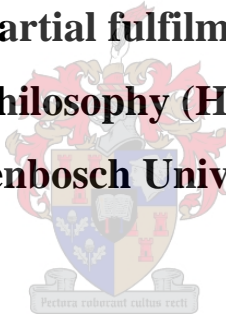


**INVESTIGATING ADHERENCE FOR PEOPLE LIVING  
WITH HIV AND AIDS ON ART IN DURBAN, KWAZULU  
NATAL, SOUTH AFRICA**

**NONDUMISO DLOMO**

**Assignment presented in partial fulfilment of the requirements for  
the degree of Master of Philosophy (HIV/AIDS Management) at  
Stellenbosch University**



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## **DECLARATION**

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

February 2010

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## **ABSTRACT**

The study sought to investigate adherence for people living with HIV who are on ART. Since high levels of adherence of more than 95% are required to achieve the durable suppression of the viral load, the researcher finds it very important to find out whether the people are doing what is expected of them. While the rollout of antiretroviral (ARV) therapy has brought much excitement and hope to both patients and practitioners in South Africa, it has also brought many new questions and challenges, including adherence. Adherence is therefore very crucial to the success of ART. The research sought to investigate adherence in resource-poor settings.

The research was conducted on patients attending Ithembalabantu clinic in Umlazi, Durban, Kwazulu Natal, South Africa. Respondents were recruited as they come to the clinic to collect their medication.

Triangulation of qualitative and quantitative research was used to collect data in the study. The quantitative data involved 90 questionnaires. The qualitative data involved 15 semi structured interviews.

The results indicated that adherence to ART is very high and satisfactory among the sample population with 79% who never skipped or missed their medication and 64% who indicated that they followed their specific schedule all the time; and 88% of the respondents were aware of the dangers of sleeping without a condom more especially while on ART. The results showed that there is a very high level of condom usage among the sample population. The respondents from the in-depth interviews indicated that participants are not affected by the factors that lead to poor adherence.

The only problem that needs urgent attention is the importance of the knowledge of viral load and CD4 count. The participants seemed to be confused by the two and most of them did not know why they are measured.

## **OPSOMMING**

Hierdie studie het gepoog om vlakke van getrouheid aan volgehoue deelneming te ondersoek onder MIV positiewe persone wie antiretrovirale terapie (ART) ontvang. Omdat hoë vlakke van getrouheid van meer as 95% nodig is om duursame suppressie van die virale lading te bereik, voel die navorser dat dit baie belangrik is om uit te vind of persone doen wat van hulle verwag word. Terwyl die uitrol van ART opgewondenheid en hoop vir beide pasiënte en praktisyne in Suid-Afrika gebring het, het dit ook baie nuwe vrae en uitdagings gebring, getrouheid ingesluit. Getrouheid is dus beslissend vir die sukses van ART. Die navorsing het gepoog om getrouheid in hulpbron-swak areas te ondersoek.

Die navorsing is uitgevoer op pasiënte wat die Ithembalabantu kliniek in Umlazi, Durban, Kwazulu Natal, Suid-Afrika bywoon. Respondente is gewerf soos hulle na die kliniek toe gekom het om hul medikasie te kry.

Triangulasie van kwalitatiewe en kwantitatiewe navorsing is gebruik om data in te samel. Die kwantitatiewe data is deur vraelyste ingesamel en die kwalitatiewe data is deur 15 semi-gestruktureerde onderhouds ingesamel.

Die resultate het gewys dat getrouheid aan ART hoog en voldoende onder die steekproef populasie is met 79% wie nooit hul medikasie gemis het, 64% wie aangedui het dat hulle hul spesifieke skedule heeltyd volg, en 88% van die respondente is bewus van die gevaar van seks sonder 'n kondoom, veral vir persone op ART. Die uitslae wys dat daar 'n hoë valk van kondoom gebruik onder die steekproef populasie is. Die respondente in die onderhoud groep is nie deur die faktore wat tot swak getrouheid lei geaffekteer nie.

Die enigste probleem wat dringende aandag benodig is die belangrikheid van kennis van virale vrag en CD4 telling. Dit het voorgekom asof die deelnemers deur die twee verwar word en meeste van hulle het nie geweet waarom hulle gemeet word nie.

## **ACKNOWLEDGEMENTS**

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## ACRONYMS

AHF	Aids Healthcare Foundation
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
ASSA	Actuarial Society of South Africa
AZT	Azidothymidine
CD4	Cluster of differentiation 4
DOH	Department of Health
HAART	Highly Active Retroviral Treatment
HIV	Human Immunodeficiency Virus
HIV-1	Human Immunodeficiency virus-1
ILO	International Labor Organization
MEMS	Medical Event Monitoring Systems
NGOs	Non-government organizations
NNRTIs	Non-nucleoside reverse transcriptase inhibitors
NRTIs	Nucleoside analogue reverse transcriptase inhibitors
NtRTIs	Nucleotide analogue reverse transcriptase inhibitors
PIs	Protease inhibitors
PLHA	People Living With HIA/AIDS
PMTCT	Prevent mother-to-child-transmission
RNA	Ribonucleic Acid
TAC	Treatment Action Campaign
UNICEF	United Nations International Children's Emergency Fund
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
ZDV	Zidovudine

## **CHAPTER 1**

### **INTRODUCTION**

#### **1.1 Introduction**

Since HIV was discovered in the human body in 1981, it still continues to be one of the most the destructive epidemics in human history. More than 2.1 million people have died from HIV/AIDS (UNAIDS, 2007). Over 6800 persons become infected with HIV every day. Over 5700 persons die from AIDS, mostly because of inadequate access to HIV prevention and treatment services. The estimated number of persons living with HIV/AIDS worldwide in 2007 was 33.2 million, a reduction of 16 % compared with the estimate of 30.5 million published in 2006 (UNAIDS, 2006). HIV/AIDS hinders development in all countries with a high prevalence rate. It also threatens health, economic and social progress. It also reduces life expectancy or deepens poverty (UNAIDS, 2004a).

In the 2005 World Summit Outcome (resolution 60/1), world leaders committed to a massive scaling up of HIV prevention, treatment and care with the aim of coming as close as possible to the goal of universal access to treatment by 2010 for all who need it. Leaders of the Group of Eight countries express their strong support for working towards this goal.

In response to the request of General Assembly contained in its resolution 60/224, the secretariat and co-sponsors of the Joint United Nations Programme on HIV/AIDS (UNAIDS) have helped to facilitate inclusive, country-led processes to develop practical strategies for moving towards universal access (UNAIDS, 2006).

The country processes build on earlier efforts, such as '3 by 5' (treating 3 million people by 2005 initiative) to expand HIV treatment. The WHO strategy was launched in 2003 to provide antiretroviral therapy to people living with HIV/AIDS in developing countries. A number of key challenges that stand in the way of scaling up towards universal access emerged from consultations.

Financing to implement the AIDS plan is adequate and funding is always unpredictable and of too short duration, reducing the ability of governments to sustain the delivery of AIDS programmes. UNAIDS has identified six major requirements for reaching the common goal in helping to overcome major obstacles impeding countries from scaling up integrated AIDS programmes and moving towards universal access (UNAIDS, 2007).

The number of people on ART in sub-Saharan Africa has surpassed one million for the first time, a ten-fold increase in treatment access in the region since December 2003 (UNAIDS,2006). In low-and-middle-income countries, just over 1.6 million persons were receiving antiretroviral therapy at the end of June 2006, a 24% increase over the 1.3 million who had access to the drugs in December 2006, and four times the 400,000 people receiving treatment in these countries in December 2003 (UNAIDS,2006). To date, 14 low and middle-income countries have met the '3 by 5'. Out of 49 WHO/UNAIDS 'focus countries' in the '3 by 5' initiatives, 40 have established national targets for treatment access, and 34 are developing or has completed implementation plans.

South Africa launched its planned scale-up in November 2003. One of the Operational Plan goals is to provide comprehensive care and treatment of the National health system in South Africa (DOH, 2003). The South African Operational Comprehensive Care and Treatment for People Living with HIV/AIDS aimed to have 381,177 people on Government funded ART's by 2005-2006. Only 85,000 people in the public sector were receiving treatment by September 2005. The latest WHO estimate is 460, 000 South Africans receiving ART's at the end of December 2007 equating to 28 % of those in need of treatment.

Antiretroviral therapy is the treatment that is available for People Living with HIV/AIDS. A patient who adheres to this treatment has a chance of living for a long time. Lack of strict adherence to highly active antiretroviral ARV therapy is considered to be one of the key challenges to AIDS care worldwide. Estimates of the average rate of non-adherence with ARV therapy range from 50%-70% in many different social and cultural settings and the risk associated with non-adherence are extensive at both individual and societal levels.

Non-adherence of antiretroviral treatment is a problem. It may result in rapid rebound of plasma viraemia, leading to treatment failure. Adherence is therefore perceived as a significant barrier to delivery of ARV therapy in Sub-Saharan Africa and particularly South Africa. I decided to investigate the rate or level of adherence and to measure the impact of various levels of non-adherence on ARV therapy outcome.

The main focus of this study is on adherence to ART at Ithembalabantu clinic at Umlazi. Adherence to ART is very important to prolong the lives of People Living with HIV/AIDS and also to avoid drug resistance.

## **1.2 Background to the research**

Very few studies have been published relating to medication adherence to antiretroviral (ARV) treatment in resource-poor-settings and looking at particularly one of the clinics in KwaZulu Natal which is the most populous province in South Africa with the highest HIV-1 adult prevalence rate.

### **1.2.1 The epidemiology of HIV/AIDS**

It is very difficult to determine how many people are infected with HIV and AIDS worldwide. The reason is that not many people come forward for testing; therefore it is too difficult to definitely diagnose HIV infection in the absence of HIV testing. Poor surveillance systems in many countries also make reporting of detected cases harder. Most available figures are, therefore, only estimates of the number of people infected with HIV. All estimates indicate the lowest and the highest number of people possibly affected. This study will use the median estimate that is derived from these numbers.

### **1.2.2 The Global epidemic**

At the end of December 2007, an estimated 33.2 million were living with HIV worldwide (UNAIDS, 2007). In 2007, 2.5 million people were newly infected with HIV (UNAIDS, 2007), 2.1 million adults and 420,000 children under 15 years. Out of the Global total People Living with HIV, 30.8 million are adults, 15.4 million women, and 2.1 million children under 15 years.

In 2007 also, 2.1 million people died because of AIDS related illnesses, 1.7 million adults and 290,000 children under 15 years.

### 1.2.3 The Sub Saharan epidemic

At the end of 2007, an estimated 22 million of people were living with HIV in sub-Saharan Africa. An estimated 1.9 million people were newly infected with HIV (UNAIDS, 2007). Two thirds (67%) of the global total of 33.2 million people with HIV live in this region, and three quarters (75%) of all deaths in 2007 occurred in the region. Sub-Saharan Africa's prevalence varies significantly from country to country in both scale and scope. Adult National HIV prevalence is below 2% in several countries of west and central Africa, as well as in the horn of Africa, but in 2007 it exceeded 15% in seven Southern African countries, mostly in Central and East Africa (Cameroon, the Central African Republic, Gabon, Malawi, Mozambique, Uganda, and the United Republic of Tanzania).

Recent epidemiological trends have shown that HIV in sub-Saharan Africa have stabilized, although often at very high levels, particularly in Southern Africa (UNAIDS, 2007). Additionally, in a growing number of countries, adult HIV prevalence appears to be falling. For the region as a whole, women are disproportionately affected in comparison with men, with especially stark differences between the sexes in HIV prevalence among young people. In Southern Africa, reductions in HIV prevalence are especially striking in Zimbabwe, where HIV prevalence in pregnant women attending antenatal clinics fell from 26% in 2002 to 18% in 2006.

In Botswana a drop in HIV prevalence among pregnant 15-19 year olds (from 25% in 2001 to 18% in 2006) suggests that the rates of new infections could be slowing (UNAIDS, 2006). In Malawi and Zambia HIV have stabilized, amid some evidence of favorable behavior changes and signs of declining HIV prevalence among women using antenatal services in some urban areas. HIV data from antenatal clinics in South Africa suggests that, country's HIV might be stabilizing but there is no evidence yet of major changes in HIV-related behavior. The estimated 5.7 million South Africans living with HIV in 2007 made the country with the highest HIV prevalence in the world. The 26% HIV prevalence found in adults in Swaziland in 2006 is the highest prevalence ever documented in a national population-based survey anywhere in the world.



In Lesotho and parts of Mozambique, HIV prevalence among pregnant women is increasing. In some of the provinces in the central and southern zones of the country, report adult HIV prevalence exceeding 20% (UNAIDS, 2008). HIV prevalence in the comparatively smaller epidemic in East Africa has either reached a plateau or is receding. After dropping dramatically in the 1990s, adult national HIV prevalence in Uganda has stabilized at 5.4% but there are signs of a possible resurgence in sexual risk-taking that could cause the epidemic to grow.

The proportion of adult men and women who say they had sex with a person who was not a spouse and did not live with the respondent has grown since 1995 (from 12% to 16% for women and 29% to 36% for men).

The comparatively smaller HIV prevalence in West Africa is stable or are declining, as is the case for Burkina Faso, Cote d'Ivoire, and Mali. In Cote d'Ivoire, HIV prevalence among pregnant women in urban areas fell from 10% in 2001 to 6.9% in 2005. The largest prevalence in West Africa, in Nigeria, the continent's most populous country have stabilized at 3.1 %, according to HIV infection trends among women attending antenatal clinics.

#### 1.2.4 The Epidemiology of HIV in South Africa and KwaZulu Natal

With an estimated 5.5 million PLHA (UNAIDS, 2006), South Africa is the country with the largest number of infections in the world. The country's DOH estimated that 18.3 % of adults (15-49) are living with HIV in 2006 (DOH, 2007). More than half (55%) of all South Africans infected with HIV reside in KwaZulu Natal and Gauteng provinces (Dorrington et al., 2006).

The latest HIV data collected at the antenatal clinics suggest that HIV infection levels might be leveling off, with prevalence in pregnant women at 30% in 2005 and 29% in 2006 (DOH, 2007). The decrease in the percentage of young pregnant women (15-24 years) found to be infected with HIV also suggests a possible decline in the annual number of new infections.

The epidemic varies considerably between provinces. HIV prevalence among pregnant women is highest in the populous KZN province (39%); lowest and highest prevalence has been found in parts of KZN. For example, in Amajuba district, 47% of women attending antenatal clinics tested positive in 2006 (DOH, 2007), as did 51% of women aged 25-29 years who participated in earlier household-based HIV survey in the rural district of UMkhanyakude (Welz et al., 2007). In the rural district in the North of KZN, an HIV incidence of 8% was found in men and women aged 25-29 years.

On the trends, and in the absence of effective programmes, it is estimated that two-thirds of the 15-year-olds in that district could be infected with HIV by the time they reach their 35<sup>th</sup> birthday (Barnighausen et al., 2007). Young women in South Africa face greater risks of becoming infected than men. Among 15-24 year olds, women account for about 90% of new infections (Rehle et al., 2007). HIV incidence is being found in men towards the upper end of this age group: in Northern KZN study, and estimated 8.8 % of men aged 24-29 years has been infected in the previous year (Barnighausen et al., 2007).

An estimated 1.8 million South Africans have died from Aids-related diseases since the epidemic began (Dorrington et al., 2006). Total annual deaths (from all causes) increased by 87 % from 1997-2006 (from 316 505 to 591 213) (SSA, 2005 and 2006), with at least 40 % of those deaths estimated to be Aids-related (Bradshaw et al., 2004).

Rising death rates lowered life expectancy at birth to 49 years for males and 52.5 years for females in 2006, and have contributed to the decline in the country's population growth rate from 1.25 % in 2001-2002 to more slightly more than 1 % in 2005-2006 (SSA, 2007).

The major causes and determinants of the epidemic in SA are social and sexual networks. The context for these social and sexual networks is that of a newly democratic society emerging from a history of social disruption and racial and gender discrimination associated with inequitable distribution of resources as a result of Apartheid.

The inequitable distribution of resources massively disadvantaged the majority of the population. This has resulted in a bimodal society, which is also reflected in the spread of disease within the population. Poverty related diseases including HIV and AIDS, TB and Malaria affect mainly the previously disadvantaged sections of the population.

#### 1.2.5 The impact of HIV in SA

The majority of people infected with HIV and AIDS are those who are already in their productive years. In sub-Saharan Africa, people aged 15-49 have the highest productivity. Households depend on their labor for support. HIV and AIDS, therefore has a profound impact of both the macro and micro levels of the economy (Sunter & Whiteside, 2000).

The demographic impact of HIV and AIDS on the South African population is also apparent in statistics such as the under 5 mortality rate, which has increased from 65 deaths per 1000 births in 1990 to 75 deaths per 1000 births in 2006 (DOH,2006).

Mortality rates in 1990 suggest that a 15-year old had a 29 % chance of dying before the age of 60, but mortality rates in 2006 suggested that 15-year olds have a 56 % chance of dying before they reach 60. Other estimates provided by the Actuarial Society of South Africa for 2006 include:

- 1.8 million AIDS deaths occurred in South Africa, since the start of the epidemic.
- Around 740 000 deaths occurred in 2006, of 350 000 were due to AIDS (approximately 950 AIDS-related deaths per day).
- 71 % of all deaths in the 15-49 age groups were due to AIDS.
- Approximately 230 000 HIV-infected individuals were receiving antiretroviral treatment, and a further 540 000 were sick with AIDS but not receiving antiretroviral treatment.
- 300 000 children under the age of 18 experienced deaths of their mothers.
- 1.5 million children under the age of 18 were maternal or double orphans (i.e. had lost a mother or both parents), and 66 % of these children had been orphaned as the results of HIV and AIDS (ASSA, 2006).

