Chapter 1
Introduction

1.1 Introduction

About two thirds of people with Human Immunodeficiency Virus (HIV) are living in sub-Saharan Africa (UNAIDS /WHO/AIDS, 2008). 20% of all deaths can be attributed to HIV/AIDS making it the biggest single component of the diseases burden in Africa (WHO, 2000). New Resources are becoming available for prevention, care and support and ART is one of these new resources (Cresse, Floyd, Alban & Guinness, 2002).

Anti Retroviral Therapy (ARTs) are made available free of charge but some patients still default on their treatment. More distressing is that people start on an ART regimen and then stop along the way. Like the Multiple Drug Resistance TB that has emerged in South Africa, defaulting on ARV regiments could have dire implication as far as resistance is concerned.

It has been proven that with ARTs, HIV positive patients can live long and productive lives. HIV infection is no longer a death sentence with a scary waiting period. HIV positive persons kept alive with ARTs are able to contribute meaningfully and economically to the society. The longer a person can economically be functional the better for the society.

As such, this research aims to investigate the fundamental reason why patients on ARTs decide to stop their treatment. The hope is that once these reasons are identified, the government can begin to address them.

1.2 Background

This research study was carried out at the HIV/AIDS clinic at Tshwane District Hospital (TDH) in Pretoria. The study looked at HIV positive patients who are 'lost to follow-up' during the course of antiretroviral therapy (ART) treatment. Patients' files were reviewed in order to determine how many patients were 'lost to follow-up' and to prevent this from happening by ensuring better compliance through making recommendations.

The introductory chapter outlines the global situation of HIV/AIDS and the extent of HIV infection in South Africa specifically. It also provides the context within which the research topic emanates, as well as the purpose of the research. It explains the situational analysis of the research clinic, the booking and appointment systems, and enrolment and inclusion criteria for ART medication. Some of the difficulties encountered in the clinic are also discussed. The rationale for the research study and a number of concepts are introduced in order to provide an overview of the management of HIV/AIDS.

1.3 An overview of the HIV/AIDS pandemic

Human Immunodeficiency Virus (HIV) disease has become a global challenge. It has developed into a pandemic which is responsible for 2.8 million deaths a year with 38.6 million people living with this disease worldwide (UNAIDS/WHO/AIDS, 2008).

However, Sub-Saharan Africa carries 70% of the global burden of HIV infection, which results in 8 000 deaths a day worldwide. Also, South Africa also has the highest HIV incidence and prevalence in the world (Oyugi, Byakika, Raglan, Laeyendecker, Mugerwa, Kiyo, 2007; UNAIDS/WHO/AIDS, 2008). On the other hand, surveillance is suggesting that infection levels might be levelling off. Prevalence levels among pregnant women were at 30% in 2005 and 29% in 2006 (Department of Health, South Africa, 2006).

About 3 million people in the Sub-Saharan region become infected with the disease each year while 2 million die of the disease. The young, sexually active and economically active group are the most affected, although other groups are also affected. This puts emphasis on the fact that all groups of people and ages are affected albeit differentially (Rosen, Fox & Gill, 2007).

Of the 38.6 million people living with the virus worldwide, 68% of adults and nearly 90% of children infected live in Sub-Saharan Africa (UNAIDS/WHO/AIDS, 2008); and of the global total of 2.1 million adults and child deaths due to AIDS in 2007, 1.6 million occurred in this region. An estimated 1.7 million people were newly infected

with HIV in 2007 alone. Unlike other regions, the majority of people living with HIV in Sub-Saharan Africa (61%) are women (UNAIDS/WHO/AIDS, 2008).

HIV is transmitted mostly through sexual practises, contact with blood, breast milk and vertical transmission of mother to child. By the year 2000, South Africa was already ahead of all figures predicted by most actuarial models. The prediction of 4.2 million HIV positive people by 2002 was reached by 2000. This pattern has culminated in the present scenario (Whiteside & Sunter, 2000; Grimwood, Crewe & Betterrridge, 2000; UNAIDS/WHO/AIDS, 2008).

The primary target of HIV in the body is a type of immune cell called the CD4. CD4 plays a pivotal role in the body's defense against disease-causing microorganisms (i.e. pathogens) producing HIV-infected CD4 cells. Consequently, the infected person's levels of CD4 cells in the blood slowly decline, leaving him or her increasingly vulnerable to infections by microorganisms, such as opportunistic infections, which would normally be controlled by the immune system (Meyerhoff, 2001).

1.4 Emergence of antiretroviral therapy

Early in the AIDS epidemic, most HIV infected people died within 10 years of contracting the virus. Antiretroviral therapy (ART) was consequently developed to treat HIV/AIDS sufferers. AZT (Zidovudine), previously designed to treat cancer, was the first attempt made to curbing the effects of HIV. Although the drug slowed the progress of the disease, it did not demonstrate a better survival rate in the patients.

It was later discovered that the use of one or more ARTs was more effective. In 1996, combined ART was developed. Although HIV is still an incurable disease, it is now managed as a chronic disease just like hypertension and diabetes (Ware, Idoko, Kaaya, Biraro, Wyatt, Agbaji, Chalamilla & Bansberg, 2009). While ART controls HIV/AIDS, it is not a cure, but helps to strengthen the immune system of the sufferer. Due to the availability of drugs, HIV is better managed, but requires about 98% drug adherence even when the viral load is undetectable.

The combination of these drugs together with specific chemoprophylaxis or chemotherapies helps to fight off Acquired Immunodeficiency Syndrome (AIDS) related diseases such as pneumonia and diarrhoea and reduce the virus to an undetectable level in the body (Collini & Obasi, 2006; Bautista-Arrendongo, Dymtraczenko, Kombe & Bertozzi, 2008; HIV & AIDS Care, 2007-2008; Ware, et al., 2009).

Thus ART, which is a lifetime treatment similar to the treatment of other chronic diseases, has enhanced the quality of life of those living with the virus and is the "single most dramatic development in the treatment of HIV" (Amico, et al., 2006). But for maximum efficiency, HIV infected individuals are required to take the drugs regularly for the rest of their lives.

Moreover, the survival of HIV infected individuals is dependent on the state of their immune system at the time of commencement of treatment, as well as their adherence to treatment. As a result, strict adherence to medication is critical to guarantee beneficial rewards of ART medication (Collini & Obasi, 2006; Rosen, et al., 2007; Hallet, Gregson, Dube & Garnett, 2008).

ART has thus transformed the management of HIV infection in Sub-Saharan Africa, but requires a great commitment from patients. Adherence is very demanding and resistance to the medication develops rapidly after missed doses. In South Africa, the protocols for the initiation of ART involve at least three visits before the regimen is started; frequent follow-up clinic visits and extensive counselling. A waiver occurs when the clinical condition requires immediate initiation such as in pregnant women and very sick patients. The process entails clinical and immunological staging and ongoing monitoring (Dalal, McPhail, Mqhayi, Wing, Feldman & Cherisch, 2008; Bautista-Arrendongo, et al., 2008).

Moreover, the provision of ART is resource intensive for health care services and those receiving the treatment. Even where medication is dispensed free of charge, there are indirect costs for patients, e.g. missed days of employment resulting in loss of earnings, additional transport costs and other out-of-pocket expenses.

Other obstacles could be social, cultural and behavioural barriers to conformance to medication (Dalal, 2008; Ware, et al., 2009). However, near perfect levels of adherence are being achieved despite difficult obstacles in the poorest region of the world (Ware, et al., 2009).

Abrupt discontinuance of treatment is a waste of resources that are already in short supply. In addition, discontinuation results in poorer health outcomes, which in turn puts additional stress on health care system. More so, the complexity of the drug regimen is increased such that the re-initiation process increases the toxicity in the patient and is undertaken at a higher cost to the state. Further resources would then be required to treat patients when they become ill after treatment default (Rosen, et al., 2007).

Globally, the successes achieved in the treatment of HIV will have a profound effect on the achievement of the Millennium Development Goals (MDG). Yet, sustaining prevention is one of the greatest challenges of HIV prevention (UNAIDS/WHO/AIDS, 2008). In South Africa for example, the ART roll out was only implemented in public hospitals in April 2004 as there was a prolonged delay in the response of South Africa to the pandemic.

For the purpose of this study an individual/patient is defined as 'lost to follow-up' if placed on ART and decides to stop treatment for a month during the course of treatment in 2007 and 2008.

1.5 HIV as a chronic disease

According to Gallant (2008), ART is not like medication used for diseases such as hypertension and diabetes. In the treatment of these other chronic conditions, although it is not ideal to consciously miss a dosage of the medication, it can still work when taken at a later stage. Since most medication used for chronic conditions is not toxic, which it is in the treatment of HIV/AIDS, it can be easily managed by the patients themselves. Therefore, patients are able to adapt and self manage as a solution to avoid missing doses.

The notion, that self management is a solution for patients to manage their medication and avoid missing doses of their medication is supported by Bodenheimer, Loring, & Holman, et al., (2002). Given that the patient is seen as central to the management of his/her disease, the self management process therefore empowers the patient as a co-partner in treating the disease alongside the medical team.

ART, due to its complexities, however can also lead to resistance. Subsequently, missed doses affect the efficacy of the drugs by rendering it less effective and further increasing the level of toxicity. Mutation is also a negative result for non-adherence (Rosen, et al., 2007; Gallant, 2008).

The research of Ware, et al., (2009) found that individuals living with HIV/AIDS in Sub-Saharan Africa generally take more than 90% of the prescribed doses of antiretroviral therapy unlike their counterparts in North America. The outcome of this research dispels the notion that adherence is generally inadequate in settings of extreme poverty.

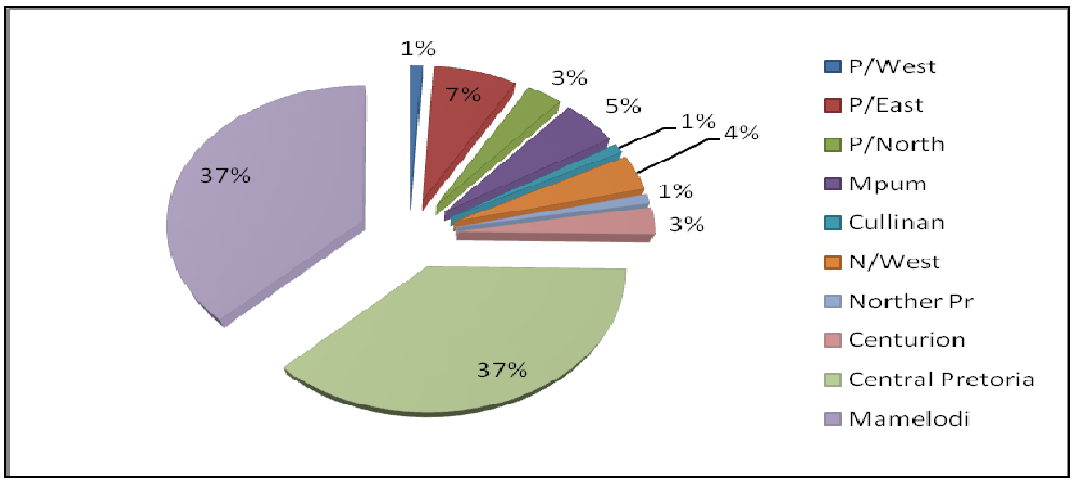
It was further explained that HIV positive patients usually overcome economic obstacles by making use of deliberate strategies to prioritise adherence. This could be in form of borrowing, begging, doing without, re-allocating resources and making 'impossible choices' in favour of ART, indicating behaviour of responsibility on the part of the patients.

1.6 HIV/AIDS treatment centre: The research study clinic

In April 2004, ART was rolled out in the Gauteng province of South Africa. It was rolled out at the ARV clinic of the Tshwane District Hospital (TDH) in July 2004 as part of services rendered by the Pretoria Academic Hospital (PAH). PAH now known as the Steve Biko Academic Hospital, is a tertiary health facility that relocated from its former premises in 2006. The move to the new site saw the management of the clinic transferred to Tshwane District Hospital, which is occupying the old premises. The clinic serves the population of Pretoria Central, which is about 400 000 people (2001 census report).

Although the ARV site is in Central Pretoria and is expected to serve the Central Pretoria community and environs, only 37% of its clientele comes from this area. Some of the patients travel extensive distances to reach the clinic. Patients come from as far as Hammanskraal, Bronkhorstspruit, Mpumalanga Province and Centurion in Johannesburg. 37% of the patients also come from Mamelodi about 30 kilometres away (Graph 1).

Graph 1: Residential areas of patients treated at the ARV clinic of Tshwane District Hospital



1.6.1. Staff Establishment

The staff complement consists of permanent staff on the establishment of the hospital as well as employees of a Non-Governmental Organisation (NGO) called the Foundation for Professional Development (FPD). Hospital staff include: two full-time Principal Medical Officers, two Senior Medical Officers, one Social Worker, one Dietician, one Project Manager, one Unit Manager, one TB Co-coordinator, one Professional Nurse as well as two Administration Clerks. The FPD staff complement consists of three Doctors on a part-time basis, four Lay Counsellors, one Data Capturer, one Professional Nurse and one enrolled Nurse Auxiliary.

1.6.2. Enrolment criteria for ART and referrals

In South Africa, ART is free in public health facilities and the enrolment criteria are in accordance with the World Health Organisation (WHO) Guidelines Stages as stipulated in the National Antiretroviral Treatment Guidelines 2004 (Appendix 1).

In order to avoid burdening staff unnecessarily, as well as overloading the capacity of the clinic, patients on the ART regime who are considered to be clinically stable are expected to be down-referred to primary health centres (PHC) or ARV sites closer to their homes. Down-referring these individuals free the clinic to attend to other individuals who are in need of more attention and care. This also allows the clinic to take on new patients for treatment.

However, individuals are reluctant to be down-referred and there are many reasons given for this. The most common being that patients are reluctant to attend the health facility closest to their place of residence because of stigmatization by the community, leading to unintended consequences (Kalichman & Simbayi, 2004). Consequently, HIV infected individuals may use ARV sites that are very far from home.

