staff which hindered the quality of counseling received.

5.2.3 The role of social work in addressing the problem of non-adherence to ART.

The third objective sought to analyse the role of the social work profession in addressing the problem of non-adherence to ART. This objective was realised in this study. As pointed out in Chapter 2, social workers in an ART dispensing facility are a part of the HCWs. Their role is to coordinate the services of the medical team for the optimum benefit of the patient and assessing the patient for psychosocial issues, including tangible needs that could affect their ability to engage in services and manage treatment (Poindexter, 2010). The sampled social worker in this study specifically described her role in an ART facility as being to perform three sessions of preparatory counselling. In the first session, ground work for adherence would be set, followed by more adherence counselling. The last session of counselling relates to assessing the patient’s readiness for ART initiation.

In working with individuals, groups, families, organisations and communities on the management of HIV and helping people in their adherence efforts, a social worker executes different professional roles and promotes people's human rights. In the South African setting, literature (ISDM, 2005) has shown that the developmental stance that social workers adopt ensures that services are people-centred by putting emphasis on:

- Participation of patients in their own problem-solving process as a form of self-esteem.
- Self-reliance in situations where patients are connected to each other and encouraged to form coalitions with others, including connecting with their environment as a form of social support.
- Empowerment which involves shifting power relations towards people achieving greater control and influence over their lives, their decisions and resources around them, that impact on the quality of their lives.
- Universal access of services to all in terms of proximity, and usage, and ensuring that people are not denied access to ART services either because of lack of resources or lack of knowledge of how to access such services.
- Equity, which is about ensuring that resources are distributed on the bases of need, priorities and historical imbalances (ISDM, 2005: 11).

5.2.4 Strategies deployed in South Africa in order to address the problem of non-adherence to ART?

This objective sought to examine strategies deployed in South Africa in order to address the problem of non-adherence to ART. This objective was realised in this study. As a way of showing commitment but also initiating people on ART, the South African government literature reviewed has shown in Chapter 2 commitment in adopting strategies that help retain those on ART. One such strategy is the introduction of the fixed-dose combination antiretroviral (FDC).

> "FDC it is proven is more effective compared to the current ARV regimen is more convenient in terms of having fewer side effects; It requires fewer laboratory tests to measure CD 4 Count; It does reduce the problem of pill burden especially for patients who present other chronic illnesses; and it can also be

easily remembered since it is only one pill" (Moodley, 2015: 1; Health 24, 2013: 1).

5.2.5 Contextualising global strategies in order to enhance maximum adherence to ART in the demarcated area of the North West Province.

This objective was to contextualise global strategies in order to enhance maximum adherence to ART in the demarcated area of the North West Province. This objective was realised in this study through the implications stated in 5.3

5.3 IMPLICATIONS

The implications for policy, theory, and practice in order to enhance maximum adherence to ART in the demarcated area of the North West Province are noted as follows:

5.3.1 Regarding policy

In order to address health care and systems-related challenges involving patients having to walk long distances when collecting their ARVs, long awaiting times at the clinics, few counselling rooms, and shortages of staff – factors which impact negatively on the quality of counselling received, a re-design of health care services offering ART in the demarcated area of study is recommended. It should address the questions of proximity, size and number of counselling rooms, cleanliness of the clinic and the friendliness of HCWs, with a regular supply of ARVs. There is also a need for ensuring that PLWHA have access to legal services.

In line with the developmental principles of social work (2.8.2.2), those of participation, empowerment and partnership, it is recommended that any policy recommended should first consider stakeholder participation which includes prospective client systems (consumers of that policy) before implementation. The aim is to correlate the desired policy with practical challenges experienced by patients on ART.

5.3.2 Regarding theory

HIV and AIDS is a specialised field; as a result there is need to bolster human resource capacity (social workers included) by investing in their training programmes which should ensure that they stay current in terms of any development around ART, HIV and AIDS and on ART initiation and its management.

5.3.3 Regarding practice

The number of a well-trained multidisciplinary team of HCWs should be increased as a way of addressing the problem of staff shortages. It should be ensured that this team fully respect, protect and promote people’s rights which include the right to equality, the right to human dignity, the right to life, the right to freedom and security and the right to not being subjected to medical or scientific experiments without their informed consent. With an expanded labour force, working hours of different dispensing sites in the demarcated area of study should be extended for those who cannot collect their medication during the current stipulated times of operation (07h00 – 16h00).

There is also a need to assess the patient’s readiness to start ART. This can entail evaluating the patient’s knowledge about the HI virus, the prevention of further infection, including treatment which involves using ARVs. Further information can be provided about HIV viral load and CD4 Count, the benefit of ART adherence including the result of non-adherence.

There is also a need to identify possible barriers to ART adherence before ART initiation, and these include

- Identifying and addressing literacy barriers.
- Assessing cultural beliefs, perceptions, and expectations about taking ART.
- Assessing structural issues such as lack of privacy at home, lack of income, unpredictable daily schedule, etc.

5.4 ASSUMPTIONS OF THE STUDY REVISITED

All the assumptions on which this study was based as provided in Chapter 1 are accepted, confirming indeed that:

Inadequate information on how the ARV drugs function is significantly related to the rate and nature of non-adherence to ART:

In this study it emerged that the patients on ART who skipped their ART doses apparently were unaware that such behaviour could lead to among others – a viral resistance to one or more antiretroviral medications, and possibly to death, as demonstrated from their non-adherence to ART behaviours.

There are relations between motivation (intrinsic and external) and adherence to ART medication:

As shown in Chapter 2 literature reviewed, Enriquez and McKinsey (2011) established that for ART adherence pertinent intrinsic factors such as: self-respect, optimism about the ARV therapy, a will to live, acceptance of the HIV condition, and an appreciation of the need for adherence were serving as internal motivating factors. External factors ought to entail: making use of reminder tools such as pill organizers, perception of a positive health care provider–patient relationship, and having social support.

The stigma associated with HIV infection significantly relates to non-adherence to ART medication:

Much as all the sampled patients had disclosed their HIV status to their families and friends, it was revealed in this study that they reported stigma and discrimination associated with HIV infection from their past intimate partners together with their intimate families. This type of discrimination clearly had a toll on their psychosocial being with possibilities of stigma and discrimination-related factors.

5.5 LIMITATIONS OF THE STUDY

I. For the in-depth interviewees and focus group discussants, questions were phrased in English, and then translated into the Setswana language for participants who could not follow in English. Answers were then written and presented finally in English. Much as every effort was put to ensuring that no information was lost, valuable information could have been lost in the process of translation.

II. Since adherence and non-adherence to ART were measured based on self-reports of missed doses, possibilities that this might have been influenced by a subjective factor cannot be ruled out.

III. Much as every effort was considered to ensure that the selection of the participants was objectively carried out, possibilities of selection bias might have occurred as only those who were on ART at the time of the study were included. Those who might have dropped out of ART altogether were not traced and as a result were excluded from this study.

5.6 STRENGTHS OF THIS STUDY

This study does bear certain strengths such as:

- **The question of inclusivity**

Both male and female qualified for inclusion in this study either as HCWs or as patients on ART. HIV and AIDS do affect both genders, equally so, service providers are from both genders. Eliciting the views of both genders in ART adherence and non-adherence was deemed inclusionary.

- **Methodological triangulation**

Data collection techniques were used in this study. Semi-structured interviews and open-ended questions were used, with scope for the participants to raise issues that the researcher had not anticipated. Also, the interviewer was able to allow the conversation to flow freely as the researcher was equally able to steer it in such a way that specific questions could be introduced. As a result, trustworthiness in the form of credibility, dependability, conformability and transferability were enhanced.