The economy also is affected as the ILO demonstrated in 2004, and again with more recent data in 2006, that the rate of economic growth in countries heavily affected by HIV and AIDS has been reduced by the epidemic's effect on labor supply, productivity and investment over the last decade or more. According to the assessment, 3.7 million labor force participants aged 15-64 years were living with HIV/AIDS or with AIDS in South Africa (ILO, 2006).

Households and communities experience the immediate impact of HIV and AIDS, because families are the main caregivers for the sick and suffer AIDS-related financial hardships. During the long period of illness caused by AIDS, the loss of income and cost of caring for a dying family member can impoverish households (Ashford, 2006).

The problem of orphan and vulnerable children will persist for years, even with the expansion of prevention and treatment programmes. Studies in several districts in South Africa found that the majority of orphans are being cared for by grandparents, family members or through self-care in child-headed households. Orphans and Vulnerable Children are at high risk of HIV infection, as they face numerous material, emotional and social problems. They also face discrimination and stigma. Many of them drop out of school due to the inability to pay school fees and also suffer from malnutrition and ill health and are in a danger of exploitation and abuse (UNAIDS, UNICEF, USAID 2004).

Less emphasis has been given to the psychosocial impacts of the diseases which are related to illness and death of parents, children and other family members; caring for people who are ill and dying of AIDS, and living with and coping with an HIV positive diagnosis. Psychological distress and psychological disorders are also more prevalent amongst PLHA, and the importance of mental health programmes in relation to HIV and AIDS has long been overlooked (Baingana et al., 2004).

HIV and AIDS affect both the supply and demand of health care systems. On the supply side of health systems, the human resources effects of HIV are two-fold: the stress and morale impacts of rapidly changing epidemiological, demand and mortality profiles in patients caused by HIV and AIDS, and HIV infection in providers themselves. In a survey of 512 public sector workers in four provinces, 16.3 % were HIV infected (Shisana et al., 2003). An HIV prevalence study at the Helen Joseph and Coronation Hospitals with 91 % response rate, found that 13.7 % of 644 nurses were HIV infected and 19% had AIDS defining CD4 cell counts (Connelly et al., 2007).

The epidemic also affects the supply and demand for primary and secondary schools. On the supply side, infected teachers will eventually become chronically ill, with increased absenteeism, lower morale and productivity. A South African Education Sector study found a sero-prevalence of 12.7 % among teachers and significant gender, racial and geographical differences (Shisana et al., 2005b).

#### 1.2.6 What is ART?

Antiretroviral treatment is the main type of treatment for HIV and AIDS. It is not a cure, but it can stop people from becoming ill for many years. The treatment consists of drugs that have to be taken every day for the rest of a person's life. The main aim of antiretroviral treatment is to keep the amount of HIV in the body at a low level. It stops any weakening of the immune system and allows it to recover from any damage that HIV might have caused already. The drugs are often referred to as antiretroviral, anti-HIV, anti-Aids drugs, HIV antiretroviral drugs or ARVs.

Taking two or more drugs at a time is called a combination therapy, dual or triple therapy. Taking a combination of three or more drugs is sometimes referred to as Highly Active Antiretroviral Therapy (HAART). HAART are drugs that attack different parts of HIV or stop the virus from entering blood cells. Even among people who respond to HAART well, the treatment does not get rid of HIV. The virus continues to reproduce but at a slower pace.

There are three different categories of ART, namely mono, dual and triple therapy. Monotherapy is the Nevirapine that was given to pregnant HIV positive mothers to prevent them from passing the virus onto their babies. It is no longer allowed as a single dose.

The dual therapy is the presently used combination of Nevirapine and AZT to prevent mother-to-child-transmission of HIV (PMTCT). The triple therapy is the combination of treatment for all people who are HIV positive.

Mono-and dual-therapy is not recommended as drug resistance develops quickly, and renders ART unable to fight HIV as triple combination (Sunter & Whiteside, 2001). A combination of pills from three different categories of ARV drugs are therefore provided in South African government. All references to ART in this study will refer to triple combination therapy called HAART.

There are five main types of ARVs:

- Nucleoside analogue reverse transcriptase inhibitors (NRTIs), which target an HIV protein called reverse transcriptase.
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs), which also target reverse transcriptase.
- Nucleotide analogue reverse transcriptase inhibitors (NtRTIs), which also target reverse transcriptase.
- Protease inhibitors, (PIs), which target an HIV protein called protease.
- Fusion inhibitors, which target the point where HIV binds into cells of the immune system.

Each class of drugs attacks HIV in a different way. Generally, drugs from two (or sometimes three) classes are combined to ensure a powerful attack on HIV.

### 1.2.7 Access to Antiretroviral Therapy

While richer countries began to use a combination of antiretroviral therapy to effectively treat HIV in 1996, this treatment was for a long time only available to a small minority of South Africans who could afford to pay for private health care.

In March 2003, the TAC laid culpable homicide charges against health minister and her Trade and Industry colleague, claiming that they were responsible for the death of 600 HIV positive people a day in South Africa who had no access to antiretroviral therapy. By this time, many poor African countries including Uganda, Nigeria, Zambia and Botswana were already implementing public treatment programmes.

In November 2003, the government eventually approved plans to provide public access to the drug, in the form of Operational Plan for Comprehensive care and Treatment for PLHA. The governments 2003 plan aimed to have 381,177 people on governments funded ARVs by 2005-2006, only 85 000 people in the public sector were receiving treatment by September 2005 (SA, info.gov, 2005).

The latest WHO estimate is 460 000 South Africans receiving ART at the end of 2007, equating to 28% of those in need of treatment (WHO, 2008). According to government figures, around 418 000 patients had started treatment by February 2008. However, the pharmaceutical company Aspen, which makes most of the antiretroviral drugs used in South Africa, estimates that only 340 000-350-000 were still on treatment in Feb 2008 (others have died or stopped taking the drugs). Aspen has calculated that no more than half of those who need treatment will be receiving it by 2009 (Business Day, 2008).

South Africa's national HIV treatment programme has been the topic of much debate. The South African government was initially hesitant about providing antiretroviral treatment to HIV-positive people, and only started to supply the drugs in 2004 – years after many other nations had begun to do so – following pressure from activists. Even since 2004, the distribution of antiretroviral drugs has been relatively slow, with only around 28% of people in need receiving treatment at the end of 2007 (WHO, 2008).

### **1.3 Problem statement**

According to Government figures, around 418 000 people had started treatment by February 2008. The pharmaceutical company Aspen, which makes most of the antiretroviral drugs used in South Africa, estimates that only 340 000-350-000 were still on treatment in Feb 2008 (others died or stopped taking the drugs) . The Aspen statement made us realize that it is very important to regularly observe whether people on ART are adhering to treatment (Business Day, 2008). This study is only investigating the adherence of antiretroviral treatment to patients taking them. The study also takes into consideration the factors grouped and used by WHO i.e. socioeconomic factors, healthcare team and system-related factors, condition-related factors, therapy-related factors and patient-related factors.

### **1.4 Research design and methodology**

The researcher selected both interviews and questionnaires in investigating adherence for PLHA on ART in Durban, Ithembalabantu clinic. These tools were both chosen because they are both inexpensive and allowed data collection to be done within a short period of time. The researcher used a tape recorder for semi-structured interviews and questionnaires for a survey. The study used theoretical sampling in selecting participants for semi-structured interviews.

### **1.5 Purpose of the study**

The increased focus on ART as a strategy to mitigate the impact and further spread of HIV and AIDS epidemic underlines the importance of investigating obstacles to the effectiveness of ART. Very few studies, especially in developing countries, including SA are conducted on adherence to HIV treatment.

It is also difficult to predict adherence to antiretroviral therapy unless you interact with the people who are taking them. The study investigates the problems faced by PLHA taking treatment.



## 1.6 Research Objectives

To determine levels and consistency of adherence.

To determine the relationship between adherence and virologic response.

To determine factors that influence adherence to HAART.

Quantitative and qualitative methods were both used to achieve these objectives. The data was collected at Ithembalabantu Clinic at Umlazi.

## 1.7 Organization of the Research Report

This thesis has been organized into **six chapters**. The **first chapter** provides background information and rationale for the study as well as the aims of the research. The **second chapter** is a review of relevant literature on adherence and factors affecting adherence. The **third chapter** describes the research methodology used. It discusses how the study was conducted and justifies the choice of data collection method used. The **fourth and fifth chapters** outline the results of both qualitative and quantitative data analysis. The **sixth chapter** offers a discussion of the findings and the **seventh chapter** is about conclusion and recommendations. The conclusion summarizes the research discussed and provides recommendations for further research.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

Providing successful treatment for the exceptionally growing population of HIV-related individuals in developing countries is one of the largest public health problems in the world. This concern is particularly urgent in S.A. as the country with the highest number of PLHA in the world (UNAIDS, 2007). Antiretroviral treatment for HIV is starting to become increasingly available in developing countries. ART have significantly improved the mortality and morbidity of individuals infected with HIV (Satten et al., 1998). However, lack of adherence to HAART remains a key challenge to the successful management of patients with HIV and AIDS.

In countries with widespread access to highly active antiretroviral therapy (HAART) has become a chronic manageable illness requiring long-term therapy (Liu et al., 2006). As a result, maximizing patient quality of life (QOL) is now a primary focus of care and treatment strategies for PLWHA. To accomplish this goal, much work has been done to characterize changes that occur in self-reported QOL over time and identify factors that influence the QOL (Liu et al., 2006) in patients taking HAART. As access to HAART expands globally (UNAIDS, 2004b), these same issues need to be explored in resource-poor countries to form program and policy decisions about HAART roll-out strategies and interventions to maximize quality adjusted survival.

Sub-Saharan Africa, which accounts for 67 % (two-thirds of the global) of all HIV infection (UNAIDS, 2007), is currently a major focus of HAART expansion efforts. While several studies have demonstrated the feasibility and efficacy of HAART in resource-poor settings (Laniece et al., 2003), few have assessed whether HAART is effective at improving patients quality of time over time.

Knowledge about factors that influence quality of life among persons taking HAART in resource-poor settings is extremely limited. The gap undermines the ability of clinicians, policy makers and program planners functioning and well being of PLHA taking HAART.

On the 19 November 2003, the South African Cabinet approved the 'Operational Plan for Comprehensive HIV and AIDS care Management and Treatment for South Africa' which includes the provision of HAART for free in the public sector (DOH, 2003a). The plan states that 1.4 million South Africans, should be able to access treatment before year 2009 (DOH, 2003a). In South Africa, approximately 230 000 HIV-infected individuals were receiving HAART, and a further 540 000 were sick with AIDS but not receiving HAART (ASSA, 2006).

When aiming to provide treatment for more than a million South Africans, it is important to map factors determining the success of ART in the country. The level of adherence determines the level of infectiousness, and how long the individual patient will live, and be productive. This study focuses mainly on adherence and factors affecting adherence after commencing ART.

## **2.2 Antiretroviral therapy and adherence**

Many studies have documented the relationship between adherence and ART and virology, immunologic, clinical outcomes, including progression to AIDS, occurrence of opportunistic infections and survival, with 95% adherence as the 'gold standard' (Howard et al., 2002; McNabb et al., 2001; Paterson et al., 2000). In order to suppress the HIV RNA to undetectable levels (<50 copies/ml) the rates of adherence have to be above 95 %, but even with these adherence levels, some patients display detectable HIV RNA (Stone, 2001; Mannheimer et al., 2002; Weidle et al., 2002).

One study found that adherence to HAART of 80 % or greater was significantly associated with improved quality of life over time (Mainheimer et al., 2005) while another showed no association between adherence and quality of life.

Several studies in United States and Europe reveal that only a minority (20-40 %) of patients are able to achieve such high adherence levels. Adherence rates for ART, as measured by electronic monitoring, generally range from 50-80% (Arnsten et al., 2001; B; Howard et al., 2002; Paterson et al., 2000). Evidence also suggests that adherence rates decrease over time. Before implementation of universal access to AIDS medication, it has been hypothesized that this level of adherence could not be achieved in 'developing' nations. Studies of adherence to ART on

poor resource-poor settings are limited, and the sample sizes in the existing studies are relatively small. The findings from a recent systematic review indicated that adherence to ART among patients in sub-Saharan Africa compares favorably with adherence rates in North America: among the included African studies (totaling 12 116 patients, 77 % of patients achieved adequate adherence, while the corresponding proportion from North America was 55 % (17573 patients) (Singh et al., 2006). However, the authors of the review stressed that ‘efforts to sustain adherence in Africa and elsewhere remain important goals to optimize outcomes for individuals and global treatment.

One of the more concerning outcomes related to poor adherence is the development of drug-resistant viral strains. Seth sought to define the level of adherence associated with the greatest risk of resistance. Not only does poor adherence put efficacy of treatment for patient at risk, it also leads to the emergence drug resistance (Seth, 2004). This in turn will compromise future treatment options for individuals and increase the risk exposing others to drug-viral strains. Non-adherence has been directly associated with treatment failures (Paterson et al., 2000), viral rebound and a need for regimen switching. As treatment options are limited, this poses an urgent challenge.

The HIV-virus mutates in response to ART (Sunter & Whiteside, 2001; Bangsberg et al., 2002b). How fast the virus mutates depends on the level of adherence. Resistance develops to certain antiretroviral combinations (Manheimer et al., 2002). When one is not adhering to ART, the drug-resistant HIV can be transmitted to sexual partners, resulting in drug-resistance in both partners (Chiarella et al., 2004).

The prevalence of ART-resistant HIV in newly acquired infections in North America and Europe is estimated to range from 8-26 % (Waineberg et al., 1998). In a study by (Kozal et al., 2004), 15 out of 333 patients on ART were found to both have ART-resistance and engage in high risk sexual behavior. These 15 patients exposed 28 partners of a negative or unknown status to HIV infection.

All interventions to promote or enhance adherence are reliant on accurate and adequate adherence measurement. Such measurement has proved to be problematic. A number of studies have explored adherence measurement to generate a gold standard for audit and research purposes. Most adherence studies use selection (or single indicator) from five forms of measurement including patient self-report, doctor-report, repeat prescription filling, mechanical devices such as MEMS cap (MEMS view 1998) and biological markers which were claimed will measure drug levels directly and indirectly. Some describe electronic devices as gold standard, while others use multiple measures to log adherence. Yet electronic caps can only tell if the container was opened and not whether the compound was indigested. It runs a risk of erroneously counting someone as adherent who opens the bottle but does not take the compound. It also runs the risk of counting someone as non-adherent who removes multi-doses at one time , takes them all at the correct time, but is only recorded on the single occasion opening the container. Attempts to measure adherence, do not interfere with levels of adherence (Sherr, 2000). Efforts have been made to determine characteristics of patients who are particularly likely to be non-adherent (Simoni, et al., 2006).

### **2.3 What factors influence adherence to antiretroviral treatment?**

Assessing adherence and providing adherence interventions in different settings requires formative research and use of available data before transporting instruments and interventions from Western cultures to developing countries. Formative research on adherence in India can also lay groundwork for developing a hypothesis about adherence or generating additional research questions. In India, demographic and cultural issues, such as the doctor-patient relationship, for example, may play a role in adherence assessment.

A key determinant of antiretroviral therapy adherence is the complexity of the regimen (Chesney, 2000). Factors such as pill burden (Bartlett, 2002), dietary restrictions (Stone, 2001), and dose frequency (McNabb, 2003) contribute to treatment complexity, thus increasing patient difficulty in achieving desirable adherence rates and health outcomes. Consequently, the need exists for simpler regimens as combination therapies that may effectively boost patient medication adherence.

Barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia, identified and classified the findings into three themes, i.e. factors related to patients' beliefs and behaviors such as forgetfulness, experiencing better health, busy work schedules, living alone, excessive alcohol consumption, beliefs about ART and side-effects; factors related to socio-economic and cultural factors such as stigma and discrimination, disclosure of one's status as HIV positive, concerns about confidentiality, use of alternative treatments and lack of food and health service-related factors such as lack of communication about ART between healthcare professionals and patients, time constraints during consultations, lack of counseling skills and patient follow up, lack of infrastructure to conduct counseling, and long distances to health facilities.

Existing evidence from developed countries suggest that the factors influencing quality of life to PLHA on HAART fall into three categories: clinical, psychosocial and socio-demographic.

Clinical outcomes associated with improved quality of life in PLHA taking HAART include lower CD4 cell count at HAART initiation, increased CD4 cell count over time lower initial viral load and presence of symptoms of HAART initiation (Nieuwkerk et al., 2001). One study found that adherence of 80 % or greater was significantly associated with improve quality of life over time (Mainheimer et al., 2005) while another showed no association between adherence and quality of life (Liu et al., 2006). A number of socio-demographic factors have been associated with poorer quality of life among PLHA taking HAART, including old age, (Mannheimer et al., 2005).

There have been many studies examining factors associated with adherence to ART in the US and Europe countries where treatment has been available since mid-1990s. Generally these factors are categorized into (1) individual factors such as substance abuse, age, attitude towards treatment and psychological characteristics, (2) medication characteristics, such as dosing complexity, and a number pills or food requirements, (3) interpersonal characteristics, such as the doctor-patient relationship and other social supports and (4) the general systems within which care is administered (Chesney, 2000; Fogarty et al., 2002).

(Gehi, AK, et al., 2004) also studied the effect of adverse drug effects and compliance and found that 50 % of patients in the study experienced adverse drug effects and it was the most common reason given for non-adherence in those patients. Most organ systems can be affected, depending on the drug or class of drugs being used; proper identification of adverse effects can therefore be difficult.