According to national guidelines, home visits to prospective HIV positive patients are required before being put on antiretroviral treatment. These visits help to access and understand home circumstances, correctness of personal details, support structures including disclosure and drug storage facilities such as refrigerators (National Antiretroviral Treatment Guidelines, 2005).

Where individuals default, home visits by lay counsellors or home based care workers to the homes of the defaulters are again expected by the National Department of Health in accordance with guidelines. Once more, this is not always possible due to a shortage of human resources at the clinic.

However, shortages of staff are not only particular to South African ARV sites, Zachariah, et al., (2006) attested to the fact that in Kenya, the continuous follow up of patients is difficult due to a lack of sufficient human resources. To bridge this gap

though, telephonic follow ups are made, but this is not always as successful as home visits.

HIV infected individuals undergo a full medical assessment for HIV related diseases and in preparedness for eligibility for ART, which is essentially based on clinical findings. The individual should be at Stage IV or a CD4 count of 200 or less (WHO guidelines) and adherence is promoted through a patient-centred approach. This has subsequently changed.

A patient undergoes one-to-one counselling sessions with trained counsellors three times before treatment is initiated. These counsellors are provided by the NGO previously mentioned, which has been supporting the clinic since its inception with both human and material resources.

HIV infected individuals are also counselled on probable drug reactions. Some of the patients' demographic details needed in the clinic are the employment status, or income generation activity of the individual, contact numbers, residential address, age, sex and marital status as well as HIV disclosure status.

1.6.3. Booking and appointment systems

As at February 2009, there were 4 800 active patients on the clinic's register and over 2 500 of these were on ART treatment. The waiting period for new patients to be seen for the first consultation is four weeks. For pregnant women, it is one week and the oncology (cancer) patients two weeks. Eight to 10 new patients are seen on a daily basis. According to the longest serving member of staff of this clinic, Dr. Magriet Spies (Chief Social Worker), tracing of 'lost to follow-up' defaulters was easier in 2004 and 2005, the early years of the clinic.

Since there were not many patients attending the clinic at that time, on a daily basis the pharmacist submitted the names of patients who were expected to collect their monthly supply of medication for that day and did not arrive. Immediate follow-ups were then made and impediments to treatment were quickly addressed. However, this system has fallen away for three main reasons.

Firstly, there was no documented procedure and system in place at the pharmacy. So when the only pharmacist who initiated this system left the clinic, there was no immediate replacement or handover to the next pharmacist. Consequently, daily submission to the social worker of the names of patients who did not arrive for treatment ceased.

Secondly, the number of patients increased significantly. Moreover, the pharmacy was always short of manpower and as such did not have the capacity to cope with attending patients as well as paying attention to the number of patients who were coming for treatment.

Thirdly, the data collection system was not optimal, leading to inadequate follow-up of patients in general.

While it was possible in 2004 and 2005 for the pharmacist to identify patients who were 'lost to follow-up' promptly, currently, it is not possible to do this due to improper data collection. This notion emphasised the importance of developing a sustainable patients' follow-up system to encourage good adherence results, but which is impossible due to the ever increasing number of patients.

When a choice of regimen fails or a patient stops treatment for a while and then comes back to the clinic, a counselling form is filled in order to understand why the treatment failed and/or why s/he defaulted (Appendix 2). This form has, however, not been of help to those who are 'lost to follow-up' and do not come back to the clinic.

Depending on the clinic, 'lost to follow-up' are classified differently. It could be that the patient misses one monthly clinic visit or did not have medication for a month (Maskew, MacPhail, Menezes & Rubel, 2007). In some other cases, patients may be classified 'lost to follow-up' if they have missed two or more consecutive clinic appointments or have not been seen for two to three months (Yu, Chen, Wang, Chang, Makombe, Schouten & Harries, 2007).

1.7 Treatment Readiness Assessments

The three counseling sessions take place before the initiation of ART in order to exclude tuberculosis (TB), pregnancy and any opportunistic infections. Home circumstances and contact details are confirmed, support structures, including disclosure, are encouraged and investigation into local drug storage facilities are clarified.

By the third counseling session, the patient should have accepted his/her HIV status have a clear understanding of the importance of adherence and value the importance of all scheduled treatment visits enough to keep to them.

Depending on the patient's medical condition, e.g. cancer, TB or pregnancy, the three counseling sessions may be waived as valuable treatment time may be lost. Hence, it is possible to visit the clinic for the first time and be initiated the same day.

Patients attend the clinic on a monthly basis to collect medication and are seen by professionals (doctors and nurses) who monitor drug tolerance, adverse events and adherence. However, due to the number of patients, stable patients are sometimes given 2-3 months supply of medication, thereby creating space for new patients to be attended to. However, this is not without its shortcomings.

1.8 Problem Statement

Compliance seems to be problematic for some individuals. The reasons why HIV positive patients comply with ART or not are sometimes not known, but possible solutions to reverse non-compliance need to be explored in order to help this group of patients to comply.

At TDH it is known that not all HIV positive patients comply with treatment and are eventually 'lost to follow-up'. Knowing the reasons for non-compliance help in looking for ways to resolve possible deterrents to 'lost to follow-up'. Adherence to medication is crucial because it helps to achieve long term suppression of the disease as well as to avoid replication of the HIV (Heath, Singer, Oshaughnessy, Montainer & Hogg, 2005).

The research problem that emanated from the above is:

What causes HIV positive people to be 'lost to follow-up' during the course of ART regimens given the fact that the treatment is available and obtainable free of charge in public health facilities? *Will knowing the characteristics of HIV positive patients and putting the necessary measures in place be sufficient effort to mitigate against the phenomenon of 'lost to follow up'? Are socio-economic factors determinants of 'lost to follow-up' in HIV positive people?*

1.9 Justification of the study

According to the national guidelines for ART (Department of Health national guidelines, 2005), patients should not miss their treatment. A patient who misses medication is at risk of increasing the possibility of resistance developing to standard regimens and of having to use more expensive and toxic medications, thereby increasing the chances of more severe side effects.

Missing treatment and medication can lead to other medical conditions or even death. Knowing the reasons why patients miss treatment will help the management of the clinic to put measures in place to guard against the impediments that contribute to non-adherence to treatment.

1.10 Purpose of the study

The purpose of the study was to determine the characteristics of patients who were 'lost to follow-up' at the ARV clinic of Tshwane District Hospital, in a bid to find ways to minimize it.

1.11 The objectives of the study

This study aimed at looking at the profile and patterns of patients that were 'lost to follow-up' from 2007 to 2008 with a view to determining the characteristics so that interventions might be put in place to reduce the occurrences.

Record keeping and the smooth running of the ARV clinic is a management function. Therefore a subsidiary aim was to strengthen monitoring and evaluation of record keeping in order to effect positive change. Specific objectives included the following:

- To determine the demographic profile and socio-economic profiles of patients that are 'lost to follow-up', e.g. age, sex, race, marital status, residential area, educational levels and employment status ; and
- To identify how far into the treatment period HIV infected people defaulted while on ART treatment.

The implications of 'lost to follow-up' could be dire in the treatment of HIV. These could be resistance to first line treatment or toxicity to the mixture of the ART regimen. Adherence to medication will prolong and improve the patient's quality of life.

1.12 Assumption

- All files of HIV positive patients who did not turn up for scheduled appointments or for their monthly medication collection were assumed as 'lost to follow-up'

At the time of this study there was no patient tracing system in place at this clinic, patients and relatives self-report deaths and relocation. This meant that patients who were dead, but not reported to the clinic by relatives or friends, and relocated or chosen to stop ART were included in the study.

1.13 Conclusion

Chapter two is the literature review. Chapter three outlines the propositions; the research methodology is presented in chapter four while the findings and the results are presented the chapter five. The interpretation of the results is presented in chapter six and chapter seven covers the conclusion in relation to the research problem. Suggestions on future research are also discussed in the last chapter in view of the findings.

Chapter 2

Literature Review

2.1 Introduction

The phrases 'lost to follow up' and 'defaulter' are used interchangeably in some literature. A defaulter is a patient who fails to fulfil the obligation to attend the clinic appointment and/or misses his/her medication. While a patient who is 'lost to follow up' can mean the same thing (Rosen, et al., 2007).

However, for the purpose of this study an individual/patient is regarded as 'lost to follow-up' if placed on ART and s/he decide to stop during the course of treatment for a month between 2007 and 2008.

According to Benatar (2004), worldwide HIV/AIDS in 2000 accounted for 38% of total years of life lost from premature death; 47% of this was females and 33% males. This scenario made HIV/AIDS one of the most difficult public health challenges the world has seen (Nachega, Knowlton, Deluca, Schoeman, 2006).

ART works by stopping the HI virus from multiplying and by preventing it from reproducing or mutating. However, missing prescribed doses means that there may not be enough of the dosage of the medicine in the patient's system to keep the virus from mutating (Rosen, et al., 2007; Gallant, 2008).

Dissemination of ART has transformed HIV infection from a 'death sentence' to a manageable chronic disease. Although HIV is still not a disease to be trivialised and patients have to make a commitment to properly manage it, and for this to happen, full adherence is required. Consequently, having to take ART is a lifetime process (Rosen, et al., 2007).

Nevertheless, taking ART irregularly or stopping the use of the medication makes the users very sick or may even result in death. The other factor is that missing doses reduces the effectiveness of the drug, which will necessitate the use of more toxic drugs

at a higher cost, as well as negating the gains and benefits sought by the implementation of the treatment programmes (Rosen, et al., 2007).

There are many reasons for non-compliance to medication. Adherence to chronic medication is usually 50% (Rosen, et al., 2007). A study in Malawi showed that 50% of 'lost to follow up' patients died, 27% were untraceable and the rest just decided to stop their ART without any reason, emphasising that patients are 'lost to follow up' for different reasons and these reasons need to be examined.

When patients do not attend the clinic or stop treatment (lost to follow-up), this may result in adverse ART outcomes that are likely to negatively influence the efficacy of the antiretroviral treatment. In some other cases, patients might have died or migrated but be declared as 'lost to follow-up'. The overall cause of 'lost to follow up' is not practically feasible (Zachariah, et al., 2008).

2.2 Theoretical context

Although South Africa has one of the highest HIV prevalence in Sub-Saharan Africa, it is also one of the countries that have a comprehensive HIV treatment plan and excellent guidelines (Department of Health, 2005). Despite this, HIV infected people still miss their ART regimen. The use of ART has been proven to greatly reduce HIV mortality (Robbins, Daniles, Brock, Zheg, Choe & James, et al., 2007; Timothy, Halliet, Sabata & Geof, 2008) and consequently, adherence to ART is a powerful predictor of survival for individuals with HIV (Mills, Nachega, Buchan, Orbinski, Attaran, Singh, 2006).

Therefore, this study aimed to investigate non-adherence to ART by looking at what happens at the ARV clinic of TDH. The objective of the study was to demonstrate the demographic and socio-economic profiles of HIV positive people who were 'lost to follow- up', while further promoting ART compliance and the benefits associated with it.

The residential areas, the types of dwelling in which the patients live and the method that patients have chosen to manage the ART are noteworthy to medication adherence.

Abuse of alcohol has been proven to affect the efficacy of ART; as a result patients were asked if they indulged in alcohol and smoking.

Disclosure enhances the well being of HIV positive people, thus disclosure and to whom the disclosure is made part of the variables analysed. Support structures are very important to people living with HIV/AIDS as they form part of their psychological well being. Thus, the data collecting tool sought to find out if the patient had any support structure. The time of initiation of the ART treatment, the time of the first clinic visit at the ART site and the last visit formed part of the data collecting tool.

The type of regimen the patient was put on at initiation in relation to the regimen before being 'lost to follow up' was considered of value. It was also important to see whether at any point during treatment medication was changed due to adverse reaction. Knowing about patient reaction to medication could explain, to a certain degree, why patients might not want to continue or miss medication (Collini & Obasi, 2006).

The most commonly used ART drugs in poor resource settings, according to WHO, are Lamivudine, Stavudine, Nevirapine, Efavirenz, Zidovudine etc. All these drugs are known for their effectiveness but are not without side effects, although they are also known to be effective in suppressing viral load and preventing new infection.

For example, the use of Stavudine has been associated with peripheral neuropathy, while Nevarapine has been associated with more side effects than others with the risk of hepatitis especially in women with a low CD4 count. These side effects usually lead to treatment discontinuation (Collini & Obasi, 2006). Co-infection of HIV with TB is well documented and was therefore one of the variables in the data collection tool.

2.3 HIV, sex and employment status and relationship with adherence

The choice to include sex and employment status as variables was to see whether there are associations or correlations with HIV infection in men and women. Relationship status is explored in association with HIV prevalence. Association between HIV infection and sex was also explored in order to see whether there were more HIV positive women than HIV positive men in keeping with the population census of 2001.

The sex, the ages and financial capability of the participants was compared to demonstrate if there was a significant difference given their gender, employment status and ages. Nicastri, Angeletti, Palmisano, Sarmati, Chiesi & Andreoni (2005) in their study found that female HIV positive patients were significantly younger and abused drugs less than their male counterparts, which is a risk factor for the efficacy of ART.

Females often had higher CD4 counts and lower viral loads (Nicarstri, et al., 2005). This finding was compared to the findings of this study to establish whether there was a concurrence. The study by Edwards, (2006) found that a typical HIV positive woman is young, usually child bearing age and economically compromised.

However, due to the delay in initiation of ARV in women, clinical progression of the disease appeared to progress faster in women than men with similar clinical profiles. This difference can also be attributed to "gynaecological morbidity as well as pregnancy" (Nicastri, et al., 2005:578).

Even when ART is dispensed for free, unemployed patients who live far away from attending health facilities fail to attend clinics due to a lack of transportation or the cost of transportation and consequently fail to attend the clinic appointments (Hardon, Davey, Gerrits, Hodgkin, Irund & Kgatlwane, et al., 2006). Thus there seemed to be a relationship between employment and adherence.

Even when ART is not charged for, patients sometimes have to pay for registration and user fees, which, in some instances, become deterrents to attendance because the patients are unable to pay these costs due to unemployment, further emphasising the interrelationship of attendance at clinics to employment (Hardon, et al., 2006).