In-depth interviews were used to provide a deep understanding of what people on ART are doing and thinking, including the reasons why they adhere or not adhere to their ARV regimen. . The rationale for the use of an in-depth interview was to gain a rich, nuanced understanding of the thinking (motivation) that drives behaviour and attitude formation regarding ART. The schedule was prepared in such a way that the same questions would be posed to each person. There were no predetermined responses; instead the interviewer was free to probe and explore within some of the predetermined areas of inquiry.

With the use of the focus group, participants were asked questions about their perceptions, opinions, beliefs and attitudes towards ART. Questions were posed in an interactive group setting where participants were free to talk with other group members regarding their personal experiences. The main purpose for using this technique was to promote self-disclosure among participants. It also helped to establish what people in a group really think and feel and are experiencing in their personal lives regarding adherence or non-adherence to ART.

Key informant interviews were used to help in providing valuable knowledge that would lead to a better understanding of a setting which was providing ART services. In addition, key informants also helped to identify emerging themes in the interview process, based on their insight of the subject matter of ART.

- **Qualitative nature of the study**

The qualitative approach used generated information that was very detailed and collected from the habitat and setting of participants. Participants narrated their stories, which were presented verbatim. Paraphrased statements were used to further substantiate the information gathered. These statements were often coupled with elaborated probes to obtain a full picture of the situation.

- **Language used**

The researcher spoke the indigenous language of the participants with ease which is Setswana. Also, with HCWs the researcher was able to communicate in English – hence knowledge of these two languages ensured that valuable and rich information as presented by the participants was not lost.

5.7 RECOMMENDATIONS FOR FURTHER RESEARCH

Based on the findings of this research, the following recommendations are made for future research:

- A mixed method research approach focusing on adherence and non-adherence to ART in the North West province of South Africa would corroborate the findings and extend their robust outlook.

- An exploratory research project should be undertaken that focuses more on male ART patients – because of their apparent poor use of medical services.

- A study examining the perceptions and beliefs of the employers towards HIV positive employees would add substance to the findings of the current study.

- Strategies and services that can be used in order to enhance maximum adherence to ART ought to be more extensively investigated.

- How barriers to ART can be addressed is a rich area for further research that could strengthen the preliminary findings of this current study.

5.8 CONCLUSION

This study was set out to examine non-adherence to ART in the Maquassi Hills, in the North West province. A variety of literature was reviewed which pointed to numerous barriers to ART. These barriers were then contextualised within the demarcated area of study and as experienced by sampled participants. The theoretical frameworks underpinning this study which are the HBM and the strength-based perspective provided clear guidelines that could be used to understand the resilience and inherent capabilities of the selected participants on ART. It is hoped that through these findings, ART adherence in the demarcated area of study can be enhanced – thus contributing to the health of individuals, families, communities, and ultimately of the nation.

REFERENCES

Abdissa, A.E. 2013. Determinant factors affecting adherence to antiretroviral therapy among HIV infected patients in Addis Ababa. Unpublished Master's Dissertation: University of South Africa.

Acton, Q.E. 2013. *Virus diseases: New insights for the health care professional*. Scholarly editions: Atlanta. Georgia

Alias, N.A. 2012. *Instructional technology research, design and development: Lessons from the field*. Hershey: IGI Global publishers.

Ambrosino, R; Heffernan, J & Shuttlesworth, G. 2008. *Social work and social welfare: An Introduction*. 6th ed. New York: Thomson Brooks/Cole.

Ayalu, A & Sibhatu, B. 2012. Determinants of adherence to antiretroviral therapy among HIV-infected patients in Africa. *AIDS Research and Treatment, 2012: 1-8.*

Babbie, E. 2007. *The practice of social research*. 11th ed. Belmont: Thomson Wadsworth.

Barber, S., Ntilivamundla, S., Babatunde, S. & Khan, T. 2015. Adherence and antiretroviral therapies (ART). WHO – South Africa: Unpublished.

Barbra, T. 2014. *An introduction to applying social work theories and methods*. England: McGraw-Hill.

Bless C., Higson-Smith, C. & Kagee, A. 2006. Fundamentals of social research methods: An African perspective 4th ed. Cape Town: Juta & Co. Ltd.

Bloor, M. & Wood, F. 2006. *Keywords in qualitative methods: A vocabulary of research concepts*. London: SAGE.

Braun, V & Clarke, V. 2013. *Successful Qualitative research: A practical guide for beginners*. London: SAGE.

Brikci, N & Green, J. 2007. A guide to using qualitative research methodology. London: Medecins Sans Frontieres

Canadian Association for Social Work Education (CASWE), 2013. http://www.caswe-acfts.ca/en/. Date of access: 03 March 2014.

Centre for Disease Control and Prevention. 2005. National vital statistic report, Department of Health and Human: Unpublished.

Clark-Carter, D. 2004. *Quantitative psychological research: A student's handbook*. East Sussex: Psychology Press.

Dagnew, Y.W. 2009. Factors influencing anti-retroviral therapy adherence in Ethiopia. Master's dissertation: University of South Africa.

Daniel, P.S. & Sam, A.G. 2011. *Research methodology*. Delhi: Kalpaz

D' Cruz, H. & Jones, M. 2014. *Social work research in practice: Ethical and political contexts*. London: SAGE.

Denzin, N.K, & Lincoln, Y.S. 2000. *Strategies of inquiry: Handbook of qualitative research.* California: Thousand Oaks.

De Vos, A.S, Strydom, H., Fouché, C.B., & Delport, C.S.L., 2011. *Research at grass roots for the social sciences and human service professions*. 4TH ed. Pretoria: Van Schaik publishers.

De Vos, A.S & Fouché, C.B. 2001. *General introduction to research design, data collection methods and data analysis, in research at grass roots: A primer for the caring professional*. Pretoria: Van Schaik publishers.

De Vos, A.S. 2009. Qualitative data analysis and interpretation (In De Vos, A.S, (ed.)., Strydom, H., Fouché, C.B & Delport, C.S.L. *Research at grass roots for the social sciences and human science professions*. Pretoria: Van Schaik).

Diggs-Brown, B. 2011. *Cengage advantage book: Strategic public relation. An audience focus approach*. Wadsworth: Cengage Learning.

DuBois, B. & Miley, K. 2010. *Social work: An empowering profession*. 6th ed. Boston: Pearson.

Duke, N.K. & Mallette, M.H. 2011. *Literacy research methodologies*. New York: The Guilford press.

Dzinza, T. 2007. Perceptions and beliefs of physicians about adherence to anti-retroviral treatment by patients in the South-East district of Botswana. Unpublished Master's dissertation. University of South Africa.

Enriquez, M. & Mckinsey, D.S. 2011. *HIV/AIDS – Research and palliative care*, 3: 45-51.

Fain, J.A. 2009. *Reading, understanding and applying nursing research*. 3rd ed. Philadelphia: F.A. Davis Company.

Galletta, A. & Cross, W.E. 2013. *Mastering the semi-structured interview and beyond: From research design to analysis and publication*. New York: NYU Press.

Global AIDS Update, 2015. Geneva: UNAIDS

Goudge, J. & Ngoma, B. 2011. Exploring antiretroviral treatment adherence in an urban setting in South Africa. *Journal of Public Health Policy*, 32: S53-S64.

.

Gravetter, F.J. & Forzano, L.B. 2003. *Research methods for the behavioural sciences.* Belmont: Wadsworth/Thomson Learning.