Factors that are consistently related to non-adherence include side effects and depression, poor social support, patient provider relations, attitudes such as mistrust, skepticism about treatment and medications. Other factors have been less consistently linked to poor adherence, including gender, ethnicity, age, education, lack of stable housing, anxiety, regimen complexity and substance abuse (Gifford et al., 2000; Mehta et al., 1997).

Education level and also age were identified as important predictors of compliance with ART therapy. Compliance to antiretroviral medication as reported by AIDS patients assisted at the University Hospital of the Federal University of Mato Grosso do Sul. Forgetfulness was the most common reason given by patients, followed by running out of medication. Other predictors of poor adherence identified were complexity of dosing regimens and pill fatigue.

Some studies found that youth (aged 18-25 years) were particularly prone to poor compliance. Reasons included skepticism about efficacy of medication, cost involved, stigma of disease and 'feeling different' as well as confusion about how to take the medication. The authors concluded that this age group may require developmentally appropriate, empowerment-based treatment approaches to help with treatment difficulties and adherence.

Another group prone to adherence problems is those with low literacy levels, (Kalichman, S.C., et al., 1999). Nurse delivered antiretroviral treatment adherence intervention for people with low literacy skills and living with HIV/AIDS. Some studies found that people living with HIV/AIDS who have low health literacy show poor treatment adherence and more adverse health outcomes.

Moyle studied compliance in an Edinburgh-based population and found that while higher educational level was associated with better adherence, such patients still had difficulty with work-time dosing as well as with depression and negative thoughts about treatment (Moyle, 1998). It was found that patients' knowledge of improve CD4+count and viral load results had a positive impact on adherence.

There are very few studies in the literature that have identified factors associated with adherence in Brazilian context. Some studies conducted in Brazil have shown that adherence self-efficacy (belief in one's ability to adhere), frequency of dosing, prescription literacy and medication beliefs were related to adherence or response to therapy outcomes (Pineiro et al., 2002). Another study found that forgetfulness, alcohol use and misunderstanding were reasons given non-adherence by patients in an AIDS outpatient clinic of a public teaching hospital in Brazil (Brigido et al., 2001).

## **2.4 Summary**

Most of the factors related to adherence were derived in quantitative studies. The factors influencing adherence to ART are grouped into the same dimensions by many studies and reported in the same sequence as used by the World Health Organization. Those factors are socio economic factors, health team and system related factors, condition-related factors, therapy-related factors, patient-related factors and patient-related factors.



## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 Introduction**

The choice of methodology is guided by the objectives of the study as well as the time and resources available to conduct it. Most of this chapter outlines and justifies the methods used in this study. Four main phases were considered in chronological order: (1) study design; (2) study setting; (3) methods of data collection and (4) methods of data analysis. As part of data analysis, issues around reliability and generalizability of data were considered. The last chapter outlines the limitations of the study.

#### **3.2 Study design**

Polit and Beck describe a research as an outline for conducting a study in such a way that maximum control will be exercised over factors that could interfere with the validity of research results (Polit & Beck, 2004). The research design is the researcher's overall plan for obtaining answers to research questions guiding the study. Burns and Grove state that a research design is "the end results of a series of decisions made by the researcher concerning how to implement the study" (Burns & Grove, 2001).

The triangulation research technique was chosen, as it is used to examine the phenomenon from multiple perspectives. The study used a combination of quantitative and qualitative methods to explore the objectives of the study. Since every method has its weaknesses, triangulation offers a way to strengthen the study by counterbalancing this weakness with the strength of the other method(s) (Jick, 1983). Triangulation technique therefore increases the reliability and validity of the study.

Burns and Grove refer to quantitative research as "a formal, objective and systematic process in which numerical data are used to obtain information about the phenomenon under study" (Burns & Grove, 2001), and point out that quantitative studies seek to describe variables, examine relationships among variable, and determine cause-effect interaction between variables.

Moreover, rigour helps to identify and limit the effects of extraneous variables not under study (Burns and Grove, 2001).

A qualitative design is structured to look for what is special and different, what distinguishes the case or group, what characterizes the community and its values” (Seaman, 1987). Qualitative research focuses on a phenomenon that occurs in natural settings, that is, in the real world. They study those phenomena in all their complexity.

Little research has been conducted on ART and Adherence. Conducting qualitative research to provide in-depth information on the subject will help investigating adherence to ART. Qualitative methods provide information on processes, activities and episodes, rather than statistics (Yin, 1984). The study used phenomenological study because it focuses to a person’s perception of the meaning of an event. It attempts to understand people’s perceptions, perspectives, and understanding of a particular situation.

Time pressure, resources and financial constraints of conducting this study forced the researcher to conduct a cross-sectional study. A cross-sectional study is the simplest variety of descriptive or observational epidemiology that can be conducted on representative samples of a population. It is used as a useful way to gather information.

### **3.3 Study setting**

Kwazulu Natal is situated on the North Indian Ocean of South Africa. It is densely populated with approximately ten million people. The majority of the population is isiZulu speaking Africans. Umlazi is situated 17 km southwest of central Durban. It has a population of approximately 2.4 million, and is South Africa’s second biggest black location after Soweto.

There are shack settlements surrounding Umlazi as well as backyard shacks in the township. The Prince Mshiyeni Hospital, a 1200 bed facility is the only main referral hospital for Umlazi’s 21 Primary Health Care Clinics.

### 3.3.1 Study site

The study was conducted among PLHA on ART at the Ithembalabantu Clinic at Umlazi Township in Durban, Kwazulu Natal, South Africa. The name of the clinic is appropriately named the 'People's Hope'.

Aids Health Foundation with local partners opened Ithembalabantu (People's Hope clinic). The clinic is located in a shopping centre in Umlazi, in an accredited VCT site with several counselors working in conjunction with the Kwa-zulu Natal Department of Health. Services provided on site include: counseling and testing; CD4 tests and lab monitoring; care and support (social service support and counseling); treatment education classes; antiretroviral and opportunistic infection treatment; and skills and capacity building classes. In September 2005, AHF and partners increased ART treatment to the Ithembalabantu clinic and the surrounding areas. In addition to scaling up the Ithembalabantu clinic, AHF established a down referral network involving Primary Health Clinics in the area.

This system allows the Ithembalabantu clinic to test and identify more people who are living with HIV, refer stable clients to other local clinics, establish itself as an initiation center for more intensive scale-up of ART, and follow patients who experience complications with their regimens.

It began treating its first patients in February 2002 with the goal of demonstrating the feasibility and effectiveness of HIV/AIDS treatment in resource-poor settings. The intention of the US partner was to counsel and treat two million PLHA free of charge in SA by 2006. The treatment was totally free of charge to patients, as the drugs, CD4 counts, VCT and staff salaries are sponsored by foreign NGOs.

At the time the research was conducted, the clinic had 6169 patients on ART (Patient records, Ithembalabantu Clinic, 2009). All the patients attending the clinic were African, with the exception of few coloureds. The ages of PLHA on ART in the clinic ranged 18 to 62 and close

to 90 percent of them were unemployed (Personal conversation with M & E officer at Ithembalabantu Clinic, 2009). The majority of the patients reside at Umlazi. However, a substantial number of people come from other townships such as Claremont, Kwa-mashu, Chesterville, Umbumbulu, Kwa-makhutha, Inanda, etc.

### **3.4 Methods of Data Collection**

The study used the triangulation technique to collect data. Semi-structured interviews and the questionnaire were both used in the study. The triangulation approach was used as an approach to data analysis that synthesizes data from multiple sources. It was used because it seeks to quickly examine existing data to strengthen interpretations and improve policy and programs based on the available evidence.

#### **3.4.1 Semi-structured interviews**

The study used the in-depth, unstructured interview, which is a tool which uses an open-ended, discovery-oriented method that is well suited for describing both program processes and outcomes from the perspective of the target audience. The semi-structured format was used. This format allows the skills of the interviewer to respond to the interview situation to follow relevant lines of enquiry. The format is also good at collecting more factual information. Although it will have some pre-planned questions to ask during the interview, it also allowed questions to flow naturally, based on information provided by the respondent. Therefore, a semi-structured interview based on semi-structured interview schedule provides the best from both worlds. It can capture in-depth information also allows for the collection of highly specific information within a narrow area of research (Seaman, 1987). In this study, the research objectives are fairly narrow and the issues under investigation are clear and focused. One could argue that a semi-structured interview would be more appropriate to use than an in-depth interview which is more open-ended and driven by the information the participant provides (Babbie & Mouton, 2001).

To ask appropriate follow-up questions, several probes were incorporated in the data collection tool. The precise and understandable probes were used because they increase the likelihood of getting coherent and comparable information.

Informal conversations with the nurses at Ithembalabantu clinic aided in the development of relevant probes and topics in the semi-structured interview schedule.

One of the disadvantages of using the semi-structured interviews is that it can be difficult to control interviewees. A semi-structured interview does not allow issues that participants find important to be explored openly. This is a major constraint since the aim of an exploratory study is to undertake a preliminary investigation prior to a structured study of the phenomenon (De Vos, 1998). Presenting a very narrow focus might prevent the initial study from providing enough general information that a more structured study might need.

All participants were interviewed in isiZulu, since almost all PLHA attending at Ithembalabantu clinic are isiZulu speaking. The semi-structured interviews were recorded using a tape recorder and written notes were taken.

#### 3.4.2 Survey

Based on the information gathered in the semi-structured interviews, a survey questionnaire was developed. The survey was administered face to face. Survey research involves acquiring information about one or more groups of people, about their characteristics, opinions, attitudes, or previous experiences by asking them questions and tabulating their answers. The other name for the approach is descriptive or normative survey. Unlike a semi-structured interview, whereby the research may follow the standard questions with one or more individually tailored questions to get clarification or probe a person's reasoning, a survey asks a standardized set of questions and nothing more.

The strengths of a survey are that it is more structured and easy to administer. One can manage to study a large sample of informants without difficulty, the data can be collected over a short

period of time, and one can also manage to study fairly large number of variables (Babbie & Mouton, 2001).

Using a survey, one is also less likely to get 'don't know' answers, and it is likely to improve the accuracy of the data (Struwig & Stead, 2001). The interview has with this method the opportunity to clear up misunderstandings and rephrase questions to make them easier for the respondent to understand (Babbie, 1999).

With survey questionnaires, as with several other methods, respondents might not answer truthfully because they cannot remember or they wish to present themselves in a socially acceptable manner. Survey questionnaires also make it easier for the respondent to lie, since the survey only requires short answers and has no follow up questions. This is especially important to keep in mind in this study, which deals with sensitive issues such as HIV/AIDS (Catania et al., 1990).

### **3.5 Sampling**

#### **3.5.1 Semi-structured interviews**

Three pilot interviews were conducted to test the interview schedule. After the interview schedule was developed further, 15 semi-structured interviews were conducted. Seven of the participants were male, and eight were female. The reason why there was no balance between both sexes was because there were 24% percent male patients in the clinic.

The concept of theoretical sampling was applied when choosing participants for semi-structured interviews. Theoretical sampling selects participants on the basis of relevant categories, issues, themes, and concepts that emerge prior to and during data collection (Strauss & Corbin, 1990). The objective of theoretical sampling is to uncover diversity by facilitating the identification of a full range of possibilities that are theoretically relevant to the research question (Strauss & Corbin, 1990). The study therefore attempted to uncover diversity data within a small number of participants with a variety of characteristics. In order for the study to get a good theoretical

sampling, participants to achieve diversity in age and time on ART were chosen. The participants were only included if they fulfilled the criteria, i.e. patients who are 18 years of age and older and who are two months and more on ART. The participants were recruited when they came into the clinic to collect their medication or having doctor's appointments.

The gold standard in a qualitative study is to saturate all themes arising from the data collected. If saturation was to be achieved in the study, more interviews were to be conducted until no new themes came up of transcripts (Strauss & Corbin, 1990). The gold standard was not used and applied in this study because of time constraints and the availability of resources.

The main aim of the semi-structured interviews in this study was to discover the basic categories and few of its properties which therefore its aim is in line with exploratory study (Glazer & Strauss, 1967). It is in line with exploratory study because its aim is to uncover generalizations and develop hypothesis around a little known subject. Findings should later be investigated and tested with more precise and more complex designs (De Vos, 1998).

Since the study decided not to aim for saturation, implications for the transferability of data will be an issue. There will be a chance that the other researchers conducting same studies at Ithembalabantu clinic might discover other categories and themes not discovered here and may have different answers than the ones presented here.

### 3.5.2 Survey questionnaire

Ten pilot questionnaires were conducted to test the effectiveness of the questions in the survey. After the questionnaire had been altered, 90 questionnaires were filled in. Only patients 18 years and older who are taking treatment for two months or more were included in the study. The participants were recruited when they came into the clinic to collect their medication. The participants were chosen on the basis of their willingness to participate in the study. All those who were willing, fulfilled the criteria for inclusion and agreed to sign a written informed consent form were included in the study. The questionnaire was only started after all the respondents have understood their rights and signed the informed consent form.

The study aimed to conduct 150 questionnaires but due to limited number of people in the sample population, it was difficult to find the participants who had been on ART for longer than two months.

### **3.6 Methods of Analysis**

#### **3.6.1 Semi-Structured Interviews**

After transcribing and translating the semi-structured interviews, a grounded theory approach was employed to analyze the qualitative data. Glaser and Strauss, the founders of grounded theory, came up with the constant comparative method of data analysis (Glaser & Strauss, 1967; Maykut & Morehouse, 1994). This method is used to generate a theory within a new area of research (Maykut & Morehouse, 1994).

Grounded theory is suitable for studies that have no theoretical propositions stated in the beginning of the project (Maykut & Morehouse, 1994). No studies have been conducted within the area of ART and adherence among heterosexuals at the clinic, and little is known about the subject. Grounded theory is therefore suited for this analysis.

Three main steps were followed (Maykut & Morehouse, 1994). First each line in the transcripts as well as the individual interviews was given a number. This process made it possible to refer to all the different segments in the transcripts. The smaller units of meaning within the data were then identified, which helped to define larger categories of meaning (Guba & Lincoln, 1985 – cited in Maykut & Morehouse, 1994). These units of meaning were often sentences that were responses to certain questions. The meaning was reviewed for recurring concepts and themes. From this, one prominent theme was chosen. The utilized categories were then carefully examined to see which of them fell under this theme. When no more units of meaning could be placed under the first theme, a second theme was chosen. When analyzing the findings in detail, 11 themes emerged. A theme was introduced in the category in which it has more weight. The themes were grouped into the main categories related to the objectives stated above. These categories are included in chapter 4.



One of the great biases in open-ended interviews is the influence of the analyst's subjectivity in the interpretation-phase (Babbie, 1999). To minimize this bias, the process described above, were followed rigorously.

### 3.6.2 Survey questionnaire

The data from the survey questionnaire that were administered by face-to-face were data captured and cleaned using Microsoft Office Excel 2007. The same software was used to analyze data.

The data were re-structured and all 90 respondents were included in the analysis as they match the criteria and the main objectives of the variables of this study. The study is open to error because of the small sample size and hence reduces generalizability. Pivot Table Wizard in Excel was used to calculate frequencies and percentages.

## **3.7 Transferability, Generalizability and Reliability**

People who are on ART clearly understand what is expected of them before they made their decisions about taking medication. They attended classes which taught them about ARV treatment including, how and when to take them, what are the consequences of taking them as well as the expected behavior. Their prior knowledge about ART and adherence can be an obstacle to acquiring truthful answers.

Both questionnaire and interviews first asked questions about the demographic characteristics before adherence questions. In the semi-structured interviews some questions were asked twice, but in different ways. The consistency check was employed to increase reliability, and as a way to assess the accuracy of the information given by the participants.

The reliability and validity of answers given by the informants was kept in mind when reading the interview transcripts and analyzing the collected qualitative data. Due to the possibility of providing desirable answers, over reporting of adherence is likely to happen.

The respondents knew that they are expected to adhere to ART. They knew that poor adherence to their medication will have a negative impact on their lives. They knew that adhering to treatment is the right thing to do. The danger of getting desirable answers is even greater.

The survey was not aimed at generalizing on behalf of other South African people who are on ART because the study setting and its population are very specific. The sample did not present other ART patients in other clinics providing similar services because the number of patients interviewed was limited, and saturation was not reached. The semi-structured interviews would not for these reasons aim for transferability, which is used to judge the extent to which qualitative findings can be applied to other contexts (Sandelowski, 1986).

As mentioned previously, the qualitative sampling and analysis used theoretical sampling, and through that approach rather aim to emphasize the uniqueness of human experiences and contexts, which thus seeks variation not repetition (Sandelowski, 1986).

Even though no random sampling was employed, it could be argued that the respondents in this study, which constitutes of less than 10% of the patients in the clinic, are representatives of the clinic. The structured interviews were therefore generalized on behalf of ART patients at Ithembalabantu clinic.

### **3.8 Ethical Considerations**

The respondents who participated on this study were taking ART treatment at the clinic. They were interviewed and the questionnaires were filled at the clinic while they were coming to collect their medication. The respondents were sick, and suffered from a highly stigmatized disease. The researcher approached the potential respondents while they were waiting for their medication. The researcher made sure that they fulfilled the inclusion criteria, and then proceeded explaining to them the purpose of the study. After having assured them of the anonymity and confidentiality, they were asked if they were willing to participate in the study. The respondents were then asked to read and sign the informed consent form.

The study did not interview or issue questionnaires to patients who had been on ART for less than two months as the patient might still have low CD4 count, and feel physically weak. The side effects of the antiretroviral treatment can be also be more severe the first month of treatment. People under 18 years of age were not interviewed as they by South African law are not considered adults, but part of the vulnerable group. Special ethical precautions have to be taken if one is to interview persons who are under the age of 18. Ethical clearance was obtained from Ithembalabantu clinic.