2.4 Relationship between ART, adherence and gender

Several studies failed to show a significant association between gender and antiretroviral therapy adherence and most studies that found no association between gender and adherence were limited to a small group of participants (Patersons, et al., 2000; Wagner, 2002; Carrieri, et al., 2003; Golin, et al., 2002). However, active alcohol and drug abuse

have been found to be associated with worse adherence in several studies (Wagner, et al., 2002; Carrieri, et al., 2003 & Golin, et al., 2002)

70-80 % of HIV transmissions occur through heterosexual relationships. 50% of new daily infections are female; half of the 12.7 million people who have died of the disease were women. Women account for 55% of those living with the disease in Sub-Saharan Africa (Matlin & Spence, 2000).

Women's position in society, their economic capability, social behaviours and societal expectation are leading to a situation where more women are dying of the disease. This makes HIV/AIDS a gender-based issue and needs to be addressed as such for it to be eliminated (Matlin & Spence, 2000).

Alcohol use was associated with worse adherence in women. For men and women worse adherence is associated with lack of 'long term housing', not belonging to an HIV social support group, drug abuse and side effects as a result of ART medication (Berg, Demas, Howard, Schoeman, Gourevitch & Arnsten, 2004).

2.5 ART and residential area

In keeping with Primary Health Care guidelines, patients are supposed to be living within a five kilometre radius of the clinic or health facility that they attend. Living farther than this can later constitute a problem especially where the patient is unemployed.

In addition, there is more likelihood that a patient will miss a scheduled appointment due to transport costs. Patients should be able to attend the clinic on a regular basis in order to maintain the treatment regimen as lack of compliance has direct implications for the development of resistance to the first line ART drugs. This resistance will ultimately lead to increasing costs in the future. The second line regimen costs five to10 times more than the first line and there is a high likelihood of increase in mortality rate (Zachariah, et al., 2008).

A huge collaborative research study of 13 Sub-Saharan African countries indicated that 15 % of patients are 'lost to follow up' in the first year of treatment. The study previously cited (Rosen et al., 2008) showed that some of these patients classified as 'lost to follow up' might be patients who had taken extended breaks from therapy (Appendix 2). This group of patients have identified alternate sources of treatment and might only return when their conditions have worsened. Attempts to trace 'lost to follow up' patients in Malawi showed that 50% of them had died, 27% were untraceable and the rest had stopped their ARV (Rosen, et al., 2007).

There is very little in the literature about the relationship between conformance to ART medication and the type of dwelling and residential area of the recipient, but given the past history of South Africa in relation to accommodation and where people reside, the researcher is of the opinion that the phenomenon is yet to be investigated.

Research has shown that 62% of the urban population in South Africa live in slums often referred to as informal settlements and/or shacks. Slums are known for their substandard structural qualities, overcrowding and insecurity of tenure. This could be the only option of housing open to unemployed/low paid employees. Informal settlements are known for their inadequacy of basic health care needs such as inadequate drinking water, poor sanitation and basic services that are central to the well being of individuals and which are intensified by the impact of HIV/AIDS (ICAD, 2010).

HIV prevalence has been known to be higher in slums as compared to non-slum areas. However, in high density areas overcrowding and poor living conditions are known to increase the risk of opportunistic infections in HIV positive people. Forced eviction is not uncommon in these kinds of settlements. Eviction can also disrupt visitation to clinics to collect medication and/or for other treatments. As such, there is a connection between suitable housing and improved health outcomes in HIV positive people (UNAIDS, 2006; ICAD, 2010)**.**

2.6 HIV, support and disclosure

Many HIV positive women are from "underprivileged populations for whom discrimination, violence and other stressful conditions are common" (Nicastri, et al.,

2005: 578). These women may also be at risk of adverse health outcomes due to being compromised.

Moreover, it is demonstrated that when HIV infected people have support, either through disclosure to family members or association with a support group, they tend not to default on ART. Barriers to adherence included perceived stigma, feeling unloved or uncared for (Edwards, 2006). Consequently, community support is associated with lower death rates and better compliance to ART, which eventually leads to better health outcomes (Zachariah, et al., 2006).

In India, the moral double standard imposed on women, especially those who are HIV positive, encourages "abuse, discrimination, and stigmatisation within the home and in the society" (Solomon, Venkatesh, Brown, Verma, Cecilia & Daly, 2008). The increased availability and accessibility of ART has greatly improved the quality of life of HIV positive women and men.

Depending on the society, disclosure of HIV status could lead to alienation and economic deprecation, exclusion and stigmatisation as found in India (Solomon, et al., 2008). In spite of this, it is strongly recommended that patients disclose their status to at least one friend or family member or join a support group.

The finding of the research study of Collini & Obasi (2006) showed that patients who disclosed their status were three times more likely to maintain adherence. While the fear of stigmatisation by the sexual partner also associated adherence to medication. It is crucial that HIV positive patients accept their status and are able to attend the clinic on a regular basis and are able to maintain the treatment chain in order to achieve good outcomes (Department of Health, 2004).

2.7 ART regimen and complications

In recent times, complications resulting from the combination of antiretroviral therapies have been recognised. Diseases such as osteoporosis, lactic acidemia, hepatic dysfunction, ascites, encephalopathy etc. are not uncommon (Schambelan, Constance, Benson, Carr, Currier, Dube, Gerber, 2000). In addition, ART has changed the management of HIV tremendously, but toxicity to antiretroviral associated drugs is a

reality of self-monitoring found to be a good marker of good adherence (WHO, 2006; Amoroso, Sheneberger, Edozien, Fielder, Ettienne & Stafford, 2007).

Due to metabolic complications with the use of ART, it is essential to have an understanding of pre-existing medical problems in order not to complicate the diseases, for example ART not monitored may lead to lipid elevation. Despite these complications ART should not be withheld for the fear of making the complications worse (Schambelan, et. al., 2000).

Appositive change in CD4 or its negative slope can indicate virological failure. However, better outcomes are said to be achieved when patients are initiated when the CD4 levels are relatively high (Basson, Ndwapi, Rollins, Avalos, Gross, Ballany, Mogorosi, Friedman, 2006).

Research has shown that as the complexities of a prescribed regimen increase, so do the rates of non-compliance to the medication. As the complexity of the medication increases, which at times is unavoidable, so does the inconvenience and difficulty in the performance of normal daily duties. Once the effects of the drug become more complex and affects daily living in one way or another, patients may tend to discontinue the regimen (Metha, Moore & Graham, 1997)**.**

2.8 HIV and TB

The correlation between HIV and TB is well documented, so statements enquired about the incidence of TB rather: how many months was the patient on ART and when was the patient last seen at the clinic.

In the South African context, the TB cure rate is only 65%. It is not uncommon to find that there is a correlation between TB with HIV (Rosen, et al., 2007). Infection with Tuberculosis Mycobacterium is amongst the highest of HIV related opportunistic infections (Kim & Farmer, 2006; Rosen, et al., 2007).

While TB usually affects the lungs it can also affect other organs such as the liver, gastrointestinal tract as well as the central nervous system; and in most cases, co-infection with HIV is the major factor worldwide.

TB treatment requires temporary rather than permanent commitment. Adherence is only 75% in the African region, which further affects HIV management in the case of co-infection (Kim & Farmer, 2006). It is therefore critical for HIV positive people who are on ART to keep to their treatment as this will reduce the chances of drug resistance and opportunistic infection.

Immuno-suppression is one of the results of HIV-related TB (William & Jones, 2001). There is the possibility of mal-absorption of the TB drugs as well as complex drug interaction between the TB drugs and the ART; however the use of multi-drug therapy is complicated by toxicity and adverse reaction (William & Jones, 2001). Integrating HIV and TB provide a safe, practicable and successful strategy to combat the two diseases (Gandhi, Moll, Lalloo, Pawinski, Zeller, Moodley, Meyer & Friedland, 2009)

2.9 Alcohol and HIV

One of the strong predictors of non-adherence to ART which could lead to 'lost to follow-up' is the use of alcohol (Lucas, Gebo, Chaison & Moore, 2002). This is one of the ways that HIV positive people use to relieve stress and thus have been significantly identified with non-adherence to ART (Arnsten, Demas, Grant Gourevitch, Farzadegan & Howard, 2002).

Of the 40 million HIV positive people, 2.6 million are found in Sub-Saharan Africa (UNAIDS, 2006) where consumption of alcohol is high. There is evidence that alcohol contributes to the spread of sexually transmitted diseases (STIs) and HIV/AIDS (Kalichman, et al., 2007).

Moreover, alcohol is a central nervous depressant and could impair judgment even in moderate quantities. It can therefore increase risk taking and diminish personal control thereby encouraging risky behaviors which will be counter-productive in HIV positive people (Mbulaiteye, Ruberantwari, Nakiyingi, Carpenter, Kamali & Whitworth, 2000).

In addition, it is suggested that neuropsychological deficits are one of the most common manifestations of brain involvement in HIV infection (Meyerhoff, 2001; Green, Saveanu & Bornstein, 2004:249). Deficit in "memory, mental flexibility, psychomotor slowing reaction time and decisions making are commonly reported in HIV positive people" (Green, et al., 2004: ibid). Supported by very limited research so far, literature has shown that HIV infection and heavy alcohol consumption adversely affect the immune systems, which lead to infections such as pneumonia and of the central nervous system (CNS) functions (Meyerhoff 2001; Endal, 2008).

Animal studies, however, suggested that alcohol impairs various aspects of the immune system and increases the susceptibility to HIV infection, but may not accelerate progression of the HIV disease (Meyerhoff, 2001). Moreover, the study of Green, et al., (2004) demonstrated a significant difference for alcohol use by the research subjects and that HIV infection and previous and current history of alcohol use affect cognitive function.

Nevertheless, heavy alcohol use and/or ongoing alcohol abuse may interfere with the patient's adherence to antiretroviral treatment regimen (Lucas, et al., 2002). This is supported by limited studies that suggested that alcohol can interfere with the normal functions of various components of the immune system, thereby impairing the body's response with a suggestion that chronic alcohol consumption adversely affects the peripheral immune system, (Meyerhoff, 2000).

Research conducted on HIV positive patients at Tygerberg hospital in South Africa confirmed 10% alcohol dependence and 34.94% major depression in its research subjects. Men are more likely than women to abuse alcohol. Accordingly, alcohol dependence and psychiatric disorders are not uncommon in HIV positive patients.

Depending on the patient's social support, alcohol abuse could be some of the ways patients cope with the HIV infection (Olley, Gxanza, Seedat, Stein, Theron, Talijaard, et al., 2003). Consequently, no active alcohol abuse or the abuse of other substances is allowed with the use of ART and, ideally, efforts should be made to address substance

abuse before the initiation of ART to "maximise clinical response" (Lucas, et al., 2002:768). Changes in alcohol abuse have been associated with adherence.

2.10 Generation of Propositions

The literature review has been used to generate the propositions that are postulated in the following chapter. These propositions were developed to determine answers to the research questions introduced in the first chapter:

What causes HIV positive people to be 'lost to follow-up' during the course of ART regimens given the fact that the treatment is available and obtainable free of charge in public health facilities? *Will knowing the characteristics of HIV positive patients and putting measures in place be sufficient effort to mitigate against the phenomenon of 'lost to follow up'? Are socio-economic factors determinants of 'lost to follow-up' in HIV positive people?*

The propositions were tested against the results that were obtained from the research instrument.

2.11 Conclusion

This chapter attempted to highlight information currently available in literature. The similarities of 'lost to follow-up' patients pertaining to HIV/AIDS and in relation to other chronic diseases were demonstrated. The relationship between some of the variables and conformance to medication were explained. An attempt was made to define 'lost to follow-up' in relation to the study. The propositions generated from the literature review will be presented in chapter three.

Chapter 3

Propositions

3.1 Propositions

There is one main proposition with five sub-propositions. The main proposition is the following:

Demographic and socio-economic factors of HIV positive patients will determine whether they will be 'lost to follow-up' during the course of ART treatment.

Each of the following subsections begins with a sub-proposition, followed by the references from the literature, upon which the proposition is based.

3.2 Sub-proposition 1: Sex, age and financial capability

It is likely that there are a greater number of HIV positive female patients and that they are likely to be more economically compromised than their male counterparts.

This proposition is based on the findings that patients are 'lost to follow-up' in most underdeveloped countries due to the inability to pay when necessary (Zachariah, et al., 2008). Evidence showed that 48% of HIV positive females and 33% of HIV positive males were lost to premature death due to HIV/AIDS.

The studies previously cited also showed that female HIV positive patients are significantly younger and also abuse drugs less than their male counterparts, thereby interfering with the efficacy of the ART (Nicastri, et al, 2005; Edwards 2006).

3.3 Sub-proposition 2: Social support

HIV positive patients with social support through disclosure to members of families, spouses or support groups tend not to be 'lost to follow-up' because of the support that helps them adhere to ART treatment.

This proposition is based on the findings that when HIV positive people have support, either through disclosure to family members or support groups, they tend to stay on medication and are not 'lost to follow-up' (Edwards, 2006). Community support is also related to compliance to medication. By disclosing their HIV status, a patient is more likely to remain on medication due to encouragement from family members and significant others (Collini & Obasi, 2006; Edwards, 2006 & Zachariah, et al., 2006).

3.4 Sub–proposition 3: Change in ART regimen

It is likely that patients who have had an adverse reaction to ART medication and/or a change in regimen will eventually stop taking the medication and be 'lost to follow-up'.

This proposition is based on the findings that the use of ART greatly reduces mortality by demonstrating effectiveness (Robbins, et al., 2007; Timothy, et al., 2008). Patients can, however, have adverse reactions and side effects to the medication, which might lead to discontinuation of medication (Zachariah, et al., 2006).

3.5 Sub-proposition 4: Type of residence and distance of residence from ART site

It is likely that patients who live in informal residences and/or live more than five kilometres from the ARV site are more likely to be 'lost to follow-up' due to distance and other the socio-economic factors in the area of residence.

When HIV positive people are unemployed, transportation costs and other hidden hospital costs become financial burdens to attendance at the ART clinic. HIV prevalence has also been known to be higher in slums as compared to non-slum areas. High density areas, overcrowding and general poor living conditions are known to increase the risk of opportunistic infection in HIV positive people (UNAIDS, 2006; ICAD, 2010).