Guidelines for the use of antiretroviral agents in HIV-1 infected adults and adolescents. 2014. http://aidsinfo.nih.gov/guidelines. Date of access 28 April 2016

Gupta, G. 2000. Gender, sexuality, and HIV/AIDS: The what, the why and the how. Plenary address XIII International AIDS conference, held in Durban, South Africa, on the 12 July 2000.

Haacker, M & Claeson, M. 2009. HIV and AIDS in South Asia: An Economic development risk. Washington DC: The World Bank

Habib, M.D., Pathik, B.B., Maryam, H. 2014. *Research methodology: Contemporary practices: Guidelines for academic researchers*. Cambridge: Cambridge scholars publishing.

Hansana, V., Sanchaisuriya, P., Durham, J., Sychareun, V., Chaleunvong, K., Boonyaleepun, S & Schelp, F.P. 2013. Adherence to antiretroviral therapy (ART) among people living with HIV (PLHIV): a cross-sectional survey to measure in Lao PDR. *BMC Public Health*13: 617. http://www.biomedcentral.com/1471-2458/13/617. Date of access: 21 October 2016

Hardon, D; Hodgin, C. & Fresle, D. 2004. How to investigate the use of medicines by consumers. Switzerland: World Health Organization

Health 24. 2013. HIV/AIDS. http://www.healt24.com. Date of access 25 August 2016

Henning, E., Van Rensburg, W & Smit, B. 2004. *Finding your way in qualitative research.* Pretoria: Van Schaik

Hewitt –Taylor, J. 2011. *Using research in practice: It sound good, but will it work*? Palgrave: Macmillan.

Hiko, D., Jemal, A., Sadhakar, M., Kleric, M.W. & Degene, T. 2012. Determinants of non-compliance to antiretroviral therapy among adults living with HIV/AIDS: A systematic review. Department of Epidemiology, College of Public Health and Medical Science. Jimma University. Unpublished dissertation.

HIV/AIDS in South Africa. 2010. Pretoria: Department of Health.

Hlophe, H.I. 2010. The role of treatment buddies in the public sector antiretroviral programme. Unpublished Doctoral Thesis. University of Free State.

Holloway, I. & Wheeler, S. 2013. *Qualitative research in nursing and health care*. West Sussex: John Wiley and Sons.

Igwegbe, A.O., Ugboaja, J.O & Nwajiaka, L.A. 2010.Prevalence and determinants of non-adherence to antiretroviral therapy among HIV-positive pregnant women in Nnewi, Nigeria. *International Journal of Medicine and Medical Sciences,* 2(8): 238-245

Integrated Service Delivery Model (ISDM). 2005. Department of Social Development (Republic of South Africa): Pretoria: Department of Social Development.

International Federation of Social Workers (IFSW). 2014. Global definition of Social Work. http://ifsw.org/get-involved/global-definition-of-social-work. Date of access: 10 March 2015.

Jean-Bapitiste.2008. Factors associated with adherence to antiretroviral therapy in Rwanda: A multi-site study. United States Agency for International Development: USAID

Johnson, L.F. 2012. Access to antiretroviral treatment in South Africa, 2004-2011.*The Southern African Journal of HIV Medicine.* 13(1) Online.

.**Kagee, A**. 2008. Adherence to antiretroviral therapy in the context of the national roll-out in South Africa: Defining a research agenda for psychology. *South African Journal of Psychology*, 38(2): 413-428.

Kagee, A., Remien, R.H., Berkman, A., Hoffman, S., Campos, L. & Swartz, L. 2011. Structural barriers to ART adherence in Southern Africa: Challenges and potential ways forward. *Global Public Health,* 6 (1): 83-97. doi: 10.1080/17441691003796387.

Kaguiri, E. 2014. Role of social support on adherence to antiretroviral therapy among patients attending ampath clinic at Moi teaching and referral hospital, Eldoret, Kenya. Unpublished Master's dissertation: Moi University.

Keen, A. 2013. Saturation in qualitative research. https://www2.rch.org.uk/_data/assets/pdf. Date of access: 14 July 2016

Kruger, R.A. & Casey, M.A. 2007. *Focus Groups: A practical guide for applied research*. 4th ed. California: Sage. INC.

Kumar, C R. 2008. *Research methodology*. New Delhi: APH Publishing Corporation

Lahey, A. 2001. *An introduction to psychology*. New York: MacMillan.

Leedy.P.D. & Ormond, J.E.2005. *Practical research: Planning and design*. New York: Pearson Merrill Prentice.

Lincolin, Y.S & Guba, E.G. 2005. *Naturalistic inquiry*. Newbury: Sage

Maree, K.2007. *First steps in research*. Pretoria: Van Schaik. .

Maree, K. & van der Westhuizen, C. 2007. Planning a research proposal. (*In* Maree, K. ed. *First Steps in Research.* Pretoria: Van Schaik).

Masokoane, K.Q. 2009. Adherence and non-adherence to antiretroviral treatment in HIV positive people in Port Elizabeth. Unpublished Masters Dissertation. Nelson Mandela Metropolitan University..

Mbali, M. 2004. Aids discourse and the South African State: Government denialism and post- apartheid AIDS policy making in transformation. South Africa: Unpublished.

Menamo, E.D. 2014. Impact of household food insecurity on adherence to antiretroviral therapy (ART) among urban PLHIV: The case of Hawassa City, SNNNPR state, Ethiopia. Anchor Academic.

Miles, M.B. & Hubberman, A.M. 1984. *Qualitative data analysis: A sourcebook of new methods.* 2nd ed. Washington DC: SAGE.

Mishra, R.C. 2005. *Educational research and development.* New Delhi: APH Publishing.

Moodley, R. 2015. OneARV pill a day. South African Government News Agency. http://www.sanews.gov.za.Date of access 25 August 2016

National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa. 2011. Pretoria: Department of Health,

National Antenatal Sentinel HIV &Syphilis Prevalence Survey in South Africa. 2008. Pretoria: Department of Health.

National Department of Health South Africa, 2015. National consolidated guidelines: For the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. Pretoria: Department of Health

Noble, M., Ratcliffe, A & Wright, G. 2004. *Conceptualizing, defining and measuring poverty in South Africa – An argument for a consensual approach*. England: CASASP

Novikov, A.M. & Novikov, D.A. 2013. *Research methodology: From philosophy of science to research design.* New York: CRC press.

Nsiba, S., Irunde, H & Comoro, C. 2010. Barriers to ARV adherence among HIV/AIDS positive persons taking anti-retroviral therapy in two Tanzanian regions 8-12 months after program initiation. *Journal of AIDS Clinic Research,* 1/111 doi: 10.4172/2155-6113.

Nziyane, L.F. 2010. Practice guidelines for the integration of child-headed households into extended families. Unpublished Doctoral thesis. University of South Africa.

Orrell, C., Bangsberg, D., Badri, M.R., Wood, R. 2003. Adherence is not a barrier to successful antiretroviral therapy in South Africa. *AIDS* 17: 1369-1375.

Padgett, D.K. 2008. *Qualitative methods in social work research*. Italy: Sage Publication, INC.

Patton, M.Q. 2002. *Qualitative research and evaluation methods*. 3rd ed. California: Thousand Oaks.

Pitney, W.A. 2004. Strategies for establishing trustworthiness in qualitative research. *Readers Digest Athletic Therapy Today* 9(1): 26-28.