### **3.9 Summary**

This study employed triangulation, which involved the use of quantitative and qualitative methods. The qualitative part of the study which consisted of semi-structured interviews was completed first. The information gathered in 15 semi-structured interviews informed the development of the survey questionnaire. In the quantitative part of the study, survey questionnaires were conducted face-face. Respondents were patients at Ithembalabantu clinic at Umlazi outside Durban in Kwazulu-Natal.

## **CHAPTER 4**

### **QUALITATIVE ANALYSIS**

#### **4.1 Introduction**

The study used in-depth interviews to determine the life experiences of the people living with HIV/AIDS who are taking ART. An in-depth, unstructured interview is a tool which uses an open-ended, discovery-oriented method that is well suited for describing both program processes and outcomes from the perspective of the target audience. In designing the framework to develop an adherence intervention that can be tailored to patients' individual situations, information from the patients' perspective is essential. Sustaining high levels of adherence to antiretroviral therapy is difficult for many patients, but recent applied research among persons with HIV infection, including a study carried out in Barbados, offers hope (Smith, et al., 2003). These studies demonstrated that high levels of adherence to HAART is entirely possible with proper clinical management, strong patient confidence in the clinician and in the treatment, and effective involvement of patients as active agents in their own care and treatment. A number of factors have been associated with adherence to HAART and are commonly divided into five intersecting categories (Reiter et al., 2000) namely: patient variables, treatment regimens, disease characteristics, patient provider relationship and clinical setting. The analysis of data in this study only used four of the intersecting categories.

#### **4.2 Characteristics of the participants**

The total number of participants interviewed was fifteen. Out of the participants, seven were male and eight were female. There were many female interviewed due to more female attending the clinic than male. The numbers concluded to the fact that women are more at risk of contracting infection than men. Of the respondents, two were between ages 20-29, four between ages 30-39, seven between ages 40-49, two between ages 50-59.

### 4.3 Analysis of Data

#### 4.3.1 Patient variables.

Patient-related factors represent internal factors, including trust and belief in the therapy, the motivation to take therapy, knowledge of HAART and adherence, forgetting, moods and substance use. Quantitative studies indicated that patients treated with HAART are motivated to be adherent by trust and belief in the benefit of antiretroviral therapy (Remien, et al., 2003).

Most of the patients gave similar answers when they were asked the advantages of being on HAART. Almost all of them mentioned that ART improved their health as they were attacked by opportunistic diseases.

*I like ARV's. They helped me regain my strength when I was attacked by opportunistic diseases. My CD4 had dropped and now it has gone up.*

*Male, age 30*

Most of the patients showed their belief in HAART. When they were asked of the disadvantages of HAART, they answered that there are no disadvantages except for the problems they experienced during the first month of being on HAART and changes in their bodies.

The participants seemed to know the importance of taking their medication on time. Although they experienced problems and some of them still experiencing problems, it didn't affect their adherence to HAART.

*I only had a problem during the first month but now I'm alright.*

*Female, age 40*

*My breasts are growing bigger and bigger.*

*Female, age 28/ male, age 40*

For some time people who are living with HIV had a problem of choosing the medication to take between traditional medication and ART. Other patients even decided to use both treatments. When they were asked whether there was any medication they are taking besides ART, they all answered that they don't take other medication other than ART and the medication prescribed by the doctor.

*I only take ART and vitamin tablets prescribed by Dr Mabaso only.*

*Male, 28*

#### 4.3.2 Treatment regimens.

Both qualitative and the quantitative studies showed that many patients experience side effects when taking HAART, and that these are an important reason for non-adherence (Sigiel, et al., 2000). Patients choose to give the body time to rid itself of medicine and recover from the resulting side effects by skipping doses (Laws, et al., 2000).

Most of the participants mentioned that they have never skipped taking their medication. They know that you don't need to take your medication after an hour of the time that you were supposed to take them. One said he did not take the medication on the day he forgot because he knows it will do more harm than good. All of them believed in ART relating to their state of conditions before they started treatment.

*The providers told me that the other medication last 12 hours in my body and the other 24 hours, so I make sure that I don't skip my medication to keep the medication in my body.*

*Male, age 30*

*I'm always carrying water with me because I have to make sure that I drink my medication*

*Female, age 51*

Most of the participants mentioned that they experienced side effects during the first three months when they started ART. Two male participants experienced problems with their libidos, three complained of foot cramps, the two complained that their breasts grew bigger and bigger everyday and the rest mentioned that they have no problems.

The participants seemed to know the importance of taking their medication on time. In spite of the problems they have about the treatment, nothing is stopping them from taking their medication.

*I have a libido problem, but it cannot stop me from taking medication.*

*Male, age 45*

#### 4.3.3 Disease characteristics

Social support was found to influence adherence to antiretroviral medication. Support from family members, including children, and friends play a role in adherence to therapy (Adam, et al, 2003). Social support has a positive influence on adherence if it is substantial and practical, reminding to take medication, actually giving out medication and/or offering food and drink to accompany the intake of medication (Wood, et al., 2004). By comparison, a partner who takes medication on different schedule or who discourages the taking of medication may lead to adherence problems.

All the participants had taken a decision that they are taking treatment and that there is nothing or no one that can stop them from doing so. Their concern and priority is prolonging their lives. When they were asked whether taking tablets influenced disclosure of HIV/AIDS, fourteen of them answered that they have disclosed their status to more than a supporter and only one participant disclosed only on the supporter because her sons are old and afraid to tell them, but they see her taking medication.

Although there are still signs of stigma and discrimination among our communities, it doesn't stop ART patients from disclosing to at least one person. Of the women in the study, few of them mentioned that they were dumped by their partners after disclosing their status. Most of them preferred to disclose to the family only other than friends. They said when disclosing to other peoples other than the family; their status will be known by many people. Nine of the participants disclosed their status after starting treatment and six disclosed before ART.

*I don't have a problem coming here because I don't stay here, they don't know me.*

*Female, age 51*

*I don't care, they can see me but I'm glad I know my status and they don't.*

*Male, age 30*

*It is scary to come here but because you know why you come here, it doesn't matter and I don't care.*

*Male, age 40*

*I don't have a problem because in my neighborhood, most of us are HIV positive, besides the focus is my child. He wants to be a doctor and I want to prolong my life to see him as a doctor.*

*Female 28*

All the participants have support from the people they have disclosed to and they seemed all get support from the families, friends and children.

*I told my partner, he even accompanies me to collect my medication, ask me if I took my medication.*

*Female, age 32*

*My partner, who is a social worker, was the one who told me to come to the clinic and she is making sure I take my medication every day.*

*Male, age 40*



#### 4.3.4 Patient provider relationship

The belief that good physician-patient relationship is associated with better adherence to antiretroviral regimen for HIV is widespread (Mehta, et al., 1997) and supported by several qualitative studies (Malcom, et al. 2003). Faith in the health care provider and the experience of a good relationship with the health care provider that is based on trust and professional support seem to influence adherence positively (Golin, et al., 2002).

All the participants said they are happy with the health care providers at the clinic and some of them said that is why they have decided to attend clinic at Ithembalabantu due to their good track record.

*They are very strict. They become mad at you if you don't bring your container on the day of the visit. They always count the pills left to see if they correspond with the amount expected.*

*Male, age 40*

*They took me to the counselor a couple of times because I didn't come to collect my medication as per appointment. The reason was that I wasn't ready to take medication. My mother told me to come here but now I'm coming on the expected date.*

*Female, age 28*

*They are counting the pills from the container. You can fool them by throwing them but at the end of the day, you will be fooling yourself because this is your life.*

*Male, age 30*

#### **4.4 Summary**

The findings of the qualitative study found that the people on ART are assertive about their status. The results showed that they have support from their families, friends and children, the communication and understanding is acceptable between them and their health care providers. They seemed to experience side effects but they can manage them and they will not stop them from continuing with the medication. Mostly they take their medication regularly because they know what they are doing to them and the consequences of not adhering to them. All in all, the standard of adherence according to this qualitative study is acceptable.

## CHAPTER 5

### QUANTIATIVE ANALYSIS

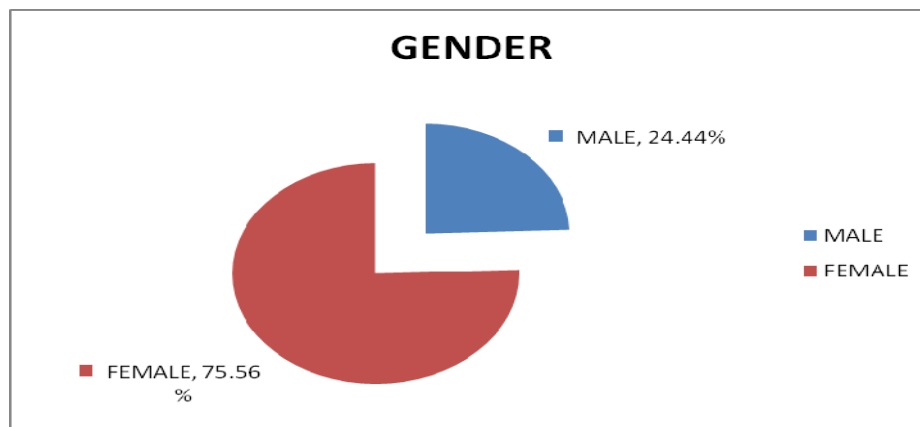
#### 5.1 Introduction

This chapter presents the data analysis. The questionnaire had six sections: demographic information, knowledge of viral load and CD 4 count, knowledge about ARV treatment, perception of risk of transmission, perceptions and attitudes towards ART and disclosure after starting ART treatment. A total of 90 questionnaires were administered face to face with the respondents and a 100% response rate was obtained. The findings resulting from the questionnaires were presented. Bar, pie, column graphs and tables were used in each section of the questionnaire to interpret the findings.

#### 5.2 Demographic information

This section included the respondent's gender, age, educational level, marital status, work situation and known family or friends AIDS death.

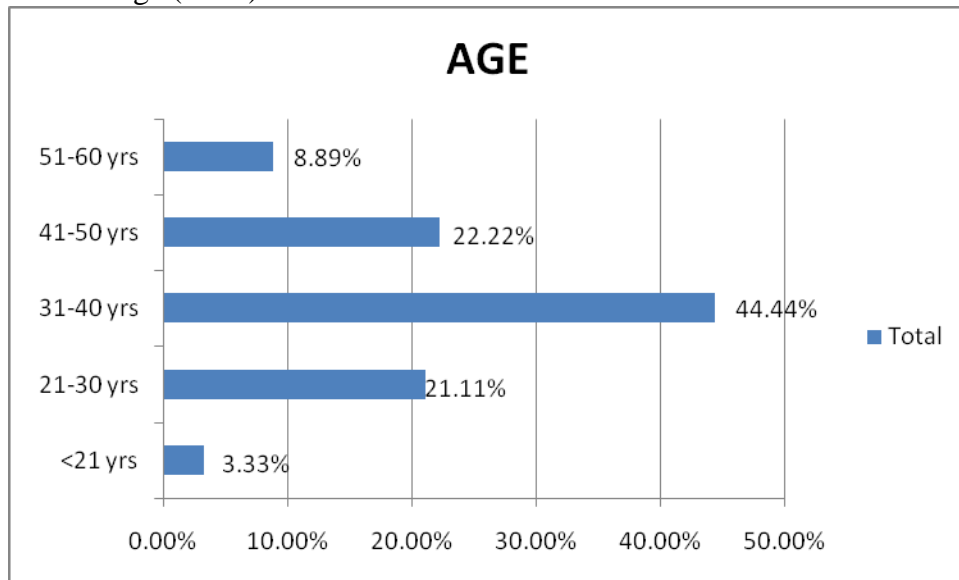
##### 5.2.1 Respondent's gender (n=90)



**Figure 5.1**  
**Respondent's gender (n=90)**

Of the respondents, 75.56% (n=68) were females and 24.44% (n=22) were males (see figure 5.1).

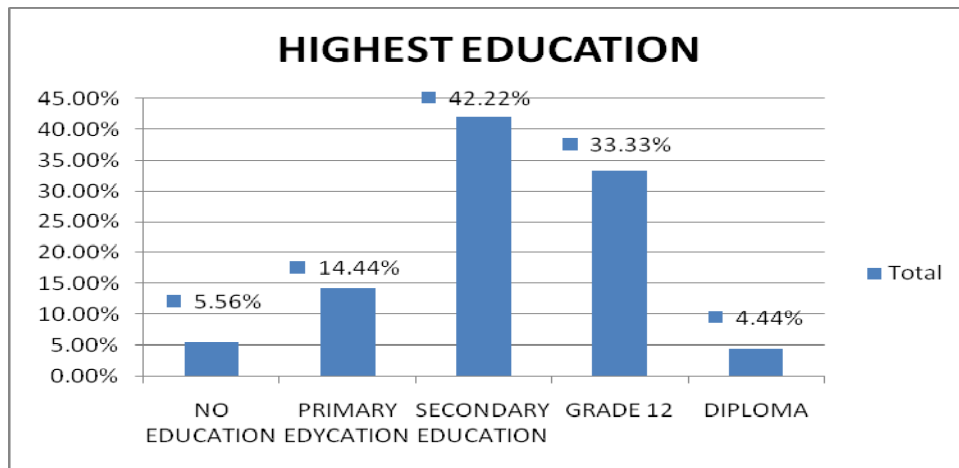
## 5.2.2 Respondent's age (n=90)



**Figure 5.2**  
**Respondent's age (n=90)**

Of the respondents, 3.33% (n=3) were below 21 years, 21.11% (n=19) were between 21-30 years, 44.44% (n=40) were between 31-40 years, 22.22% (n=20) were between 41-50 and 8.89% (n=8) were between 51-60 years (see figure 5.2).

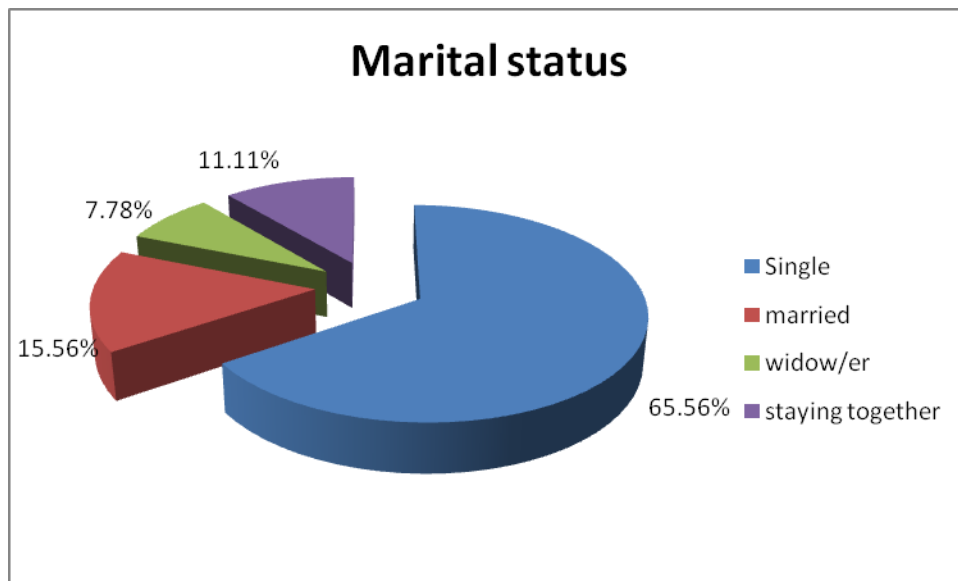
### 5.2.3 Respondent's highest education (n=90)



**Figure 5.3**  
**Respondent's highest education (n=90)**

Of the respondents, 5.56% (n=5) had no education, 14.44% (n=13) had primary education, 42.22% (n=38) had secondary education, 33.33% (n=30) had grade 12 and 4.44% had diploma (see figure 5.3).

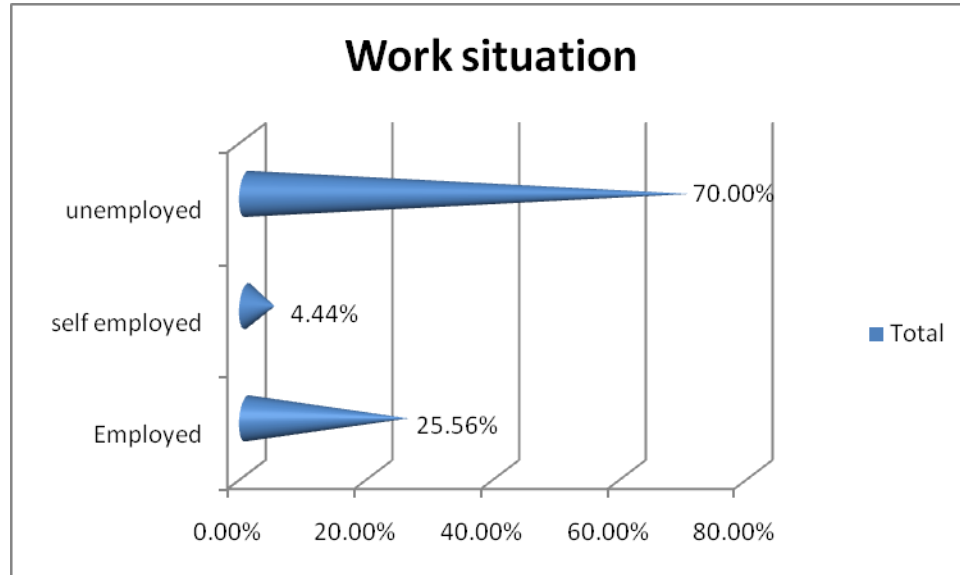
#### 5.2.4 Respondent's marital status (n=90)



**Figure 5.4**  
**Respondent's marital status (n=90)**

Of the respondents, 65.56% (n=59) were never married, 15.56% (n=14) were married, 7.78% (n=7) were widowed and 11.11% (n=10) were staying with their partners (see figure 5.4).

