

**FACTORS CONTRIBUTING TO NON-ADHERENCE OF PATIENTS TO HIGHLY
ACTIVE ANTIRETROVIRAL TREATMENT AT KANYAMAZANE CLINIC,
EHLANZENI DISTRICT, MPUMALANGA PROVINCE**

by

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DECLARATION

I, Maria Sizakele Mahlalela, declare that the mini-dissertation “Factors contributing to non-adherence of patients to highly active antiretroviral treatment at Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province” hereby submitted for the degree Master of Curationis (MCur) to the University of Limpopo has not previously been submitted by me for a degree at this or any other university, that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

Signature

Date

Mahlalela M.S (Mrs)

DEDICATION

This dissertation is dedicated to my beloved husband, Sibusiso Mahlalela, for great commitment and continuous support, encouragement, and understanding during my studies. I wholeheartedly appreciate all his contributions and for the patience he has invested in my studies. I also dedicate this dissertation to my sons Mngqobi, Siyanda, and Anele – young as they are – for their understanding that mommy needs to be alone when busy with her studies; to my mother, Rebecca Sifundza, my late father, Mrashiya Ncongwane, and to my four brothers Lucky, Ntokozo, Sikelela, and Bheki Ncongwane. I also dedicate this study to all the patients at Kanyamazane Clinic, Mpumalanga Province.

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ABSTRACT

Background: The national HAART programme in South Africa was launched in April 2004. Highly Active Antiretroviral Therapy (HAART) is the medication that slows down the progression from HIV to AIDS, while it had been introduced in Western countries in 1996. Adherence to ART is the major factor in ensuring the virologic success of an initial regimen and is a significant determinant of survival for HIV-infected patients with the wild type virus who are on highly active antiretroviral treatment. Patients with suboptimal adherence are at risk, not only of HIV progression but also of the development of drug resistance and consequent narrowing of options for future treatment. Sub-Saharan Africa carries the highest burden of HIV infections and HIV / AIDS related mortality in the world. South Africa is reported to have the largest population living with the HIV infection.

Aims: The aim of the study was to explore factors that contributed to non-adherence of patients to HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province.

Study method: A qualitative, exploratory, descriptive, and contextual research design was used for this study. A non-probability purposive sampling method was used to select participants ranging from 15 to 60 years of age and who were on HAART for more than one year. Fifteen participants were selected and the sample size was determined by data saturation. Semi-structured interviews were conducted to collect data through the use of an interview guide on their structured follow-up dates and audio recordings of the interviews were made. Data was analysed following the Tesch's method. Themes and sub-themes were developed.

Results: Findings indicate that factors contributing to non-adherence of patients to HAART are the patient-provider relationship and delivery of services, waiting hours and overcrowding, working hours of the facility, forgetfulness and experiencing better health, belief systems, side-effects, pill burden, migration due to employment, poverty and unemployment, as well as disclosure, stigma, and discrimination.

Conclusion and recommendations: The study recommends that HAART services should be provided every day, including on weekends, to improve access and to

reduce waiting times; and economic empowerment through skills acquisition programmes to participants and provision of jobs to earn a living.

Keywords: Non-adherence, highly active antiretroviral treatment, regimen, drug resistance.

DEFINITION OF CONCEPTS

- **Adherence**

Adherence means taking every dose of medication strictly as prescribed (Van Dyk, 2008). In this study, adherence refers to the taking of highly active antiretroviral treatment (HAART) as prescribed.

- **Highly Active Antiretroviral Treatment**

Highly active antiretroviral treatment is the medication that slows down the progression from HIV to AIDS (Van Dyk, 2008).

- **Mutation**

Mutation means a permanent change in the DNA sequence of genes and occurs when a DNA gene is damaged in such a way that it alters the genetic message (Loewe, 2008).

- **Non-adherence**

Non-adherence is defined as the extent to which patients are not able to follow the recommendations for prescribed treatment (Hugtenburg, Timmers, Elders, Vervloet and Van Dyk, 2013). In this study, non-adherence is defined as taking less than 95% of HAART doses during the previous month.

- **Wild type virus**

Wild type virus is a type of virus that occurs most commonly in nature in the absence of drug pressure, and it does not have drug mutations contained in its genetic sequence, meaning that it is a virus that decreases when the drug concentration gets increased (Parkin, Hellmann, Whitcomb, Kiss, Chappey and Petropoulos, 2004).

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
HAART	Highly Active Antiretroviral Treatment
HIV	Human Immunodeficiency Virus
HCT	HIV counselling and testing
NIMART	Nurse Initiated Management of Antiretroviral Treatment
PMTCT	Prevention of mother to child transmission
TB	Tuberculosis
UNAIDS	United Nations Joint Programme on HIV / AIDS
US	United States
VL	Viral load
WHO	World Health Organisation

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

1.1.1 Background information on HIV / AIDS

Non-adherence to HAART is a problem that is leading to considerable risks and problems for the patient, the patients' social network, and the society. Deteriorating health status and eventual death of the patient may lead for family and other dependents to loss of income, higher health care expenses, and orphans who need to be taken care of. Health care providers have to face the additional burden of dealing with the opportunistic infections that might develop. Also, the patient might develop a resistant HIV strain and, as a result, becomes more infectious due to incomplete viral suppression; therefore, the chance of treatment failure increases (Gill; Hamer; Simon; Thea & Sabin, 2005). Although strict adherence is of life-saving importance, HIV-infected people on HAART often do not manage to reach optimal adherence levels.

HIV/AIDS continue to be a major public health problem with far reaching consequences for the development and the national security of WHO / AFRO Member States. Sub-Saharan Africa carries the highest burden of HIV infections and HIV / AIDS related mortality in the world (WHO, 2012). According to estimates from the UNAIDS Global Report 2013, around 35.3 million people were living with HIV at the end of 2012. More than 60% of the HIV-infected population live in African countries. South Africa is reported to have the largest population living with the HIV infection, followed by Nigeria while India has the third largest infection rate. India is estimated to have 23.9 lakh (2.39 million) people infected with HIV, at an estimated adult HIV prevalence of 0.31% (WHO, 2012). Adult HIV prevalence among men is 0.36%, while among women it is 0.25% (UNAID & WHO, 2013). In 2011, 2.5 million people were newly infected with HIV. An estimated 1.7 million people died of AIDS related illnesses, i.e. 700 000 fewer new infections worldwide than ten years ago and 600 000 fewer deaths than in 2005 (WHO, 2012).

Sub-Saharan Africa is the worst affected region in the world and is the only region in the world where women are disproportionately affected by the HIV epidemic in comparison with men, with the proportion of women hovering around 60% over the last five years and nearly 90% of all children living with HIV / AIDS. The HIV / AIDS epidemic in Africa is occurring in a context of increased poverty, food insecurity, indebtedness, poor economic performance, gender inequality, gender-based violence, conflict, natural disasters, ignorance, fear, stigma, and discrimination (UNAIDS & WHO, 2013).

South Africa is one of the countries in Sub-Saharan Africa that is heavily affected by the epidemic. South Africa has the highest burden of HIV / AIDS in the world, with 5.6 million people living with the virus and over 400000 newly infected annually. Since 2004, the U.S. government has committed more than US\$ 4 billion to combating HIV / AIDS in South Africa; the largest U.S. investment in HIV / AIDS treatment worldwide. Continued progress in controlling HIV / AIDS in South Africa, the epicentre of the pandemic, is pivotal to sustained progress against the disease worldwide (Stephen-Morrison, Stash, Summers, Canfield, Gleason, Kramer, Oswald, Ross & Walsh, 2013). Over the past three years, a joint United States–South Africa effort has been underway to transfer responsibility for HIV / AIDS programming and policies to the South African government. Stephen-Morrison *et al.* (2013) state that the South African and US governments negotiated a Partnership Framework outlining the broad terms of this transition; the agreement was signed in October 2010 by the then Secretary of the State and the South African counterpart. Through this process, the United States has begun to move from a leading role in the provision of lifesaving services to an approach focused increasingly on technical support.

1.1.2 Access to Highly Active Antiretroviral Treatment

Through combined efforts of affected countries and international partners, there is substantial and continuing progress towards providing HIV interventions in low and middle income countries in the following regions: Sub-Saharan Africa; Latin America and the Caribbean; East, South and South-East Asia; Europe and Central Asia; as well as North Africa and the Middle East. One of the interventions is access to antiretroviral therapy for HIV-infected people (WHO, 2003). In 2003 due to concerns

of limited access to ART, the WHO “3 by 5” initiative was launched as a strategy for ensuring that 3 million people living with HIV / AIDS in low and middle income countries had access to treatment by the end of 2005 which meant meeting 50% of the estimated need (WHO, 2005). Although the WHO target of providing access to ART for 3 million people by 2005 was not achieved, by the end of June 2005 an estimated 1 million people in low and middle income countries had access to ART (WHO, 2003; WHO, 2005).

Despite progress, global access to antiretroviral therapy remains low. Only 31% of people in need of ART in the world were receiving it in 2007 and an estimated 2.5 million people were newly infected with HIV in the same year. About 3 million people were receiving ART in the low and middle income countries at the end of 2007 which is nearly 950 000 more compared to the end of 2006 (WHO, 2008a). The greatest increase was in Sub-Saharan Africa where about 2.12 million people were receiving ART at the end of 2007 compared to 1.38 million people in 2006 (an increase of 54%). At 32%, coverage is higher in eastern and southern Africa than in western and central Africa at 25% (WHO, 2008b).

The state of HIV treatment in South Africa can only be viewed in the context of years of doubling the effectiveness of treatment at the highest levels of government, and the initial delay and slow pace of delivering a public antiretroviral programme (USAID, 2011). The national HAART programme in South Africa was launched in April 2004. The Treatment Action Campaign is advocating for the right of people living with HIV / AIDS and has established that the planned target is to have 80% of people on HAART by 2016. Prevention efforts are beginning to bear fruit, with indications of behavioural change and declines in HIV prevalence rates in a number of high-burden countries. Many countries have also made significant progress in expanding access to ART. About 2.1 million people were receiving antiretroviral therapy in the Sub-Saharan Africa region at the end of 2007, and regional coverage increased from barely 2% in 2003 to 30% in 2007. Despite this significant progress in ART, there is still a need to reach all the people in need and to improve some areas, such as HIV counselling and testing (HCT) and Prevention of mother to child transmission (PMTCT).

1.1.3 Highly Active Antiretroviral Treatment and adherence

Highly Active Antiretroviral Therapy (HAART) is the medication that slows down the progression from HIV to AIDS and was introduced in Western countries in 1996. The progression of AIDS starts with the HIV infection. If untreated, this process takes six to eight years in developing countries (Barnett & Whiteside, 2006). The virus uses CD4+ T-helper cells, cells that are an important part of the immune system, for its own replication. In this process, the CD4+ T-helper cells are destroyed. Because these particular CD4 cells are responsible for the coordination of the immune system in case of infection, an HIV-infected individual becomes more susceptible to other diseases, the so called opportunistic infections that lead to death of the patient. Without treatment, a patient lives one to two years after the onset of AIDS (Barnett & Whiteside, 2006). The currently used medication HAART consists of two or more different antiretroviral drugs that are working in combination to increase life expectancy by many years.

Drugs disrupt HIV replication so that the number of CD4+ T-helper cells can increase. Therefore, the susceptibility for opportunistic infections decreases and the viral load stabilises or decreases. The medication can dramatically improve the clinical status and outcomes, particularly physical functioning and quality of life, in those with advanced HIV (McInerney; Ncama; Wantland; Bhengu; McGibbon; Davis; Corless & Nicholas, 2008); reduce morbidity and mortality due to AIDS (Gill *et al.*, 2005), and lead to lower incidence of HIV through lower viral load (UNAIDS & WHO, 2013). Although HAART does not cure HIV infection, it delays the degenerative effects of the virus and can even make the virus undetectable. Strict adherence to HAART is essential to be effective (Gill *et al.*, 2005). Adherence to medication means that a patient takes all the doses of medication as prescribed. This implies that the meaning of adherence depends on the prescribed medication because different types of medication require different number of daily doses. Successful virologic suppression can only be reached when taking at least 95% of the prescribed doses. Missing more than 5% of the doses lead to an increased risk of getting opportunistic infections and a quicker progression towards AIDS.

Long-term successful suppression depends on strict adherence (Rabkin & Chesney, 1999). Non-adherence to HAART is a problem leading to considerable risks and

problems for the patient, the patients' social network, and the society in general. Deteriorating health status and eventual death of a patient may cause a family and other dependents a loss of income, higher health care expenses, and possibly orphans to take care of. Health care providers have to face the additional burden of dealing with the opportunistic infections that will develop. The patient may also develop a resistant HIV strain and may become more infectious, because of incomplete viral suppression while the chance of treatment failure is increasing (Gill *et al.*, 2005). Although strict adherence is of life-saving importance, HIV-infected people on HAART often do not manage to reach optimal adherence levels.

Adherence to ART is the major factor in ensuring the virologic success of an initial regimen and is a significant determinant of the survival for HIV-infected patients with a wild type virus who are on highly active antiretroviral treatment (Paterson; Swindells; Mohr; Brester; Vergis; Squier; Wagener & Smith, 2000). Adherence is second only to the CD4 cell count as a predictor of the process of progression to AIDS and death (Remien; Hirky; Johnson; Weinhardt; Whittier & Minh Le, 2003). Adherence rates approaching 100% are needed for optimal viral suppression, yet the average HAART adherence in the United States is approximately 70% (Chesney; Morin & Sherr, 2000). Individualised assessment of and support for adherence are essential for patients to be successful with HAART (Russel; Bunting; Graney; Hartig; Kirsner & Brown, 2003). Patients with suboptimal adherence are at risk not only of HIV progression, but also of the development of drug resistance and consequent narrowing of options for future treatment (Chesney, 2000). For most ART programmes in Sub-Saharan Africa including South Africa, the emphasis has been on initiating people on ART than on ensuring effective use of medicines. This is because their performance is measured in terms of access rather than the adherence that is necessary for sustained health benefits and to safeguard public health against the risk of drug resistance caused by non-adherence to the antiretroviral drugs (WHO, 2006).

According to the South African national guidelines, patients must also show willingness and readiness to take HAART strictly according to health care advice in order to avoid poor adherence and drug failure (USAID, 2011). In 2011, the government of South Africa amended treatment guidelines to include the initiation of

treatment at a CD4 cell count of 350 cells or less and at a stage 4 AIDS defining disease (Department of Health, 2011). The current unregulated availability of HAART in developed countries is calculated to accelerate the emergence of drug resistance. The government must ensure that the distribution of HAART occurs in the context of policies, practices, and procedures that promote rational HAART use and encourage patient adherence. In one cohort study conducted by Margaret (2012) it was estimated that drug-resistance mutations would occur in 25% of patients who reported very high but not perfect (92-100%) adherence to HAART.

The relationship between suboptimal adherence and resistance to HAART is very complex and is not thoroughly understood (Margaret, 2012). Non-adherence to a HAART regimen is one of the most pressing behavioural problems in the clinical management of HIV-infected patients. Deviations from the prescribed regimen may allow the virus to resume rapid replication and develop drug resistant mutations that could cause the prescribed drugs to become useless (Oyugi, Byakika-Tusiime, Ragland, Laeyendecker, Mugerwa, Kityo, Mugenyi, Quinn & Bangsberg, 2007).

The critical factors that influence adherence are grouped into four main categories: Patient factors such as use of drugs and alcohol, age, sex, cultural beliefs, or ethnicity; medication regimen such as dosing complexity, side-effects, number of pills, or food requirements; the relationship between patient and health care provider, as well as the system of care. Patients' behaviour is the critical link between a prescribed regimen and treatment outcomes. The most effective regimen will fail when the patient does not take the medication as prescribed or refuses to take it at all. Consequently, all things being equal, the most important factors influencing adherence are patient-related (Chesney, 2000; WHO, 2003). Non-adherence has been found to diminish the benefit of HAART and increases AIDS-related morbidity, mortality, and hospitalisation. Based on this background, the factors contributing to non-adherence of patients to HAART at Kanyamazane Clinic, Ehlanzeni District in the Mpumalanga Province was determined.

1.2 PROBLEM STATEMENT

The high rate of non-adherence is still a major public health concern. The Mpumalanga Province is ranked number 2 in terms of HIV / AIDS prevalence rate in 2011, number one being the KwaZulu-Natal Province (Department of Health, 2011). Inadequate adherence to HAART leads to treatment failure and the emergence of resistant viruses with eventual exhaustion of treatment options. Adherence is the only factor that can be controlled to delay the development of virus resistance; it is, therefore, imperative to develop measures for optimally enhancing adherence, as well as for exploring factors that contribute to non-adherence of HAART in patients at Kanyamazane Clinic, Ehlanzeni District in the Mpumalanga Province of South Africa.

The HIV pandemic is one of the most serious health crises that the world faces. The Sub-Saharan Africa region is by far the worst affected in the world by the pandemic. HIV prevalence varies considerably across this region, ranging from less than 1% in Madagascar to over 26% in Swaziland (WHO, 2008a). South Africa, as part of Sub-Saharan Africa, is severely affected by the HIV pandemic. This implies that the number of patients to be started on HAART would be increasing. The Department of Health of the Mpumalanga Province has endeavoured to make health care facilities and services accessible to the majority of people, even in the under- resourced areas.

Referring to the statistics of the Kanyamazane clinic for 2010-2011 and clinic records, about 25% of people living with HIV / AIDS on HAART were found to have virologic failure ($VL > 1\ 000$ copies / ml) on two occasions, despite intensive adherence counselling or immunological failure (CD4 count dropping) resulting in the changing of the prescribed treatment regimen to another regimen of HAART at 24 months or a shorter period of time. Once patient has begun HAART non-adherence, it can have important implications for virus replication, disease progression, emergence of drug resistance, and death for people with HIV / AIDS. The high rate of non-adherence behaviour of HAART at the Kanyamazane Clinic has been observed; patients are struggling with adherence. The need to explore and describe factors contributing to non-adherence of patients to HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province has been identified.

1.3 RESEARCH QUESTION

What are the factors that contribute to non-adherence of patients to HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province?

1.4 AIM OF THE STUDY

To explore factors that contribute to non-adherence of patients to HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province.

1.5 OBJECTIVES OF THE STUDY

The objectives of the study were:

- to determine the problems encountered by patients regarding adherence to HAART;
- to determine support structures of people living with HIV / AIDS; and
- to determine if the patients on HAART are taking additional medication.

1.6 RESEARCH METHODOLOGY

A qualitative, exploratory, descriptive, and contextual research design was used to explore factors contributing to non-adherence of HAART as described by participants at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province. The population were all HIV / AIDS infected patients on HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province and a non-probability purposive sampling method was used. The sample size of fifteen participants was determined by data saturation. Patients on HAART for less than one year, children less than 15 years old, and adults over 60 years of age were excluded from the study. Semi-structured interviews were used to collect data according to a guide and the interviews on their structured follow-up dates were audio recorded until saturation of data was reached. Data was analysed by following the Tesch's method that comprises eight steps, according to Cresswell (2009). The details of the methodology are discussed in Chapter 3.

1.7 SIGNIFICANCE OF THE STUDY

The study may be beneficial to the patients, policy makers and health care providers, since it will provide them with a starting point for changes that might help to ensure greater adherence to HAART. Interventions will be based on the research findings after completion of the study. Knowledge gained from this study about factors contributing to non-adherence to antiretroviral therapy by HIV-positive patients will assist with making recommendations with regard to the development of appropriate health education strategies to empower patients about the importance of adherence to HAART. The information is used to develop guidelines and education materials that can be used in adherence counselling before patients are started on HAART and during the follow-up period after starting. The findings will also contribute to the review of the HIV / AIDS treatment protocols and policies, related in-service education for medical personnel, and review of health education programmes for HIV-positive patients with the aim of improving the clinical management of HIV / AIDS.

1.8 CONCLUSION

This chapter introduced and described a comprehensive overview of the study. Background information about HIV / AIDS; HAART, and adherence in the context of the world, the Sub-Saharan Region, and South Africa are discussed. The problem statement, significance, research question, purpose, and research objectives of the study are indicated. The research design and methodology with regard to study population, sampling, data collection, and analysis are provided. Chapter 2 provides an account of the literature review.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

An introduction and a comprehensive overview of the study were discussed in Chapter 1 while this chapter is dealing with a literature review. A literature review is conducted to generate a picture of what is known about a particular situation and the knowledge gaps of the situation that exist. Through a literature review, the researcher is able to clarify which problems have been investigated, require further investigation or replication, or have not been investigated at all. The purpose of a literature review in this qualitative research project is to analyse the contributing factors of non-adherence to HAART, as well to assemble and relate these factors to the person in treatment, the disease, the treatment, and the health and social support service.

The primary rationale for reviewing literature relevant to this study was to gain an understanding of the information available about factors related to non-adherence to HAART within the context of HIV / AIDS, HAART, and adherence measurement methods. Reviewed documents on adherence were obtained from websites and peer-reviewed research articles from journals. Factors that emerged from the literature review included the measurements to adherence and the related factors contributing to non-adherence to HAART. Measurements to adherence involved self report, pill counts, pharmacy refill records, electronic drug monitoring and therapeutic drug monitoring. The related factors contributing to non-adherence to HAART included complexity of medication regimen, perceived stigma and discrimination, poverty and financial problems, perceived social support, lack of communication between patients and health care providers, health system barriers, patient's behaviour, religious beliefs, lack of knowledge, alcohol and substance abuse.

2.2 MEASURING ADHERENCE

Medication adherence is an individual, complex, and dynamic behaviour that presents measurement challenges. Accurate measurement of antiretroviral therapy adherence is essential for evaluating interventions aimed at improving adherence and preventing viral resistance. There is no standard for measuring adherence.

Measurement of medication adherence is further complicated by the diversity of available measures, which have different utility values in clinical and research settings (Berg & Arnsten, 2006; Chesney, 2006). Commonly used methods for measuring adherence include indirect measures; such as self-reports, electronic drug monitoring, pill counts, and pharmacy refill records and direct measures, including detection of drugs or drug metabolites in plasma (Berg & Arnsten, 2006; Osterberg & Blaschke, 2005).