Poggenpoel, M. 1998. Data analysis in qualitative research. (In De Vos, A.S. (ed). Strydom, H., Fouché, C.B., Poggenpoel, M. & Schurink, E.M. Research at Grass Roots a premier for the caring professions. Pretoria: Van Schaik. 493 p).

Pointdexter, C.C. 2010. *Handbook of HIV and Social work: Principles, practice, and populations*. New Jersey: John Wiley and Sons.

Polit, D.F. & Beck, C.T. 2010. *Essentials of nursing research: Appraising evidence for nursing practice*. Philadelphia: Lippincott Williams and Wilkins.

Potter, W.J. 2013. *An analysis of thinking and research about qualitative methods.* New Jersey: Erlbaum Associates

Republic of South Africa. 1996. Constitution of the Republic of South Africa. Act 108 of 1996 Pretoria: Government Printers.

Riazi, A.M. 2016. *The Routledge encyclopaedia of research methods in applied linguistics*. Australia: Routledge.

Ritchie, J. & Lewis, J., Nicholls, C.M. & Ormston, R. 2013. *Qualitative research practice: A guide for social science students and researchers*. 2nd ed. California: SAGE.

Roller, M.R. & Lavrakas, P.J. 2015. *Applied Qualitative research design: A total quality framework approach.* New York: The Guilford Press

Roura M., Busza, J., Wringe, A., Mbata, D., Urassa, M & Zaba, B. 2009. Barriers to sustaining antiretroviral treatment in Kisesa, Tanzania. *AIDS Patient Care STDs*, 23(3): 203-210.

Sanjoba, N., Frich, J.C. & Fretheim, M.D. 2012. Barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia: A qualitative study. *Journal of Social Aspects of HIV/AIDS*, 5(3): 136-143.

Schultz, C. 2014. Social work practice in HIV/AIDS. Social work practice in HIV/AIDS: Canadian Association of Social Workers. . http://www.casw-acts.ca/en/social-work-practice-hivaids.Date of access: 21 February 2014.

Schonneson, L.N., Diamong, P.M., Ross, M.W., Williams, M & Bratt, G. 2006. Baseline predictors of three types of antiretroviral therapy (ART) adherence: 2-years follow-up. *AIDS Care,* 18 (4): 407-414

Schurink, E. M.2002. Participant Observation. (In De Vos, AS, (ed). Strydom, H., Fouché, C.B., Poggenpoel, M. & Schurink, E. M. *Research at Grassroots a premier for the caring professions*. Pretoria: Van Schaik Publishers.

Seema-Rani.2013. The psycho-social aspects of non-adherence in ART therapy in HIV/AIDS and social work intervention: A case study in Delhi. *Bonfring International Journal of Industrial Engineering and Management.*3 (2): 70-73.

Semakula, D. 2010. Delay to access antiretroviral therapy in people living with HIV/AIDS in Potchefstroom. Unpublished Master's Dissertation. University of Witwatersrand.

Sharan, M.B. 2009. *Qualitative research: A guide to design and implementation*. San Francisco: John Wiley and Sons.

Shigdel, R. 2012. Factors associated with adherence to antiretroviral therapy in HIV-infected patients: A cross-sectional study in Kathmandu district, Nepal. Unpublished Master's Dissertation. University of Tromsø.

Silverman, D. 2000. *Doing qualitative research: A practical handbook*. London: SAGE.

Skhosana, N; Struthers, H; Gray, G.E & McIntyre, J. 2006. HIV disclosure and other factors that impact on adherence to antiretroviral therapy: The case of Soweto, South Africa. *African Journal of AIDS Research,* 5(1): 17-26.

Spiegelberg, E. 2012. Doing phenomenology: Essays on and in phenomenology. Springer: Science and Business media.

Squire, C. 2007. HIV/AIDS in South Africa. http://eprints.lse.ac.uk/24960/.Date of access: 21 March 2016.

Statistics South Africa. 2015. National and provincial labour market: Youth. Pretoria: Statistics South Africa.

Statistics South Africa. 2013**.** Census 2013. Pretoria: Statistics South Africa.

Statistics South Africa. 2011**.** Census 2011. Pretoria: Statistics South Africa.

Steel, G., Nwokike, J & Josh, M.P. 2007. Development of a multi-method tool to measure ART adherence in resource-constrained settings: The South African experience. Arlington: RPM Plus.

Strydom, H. 2011. Ethical aspects of research in the caring professions. *(In* De Vos, A.S, (ed). Strydom, H., Fouché, C.B., Poggenpoel, M. &Schurink, E.M. Research at Grass Roots a premier for the caring Professions. Pretoria: Van Schaik.

The Local Government Handbook. 2014. http://www.localgovernment.co.za/locals/view/192/maquassi-hills-local-municipality Date of access 19 June 2013.

Training Guide on Adherence to Antiretroviral Therapy in Adults.2004. Horizon/Population Council, International Centre for Reproductive Health and Coast Province Hospital. Mombasa – Kenya: Population Council.

Turmen, T. 2003. Gender and HIV and AIDS: International Federation of Gynaecology and Obstetrics. Switzerland*:* Elsevier Science Ireland Publishers.

Turner, L.W., Hunt, S.B, DiBrezzo.R. & Jones.C.2004. Design and implementation of an Osteoporosis prevention program using Health belief model: *American Journal of Health studies*, 19(2): 115-121.

UNAIDS. 2015. Access to antiretroviral therapy in Africa: Status report on progress towards the 2015 targets. Switzerland: UNAIDS.

UNAIDS FACT SHEET. 2016. http://www.unaids.org/sites/default/files/media_... Date of access: 25 July 2016.

UNAIDS report on the global AIDS epidemic. 2013. UNAIDS: Geneva

Van Dyk, A.C. 2011. Treatment adherence following national antiretroviral rollout in South Africa. *African Journal of Aids Research,* 9(3): 235-247.

Van Dyk, A. 2004. *HIV/AIDS care and counselling: A multidisciplinary approach*. 2nd ed. Cape Town: Pearson Education

Vawda, Y.A & Variawa, F. 2013. Challenges confronting health care workers in government's ARV rollout: Rights and responsibilities. *P.E.R/PELJ,* 15(2): 487-569.

Vermeulen, J.H. 2011. Identifying structural barriers to antiretroviral therapy adherence. Unpublished Master's Dissertation. Stellenbosch University.

Volberding, P., Sande, M., Lange, J., Greene, W & Gallant, J. ed. 2007. *Global HIV/AIDS medicine.* New York: Elsevier.

WHO. 2003. Adherence to long-term therapies: Evidence for action. Geneva: WHO.

WHO. 2015. Global update on the health sector response to HIV, 2015. Geneva: WHO

WHO Guidelines. 2013. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Geneva: WHO.

WHO. 2013. World health report 2013: Research for universal health coverage.