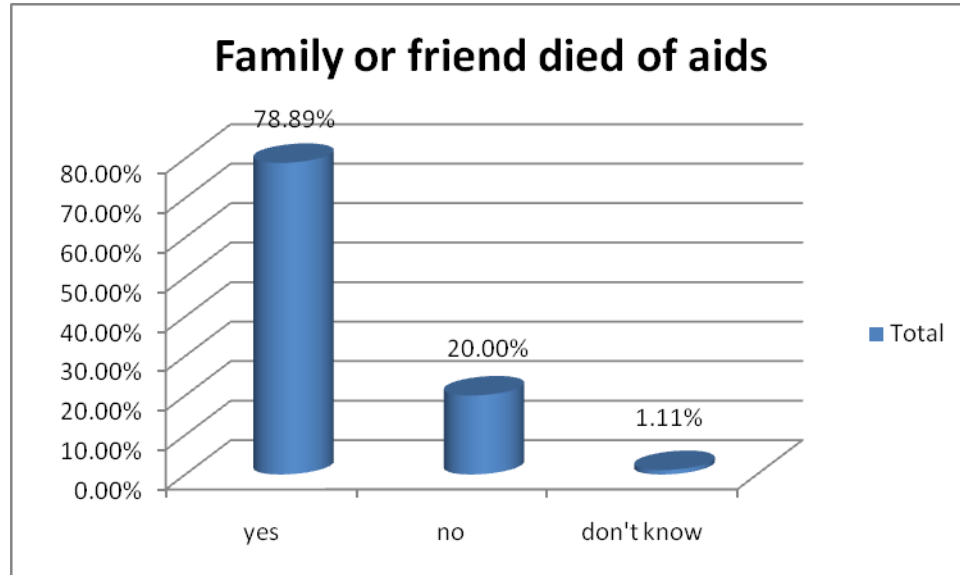
### 5.2.5 Respondent's work situation (n=90)



**Figure 5.5**  
**Respondent's work situation (n=90)**

Of the respondents, 25.56% (n=23) were employed, 4.44% (n=4) were self employed and 70.00% (n=63) were unemployed (see figure 5.5).

### 5.2.6 Respondent's known family or friends AIDS death (n=90)



**Figure 5.6**  
**Respondent's family or friend died of AIDS (n=90)**

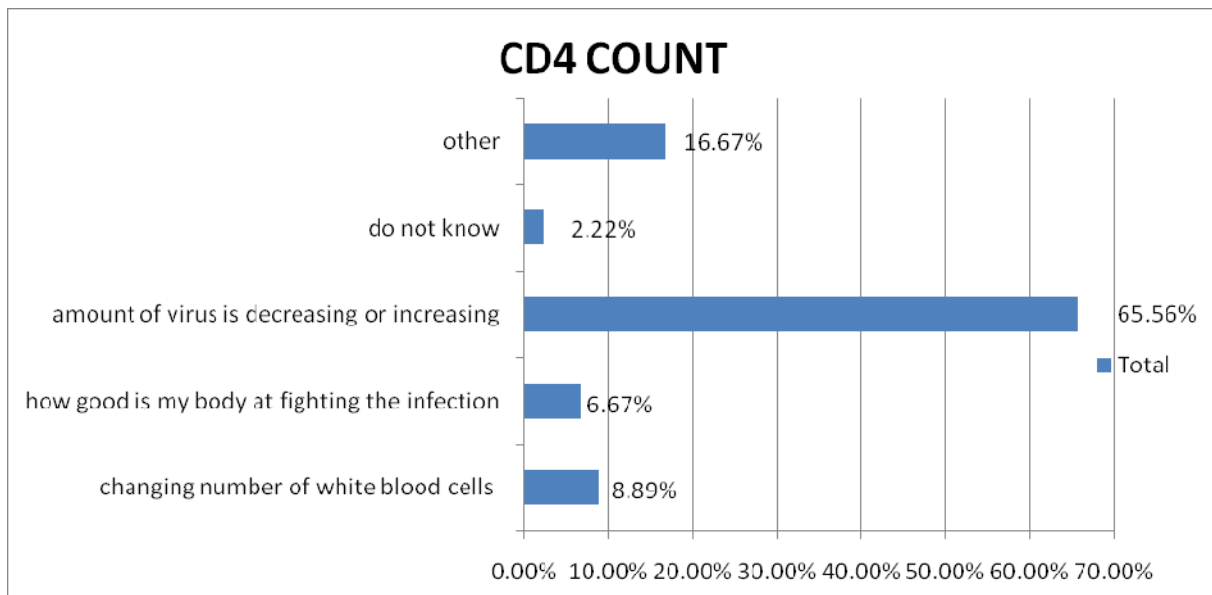
Of the respondent, 78.89% (n=71) had their family members or friends died of AIDS, 20.00% (n=18) had no family or friend died of AIDS, and 1.11% (n=1) doesn't know whether is there any friend or family died of AIDS (see figure 5.6).



### 5.3 Knowledge of viral load and CD4 count

Section C of the questionnaire examined the respondent's knowledge of the viral load and CD4 count. A total of 2 questions were prepared and used.

#### 5.3.1 CD4 count measure

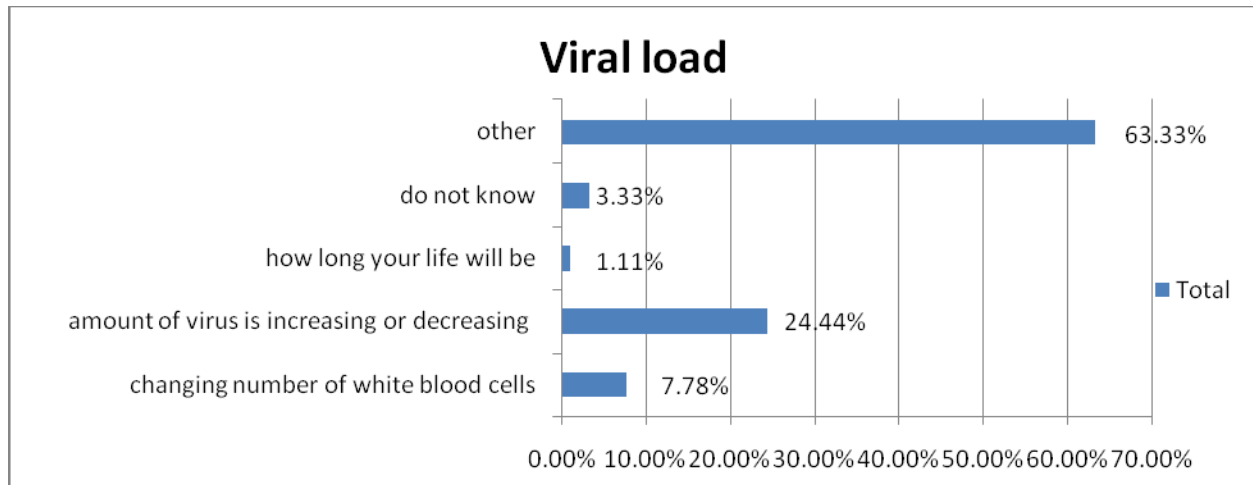


**Figure 5.7**

#### **CD4 Count Measure (n=90)**

Of the respondents, 8.89% (n=8) feel that CD4 measure the changing of white blood cells in the immune system, 6.67% (n=6) feel that CD4 measure how good the body is fighting the infection, 65.56% (n=59) feel that CD4 measure whether the amount of virus in the blood is decreasing or increasing, 2.22% (n=2) don't know what the CD4 count measure and 16.67% (n=15) feel that CD4 is measuring other (see figure 5.7).

## 5.3.2 Viral load measure (n=90)

**Figure 5.8****Viral load measure (n=90)**

Of the respondents, 7.78% (n=7) feel that viral load measure the changing of white blood cells in the immune system, 24.44% (n=22) feel that viral load measure whether the amount of virus in the blood is decreasing or increasing, 1.1% (n=1) feel that viral load measure how long your life will be, 3.33% (n=3) do not know what viral load measure and 63.33% (n=57) feel that viral load measure something else (see figure 5.8).

## 5.4 Knowledge about ARV treatment

Section C of the questionnaire examined the respondent's knowledge about ARV treatment. A total of 5 questions were used.

### 5.4.1 Knowledge about ARV treatment (n=90)

ITEM		True		False		Do not know		Total	
		N	%	N	%	n	%	n	%
1	ARV's will remove the virus from the body	5	5.56	81	90.00	4	4.44	90	100.00
2	The virus will stay hidden if I take my medication correctly	86	95.56	4	4.44	0	0	90	100.00
3	The HIV tries to trick ARV's by changing its form	64	71.11	18	20.00	8	8.89	90	100.00
4	ARV's can cure AIDS if taken few months after being infected	3	3.33	84	93.33	3	3.33	90	100.00
5	The HIV will become resistant to ARV's and stop working	39	43.33	37	41.11	14	15.56	90	100.00

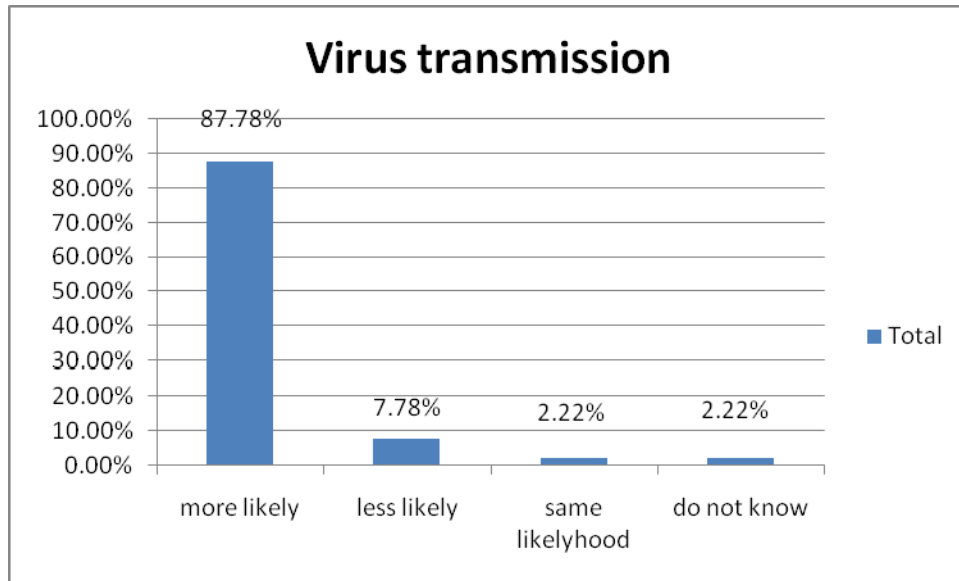
**Table 5.1**  
**Knowledge of ARV treatment (n=90)**

Table 5.1 indicates that the majority or 90% (n=81) of the respondent said it is false that ARV's will remove the virus from the body; 95.56% (n=86) said it is true that the virus will stay hidden in the body as long as a person is taking medication correctly; the majority of the respondents said it is true that HIV tries tricking the ARV by changing its form 71.11% (n=64); 93.33% (n=84) said it is not true that ARV's can cure AIDS if taken few months after being infected. With regard to HIV becoming resistant to ARV and that ARV's can stop working, the respondents were divided, with 43.33% (n=39) said it is true, 41.11% (n=37) who said it is false and the 15.56% (n=14) respondents feel that they don't know the answer.

## 5.5 Perception of risk transmission

Section D of the questionnaire examined the respondent's knowledge of the risk of transmission of the virus

### 5.5.1 Transmission virus more or less like while on ART compared before on ART (n=90)



**Figure 5.9**  
**Virus transmission (n=90)**

Of the respondents, 87.78% (n=79) answered that it is more likely to transmit the virus to a part even if you on ART or not on ART, 7.78% (n=7) answered that it is less likely that virus can be transmitted while on ART rather than not on ART, 2.22% (n=2) answered that the transmission is the same whether on ART or not on ART, 2.22% (n=2) don't know the answer to the question (see figure 5.9).

## 5.5.2 The danger of sleeping without the condom (n=90)

ITEM		Very dangerous		Dangerous		Somewhat dangerous		Not very dangerous		Not dangerous		Do not know		Total	
		n	%	N	%	n	%	N	%	n	%	n	%	n	%
1	Sleep without a condom before ART	71	78.89	18	20.00	0	0.00	0	0.0	1	1.11	0	0.00	90	100.00
2	Sleep without a condom after ART	80	88.89	10	11.11	0	0.00	0	0.0	0	0.00	0	0.00	90	100.00

Table 5.2

**Danger of sleeping without a condom (n=90)**

Table 5.2 indicates that 78.89% (n=71) answered that it is very dangerous to sleep without a condom before you started ARV treatment, with 20% (n=18) who also feel that it is dangerous to sleep without a condom before you started ARV treatment. Out of 90 respondents, 88.89% (n=80) said it is very dangerous to sleep without a condom even if you are on ART treatment, with 11.11% (n=10) feel that it is dangerous to sleep without a condom after you started ART.

## 5.5.3 ARV's and risks (n=90)

ITEM		Agree		Disagree		Do not know		Total	
		N	%	n	%	n	%	N	%
1	Harmful to have a baby while on ARV's	49	54.44	38	42.22	3	3.33	90	100.00
2	Can have a baby if my CD4 is above 800	38	42.22	33	36.67	19	21.11	90	100.00
3	Cannot have a baby with an unknown status	61	67.78	28	31.11	1	1.11	90	100.00
4	ARV's reduce risk of transmission	6	6.67	83	92.22	1	1.11	90	100.00
5	Treatment with ARV's make use of condom less important	0	0.00	89	98.89	1	1.11	90	100.00
6	No transmission if taking ARV's	2	2.22	87	96.67	1	1.11	90	100.00
7	If a cure is discovered I will stop using condom	4	4.44	85	94.44	1	1.11	90	100.00

**Table 5.3**  
**ARV's and risks (n=90)**

Table 5.3 indicates that of the respondents, 67.78% (n=61) believed that they cannot have a baby if they do not know the status of the partner; 92.22 % (n=83) disagree that ARV's can reduce the risk of transmission; 98.89 (n=89) disagree that treatment with ARV's , makes using condoms less important; 96.67% (n=87) disagree that you cannot transmit the HIV virus to a partner when you are taking ARV's assuming not using a condom; 94.44% (n=85) disagree that they will stop using a condom if cure for HIV virus is found. With regard to the statement that it is harmful to have a baby while on ARV's, the respondents were divided: 54.44% (n=49) agree, 42.22% (n=38) disagree, and 3.33% (n=3) do not know the answer.

With regard to the statement that it is okay to have a baby if CD4 count is above 800 and the viral load is undetectable, also the respondents were divided: 42.22% (n=38) agree, 36.67% (n=33) disagree, and 21.11% (n=19) do not know the answer.

## 5.6 Perception and attitude towards ART

Section E of the questionnaire examined the respondent's perception and attitude towards ART. The answers will show clearly whether the respondents adhere to the treatment by looking at their answers.

### 5.6.1 Perception towards ART (n=90)

ITEM		Strongly agree		Agree		Undecided		Disagree		Strongly disagree		Total	
		n	%	n	%	N	%	n	%	n	%	n	%
1	Aids less serious because ART	2	2.22	38	42.22	1	1.11	45	50.00	4	4.44	90	100.00
2	Too early to say ARV's are successful	1	1.11	4	4.44	3	3.33	79	87.78	3	3.33	90	100.00
3	With ARV's aids can be manageable	5	5.56	79	87.78	1	1.11	5	5.56	0	0.00	90	100.00
4	ARV's not effective as meant to be	2	2.22	0	0.00	2	2.22	79	87.78	7	7.78	90	100.00

**Table 5.4**  
**Perception towards ART (n=90)**

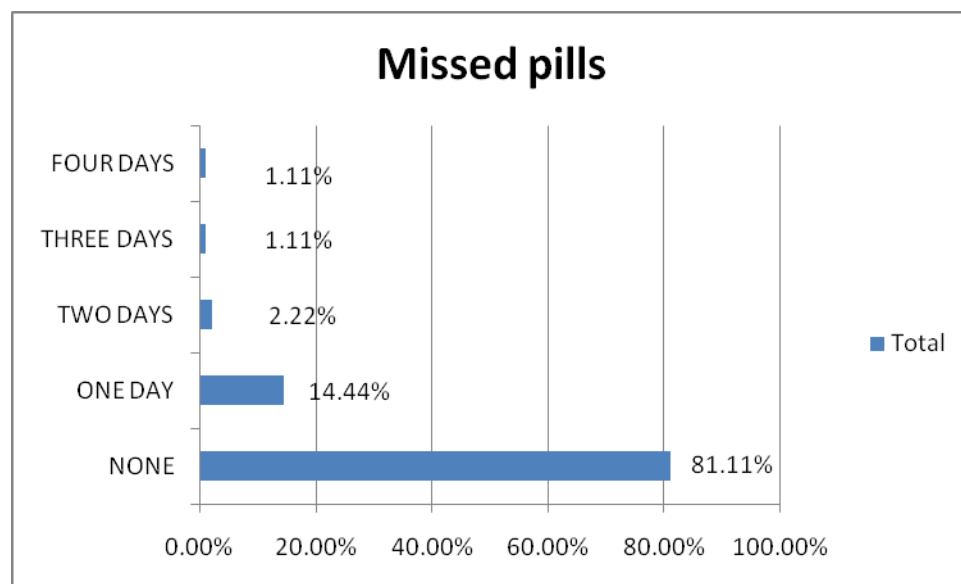
Table 5.4 indicates that of the respondents, 87.78% (n=79) disagree that it is too early to tell if ARV's will be successful in the long run; 87.78% (n=79) agree that because of ARV's, AIDS can be managed like any other disease; 87.78% (n=79) disagree that ARV medication are not as effective as they are made to be.