2.2.1 Self-report

Self-report is the most commonly used adherence measure in clinical and research settings because it requires a low staff and respondent burden. It is also inexpensive and flexible, and takes little time. In clinical settings, self-reporting allows for a discussion of reasons for missed doses and potential solutions. A systematic review of 77 studies employing various self-report measures of antiretroviral therapy adherence reported that self-reported adherence correlated significantly with HIV viral load in 84% of recall periods. In a meta-analysis of 65 studies, the odds of having a detectable HIV viral load was more than double in non-adherent patients in comparison with adherent patients (Berg & Arnsten, 2006; Nieuwkerk & Oort, 2005; Simoni, Kurth, Pearson, Pantalone, Merrill & Frick, 2006b). Stone, Jordan, Tolson, Miller and Pilon (2009b) reported that HIV-infected patients who began HAART during the period 1990-1999 in a Barcelona hospital in Spain, adherence was assessed by self-report and pharmacy refill. There are several limitations associated with self-report; including non-standardised questions, reliance on recall of forgotten events, and its vulnerability to social desirability in patients' given reports on adherence. The patients' reports also tend to reflect only short-term or average adherence and often overestimate adherence. A study in Uganda showed that self-report as a measure of adherence had a high degree of correspondence with other objective measures, such as electronic medication monitoring, thus more applicable as a measure of adherence in resource limited settings (Berg & Arnsten, 2006; Chesney, 2000; Oyugi *et al.*, 2007).

2.2.2 Pill counts

Pill counts that involve counting the number of pills which remain in the patients' bottles or vials have been widely used to measure adherence to medications in clinical settings. The patient brings back the actual pill containers in order for the health professionals to physically count the remaining pills. The return of excess pills provides tangible evidence of non-adherence. However, firstly this method has shortcomings because patients can deliberately remove and dump some pills before their next visit in order to appear adherent since they are aware of the pill counts. As a result, pill counts typically overestimate adherence. Secondly, the method does not provide information about other aspects of taking medication, such as dose timing and drug holidays which are important in determining the clinical outcome. Sometimes, the patients may perceive pill counting as threatening and suggesting a lack of trust in their self-reported adherence (Berg & Arnsten, 2006; Chesney, 2000; Osterberg & Blaschke, 2005). In research settings, unannounced pill counts have been used to minimise the risk of pill dumping (Bangsberg, Hecht, Charlebois, Zolopa, Holodniy, Sheiner, Bamberger, Chesney & Moss, 2000). A study completed in Cape Town found a median adherence rate of 93.5% over a 48 week period, using patient pill returns to measure adherence (Nachega, 2009).

2.2.3 Pharmacy refill records

Using pharmacy refill records to measure adherence is common among settings where medications are provided and financed in a single location, especially in a closed pharmacy system, provided that the refills are measured at several points in time. With electronic medical records, a closed pharmacy system can provide the clinician or research scientist with objective information about the rates of refilling prescriptions that can be used to assess whether a patient is adhering to the drug regimen or not (Osterberg & Blaschke, 2005; Steiner & Prochazka, 1997).

The underlying premise of this method requires the identification of patients who do not receive timely refills from the pharmacy, who are missing doses as measured by prolonged periods between refills, or who are not taking the medication at all.

Adherence rates from pharmacy refill records are determined by comparing the actual with expected refill dates or by identifying "medication gaps", defined as

periods during which the patient's supply of medication is assumed to have been exhausted (Inciardi & Leeds, 2005; Steiner, Koepsell, Fihn & Inui, 1988). In several studies, pharmacy refills have been shown to correlate significantly with HIV viral load (Grossberg, Zhang & Gross, 2004; Low-Beer, Yip, O'Shaughnessy, Hoggs, & Montaner, 2000). In a study comparing long term adherence to HAART as measured by two practical and inexpensive methods (self-reports and pharmacy refills records) at an HIV clinic in Melbourne, Australia; there was a correlation between self-reports and pharmacy refill records using < 95% level of adherence as non-adherent for pharmacy refill records and < 97% as non-adherent for self-reports. However, pharmacy refills identified about twice as many individuals to be non-adherent as had been identified with self-reports; the study showed a statistical difference of 27% versus 14% (Fairly, Permana & Read, 2005).

2.2.4 Electronic drug monitoring

Electronic drug monitoring is often treated as the adherence "gold standard" because it produces adherence rates with lower central tendencies and more variance than other measures and correlates more closely with HIV viral load than other individual measures. Benefits include the ability to examine the patterns of adherence and detailed aspects of medication taking, such as dose interval adherence (Arnsten, Demas, Farzadegan, Grant, Gourevitch, Chang, Buono, Eckholdt, Howard & Schoenbaun, 2001; Liu, Golin, Miller, Hays, Beck, Sanandaji, Christian, Maldonado, Duran, Kaplan & Wenger, 2001).

2.2.5 Therapeutic drug monitoring

Monitoring of drug levels is a well-known therapeutic intervention considered as a direct objective measure of medication adherence that is feasible in clinical and research settings, most especially when inadequate plasma drug levels arising from pharmacokinetics or adherence factors are the major cause of treatment failure (Hugen, Langebeek, Burger, Zomer, Leusen, Schuurman, Koopmans & Hekster, 2002; Osterberg & Blaschke, 2005). Low drug levels in the plasma have been associated with self-reported adherence and virologic failure. For example, in a cross-sectional study done to examine the relationship between untimed drug levels and adherence in 83 individuals, an abnormal low drug level had a specificity of 88%

for detecting adherence of 90% or less (Liechty, Alexander, Harrigan, Guzman, Charlebois, Moss & Bangsberg, 2004; Murri, Ammassari, Gallicano, Deluca, Jacobson, Wu & Antinori, 2000). Factors other than those affecting adherence may affect drug levels, such as drug-drug interactions and diet (Conway, 2007; Paterson *et al.*, 2000; Wood, Hogg, Yip, Harrigan, O'Shaughnessy & Montaner, 2004b). Technically, this method is limited by the fact that serum drug levels only reflect adherence over the past 24 hours and patients who are aware of a planned visit may ingest medication in anticipation of the test (Berg & Arnsten, 2006; Chesney, 2000).

2.3 ADHERENCE TO ANTIRETROVIRAL THERAPY

The relationship between adherence and therapeutic success has been demonstrated across a range of highly active antiretroviral therapy (HAART) regimens; including Nucleoside reverse transcriptase inhibitors, Protease inhibitors, and Non-nucleoside reverse transcriptase inhibitors. Through the suppression of plasma HIV-1 RNA, HAART has been shown to improve CD4 cell counts and, in turn, to decrease morbidity and mortality among HIV-infected patients. These benefits of HAART in the management of HIV are well established in a number of settings.

The success depends on the patients' ability to adhere to ART which is influenced by factors that may be within or beyond the clinical environment. An extremely high level of adherence (< 95%) is required to guarantee treatment effectiveness due to rapid replication and mutation (Conway, 2007). Some reports have a differing view, that virologic success is possible with less than 95% adherence (Bangsberg *et al.*, 2000; Martin, Del Cacho, Codina, Tuset, De Lazzari, Mallolas, Miro, Gatell & Ribas, 2008; Paterson *et al.*, 2000). Poor adherence can lead to clinical, immunological, and virologic failure with the latter resulting in the spread of drug resistant forms of the virus, which is of public health concern. It can also lead to increased costs to health services and society as a result of direct financial costs of failed treatment and higher hospitalisation rates.

Indirectly, there are costs of lost productivity of patients and a burden on family caregivers. Non-adherence or sub-optimal adherence to ART is of concern, particularly in countries that lack capacity to monitor drug resistance and that experience shortage of second line regimens that are prohibitively expensive

(Bangsberg, Hecht, Charlebois, Chesney and Moss, 2001; Cohen, 2007; Stevens, Kaye & Corrah, 2004; Sokol, McGuigan, Verbrugge & Epstein, 2005). In Sub-Saharan Africa, initial findings about adherence have been promising. A meta-analysis found that a pooled estimate of 77% of patients in African settings achieved adequate adherence (most often measured as taking 95% of prescribed pills) compared to just 55% of patients in North American settings.

In addition, high levels of adherence and positive outcomes of ART have been observed in some home-based ART care studies and in multi-site studies that include Botswana, Tanzania, and Uganda (Mills, Nachega, Buchan, Orbinski, Attaran, Singh, Rachlis, Wu, Copper, Thabane, Wilson, Guyatt and Bangsberg, 2006b; WHO, 2006). In Senegal, notable declines have begun to be reported among people on more long term therapy (Laniece, Ciss, Desclaux, Diop, Mbodj, Ndiaye, Sylla, Delaporte & Ndoeye, 2003). Wakibi, Ng'ang'a and Mbugua (2011) conducted studies in Nairobi, Kenya that found a prevalence of non-adherence found of 18% compared to the continental prevalence of 23% for Africa, 21% in Ethiopia, and 22% in Cote d'Ivoire. South West Ethiopia reported 24% of non-adherence. The 18% of non-adherence in Kenya reported skipping HAART due to being busy and forgetting.

2.4 RELATED FACTORS CONTRIBUTING TO NON-ADHERENCE TO HAART

Chesney (2000) states that before measures are implemented to improve adherence, it is essential to identify the main factors that contribute to the inability of patients to take their medications as expected or suggested. Many factors; including behavioural, socio-demographic, and provider related characteristics; have been reported to influence non-adherence to HAART. McDonnell-Holstad, Pace, De and Ura (2006) reported conflicting evidence about the association between socio-demographic factors and adherence behaviour. Some of the factors identified in these studies that positively or negatively affect adherence include: Costs of treatment, risks of illness like recurrence and severity of disease symptoms, benefits of treatment like decreased symptom frequency and severity plus prevention of hospitalisation, barriers like complex drug regimens and cues to act like symptom exacerbation, pillboxes plus appointment reminders, knowledge about the target disease, and prior contact with it. These factors are normally grouped into the following categories: Patient-related factors, treatment regimens, disease

characteristics, patient-provider relationships, and clinical settings. There is an interrelationship among these factors (Ammassari, Trotta, Murri, Castelli, Narciso, Noto, Vecchiet, Monforte, Wu & Antinori, 2002; Chesney, 2000; Ickovics & Meade, 2002). Ammassari *et al.* (2002) reviewed published studies conducted in different settings which reported that the most common reasons for skipping HAART included complexity of medication regimens (7-52%), difficulty of integrating treatment schedules into their daily activities (36-57%), fear of side-effects (13-42%), worries about disclosure (14-33%), and forgetfulness about taking medications (30-66%). MacDonnell *et al.* (2006) indicated that common predictors of non-adherence in India included depression, psychiatric morbidity, active drug or alcohol use, stressful life events, lack of social support, and the inability to correctly identify the regimen or describe the relationship between adherence and drug resistance.

2.4.1 Complexity of medication regimen

Medication regimen complexity has been cited as one of the most common related factors contributing to non-adherence of HAART. Adherence rates decrease with increasing regimen complexity (Stone, Hogan, Schuman, Rompalo, Howard, Korkontzeelou & Smith, 2009a). Regimen complexity includes pill burden, dosing schedule, prescribed dosage form, medication side-effects, special requirements associated with medication use, food and lifestyle restrictions, medication storage requirements, routine laboratory tests associated with HAART use, and the ease with which a patient can obtain prescription refills (Stone *et al.*, 2009a). These factors also influence the individual's understanding of their medication regimen and potential adherence. Conn, Taylor and Kelly (2009); and George, Phun, Bailey, Kong and Stewart (2004) used the medication complexity index to examine the association between medication complexity and adherence in 178 older patients and findings revealed that increased regimen complexity was associated with lower rates of adherence to treatment. Jones, McPherson-Baker, Lydston, Camille, Brondolo, Tobin and Weiss (2007) reported that the complexity of the regimen and side-effects caused by treatment regimen were clearly associated with non-adherence.

A study conducted by Stone *et al.* (2009a) involving 299 people living with HIV / AIDS on HAART found that the attributes of regimen complexity with the greatest impact on perceived ability to adhere to HAART were in order of importance: Pill burden,

dosing frequency, adverse events, dietary requirements, pill size, number of refills, number of prescriptions, number of bottles, and bedtime dosing. Most antiretroviral medication required multiple dosing per day. Stone *et al.* (2009a) found that patients preferred twice daily dosing to thrice a day dosing. Findings of Clay, Taylor, Glaros, McRae, Williams, McCandless and Oelklaus (2008); and De Clercq (2006) indicated that patients preferred once daily dosing, for example a fixed dose combination pill with lower side effect potential, such as Atripla (combination of efavirenz, emtricitabine and tenofovir) and Truvada (combination of emtricitabine and tenofovir). These fixed dose combination pills were regarded as a major milestone towards improving patients' adherence to HAART. A meta-analysis of eleven studies conducted by Frank (2002) showed 1.0-4.8% improvement in adherence rates in patients on once daily dosing compared to those with twice daily dosing of HAART. Once daily fixed dose combinations are common in developing countries and in South Africa, as one of the resource limited setting, these fixed doses are now common in the public sector since 2013. ART regimens have toxicities and adverse side-effects that vary from mild to severe and acute to chronic, which can be a barrier to adherence (Catz, Kelly, Bogart, Benotsch & McAuliffe, 2000). Similar findings from several studies conducted in both undeveloped and developing countries revealed that patients who experienced side-effects were more likely to be non-adherent (Mills, Nachega, Bangsberg, Singh & Rachlis, 2006a; Protopopescue, Raffi, Roux, Reynes & Dellamonica, 2009; Wasti, Randall, Simkhada & Van Teijlingen, 2012).

Hansel, Bucher, Nuesch and Battegay (2001) also state that patients who have been on ART for less than two years were more likely to be non adherent and side-effects may be one of the related factors because the literature shows up to 45% of ART prescribed patients discontinue one or more of the drugs within a year of initiation due to side-effects and the inconvenience of the regimen (Lewis, Colbert, Erien & Meyers, 2006). Side-effects have also been consistently associated with decreased adherence and patients who experience more than two adverse reactions are less likely to continue their treatment. HAART can lead to serious adverse events; including transient reactions such as nightmares, hallucinations, diarrhoea, and vomiting; longer-lasting effects such as peripheral neuropathy, lipodystrophy, and metabolic changes are also likely to be factors. The literature on side-effects clearly shows that optimal adherence occurs with medications that remove symptoms

whereas adherence is reduced by medications that produce side-effects (Chesney, 2000; Max & Sherer, 2000; Roberts & Mann, 2000; Stone, 2001).

Patients quickly discontinue therapy or request changes of medications when they experience side-effects. Both real and perceived side-effects account for more regimen changes than does treatment failure. The symptoms that cause the most distress are fatigue, diarrhoea, nausea, and stomach pains; most of these symptoms can be successfully treated (D'Armino, Lepri, Rezza, Pezzoti, Antinori, Phillips, Angarano, Colangeli, De Luca, Ippolito & Caggese, 2000; Mocroft, Youle, Moore, Sabin, Madge, Lepri, Tyrer, Chaloner, Wilson, Loveday, Johnson & Philips, 2001). One serious side-effect that may affect adherence to ART in the long term is lipodystrophy. Lipodystrophy affects between 30% and 60% of persons on HAART. Its physical manifestation varies greatly but can include fat accumulation on the upper back and neck (buffalo hump), under the muscles of the abdomen (crix belly or protease pauch), lipomas, and breast enlargement. There might also be peripheral wasting of the fat in the face, legs, arms and buttocks (Carr, Samaras, Burton, Law, Freund, Chisholm & Cooper, 1998; Gervasoni, Ridolfo, Trifiro, Santambrogio, Norbito, Musicco, Clerici, Galli & Moroni, 1999; Graham, 2000).

Lewis *et al.* (2006) suggest that health care providers should review possible anticipated side-effects and develop treatment plans that prevent and reduce the likelihood of side-effects from happening. A study in Blantyre, Malawi by Bangsberg, Perry, Charlebois, Clark, Robertson, Zolopa and Moss (2001) found that among patients receiving HAART, the most common reasons for non-adherence were financial difficulties and a shortage of drugs.

2.4.2 Perceived stigma and discrimination

People living with HIV / AIDS are often subject to stigmatisation and discrimination. It has been noted that stigma in relation to HIV may be a barrier to HAART adherence, mainly due to interaction between adherence and disclosure (Klitzman, Kirshenbaum, Dorge, Remiem, Ehrhardt, Johnson, Kittel, Deya, Morin, Kelly & Lightfoot, 2004).

Stigma, in association with the general knowledge of the population about HIV / AIDS and HAART treatment, is an important determinant of adherence in the settings of

Sub-Saharan countries according to studies conducted recently (Birbeck, Chomba & Kvaslund, 2009; Chesney, 2006; Nash, Wu, Lul, Hoos & Sadr, 2011). The evidence is much clearer that stigma and discrimination present barriers to good adherence to HAART; perceived stigma and internal stigma are inversely associated with adherence in the United States, United Kingdom, Botswana, and China (Calin, Hetherington & Brook, 2007; Dlamini, Wantland, Makoae, Chirwa, Kohi, Greeff, Naidoo, Mullan, Uys & Holzemer, 2006; Kip, Ehlers & Van der Wal, 2009; Melchior, Nemes, Alencar & Buchalla, 2007; Nam, Fielding, Avalos, Dickinson, Gaolathe & Geissler, 2008; Naidoo, Dick & Cooper, 2009; Rajabiun, Mallinson, McCoy, Coleman, Drainoni, Rebholz & Holbert, 2007; Rao, Kekwaletswe, Hosek, Martinez & Rodriguez, 2007; Roberts, 2005; Sabina, Desilva, Hamera, Keyid, Yuae, Wene, Taof, Heggenhougana, Setonf, Wilsong & Gill, 2008; Stirratt, Remien, Smith, Copeland, Dolezal & Krieger, 2006; Thrasher, Earp, Golin & Zimmer, 2008; Ware, Idoko & Kaaya, 2006a). In one United States study patients with high stigma concerns were 3.3 times more likely to not adhere to their ART regimen (Dlamini *et al.*, 2006). However, a study in the city of Pev demonstrated that stigma decreased and adherence improved with intensive investments in daily adherence support (Forsyth, Vandormael, Kershaw & Grobbelar, 2008).

In the United States, respondents reported experiencing stigma by general community members and friends, followed by health providers (Cao, Sullivan, Xu, Wu & China, 2006; Yu, Lau, Mak, Cheng, Lv & Zhang, 2009; Zukoski & Thorburn, 2009). Adeneye, Adewole, Musa, Onwujekwe, and Odunukwe (2006) state that people living with HIV / AIDS are unwilling to seek treatment at the nearest health facility due to fear of stigmatisation. Family plays a crucial role in any kind of treatment (Skovdal, Campbell, Nhongo, Nyamukapa & Gregson, 2011a). Major issues related to family that influence adherence include presence of anxiety, depression, active substance abuse, the presence of HIV infection in another family member, fear of disclosure of HIV-positive status to the family, family disruptions, as well as belonging to racial minorities and other vulnerable groups of the population (Amberbir, Woldemichael, Getachew, Girma & Deribe, 2008; Byakika-Tusiime, Crane & Oyugi, 2009; Nash *et al.*, 2011).

Studies revealed that patients were too embarrassed to take their ART treatment in front of other people and were concerned about privacy when collecting repeat prescriptions and taking medication (Furber, Hodgson, Desclaux, Mukasa, 2004; Rao *et al.*, 2007; Wasti, van Teijlingen, Simkhada, Randall & Baxter, 2011). Social or family stigmatisation and fear of the consequences of revealing HIV infection status to sexual partners are closely related to poor adherence (Nachega, Stein & Lehman, 2004). Findings about the context of PMTCT services in Malawi and South Africa indicate that fear of stigma and discrimination; along with fear of household conflict, divorce, and lack of support from husbands; has been found to be the reason for women dropping HAART (Bwirire, Fitzgerald, Zachariah, Chikafa, Massaquoi, Moens, Kamoto & Schouten, 2008; Varga & Brookes, 2008). Birbeck *et al.* (2009); Skovdal *et al.* (2011a); and Watt, Maman and Earp (2009) suggest that family members and friends can play the role of treatment partners and provide much needed support. Also, patients need to be encouraged by health care workers to disclose their HIV-positive status.

2.4.3 Poverty and financial problems

Socioeconomic factors; such as poor living conditions, unemployment, financial problems, poverty, and high transport costs are found to be barriers to HAART adherence. Distance to the treatment centres is found to be of great concern to people living with HIV / AIDS and a key factor that prevents adherence (Posse, Meheus, Van Asten, Van der Ven & Baltussen, 2008). In one study conducted in Nepal by Wasti *et al.* (2012) reveal that patients who travel more than one hour to hospital are more likely to be non-adherent. Participants in the study stated that although patients were willing to take ART, they became non-adherent because of difficulties in reaching the treatment centres due to unexpected transport issues, long travel distance, geographical difficulties (including transportation services in many remote areas), and the seasonal deterioration of poorer roads during the rainy seasons. Travel time and access to treatment centres are barriers to HAART adherence and better access to care is significantly associated with optimal adherence (Wasti *et al.*, 2011). Studies in Uganda and Tanzania reported that transportation costs were considered serious obstacles to taking ART (Mshana, Wamoyi & Busza, 2006; Tuller, Bangsberg, Senkungu, Ware, Emenyonu & Weiser,

2010) and had implications not only for day-to-day adherence but also for skipping follow-up visits (Orrell, 2005).

Money emerges as the most commonly mentioned barrier to adherence in most studies as most respondents reported economic worries related to the cost of transport and food, as well as having missed HAART doses because they don't have enough money to go to the health facility to collect their repeat prescriptions (Ramadhani, Thielman & Landman, 2007; Steele & Grauer, 2003; Mshana *et al.*, 2006; Sanjobo, Frich & Fretheim, 2008). ART associated costs have been found to be the barrier to adherence in other developing Asian countries and many other developing countries (Wasti *et al.*, 2011; Mills *et al.*, 2006b; Weiser, Tuller, Frongillo, Senkungu & Mukiibi, 2010; Posse *et al.*, 2008). A study in India found that almost all the participants reported the cost of HAART as a barrier to adherence (Kumarasamy, Safren, Raminani, Pickard & James, 2005), which is inconsistent with the findings of the study conducted in Botswana that shows that adherence is higher when cost is not an obstacle and poor patients are able to achieve excellent rates of adherence when they have access to free laboratory monitoring and subsidised ART (Weiser *et al.*, 2010).