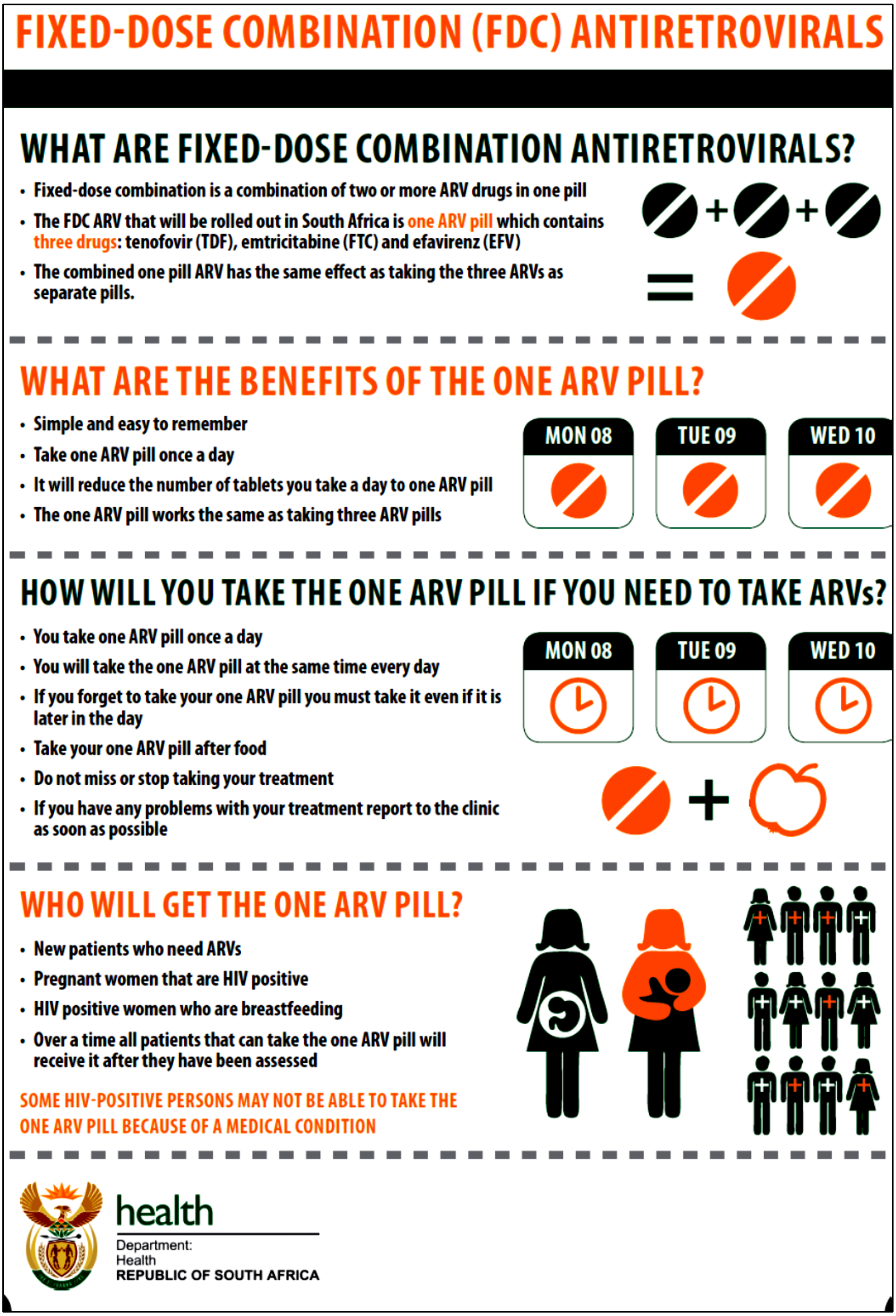
Wiseman, A.W & Glover, R.N. 2012. *The impact of HIV/AIDS on education worldwide*. England: Emerald publishers

Zastrow, C. 2009. *Introduction to social work and social welfare: Empowering people*.11th ed. Belmont: Brooks/Coles Publishers.

Zastrow, C.H., and Kirst-Ashman, K.K. 2006. *Understanding human behaviour and the social environment* Australia: Brooks/Cole.

ANNEXURES

ANNEXURE 1: FIXED-DOSE COMBINATION ANTIRETROVIRALS POSTER



FIXED-DOSE COMBINATION (FDC) ANTIRETROVIRALS

WHAT ARE FIXED-DOSE COMBINATION ANTIRETROVIRALS?

- Fixed-dose combination is a combination of two or more ARV drugs in one pill
- The FDC ARV that will be rolled out in South Africa is one ARV pill which contains three drugs: tenofovir (TDF), emtricitabine (FTC) and efavirenz (EFV)
- The combined one pill ARV has the same effect as taking the three ARVs as separate pills.

WHAT ARE THE BENEFITS OF THE ONE ARV PILL?

- Simple and easy to remember
- Take one ARV pill once a day
- It will reduce the number of tablets you take a day to one ARV pill
- The one ARV pill works the same as taking three ARV pills

HOW WILL YOU TAKE THE ONE ARV PILL IF YOU NEED TO TAKE ARVs?

- You take one ARV pill once a day
- You will take the one ARV pill at the same time every day
- If you forget to take your one ARV pill you must take it even if it is later in the day
- Take your one ARV pill after food
- Do not miss or stop taking your treatment
- If you have any problems with your treatment report to the clinic as soon as possible

WHO WILL GET THE ONE ARV PILL?

- New patients who need ARVs
- Pregnant women that are HIV positive
- HIV positive women who are breastfeeding
- Over a time all patients that can take the one ARV pill will receive it after they have been assessed

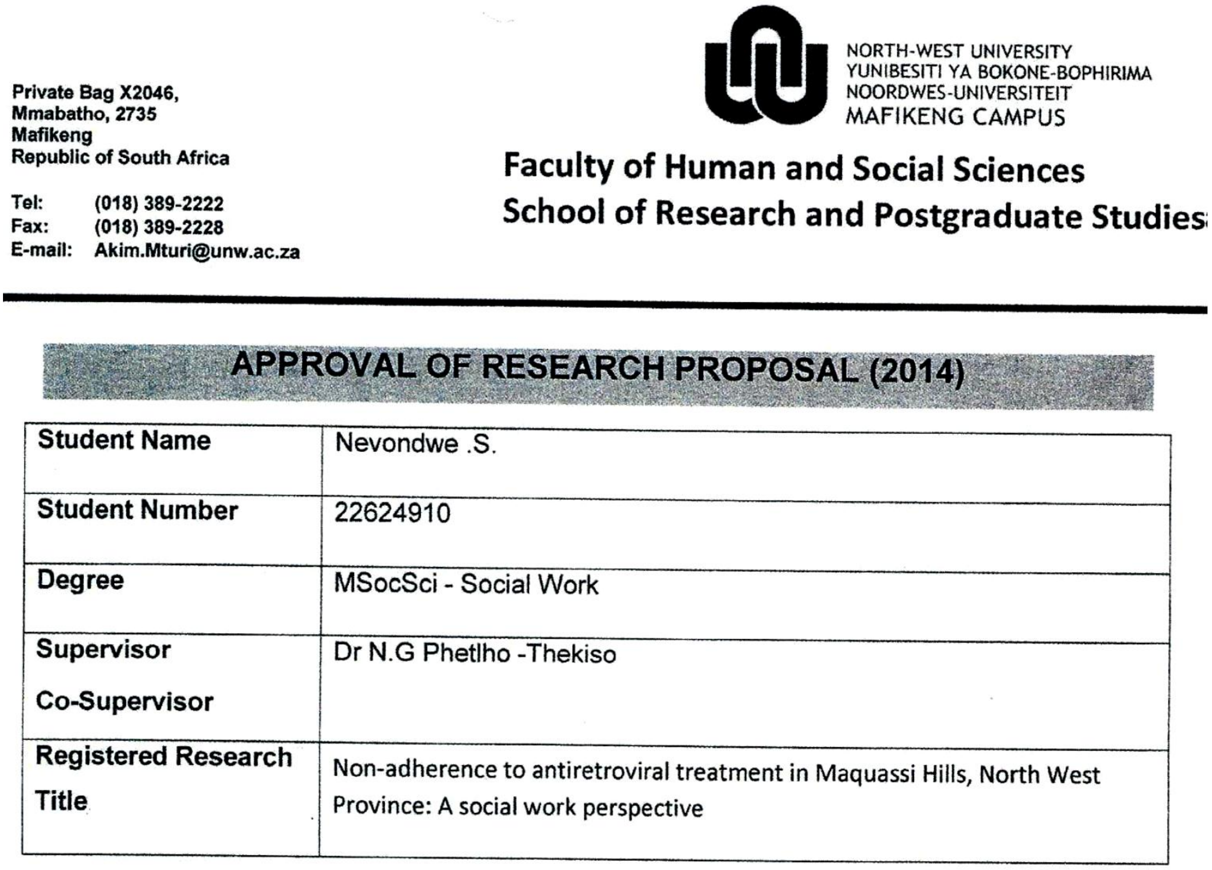
SOME HIV-POSITIVE PERSONS MAY NOT BE ABLE TO TAKE THE ONE ARV PILL BECAUSE OF A MEDICAL CONDITION