With regard to the statement that AIDS has become a less serious illness because of ARV's, the respondents were divided: 2.22 (n=2) strongly agree, 42.22% (n=38) agree, 1.11% (n=1) is undecided, 50.00% (n=45) disagree and 4.44% (n=4) strongly disagree.

### 5.6.2 Attitude towards ART

The following figures and statement indicates the respondents' attitude towards ART.

#### 5.6.2.1 Days of pills missed (n=90)

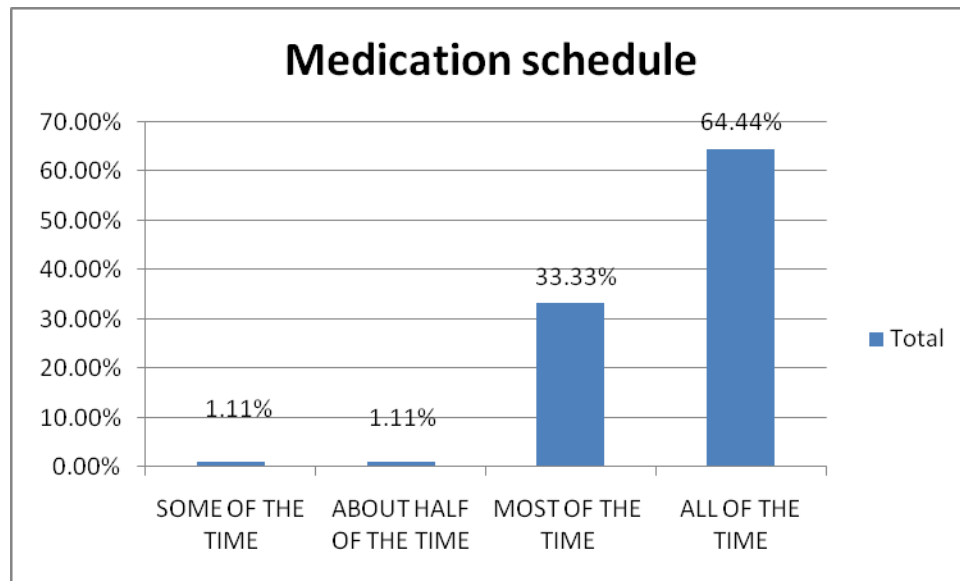


**Figure 5.10**  
**Days of pills missed (n=90)**

Of the respondents, 81.11% (n=73) none of the pills have been missed, 14.44% (n=13) have missed a pill one day during the past month, 2.22% (2) have missed pills two days during the past month, 1.11% (n=1) have missed pills three days during the past month and 1.11% (n=1) have missed pills during the past month (see figure 5.10).

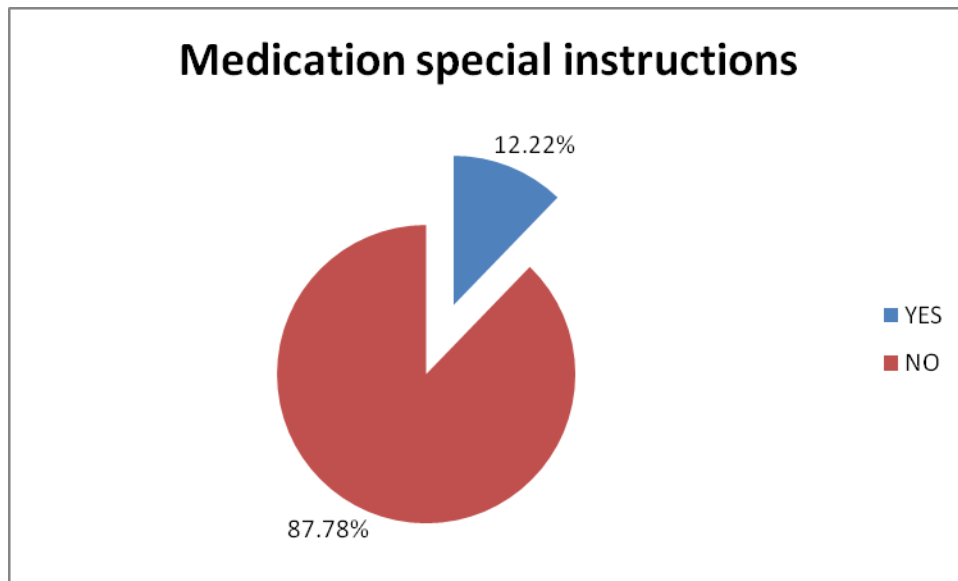


## 5.6.2.2 Follow medication schedule (n=90)

**Figure 5.11****Medication schedule (n=90)**

Of the respondents, 64.44% (n=58) followed their specific schedule all of the time last month, 33.33% (n=30) followed their specific schedule most of the time last month, 1.11% (n=1) followed the specific schedule about half of the time last month and 1.11% (n=1) followed the specific schedule some of the time last month.

## 5.6.2.3 Medication special instructions (n=90)

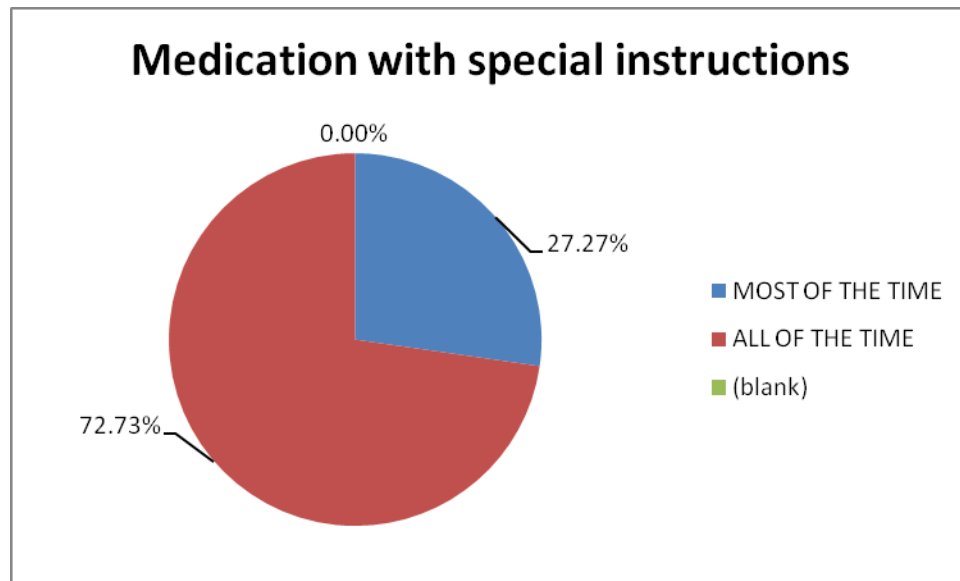


**Figure 5.12**

**Medication special instructions (n=90)**

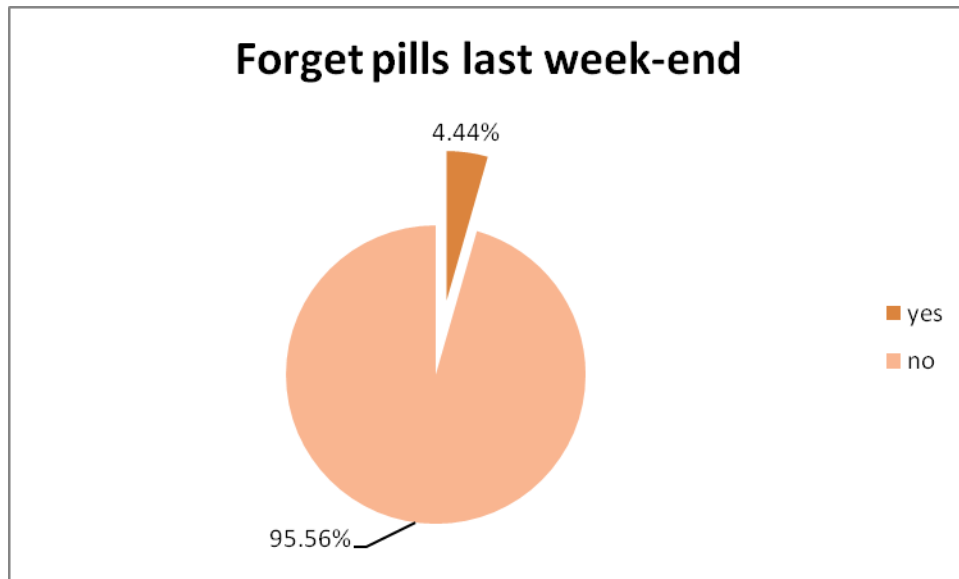
Of the respondents, 87.78% (n=79) answered that their medication has no special instructions such as take with food, on an empty stomach or with plenty of fluids; 12.22% (n=11) answered that their medication has special instructions.

## 5.6.2.4 How did you follow instructions last month (n=90)

**Figure 5.13****Medication with special instructions (n=90)**

Of the respondents with special instructions on their medication, 72.73% (n=8) answered that they followed the instructions all of the time over the last month and 27.27% (n=3) answered that they followed the instruction most of the time over the last month.

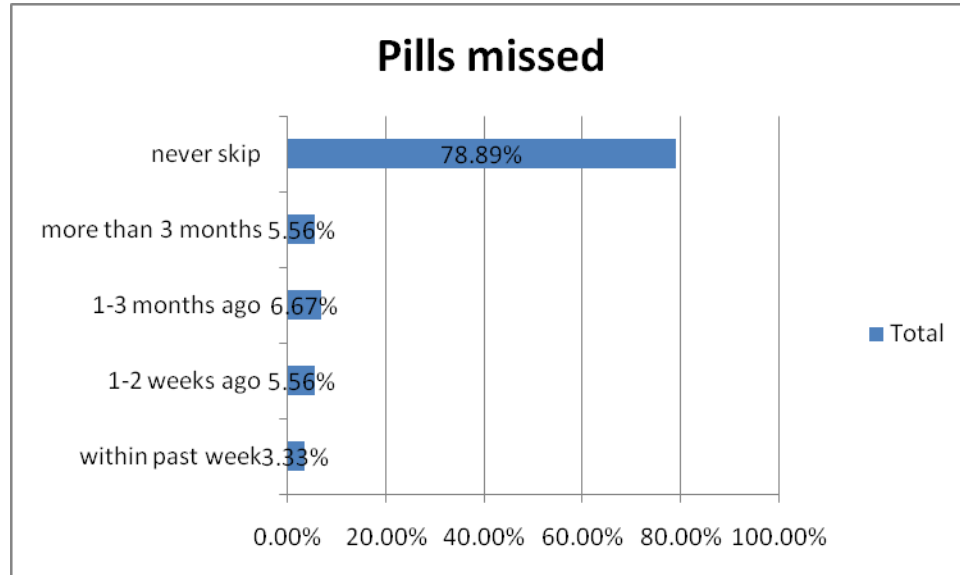
## 5.6.2.5 Forgetting pills on week-ends (n=90)



**Figure 5.14**  
**Forgetting pills last week-end**

Of the respondents, 95.56% (n=86) did not forget to take medication last week-end and 4.44% (n=4) did forget the medication over the last week-end.

## 5.6.2.6 Last time missing medication (n=90)



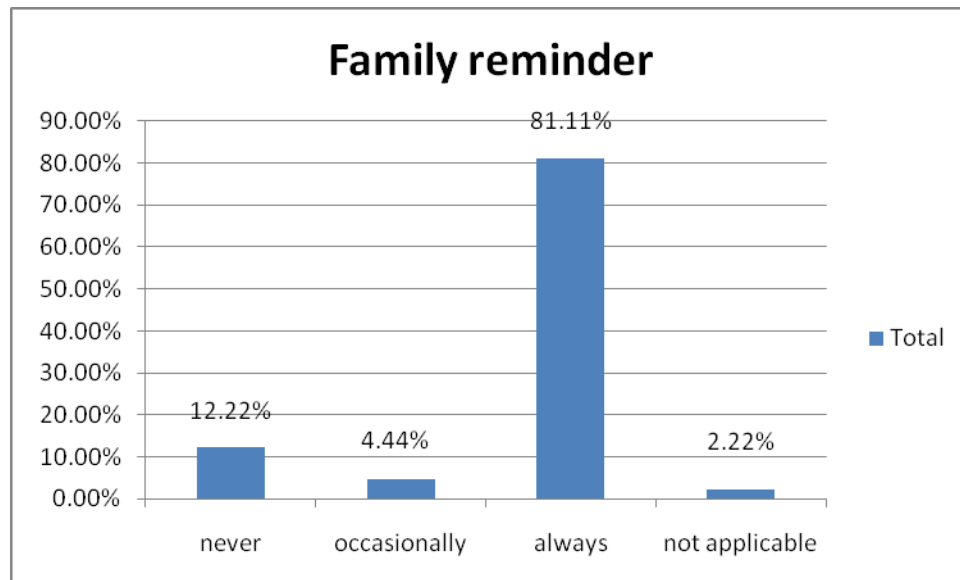
**Figure 5.15**  
**When did pills missed (n=90)**

Of the respondents, 78.89% (n=71) answered that they have never missed their medication, 5.56% (n=5) missed taking their medication more than 3 months ago, 6.67% (n=6) missed taking their medication 1-3 months ago, 5.56% (n=5) missed taking their medication 1-2 weeks ago and 3.33% (n=3) within the past week.

## 5.7 Disclosure after starting ARV treatment

This section of the questionnaire examined the respondent's disclosure to their closed ones after they have started ARV treatment or medication.

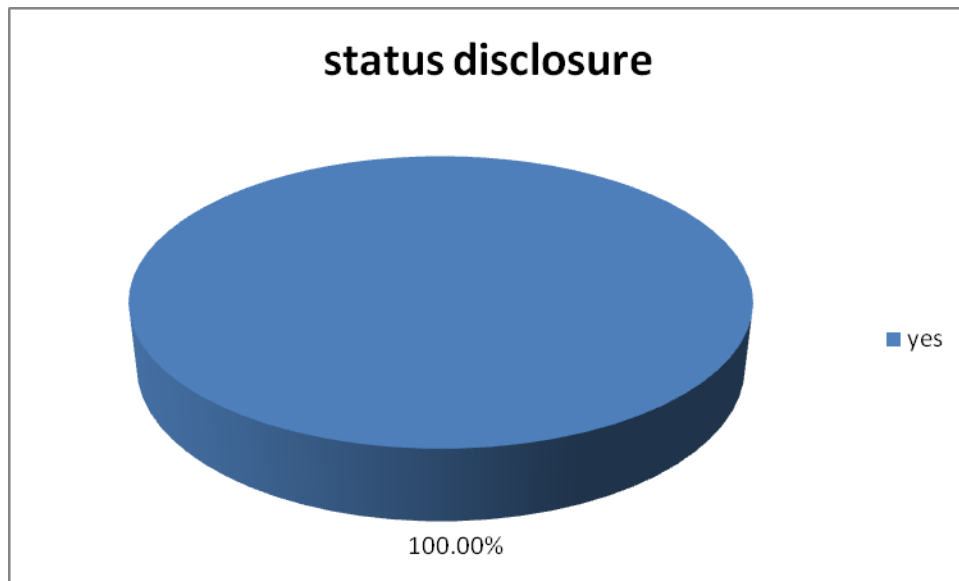
### 5.7.1 Family reminder (n=90)



**Figure 5.16**  
**Family reminder**

Of the respondents, 12.22% (n=11) said that they have never been reminded by their family members to take their medication, 4.44% (n=4) were occasionally reminded to take their medication, 81.11% (n=73) were always reminded to take their medication and 2.22% (n=2) said the statement is not applicable to them.

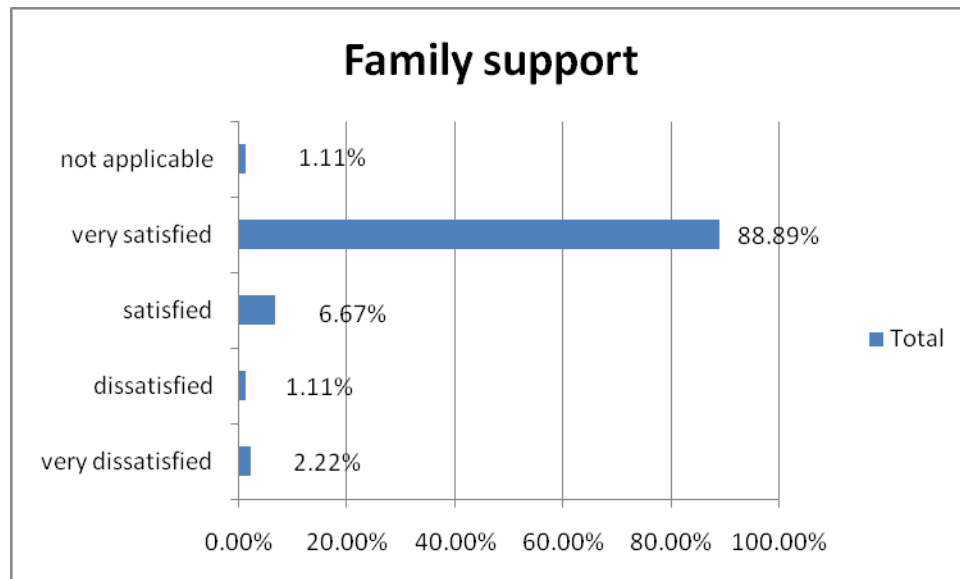
## 5.7.2 Have you disclosed the status to anyone? (n=90)



**Figure 5.17**  
**Status disclosure (n=90)**

Of all the respondents, 100% (n=90) answered that they all disclosed their status to someone else.