Simoni, Frink, Lockhart and Liebovits (2006a); and Coetzee, Boule, Hildebrand, Asselman, Van Cutsem and Goemaere (2004) find that people living in poverty are unable to take their HAART medication in the way they are required to. The competing demands of several responsibilities; such as work and family life, along with the stresses associated with poverty, and difficult life circumstances; such as unemployment may be barriers to HAART adherence. Skovdal, Campbell, Madanhire, Nyamukapa and Gregson (2011b); and Nachega, Knowlton, Deluca, Schoeman, Watkinson, Chaisson and Maartens (2006) find that patients avoid taking treatment whenever food is unavailable because they believe that medication need to be taken with food. Studies conducted in Uganda and in Cape Town, South Africa similarly found no association between socioeconomic status and ART (Weidle, Nafuna, Solberg, Lietchty, Sendagala, Were, Mermin, Buchacz, Behumbiize, Ransom & Bunnell, 2006; Orrell, Bangsberg, Badri & Wood, 2003). A meta-analysis of HAART adherence in which 31 studies from North America and 27 studies from Sub-Saharan Africa were incorporated, found high levels of adherence in African

settings; however, it remained a concern among patients in North America (Mills *et al.*, 2006b).

2.4.4 Perceived social support

Lack of social support has been found to be a barrier to HAART adherence (Stirrat *et al.*, 2006). Social support is a strong predictor of medical adherence (Bearman & La Greca, 2002). Social support for adherence is defined as encouragement by family and friends for the patient to co-operate with the recommendations and prescriptions of a health professional (DiMatteo, 2004). Gonzalez, Penedo, Frank, Anton, Duran, McPherson-Baker, Ironson, Isabel Fernandez, Kimas, Fletcher and Schneiderman (2004) found that perceived social support and a positive state of mind were associated with increased adherence to HAART whereas depression had the opposite effect. Low self-efficacy beliefs, depression, and feelings of hopelessness are thought to mediate non-adherence behaviour among people with inadequate social support (Simoni *et al.*, 2006a). In South Africa, people living with HIV / AIDS in the public sector ART programme are encouraged to disclose their HIV status to at least one family member or friend and this person is called a treatment supporter.

According to Nachega *et al.* (2006), treatment supporters are normally trusted confidantes who have moral authority over the patient and they influence their health decisions and assist them to take their medication as prescribed. Similar findings were found from in-depth interviews in 5 studies conducted in Africa that social and family support, communication, and access to care that anticipated patients' individual needs played an important positive role and family acted as a facilitating factor of adherence, primarily among children and women (Mills *et al.*, 2006b; Wasti *et al.*, 2011; Mimiaga, Safren, Dvoryak, Reisner & Needle, 2010; Remien *et al.*, 2003).

A meta-analysis reported that adherence is 1.74 times higher in patients from cohesive families (DiMatteo, 2004), whereas absence of this is a factor leading to poor adherence (Diabate, Alary & Koffi, 2007). There is strong evidence that positive social support, including being married, is associated with adherence to HAART (Holstad, Pace, De & Ura, 2006; Parruti, Manzoli, Toro, DAmico, Rotolo, Graziani, Schioppa, Consorte, Alterio, Toro & Boyle, 2006). In a qualitative study of HIV

positive women, participants reported that ruptures in positive social support; such as the death of a spouse, the end of an intimate relationship, and family conflict resulted in some of them questioning their need to adhere to medication (Wood, Tobias, McCree, 2004a). A qualitative study conducted in the KwaZulu-Natal Province, South Africa and in Soweto by Nachegea, Lehman, Hlatshwayo, Mothopeng, Chaisson and Karstaedt, (2005) find that ensuring HAART adherence depends on patients revealing their HIV status in order to receive direct social support; patients who report greater openness about their HIV status are likely to have higher rates of adherence.

2.4.5 Lack of communication between patients and health care providers

The patient and health care provider relationship and the patients' degree of satisfaction with health services influence their adherence to HAART (Roberts, 2002). A meaningful and supportive relationship between the patient and health care provider can help to overcome significant barriers to adherence. Factors that have been identified as strengthening the relationship between patient and health care provider by Schneider, Kaplan, Greenfield, Li and Wilson (2009) include perception of provider competence, quality and clarity of communication, compassion shown by the provider, involving the patient as an active participant in treatment decisions, and convenience of the regimen. Patients become frustrated with health care providers when misunderstandings occur, treatment becomes complex, side-effects go unmanaged, and the patient is blamed for being a "bad patient".

In a study done by Gao and Nau (2000), difficulty in following physician's instructions is a significant barrier to medications adherence. This suggests that patients' medication adherence can be improved by enhancing the relationship and communication between patients and health care providers (Chesney, 2000; Stone, Clarke, Lovell, Steger, Hirshhorn, Boswell, Monroe, Stein, Tyree & Mayer, 1998; WHO, 2003). When patients trust their doctors, feel valued, and are confident that their privacy will be respected, they are more likely to adhere to HAART (Molassiotis, Morris & Trueman, 2009). These issues are particularly relevant in the South African context where, because of the scale of the epidemic and widespread shortages of health care professionals in the public sector, fewer opportunities for forging good relationships among doctors, nurses, and patients may occur. Molassiotis *et al.* (2009) found that inadequate provision of health education, lack of clear instructions

about treatment plans, and reduced positive reinforcement by health care providers are associated with decreased adherence intentions.

2.4.6 Health system barriers

Health system barriers affect adherence, especially a regular and timely supply of medication to patients. An unreliable supply of medications can severely reduce patient adherence rates. WHO (2007) state that in the majority of the Sub-Saharan countries in Africa struggle with weak procurement and supply management systems that lead to frequent shortages of HAART and other essential inputs. In a survey of 91 low and middle income countries in 2008, 34% had experienced at least one stock out of a required ART medication (WHO, 2007). Limited availability and accessibility of antiretroviral medications and health care facilities for diagnosis and treatment of HIV / AIDS, out- of-pocket payments, high cost of ART, presence of health care providers experienced in ART provision, waiting times and operating hours, availability of counselling services, and social and psychological support for people living in both developed, as well as undeveloped countries can influence adherence positively or negatively (Biadgilign, Reda, Deribew, 2011; Skovdal *et al.*, 2011a; Hardon, Akurut, Comoro, Ekezie & Irunde, 2007; Grant, Logie, Masura, Gorman & Murray, 2008; Meyer-Rath & Richter, 2007). A recent study from South Africa by Nachega, Mills and Schechter (2010) indicates that improving adherence is cost effective and helps to reduce health care costs, especially for hospital care.

2.4.7 Patients' behaviour

Patient's behaviour is a critical link between a prescribed regimen and treatment outcomes. Consequently, the most important factors influencing adherence are patient related and under the patients' control; attention to these factors is a necessary and important step in improving adherence (Chesney, 2000). From studies done, socio-demographic factors generally do not predict adherence behaviour although some studies have found that men, white ethnicity, older age, higher income, higher education, and literacy correlate with better adherence (Eldred, Wu, Chaison & Moore, 1998; Gifford, Bormann, Shively, Wright, Richman & Bozette, 2000; Kleeberbeger, Phair, Strathdee, Detels, & Kingsley, 2001; Weidle *et al.*, 2006); whilst in a study conducted in India, high adherence was seen in females in

comparison with males due to the greater degree of family support (Akhila, Arbind, Chandrashekar, Aarathi, Satish, Prabha, & John, 2010). Psychological factors that have been identified by several researchers related to adherence behaviour include depression and psychiatric illness, active substance abuse (especially alcohol and intravenous drugs), self- efficacy, lack of knowledge, culture, and religious beliefs. Cohen (2007) describes an increase adherence of those patients with a history of opportunistic infections. The authors postulate that experience with illness stokes the desire for health and a motivation to adhere.

- **Religious beliefs**

Religious beliefs are complex concepts and are part of the basic assumptions that shape people's identities and strongly affect their decision making, such as taking medication on fasting days (Wasti *et al.*, 2011). Borrás, Mohr, Brandt, Gillieron, Eytan and Huguelet (2009) find that religious beliefs play an important role in influencing adherence, and over a third of patients use religion to assign various meanings to their illness. Findings of a study conducted in Nepal by Wasti *et al.* (2012) reveal that few patients believe ART is curing HIV / AIDS and are unclear about how long they should take ART.

It has been suggested that incorporating discussions about spiritual beliefs into adherence counselling could foster adherence in Uganda (Wanyama, Castelnuovo, Wandera, Mwebaze, & Kambuku, 2007). Necessity and concerns about beliefs with respect to HAART may influence treatment uptake and adherence behaviour. Horne, Buick, Fisher, Leake, Cooper and Weinman (2009) find that the necessity concerns framework accurately predicts treatment uptake adherence to HAART among 153 participants. Another study find people living with HIV / AIDS with higher necessity scores relative to concerns are more likely to have higher CD4 counts compared to those with low scores (Horne *et al.*,2009). In South Africa's black communities, beliefs about witchcraft and traditional healers are rooted in the traditional healing paradigm and this could potentially influence adherence behaviour.

Negative beliefs about the efficacy of HAART may also affect adherence behaviour. For example, one study conducted by Kleeberbeger *et al.* (2001), reports that better adherence is found in patients who believe that antiretroviral medication is effective.

Siegel, Karus and Schrimshaw (2000) show that African American men are more likely than Caucasian men to report scepticism about medication and their ability to adhere to such medication, thus giving a racial dimension to patients' beliefs and knowledge.

- **Lack of knowledge**

Patient's knowledge and beliefs about disease and medication can influence adherence. Understanding the relationship between adherence and viral load and between viral load and disease progression is an integral component of good adherence. Similar findings from different studies conducted in Brazil, India, and Uganda report that education may impact adherence in several ways; including facilitating communication with health care providers, increasing retention of information provided by health care workers, and thereby enhancing adherence to an ART medication regimen (Bonolo, Cesar, Acurcio, Ceccato, De Padua, 2005; Murphy, Roberts, Hoffman, Molina & Lu, 2003; Sarna, Pujari, Sengar, Garg & Gupta, 2008). Johnson, Jacobson, Gazmararian and Blake (2010) state that patient with limited literacy might be reluctant to ask other people for the kind of help they need to take their medication correctly. Better educated people convinced of ART efficacy, perhaps as a result of educational programmes, show better adherence (Kleeberbeger *et al.*, 2001).

- **Alcohol and substance abuse**

Drug abuse and alcohol consumption are factors that further threaten proper adherences to ART. Some studies have demonstrated that a history of substance abuse is unrelated to adherence, although active substance abuse is one of the stronger predictors of non-adherence (Chesney, 2000; Kleeberbeger *et al.*, 2001; Gordillo, Del Amo, Soriano & Gonzalez-Lahoz, 2000; Ostrop, Hallett & Gill, 2000; Roberts & Mann, 2000). Several studies have consistently shown that active alcohol use and substance abuse make it more difficult for patients to adhere to HAART (Stirrat *et al.*, 2006; Weiser, Wolfe & Bangsberg, 2006). One survey study in Botswana found that nearly 40 per cent of the patients surveyed admitted missing a dose because of alcohol consumption (Kip *et al.*, 2009). Samet, Horton, Meli, Freedberg and Palepu (2009) find that patients who consume alcohol are three times

more likely of skipping doses, forgetting, running out of pills, and having irregular medication taking patterns. Cook, Sereika, Hunt, Woodward, Erlen and Conigliaro (2009) lower the perception of risk while forgetfulness is believed to be the mechanism by which alcohol causes non-adherence. Similar studies also indicate that alcohol is highly related to reducing adherence (Gill *et al.*, 2005). A systematic review in 2009 found that HIV / AIDS patients who used alcohol were 50-60% more likely to adhere less to their prescribed medication (Hendershot, Stoner, Pantalone & Simoni, 2009).

2.5 CONCLUSION

This chapter discussed the literature review and described an overview of the role of adherence to HAART in the effective treatment of HIV/AIDS. Different methods of adherence measurement used both in clinical and research settings and their advantages and disadvantages when used in different study settings are highlighted. Related factors contributing to non-adherence to HAART according to the findings of different studies have been reviewed. However, for most of the studies the study settings were in developed countries and few had been done in Sub-Saharan Africa, including South Africa. The next chapter discusses research methodology.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

Chapter 2 discussed the literature review while this chapter covers the research methodology that outlines a logical process of the research and what processes and procedures are followed to answer the research question and to achieve the research objectives. The aim of the study was to explore factors that contributed to non-adherence of patients to HAART at the Kanyamazane Clinic.

3.2 STUDY SITE

The study was conducted at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province. The Mpumalanga Province is one of the 9 provinces in South Africa, and has 3 districts that are: Gert Sibande, Nkangala, and Ehlanzeni. The Ehlanzeni District has 5 municipalities, namely: Nkomazi, Thaba-chweu, Bushbuckridge, Umjindi, and Mbombela municipality. Ehlanzeni district has 121 clinics, 31 clinics are under Mbombela. Umjindi has 11 clinics, Thaba-chweu has 10 clinics, Bushbuckridge has 38 clinics, and Nkomazi has 31 clinics. The Kanyamazane Clinic is one of the clinics of the Mbombela Municipality and is situated about 26 kilometres to the East of Nelspruit. During the study the Kanyamazane Clinic was currently serving a total of 3 845 patients on HAART, 2 500 were females and 1 345 were males. According to the captured data, 280 patients have left the programme. The Kanyamazane Clinic is situated in a semi-urban area that is characterised by a number of formal settlements while 70% of the population are employed. Some of the people are from other places and they are staying there because of work, since the Kanyamazane Clinic is near the city of Nelspruit.

3.3 STUDY METHOD

Qualitative research is an interdisciplinary, trans-disciplinary, and sometimes counter-disciplinary field. It crosscuts the disciplines of the human sciences, social sciences, and the physical sciences (Denzin & Lincoln, 2000). Denzin and Lincoln (2000) also state that qualitative research is many things at the same time and is multi-paradigmatic in focus, since its practitioners are sensitive to the value of the

multi-method approach, and they are committed to the naturalistic perspective and to the interpretive understanding of human experience. De Vos, Strydom, Fouché and Delport (2005) define qualitative research as an umbrella term for different approaches or paradigms, each having its own theoretical background, methodological principles, and aims.

Qualitative research is constantly in flux and changing and it is clear that as we strive to make sense of the social world and create new knowledge or revisit what is known, new research perspectives will evolve in an effort to answer an unanswered philosophical question related to the representation of another (Denzin & Lincoln, 2000). A qualitative research approach was used, since the method focused on an in-depth understanding of the phenomenon under investigation, with the subjective exploration of reality from the perspective of the population being studied (De Vos *et al.*, 2005).

3.4 STUDY DESIGN

An exploratory, descriptive, and contextual design was used to explore the factors contributing to non-adherence of HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province. Burns and Grove (2005) define a research design as a blue print for conducting a study that maximises control over factors that could interfere with the desired outcome or findings of the study. Babbie (2010) defines research design as the comprehensive plan for obtaining answers to the research question being studied, including specifications for enhancing the scientific integrity of the study. It is essentially the architectural backbone of the study.

3.4.1 Exploratory design

An exploratory design was chosen in this study to assist in exploring the factors contributing to non-adherence of HAART by patients at the Kanyamazane Clinic. Exploratory studies are appropriate for more persistent phenomena (Babbie, 2010), and non-adherence behaviour of HAART by patients at the Kanyamazane is persistent. According to Babbie and Mouton (2009), a research project is exploratory when the researcher examines a new area of interest or topic, especially where a phenomenon under study is persistent. (Babbie, 2010) adds that exploratory studies are useful when the researcher wishes to assess and understand a phenomenon in a

new light, asks questions, and searches for new insights. This notion concurs with Burns and Grove (2005) view about exploratory studies that are designed to increase the knowledge of the field of study. An exploratory design aims at establishing the facts, gathering new data, and gaining new insights into the phenomena (Mouton, 1996).

3.4.2 Descriptive design

A descriptive design was chosen for the study in order to describe the factors that contributed to non-adherence of patients to HAART, and was also used to obtain complete and accurate information about the factors contributing to non-adherence of patients to HAART. Descriptive design aims at processing the meaning of, and understanding, data as described by the participants (Babbie & Mouton, 2009). Descriptive research is described by Burns and Grove (2005) as a research design that provides an accurate portrayal or account of characteristics of a particular individual, situation, or group. It is a way of describing what exists, discovering new meaning, determining the frequency with which something occurs, and categorising information. Descriptive studies are usually conducted when little is known about a phenomenon. The purpose of descriptive studies is to observe, describe, and document aspects of a situation as it naturally occurs and sometimes to serve as a starting point for hypothesis generation or theory development (Burns & Grove, 2005; Babbie, 2010).

3.4.3 Contextual design

A contextual research design was used with the aim of understanding the phenomenon as described by the participants (Babbie & Mouton, 2009). After exploring and describing the factors contributing to non-adherence of patients to HAART, the findings were understood within the context of their lived world.

3.5 POPULATION AND SAMPLING

3.5.1 Population

Population is the entire aggregation of cases that meet a designated set of criteria (Polit & Hungler, 1995). It is the group of people about whom the researcher wants to draw conclusions (Babbie & Mouton, 2009). Population, in this study, were all

HIV / AIDS infected patients on HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province. The Kanyamazane Clinic is serving a total of 3 845 patients on HAART, 2 500 are females and 1 345 are males.

3.5.2 Sampling

A sample is a subset of the population considered for actual inclusion in the study (De Vos *et al.*, 2011). Sample refers to the process of selecting a portion of the population to represent the entire population (Polit & Hungler, 1995). Non-probability purposive sampling was used. Purposive sampling was used to select the sample that was particularly knowledgeable about the issues under study (Polit & Hungler, 1995). Fifteen participants were selected for the study; thirteen of them were female patients and two were males aged between 15 and 60 years of age on HAART for more than one year and are loss to follow-up for three months. The sample size was determined by data saturation.

3.5.3 Inclusion and exclusion criteria

- **Inclusion criteria**

All HIV/AIDS infected patients aged between 15 and 60 years of age on HAART for more than one year, but not adhering to HAART and were loss to follow up were included in the study.

- **Exclusion criteria**

All HIV / AIDS infected patients on HAART for less than one year; those who were adhering to HAART, children younger than fifteen and adults over sixty years of age were excluded from the study. Loss to follow-up patients found to be over sixty years were rare, and their estimated optimum adherence rate usually was > 95%. The parents of patients younger than 15 years were taking responsibility for their treatment and made sure that they attended the clinic on a monthly basis to collect HAART.

3.6 DATA COLLECTION

According to Burns and Grove (2005), data collection is defined as the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions of a study.

3.6.1 Development of data collection instrument

An interview guide was developed as a frame of reference and the questions were open-ended so that participants could express their feelings, beliefs, knowledge, and points of view. The interview guide was developed in English and in the local language used of the participants, the Siswati language, to facilitate understanding, since the study included both educated and illiterate study participants.

3.6.2 Data collection method

Data was collected by means of semi-structured interviews. These interviews were conducted individually in a private consultation room while using a guide and audio recording each interview. Bogdan and Biklen (2003) define an interview as a purposeful conversation, usually between two people (but sometimes involving more), that is directed by one person in order to obtain information. Semi-structured interviews were selected as a method of choice, since they provided the participants with opportunities to express themselves in ways that they could not in questionnaires, to express their feelings, beliefs, knowledge, and points of view. Interviews also provide an opportunity for immediate verification of answers, room for expression of ideas, and clarification. Kumar (2005) agrees that interviews are more appropriate for complex situations. Interviews give the interviewer the opportunity to prepare the participant before asking sensitive questions and explaining difficult questions in person. It also has wider applications, thus can be used with children, as well as illiterate people. An opportunity is also provided for insight into the construction of participants' answers and how it reflects on their ideologies or interests. De Vos *et al.* (2011) suggest that qualitative interviews should be interactive and sensitive to the language and concepts used by the interviewee and interviewers should thus keep the agenda flexible. The disadvantages of interviews include that they are time consuming and are dependent on the quality of the interviewer (Kumar, 2005).

Data was collected at the Kanyamazane Clinic from patients who were not adhering to HAART on their structured follow-up dates. The central question was posed in the same manner to each participant and was as follows: “*What are the difficulties that led you not to adhere to HAART?*” followed by probing questions after each participant had responded to the central question. An audio recorder was used to record the conversation during the interview with the consent of the patient and field notes were taken during the semi-structured interview to note verbal and non-verbal cues of the participants. Data was collected until saturation of data was reached. Kumar (2005) suggests that for the researcher to have explored the diversity of a topic, a saturation level has to be reached. That is achieved by continuing with data collection for as long as there is new information to be gathered. When no new information is gathered, then the researcher is considered to have reached the saturation point. The number of participants who took part in the study was determined by the saturation of the data.

3.7 BIAS

According to Kumar (2005), bias differs from subjectivity and is unethical. Subjectivity is based on the researcher’s competence, training, educational background, and philosophical perspective; whereas bias is a deliberate attempt by the researcher to either hide something or highlight something disproportionate to its true existence. Denzin and Lincoln (2000) add that complete elimination of bias in qualitative research is not possible, however, the researcher should make every effort to minimise it with the purpose of absorbing fresh and new experiences.

- **Respondent bias**

Prior to the study, participants were provided with comprehensive and clear information with regard to their participation in the study. Interviews were conducted in the participant’s home language in order to avoid misunderstandings that might have led the study to be biased. An atmosphere that would encourage the patient to speak freely was provided; privacy and confidentiality was emphasised for participants to answer questions freely and without fear.

3.8 DATA ANALYSIS

According to De Vos *et al.* (2011), data analysis is a process of bringing about order, structure, and meaning to collected data. Data analysis is the process of systematically organising the interview transcripts, field notes, and other accumulated materials until they are understood in such a way that they address the research questions and present the results and create understanding to other people (Norman, Denzin, Yvonna & Lincoln, 2003). According to Pope (1999), the researcher's task includes not only recording descriptive data and analysing it, but also making sense of the data by shifting and interpreting them. Marshall and Rossman (1999) define data analysis as a search for general statements about relationships among categories of data. Before data collection started, the researcher had planned to collect and record data in a systematic manner that was appropriate and would facilitate analysis. Data was analysed manually using content analysis in which the content of the interviews were analysed to identify main themes from the participants' responses. This was done according to Tesch's method comprising eight steps as suggested by Creswell (2009).