Forced eviction is not uncommon in these kinds of settlements and eviction can also disrupt visitations to the clinics to collect medication and/or go for other treatments. Unemployment, at times, is one of the factors why people live in this sort of

accommodation. As such, there is a connection between housing and improved health outcomes in HIV positive people (UNAIDS, 2006; Zachariah, 2008; ICAD, 2010).

3.6 Sub-proposition 5: Abuse of alcohol

It is likely that patients who abuse alcohol as a coping mechanism will be 'lost to follow-up'.

Alcohol abuse has been found to be one of the ways in which HIV positive patients deal with stress, which will eventually lead to non-compliance with ART medication (Mbulaiteye, et al., 2000; Arnsten, et al., 2002; Kalichman, et al., 2007). The abuse of alcohol accelerates the progression of HIV with adverse effects on cognitive functions, which might lead to increases in 'lost to follow-up'. Alcohol can impair the immune system leading to infections such as pneumonia.

Men are more likely than women to abuse alcohol (Meyerhoff 2001; Lucas, et al., 2002; Simon, et al., 2002; Olley, et al., 2003; Green, et al., 2004; Endal, 2008). HIV positive female patients are younger with lower viral loads and are economically compromised than their male counterparts. (Nicastri, et al., 2005; Edwards, 2006)

3.7 Conclusion

The research study and theory previously discussed have been compressed into one main proposition and five sub-propositions in this chapter. These propositions were then tested in order to see whether demographic and socio-economic profiles affect the phenomenon of 'lost to follow-up'.

The main research questions are:

What causes HIV positive people to be 'lost to follow-up' during the course of ART regimens given the fact that the treatment is available and obtainable free of charge in public health facilities? *Will knowing the characteristics of HIV positive patients and putting measures in place be sufficient effort to mitigate against the phenomenon of 'lost to follow-up'? Are socio-economic factors determinants of 'lost to follow-up' in HIV positive people?*

Chapter 4 explains the methodology used.

Chapter 4

The Research Methodology

4.1 Introduction and research setting

This chapter describes the method employed to gather the data, to test the sub-propositions formulated in the previous chapter and to look at relationships between the variables.

The panel of assessors at the School of Public Health University of the Witwatersrand suggested a change from a comparative study to one without a pre-requisite for submission to the Ethics Committee. The study commenced after the approval of the Human Research Ethics Committee (medical) of the University of the Witwatersrand, Protocol Number: M081150 on February 16 2009.

The next section describes the research methodology, the research instrument used, the construction and the structure of the population as well as the sample size and the pilot study. The different aspects of the research methodology are also discussed below.

Some of the variables tested were age, gender, residential area and type of dwelling, race, level of education, employment, relationship status, substance abuse and financial support. Others were WHO staging of the disease at the initiation time and at the time of last visit, body weights before the start of the ART and body weights at the last visit before 'lost to follow-up'.

4.2 Ethical consideration

HIV/AIDS is still regarded as a confidential illness. All necessary precaution was taken to protect the identity of all patients' files that were involved in the study.

4.3 Study population

The study population was all those 'lost to follow-up' since the inception of the clinic in 2004 at the ARV clinic of Tshwane District Hospital (TDH).

4.4 Sample

At this clinic, in 2007 and 2008, there was no Patient Tracing Mechanism (PTM) in place. The clinic relied solely on relatives to report deaths or relocation of patients; as a result self-reporting was the only Patient Tracing System in place. Therefore, all patients that have not arrived for treatment or medication collection after a month were regarded as 'lost to follow-up'.

The sampling strategy adopted used a convenience sample of those HIV positive patients 'lost to follow-up' in 2007 and 2008 respectively. These are patients that had not turned up for scheduled clinic visits and/or for medication collection. This was an unavoidable selection bias.

The researcher was aware of the selection bias since some of these patients might have died or relocated to other localities but as this information was unreported these patients were erroneously classified as 'lost to follow-up'

In 2007, 182 patients were 'lost to follow-up' and in 2008, 168 patients, which made the sample size 350. 15.7 1% of those on ART were regarded as 'lost to follow-up'.

As previously mentioned, for the purpose of this study a patient is defined as 'lost to follow-up' if placed on ART and s/he decided after a month to stop treatment during 2007 and 2008.

4.5 Inclusion criteria

In 2007 and 2008, all HIV positive patients' files that were 'lost to follow-up' at the HIV clinic at Tshwane District Hospital were included in the study.

4.6 Pilot study

A pilot study was carried out on five files from 2007 and five files from 2008 of those 'lost to follow-up' to assess the feasibility of the study. In order to ensure consistency and reliability the clinical manager and nursing manager in charge of the clinic were consulted. Corrections and adjustments were made in order to achieve uniformity.

4.7 Method

The method of research used for this study was a descriptive, cross-sectional, retrospective study of records of HIV positive patients who defaulted on their ART over a two-year period. This type of study design was chosen because it was found to be the most appropriate for the study.

Items such as knowledge of HIV/AIDS, ethnic grouping, which according to the clinical manager were not of significant clinical value, were taken out of the data collection tool and others added. A revised data collection tool was then used (Appendix 3).

Some information was retrieved from a form designed by the National Department of Health for the Comprehensive HIV/AIDS Programme filled out for each patient and attached to the back of every patient's file (Appendix 4). Due to the disorganisation of information in the files, completion of each data collection form for each patient's file took an average of 23 minutes to complete.

The experts in the field, who were the clinical manager and the nursing sister-in-charge of the HIV clinic, established face validity and modified the statements formulated for

the study. Thus the completed data collecting tool was considered to have face validity and was able to determine the characteristic of HIV positive patients who were 'lost to follow-up'. Face validity refers to validity "on the face of it" to the extent to which the measure makes sense (Katzenellenbogen, Joubert & Kazrim, 2005:92).

In order to maintain confidentiality, patients were not identified by names or telephone numbers; codes were used instead. Nonetheless, it was necessary to identify the residential area of the patient in order to assess whether the patient was living within the five kilometre radius of the Tshwane District Hospital ART clinic as expected by National Department of Health guidelines regarding availability of primary health care for the community.

Twenty variables were collected and these were classified into four categories: demographics, psychosocial enquiries, clinical conditions and medication. This data would help the researcher determine the characteristics of 'lost to follow-up'.
The collection of clinical data and medication were included as categories by the clinical manager of the clinic who was of the opinion that this date might shed more light on the phenomenon of 'lost to follow-up'.

Following the literature review and the pilot study, the collection tool was considered to have content validity. The twenty items on the data collection tool showed a high level of identity of the constructs under investigation. The data collecting tool was administered individually for each patient's file of those 'lost to follow-up' in 2007 and 2008.

There were four categories to the data collection tool. These statements are stated below for ease of reference in Tables 1 to 4.

Table 1: Demographic and socio-economic enquiries

Number	Questions/statements
1	The research number
2a&b	The residential area of the patient and type of dwelling
3a,b,c,d,e&f	The age of the patient, race, gender, level of education, employment and

	relationship status
10	Financial support

The first statement was the research identity for each patient in lieu of names to maintain confidentiality and anonymity. The second, third and tenth statements consisted of nine variables seeking to answer demographic and socio-economic enquiries about the patient. It could be difficult for a patient who does not have any form of employment or means of support to keep appointments at the clinic.

Table 2: Psychosocial enquiries

Number	Questions/statements
4	Do you have any dependant/s?
5	Relationship status
6 a&b	Have you disclosed your HIV status and to whom?
7	Patient was accompanied/supported by
8	Compliance with ART is managed by ...
9	If there is history of substance abuse

These seven variables seek to identify whether the patient has social support in the community or at home. HIV positive people who experience social support report less emotional stress, which can affect their immune system. When patients disclose, the fear of rejection and abandonment (UNAIDS Report, 2000), negative financial consequences (Whetten-Goldstein, Nguyen & Sugarman, 2001) or social stigma have been overcome (Saulka & Lie, 2000). There is also a high likelihood that someone will be supporting the patient by making sure that medication is not missed and visitation to the clinic is maintained.

Statements 6a and 6b help in accessing the state of acceptance of the HIV status of a patient. A patient who has managed to disclose would presumably make better effort to have some kind of social support. Positive answers to these statements would negate the fact that social problems are contributory to being ‘lost to follow-up’.

Table 3: Clinical conditions

Number	Questions/statements
11	WHO Staging of HIV infection at the first clinic visit
12	WHO Staging of HIV infection at the first clinic visit
13	Body weight at first visit
14	Response to TB incidence

All the above four variables help in the determination of the clinical condition of the patient.

Patients gain weight when they respond to ART. Correlation of body weight at initiation versus the last visit before 'lost to follow-up' would be of interest, as well as the WHO staging before the ART and at the time of last visitation. Demographic variations and trends between the different gender and stage of the HIV virus would also be of significance.

Table 4: Medication: ART

Number	Questions/statements
15	Medication at initiation stage
16	Medication as at the time of last visit
17	Period of treatment (Number of months on treatment)
18	Missed appointment in the course of coming to clinic

All ART medication has side effects that affect patients differently and some of the side effects can be fatal. There could also be associations between the period of 'lost to follow-up' and a specific regimen. Missed appointments might be an indication of a patient being at risk for 'lost to follow-up'.

4.7 Data Analysis

The data on the computer of the researcher was password protected to further ensure that confidentiality was maintained. Only designated research numbers were used. Each file was colour coded in orange to delineate it from other research studies that the files have been used for previously. The data was collected over a three-month period. Each data collecting tool was given a research number to ensure confidentiality. Descriptive statistics explain the results in the next chapter.

Excel and *Stata version 10* were used for the descriptive statistics explained in the results in the next chapter

Chapter 5

Results

5.1 Introduction

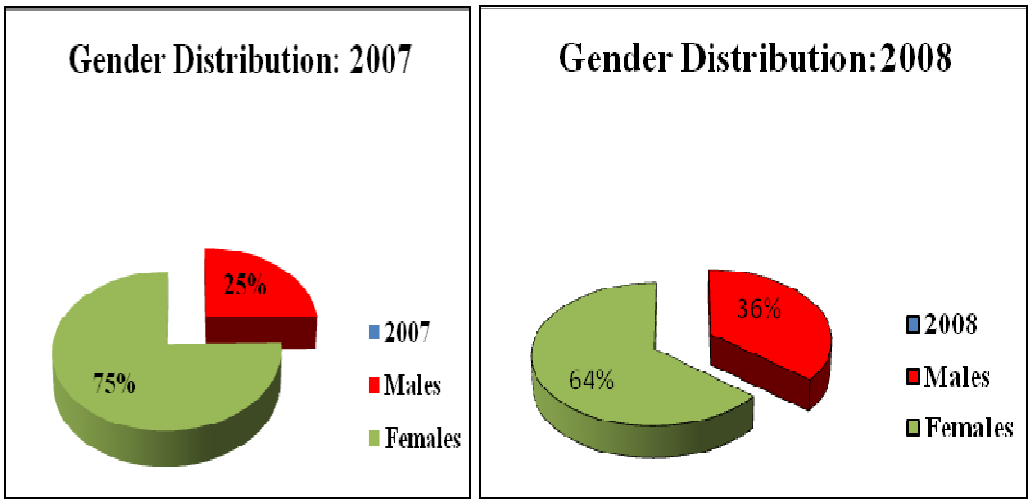
The results of the study are summarised in this chapter. Results are represented in graphical, tabular and summary form to aid interpretation. 350 files were analysed in the study. There were inconsistencies in collecting information; information regarding some statements on the data collection tool was not available in the patients' files.

5.2 Results

5.2.1 Gender

In total, 350 files were analysed, of which 182 files were for 2007 and 168 files for 2008. Of the 182 files for 2007, 46 (25%) were males and 136 (75%) females. Of the 168 files for 2008, 60 (36%) were males and 107 (64%) females.

Graph 2a & 2b: Gender Distribution 2007 & 2008

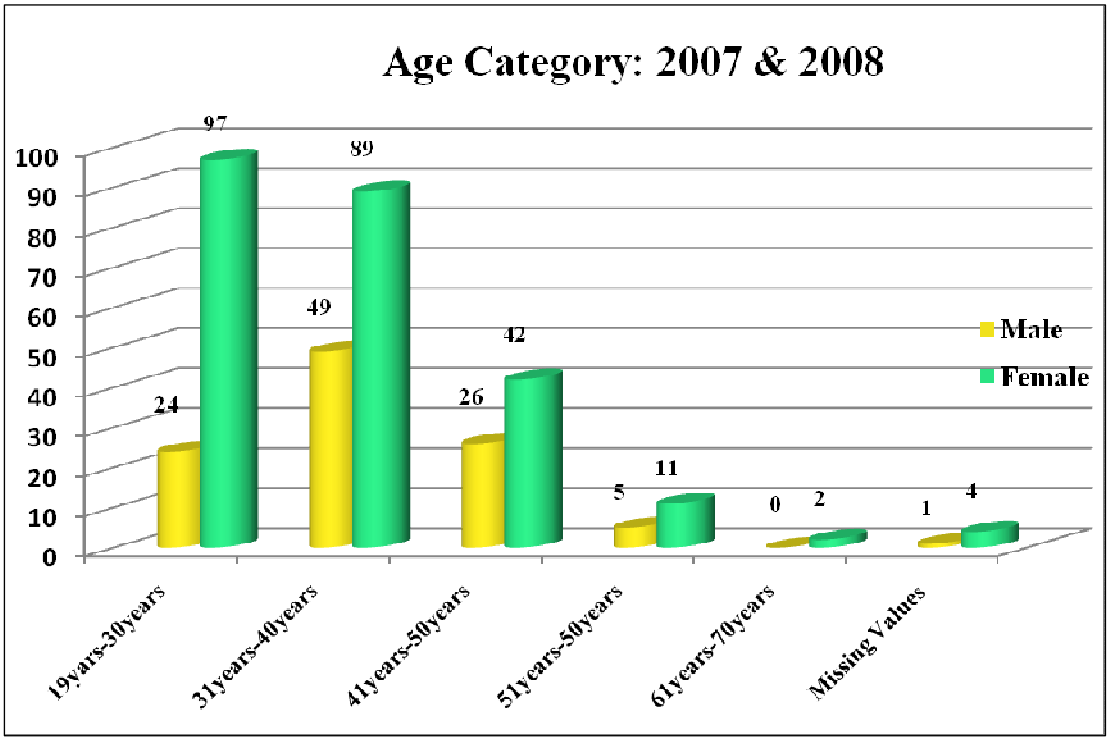


5.2.2 Age distribution

The mean age was 35 years old. The minimum age was 19 years old, while the maximum age was 70 years old. 97 females were between the ages of 19-30 years, while there were only 24 males in the same category. 89 females were between the ages of 31-40 years and there were 49 males in the same category.