health
Department:
Health
REPUBLIC OF SOUTH AFRICA

Source: South African National Department of Health (2013)

ANNEXURE 2

NWU APPROVAL OF THE RESEARCH PROPOSAL



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APPROVAL OF RESEARCH PROPOSAL (2014)

Student Name	Nevondwe .S.
Student Number	22624910
Degree	MSocSci - Social Work
Supervisor **Co-Supervisor**	Dr N.G Phetlho -Thekiso
Registered Research Title	Non-adherence to antiretroviral treatment in Maquassi Hills, North West Province: A social work perspective

ANNEXURE 3

INTERVIEW SCHEDULE FOR IN-DEPTH INTERVIEWS IN ENGLISH

3.1 BIOGRAPHICAL DATA OF PARTICIPANTS

- **Gender**

Female	
Male	

- **Age (**Please state your age category)

18-25	26-35	36-45	46 +

- **Marital Status** (What is your present marital status?)

Single	Married	Divorced	Widowed	Other

- **Highest level of education** (What is the level of formal education that you have attained?

No Schooling	Primary education	High School education	Tertiary education

- **Employment Status** (Please tell us about your employment/unemployment status?)

Unemployed	Informally employed	Formally employed	Other specify

- **Main source of income (**Please tell us about your main source of income

Social grant/s	Own income/salary	Combined income/salary	Other specify

- **Combined monthly income (**What you say is your approximate combined monthly income?)

0-900	1000-2500	2600-3500	3600 and above

3.2 BRIEF HISTORY ON ART AND COLLECTION OF MEDICATION MODE

- **Duration on ART (**For how many years have you been on ART?)

Two years	Three years	Four years	Five years +

- **Where do you collect your HIV medication?**

Clinic	Hospital

What means of transport do you use to collect your ARVs?

.Walk	Cycle	Taxi	Other (Specify)

- **State the distance you travel when having to collect your HIV medication?**

0-10 km	11-20 km	21-30 km	31-40 km	41-50 km	51 and above

3.3 OPINION QUESTIONS

Please briefly explain:

- How your medication is supposed to be taken?
- What you will you do if you miss a schedule dose of your ARVs?
- What the possible side effects of your HIV medication are?
- Whether you are concerned about being seen by others when you collect your ARVs?
- What type of support you do receive from your Health care provider?
- What type of support do you receive from your significant others?
- Whether you adhere maximally to the ARV regimen?

ANNEXURE 4

INTERVIEW SCHEDULE FOR IN-DEPTH INTERVIEWS IN THE SETSWANA LANGUAGE (LENANEO POTSOLOTSO LA MOTHO KA MONGWE LE LE TSENELETSENG KA SETSWANA)

4.1 LENANEO KITSISO LA BA TSAYA KAROLO

- **Bong**

Mme	
Ntate	

- **Dingwaga (**O wela mo dingwageng difeng)

18-25	26-35	36-45	46 +

- **Seemo sa lenyalo** (O eme kae mo nyalong)

Mongwe	Nyalane	Tlhalane	Moswela	Dingwe

- **Dithuto tse o feletseng mo go tsona**

Ga wa tsena sekolo	Thuto e e kwatlase	Thuto e e kwa godimo	Thuto e e kwa pele

- **Maemo a tiro** (Rebolele ka maemo a gago a go dira/ le a go sa dire)

Botlhoka tiro	Tiro ya nakwana	Tiro ya popota	Tiro engwe (Tlhalosa)

- **Letseno (**Rebolele ka letseno la gago)

Madi a disusa	Letseno la gago	Letseno le letlhakanetsweng	Letseno le lengwe (Tlhalosa)

- **Letseno le le tlhakaneng la kgwedi**

0-R900.00	R1000.00 -R2 500	R2 600-R3500	R3 600+

4.2 KA BORIPANA TIKOLOGO YA GOTSAYA KALAFI YA KOKWANA TLHOKO

- **Ona le ngwaga tse kae onwa dipilisi tsa kokwana tlhoko ?**

Ngwaga tse pedi	Ngwaga tse tharo	Ngwaga tse nne	Ngwaga tse tlhano le go feta

- **amogela kalafi ya gago ya kokwanatlhoko ko kae?**

Tliliniki	Bookelong

O dirisa sepalangwe se feng go ya go tsaya kalafi ya gago ya kokwanatlhoko?

.Tsamaya	Baesekele	Tekesi	Dipalangwa tse dingwe (Tlhalosa)

- **Tlhalosa gore o tsamaya sekgala se se kae go ya go tsaya kalafi ya gago ya kokwanatlhoko?**

0-10 km	11-20 km	21-30 km	31-40 km	41-50 km	51km+

4.3 TSHWAELO YA DIPOTSO

- A o a itse gore o tshwanetse go tsaya kalafi ya gago jang?

- O tlile go dira jang ga o lebetse gonwa kalafi ya gago ya kokwanatlhoko?

- Ke matshwao a feng a a sa itumediseng, o a itemogetseng fao dirisa kalafi ya gago ya kokwanatlhoko?

- A o a tshwenyega go bonwa ke batho ba bangwe ga o ya go tsaya kalafi ya gago ya kokwana tlhoko?

- Ke mofuta o feng wa tshegetso e batlhokomedi ba pholo ba go fang yona?

- Ke mofuta o feng wa tshegetso eo e bonang gotswa bathong ba botlhokwa mo go wena?
- A o nwa (tsaya) jaaka go tshwanetse kalafi ya gago ya kokwanatlhoko sentle?

ANNEXURE 5

INTERVIEW SCHEDULE FOR THE FOCUS GROUP IN RELATION TO USING ARVs IN ENGLISH

- What are your medication related challenges (taste, size of the pills, dietary restrictions?

- What are your socio-economic challenges (poverty, unemployment, lack of transport etc.)?

- What is your stigma and discrimination related challenges (fear of disclosing status to partner or family)?

- What are your health-care and Systems-related challenges (distance of setting, health care provider-patient relationship, waiting time, availability of counseling services, privacy at ART clinic, follow-up services)?

- How do you overcome all these challenges?

- How can adherence to ART be facilitated

ANNEXURE 6

INTERVIEW SCHEDULE FOR THE FOCUS GROUP IN RELATION TO USING ARVs IN SETSWANA (LENANEO POTSOLOSO LA SETLHOPHA SA BATHO LE LE MABAPI LE TIRISO YA KALAFI YA KOKWANA TLHOKO KA SETSWANA)

- Ke dikgwetlho di feng tse o kopang le tsona mabapi le kalafi gago (Dikai-tatso, bogolo jwa pilisi, lenaneo la dijo tse o tshwanetseng go dija mme a sena tsone)?