Step 1: The researcher started by listening to the audio recordings repeatedly and transcribing all information verbatim.

Step 2: The researcher then read through all the transcripts and the field notes to get some sense of the data and to gain background information. Some ideas that came to mind were written down. Some topics that matched the content were identified and listed.

Step 3: Thirdly, the researcher read through all the other transcripts and identified topics. Attention was given to the meaning of the data. The researcher compiled a list of all the topics and organised them in a column. Similar topics were identified and clustered together into major topics. The best fitting name was selected for the cluster of each major topic.

Step 4: The researcher subsequently created columns for the unique clusters of topics while topics that could neither be clustered nor fitted into another column were listed in a separate column of exceptions.

Step 5: The topics were interpreted, and the clustered topics and unique topics were abbreviated as codes. The codes were written next to the relevant segments.

Step 6: The organised data was ready for refinement and descriptive wording of the topics. These topics became categories that were combined with other similar topics to reduce the number of categories.

Step 7: Abbreviations were chosen for the categories and a final alphabetical list of the codes was compiled.

Step 8: After coding with the assistance of an independent coder had been completed, the content of each category was summarised. The categories, themes and sub-themes had been identified after which the themes were discussed at length.

3.9 MEASURES TO ENSURE TRUSTWORTHINESS

The quality of the research is related to the trustworthiness and integrity of a research study. Validation also depends on the quality of the researcher's work during the investigation. Trustworthiness is a moral value considered to be a virtue (Shenton, 2004). Trustworthiness involves establishing credibility, transferability, dependability, and conformability to ensure valid interpretation of data (Lincoln & Guba, 2005).

3.9.1 Credibility

The validity of qualitative research relates to the credibility of a study. Credibility refers to the confidence in the truth of the findings. To ensure credibility, the following steps were taken during this research study:

- **Prolonged engagement**

The researcher spent two weeks in the field to establish relationships of trust while trying to ensure that no distortions took place while the participants were interviewed by allowing for free flow of information.

- **Triangulation**

Multiple methods were utilised during data gathering. An audio recorder was used to record interview conversations with the participants and field notes were taken and numbered accordingly during each interview to reduce the possibility of data being excluded during the process and to increase credibility.

- **Consultation with the supervisors**

The supervisor and co-supervisor listened to the recorded interviews. The report findings were discussed with the supervisors and the audio recordings were available to validate data.

- **Member checking**

The researcher returned the emerging findings to the participants to discuss and confirm the construction of data.

- **Feedback to participants**

Feedback was given to participants with the purpose of verifying the recorded data in order to correct any misinterpretations.

- **Participants' home language**

Interviews were conducted in the participant's home language (Siswati) in order to prevent the study from being biased by avoiding misunderstandings.

- **Follow-up interviews**

Follow-up interviews with patients were conducted to check whether patients responded in the same way.

3.9.2 Transferability

Transferability refers to the degree to which the results of a study can be generalised from a specific situation to another (De Vos *et al.*, 2011). According to Golafshani (2003), if the setting of the study is similar to other parts of South Africa given variations of different parameters like age, gender, diagnosis, and treatment regimen; the transferability of the results may be extended to other similar sociocultural settings. Green (1999) states that qualitative studies are not usually intended to be

generalised, and also suggests that using a small size sample does not, in itself, threaten the potential generalisability of a qualitative research study. The strength of qualitative research lies in its transferability, instead of generalisability which means that it is possible for other researchers to make use of the study if they find it relevant to their situation. To ensure transferability, the following steps were followed:

- **A detailed description of methodology used in the study**

Transferability was enhanced by providing sufficient details of the context of the fieldwork for the person who would be generalising the information to be able to decide whether the findings could be justifiably applied to the other settings.

- **The use of purposive sampling**

Purposive sampling, that was based on the researcher's judgement to maximise the range of specific data, was used.

3.9.3 Dependability

Dependability refers to determining whether the research process is logical, well documented, and audited (De Vos *et al.*, 2011). Dependability was ensured by the following steps:

- **Dependability audit**

Field notes were written and verbatim capturing of the interviews was done that facilitated an auditing process.

- **Independent coder**

Raw data was submitted to an independent coder who was regarded as an expert in the field of qualitative research to conduct an independent examination of the data and to confirm the outcomes (Appendix 4).

3.9.4 Confirmability

Confirmability refers to whether the findings of the study could be confirmed by another person (De Vos *et al.*, 2011). Lincoln and Guba (2005) agree that

confirmability guarantees that findings, recommendations, and conclusions are supported by the data. Confirmability was enhanced by the following steps:

- **Verification of data in the field**

Steps were taken to demonstrate that findings emerged from the data and not from the researcher's own predispositions by checking and re-checking data throughout the study. The researcher asked the same questions during follow-up sessions to check whether the patients would provide the same responses.

- **Audit trail**

The audio recordings were submitted to the supervisors to listen to with the aim of verifying whether the data on the recordings corresponded with that of the field notes.

3.10 ETHICAL CONSIDERATIONS

Ethical standards were ensured by obtaining permission and ethical clearance from the appropriate authorities. Verbal and written informed consent was obtained from the participants in either English or Siswati after being provided with comprehensive and clear information about their participation in the study. The rights of the participants were protected and included aspects; such as confidentiality, anonymity, and avoidance of discomfort and harm (De Vos *et al.*, 2011).

The researcher adhered to the following ethical standards:

3.10.1 Permission and ethical clearance

Ethical clearance was given by the Medunsa Research Ethics Committee (MREC), and permission to conduct the study was obtained from the Ethics Committee of the Mpumalanga Province, Department of Health and Social Development and from the supervisor at the Kanyamazane Clinic.

3.10.2 Informed consent

Participants were provided with comprehensive and clear information with regard to their participation in the study. Participants were informed that their participation was voluntary; they had a right to decide whether or not to participate in the study without

risk of penalty and to withdraw from the study at any time. Information was provided in a verbal and recorded form for credibility, to take into consideration those participants in the population of the study who might have been illiterate; the literate participants were provided with a consent form, with all the information that was discussed, to sign if they agreed to participate in the proposed study (De Vos *et al.*, 2011).

3.10.3 Confidentiality and anonymity

Participants were informed about their right to privacy and the steps that would be taken to ensure that no breach of this principle would take place. Participants were assured that the information collected from or about them would remain private, and data was collected in a private consultation room. Privacy was ensured through anonymity and confidentiality (De Vos *et al.*, 2011).

Anonymity refers to the researcher's act of keeping the subjects' identities a secret with regard to their participation in the study (Babbie, 2007). Anonymity was ensured by not audio recording real names of the participants; to ensure anonymity, each participant was provided with a codename that was used throughout the study while discussing data.

The list of participants' names was kept safe for follow-up in case there were issues that needed following up (De Vos *et al.*, 2011). Confidentiality refers to the researcher's responsibility to prevent all data gathered during the study from being divulged or made available to any other person (Brink, 2006). Participants were assured that audio recordings of interviews would be kept locked in a secure safe place where no unauthorised person would gain access to the study data.

3.10.4 Avoidance of discomfort and harm

Protection from discomfort and harm can be provided either physically or emotionally, and may be needed during a qualitative research project (Babbie, 2007). Participants were informed before the interview about the potential impact of the investigation to provide participants with an opportunity to withdraw if they wished to do so, and withdrawal from the study was handled with the utmost sensitivity. Debriefing sessions were conducted after the study to give participants an opportunity to work

through their experiences and its aftermath, and the possible harm that might have arisen in spite of all precautions to minimise any negative impact. The researcher rectified any misperceptions that might have arisen in the minds of participants after the research project (De Vos *et al.*, 2011). The researcher tried by all means to avoid harming participants by the careful structuring of questions. Questions that could have upset the participants were avoided, and signs of distress of participants were monitored in the event that they needed to be referred for counselling at the premises of the clinic (Brink, 2006).

3.11 CONCLUSION

This chapter described and discussed the research design and methodology used in the study; study site (including population); sample and sampling technique; data collection method and development of research instrument; data analysis; measures to ensure trustworthiness that include credibility, transferability, dependability, and conformability; and ethical considerations involving aspects; such as obtaining permission and ethical clearance, informed consent, confidentiality and anonymity, and avoidance of discomfort and harm. The next chapter discusses the data analysis, as well as the presentation and interpretation of results.

CHAPTER 4

DATA ANALYSIS, PRESENTATION, AND INTERPRETATION OF RESULTS

4.1 INTRODUCTION

Chapter 3 discusses the research methodology while this chapter reports on the results of the data analysis in terms of the themes identified after the participant interviews. Themes and sub-themes are discussed in this chapter followed by direct quotations that provide support for and clarity about the themes and participants' experiences. Some of the statements may appear in more than one theme where they reflect different meanings. Four themes emerged from the interviews and were separated into four categories: Health care team and health care system related factors, patient related factors, medication related factors, and socioeconomic factors.

4.2 DEMOGRAPHIC DATA

Fifteen patients participated in this study and they were two males and thirteen females. The participants were between 18 and 53 years old. Participants' marital status was as follows: Five of them were married, two were widows, and eight were single. The majority of the participants were unemployed, and those who were working in lower income job positions. Both male participants were working as security guards while three females were domestic workers. Ten of the participants were unemployed.

4.3 RESULTS AND DISCUSSION

Data was analysed manually, using content analysis in which the content of the interviews were analysed to identify main themes from the participants' responses. Tesch's method comprising eight steps as suggested by Creswell (2009) was used during data analysis; four themes and eleven sub-themes emerged. The results are discussed based on factors contributing to non-adherence of patients to HAART. Table 4.1 represents the themes and sub-themes that have emerged during data analysis.

Table 4.1: Themes and sub-themes

THEMES	SUB-THEMES
1. Health care team and health care system factors	1.1 Patient-provider relationship and delivery of services 1.2 Waiting hours and overcrowding 1.3 Working hours of the facility
2. Patient related factors	2.1 Forgetfulness and experiencing better health 2.2 Suicidal reaction 2.3 Belief systems
3. Medication related factors	3.1 Side-effects 3.2 Pill burden
4. Socio economic factors	4.1 Migration due to employment 4.2 Poverty and unemployment 4.3 Disclosure, stigma, and discrimination

4.3.1 THEME1: HEALTH CARE TEAM AND HEALTH CARE SYSTEM RELATED FACTORS

Several factors were identified to have contributed to non- adherence of participants to HAART. Participants reported experiencing problems pertaining to long waiting hours at the clinic, patient-provider relationships and delivery of services, overcrowding, and working hours of the facility.

- **Sub-theme 1.1: Patient-provider relationships and service delivery**

The relationship with the health care providers can be very important to patients. Participants were not satisfied with the health care provided. In situations where patients receive good and adequate attention, it goes a long way in boosting their morale towards visiting the clinic and using their drug regimens. Two of the participants in this study indicated that they had a negative experience with staff members. They also complained about a shortage of care, lack of respect by nurses, staff attitude, lack of good and adequate services, and communication with patients. Two participants stated that the nurses were rude and shouted at them sometimes,

which also contributed to non-adherence of HAART. Verbatim quotations support these observations:

“You ended up not taking your pills because there is no good care at the clinic, nurses do not give us love as patients they treat us badly shouting at us and chasing us to stay outside the clinic as there are no enough chairs inside the clinic and the security guards are also pushing us with the support of nurses”.

“I was returned back home for two consecutive months by the sisters working in the file room because I lost my appointment card”.

These findings are congruent with the study of Fisher, Fisher, Amico and Harman (2006) that report participants who perceived nurses as rude and impolite, which they found discouraging. Roberts (2002) report that the patient and health care provider relationship and the patients' degree of satisfaction with health services influence their adherence to HAART.

Some of the participants in the present study mentioned that nurses at the clinic were inclined to spend long hours when they went on tea and lunch breaks, and they left as a group, leaving patients unattended with no one to assist them; as a result, most patients lost patience and ended up leaving the facility without their medication. This is evident from one participant who indicated that:

“I am a grade 12 learner, I wake up early and arrive at the clinic at 05:00 to fetch my medication so that I can be attended early with the hope of arriving at school during school break because my return date given at the clinic is during week days and I supposed to be attending classes, and on my arrival at the clinic there was long queue and nurses take long period to come back from tea break and if they come back they attend few patients then they all return back for lunch leaving us unattended, and I ended up being very late at school and without medication then I decided to stop my medication because [I] am missing my studies and I am afraid to tell my teacher why I'm late”.

Another participant who had the same experience stated: *“When nurses go for lunch they do not come back”.*

In agreement with these findings, studies conducted by Chesney (2000); Stone *et al.* (1998) found that hostility, unkindness, and a lack of empathy from staff members were reported by the participants.

Another reason for the missed visit was fear of retribution due to missing a visit. Participants shared feelings of being scared of facing the health care providers at the clinic after missing scheduled visits and out of fear they might have missed more. This statement was supported by the response of another participant, who said:

“In this clinic, the way nurses treat us you even become afraid to ask anything concerning your health because of the bad treatment we receive from them and you prefer to ask patients next to you rather than nurses, then I’ve decided to stop my ARVs and go consult to the traditional healer where I get my medication at the same time without suffering and I feel better with my traditional medication and I see a lot of improvement than before on ARVs”.

A study conducted by Schneider *et al.* (2009) reveal that the negative experiences patients have with staff contributed to the patients’ unwillingness to attend certain clinic visits, and they, however, are attributing it to being ill-treated as a result of their lack of punctuality for scheduled clinic visits. Mollasiostis *et al.* (2009) find that inadequate provision of health education, lack of clear instructions about treatment plans, and reduced positive reinforcement from health care providers are associated with decreased adherence intentions. Factors that have been identified as strengthening the relationship among patients and health care providers by Schneider *et al.* (2009) include perceptions of provider competence, quality and clarity of communication, compassion shown by the provider, involving the patient as an active participant in treatment decisions, and convenience of the regimen.

- **Sub-theme 1.2: Waiting hours and overcrowding**

Long waiting times and overcrowding emerged as one of the factors contributing to non-adherence of HAART. The long hours spend by patients at the clinic waiting for health care providers and during consultations have also been mentioned as one of the factors contributing to non-adherence. Participants indicated that overcrowding at the facility caused them inconvenience, resulted in extended waiting times, and there

was a lack of privacy while they were being attended to. The importance of arriving early in the morning on the date of scheduled clinic visits was also emphasised by the participants; some had even arrived at four or five in the morning with the expectation that they would be able to go home early in the afternoon. Although they arrived early in the morning, their visit could still be a lengthy one. Straight-forward activities; such as collecting files, having blood pressure taken, waiting for blood to be taken, and also waiting for medication at the pharmacy; were all considered to be frustrating and time consuming activities. This was indicated by the participant who said, *"...at the clinic, you spend the whole day just to fetch your medication even if you wake up early"*.

Another participant added by saying *"I wake up early and found the clinic already full of patients"*.

These findings are reinforced by three studies in Uganda, Tanzania, and Botswana conducted by Hardon (2007) which show that the problem of long waiting times is cited as a major challenge to adherence.

Some of the participants reported that they arrived early at the clinic, at 05:00 in the morning, to enable them to finish early and return back to work if possible but they ended up leaving the facility late, around 15:00 in the afternoon; sometimes they left without medication and were told to return the following day. This made it difficult for them to come back because they still had to face long queues, leaving them with no option but to discontinue HAART; they only returned after contracting opportunistic infections. Some participants stated that the clinic was always full of patients and there were long queues in all the sections where they had to go before they actually would get their medication. One participant said:

"I arrive early at around 05:00 at the clinic to queue for a number at the main gate of the clinic, and then proceed to another queue at the window to get my file where sometimes they told me that my file is missing and I must come back the following day. If it happens I get my file I have to proceed and queue for vital signs and consultation, I queue for bloods and then at the pharmacy to collect my medication and that is frustrating that is why I told myself to skip months in collecting my medication".

In support of this findings, studies conducted by Mshana *et al.* (2006); Sanjobo *et al.* (2008); and Nachega *et al.* (2006) indicate that participants expressed a degree of inconvenience due to lengthy waiting periods when being attended to by the nurses and having their prescriptions filled at the pharmacy.

- **Sub-theme 1.3: Working hours of the facility**

Opening and closing times of HAART services offered at the clinic contribute to non-adherence. One female participant reported that HAART services were provided only on specific days and not on weekends and she only had enough time on weekends to go and collect her medication because she was attending school during weekdays. This was pointed out by one participant who said, *“I think if they were issuing us treatment on weekend because during the week I am attending classes and I am free on weekends I wouldn’t stop my medication”*.

Similar findings are presented in studies conducted in both developed and undeveloped countries during which the participants revealed that operating hours influenced adherence to HAART, positively or negatively (Biadgilign *et al.*, 2011; Skovdal *et al.*, 2011a; Hardon *et al.*, 2007; Grant *et al.*, 2008; Meyer-Rath & Richter, 2007).

4.3.2 THEME 2: PATIENT RELATED FACTORS

Forgetfulness and experiencing better health, suicidal reaction, and beliefs of patients were mentioned as factors contributing to non-adherence of the participants.

- **Sub-theme 2.1: Forgetfulness and experiencing better health**

Findings in this study reveal that forgetfulness and experiencing better health contribute to patients not taking their HAART. Two female participants mentioned that they forgot the routines of taking medication as a result of stress due to social problems. Also, one female participant reported to have stopped taking medication because she was feeling better and overwhelmed with ‘pride’, because she was looking physically fit and was back in her healthy, functional state. One participant said, *“If you see yourself healthy and fit, you tend to forget and skip doses and ended up not taking anything at all.”* Another participant indicated *“I do take my medication*

but not the way it supposed to be taken and I collect them monthly but my problem is, I forgot to drink my pills due to social problems”.

Studies by Mukhtar-Yola, Adeleke, Gwarzo and Ladan (2006); and Uzochukwu, Onwujekwe, Onoka, Okoli, Uguru and Chukwuogo (2009) concur with findings of this study that patients with HIV / AIDS are failing to take their medication as required on account of forgetfulness. Findings on this issue are mixed (Hardon *et al.*, 2007). Findings of the study conducted by Lekhuleni, Mothiba, Maputle and Jali (2013) also indicate that participants who were on ARVs left the treatment at home whilst visiting relatives and friends because of forgetfulness. Patient forgetfulness to take their oral dose contributes significantly to non-adherence and makes it an issue of considerable debate. The patient-centred perspective on adherence points an accusing finger to the patient habit of forgetfulness. Ammassari, Trotta, Murri, Castelli, Narciso, Noto, Vecchiet, Monforte, Wu and Antinori (2002) review published studies conducted in different settings which reported that the most common reasons for skipping HAART included forgetfulness to take medication.

- **Sub-theme 2.2: Suicidal reaction**

Suicidal reaction was pointed out as one of the factors contributing to non-adherence by two participants. The two participants expressed a desire to end their lives; they mentioned suicidal ideation with the thought that if they stopped taking HAART they would die. During the time of interview, they were both emotional. One participant discontinued medication because she was undergoing a lot of stress. She was rejected by her boyfriend and family members. Another participant concurred:

“I was rejected by my boyfriend after my family member disclosed to him that I am on HAART and he was not aware of my HIV-positive status. I was angry and I was thinking that if I stop to take my pills I will die... and I really wanted to die”.

A participant seemed to be pessimistic about the future, she stated that she does not care after all, she is staying alone and nobody cares about her, and her daughter rarely come to visit her. She reported that she used to work piece jobs in town and because of recurrent illnesses; she was then useless and unable to work. She mentioned that there was no improvement on treatment. She also verbalised that she

told herself it was better to die than to suffer from drinking medication that did not help her and prolonged illness. She then decided to stop taking medication. This was substantiated by another participant who said, *“haaa... the reason is, I told myself that is better to go in this world, is better to go than to live in this situation of suffering from taking medication”*.

These findings are similar to those of Wood *et al.* (2004a) that many HIV-positive people portray a sense of hopelessness and of lacking the will to live with this chronic disease.

- **Sub-theme 2.3: Belief systems**

Patient’s knowledge and beliefs about disease and medicine can influence adherence. Participants mentioned different belief systems as a contributory factor to their adherence to medication. A belief system includes cultural belief, religious belief, and individual beliefs.

- **Cultural belief**

One female participant mentioned that she stopped HAART because she felt that was not working for her and she could not see any improvement in her illness. She then decided to go and consult traditional healers; after those consultations, she noticed improvement after she had started to take traditional medication and she felt better than before when she had been on HAART. This statement was supported by one participant, who said:

“Truly speaking ARVs are not helping me, I’ve decided to go and consult to a traditional healer in Swaziland and she gave me a traditional medication and I alternate my traditional medication with my ARVs”.

There are similarities between the findings of this study and those of Jali (2012) who earlier found that participants used both health systems when they were ill because both systems were complimentary to each other. Findings of this study also concur with those of Mukhtar-Yola *et al.* (2006); Olowookere, Fatiregun, Akinyemi, Bamgboye and Osagbemi, (2008); Skhosana, Struthers, Gray and McIntyre (2006); and Uzochukwu *et al.* (2009) in their study conducted in Africa reveal that many patients have opted out of antiretroviral treatment in favour of an alternative

treatment, such as traditional medicine. Rowe, Makhubela, Hargreaves, Porter, Hausler and Pronyk (2005) discovered that some patients put more trust in traditional healers because they were supposed to heal HIV while HAART only slowed down the process.

- **Religious belief**

Religious belief is reported to have a negative impact on adherence of patients to HAART. One participant reported strong belief in God that helped her feel positive about the future. She mentioned that God was the most superior physician of her illness; she reported that she chose to stop medication because she wanted to rest for a certain period because medication made her sick after a year on treatment and she prayed and believed that her life was in God's hands. One participant indicated, *"I chose to stop medication because I wanted to rest for a certain period; I prayed and trust God that my life is in God's hands. I don't believe on medication but I believe in God"*.

In support of these findings, Borrás *et al.* (2009) reveal that religious beliefs play an important role in influencing adherence and over a third of the patients use religion to assign various meaning to their illness. Negative beliefs in relation to the efficacy of HAART may also affect adherence behaviour. In one study conducted by Wenger *et al.* (1999), it is reported that better adherence is found in patients who believe antiretroviral medication to be effective. The role of religion on patients' ART adherence is associated with influence of religious beliefs and values of a religious institution on the patients' willingness to take their ART medication (Lima, Fernandes, Rachlis, Druyts, Montaner & Hogg, 2009).