## 5.7.3 Family support (n=90)



**Figure 5.18**  
**Family support (n=90)**

Of the respondents, 2.22% (n=2) said they are very dissatisfied with the support that they get from their families, 1.11% (n=1) not satisfied or dissatisfied with the support from family, 6.67% (n=6) satisfied with the family support, 88.89% (n=80) are very satisfied with the support they get from their families and 1.11% (n=1) feel the statement is not applicable.



## 5.7.4 Status disclosure and partners (n=90)

ITEM		Strongly agree		Agree		Neither agree or disagree		Disagree		Strongly disagree		Refused		Total	
		n	%	N	%	N	%	N	%	n	%	n	%	n	%
1	No need of a condom if both HIV	5	5.56	3	3.33	1	1.11	73	81.11	8	8.89	0	0.00	90	100.00
2	Difficult to keep status a secret if staying together	4	4.44	80	88.89	0	0.00	5	5.56	1	1.11	0	0.00	90	100.00
3	ARV make it easier to open about your status	0	0.00	81	90.00	0	0.00	7	7.78	2	2.22	0	0.00	90	100.00
4	Difficult to insist on condom if status not disclosed	1	1.11	75	83.33	3	3.33	11	12.22	0	0.00	0	0.00	90	100.00

**Table 5.5****Disclosure and partners (n=90)**

Of the respondents, the majority of respondents 81.11% (n=73) disagreed that there is no need to use a condom if both partners got HIV; 88.89% (n=80) agreed that it is difficult to keep your status when you are staying with a partner; 90.00% (n=81) agreed that being on ARV's makes it easier to be open about your status and 83.33% (n=75) agreed that it is difficult to insist on condom use when you have not disclosed your status to your partner.

## **5.8 Summary**

The findings of the quantitative analysis indicated that people on ART satisfactory adhere to their treatment with 79% who never skipped or missed their medication. The respondents indicated that they always follow their specific schedule all the time.

The only problem that was shown by the analysis was the knowledge of viral load and CD 4 count. Most of the respondents were confusing CD 4 count with viral load with very few who have knowledge of both. Most of them don't even know why they are measured.

## **CHAPTER 6**

### **DISCUSSIONS OF FINDINGS**

#### **6.1 Discussion**

The aim of this study was to investigate adherence for people on ART, focusing on the levels and consistency of adherence, the relationship between adherence and virologic response and factors influencing adherence to ART. Little is known about achievable levels of antiretroviral treatment (ART) adherence in resource-limited settings. This chapter contains a discussion and key findings of the quantitative and qualitative results presented in the two preceding chapters in the light of the literature review.

There was a higher proportion of female (76%) than male (24%) in the sample. This was mainly due to the fact that there were a higher proportion of female (74%) attending the clinic (Patients' records, Ithembalabantu clinic, 2009). The relatively low number of males attending the clinic was not surprising. Studies have found that females are more likely to attend VCT services and also, actively seek health care than male (Shisana et al., 2005). Many of the males receiving medication at the clinic were working. They were therefore not able to pick up the medication themselves or they couldn't wait and in a hurry to leave the clinic. Many of the males were therefore not be able to participate in the study. This exacerbated the disparity in the sample. This discussion will integrate the results of the quantitative and qualitative studies as recommendations for healthcare providers in the field of HIV.

Adapting medication to life rather than life to medication is the first and most important strategy to promote adherence. Belief and education are certainly keys for adherence. Studies have shown that education is a cornerstone for establishing adherence to any long term therapy (Eckman, et al., 1990). HIV and antiretroviral therapy education are essential components needed for establishing the requisite belief in HAART that serves as a foundation for adherence (Tuldra, et al., 2000).

The quantitative analysis indicated that of the respondents, 79% said they have never missed the pills, 81% always reminded to take their medication which automatically concluded to the possible adherence and that they were able to manage side effects. The rapid replication and mutation rate of HIV, means that very high levels of adherence, >95%, are required to achieve the durable suppression of the viral load. The remaining 19 % respondents that have missed their pills are in danger of less than 95% of the required adherence.

The participants in the semi-structured interviews indicated that it is very important to take the antiretroviral drugs at the same time every day. The respondents know why they need not to skip their medication. They kept on referring to what they have been told at their four day training, that the other medication functions on their body for 12 hours and the others for 24 hours, therefore if they skip their medication, their bodies might function without medication and protection and the virus might get the chance to act on that moment.

The findings on antiretroviral treatment adherence in this study were similar to the findings of the study adherence to antiretroviral therapy in HIV-infected adults in Soweto, South Africa (Nachega, et al., 2004). The study conducted a cross-sectional study of adherence among patients at Chris Hani Baragwanath Hospital's Adult HIV Clinic in Soweto, South Africa. The study indicated that the adherence reported by patients for the month was >95% for 58 patients (88%), 90-95% for 6 (9%) and, < 90% for 2 (3%). The main reasons given for missing doses were being away from home (30%), difficulty with the dosing schedules (23%), and running out of pills (12%). Adherence decreased considerably with fear of being stigmatized by the sexual partner. Plasma HIV RNA levels were <400 copies/ml in the majority of patients (73% of those with adherence >95% and 88% of patients with < or =95% adherence) and the overall median CD4 (+) cell count rose to 324/mm<sup>3</sup>. High adherence and viral suppression are achievable for a significant proportion of HIV-infected patients taking ART in a resource-limited area such as Soweto, South Africa. The study suggested that strategies to maximize adherence should emphasize ready access to affordable and simple ART regimens, as well as HIV education programs to help increase awareness and decrease disease stigmatization.

In general, it appeared that HIV Education programs and affordable and simple ART regimens as suggested by the study to maximize adherence could be the solution. The participants in the semi structured interviews indicated that they didn't skip their medication because the providers told them from the clinic the consequences for skipping medication.

One of the aims of this study was to determine relationship between adherence and virologic response. Almost all the respondents' files showed that their CD 4 increases and other showed that they are fluctuating. The findings from the study's survey showed that of the respondents' CD 4 count, 57 (63 %) increased, 27 (30%) haven't got their second CD 4 count results and 6 (7 %) decreased. The number of respondents demonstrating virologic suppression in this study is comparatively higher than the findings in the study 'Predictors of suboptimal virologic response to highly active antiretroviral therapy among human immunodeficiency virus-infected adolescents: analyses of the reaching for excellence in adolescent care and health (REACH) project' (Ding, et al., 2009). The study indicated that of the 154 adolescents enrolled in the study, 50 (32.5%) demonstrated early and sustained virologic suppression while receiving HAART. The remaining 104 adolescents (67.5%) had a poor virologic response. Adequate adherence (>50%)-reported by 70.8% of respondents-was associated with 60% reduced odds of suboptimal virologic suppression in a multivariable logistic regression model (adjusted odds ratio = 0.4; 95% confidence interval, 0.2-1.0). Exposure to suboptimal antiretroviral therapy prior to HAART, on the other hand, was associated with more than 2-fold increased odds of suboptimal virologic response (adjusted odds ratio = 2.6; 95% confidence interval, 1.1-5.7). The study concluded that two-thirds of human immunodeficiency virus-infected adolescents in the current study demonstrated a suboptimal virologic response to HAART. Non-adherence and prior single or dual antiretroviral therapy were associated with subsequent poor virologic responses to ART.

The study 'Antiretroviral failure despite high levels of adherence: discordant adherence-response relationship in Botswana' (Bisson, 2008) argued that although adherence to antiretroviral therapy may be higher in sub-Saharan Africa, knowledge regarding the magnitude of adherence needed to maintain virological suppression in this setting is limited.

The findings of the study indicated that of 302 participants, 57 cases were compared with 245 controls with respect to adherence levels on no nucleoside reverse transcriptase inhibitor-based HAART. Median adherence levels, as measured using pharmacy refill patterns, were consistently high but differed among cases and controls (91%, interquartile range 83%-97% for cases vs. 97%, interquartile range 91%-100% for controls,  $P < 0.001$ , rank-sum test). Adherence  $<95\%$  was independently associated with virological failure (odds ratio 4.19, 95% confidence interval 2.2 to 8.3). It has reported that very high rates of adherence were present in the setting, yet virological failure occurred nonetheless. With the above study, it cannot be predictable that the 6(7 %) respondents with the decreased CD 4 count is caused by skipping dose but it can be a virologic failure. Future work should therefore explore other factors that might explain treatment failure in the setting of high levels of adherence.

One of the aims of this study was to determine the factors influencing adherence. When HAART was introduced, information on possible side effects and instructions on how to manage these side effects was given. It is important that possible side effects should be explained clearly so that patients understand properly how their medications work. During every follow-up visit, any ambivalence toward the medications (they heal but are also toxic) should be discussed. All patients who start treatment should be prepared for the possibility of unpleasant and distressing side effects and advised how to handle them.

The participants in the semi-structured interview indicated that they experienced side effects during their first month of starting the treatment. Others said that they are still experiencing side effects such as growing breasts, feet cramps and libido problems but their side effects are not stopping them from adhering to their treatment. They said they are using cell phone alarms, radio and TV programmes as their personal reminders.

The patient's acceptance of being HIV positive should be discussed, as acceptance improves the chances of adherence. If medically possible, it may be better to delay treatment while helping the patient to accept the disease. Furthermore, a patient should be prepared for the fact that starting HAART can renew the confrontation with being HIV positive, which can lead to psychological distress and, therefore, to non-adherence. Follow-up should be arranged to give support.

Secrecy is threatened by taking treatment. The possibility of disclosure should be discussed with the patient as openness leads to a higher level of adherence. The fact that disclosure can lead to negative comments from others, which may adversely influence adherence, should also be discussed. If disclosure is not an option, a patient can be informed how to handle taking medicine in secret to prevent skipping doses. If HIV-related symptoms are present, actions should be taken to diminish or manage those symptoms.

The quantitative analysis indicated that of the respondents, all of them indicated that they have disclosed their status at to one person and 89% said they are satisfied with the support they get from their families or people that they have disclosed to. The participants in the qualitative analysis indicated that they don't care about what anyone can say about them, all they care about is taking care of their lives. They all seemed to have accepted their status. They believe in ART saying that they know where they are coming from before they have started ART as most of them were very sick, attacked by opportunistic diseases.

Feedback about positive reactions of the body should be used to support adherence. Showing a decreasing viral load and an increasing CD4 cell count will build trust in the medication. As trust and belief can change over time with subjective experience or through information from others, it is necessary to discuss this theme during every follow-up visit. Pointing out the value of treatment for the patient's life during follow-up visits enhances motivation.

Information appropriate to a patient's level of understanding will lead to the patient having correct knowledge of what constitutes good adherence practice. Because a patient's personal interpretation of good adherence practice may be based on misconceptions that are used to justify risky behavior, it is important to ask patients to describe their behavior and if necessary to repeat instructions.

Discussing details of the circumstances that lead to forgetting medication can reveal aspects that need attention in order to improve adherence. Attention should be given to personal skills, such as the capacity to organize one's life and one's activities and the ability to anticipate risk situations.

In case of depression, a patient should be advised to undergo treatment before starting HAART. In case of substance use, it is important to find a way to minimize the risk that substance use will remain the first priority in life. Professional support or daily observed therapy can be an option.

The quantitative analysis indicated that the respondents were confused and not sure of the answers about CD4 and viral load. They did not completely understand the concept of infectiousness, as they did not manage to distinguish between viral load and CD 4 count. However, they indicated that ART made the virus decrease in their blood but never linked this to infectiousness and viral load. Only 9% of the respondents gave the correct answer about why the CD4 is measured, 66% gave answers that showed that they are confusing CD 4 with viral load and the rest they gave wrong answers and 2% said they don't know what CD4 measure. Only 24% of the respondent gave the correct answer about why viral load is measured, with 63% saying the answer is not in the statement. This showed that the participants have no appropriate information about CD4 and viral load and what role are these two playing in their life and ART. These findings identify (Marseille et al., 2002) argument as flawed, as it indicates that the respondents did not understand the concept of infectiousness, and that commencing ART has provided a reason for using condoms.



A trusting relationship with the healthcare provider is essential. This relationship is built on support and open communication. Providers should give clear instructions on how to take medication, explain the relationship between adherence and viral load and offer good medical follow-up.

The qualitative analysis indicated that respondents have good relationship with the providers. All of them said the providers knows what they are doing, that they are very supportive, always listen to their problems and give referrals if needs be. They all responded that they are very strict with adherence.

About two participants said that the providers need you to bring the containers so they will see whether the amount of pills in the box corresponds with the ones expected from the box. About two respondents said they have been taken to the counselor for discipline for not coming to the clinic to collect their medication on the expected date.

Acquiring insight into a patient's social support systems and counseling on how to use them is a valuable strategy in optimizing adherence. Social support has to be substantial and practical, such as reminders to take medication. Attention should also be paid to possible negative influences on adherence in the patient's environment, perhaps coordinating the (medication) schedules of partners or dealing with a discouraging influence.

The quantitative analysis indicated that 81 % of the respondents are always reminded to take their medication with 12 % who are never reminded to take their medication. The result proves that the reminder to take medication plays a role in adhering to medication and should be emphasized to people on pre-treatment trainings.

Some studies agreed with the factors that were analyzed in this study. A system review of developed and developing nation patient-reported barriers and facilitators (Mills, et al., 2006) reported that in their findings, the important barriers in both settings included fear of disclosure, concomitant substance abuse, forgetfulness, suspicions of treatment, regimens that are too complicated, number of pills required, decreased quality of life, work and family responsibilities, falling asleep, and access to medication. The important barriers to adherence are therefore consistent across multiple settings and countries.

The other study on barriers to antiretroviral adherence among HIV-infected adults (Murphy, 2000) reported that the most difficult barriers for patients revealed from quantitative data were sleeping through dose time, problems in following special instructions, and changes in daily routine.

From the qualitative data, four categories of barriers and aids to adherence emerged: patient characteristics, the health care provider-patient relationship, the health care system, and issues related to the medication regimen.

## 6.2 Key findings

The study has found relatively high levels of consistent adherence to ART among people on HAART. More than 70 percent of the respondents never skipped or missed their medication and more than 60% followed their specific schedule all the time. The level of adherence is consistent with the findings from similar studies (Nachega, et al., 2004).

Since most of the participants started ART after they were very sick, attacked by opportunistic diseases, ART programme could be the factor that contributes to relatively high levels of ART adherence.

## **CHAPTER 7**

### **CONCLUSION AND RECOMMENDATIONS**

#### 7.1 Recommendations

Based on the findings of the study, the researcher makes the following recommendations for practice and further research.

Although the study showed the relatively high levels of adherence, the development of practical guidelines for implementing adherence management strategies are recommended which include, the issue of continuous adherence counseling; bringing treatment closer to the people; family care model approach to HAART, practical reminders, adherence case management, medication organizer.

Ithembalabantu is the only private clinic around Durban and surrounding areas also used by people travelling more than 50 km, therefore to avoid people not collecting their treatment at the stipulated dates, consideration of transport vouchers to people who genuinely cannot afford the cost of transport to collect their medications.

The high levels of adherence does not guarantee adherence for a long time, therefore it is recommended that adherence be monitored uniformly with simple practical tools like pill count register and patient recall. Data generated should be reviewed periodically in order to know the rate and trend of adherence to HAART.

Although participants said that they have disclosed their status to someone but they are still afraid for their status to be known by friends and the community because of stigma and discrimination. Community mobilization aimed at mitigating stigma and discrimination should be sustained as this will help create an environment in which people can disclose and take medicines without fear.

There was a participant who said that their employers told him to stay home because he is not fit for work after disclosing to them that he is on treatment. Rights of people in employment to access treatment without fear of discrimination must be protected by enforcement of appropriate legislations. Workplace sensitization should be done; toll free lines should be created for people to complain in case of violation.

The study indicated that there are fewer male than female attending the clinic and that there were women who were dumped by their partners disclosing their status. Program targeting men on HIV/AIDS issues should be emphasized. This will help increase the enrolment of men, help them understand the gender issues around HIV/AIDS and finally mobilize them to protectors and supporters of women in fight against HIV/AIDS treatment and prevention.

Most of the respondents who never missed their medication reported that they use the radio and their cell phones as their reminders. In order to deal with the issue of forgetfulness, radio stations, TV stations and mobile operators could send periodic signals with jingles reminding people to take their medications, therefore it should be emphasized to the patients all the time they visit the clinic.

The feedbacks that the patients are receiving from the health care providers about the progress of the ARV in their bodies are important. They will encourage them not to skip their medication but adhere to their medication. The knowledge from the training sessions also the information appropriate to a patient's level of understanding will lead to the patient having correct knowledge of what constitutes good adherence practice. Knowledge, talking and showing CD4 count and viral load is therefore very important as both part of the training and regular feedback during the time of visits to build trust of the medication.

Continuous operational research on adherence since adherence is dynamic. Research is urgently needed to determine patient-important factors for adherence.

## 7.2 Future research

The following topics are recommended for further research:

- Psychological factors and adherence to ART.
- Socio-economic factors and adherence to ART.
- Investigating sexual behaviors for people on ART

## 7.3 Limitations of the study

The study was only conducted in one clinic which is Ithembalabantu clinic at Umlazi. The sample population used by the study was less than 10% of the people who are taking their medication at Ithembalabantu. The study had a sample size of 90 respondents while the clinic has 6159 patients taking medication.