There were 42 females in the category of 41-50 years, while the males in the same category numbered 26. Eleven females were the 51-60 years category and five males were in the same category. There were only two females in the 61-70 years and five missing values. In total 120 HIV positive people were in the 19-30 years old bracket and 148 between 30-40 years and 68 were between 40-50 years, with 16 people in the 51-60 years category.

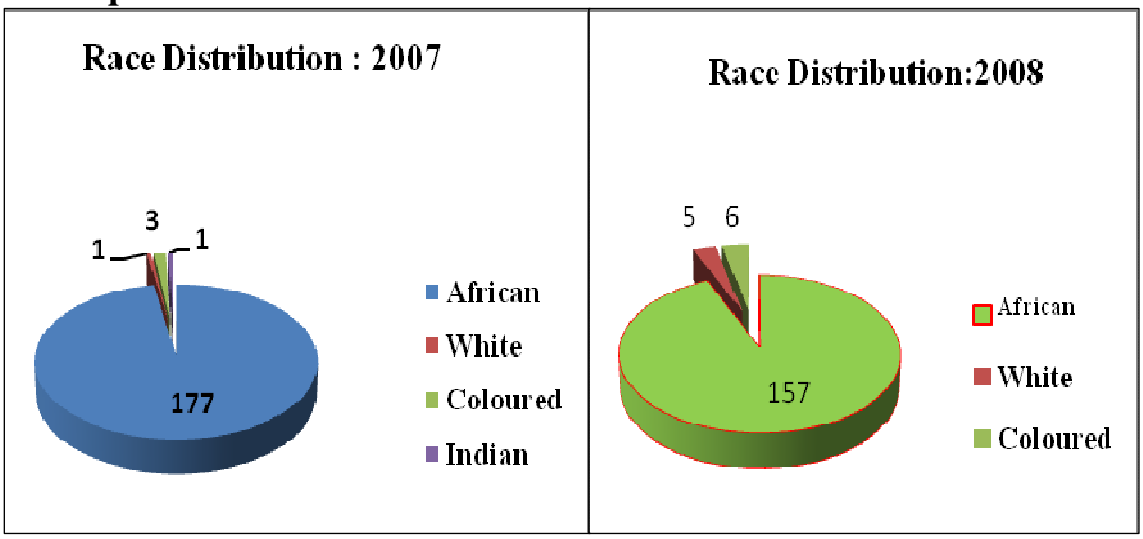
Graph 3: Age Profile 2007 & 2008



5.2.3 Race distribution

Of the numbers in 2007, 177 (97%) were African descendants, 1 (1%) white, three (2%) people of mixed race (coloured) as well as 1 (1%) of Indian descendant. In 2008, (93%) were Africans, 5 (3%) were whites, 5 (3%) were coloureds and 1 (1%) person was from another group classified as others. There were 334 Africans in total.

Graphs 4a & 4b: Race distribution 2007 & 2008

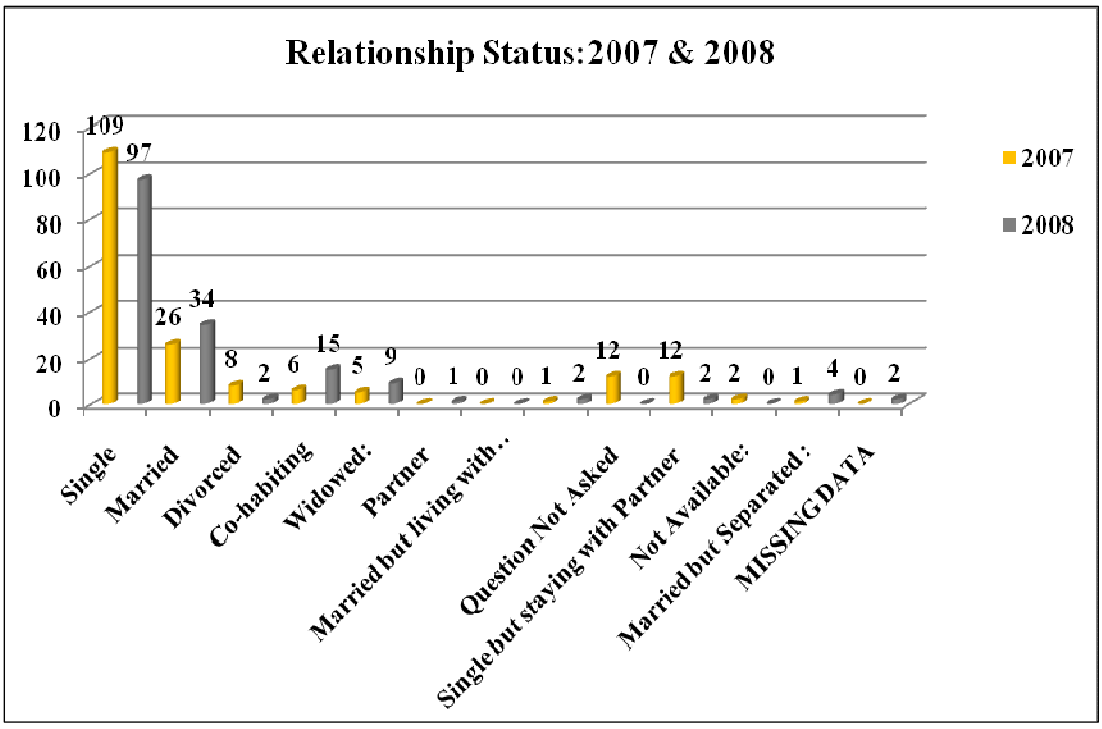


5.2.4 Relationship status

In 2007, 109 (60%) HIV positive people were single, while 26 (14%) HIV positive people were married. Eight (4%) declared that they were divorced. Data was missing for 12 (7%) people; and another 12 (7%) declared that they were single but staying with partners.

In 2008, the scenario was slightly different but not significantly. Of the 168 HIV positive patients 97 (58%) people were single. Unlike the 26 (14%) people that were married in 2007, 34 (20%) HIV positive people were married in 2008, 15 (9%) were divorced and 9 (5%) were co-habiting.

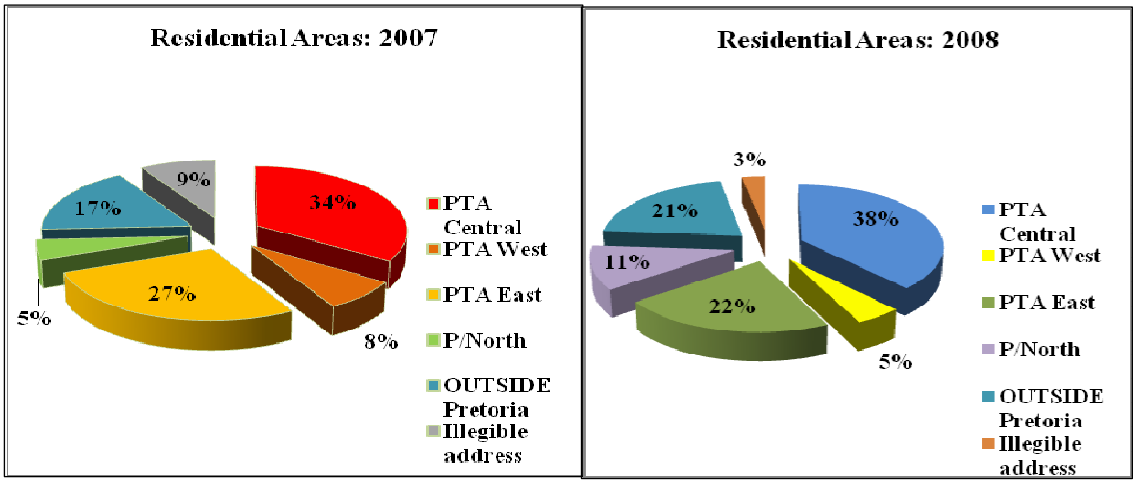
Graph 5: Relationship Status 2007 & 2008



5.2.5 Residential areas

In 2007, only 62 (37%) patients lived within the referral cluster, which was Pretoria Central. 14 (8%) came from Pretoria West, 50 (27%) from Pretoria East, 9 (5%) from outside Pretoria and 16 (9%) addresses were illegible. The scenario was not particularly different in 2008. 64 (38%) of the patients lived in Pretoria Central and 35 (21%) came from outside Pretoria. The information regarding residential status was retrieved from patients' files.

Graphs 6a&6b: Residential Areas 2007 & 2008

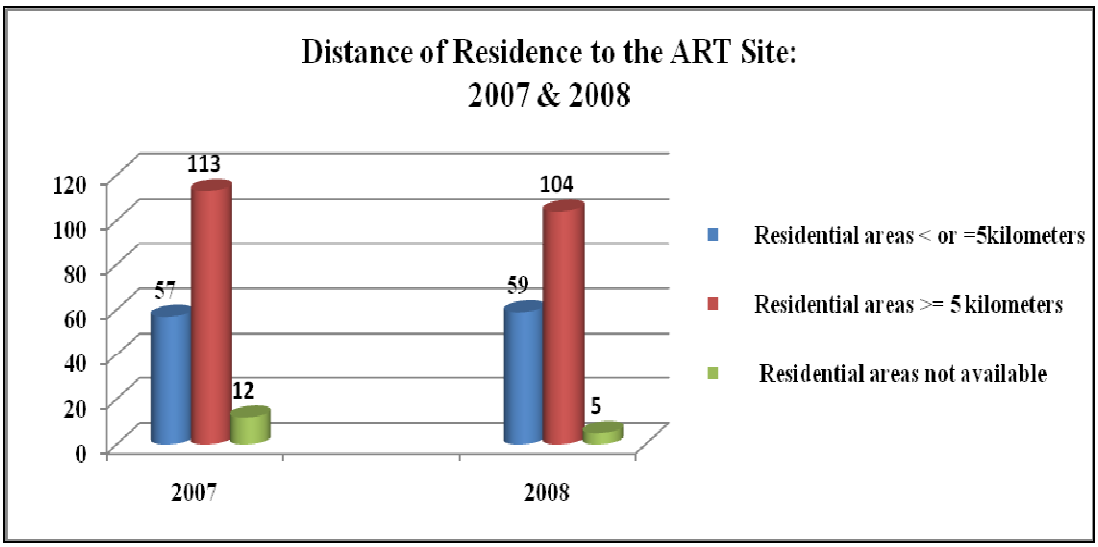


5.2.6 Distance of residence from ART site

In 2007, 57 (31%) of the 182 HIV positive people were living up to five kilometres and less from the ART site. 113 (62%) HIV positive people lived more than five kilometres away. Information on residence was missing for 12 (7%) patients.

In 2008, 59 (35%) HIV positive people lived five kilometres or less from the ART site while 104 (62%) HIV positive people lived more than five kilometres away. Information regarding the address for 5 (3%) patients was missing.

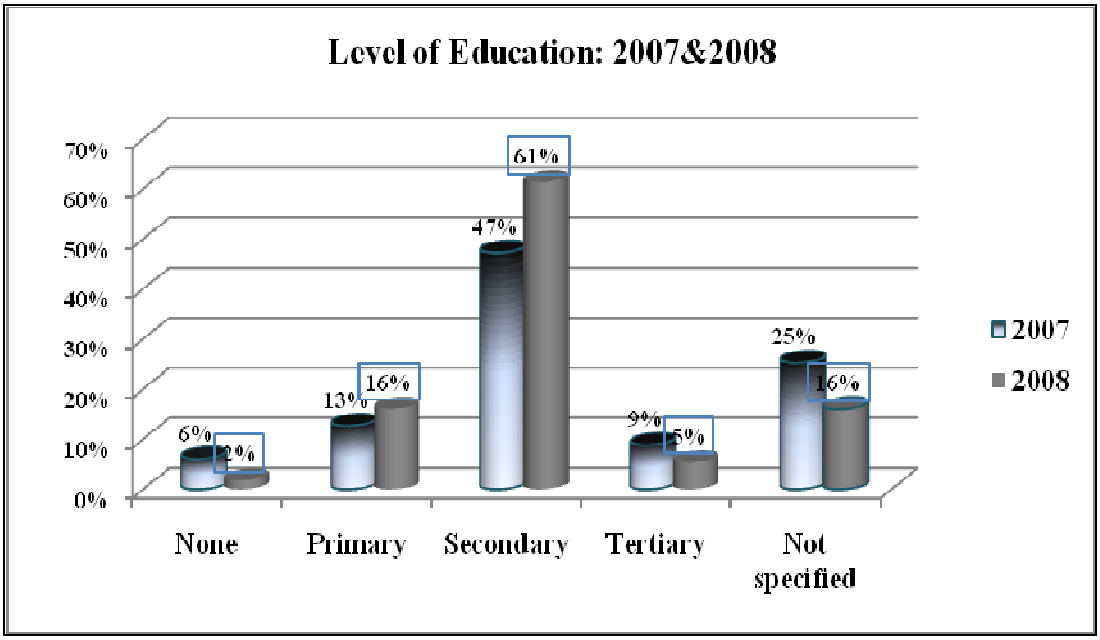
Graph 7: Distance of Residence to ART Site 2007 & 2008



5.2.7 Level of education

Similarity between the two years was noted in the level of education the patients had received. Information from the patients' records revealed that 86 (47%) of the patients had secondary education and 23 (13%) of them had primary education. 103 patients (61%) of the 2008 cohort had secondary education and 27 patients (16%) had primary education. Only a small percentage, 6% in 2007 and 2% in 2008, did not have any form of education. The level of education was not specified for 46 patients (25%) in 2007 and 26 (16%) in 2008.