- **Individual belief, attitude, and behaviour**

Patients' beliefs, attitudes, and behaviour contribute to their non-adherence to medication. One male participant indicated that he stopped HAART because he used to buy over the counter medication to boost his sexual activity and it counteracted his ARVs because when he took both types of medication he felt dizzy and lacked libido. He also reported that ARVs were a sexual stimulant but, at the same time, caused him to ejaculate early, which did not suit him because he liked sex very much and women were complaining about that. Then he decided to stop his ARVs and continue

with over the counter medication for sexual pleasure. This was confirmed by one participant, who said:

“As a man, I used to buy medication from the chemist for energy to boost my sexual activity as usual because in my mind there are always women, and when I took it together with my ARVs my penis did not erect... You see, and I felt dizziness, then I’ve decided to wait a bit with ARVs and concentrate on the one from the chemist because truly I like sex very much and my women appreciate it”.

Some participants expressed their own different views with regard to beliefs about HAART. Two of the participants responded differently:

“It is painful to know that you have to take your pills for the rest of your life, it really disturbed your normal life and it means that your life depends on pills”.

Another participant added by saying *“I was told that if you take ARVs for a long period you died early”.*

Attitudes and beliefs about the normative behaviour have also been shown to play a role in adherence (Kagee, Le Roux & Dick, 2007).

4.3.3 THEME 3: MEDICATION RELATED FACTORS

Factors related to the medication were identified by the participants during interviews, and were identified to have contributed to non-adherence. These factors include side-effects and pill burden.

- **Sub-theme 3.1: Side-effects**

Side-effects were reported as a major contributing factor to non-adherence in this present study. Two female participants and one male participant reported experiencing side-effects from medication and gave it as one of the reasons why they were not adhering to HAART. The unpleasant nature of side-effects reported by participants included nausea and vomiting, dizziness, painful feet, and lipodystrophy. Lipodystrophy was specifically mentioned by two young female participants. They

mentioned that medication changed their body shapes, their breasts became enlarged, they developed a buffalo hump at the back, their legs became thin, muscles became visible and hard like the muscles of males, their buttocks shrunk away, and people from the community started noticing that they were on ARVs. One mentioned that at school they laughed at her and only after they had been given reasons did they decide to stop. This statement was supported by one participant who said:

“My body shape has changed, I was not like that before started ARVs and now my body shaped like a stock sweet, my breasts growing big and I became fat on the upper extremities and thin on the lower extremities and I am no longer able to stand for a long period because my feet are painful, swollen and full of water. I then decided to stop medication because it doesn't help me”.

Another female participant added by stating: *“The reason was, my legs were hard with big visible muscles as if I am a man.”* (pointing at her legs). One male participant indicated, *“The pill called efavirenz made me feel dizzy then I took decision to stop a bit”.*

This is supported by the findings of the study conducted by Lekhuleni *et al.* (2013) that reports lipodystrophy as a major side effect affecting adherence to HAART. The literature on side-effects clearly shows that optimal adherence occurs with medication that removes symptoms, whereas adherence is reduced by medication that produces side-effects (Chesney, 2000; Max & Sherer, 2000; Roberts & Mann, 2000; Stone, 2001). One serious side-effect that may affect adherence to ART in the long term is lipodystrophy. Lipodystrophy affects between 30% and 60% of people on HAART. Its physical manifestation varies greatly but can include fat accumulation on the upper back and neck (buffalo hump), under the muscles of the abdomen (crix belly or protease pauch), lipomas, and breast enlargement. There might also be peripheral wasting of the fat in the face, legs, arms, and buttocks (Graham, 2000; Gervasoni *et al.*, 1998).

- **Sub-theme 3.2: Pill burden**

Pill burden was reported to have impact on adherence of participants to HAART. One participant reported that she was HIV / TB co-infected and she had to take both HAART and TB medication simultaneously and she felt that was too much for her and she couldn't understand which one of the two types of medication would help her as she did not see any improvement in her illness. The one condition ended up compromising the other because she ended up choosing to take medication for one condition, TB, and to stop taking the HAART medication. This was supported by another participant, who said:

“The drugs are too many to be taken every day in the morning and evening, and were worse when they told me that I have to take both ARVs and TB medication. I then stopped taking both medications because I did not understand which one would help me”.

These findings concur with those of Chesney *et al.* (2000) and D'Armino *et al.* (2000) that regimen complexity can greatly influence an individual's willingness and ability to adhere to antiretroviral therapy.

4.3.4 THEME 4: SOCIO-ECONOMIC FACTORS

Socioeconomic factors identified by the interviewed participants included migration due to employment, poverty and unemployment, disclosure, stigma, and discrimination. These factors were mentioned to have a great negative effect on adherence of participants to HAART.

- **Sub-theme 4.1: Migration due to employment**

One male participant mentioned migration as a main factor that led him to poor adherence of his medication. He reported that he stopped medication unintentionally, he was transferred to work far from home by his employer and he was not aware for where he could get his medication. A verbatim quotation from one male participant stated:

“I don’t have a problem in taking my ARVs, the problem is... my employer transfer me to work very far from home and I also made mistake because I didn’t come to the clinic to ask how I can get my medication”.

In support of this study, Lima *et al.* (2009) found that non-adherence to ARV care was also associated with resettlement or the passage through provinces due to employment opportunities, holidays, and significant events outside the area of the clinic where patients were receiving ART.

- **Sub-theme 4.2: Poverty and unemployment**

Four female participants reported poverty and unemployment as a problem in adhering to HAART. Participants expressed their own views with regard to poverty and unemployment in different ways. One of the participants emotionally mentioned that she decided to stop her medication because she was always fighting with her husband. Her husband insulted her, kicked her out of the house, and told her that he was not going to maintain her and her baby as they were both taking medication. The worst part was that she was unemployed and depended on her husband to continue taking medication. She also mentioned that when it was time for them to take medication, he looked at her with a bad eye. This statement was supported by this response from another participant who said:

“The reason why I stopped medication is because we were always fighting with my husband, insulting me, talking bad things, kick me out of the house, telling me that he is not going to maintain us, me and my baby as we are both taking medication for HIV and I’m not working”.

The findings of this study are similar to those of Bwiirire *et al.* (2008); and Varga and Brookes (2008) that fear of household conflict, divorce, and lack of support from husbands are found to be the reason for women dropping HAART. Birbeck *et al.* (2009); Skovdal *et al.* (2011a); and Watt *et al.* (2009) suggest that family members and friends can play the role of treatment partners and can provide much needed support.

In this study, some participants reported that they stopped medication because they did not have food and they were staying alone in the house. Another participant

reported that she depended on her daughter who rarely visited to give her mother some food. She also reported that she used to work piece jobs but at the time of the interview, she was no longer working because of illness while one of the other participants verbalised that she used to ask for food from neighbours. One participant said:

“The reason is... I don’t have food at home, and if I take medication what am I going to eat? If I take medication without food, the medication will ended up eating me and I am staying alone in that house, no-one will notice if I’m dead. I usually ask for food from my neighbours and people get tired of always giving you food”.

These findings concur with those of Mukhtar-Yola *et al.* (2006); Olowookere *et al.* (2008); Skhosana *et al.* (2006) and Uzochukwu *et al.* (2009) that many patients have opted out of antiretroviral treatment due to lack of food; it is reported as a barrier to their adherence to antiretroviral treatment in Nigeria. Living alone and unemployment have been associated with an increase in defaulting medication. ARV users in Tanzania have complained about hunger, since the body needs extra nutrition while it is regaining strength and weight, and that they could not afford the amount of food needed to satisfy their increased appetites (Hardon *et al.*, 2007).

- **Sub-theme 4.3: Disclosure, stigma, and discrimination**

Findings of this study reveal that disclosure, stigma, and discrimination are factors that are disturbing patients’ willingness to take HAART adherently. Some participants reported fear of other people knowing or noticing participants taking ART, or the effects of medication may lead to other people guessing about their illness. This resulted in taking their medication secretly or avoiding situations that might have exposed their status. These fears included being rejected, and what their community would have to say. Such concerns arise in different settings, particularly at school and in other public environments. One participant emphasised that when she went out with her friends for alcoholic drinks, she was inclined to hide her medication and adopted dosing schedules and routines to conceal her pill taking, as well as her diagnosis from her friends, which was stressful to her. Therefore, she decided to discontinue the medication. Side-effects, such as lipodystrophy, caused people to

notice, guess, and conclude that the participants were on ARVs which made them feel uncomfortable and resulted in discontinuation of medication. This statement was supported by the following response from a participant:

“I was afraid of the eyes of people at the clinic that what are they going to say, they will know that I am HIV positive and some of the patients on the same queue will go spread the rumour in the community, then I decided not to come and collect my ARVs”.

Mukhtar-Yola *et al.* (2006), Olowookere *et al.* (2008), Skhosana *et al.* (2006), and Uzochukwu *et al.* (2009) indicate that patients and health care professionals from previous studies mentioned that stigma and discrimination related to being HIV-infected were still present in their communities and families, despite the positive advantage of antiretroviral treatment. A qualitative study among ART patients in the rural US found that many patients missed doses because of fear of being identified as HIV-positive (Mills & Nabiryo, 2013).

4.4 CONCLUSION

This chapter presented and discussed the findings. Themes and sub-themes that emerged in this study are discussed in this chapter, followed by direct quotations that provide support for and clarity about the themes and participants' experiences. Lastly, the results were integrated with literature. The next chapter discusses conclusions, limitations, and recommendations.

CHAPTER 5

CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

5.1 INTRODUCTION

Chapter 4 deals with data analysis, presentation, and interpretation of results. This chapter discusses the conclusions of the study, its limitations, and makes recommendations to health care providers of HAART and facilitators of health care programmes on how to achieve and maintain adequate levels of adherence to ART in HIV-positive patients. The interviews revealed that the major factors contributing to non-adherence were the health care team and health care system, medication related factors, individual factors, and socioeconomic factors. These factors are discussed in more detail in this chapter, followed by a critical reflection on the research performed. The chapter ends with conclusions, as well as recommendations for future research and clinical practice.

5.2 SUMMARY OF THE RESULTS

- **AIM OF THE STUDY**

The aim of the study was:

To explore factors that contribute to non-adherence of patients to HAART at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province.

- **OBJECTIVES OF THE STUDY**

The objectives of the study were:

- **To determine the problems encountered by patients regarding adherence to HAART**

Participants were able to discuss their problems that led them not to adhere to their HAART, suggesting that this objective was met. Participants were experiencing problems pertaining to long waiting hours at the clinic, patient-provider relationships and delivery of services, overcrowding, working hours of the facility, forgetfulness,

experiencing better health, suicidal reaction, beliefs of patients, pill burden and side-effects, migration due to employment, poverty and unemployment, disclosure, stigma, and discrimination. All these problems were also identified as factors that were leading to non-adherence of HAART.

- **To determine support structures of people living with HIV / AIDS**

This objective was also met because most of the participants verbalised that they were receiving support from their family members who helped in reminding them to take their medication when it was time and encouraged them to live a positive life and not to discontinue treatment. Support structures at the Kanyamazane Clinic are available, and those support structures are patients' advocates from non-governmental organisations who are specifically doing home visits to patients on HAART with the aim of improving adherence and supporting the group. Due to stigma within the community, patients reveal that they do not allow those patients' advocates to visit them at home and they do not attend support groups because people will know that they are HIV-positive and on HAART.

- **To determine if the patients are taking additional medication**

Participants shared different experiences with regard to additional medication, for an example over the counter medication and traditional herbal medication. Some of the participants in this study preferred to take traditional medication instead of HAART, or else they took both. One abandoned HAART and chose over the counter medication to boost his sexual activity because when he took both, they counteracted one another with the results of feeling dizzy and lacking libido.

The study concluded that factors contributing to non-adherence of patients to HAART were divided into health care team and health care system, individual related factor, medication related factor, and socioeconomic factors. This study discovered that patients were not adhering to their treatment due to negative attitudes of health care providers at the clinic. It was further revealed that patients enjoyed support from family on adherence to their drugs. However, some patients were not adhering to their treatment due to treatment factors; such as side-effects of the drugs and pill burden, and long waiting hours at the clinic. Other identified factors hindering

adherence include religious and traditional beliefs, disclosure and stigma, migration, poverty, and unemployment.

5.2.1 Health care team and health care system

In this study, the findings show that participants were experiencing problems pertaining to long waiting hours at the clinic, patient-provider relationships and delivery of services, as well as overcrowding and working hours of the facility which led them to non-adherence of their treatment. This was evidenced by some participants who indicated negative experiences with health care providers. Participants reported that nurses treated them badly and sometimes shouted at them. They were really not satisfied with the health care provided and delivery of services. These findings are in agreement with Fisher, Fisher, Amico and Harman (2006) where participants reported that nurses were rude and impolite with them, which they found discouraging.

Overcrowding in public health care facilities compromises the quality of care available to the patients, but these experiences with facilities also obstruct the patients' willingness to endure these circumstances when attending scheduled clinic appointments. Facing these overcrowded circumstances not only contributes to lengthy clinic visits and a lack of privacy, but also means that patients have to leave as early as four o'clock in the morning to get ahead of other patients with the view of enabling them to leave the facility at a reasonable time in the afternoon. The participants, furthermore, mentioned long waiting hours due to a lack of good care and respect by nurses, since they all went for tea and lunch breaks for a long period of time, leaving behind patients unattended and some patients lost patience and left the facility without their medication and they were afraid to go back for their follow-up visits because of fear of retribution due to missing a visit and some ended up consulting with traditional healers because there were no long queues there.

Clinic operating hours were also mentioned as a factor contributing to non-adherence of patients and was evidenced by some participants who suggested that they should extend the days of issuing HAART to weekends in order to accommodate school learners and those people who were working during week days. Health professionals play a major role in helping patients to implement healthy

behaviours. This can be achieved by helping to reduce threats and barriers to action; and by improving communication with patients, minimising inconveniences, and supporting positive actions (Kagee, 2004).

5.2.2 Patient related factors

Present study results reveal that forgetfulness, experiencing better health, suicidal reaction, and beliefs of patients are factors contributing to non-adherence of HAART. These findings are in agreement with those of Chesney (2000) and Chesney *et al.* (2000) that identify forgetting as the main reason that patients provide for missing their dosages, especially when patients are asymptomatic. Several studies conducted by Mills *et al.* (2006b) and Nachega *et al.* (2004) indicate that patients forget their medication due to alcohol abuse, whilst participants in this study indicated that they were inclined to forget to take their medication due to social problems while some of them had experienced better health and decided to stop taking medication. Some participants expressed feeling of hopelessness and tried to commit suicide. They reported that they thought they would die if they stopped taking their medication until the progression of disease worsened, opportunistic infections started to appear. Subsequently, they decided to go back and re-start HAART.

Patients' beliefs also contribute to non-adherence because some patients believe that alternative means of treating HIV / AIDS could be more effective than ART. For that reason, one of the participants abandoned her ART for traditional medicine while another believed that prayers could miraculously heal her of the virus completely. However, their health conditions got worse after which they went back to ART. Rowe *et al.* (2005) discover that some patients put more trust in traditional healers because they are supposed to heal HIV while HAART only slows down the process. Some of the participants in this study preferred to take traditional medication than HAART, or else to take both. Some participants in this study were knowledgeable about the importance of not mixing HAART with traditional medication and some expressed doubts about HAART and voiced their preference for traditional medication. A study conducted by Jali (2012) indicates that participants reported that they used both health systems when they were ill because both systems were complimentary to each other. Horne *et al.* (2009) state that there may be interaction between the

traditional medication and HAART, leading to either high toxicity levels or virus resistance.

5.2.3 Medication related factors

Pill burden and side-effects; such as nausea and vomiting, dizziness, peripheral neuropathy, and lipdystrophy were found to have contributed to non-adherence of participants to HAART in this study. Previous studies done on HIV-infected patients and patients with other chronic diseases indicate that the rate of adherence is likely to decrease as the number of types of medication, the frequency of dosages, and the increasing complexity and duration of the treatment increase (Berg, Michelson & Safren, 2007; Samet *et al.*, 2009). The interaction among types of medication, and between food and medication may easily lead to confusion, and may also contribute to non-adherence (White, 2005). One participant reported confusion and misunderstanding after she had been diagnosed with tuberculosis and had to take both HAART and TB treatment concurrently. She was exposed to pill burden and decided to stop taking both treatments. Some participants indicated side-effects and lipdystrophy was the major side-effect pointed out by most of young female participants. They were complaining about change in body shape, breasts becoming enlarged, developing a buffalo hump at the back, their legs becoming thin, muscles becoming visible and hard like the muscles of males, their buttocks shrinking away, and people from the community starting to notice that they were on HAART.

5.2.4 Socio-economic factors

Factors found to contribute to non-adherence of participants to HAART in this study were migration due to employment; poverty and unemployment; disclosure, stigma, and discrimination; domestic violence; and social support. The present study, in agreement with studies by Lima *et al.* (2009), finds migration amongst HIV-positive patients to be the reason for not adhering to their treatment. However there is limited literature to support this observation. The decision to migrate is often associated with patients' socio-economic status and results from the inability to generate an income within their present environment. In agreement with the findings of Cao *et al.* (2006); Yu *et al.* (2009); Zukoski and Thorburn (2009); and Adeneye *et al.* (2006), the present study finds that patients fear disclosure of their HIV-positive status to other

people within their environment for several reasons which also affects their pill taking behaviour. Findings of this study also establish that patients choose not to disclose their HIV-positive status to certain friends due to the fact that these friends will spread the news about their HIV-positive status and that they are also on HAART.

Patients associate inappropriate disclosure with their social network discovering their HIV-positive status through services provided at the public health care facilities, thus, patients' adherence to HAART care is compromised by their fear of having to deal with stigma when accessing health care resources within their environment. Similar findings of Reis, Heisler, Amowitz, Moreland, Mafeni, Anyamele, Lacopino (2005), establish that the health care facility itself is also a prime stigmatising agent, and contributes to an already reluctant patient's unwillingness to attend scheduled clinic visits due to fear of other people who are also visiting for their same treatment because it is noticeable to others, since they are using one consultation room and they queue in a long row with either patients who are collecting their ARVs.

Some participants reported lack of food as a factor that made adherence difficult because they felt hungry after taking their drugs and they were unemployed and, therefore, would not take the drugs when they could not afford to buy food at that time. One participant also mentioned that when she took HAART without food, the drugs itself would end up eating her. In another study, it is revealed that some patients have complained about lack of emotional / psychological support from friends and family members that result in abandonment (Mukhtar-Yola, *et al.*, 2006; Olowookere, *et al.*, 2008; Skhosana, *et al.*, 2006). This study disagrees with this finding, since no participant indicated abandonment as a factor contributing to non-adherence to their antiretroviral treatment. In fact, they reported a high level of family support.

5.3 LIMITATIONS

The results cannot be generalised to neither the entire Mpumalanga Province, nor to the other provinces in South Africa, since the study is limited to one clinic in the Mpumalanga Province.

5.4 RECOMMENDATIONS

The study recommended the following:

5.4.1 Management of the clinic

- Senior management of the Kanyamazane Clinic must ensure that supervision is done regularly in that facility to ensure compliance with the the seven domains of the National Core Standards.
- Strategies should be developed to allocate two groups for tea and lunch breaks to allow the remaining group to attend the patients' needs while the other group is taking a tea or lunch break. The times should be strictly monitored by the Operational Manager of that facility.
- The department of health should extend the facility to add more consultation rooms and human resources to reduce waiting time and overcrowding.
- ART services should be integrated into the general health services; this can be achieved by the implementation of the Integrated Chronic Care Model to reduce waiting times and stigma. This will help to avoid labelling of the consultation rooms, since all patients with chronic conditions; like epilepsy, hypertension, diabetes mellitus, mental health, cardiac, HIV / AIDS, and TB; will be attended to by the same health care providers.
- The department of health should increase awareness campaigns about HIV / AIDS and HAART by means of community dialogues and target places; such as schools, churches, and traditional healers' forums.

5.4.2 Education to patients and staff members

- Customer care service workshops should be arranged for all staff members who are working at the Kanyamazane Clinic, including security guards at the gate of the facility.
- All nurses should be trained on NIMART to avoid referring patients to specific consultation rooms with the purposes of reducing waiting times and stigma.
- In-service training of all professional nurses about management of side-effects of patients on HAART should be conducted by the HIV / AIDS training coordinators.

- Health care providers should provide health education on long term side-effects, such as lipodystrophy, to all patients who are on a regime that includes stavudine.
- Community education is recommended to reduce stigma and discrimination.

5.4.3 Patient care

- Clinic staff members should treat patients with respect, care, and love to encourage adherence to HAART.
- HAART services should be provided every day, including on weekends, to improve and increase access.
- Patients should be encouraged to post reminders for the clinic days, when drugs need to be collected, and when drugs are to be taken per day. Reminders can be in the form of calendars, alarm clocks, use of cell-phone reminders, and pill boxes.
- More emphasis should be placed on patients; during their counselling sessions before and after starting HAART, patients should be instructed about the importance of treatment reminders to promote good adherence to HAART.
- Benefits and the consequences of HAART should be clearly indicated to patients during their health education and further on-going counselling should be emphasised to encourage adherence of HAART.
- Patients should be monitored monthly for early identification and management of side-effects.
- Patients should be encouraged to report early at the clinic when they experience any of the side-effects in order to be switched to the most suitable regime.
- Health care providers should initiate patients on a regime that has low possible side-effects.
- Patients should also be monitored for treatment failure due to non-adherence and drug resistance and the second line treatment alternative should be adopted by the health care professionals.
- Health care providers should provide clear and comprehensive information with regard to access of HAART care in cases where patient have to move out of the area / province due to purposes of visiting or work.

- Economic empowerment through skills acquisition programmes provided to patients and the provision of jobs to earn a living are recommended. Such action is necessitated by unemployment and its consequential seriousness for people living with HIV/AIDS.
- Families and communities should be encouraged to form support groups focused on ART to help with adherence strategies for coping with chronic illnesses.