- Ke dikgwetlho di feng tse o itemogelang tsona mabapi le moruo (Bofutsana, botlhokatiro, go tlhoka sepalamo)?

- Ke dikgwetlho di feng tse o itemogelang tsona tsa go tewa maina le kgethololo (tshabo ya go itsise molekane wa gago, kgotsa leloko la lelapa)?

- Ke dikgwetlho difeng tse di go golaganang le tirelo tsa pholo (Bokgakala, Kamano le badiri ba tsa pholo, nako ya kalafi ditirelo tsa go thoba maikutlho, sephiri, ditirelo tsa tatelo,)?

- O feta jang mo dikgwetlho tse?

- Tiriso e siameng ya kalafi ya kokwana tlhoko e ka netefadiwa jang?

ANNEXURE 7

INTERVIEW SCHEDULE FOR KEY INFORMANTS

7.1 Identifying data

- Gender
- Please provide your years of experience in offering your professional services in ART
- Please state the nature of setting you are working from
- Are you working in ART as part of a team or all by yourself?
- What is your area of function in ART?

7.2 MEDICAL AND PSYCHO-SOCIAL QUESTIONS

- What services do you offer to prepare patients medically and psycho-socially for ART?

- How do you as a service provider ensure that patients as part of their enrolment into ART have treatment supporters?

- In your services delivery how is adherence to ART facilitated?

- Is there a way of monitoring those on ART who are maximally adhering to the ARV regimen and those who are none adherents to the ARV regimen?

- What follow-up services do you offer for the non-adherents to ART?

ANNEXURE 8

CONSENT FORM FOR PARTICIPATION IN THE RESEARCH STUDY IN ENGLISH

I volunteer to participate in this research study conducted by Mr.Sheldon Nevondwe from the North-West University, Mafikeng Campus. I understand that the study aims at examining: **NON-ADHERENCE TO ANTIRETROVIRAL TREATMENT IN MAQUASSI HILLS, NORTH WEST PROVINCE: A SOCIAL WORK PERSPECTIVE**

I hereby agree to the following conditions:

- That my participation in this study is voluntary.
- I understand that I will not be paid for my participation.
- I may withdraw participation at any time without penalty.
- I understand that if during the interview session I feel uncomfortable in any way, I have the right to decline to answer any question or to end the discussion.
- That the interview will last approximately 55 minutes.
- Notes will be written during the interview. In all instances a tape recorder will be used. If I don't want to be taped, I will not be able to participate in this study.
- I fully understand that the researcher will not identify me by name, and that my confidentiality as a participant in this study will remain anonymous.
- I fully understand the explanations provided to me, and have had all my questions answered to my satisfaction

- I voluntarily agree to participate in this study.

....	....
My Signature/Thumbprint	Date
....	....
Signature of the Researcher	Date

ANNEXURE 9

CONSENT FOR PARTICIPATION IN THE RESEARCH STUDY IN SETSWANA (LOKWALO LA TUMALATSANO YA GO BA KAROLO YA DIPATLISISO)

Ke ithaopa go tsaya karolo mo dipatlisisong tse di dirwang ke rre Sheldon Nevondwe, moithuti gotswa Univesithi ya Bokone- Bophirima, kampase ya Mafikeng.

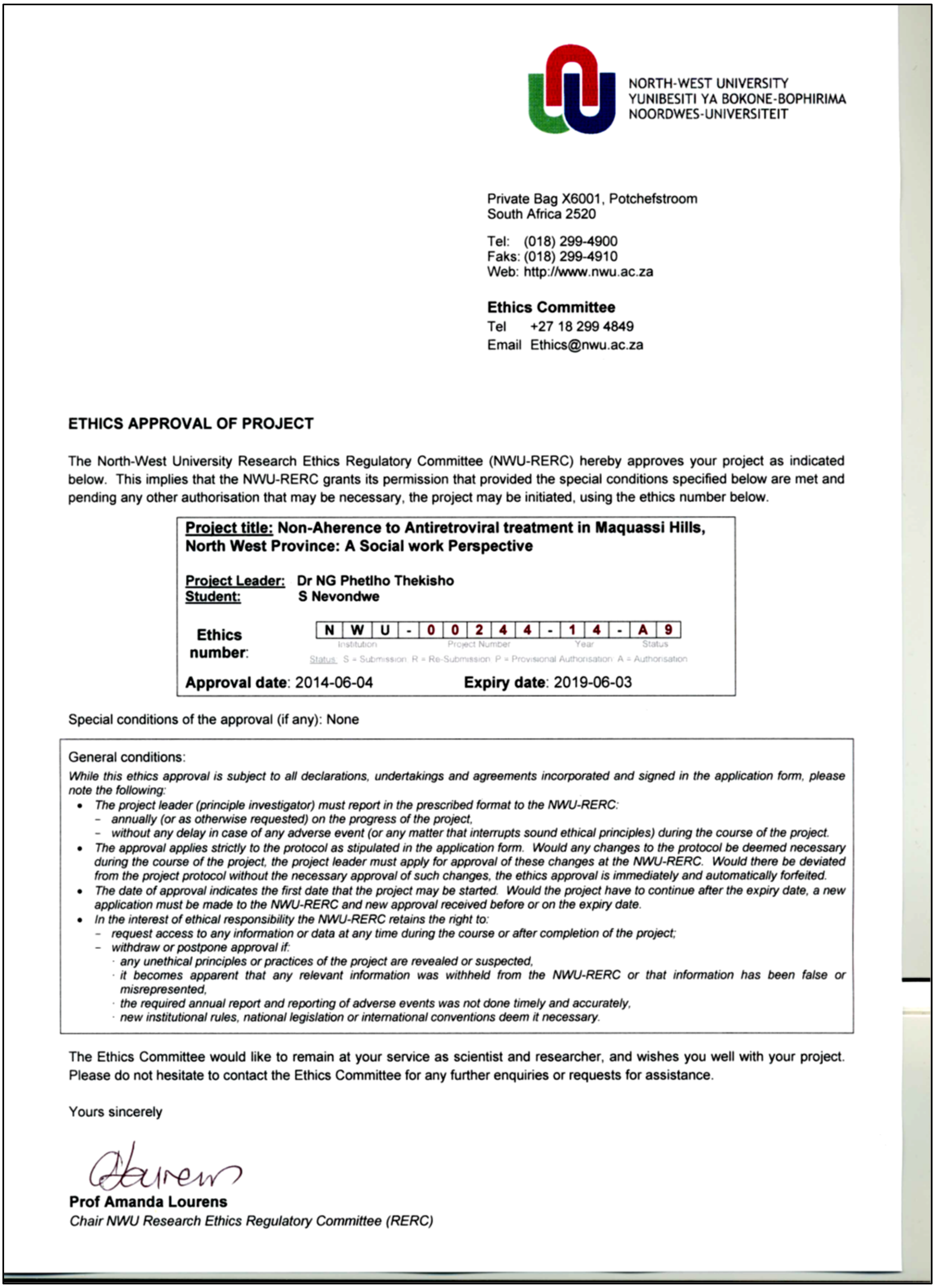
- Ke tlhaloganya gore ga gona tuelo mo go tseyeng karolo ga ka.
- Nka I kgogela morago ka nako nngwe le nngwe ntle le kotlhao.
- Ke tlhaloganya gore ke kgona go ka i kgogela morago ga ke i kutlwa ke sa phuthologa kgotsa ke sa nnisega go ka tswelela le dipotso tsa dipatlisiso.
- Dipuisano tsa rona di tla tsaya metsotso e le some a matlhanotlhano fela. Dintlha di tla gatisiwa, fa ke sa batle go gatisiwa, ke tla i kgogela morago mo dipatlisisong.
- Ke tlhaloganya sentle gore leina la ka le ka se umakiwe le gore go tsaya karolo ga me mo dipatlisisong tse ke sephiri
- Ke tlhaloganya sentle se ke se tlhaloseditsweng le dipotso tsotlhe tse ke neng ke na le tsona di arabilwe ke kgotsofetse.