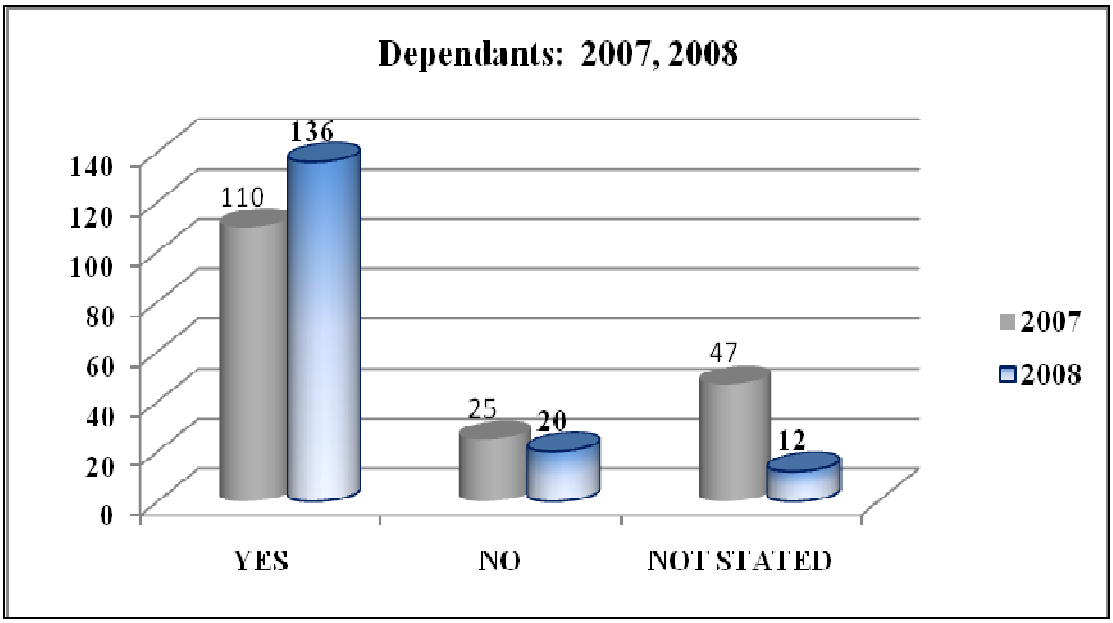
Graph 8: Level of Education 2007 & 2008



5.2.8 Dependants

In the 2007 group it was 'not stated' whether 47 HIV positive patients (26%) had dependants; 110 (60 %) patients had dependant relatives and 25 patients (14%) said they did not have. In the 2008 cohort 136 (81%) confirmed that they had dependants and 20 patients (12%) did not, while it was not stated whether 12 patients (7%) had dependants or not.

Graph 9: Dependants 2007 & 2008

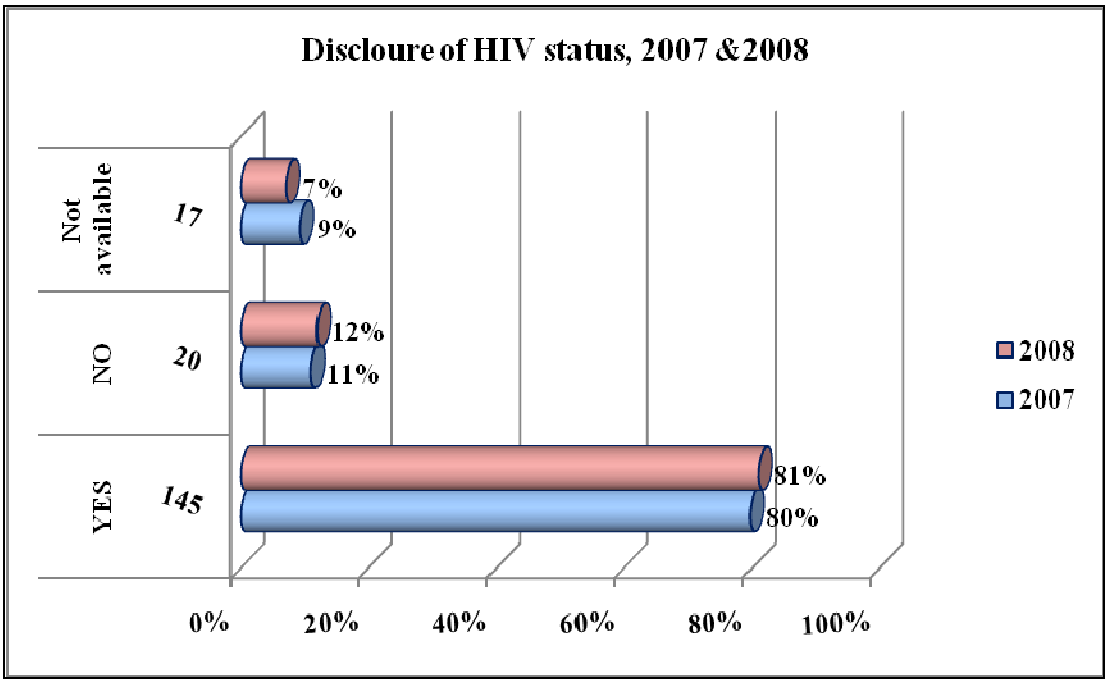


5.2.9 Disclosure of HIV status

In 2007, 80% of patients had disclosed their HIV status; 104 (57%) of the 182 patients disclosed to family members, while 20 patients (11%) disclosed to either a boyfriend/girlfriend or a partner.

In 2008, 81% disclosed their status and of the 167 patients only 65 patients (39%) disclosed to family members and 48 patients (29%) disclosed to either a boyfriend/girlfriend or a partner.

Graph 10: Disclosure of HIV Status 2007 & 2008

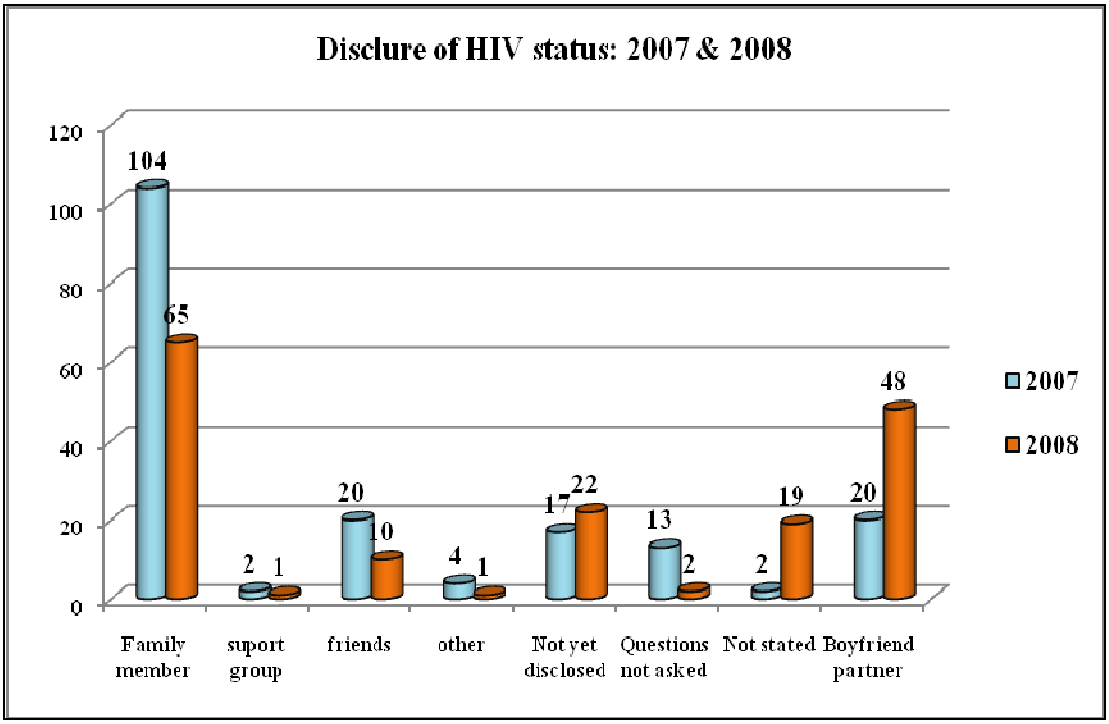


5.2.10 To whom has the patient disclosed his/her HIV status?

In 2007, 104 (57%) HIV positive patients disclosed their HIV status to family members, while 20 (11%) disclosed to friends and 20 (11%) had disclosed to boyfriend/girlfriend or partners. 19 (9%) had not disclosed their status. Unlike in 2008, when 65 (39%) disclosed to family members, 10 (6%) disclosed to friends and 22 (13%) had not yet disclosed.

The 'values labelled question not asked' referred to a retrospective situation when counsellors and Health Care Workers (HCWs) had collected the information and had put those questions to the patients. The research made use of information that was in the file.

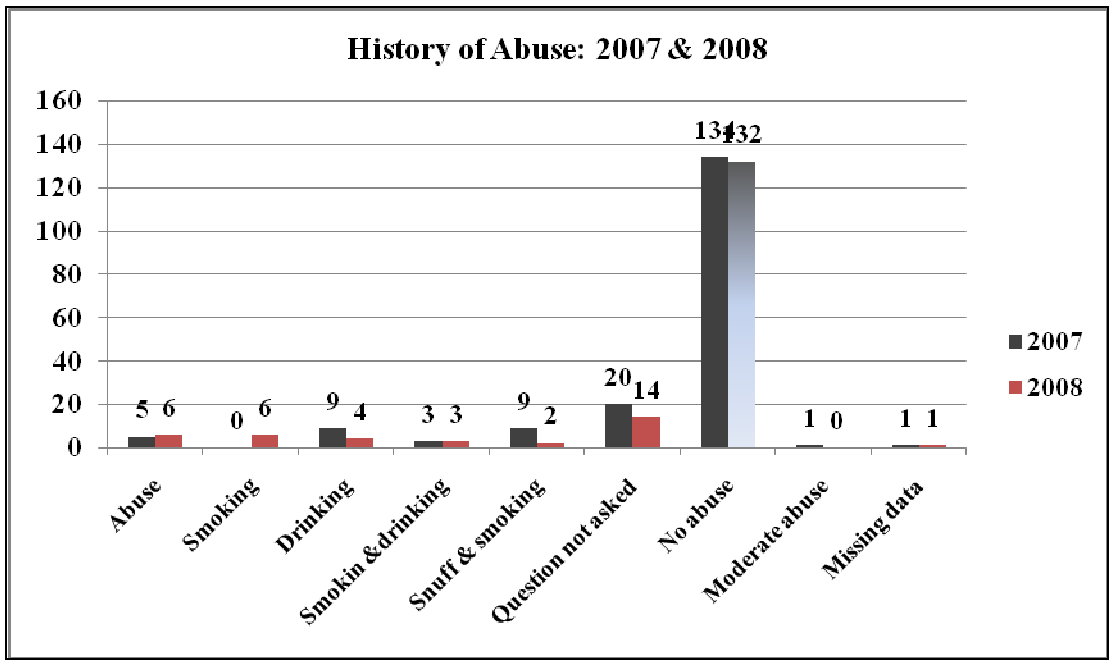
Graph 11: To whom has the patient declared his/her HIV Status 2007 & 2008



5.2.11 History of substance abuse

The majority of the patients in both years said they were not abusing any substance; 134 patients (72 %) in 2007 and 132 patients (79%) in 2008. Information regarding abuse was omitted in 11% of the 2007 cohort and 8% of the 2008 group. Only 5 patients (3%) admitted to substance abuse in 2007 and 6 patients (4%) in 2008.

Graph 12: History of Substance Abuse 2007& 2008

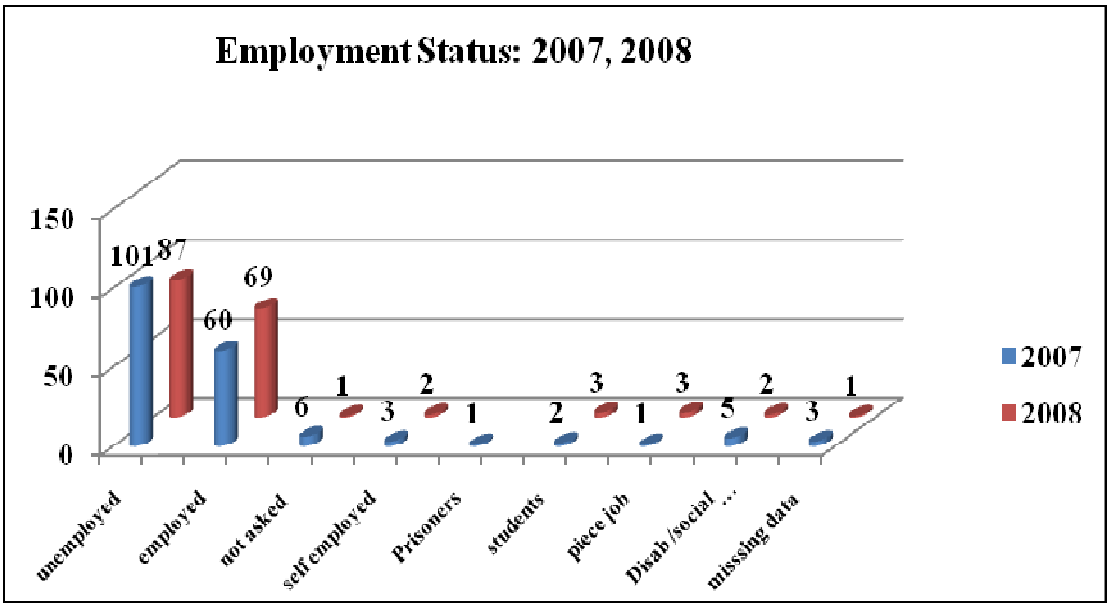


5.2.12 Employment status

In 2007, 101 (55%) HIV positive people were unemployed and 60 (33%) were employed, there was no information regarding status of employment for 6 (3%) HIV positive people, 3 (2%) were self employed, 1 (0.5%) prisoner, 2 (1%) students, 1 (0.5%) was doing a piece-job/informal work, 5 (2.7%) were on disability/social grants and 3 (2%) had data missing.