5.4.4 Research

Research should be conducted on adherence support programmes as this could possibly improve the adherence of people living with HIV / AIDS. A similar study should be conducted on more men than women, since few men participated in this study. Participants involved in this study were mostly unemployed females from a low socioeconomic background and I, therefore, recommend that similar studies are carried out on people who are employed because people from different backgrounds may present different information about non-adherence of HAART. The results obtained in this study may be evaluated in terms of their transferability to other contexts.

5.5 CONCLUSION

This chapter presented the conclusions, study limitations, and recommendations that have been outlined in relation to findings of this study with the purpose of improving the adherence of people living with HIV/AIDS on HAART at the Kanyamazane Clinic.

REFERENCES

- Adeneye, A.K., Adewole, T.A., Musa, A.Z., Onwujekwe, D., Odunukwe, N.N., Araoyinbol.D; Gbajabiamila, T.A & Idigbo, E.O. 2006. Limitations to access and use of antiretroviral therapy (ART) among HIV positive persons in Lagos, Nigeria. *World Health population*. 8(2):46-56.
- Akhiila, J.S., Arbind, K.C., Chandrashekar, R., Aarathi, A. Satish, R., Prabha, A & John, R. 2010. Factors affecting adherence to highly active antiretroviral therapy in HIV positive patients-Southern India. *Journal of Clinical and Diagnostic Research*. 4:2875-2877.
- Ammassari, A., Trotta, M.P., Murri, R., Castelli, F., Narciso, P., Noto, P., Vecchiet, J., Monforte, A.D., Wu, A.W & Antinori, A. 2002. Correlates and predictors of adherence to highly active anti-retroviral therapy. Overview of published literature. *Journal of Acquired Immune Deficiency Syndromes*. 31(3):123-127.
- Amberbir, A., Woldemichael, K., Getachew, S., Girma, B & Deribe, K. 2008. Predictors of adherence to antiretroviral therapy among HIV-infected person. A prospective study in Southwest Ethiopia, *BioMed Central Public Health*. 30(8): 265.
- Arnsten, J.H., Demas, P.A., Farzadegan, H., Grant, R.W., Gourevitch, M.N., Chang, C.J., Buono, D., Eckholdt, H., Howard, A.A & Schoenbaun, E.E. 2001. Antiretroviral therapy adherence and viral suppression in HIV-infected drug users. Comparison of self-report and electronic monitoring. *Clinical Infectious diseases*. 33(9):1417-1423.
- Babbie, E. 2010. *The practice of social research*. 12th edition. Cape Town: Oxford University Press.
- Babbie, E. 2007. *The practice of social research*. 9th edition. Cape Town: Oxford University Press: Cape town.
- Babbie, E & Mouton, J. 2009. *The practice of social research*. Cape Town: Oxford University Press.
- Bangsberg, D.R., Hecht, F.M., Charlebois, E.D., Chesney, M & Moss, A. 2001. Comparing objective measures of adherence to HIV antiretroviral therapy. Electronic

monitors and unannounced pill counts. *Journal of Acquired Immune Deficiency Syndrome and Behaviour*. 5(3): 275-281.

Bangsberg, D.R., Perry, S. Charlebois, E.D., Clark, R.A., Robertson, M., Zolopa, A.R & Moss, A. 2001. Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. *Journal of Acquired Immune Deficiency Syndrome*. 15(9):1181-1183.

Bangsberg, D.R., Hecht, F.M., Charlebois, E.D., Zolopa, A.R., Holodniy, M., Sheiner, L., Bamberger, J.D., Chesney, M.A & Moss, A. 2000. Adherence to protease inhibitors. HIV 1 Viral load and development of drug resistance in an indigent population. *Journal of Acquired Immune Deficiency Syndrome*. 14(4):357-366.

Barnett, T. & Whiteside, A. 2006. *AIDS in the Twenty-First Century*. Disease and Globalization. 2nd edition. New York: Palgrave MacMillan.

Bearman, K.J & La Greca, A.M. 2002. Assessing friends support of adolescent diabetes care. The diabetes social support questionnaire-friends version. *Journal of Paediatric Psychology*. 27(1):417-428.

Berg, C., Michelson, S & Safren, S. 2007. Behavioural aspects of HIV care: Adherence, depression, substance use, and HIV-transmission behaviours. *Infectious Disease Clinics of North America*. 21(1): 181-200.

Berg, K.M & Arnsten, J.H, 2006. Practical and conceptual challenges in measuring antiretroviral adherence. *Journal of Acquired Immune Deficiency Syndrome*. 43(1):79-87.

Biadgilign, S., Reda, A.A., Deribew, A. 2011. Knowledge and attitudes of caregivers of HIV-infected children toward antiretroviral treatment in Ethiopia, *Patient Education and Counseling*. 85(2) e89-e94.

Birbeck, G.L., Chomba, E., Kvaslund, M. 2009. Antiretroviral adherence in rural Zambia the first year of treatment availability. *American Journal of Medicine and Hygiene*. 80(4): 669-674.

- Bogdan, R.C & Biklen, S.K. 2003. *Qualitative research from education. An introduction to theory and methods.* 3rd edition. Boston. Allyn & Bacon.
- Bonolo, P.F., Cesar, C.C., Acurcio, F.A., Ceccato, M.G.B., de Padua, C.A.M. 2005. Non-adherence among patients initiating antiretroviral therapy. A challenge for health professionals in Brazil. *Journal of Acquired Immune Deficiency Syndrome.* 19:5-13.
- Borras, L., Mohr, S., Brandt, P., Gillieron, C., Eytan, A & Huguelet, P. 2009. Religious beliefs in schizophrenia. Their relevance for adherence to treatment. *Schizophrenia Bull.* 33(5):1238-1246.
- Brink, H. 2006. *Fundamentals of research methodology for health care professionals.* 2nd edition. CapeTown: Juta & Co (Pty) Ltd.
- Burns, N & Grove, S.K. 2005. The practice of nursing research. *Conduct, critique and utilisation.* 5th edition. St Louis: W.B Saunders Company.
- Bwirire, L.D., Fitzgerald, M., Zachariah, R., Chikafa, V. Massaquoi, M., Moens, M., Kamoto, K & Schouten, E. J. 2008. Reasons for loss to follow-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi. *Transmission of the Royal Society of Tropical Medicine and Hygiene.* 102(12):1195-1200.
- Byakika-Tusiime, J., Crane, J & Oyugi, J.H. 2009. Longitudinal adherence in HIV+Ugandan parents and their children initiating HAART in the MTCT-plus family treatment model. Role of depression in declining adherence over time. *Journal of Acquired Immune Deficiency Syndrome and Behaviour.* 13(1):s82-s91.
- Calin, T., Hetherington, J & Brook, G. 2007. Disclosure of HIV among black African men and women attending a London HIV clinic. *Journal of Acquired Immune Deficiency Syndrome Care.* 19:385-391.
- Cao, X., Sullivan, S.G., Xu, J., Wu, Z & China, C.P.T. 2006. Understanding HIV-Related Stigma and Discrimination in a Blameless Population. *Acquired Immune Deficiency Syndrome Education and Prevention.* 18(6)518-528.

- Carr, A., Samaras, K., Burton, S., Law, M., Freund, J., Chisholm, D.J & Cooper, D.A. 1998. A syndrome of peripheral lipodystrophy, hyperlipidemia and insulin resistance in patient receiving HIV protease inhibitors. *Journal of Acquired Immune Deficiency Syndrome*.12(7):51-58.
- Catz, S.L., Kelly, J.A., Bogart, L.M., Benotsch, E.G & McAuliffe, T.L. 2000. Patterns, correlates and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychology*. 19:124-133.
- Chesney, M.A. 2006. The elusive gold standard. Future perspectives for HIV adherence assessment and interventions. *Journal of Acquired Immune Deficiency Syndrome*. 43(1):149-155.
- Chesney, M.A. 2000. Factors affecting adherence to antiretroviral therapy. *Clinical Infectious Diseases*. 30(2):171-176.
- Chesney, M.A., Morin, M & Sherr, L. 2000. Adherence to HIV combination therapy. *Social Science & Medicine*. 50:1599-1605.
- Clay, P.G., Taylor, T.A.H., Glaros, A.G., McRae, M.P., Williams, C., McCandless, D & Oelklaus, M. 2008. 'One pill, once daily'. What clinicians need to know about atripla™. *Therapeutics and clinical risk management*. 4(2):291-302.
- Coetzee, D., Boulle, A., Hildebrand, K., Asselman, V., VanCutsem, G & Goemaere, E. 2004. Promoting adherence to antiretroviral therapy. The experience from a primary health care setting in khayelisha, South Africa. *Journal of Acquired Immune Deficiency Syndrome*.18: 27-31.
- Cohen, G.M. 2007. Access to diagnostics in support of HIV/AIDS and tuberculosis treatment in developing countries. *Journal of Acquired Immune Deficiency Syndrome*. 21(4):81-87.
- Conway, B. 2007. The role of adherence to antiretroviral therapy in management of HIV infection. *Journal of Acquired Immune Deficiency Syndrome*. 45(1):14-18.
- Conn, V.S., Taylor, S.G & Kelly, S. 2009. Medication regimen complexity and adherence among older adults. *Journal of Nursing Scholarship*. 23(4):231-236.

Cook, R.L., Sereika, S.M., Hunt, S.C., Woodward, W.C., Erlen, J.A & Conigliaro, J. 2009. Problem drinking and medication adherence among persons with HIV infection. *Journal of General Internal Medicine*. 16(2):83- 88.

Creswell, J.W. 2009. *Research design: Qualitative, quantitative and mixed methods approaches*. 3rd edition. London: Sage.

D' Armino, A., Lepri, A.C., Rezza, G., Pezzoti, P., Antinori, A., Phillips, A.N., Angarano, G., Colangeli, V., De Luca, A., Ippolito, G & Caggese, L. 2000. Insight into the reason for discontinuation of the first highly active antiretroviral therapy (HAART) regimen in a cohort of antiretroviral naïve patients. *Journal of Acquired Immune Deficiency Syndrome*. 14(5):499-507.

De Clercq, E. 2006. From adefovir to atripla™ via tenofovir, viread™ and truvada™ failure virology. 1(6):709-715.

Denzin, N.K & Lincoln, Y.S. 2000. *Handbook of qualitative research*. London: SAGE.

Department of Health. 2011. *South African national antiretroviral treatment guidelines*. Pretoria: Government Printers.

De Vos, A.S., Strydom, H., Fouche, C.B & Delport, C.S.L. 2011. *Research at grassroots for the social sciences and human service professions*. 4th edition. Pretoria: Van Schaik.

Diabate, S., Alary, M & Koffi, C.K. 2007. Determinants of adherence to highly active antiretroviral therapy among HIV-1-infected patients in Cote d'Ivoire. *Journal of Acquired Immune Deficiency Syndrome*. 21:1799-1803.

Dimatteo, M.R. 2004. Social support and patient adherence to medical treatment. A meta-analysis. *Healthy Psychology*. 23:207-218.

Dlamini, P.S., Wantland, D., Makoae, L.N., Chirwa, M., Kohi, T.W., Greeff, M., Naidoo, J., Mullan, J., Uys, L.R & Holzemer, W.L. 2006. HIV Stigma and Missed Medications in HIV-Positive People in Five African Countries. *Acquired Immune Deficiency Syndrome Patient Care & Sexually Transmitted Diseases*. 23(5): 112-120.

- Eldred, I.J, Wu, A.N. Chaison, R.E & Moore, D. 1998. Adherence to antiretroviral and pneumocystis prophylaxis in HIV disease. *Journal of Acquired Immune Deficiency Syndrome*. 18(2):117-125.
- Fairly, C.K., Permana, A & Read, T.R.H. 2005. Long- term utility of measuring adherence by self report compared with pharmacy record in a routine clinic setting. *Human Immunodeficiency Virus Medicine*. 6:366-369.
- Fisher, J. D., Fisher, W. A., Amico, K. R & Harman, J. J. 2006. An information-motivation-behavioral skills model of adherence to antiretroviral therapy. *Health Psychology*. 25(4): 462-473.
- Forsyth, B., Vandormael, A., Kershaw, T & Grobbelaar, J. 2008. "The political context of AIDS related stigma and knowledge in a South African township community." *Sahara Journal of Social Aspects of Human Immunodeficiency Virus- Acquired Immune Deficiency Syndrome*. 5(2):74-82.
- Frank, I. 2002. Once daily HAART. Toward a new treatment paradigm. *Journal of Acquired Immune Deficiency Syndrome*. 31:s10-s15.
- Furber, A.S., Hodgson, I.J., Desclaux, A., Mukasa, D.S. 2004. Barriers to better care for people with AIDS in developing countries. *British Medical Journal*. 329:1281-1283.
- Gao, X & Nau, D.P. 2000. Congruence of three self-report measures of medication adherence among HIV patients. *Annals of Pharmacotherapy*. 34:1117-1122.
- George, J., Phun, Y Bailey, M.J., Kong, D.C & Stewart, K. 2004. Development and validation of the medication regimen complexity index. *Annals of Pharmacotherapy*. 38(9):1369-1376.
- Gervasoni, C., Ridolfo, A.L., Trifiro, G., Santambrogio, S., Norbito, G., Musicco, M. Clerici, M., Galli, M & Moroni, M.1999. Redistribution of body fat in HIV-infected women undergoing combined antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndrome*. 13(4): 465-471.

Gifford, A.L., Bormann, J.E., Shively, M.J., Wright, B.C., Richman, D.D & Bozzette, S.A. 2000. Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. *Journal of Acquired Immune Deficiency Syndrome*. 23(5): 386-395.

Gill, C.J., Hamer, D.H., Slmon, J.L., Thea, D.M & Sabin, L.L. 2005. No room for complacency about adherence to antiretroviral therapy in sub-Saharan Africa. *Journal of Acquired Immune Deficiency Syndrome Care*. 19(12):1243-1249.

Golafshani, N. 2003. Understanding reliability and validity in qualitative research. *The qualitative researcher*. 8: 597-607.

Gonzalez, J., Penedo, S., Frank, J., Anton, M.H., Duran, R.E., McPherson-Baker, S., Ironson, G., Isabel Fernandez, M., Kimas, N.G., Fletcher, M.A & Schneiderman, N. 2004. Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. *Health Psychology*. 23(4):413-418.

Gordillo, V., Del Amo, J., Soriano, V & Gonzalez- Lahoz, J. 2000. Socio-demographic and psychological variables influencing adherence to antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndrome*. 13(13):1763-1769.

Graham, N.M. 2000. Metabolic disorders among HIV-infected patients treated with protease inhibitors. A new review. *Journal of Acquired Immune Deficiency Syndrome*. 25(1):4-11.

Grant, E., Logie, D., Masura, M., Gorman, D & Murray, S.A. 2008. Factors facilitating and challenging access and adherence to antiretroviral therapy in a township in the Zambian Copperbelt. A qualitative study. *Journal of Acquired Immune Deficiency Syndrome Care*. 20(10):1155-1160.

Green, J. 1999. Commentary, Generalisability and validity in qualitative research. *British Medical Journal*. 14:319-421.

Grossberg, R., Zhang, Y & Gross, R. 2004. A time-to prescription-refill measure of antiretroviral adherence predicted changes in viral load in HIV. *Journal of Clinical Epidemiology*. 57:1107-1110.

Hansel, A., Bucher, H.C., Nuesch, R & Battegay, M. 2001. Reasons for discontinuation of first highly active antiretroviral therapy in a cohort of protease inhibitor-naïve HIV-infected patients. *Journal of Acquired Immune Deficiency Syndrome*. 26:191-193.

Hardon, A.P., Akurut, D., Comoro, C., Ekezie, C & Irunde, H.F. 2007. Hunger, waiting time and transport costs: Time to confront challenges to ART adherence in Africa. *Journal of Acquired Immune Deficiency Syndrome Care*. 19(5):658-665.

Hendershot, C.S., Stoner, S.A., Pantalone, D.W & Simoni, J.M. 2009. Alcohol use and antiretroviral adherence. Review and meta-analysis. *Journal of Acquired Immune Deficiency Syndrome*. 52(2):180-202.

Horne, R., Buick, D., Fisher, M., Leake, H., Cooper, V & Weinman, J. 2009. Doubts about necessity and concerns about adverse effects. Identifying the types of beliefs that are associated with non-adherence to HAART. *International Journal of Sexually Transmitted Diseases & Acquired Immune Deficiency Syndrome*. 15(1):38-44.

Hugen, P.W.H., Langebeek, N., Burger, D.M., Zomer, B., Leusen, R., Schuurman, R., Koopmans, P.P & Hekster, Y.A. 2002. Assessment of adherence to HIV protease inhibitors. Comparison and combination of various methods including MEMS (Electronic monitoring), Patient and Nurse Report and therapeutic drug monitoring. *Journal of Acquired Immune Deficiency Syndrome*. 30(3):324-334.

Hugtenburg, J.G., Timmers, L., Elders, P.J.M., Vervloet, M & Van Dyk, L. 2013. Patient Preference and Adherence: Definitions, variants and causes of non-adherence with medication: A challenge for tailored interventions. *Clinical Pharmacology*. 7: 675-682.

Ickovics, J.R & Meade, C.S. 2002. Adherence to antiretroviral therapy among patients with HIV. A critical link between behavioural and bio-medical sciences. *Journal of Acquired Immune Deficiency Syndrome*. 30(3):98-102.

Inciardi, J.F & Leeds, A.L. 2005. Assessing the utility of a community pharmacy refill records as a measure of adherence and viral load response in patients infected with human immunodeficiency virus. *Pharmacotherapy*. 25:790-796.

- Jali, M.N. 2012. Collaboration of indigenous African and biomedical practices in the provision of health services. *African Journal for Physical, Health Education, Recreation and Dance (AJPHERD)*. 18(2): 213-227.
- Johnson, V.R., Jacobson, K.L., Gazmararian, J.A & Blake, S.C. 2010. Does social support help limited-literacy patients with medication adherence? A mixed methods study of patients in the Pharmacy intervention for limited Literacy (PILL) study. *Patient Education & Counselling*.79:14- 24.
- Jones, D.L., McPherson-Baker, S., Lydston, D., Camille, J., Brondolo, E., Tobin, J.N & Weiss, S.M. 2007. Efficacy of a group medication adherence intervention among HIV positive women. The smart/est women's project. *Journal of Acquired Immune Deficiency Syndrome and Behaviour*. 11(1):79-86.
- Kagee, A., Le Roux, M & Dick, J. 2007. Treatment adherence among primary care patients in a historically disadvantaged community in South Africa. *Journal of Health Psychology*. 12(3): 444-460.
- Kagee, A. 2004. Treatment adherence in South African primary healthcare. *South African Family Practice*. 46(1): 26-30.
- Kip, E.V., Ehlers, J & Van der Wal, D.M. 2009. Patients' Adherence to Antiretroviral Therapy in Botswana. *Journal of Nursing Scholarship*. 41(2):149-157.
- Kleeberbeger, C.A., Phair, J.P., Strathdee, S.A., Detels, R & Kingsley, L. 2001. Determinants of heterogeneous adherence to HIV-antiretroviral therapies in the multicentre AIDS cohort study. *Journal of Acquired Immune Deficiency Syndrome*. 26:82-92.
- Klitzman, R.L., Kirshenbaum, S.B., Dorge, B., Remiem, R.H., Ehrhardt, A.A., Johnson, M.O., Kittel, L.E., Deya, S., Morin, S.F., Kelly, J & Light-foot, M. 2004. Intricacies and inter-relationship between HIV disclosure and HAART. A qualitative study. *Journal of Acquired Immune Deficiency Syndrome Care*. 16:628-640.
- Kumar, R. 2005. *Research methodology. A step by step guide for beginners*. 2nd edition. London. SAGE.

- Kumarasamy, N., Safren, S.A., Raminani, S.R., Pickard, R & James, R. 2005. Barriers and facilitators to antiretroviral medication adherence among patient with HIV in Chennai, India. A qualitative study. *Journal of Acquired Immune Deficiency Syndrome Patient Care & Sexually Transmitted Diseases*.19:526-537.
- Laniece, I., Ciss, M., Desclaux, A., Diop, K., Mbodj, F., Ndiaye, B., Sylla, O. Delaporte, E & Ndoye, I. 2003. Adherence to HAART and its principal determinants in a cohort of Senegalese adults. *Journal of Acquired Immune Deficiency Syndrome*. 17(3):103-108.
- Lekhuleni, M.E., Mothiba, T.M., Maputle, M.S & Jali, M.N. 2013. Patients' adherence to antiretroviral therapy at Antiretroviral Therapy sites in Limpopo Province, South Africa. *African Journal for Physical, Health Education, Recreation and Dance (AJPHERD)*. 1:75-85.
- Lewis, M.P., Colbert, A., Erien, J & Meyers, M. 2006. A qualitative study of persons who are 100% adherent to antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndrome Care*. 18:140-148.
- Liechty, C.A., Alexander, C.S., Harrigan, R., Guzman, J.D., Charlebois, E.D., Moss, A.R & Bangsberg, D.R. 2004. Are untimed antiretroviral drug levels useful predictors of adherence behaviour? *Journal of Acquired Immune Deficiency Syndrome Care* 18(1):127-129.
- Lima, V., Fernandes, K., Rachlis, B., Druyts, E., Montaner, J & Hogg, R. 2009. Migration adversely affects antiretroviral adherence in a population-based cohort of HIV/AIDS patients. *Social Science and Medicine*. 68(6).1044-1049.
- Lincoln, Y. S & Guba, E.G. 2005. *Handbook of qualitative research*. London: SAGE.
- Liu, H., Golin, C.E., Miller, L.G. Hays, R.D., Beck, C.K., Sanandaji, S. Christian, J., Maldonado, T., Duran, D., Kaplan, A.H & Wenger, N.S. 2001. A comparison study of multiple measures of adherence to HIV protease inhibitors. *Annals of internal Medicine*. 134(10):968-977.

Loewe, L. 2008. Genetic mutation. *Nature Education*.1(1):113

Low-Beer, S., Yip, B., O'Shaughnessy, M.V., Hoggs, R.S & Montaner, J.S.G. 2000. Adherence to triple therapy and viral load response. *Journal of Acquired Immune Deficiency Syndrome*. 23(4):360-361.

Margaret A.C. 2012. Factors affecting adherence. *Infectious diseases society of America, Oxford Journals*. 30(2):171-176.