The study used the cross sectional design. With this design, no conclusion on causal links can be drawn. It can also introduce re-call bias. Studies have found that if patients are asked to answer questions concerning adherence to ART more than three months ago, the validity of the answers would be compromised (Graham et al., 2003).

Some people were in a hurry to get back to work or they sent someone to collect their medication. As a result, they couldn't stay behind for interview and survey. People who are working are therefore underrepresented in the study.

#### 7.4 Conclusion

The study investigated the adherence of ART to PLHA taking them at Ithembalabantu clinic, Umlazi. The study found that adherence is satisfactory concluding from the sample that was used by the researcher. The findings and recommendations should not serve to the patients taking medication at Ithembalabantu only but in the entire country.

In summary, this study has found that ART through proper adherence training should provide another opportunity to reinforce prevention efforts and to increase HIV-positive patient's sexual assertiveness. ART does through proper adherence training, and by having a positive effect on patients' health, increase the likelihood of consistent taking of medication. However, this is an exploratory study and therefore it has some limitations. Further research is needed to prove or refuse its findings. Research conducted at other sites with different resources available for training such as public hospitals, would be especially useful. Extensive in-depth research is needed to explore sexual behaviors of people on ART and functions around condom use amongst ART patients.

Longitudinal quantitative studies documenting adherence to ART over several years are needed to more accurately determine the consistency of patients' adherence over years. A longitudinal study is more likely to produce reliable answers as the researcher will be able to establish a better relationship with the patient, as well as being able to document changes in adherence over a period of time.

The adherence rates found in this study are comparable to other studies. Most of the studies have adherence rates of between 70 to 90 percent adherence.

HAART is predictably leads to an immunological benefit characterized by an increase in CD4 cell count, reducing, hence, the risk of AIDS-related disease progression and death. This rate is low for good virologic, immunologic, and clinical outcomes. Near perfect adherence, however, is required to maximize the likelihood of long term clinical success. Adherence is complex and multi-dimensional approach is required to tackle the barriers and strengthen the facilitators.

People from all groups of treated individuals commonly have difficulty maintaining a high level of medication adherence. To help patients benefit fully from ART, clinicians need to take time to ask about and support medication adherence. Methods to assess adherence should be used in clinical practice. Methods such as patient self-report is the most simple and economical one. Efforts must be made to increase its sensitivity for detecting non adherence. Efforts include asking about adherence regularly in an open, non judgmental and collaborative manner.

There are many ways available for clinicians to support and improve medication adherence. Alterable factors known to affect adherence, such as depression, substance abuse, homelessness, regimen complexity, medication side effects, and the therapeutic relationship between patient and provider, can be address prior to starting therapy and in an ongoing way throughout treatment. In this way adherence can be regularly assessed, problems can be addressed, side effects can be dealt with, medication can be simplified or changed if necessary, and adherence devices can be supplied where appropriate.

Critical barriers that emerged from this study include forgetfulness, lack of transport fare to health facility, non-acceptance of status, fear of discrimination and stigma, alcohol abuse, and non supportive home and work environments.

Though side effects occur in a significant proportion of the respondents in this study, it was not perceived as a barrier to adherence. The respondents showed that they were well trained to manage side effects.

Facilitators found in this study include self efficacy, social support, perceived benefits of the medication, and desire to stay alive for the sake of others. Improving adherence requires a collaborative approach with the patient the community and health workers as well as dealing with and improving the environmental and structural constraints

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*Appendix/appendices***ANNEXURE A: Permission letter**

Chairperson  
Ethics

08 December 2008

Zandile J.P School  
Sokesimbone Road  
Unit H. Umlazi  
P.O. Umlazi  
4031

Dear Sir

**RE: DISSERTATION**

I hereby request permission from your office to carry out an in-depth semi-structured interview and a survey among PLHA who are on ART. This is part of the requirements in order for me to complete my studies at the University of Stellenbosch.

My topic is **“INVESTIGATING ADHERENCE FOR PEOPLE LIVING WITH HIV AND AIDS ON ART IN DURBAN, KWAZULU NATAL, SOUTH AFRICA”**

Your consideration will be highly appreciated.

Yours sincerely

Mrs Nondumiso Dlomo

**ANNEXURE B: Consent form****INVESTIGATING ADHERENCE FOR PEOPLE LIVING WITH HIV AND AIDS ON ART IN DURBAN, KWAZULU NATAL, SOUTH AFRICA**

Dear Mr, Mrs, Miss

I am Mrs. Nondumiso Lorraine Dlomo working for KZN Department of Education, stationed at Zandile J.P. School, Unit H. Umlazi. I am currently conducting research on HIV and AIDS: **Investigating adherence for people living with HIV and AIDS on ART in Durban, Kwazulu Natal, South Africa.** This study is part of my master's degree at the University of Stellenbosch, Cape Town and should benefit future generations in our country. You have been selected as a respondent in this study. The information collected from you will be kept confidential. Participation is voluntary. Kindly tick with a cross(**X**) if you are willing to participate. Do you want to participate?

**YES**

**NO**

**MRS NONDUMISO DLOMO**



**ANNEXURE C: Semi-structured interview**

**GUIDE FOR INDEPTH-INTERVIEW WITH PLHA ON ANTIRETROVIRAL THERAPY**

**Personal information**

Age :  
 Children :  
 When did you know your HIV-status? :  
 When have you started ART? :

**Knowledge**

**1. Have you heard of ART?**

(If no, have you heard of Antiretroviral?)

(If no, what do you call the medication that you are coming to this clinic to collect?)

**2. How did you hear about Ithembalabantu?**

(Probes: Was it difficult to get treatment from here? Why/ why not?)

**3. What do you know about ART?**

(Alternatively refer to it in the same way as the patient does).

Probes: Why is it important to take the antiretroviral drugs at the same time every day? What happens to the HIV-virus when you start taking ART? How likely are you to infect your partner when you are on ART? Does the form of the HIV-virus change when you start taking ART? If yes, how can this influence your partner?

**4. What are some of the advantages of being on ART?**

(Probes: Has your health improved? If yes, what impact has that had on your life?)

**5. What are some of the disadvantages of being on ART?**

(Probes: What side effects have you experienced? How severe has these side effects been? Did you feel that you had to disclose to your family when starting to take ART? Why/ why not? Did you feel that you had to disclose to your partner when starting to take ART? Why/ why not?)

**6. What type of drugs are you currently taking and how often do you take them?**

(Probes: When do you usually take them? How do you remember to take them? Have you ever change the drugs you are taking? If yes, why? If female and Nevirapine mentioned, why are you on Nevirapine? If female and Stockrine mentioned, why are you on Stockrine?)

**7. Is there any other medication you are taking besides ART?**

(If yes, what is that other medication? What is it for? Do you alternate between them and ART? Do you take them at the same medications at the same time?)

**8. How sick were you before you started ART?**

(How long have you have been sick before you started ART? What was your CD4 count when you started ART? What is it now? What training did you receive at Ithembalabantu before you started ART? How long did this training last?)

**9. How do the antiretroviral drugs make you feel?**

(Probe: Do you think the antiretroviral drugs are working? Why/ why not?)

**10. What made you decide to come to Ithembalabantu?**

(Probes: Do you feel stigma since only HIV-positive people come to Ithembalabantu? Was it difficult to decide to come here? What made you choose to come here rather than other clinic?)

**11. How do you find providers at Ithembalabantu?**

(How strict are they with adherence? What happens to you if you do not adhere to your drugs? Does the clinic react somehow? How is the provider's attitude to people with HIV and AIDS? How do the providers help you with your adherence to ART?)

**12. How did you find out about your HIV- status?**

(Probe: Was your partner sick? Did you suspect you had HIV before you went to the doctor? Why/ why not? Did you have a partner/s at the time? If yes, was he/she/they HIV-positive? What has happened to this partner/s?)

**13. Do you think having to take tablets influence disclosure of HIV/AIDS? Why/why not?**

(Probes: Have you told your family about your status? If yes, why did you tell your family? How long after you find out about your status did you tell them? How did they react? Has disclosing to your family helped you? Why/ why not? If no, why did you not tell them? How do you manage to hide the drugs and going to the clinic from them? Are you planning on telling your family? Do you think your family know even though you have not told them? Why /why not?

Have you told your partner/s about your status? If yes, how long after you found out that you were HIV-positive did you tell him/her? How did he/she react? Why did you tell your partner? Did you find it difficult to tell him/her? Why/ why not? How has the disclosure influenced your relationship? How has it influence his view on HIV? Has it made it easier for you to talk about HIV and ART? Please describe the situation when you disclosed to your partner? If no, why have you not told him/her? If you were to tell him/her, would it be difficult? Why/ why not? Do you think your partner would leave you if you told him/her about your status? Why/ why not? Do you think your partner/s know even though you have not told him/her? Why/ why not?

**14. Did you disclose your status before or after you started ART? For those who disclosed only after they started ART: Why did you choose to disclose after you commenced ART?**

**ANNEXURE D: Survey questionnaire**

**INVESTIGATING ADHERENCE FOR PEOPLE LIVING WITH HIV AND AIDS ON ART IN DURBAN, KWAZULU NATAL, SOUTH AFRICA.**

**STUDY QUESTIONNAIRE**

**QUESTIONNAIRE #:**

**DATE OF SURVEY :**

## INTRODUCTION

I am Nondumiso Dlomo, an educator from KZN Department of Education. I am a Masters student at the University of Stellenbosch. I'm conducting a study on **ARV TREATMENT AND ADHERENCE**. I am grateful that you volunteered some of your time to answer these questions. The questionnaire is strictly confidential. The information you give and your name will never appear anywhere. You are free to ask me to clarify questions if you don't understand them. The aim of this study is to investigate barriers or factors that influence adherence to people receiving them. If you feel like that you don't want to continue with the survey, you are free and it your right to do so. It is important that you answer all questions honestly. May I continue?

Thank you.

YES	
NO	

**SECTION A: DEMOGRAPHIC INFORMATION**

Please tick using a cross (X) in the appropriate box.

1. What is your gender?

<b>Male</b>	<b>Female</b>
1	2

2. How old are you?

<b>&lt;21</b>	<b>21-30</b>	<b>31-40</b>	<b>41-50</b>	<b>51-60</b>	<b>&gt;60</b>
1	2	3	4	5	6

3. Your highest education

<b>No education</b>	<b>Primary education</b>	<b>Secondary Education</b>	<b>Grade 12</b>	<b>Diploma</b>	<b>Degree</b>
1	2	3	4	5	6

4. What is your current marital status?

<b>Single</b>	<b>Married</b>	<b>Widow/er</b>	<b>Staying together</b>
1	2	3	4

5. Which of these categories best describes your work situation?

<b>Employed</b>	<b>Self-employed</b>	<b>Unemployed</b>
1	2	3

6. Have a family member or any of your friends ever suffered or died of AIDS?

Yes	No	Don't know
1	2	3

## SECTION B: KNOWLEDGE OF VIRAL LOAD AND CD 4 COUNT

7. When did you have your first HIV test?

Month _____ Do not remember <b>95</b>	
Year _____ Do not remember <b>95</b>	

8. When did you start ARV treatment?

Month _____ Do not remember <b>95</b>	
Year _____ Do not remember <b>95</b>	

9. What was your CD4 count before you started ART?

Specify> _____ Do not remember <b>95</b>
---

10. What was your CD4 count when you last measured it?

Specify> _____ Do not remember <b>95</b>
---

11. What does the CD4 count measure?

Changing number of white blood cells in your immune system	Whether I have been using a condom or not	How good is my body is at fighting the infection	Whether the amount of virus in your blood is decreasing or increasing	Do not know	Other
1	2	3	4	99	98

12. What do the viral load measure?

Changing number of white blood cells in your immune system	Whether the amount of virus in your blood is decreasing or increasing	How well my blood is	How long your life will be	Do not know	Other
1	2	3	4	99	98

### SECTION C: KNOWLEDGE ABOUT ARV TREATMENT

Now I'm going to ask you questions concerning your knowledge about ARV treatment. Do you think the following is true or false?

13. When taking ARV the virus will be removed from my body?

True	False	Do not know
1	2	99

14. The virus will stay hidden in my body as long as I am taking ARV correctly?

True	False	Do not know
1	2	99

15. The HIV tries tricking the ARV by changing its form?

True	False	Do not know
1	2	99

16. If taken within a few months after being infected, ARV can cure AIDS?

True	False	Do not know
1	2	99



17. The HIV eventually becoming resistant to ARV, and they will stop working?

<b>True</b>	<b>False</b>	<b>Do not know</b>
1	2	99

#### **SECTION D: PERCEPTION OF RISK TRANSMISSION**

The next questions are designed to teach us more about your attitudes to HIV and ARVs. Please remember there no wrong or right answers. So fill free to tell us what you think.

18. Are you more or less likely to transmit the virus to your partner now that you are on ARV compared to when you were not on ARV?

<b>More likely</b>	<b>Less likely</b>	<b>Same likelihood</b>	<b>Do not know</b>
1	2	3	99

19. How dangerous do you think it was for you to sleep with someone without a condom before you started ARV treatment?

<b>Very dangerous</b>	<b>Dangerous</b>	<b>Somewhat dangerous</b>	<b>Not very dangerous</b>	<b>Not dangerous</b>	<b>Do not know</b>
1	2	3	4	5	99

20. How dangerous do you think it was for you to sleep with someone without a condom after you started ARV treatment?

<b>Very dangerous</b>	<b>Dangerous</b>	<b>Somewhat dangerous</b>	<b>Not very dangerous</b>	<b>Not dangerous</b>	<b>Do not know</b>
1	2	3	4	5	99

Do you agree or disagree with the following statements:

21. It can be harmful to me and my partner if we try to have a baby while I am on ARV?

Agree	Disagree	Do not know
1	2	99

22. It is ok to try to have a baby if my CD4 count is above 800 and my partner is HIV-positive with an undetectable viral load?

Agree	Disagree	Do not know
1	2	99

23. I cannot have a baby if I do not know my partners status?

Agree	Disagree	Do not know
1	2	99

24. ARV can reduce risk of transmission of infection?

Agree	Disagree	Do not know
1	2	99

25. Treatment with ARV makes using condoms less important?

Agree	Disagree	Do not know
1	2	99

26. You cannot transmit the HIV virus to your sexual partner/s when you are taking ARV? **Assuming you are not using condoms.**

Agree	Disagree	Do not know
1	2	99

27. If a cure for HIV were discovered I would stop using a condom?

Agree	Disagree	Do not know
1	2	99

**SECTION E: PERCEPTIONS AND ATTITUDES TOWARDS ART.**

How strongly do you agree or disagree with the following statements?

28. AIDS has become a less serious illness because of ARV?

<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1	2	3	4	5

29. It is too early to tell if ARV will be successful in the long run?

<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1	2	3	4	5

30. With ARV, AIDS can be managed like any other disease?

<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1	2	3	4	5

31. ARV medications are not as effective as they are made out to be?

<b>Strongly agree</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1	2	3	4	5

32. During the past week, how many days have you missed taking your pills?

<b>None</b>	<b>One day</b>	<b>Two days</b>	<b>Three days</b>	<b>Four days</b>
1	2	3	4	5

33. Most anti-HIV medications need to be taken on a schedule, such as “2 times a day” or “3 times a day” or “every 8 hours” how closely did you follow your specific schedule over the last week?

<b>Never</b>	<b>Some of the time</b>	<b>About half of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
1	2	3	4	5

34. Does any of your anti-HIV medications have special instructions, such as “take with food” or “on an empty stomach” or “with plenty of fluids?”

<b>Yes</b>	<b>No</b>
1	2

35. If yes, how often did you follow those special instructions over the last week?

<b>Never</b>	<b>Some of the time</b>	<b>About half of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
1	2	3	4	5

36. Some of the people find that they forget to take their pills on week-ends. Did you miss any of your anti-HIV medications last week-end-last Saturday or Sunday?

<b>Yes</b>	<b>No</b>
1	2

37. When was the last time you missed any of your medication?

<b>Within past week</b>	<b>1-2 weeks ago</b>	<b>2-4 weeks ago</b>	<b>1-3 months ago</b>	<b>More than 3 months ago</b>	<b>Never skip</b>
1	2	3	4	5	6

**SECTION F: DICLOSURE AFTER STARTING ARV TREATMENT**

38. How often does your family remind you to take your medication?

<b>Never</b>	<b>Occasionally</b>	<b>Sometimes</b>	<b>Always</b>	<b>Not applicable</b>
1	2	3	4	94

39. Have you disclose your status to anyone?

<b>Yes</b>	<b>No</b>
1	2

40. If yes, who have you disclosed your status to? **Multiple answers possible.**

<b>Partner/ s</b>	<b>Parent s</b>	<b>Grand parent s</b>	<b>Sibling s</b>	<b>Relative s</b>	<b>Friend s</b>	<b>neighbor s</b>	<b>Roommate s</b>	<b>Other</b>
1	2	3	4	5	6	7	8	98

41. In general, how satisfied are you with the overall support you get from your family?

<b>Very dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither dissatisfied or satisfied</b>	<b>Satisfied</b>	<b>Very satisfied</b>	<b>Do not know</b>	<b>Not applicable</b>
1	2	3	4	5	99	94

Could you please indicate how strongly you agree or disagree with the following statements.

42. When both partners got HIV, there is no need to use a condom?

<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree or disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>Refused</b>
1	2	3	4	5	97

43. It is difficult to keep your status a secret when you are staying with your partner?

<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree or disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>Refused</b>
1	2	3	4	5	97

44. Being on ARV makes it easier to be open about your status?

<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree or disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>Refused</b>
1	2	3	4	5	97

45. It is difficult to insist on condom use when you have not disclosed your status to your partner?

<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree or disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>Refused</b>
1	2	3	4	5	97