In 2008, 87 (52%) HIV positive people were unemployed, 69 (41%) were employed and there was no information for 1 (0.6%) patient while 2 (1.2%) were self employed. There were 3 (2%) students and 3 (2%) people doing piece jobs while only 2 (1.2%) were on social grants with 1 (0.6%) missing data. For 2007 and 2008, 54% (188 patients) were unemployed, 37% (130) were employed.

Graph 13: Employment status 2007 & 2008



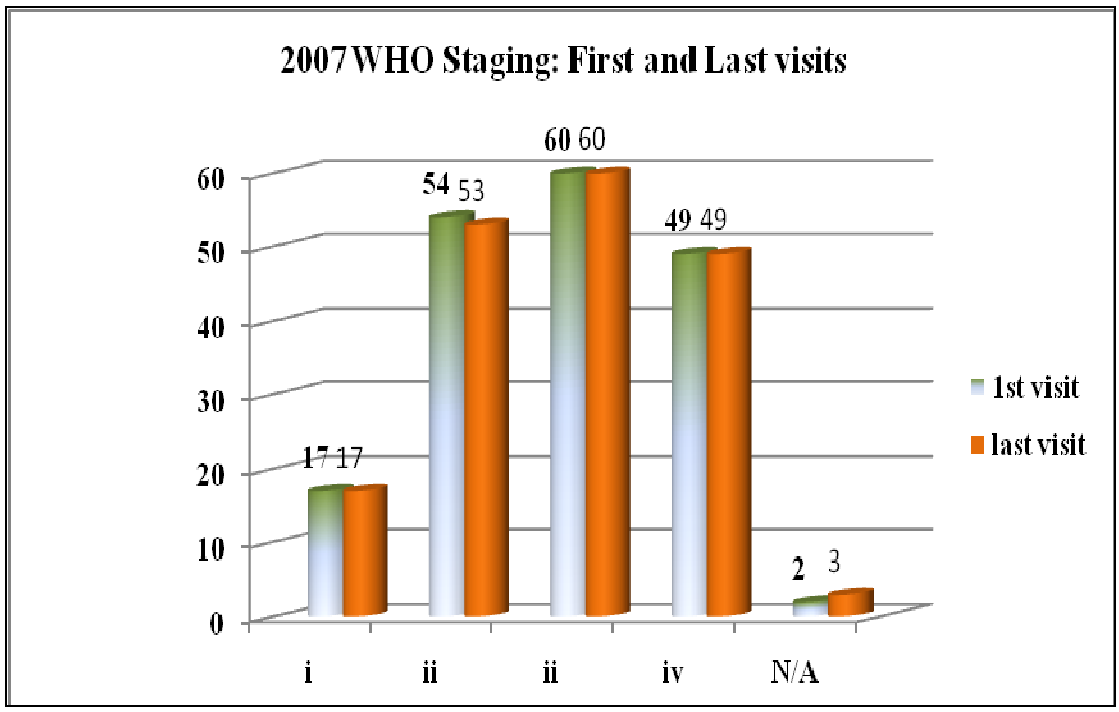
5.2.13 WHO Clinical Staging System

The WHO clinical staging system identifies the stage of the HIV disease that an individual patient is in. It was found that there was no significant difference between the WHO staging before commencement of treatment (initiation/first visit) and at the time of 'lost to follow-up' (last visit).

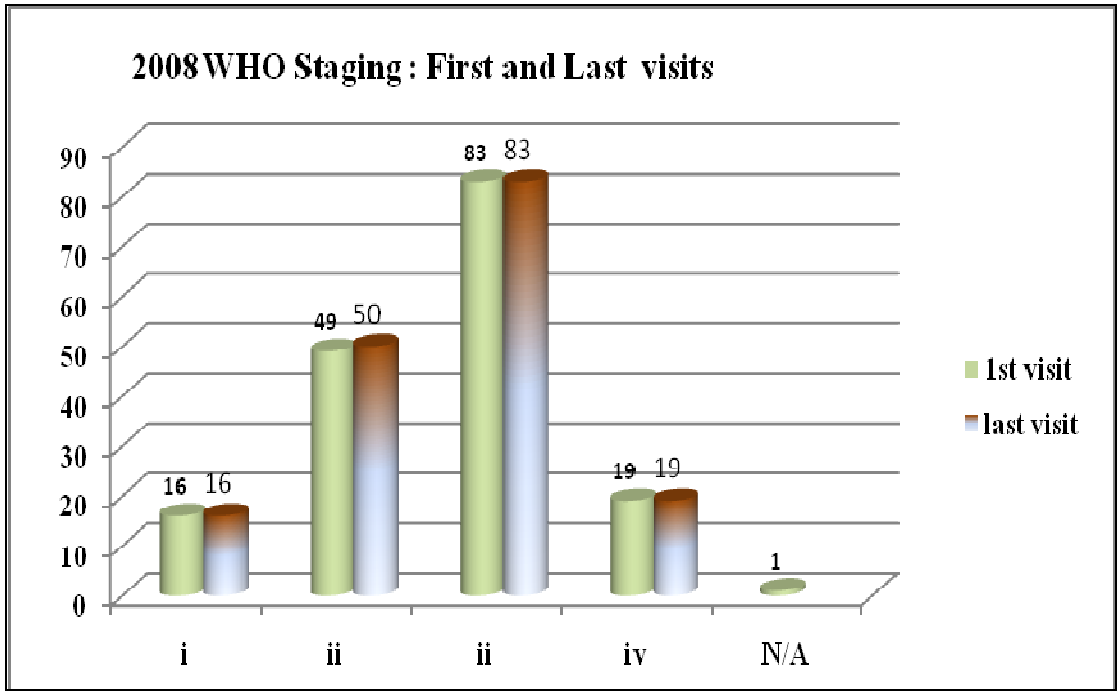
Of the 182 patients in 2007, 17 (9%) of them were in WHO stage 1 at the time of their first visit to the clinic, 54 (30%) HIV positive patients were in the second stage, 60 (33%) in the third stage and 49 (27%) in the last stage. Despite the varied treatment period of antiretroviral treatment there were no significant changes in the WHO staging of the patients by the time of 'lost to follow-up'.

The same pattern was observed in the 2008 patients. 16 (10%) HIV positive patients were in the WHO stage 1, 49 HIV positive patients (29%) were in stage 2, 83 patients (49%) were in stage 3 and 19 were in stage 4. As in the case of 2007 patients, except for a variation of about 1% from the first/initiation visit there were no significant changes in the stages at the time of 'lost to follow-up'.

Graph 14a: WHO Staging: First and Last visits 2007



Graph 14b: WHO Staging: First and Last visits 2008

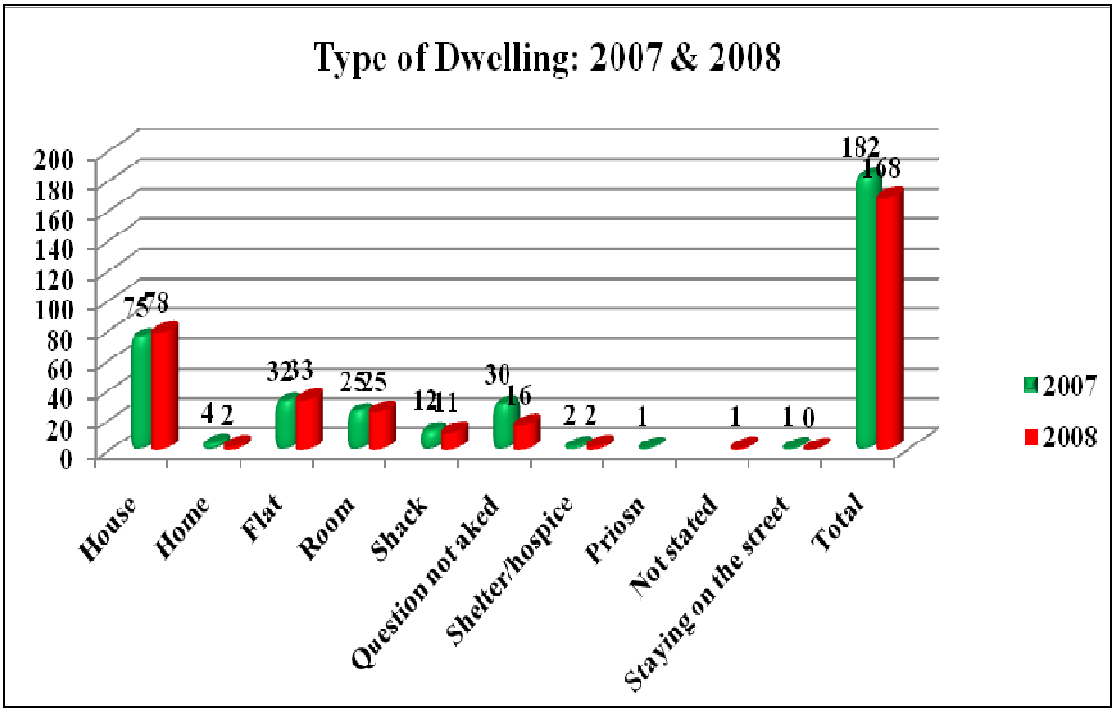


5.2.14 Type of dwelling

Of the 182 patients in 2007, 75 (41%) HIV positive patients were living in houses, while 4 (2 %) lived in homes. 32 (18%) lived in flats, 25 (14%) stayed in rooms and only 12 (7%) patients were living in shacks and type of abode was not stated for 30 (16%) patients. Two (1%) patients were residing in hospice/shelter and 1 (1%) was serving a prison term, with 1 patient (1%) staying on the street as a homeless person.

78 (47%) HIV positive patients of the 2008 files lived in houses, while 2 (1%) patients lived in homes. 33 (20%) patients lived in flats and 25 (15%) patients lived in the room category. 11 (7%) of them were living in shacks. Two (1%) patients were living in a shelter/hospice situation and the type of dwelling was unknown for 16 (10%) patients.

Graph 15: Type of Dwelling 2007 & 2008

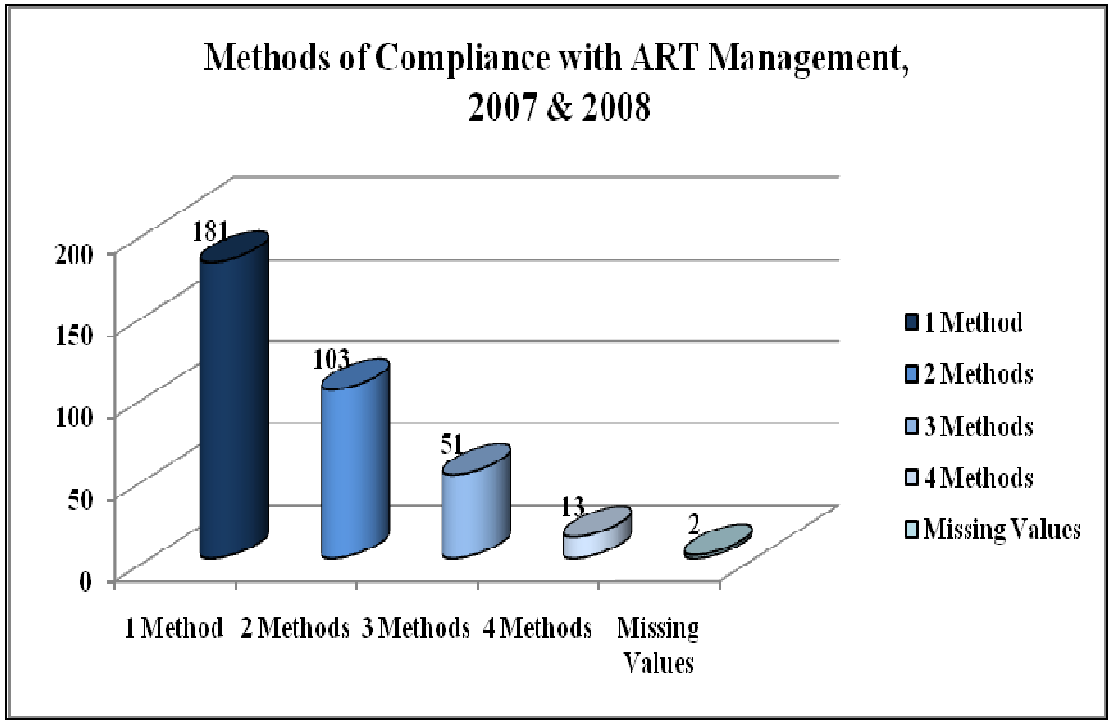


5.2.15 Compliance with ART management

The Data Collection Tool made provisions for nine methods that could be used to help patients manage compliance to ART regimen. The ART management would include the use of cell phones, pill boxes, a pill diary buddy, etc. (Appendix 3, no 6.1). Some patients decided to use more than one method to assist in the improved management of the ART regimen.

Of 350 files for both 2007 and 2008, 181 (52%) HIV positive patients used one method to assist them in the management of the regimen. 103 (29%) were making use of two methods, while 51 (15%) used three methods. Thirteen HIV positive people claimed that they used four methods to help them manage the therapy and there were 2 (1%) missing values.