Marshall, C & Rossman, G.B. 1999. *Designing qualitative research*. London. SAGE.

Martin, M., Del Cacho, E., Codina, C., Tuset, M., De Lazzari, E., Mallolas, J., Miro, J.M., Gatell, J.M & Ribas, J. 2008. Relationship between adherence level s, type of the antiretroviral regimen, and plasma HIV type 1RNA viral load. A prospective cohort study. *Journal of Acquired Immune Deficiency Syndrome Research and Human Retroviruses*. 24(10):1263-1268.

Max, B & Sherer, R. 2000. Management of the adverse effects of antiretroviral therapy and medication adherence. *Clinical Infectious Diseases*. 30(2):96-116.

McDonnell-Holstad, M.K., Pace, J.C., De, A.K & Ura, D.R. 2006. Factors associated with adherence to antiretroviral therapy. *Journal of the association of Nurses in Acquired Immune Deficiency Syndrome Care*. 17(2):4-15.

McInerney, P. A., Ncama, B.P., Wantland, D., Bhengu, B.R., McGibbon, C., Davis, S.M., Corless, I.B & P. K., Nicholas, P.K. 2008. Quality of life and physical functioning in HIV-infected individuals receiving antiretroviral therapy in KwaZulu-Natal, South Africa. *Nursing and Health Sciences*. 10: 266-272.

Melchior, R.M., Nemes, I.B., Alencar, T.M.D & Buchalla, C.M. 2007. Challenges of treatment adherence by people living with HIV/AIDS in Brazil. *Revista De Saude Publica*. 41:7.

Meyer-Rath, G & Richter, M. 2007. User fees, transport costs, and the ethics of exemption. How free is free ART. *Southern African Journal of Medicine*. 27:52-56.

Mills, E.J & Nabiryo, C. 2013. Preventing Antiretroviral Treatment Interruptions among HIV/AIDS patients in Africa. *Public Library of Science Medicine*. 10(1): 1370-1371.

Mills, E., Nachega, J., Bangsberg, D., Singh, S & Rachlis, B. 2006a. Adherence to HAART. A systematic review of developed and developing nation patient-reported barriers and facilitators. *Public Library of Science Medicine*. 3:438.

Mills, E.J., Nachega, J.B., Buchan, I., Orbinski, J., Attaran, A., Singh, S., Rachlis, B., Wu, P., Copper, C., Thabane, L., Wilson, K., Guyatt, G.H & Bangsberg, D.R. 2006b. Adherence to antiretroviral therapy in sub-Saharan Africa and North America. A meta-analysis. *Journal of the American Medical Association*. 296:679-690.

Mimiaga, M.J., Safren, S.A., Dvoryak, S., Reisner, S.L & Needle, R. 2010. We fear the police and the police fear us. Structural and individual barriers and facilitators to HIV medication adherence among injection drug users in Kiev, Ukraine. *Journal of Acquired Immune Deficiency Syndrome Care*. 22:1305-1313.

Mocroft, A., Youle, M., Moore, A., Sabin, C.A., Madge, S., Lepri, A.C., Tyrer, M., Chaloner, C., Wilson, D., Loveday, C., Johnson, M.A & Phillips, A.N. 2001. Reasons for modification and discontinuation of antiretroviral. Results from a single treatment centre. *Journal of Acquired Immune Deficiency Syndrome*.15(2):185-194.

Mouton, J. 1996. *Understanding social research*. 1st edition. Pretoria: Van Schaick.

Molassiotis, A., Morris, K & Trueman, I. 2009. The importance of the patient-clinician relationship in adherence to antiretroviral medication. *International Journal of Nursing Practice*. 13(6):370-376.

Mshana, G.H., Wamoyi, J & Busza, J. 2006. Barriers to accessing antiretroviral therapy in Kisesa, Tanzania. A qualitative study of early rural referrals to the national program. *Journal of Acquired Immune Deficiency Syndrome Patient Care and Sexually Transmitted Diseases*. 20(9):649-657.

Mukhtar-Yola, M., Adeleke, S., Gwarzo, D & Ladan, Z. F. 2006. Preliminary investigation of adherence to antiretroviral therapy among children in Aminu Kano

Teaching Hospital, Nigeria. *African Journal of Acquired Immune Deficiency Syndrome Research*. 5(2): 141-144.

Murphy, D.A., Roberts, K.J., Hoffman, D., Molina, A & Lu, M.C. 2003. Barriers and successful strategies to antiretroviral adherence among HIV-infected monolingual Spanish-speaking patients. *Acquired Immune Deficiency Syndrome Care*. 15:217-230.

Murri, R., Ammassari, A., Gallicano, K., Deluca, A., Jacobson, D., Wu, A.W & Antinori, A. 2000. Patient- reported non-adherence to HAART is related to Protease inhibitor levels. *Journal of Acquired Immune Deficiency Syndrome*. 24(2):123-128.

Nachega, J.B., Mills, E.J & Schechter, E.J. 2010. Antiretroviral therapy adherence and retention in care in middle-income and low-income countries. Current status of knowledge and research priorities. *Current opinion in Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome*. 5(1):70-77.

Nachega, J.B. 2009. Antiretroviral therapy in Africa. *Treatment Action Campaign*. 28(7): 2-10.

Nachega, J.B., Knowlton, A.R., Deluca, A., Schoeman, J.H., Watkinson, L.A., Chaisson, R.E & Maartens, G. 2006. Treatment supporter to improve adherence to antiretroviral therapy in HIV-Infected South Africa adults. A qualitative study. *Journal of Acquired Immune Deficiency Syndrome*. 43(1): S127-S133.

Nachega, J.B., Lehman, D.A., Hlatshwayo, D., Mothopeng, R., Chaisson, R.E & Karstaedt, A.S. 2005. HIV/ADS and antiretroviral treatment knowledge, attitudes, beliefs and practices in HIV infected adults in Soweto. *South Africa Journal of Acquired Immune Deficiency Syndrome*. 38:196-201.

Nachega, J.B., Stein, D.M & Lehman, D.A. 2004. Antiretroviral therapy in HIV-infected adults in Soweto. South Africa. *Acquired Immune Deficiency Syndrome Research and Human Retroviruses*. 20(10):1053-1053.

Naidoo, P. Dick, J & Cooper, D. 2009. Exploring Tuberculosis Patient Adherence to Treatment Regimens and Prevention Programs at a Public Healthy Site. *Qualitative Healthy Research*. 19(1):55-70.

- Nam, S.L., Fielding, K., Avalos, A., Dickinson, D., Gaolathe, T & Geissler, P.W. 2008. The relationship of acceptance or denial of HIV-status to antiretroviral adherence among adult HIV patients in urban Botswana. *Social Science & Medicine*. 67(2):301-310.
- Nash, D., Wu, Y., Lul, E., Hoos, D & Sadr, W.E.L. 2011. Program-level and contextual-level determinants of low-median CD4⁺ cell count in cohorts of person initiating ART in eight sub-Saharan African countries. *Journal of Acquired Immune Deficiency Syndrome*. 25(12):1523-1533.
- Nieuwkerk, P.T & Oort, F.J. 2005. Self-reported adherence to antiretroviral therapy for HIV -1 infection and virologic treatment response. A meta-analysis. *Journal of Acquired Immune Deficiency Syndrome*. 38(4):445-448.
- Norman, K., Denzin, N.K., Yvonna, S & Lincoln, Y.S. 2003. *Strategies for qualitative inquiry*. 2nd edition. London: SAGE.
- Olowookere, S. A., Fatiregun, A. A., Akinyemi, J. O., Bamgboye, A. E & Osagbemi, G. K. 2008. Prevalence and determinants of non-adherence to highly active antiretroviral therapy among people living with HIV/AIDS in Ibadan, Nigeria. *African Journal of Health Sciences*.13(3):3-4.
- Orrel, C. 2005. Antiretroviral adherence in a resource-poor setting. *Current Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome Reports*. 2(4):171-176.
- Orrell, C; Bangsberg, D.R; Badri, M & Wood, R. 2003. Adherence is not a barrier to successful antiretroviral therapy in South Africa. *Journal of Acquired Immune Deficiency Syndrome*. 17(9):1369-1375.
- Osterberg, L & Blaschke, T. 2005. Adherence to medication. *The New England Journal of Medicine*. 353(5):487-497.
- Ostrop, N.J. Hallett, K.A & Gill, M.J. 2000. Long-term patient adherence to antiretroviral therapy. *Annals of Pharmacotherapy*. 34:703-709.

- Oyugi, J.H., Byakika-Tusiime, J., Ragland, K., Laeyendecker, O., Mugerwa, R., Kityo, C., Mugenyi, P., Quinn, T.C & Bangsberg, D.R. 2007. Treatment interruptions predict resistance in HIV positive individuals purchasing fixed-dose combination antiretroviral therapy in Kampala, Uganda. *Journal of Acquired Immune Deficiency Syndrome*. 21(8):965-971.
- Parkin, N.T., Hellmann, N.S., Whitcomb, J.M., Kiss, L., Chappey, C & Petropoulos, C.J. 2004. Natural Variation of Drug Susceptibility in wild type Human Immunodeficiency Virus type 1. *Antimicrobial Agents and Chemotherapy*. 48(2):437-443.
- Parruti, G., Manzoli, L., Toro, P., D'Amico, G., Rotolo, S., Graziani, V., Schioppa, F., Consorte, A., Alterio, L., Toro, G & Boyle, B.A. 2006. *Journal of Acquired Immune Deficiency Syndrome Patient Care and Sexually Transmitted Diseases*. 20:48-56.
- Paterson, D.L., Swindells, S., Mohr, J., Brester, M., Vergis, E.N., Squier, C., Wagener, M.M & Singh, N. 2000. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Annals of Internal Medicine*. 133 (1): 21-30.
- Polit, D.F & Hungler, B.P. 1995. *Nursing research principles and methods*. 5th edition. Philadelphia. Lippincot.
- Pope, C. 1999. *Qualitative research methods*. A health focus. Cape Town: Oxford University Press.
- Posse, M., Meheus, F., Van Asten, H., Van Der Ven, A & Baltussen, R. 2008. Barriers to access to antiretroviral treatment in developing countries. A review. *Tropical Medicine and International Health*.13(7):904-913.
- Protopopescue, C., Raffi, F., Roux, P., Reynes, J & Dellamonica, P. 2009. Factors associated with non-adherence to long-term highly active antiretroviral therapy. A 10 year follow-up analysis with correction for the bias induced by missing data. *Journal of Antimicrobial Chemotherapy*. 64:599-606.
- Rabkin, J. G & Chesney, M. 1999. Treatment Adherence to HIV Medications in Ostrow. *In Psychological and Public Health Impacts of New Human Immunodeficiency Virus Therapies*. 9(2): 61-82.

Rajabiun, S., Mallinson, R.K., McCoy, K., Coleman, S., Drainoni, M.L., Rebholz, C & Holbert, T. 2007. Getting me back on track. The role of Outreach Interventions in Engaging and retaining people living with HIV/AIDS in Medical Care. *Journal of Acquired Immune Deficiency Syndrome Patient Care and Sexually Transmitted Diseases*. 21: 20-29.

Ramadhani, H.O., Thielman, N.M & Landman, K.Z. 2007. Predictors of incomplete adherence, virologic failure, and antiviral drug resistance among HIV-infected adults receiving antiretroviral therapy in Tanzania. *Clinical Infectious Diseases*. 45(11):1492-1498.

Rao, D., Kekwaletswe, T.C., Hosek, S., Martinez, J & Rodriguez, F. 2007. Stigma and social barriers to medication adherence with urban youth living with HIV. *Journal of Acquired Immune Deficiency Syndrome Patient Care*. 19(1a):28-33.

Reis, C., Heisler, M. Amowitz, L. L., Moreland, R. S., Mafeni, J. O., Anyamele, C., Iacopino, V. 2005. Discriminatory attitudes and practices by healthcare workers towards patients with HIV/AIDS in Nigeria. *Public Library of Science Medicine*. 2(8): e246.

Remien, R.H., Hirky, A.E., Johnson, M.O., Weinhardt, L.S., Whittier, D & Minh Le, G. 2003. Adherence to medication treatment: A qualitative study of facilitators and barriers among a diverse sample of HIV + men and woman in four US cities. *Journal of Acquired Immune Deficiency Syndrome and Behaviour*. 7(1):61-72.

Roberts, K.J. 2005. Barries to antiretroviral Medication Adherence in young HIV-Infected Children. *Youth & Society*. 37(2):230-245.

Roberts, K.J. 2002. Physician-patient relationships, patient satisfaction, and antiretroviral medication adherence among HIV-infected adults attending a public health clinic. *Journal of Acquired Immune Deficiency Syndrome and Patient Care and Sexually Transmitted Diseases*. 16(1):43-50.

Roberts, K & Mann, T. 2000. Barries to antiretroviral medication adherence in HIV-infected women. *Journal of Acquired Immune Deficiency Syndrome Patient Care*. 12(4):377-386.

Rowe, K.A., Makhubela, B., Hargreaves, J.R., Porter, J.D., Hausler, H.P & Pronyk P.M. 2005. Adherence to TB prevention therapy for HIV positive patients in rural South Africa: Implications for antiretroviral delivery in resource- poor setting. *The International Journal of Tuberculosis and Lung disease*. 9(3): 263-269.

Russel, K., Bunting, S., Graney, M., Hartig, M., Kirsner, P & Brown, B. 2003. Factors affecting adherence to antiretroviral therapy in people living with HIV/AIDS. *Journal of the Association of Nurses in Acquired Immune Deficiency Syndrome Care*. 14(4):37-45.

Sabina, L.L., Desilva, M.B., Hamera, D.H., Keyid, X., Yuee, Y., Wene, F., L.Taof, L., Heggenhougana, H.K., Setonf, L., Wilsong, I.B & Gill, C.J. 2008. Barries to adherence antiretroviral Medication among patients living with HIV in Southern China. A qualitative study. *Journal of Acquired Immune Deficiency Syndrome Patient Care*. 20(10):1242-1250.

Samet, J.H., Horton, N.J., Meli, S., Freedberg, K.A & Palepu, A. 2009. Alcoholic consumption and antiretroviral adherence among HIV-infected persons with alcoholic problems. *Alcoholism. Clinical and Experimental Research*. 28(4):572.

Sanjobo, J., Frich, C & Fretheim, A. 2008. Barries and facilitators to patients adherence to antiretroviral treatment in Zambia. A qualitative study. *Sahara Journal*. 5(3):136-143.

Sarna, A., Pujari, S., Sengar, A.K., Garg, R & Gupta, I. 2008. Adherence to antiretroviral therapy & its determinants amongst HIV patients in India. *Indian Journal of Medical Research*. 127:28-36.

Schneider, J., Kaplan, S., Greenfield, S., Li, W & Wilson, I. 2009. Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *Journal of General International Medicine*. 19(11):1096-1103.

Siegel, Karus, D & Schrimshaw, E.W, 2000. Racial differences in attitudes toward protease inhibitors among older HIV-infected Men. *Journal of Acquired Immune Deficiency Syndrome Patient Care*.12(4):423-434.

Shenton, A.K. 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*. 22(2):63-75.

Simoni, J.M., Frink, P.A., Lockhart, D & Liebovits, D. 2006a. Mediators of social support and antiretroviral adherence among an indigent population in New York City. *Journal of Acquired Immune Deficiency Syndrome Patient Care and Sexually Transmitted Diseases*. 16(9):431-439.

Simoni, J.M., Kurth, A.E., Pearson, C.R., Pantalone, D.W., Merrill, J.O & Frick, P.A. 2006b. Self-reported measures of antiretroviral therapy adherence. A review with recommendations for HIV research and clinical management. *Journal of Acquired Immune Deficiency Syndrome and Behaviour*. 10:227-245.

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

Skovdal, M., Campbell, C., Nhongo, K., Nyamukapa, C & Gregson, S. 2011a. Contextual and Psychosocial influences on antiretroviral therapy adherence in rural Zimbabwe. Towards a systematic framework for programme planners. *International Journal of Healthy Planning and Management*. 26(3):296-318.

Skovdal, M., Campbell, C., Madanhire, C., Nyamukapa, C.N & Gregson, S. 2011b. Challenges faced by elderly guardians in sustaining the adherence to antiretroviral therapy in HIV-infected children in Zimbabwe. *Journal of Acquired Immune Deficiency Syndrome and Patient Care*. 23(8):957-964.

Sokol, M.C., McGuigan, K.A., Verbrugge, R.R & Epstein, R.S. 2005. Impact of medication adherence on hospitalization risk and health care cost. *Medical Care*. 43(6):521-530.

Steele, R.G & Grauer, D. 2003. Adherence to antiretroviral therapy for paediatric HIV infection. Review of the literature and recommendation for research. *Clinical Child and Family Psychology Review*. 6(1):17-30.

Steiner, J.F., Koepsell, T.D., Fihn, S.D & Inui, T.S. 1988. A general method of compliance assessment using centralized pharmacy records. Discrimination and validating. *Medical Care*. 26:814-823.

Steiner, J & Prochazka, A.V. 1997. The assessment of refill compliance using pharmacy records. Methods, validity and applications. *Journal of Clinical Epidemiology*. 50(1):105-116.

Stephen-Morrisson, J., Stash, S., Summers, T., Canfield, S., Gleason, C., Kramer, A., Oswald, A., Ross, H & Walsh, T. 2013. The future of the US- South Africa HIV/AIDS partnership. *Trip Report of the CSIS Delegation to South Africa*. Centre for Strategic and International Studies. <http://csis.org/files/publication/130313>.

Stevens, W., Kaye, S & Corrah, T. 2004. Antiretroviral therapy in Africa. *British Medical Journal*. 328(7434):280-282.

Stirratt, M.J., Remien, R.H., Smith, A., Copeland, O.Q., Dolezal, C & Krieger, D. 2006. The role of HIV Sero-status disclosure in Antiretroviral Medication Adherence. *Journal of Acquired Immune Deficiency Syndrome and Behaviour*. 10(5):483-493.

Stone, V.E., Hogan, J.W., Schuman, P., Rompalo, A.M., Howard, A.A., Korkontzeelou, C & Smith, D.K. 2009a. Antiretroviral regimen complexity, self-reported adherence, and HIV patient's understanding of their regimens. Survey of woman in the HER study. *Journal of Acquired Immune Deficiency Syndrome*. 28(2):124-131.

Stone, V.E., Jordan, J., Tolson, J., Miller, R & Pilon, T. 2009b. Perspectives on adherence and simplicity for HIV- infected patients on antiretroviral therapy. Self report of the relative importance of multiple attributes of highly active antiretroviral therapy (HAART) regimens in predicting adherence. *Journal of Acquired Immune Deficiency Syndrome Clinical Science*. 36(3):808-816.

Stone, V. 2001. Strategies for optimising adherence to Highly Active Antiretroviral therapy. Lessons from research and clinical practice. *Clinical Infectious Diseases*. 33:865-872.

Stone, V.E., Clarke, J., Lovell, J., Steger, K.A., Hirshhorn, L.R., Boswell, S., Monroe, A.D., Stein, M.D., Tyree, T.J & Mayer, K.H. 1998. HIV/AIDS patients' perspectives on adhering to regimens containing protease inhibitors. *Journal of General Internal Medicine*. 13:586-593.

Thrasher, A.D., Earp, J.A.L., Golin, C.E & Zimmer, C.R. 2008. Discrimination, distrust and racial/ethnic disparities in antiretroviral therapy adherence among national sample of HIV-infected patients. *Journal of Acquired Immune Deficiency Syndrome*. 49(1):84-93.

Tuller, D.M., Bangsberg, D.R., Senkungu, J., Ware, N.C., Emenyonu, N & Weiser, S.D. 2010. Transportation costs impede sustained adherence and access to HAART in a clinic population in Southwestern Uganda. A qualitative study. *Journal of Acquired Immune Deficiency Syndrome and Behaviour*. 14(4):778-784.

UNAIDS & WHO. 2013. Report on global AIDS epidemic. <http://www.unaid.org/en/media/unaid/contestassets/documents/epidemiology>.

USAIDS. 2011. HIV/AIDS health profile. *The World Health Report*. 15(07).79-83.

Uzochukwu, B.S.C., Onwujekwe, O.E., Onoka, A.C., Okoli, C., Uguru, N.P & Chukwuogo, O. I. 2009. Determinants of non-adherence to subsidized anti-retroviral treatment in Southeast Nigeria. *Health Policy and Planning*. 24(3): 189-196.

Van Dyk, A. 2008. *HIV Care and Counselling*. 4th edition. Cape Town. Maskew Miller Longman.

Varga, C & Brookes, H. 2008. Preventing Mother-Child HIV Transmission among South African Adolescents. *Journal of Adolescent Research*. 23(2):172-205.

Wakibi, S.N., Ng'ang'a, Z.W & Mbugua, G.G. 2011. Factors associated with non-adherence to highly active antiretroviral therapy Nairobi Kenya. *Acquired Immune Deficiency Syndrome Research and Therapy*. 8(43):10-15.

Wanyama, J., Castelnuovo, B., Wandera, B., Mwebaze, P., Kambuku, A. 2007. Belief in divine healing can be barrier to antiretroviral therapy adherence in Uganda. *Journal of Acquired Immune Deficiency Syndrome*. 21:1486- 1487.

- Ware, N.C., Idoko, J & Kaaya, S. 2006a. Explaining adherence success in sub-Saharan Africa. An ethnographic study. *Public Library of Science Medicine*. 6(1):0039-0047.
- Wasti, S.P., Randall, J., Simkhada, P & van Teijlingen, E. 2012. In what way do Nepalese cultural factors affect adherence to antiretroviral treatment in Nepal? *Health Science Journal*. 5:37-47.
- Wasti, S.P., van Teijlingen, E., Simkhada, P., Randall, J & Baxter, S. 2011. Factors influencing adherence to antiretroviral treatment in Asian developing countries: A systematic review. *Tropical Medicine International Health*. 17:71-81.
- Watt, M.H., Maman, S., Earp, J.A., 2009. Its' all the time in my mind'. Facilitators of adherence to antiretroviral therapy in a Tanzanian setting. *Social Science and Medicine*. 68(10): 1793-1800.
- Weidle, P.J., Nafuna, W., Solberg, P., Lietchty, C., Sendagala, S., Were, W., Mermin, J., Buchacz, K., Behumbiize, P., Ransom, R.L & Bunnell, R. 2006. Adherence to antiretroviral therapy in a home-based AIDS care program in rural Uganda. *The Lancet*. 368:1587-1594.
- Weiser, S.D., Tuller, D.M., Frongillo, E.A., Senkungu, J & Mukiibi, N. 2010. Food insecurity as a barrier to sustained antiretroviral therapy adherence in Uganda. *Public Library of Science One*. 5:357-366.
- Weiser, S., Wolfe, W., Bangsberg, D. 2006. Barriers to Antiretroviral Adherence for Patients Living with HIV Infection and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndrome*. 34(3):2881-2888.
- Wenger, N., Gifford, A., Liu, H & Chesney, M.A, 1999. *Patient characteristics and attitudes associated with antiretroviral adherence*. VI conference on retrovirus and opportunistic infections. Washington DC.
- White, H. 2005. Adherence outcomes: It's more than taking pills. *The Lancet*. 366:1989-1991.