- Ke dumela go ka tsaya karolo mo dipatlisisong.

Tshaeno/Kgatisamonwana (Motsayakarolo): Letlha
....

Tshaeno (Mmatlisisi) Letlha
……………………………………… ....

ANNEXURE 10: NWU ETHICS APPROVAL OF THE RESEARCH STUDY



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Ethics Committee
Tel +27 18 299 4849
Email Ethics@nwu.ac.za

ETHICS APPROVAL OF PROJECT

The North-West University Research Ethics Regulatory Committee (NWU-RERC) hereby approves your project as indicated below. This implies that the NWU-RERC grants its permission that provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: Non-Aherence to Antiretroviral treatment in Maquassi Hills, North West Province: A Social work Perspective

Project Leader: **Dr NG Phetlho Thekisho**
Student: **S Nevondwe**

Ethics number:

N	W	U	-	0	0	2	4	4	-	1	4	-	A	9
Institution				Project Number						Year			Status	

Status: S = Submission R = Re-Submission P = Provisional Authorisation A = Authorisation

Approval date: 2014-06-04 **Expiry date**: 2019-06-03

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

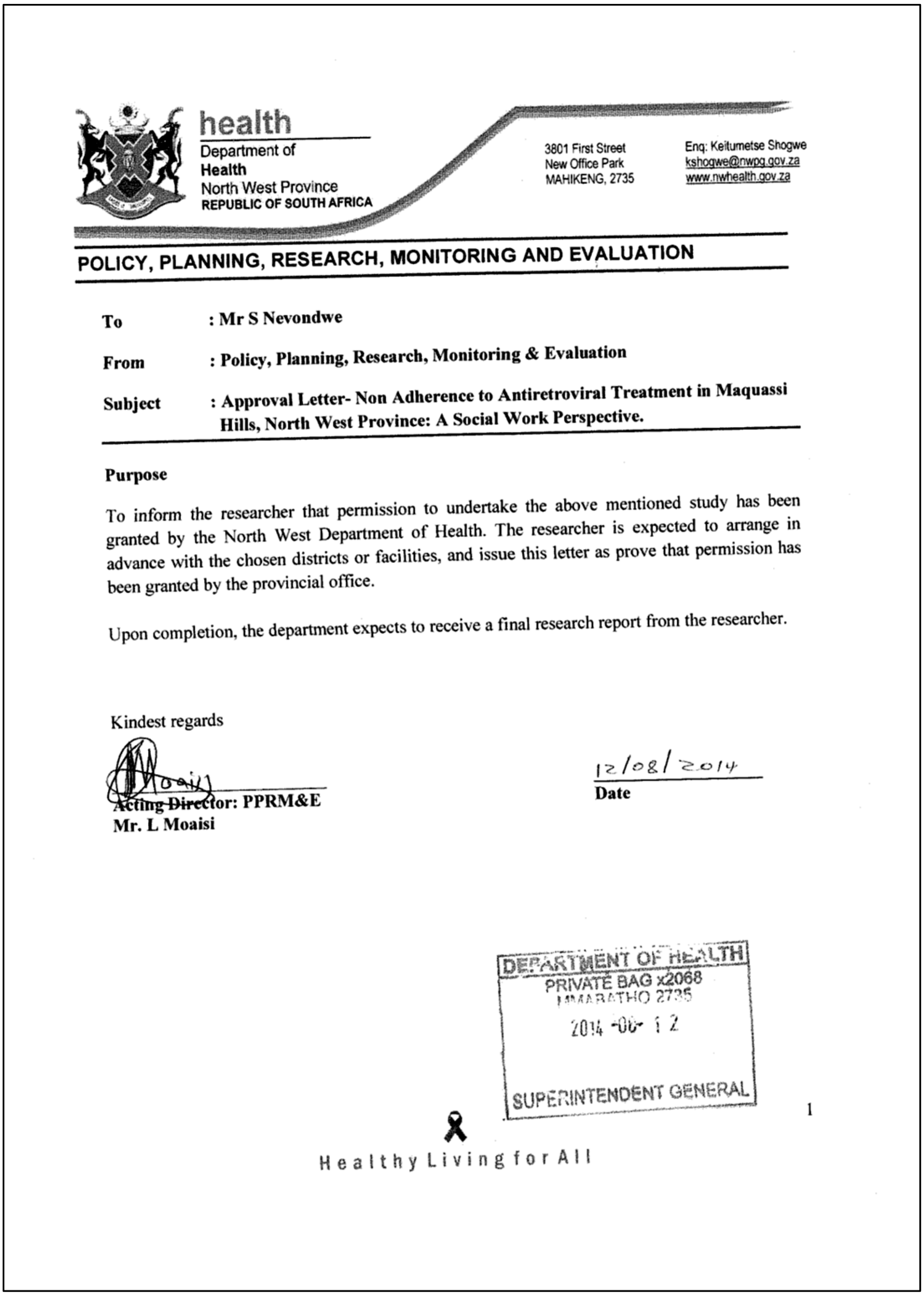
- *The project leader (principle investigator) must report in the prescribed format to the NWU-RERC:*
  - *annually (or as otherwise requested) on the progress of the project,*
  - *without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.*
- *The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-RERC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.*
- *The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-RERC and new approval received before or on the expiry date.*
- *In the interest of ethical responsibility the NWU-RERC retains the right to:*
  - *request access to any information or data at any time during the course or after completion of the project;*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the project are revealed or suspected,*
    - *it becomes apparent that any relevant information was withheld from the NWU-RERC or that information has been false or misrepresented,*
    - *the required annual report and reporting of adverse events was not done timely and accurately,*
    - *new institutional rules, national legislation or international conventions deem it necessary.*

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof Amanda Lourens
Chair NWU Research Ethics Regulatory Committee (RERC)

ANNEXURE 11: APPROVAL TO CONDUCT THE RESEARCH STUDY FROM THE PROVINCIAL DEPARTMENT OF HEALTH



health
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POLICY, PLANNING, RESEARCH, MONITORING AND EVALUATION

To : **Mr S Nevondwe**

From : **Policy, Planning, Research, Monitoring & Evaluation**

Subject : **Approval Letter- Non Adherence to Antiretroviral Treatment in Maquassi Hills, North West Province: A Social Work Perspective.**

Purpose

To inform the researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The researcher is expected to arrange in advance with the chosen districts or facilities, and issue this letter as prove that permission has been granted by the provincial office.

Upon completion, the department expects to receive a final research report from the researcher.

Kindest regards

Acting Director: PPRM&E
Mr. L Moaisi

12/08/2014
Date

DEPARTMENT OF HEALTH
PRIVATE BAG x2068
MMABATHO 2735
2014 -08- 12
SUPERINTENDENT GENERAL

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Healthy Living for All