Wood, S.A., Tobias, C & McCree, J. 2004a. Medication adherence for HIV positive women caring for children. *In their own words*. 16:909-913.

Wood, E., Hogg, R.S., Yip, B., Harrigan, R., O'Shaughnessy, M.V & Montaner, J.S.G, 2004b. The impact of adherence on CD4 cell count responses among HIV-Infected patients. *Journal of Acquired Immune Deficiency Syndrome*. 35(3):261-268.

World Health Organisation. 2012. *UNAIDS Report on the global aids epidemic*. Geneva: WHO.

World Health Organisation. 2008a. *Report on the global AIDS epidemic*. Geneva: WHO.

World Health Organisation. 2008b. *Towards universal access. Scaling up priority HIV/AIDS Interventions in the health sector. Progress report*. Geneva:WHO.

World Health Organisation, 2007. *Towards universal access. Scaling up priority HIV/AIDS Interventions in the health sector. Progress report*. Geneva: WHO.

World Health Organisation. 2006. *From access to adherence: the challenges of anti-retroviral treatment*. Geneva: WHO.

World Health Organisation. 2005. *Progress on global access to HIV antiretroviral therapy. An update on 3 by 5*. Geneva: WHO.

World Health Organisation. 2003. *Adherence to long term therapies. Evidence for action*. Geneva: WHO.

Yu, X.N., Lau, J.T.F., Mak, W.W.S., Cheng, Y.M., Lv,Y.H & Zhang, J.X. 2009. Risk and protective factors in association with mental health problem among people living with HIV who were former plasma/blood donors in rural China. *Acquired Immune Deficiency Syndrome Care- Psychological and Socio-Medical Aspects of Acquired Immune Deficiency Syndrome/Human Immunodeficiency Virus*. 21(5):645-654.

Zukoski, A.P & Thorburn, S. 2009. Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context. A qualitative analysis. *Journal of Acquired Immune Deficiency Syndrome Patient Care and Sexually Transmitted Diseases*. 23:267-276.

APPENDICES

APPENDIX 1

EXAMPLE OF A CONDUCTED INTERVIEW

Interviewer: Maria Mahlalela Interview number: 03

Interviewee: 11

Interview date: 11/11/2013

Information about interviewee

Date of birth: 28/01/1969 Gender: Female

Marital status: Married Occupation: Domestic worker

I = Interviewer

P = interviewee

I: Morning, how are you?

P: I am fine and you?

I: I am also fine, as we have discussed about the purpose of the study and signed the consent form which shows that you agree to participate in this study, so this is the day and time to discuss and don't be surprised I will be recording voices using audio tape recorder as we agreed initially. Do you remember?

P: Yes, I do remember because you told us last time. Myself I don't have a problem to discuss things that makes me not to adhere to treatment... you ended up not taking treatment because you are not taken care of.

I: There are few questions that I will ask you now with regard to non-adherence of HAART and you must feel free, nothing to be afraid of as we discussed before that your name will not be used for privacy and confidentiality. We will be using a number which refers to your name which is number 11.

P: Oh, I'm number 11.

I: Yes, What are the difficulties that led you not to adhere to HAART?

P: Woo! The difficulty is, you arrive at the clinic, wait there and became hungry and shaking knees with hunger. You queue in the window for a file and sometimes you don't get it because they will tell you that your file is missing and they will tell you to wait and I continue waiting and I was patient enough until is 13:00 still waiting. I also have needs to attend besides that. I want to take my medication and at the same time I do have other things that needs my attention I ended up leaving without my medication and because of that I am going to skip doses and when I returned back the other month they shout at me asking me why didn't I come for follow up at my structured dates given to me. When I tried to explain that I did come and there was a long queue and my file was missing and I've been waiting until 13:00 whilst I've arrived at the clinic at 05:00 and when they go for lunch they don't come back. At the clinic you spend the whole day just to fetch your medication even if you wake up early.

I: You said you arrived at the clinic at 05:00, what you were doing because the clinic opens at 07:00?

P: I supposed to take a number my child and queue because if you do not have a number you are wrong. Even those numbers are not arranged accordingly.

I: Is that all that makes you not adhering to treatment?

P: Yes, isn't I don't get it, and by the time I suppose to get it I don't get it. I arrive early at around 05:00 the clinic to queue for a number at the main gate of the clinic, then proceed to another queue at the window to get my file where sometimes they told me that my file is missing and I must come back tomorrow. If it happens, I get my file; I have to proceed and queue for vital signs and consultation then I queue for bloods and then at the pharmacy to collect my medication and that is frustrating that is why I told myself to skip months in collecting my medication.

I: Okay, there is overcrowding?

P: Yes, it is always full and there is hunger and you cannot carry containers with food to the clinic and everybody here has a problem is just that they won't tell you.

I: Let us leave other people and discuss the two of us, their turn is coming. I will ask them those questions as well if given a chance some other days. So you stayed at home without taking medication for three months because you were not taken care of by nurses?

P: Nurses do not give us love, they shout at us and they don't care whether you are old or young. We are afraid of them but they are the people that are supposed to help us. At the clinic, you arrive at 05:00 but 15:00 you would still be fighting to get your medication.

I: Are they able to explain to you the reasons for a delay?

P: No, they don't tell us, they just move up and down; they treat us badly, shouting at us, and chasing us to stay outside the clinic not to stand as there are no enough chairs inside the clinic and the security guards are also pushing us with the support of nurses.

I: You seat outside?

P: We sit outside as well, inside they are chasing us and even at 13:00 when they go for lunch they chase us until they come back and you are still waiting for your medication because you need it and sometimes you find out that you only left with medication that will last you for two days.

I: Tell me about your views regarding taking HAART.

P: Medication my child is working, and is very helpful in my body. The only problem is our nurses, I don't blame medication and I sometimes thought of going to their superiors and lodge complain so that they can help us with other easiest ways of getting our medication.

I: How do you feel about being positive and taking HAART?

P: I don't have a problem about being positive and taking medication because I was taught by nurses that with medication the virus can be controlled as long as you take your medication correctly.

I: You said you don't have a problem to take your medication but you have defaulted treatment?

P: I never stopped my medication; the nurses do not give us medication. If they can speed up the process of giving us treatment may be we wouldn't stop medication because sometimes you report at work that you will be late because you will go via the clinic to collect your medication but due to long queues and long waiting period you ended up being absent at work. (Sounds aggressive and harsh.)

I: Do you believe that HAART is helping you?

P: Yes. I do believe that medication is helping me because now is not the same as before I started treatment.

I: What happened before you started treatment?

P: Before starting treatment I was very sick, weak, and I was unable to stand for a long period though it was difficult to drink pills everyday but I tried ways they taught me and I got used to it and now I am fine I don't have a problem no pain, no what.

I: You said you like your medication and you are drinking it but your only problem is the process you undergo before getting your treatment?

P: Yes, we work for it for the whole day and the securities are pushing us

I: Are you working?

P: Yes, I am working and I am not working for whites; I'm working as a domestic worker for blacks.

I: Have you told them about your situation?

P: I told them and they are supporting me and helping me with adherence.

I: Do you receive any support from your family to help you with adherence to HAART?

P: Yes, all my children are supportive, they always remind me to take my medication it is time to take medication and my cell-phone reminds me.

I: By the time you stopped medication, what were your children said about it?

P: They were unhappy and angry that I stopped medication.

I: Thank you to hear that you got all the support at home. Is there anything that you are using such as traditional medication besides HAART?

P: No, I'm not using traditional medication; I am using boosters from the chemist to serve as ARVs if I don't have any. I am using vitamin C.

I: You are using vitamin C?

P: Yes, it gives me power.

I: Is there anyone at home whom you can send to collect treatment on your behalf?

P: There are people whom I can send but will depend if they are not at school because if I sent my neighbour she won't tolerate the queues.

I: Because you said at the clinic you wait for a long period so what is it now that makes you to go back?

P: My children were always telling me to go back and I also realised that I must go back because medication was helping me.

I: So, the queue still remains what will you do now if there is queue?

P: Nothing I will do just to learn to be patient and I am asking that the government must help us with the queue because people are dying especially here at Kanyamazane.

I: Thank you for your time. As I have said before that I am here to do research; I will forward your concerns to the relevant people.

P: Forward them my child we are suffering here, Amen.

APPENDIX 2

INTERVIEW SCHEDULE IN ENGLISH

Key questions

1. What are the difficulties that led you not to adhere to HAART?
2. Tell me about your views regarding taking HAART?
3. How do you feel about being positive and taking HAART?
4. Do you believe that HAART is helping you?
5. Have you told anyone about your HIV status and your ARVs?

Sub-questions

1. Are you working? If not, are you receiving any social grant?
2. Do you receive any support from your family to help you with adherence to HAART?
3. Are you using any traditional medication?
4. How many doses of HAART do you think you missed in a month?
5. Is there anyone at home (treatment buddy) whom you can send to collect treatment on your behalf, if you are not available?

APPENDIX 3

LUHLU LOLUDLIWANO-NDLEBE NGENISWATI

Imibuto leyingcikitsi

1. Ungangichazela yini kutsi ngabe yini bulukhuni lobuyimbangela yekutsi ungakhoni kugcika ekutsatseni emaphilisi akho engculazi ngendlela yakhona lefanele?
2. Ngitjele ngemibono yakho ekutsatseni kwemaphilisi engculazi?
3. Utiva kanjani ngekwati kutsi unaleligciwane lengculazi nangekutsatsa lamaphilisi alo?
4. Uyakholelwa yini kutsi lamaphilisi ayakusita?
5. Ukhona yini lowamtjela ngalesimo sakho saleligciwane lengculazi nangalamaphilisi akho engculazi?

Imibuto lengaphansi kwengcikitsi

1. Uyasebenta yini? Uma ungasebenti, uyahola yini sincepheteliso sahumende?
2. Bayakwamukela yini ekhaya ngekukunakekela nangekukusita ekutsatseni emaphilisi akho engculazi ngendlela lefanele?
3. Uyayisebentisa yini imbita na?
4. Mangaki emahlandla longawatsatsi ngawo emaphilisi akho enyangeni?
5. Ukhona yini ekhaya longamtfuma kutsi abobokulandzela emaphilisi akho esikhundleni sakho uma wena ungakakhoni na?

APPENDIX 4
CONSENT FORM

UNIVERSITY OF LIMPOPO (Medunsa Campus) ENGLISH CONSENT FORM

Statement concerning participation in a research project*

Name of Project / Study

Factors contributing to non-adherence of patients to Highly Active Antiretroviral Treatment at the Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province

I have read (*heard) the information on the aims and objectives of the proposed study* and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I know that sound recordings* will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this, provided that my name and clinic number are not revealed. Regarding images of the face, I understand that it may not be possible to disguise my identity, and I consent to the use of these images*.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular nurses.

I know that this study has been approved by the Medunsa Research Ethics Committee (MREC), University of Limpopo (Medunsa Campus). I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided that my privacy is guaranteed.

I hereby give consent to participate in this study.

.....

.....

Name of patient / volunteer

Signature of patient of
guardian

.....

.....

.....

Place

Date

Witness

Statement by the Researcher

I provided verbal* and / or written information regarding this Trial / Study / Project*

I agree to answer any future questions concerning the Trial / Study / Project* as best as I am able.

I will adhere to the approved protocol.

.....

.....

.....

Name of Researcher

Signature

Date

APPENDIX 5

PERMISSION TO CONDUCT THE STUDY

MPUMALANGA PROVINCIAL GOVERNMENT

Building No.3
No. 7 Government Boulevard
Riverside Park Extension 2
Nelspruit
1200
Republic of South Africa



Private Bag X 11285
Nelspruit, 1200
Tel: 013 766 3429
int: +27 13 766 3429
Fax: 013 766 3458
int: +27 13 766 3458

Department of Health

Litiko Letemphilo

Umyango WezaMaphilo

Departement van Gesondheid

Enquiries: Themba Mulungo (013) 766 3511

06 November 2013

Ms. Maria Mahlalela
P.O Box 2226
Nelspruit
1200

Dear Ms. Maria Mahlalela

APPLICATION FOR RESEARCH & ETHICS APPROVAL: FACTORS CONTRIBUTING TO NON-ADHERENCE OF PATIENTS TO HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT AT KANYAMAZANE CLINIC, EHLANZENI DISTRICT, MPUMALANGA PROVINCE

The Provincial Research and Ethics Committee has approved your research proposal in the latest format that you sent.

Kindly ensure that you provide us with the soft and hard copies of the report once your research project has been completed.

Kind regards

Handwritten signature of Mr. Molefe Machaba in black ink.

MR. MOLEFE MACHABA
RESEARCH AND EPIDEMIOLOGY

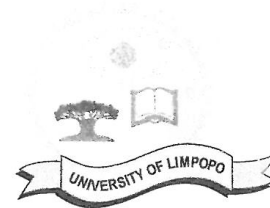
07/11/2013
DATE



APPENDIX 6

MEDUNSA RESEARCH AND ETHICS COMMITTEE CLEARANCE LETTER

UNIVERSITY OF LIMPOPO
Medunsa Campus



MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 06/2013
PROJECT NUMBER: MREC/HS/175/2013: PG

PROJECT:

Title: Factors contributing to Non adherence of patients to Highly Active Antiretroviral Treatment at Kanyamazane Clinic, Ehlanzeni District, Mpumalanga Province

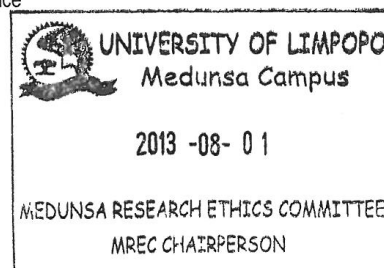
Researcher: Mrs MS Mahlalela
Supervisor: Prof ME Lekhuleni
Co-supervisor: Dr JC Kgole
Department: Nursing & Human Nutrition
School: Health Sciences
Degree: MCur Nursing Science

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 01 August 2013


PROF GA OGUNBANJO
CHAIRPERSON MREC



The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an International Organisation (IORG0004319), as an Institutional Review Board (IRB00005122), and functions under a Federal Wide Assurance (FWA00009419)
Expiry date: 11 October 2016

Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

Binding Solutions for Africa



APPENDIX 7

INDEPENDENT CODER'S REPORT

FACTORS CONTRIBUTING TO NON-ADHERENCE OF PATIENTS TO HIGHLY ACTIVE ANTIRETROVIRAL TREATMENT AT THE KANYAMAZANE CLINIC, EHLANZENI DISTRICT, MPUMALANGA PROVINCE

CODING OF THEMES AND SUB-THEMES

MAHLALELA MARIA SIZAKELE

STUDENT NO: 201221929

Table 4.1: Themes and sub-themes

Sub-themes

- 1.2. Waiting time instead of waiting hours
- 3.1. Side-effects of HAART

Sub-theme 1.1

Recommendation: Staff attitudes and delivery services

Recommendation: Participants were very dissatisfied... In instances where they received good and adequate attention their morale was high towards visiting the clinic taking and taking their medication.

- ...they also complained about poor nursing care.
- On p41, last paragraph: Three participants in the study mentioned... including the quotation deals with waiting time and should be transferred to sub-theme 1.2: Waiting time and overcrowding

Sub-theme 1.2: Waiting time and overcrowding

- Discuss issues relating to waiting time in a separate paragraph and those relating to overcrowding in another paragraph for easy reading.

Sub-theme 2.1: Forgetfulness and experiencing better health

- ...functional state. She said "*if you see... functional state*".
- Start a new paragraph at the end of the quotation.
- Findings on this issue are mixed: This sentence is not clear. Please delete.

Sub-theme 2.2: Suicidal tendencies instead of reaction

...after her family member disclosed to him...

- Start new sentence: She was also chased away by her relatives with whom she was staying.
- One participant was pessimistic about the future. She stated that she did not care... She reported that she had casual jobs in town and she had to stop working because of recurrent illnesses. She became useless and unable to work. She mentioned that there was no improvement... She then decided to stop taking medication. She expressed these sentiments as follows... The findings of this study are similar to those of Wood, Tobias and McCree (2004) that many HIV-positive... chronic illness.

Sub-theme 2.3: Belief systems

Recommendation: The study found that the belief system of participants about health and illness played a major role in influencing patients' adherence to HAART.

Cultural belief

One female participant... because she felt that the medicine was not helping her and that she was not improving. She further indicated that she then decided to consult traditional healers. She went further to state that she had noticed some improvement in her health since she started taking traditional medicine. She said: "*Truly speaking... consult a traditional healer... and she gave me traditional medication...*"

Religious beliefs

- Delete the first sentence.
- One participant reported a strong belief... which helps her to be positive about the future... She reported that she chose to stop... for a certain period because

HAART made her sick. The rest of the sentence that follows is not clear. One participant summarised this as follows “: ...*in God.*”

Health behaviours

- Patients’ beliefs... contributed... HAART. One male participant testified that... and the medication counteracted with the ARVs. He further indicated that... and lacked libido. He also reported that ARVs acted as sexual stimulants... because he enjoyed sex very much. He then decided to stop taking ARVs and to continue... This was evidenced by one participant who said, “*As a man... and when I took this medication with ARVs, my penis did not erect... you, and I felt dizzy. Then I’ve... appreciate it*”.
- Restructure the sentence as follows: Mukhtar-Yola *et al.* 2006, Olowookere *et al.* 2008, Skhosana *et al.* 2006, and Uzochukwu *et al.* 2009 in their study conducted in Africa revealed that... in favour of alternative such as traditional medicine.
- The sentence that begins with the role of religion on patients’ ART adherence... is not clear and has to be restructured and be transferred to the sub-heading on religious beliefs.

THEME 3: MEDICATION RELATED FACTORS

Participants identified factors related to HAART as contributory factors to non-adherence

Sub-theme 3.1: Side-effects

- The study found that side-effects of HAART were a major factor that contributed to non-adherence of patients to HAART.
- Two female participants mentioned lipodystrophy as one of the side-effects they were experiencing. They further indicated that the medication... ARVs. One participant mentioned that at school other pupils laughed at her because of the side-effects and so she decided to stop taking the ARVs. This was summarised as follows, “*my body shape has changed I was not like this before I started taking ARVs and now my body is shaped like a stock sweet, my breasts are growing ...me*”.

- Lipodystrophy is one of the long term side-effects that affects between 30-60% of people on HAART.

Sub-theme 2: Pill burden

- The study found that pill burden had a negative impact on ...HAART.
- Rephrase the sentence as follows: ...in her illness. She then decided to stop taking HAART but continued taking the TB treatment. This was summarised by one participant who said... Indicate the quotation.

THEME 4: SOCIO-ECONOMIC FACTORS

- Participants identified migration due to employment, poverty and unemployment, disclosure, stigma, and discrimination as factors that had a negative effect on their adherence to HAART.

Sub-theme 4.1: Migration due to employment

....He reported that he stopped medication unintentional because he... far from home.

One male participant said... Indicate the quotation.

Sub-theme 4.2: Poverty and unemployment

- Four female...as a hindrance to HAART adherence. Delete the rest of the sentence.
- One participant emotionally mentioned... because she was always fighting with her husband who was insulting her... as they were both taking medication. She also stated that she was unemployed and was depending on her husband for financial support. She went on to indicate that her husband did not give her support to take the medication and showed negative behaviours when she had to take the medication. One participant summarised this and said... Indicate the quotation.

Sub-theme 4.3: Disclosure, stigma, and discrimination

- Page 51: top page: They also stated fear of being rejected and what other members of the community would have to say.
- One participant emphasised that sometimes when she went out with friends for alcohol drinks, she tended to hide her medication and when it was time for her to take her medication she pretended to be falling asleep in an attempt to conceal her pill taking, as well as her diagnosis from her friends. This behaviour caused a lot of stress for her and so she decided to discontinue taking her HAART.
- Write United States of America (U.S.A.) and there after U.S.A. can be used.

CONCLUSION

The themes and sub-themes that emerged were analysed and discussed appropriately. Direct quotations were used to support and to provide clarity for the identified themes and sub-themes.

APPENDIX 8
EDITING CONFIRMATION



* The stars that tell the spade when to dig and the seeds when to grow *

* Isilimela – iinkwenkwezi ezixelela umhlakulo ukuba mawembe nembewu ukuba
mayikhule*

P O Box 65251
Erasmusrand
0165

13 March 2013

Dear Ms Maria Mahlalela

CONFIRMATION OF EDITING THE MINI-DISSERTATION WITH THE TITLE
FACTORS CONTRIBUTING TO NON-ADHERENCE OF PATIENTS TO HIGHLY
ACTIVE ANTIRETROVIRAL TREATMENT AT THE KANYAMAZANE CLINIC,
EHLANZENI DISTRICT, MPUMALANGA PROVINCE

I hereby confirm that I have edited the abovementioned dissertation as requested. Please pay particular attention to the editing notes AH01 to AH22 for your revision. The tracks copy of the document contains all the changes I have effected while the edited copy is a clean copy with the changes removed. Kindly make any further changes to the edited copy since I have effected minor editing changes after removing the changes from the tracks copy. The tracks copy should only be used for reference purposes.

Please note that it remains your responsibility to supply references according to the convention that is used at your institution of learning.

You are more than welcome to send me the document again to perform final editing should it be necessary.

Kind regards

A handwritten signature in black ink, appearing to read 'André Hills', is enclosed in a rectangular box.

André Hills

083 501 4124