Graph 16: Method of Compliance with ART Management 2007 & 2008



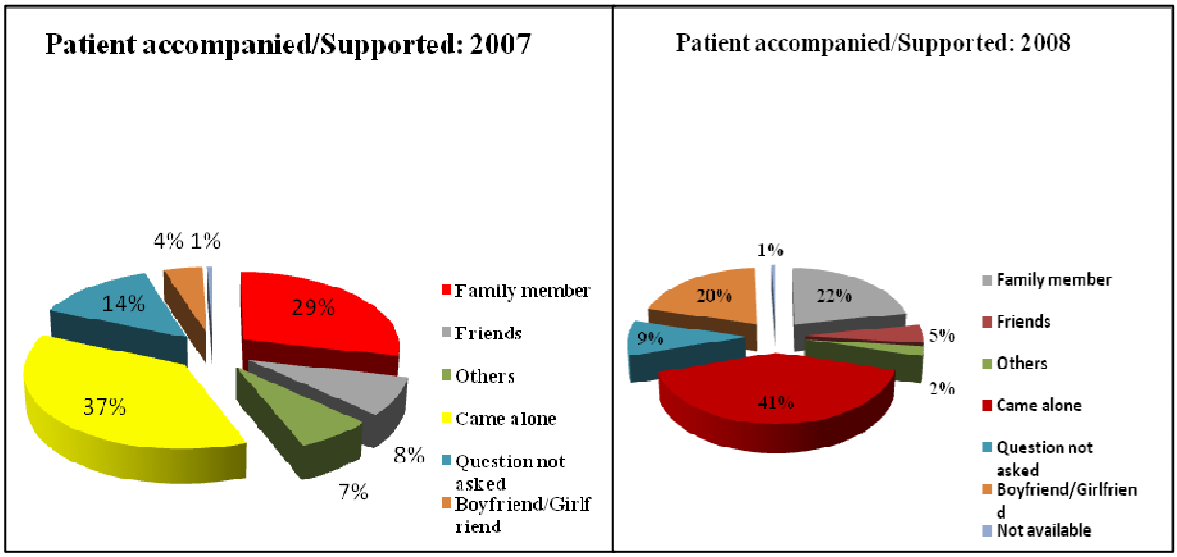
5.2.16 Patient accompanied/supported

The visit to the clinic is sometimes characterised by patients being accompanied for treatment by their significant others, especially if the patient has disclosed their status. This kind of social support helps in adhrence to the antiretroviral regime as the supporter becomes a 'buddy' in making sure patients adhere to treatment.

In 2007, the record review showed that 52 (29%) patients were accompanied to the clinic by family members, while 68 (37%) came by themselves to the clinic. There was no documented record for 25 patients (14%). Presumably counsellors did not undertake proper documentation during previous visits, and 8 (4%) patients came with partners/girlfriend/boyfriend.

In 2008, a little more than a fifth of the patients (37) were accompanied by family members and 69 (41%) of them came to the clinic by themselves. 34 (20%) of them came with a boyfriend/girlfriend or partner.

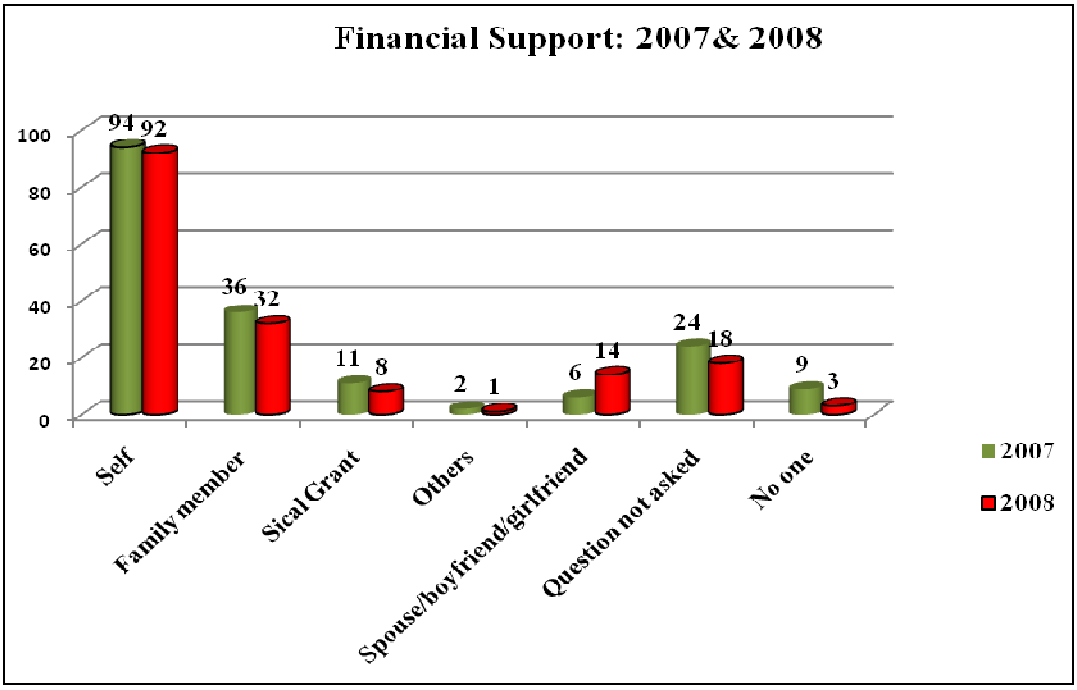
Graph 17: Patient Accompanied/Supported 2007 & 2008



5.2.17 Financial support

The majority of participants in the two years under review were supporting themselves financially; 52% (94) in 2007 and 55% (92) in 2008. Family members supported 20% (36) of patients in 2007 and 19% (32) in 2008. Spouses/boyfriends/girlfriends financially supported only 3% (6) in 2007 and 9% (14) in 2008. It seems that 13% of the patients in 2007 and 18% of the patients in 2008 were not asked about financial support as there were no records in the patients' files referring to it.

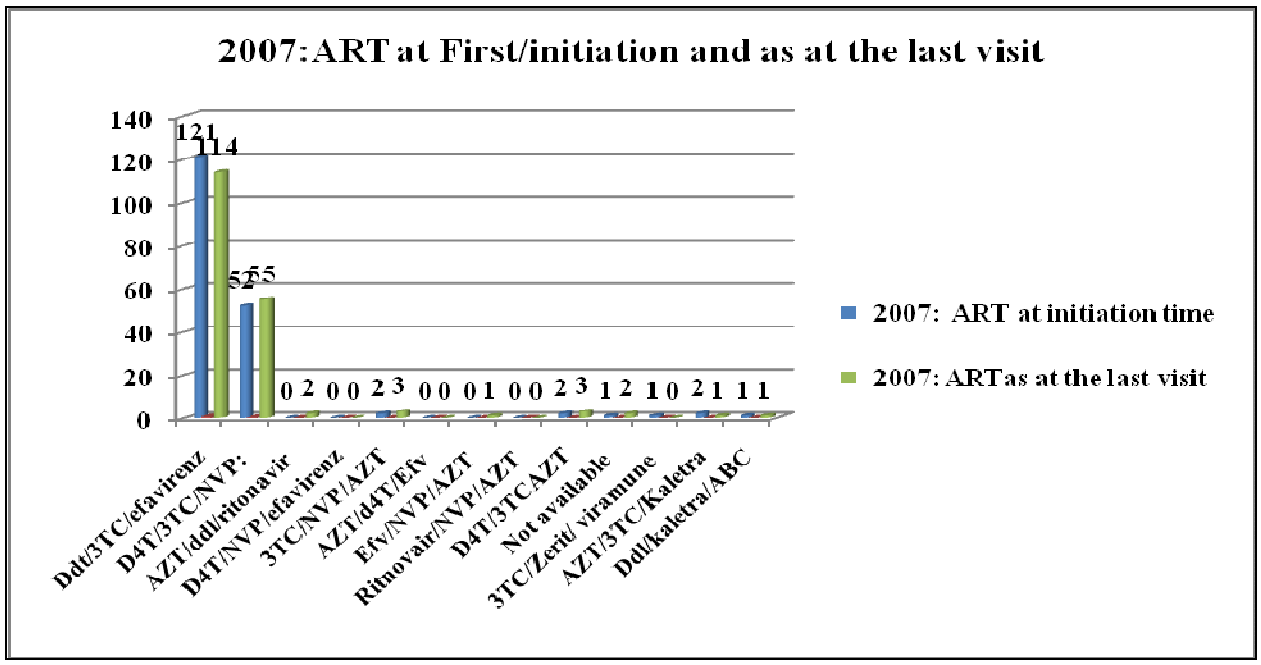
Graph 18: Financial Support of Participants 2007 & 2008



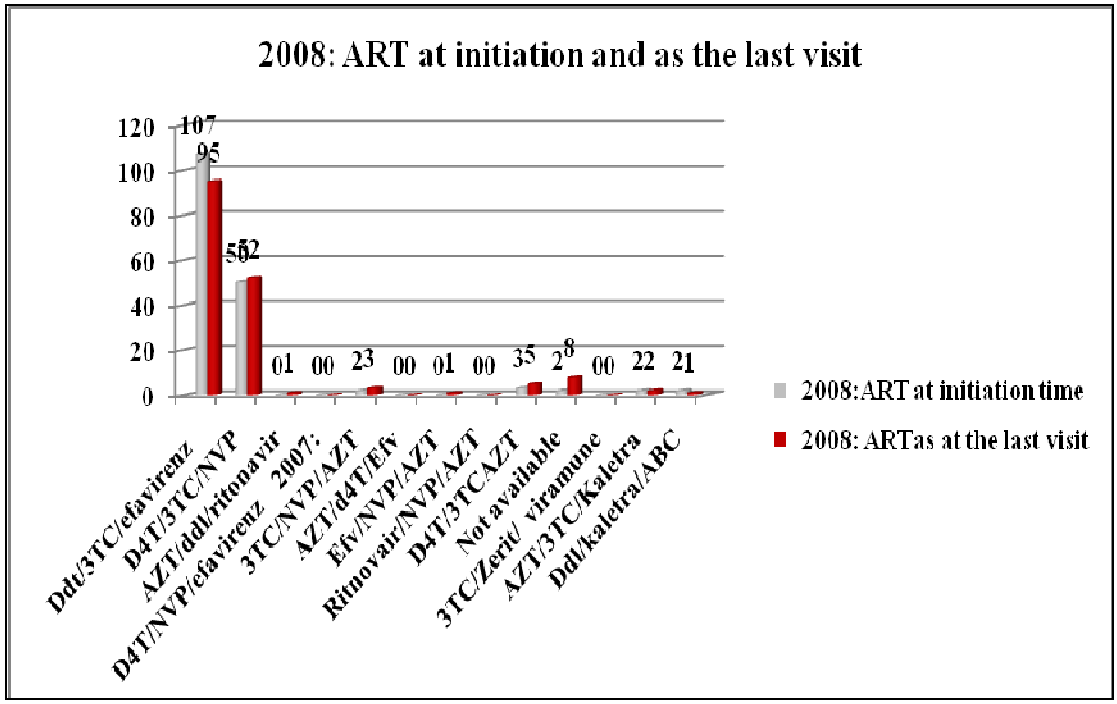
5.2.18 ART regimen and compliance

ART regimen can be altered or the regimen changed for various reasons during the course of treatment. In 2007, only 17 (9%) HIV positive patients of the 182 had changed the regimen at the time of being 'lost to follow-up', which is not important. In 2008, however, this percentage doubled. 30 (18%) patients had changed their regimen by the end of their last visit to the clinic as at the time of 'lost to follow-up'.

Graph 19a: ART at the first/initiation and as at the last visit 2007



Graph 19b: ART at the first/initiation and as at the last visit 2008

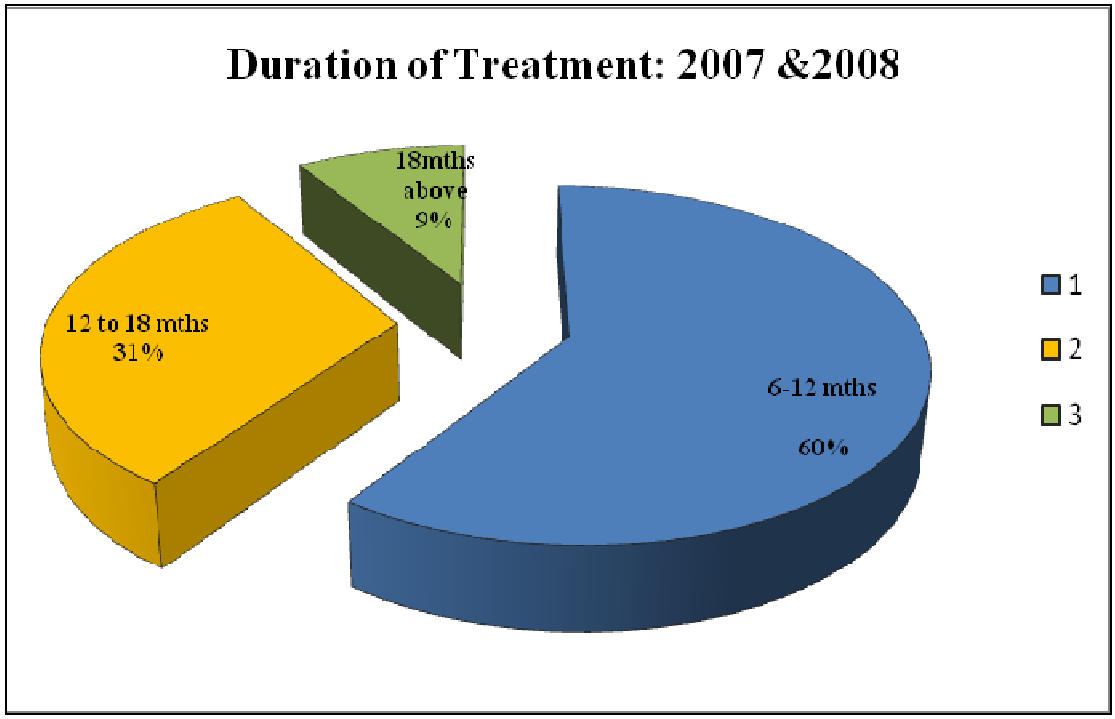


5.2.19 Duration of ART treatment

The period that a patient was on the ART regimen was categorised into three. This is because most works of research consulted at the time of this study used 6, 12 and 18 months as time periods to evaluate or monitor processes, outcomes or compliance (Metha, Moore & Graham 2000; Sethi, 2004; Boulle, Culsen, Cohen et al., 2008 & Ncholo, 2009).

It was found that 208 (60%) patients were on ART for less than and up to 12 months. Similarly, 109 (31%) patients were on treament for over 12 months and up to 18 months and only 32 (9%) were on treatment for longer than 18 months.

Graph 20: Duration of ART treatment 2007 & 2008

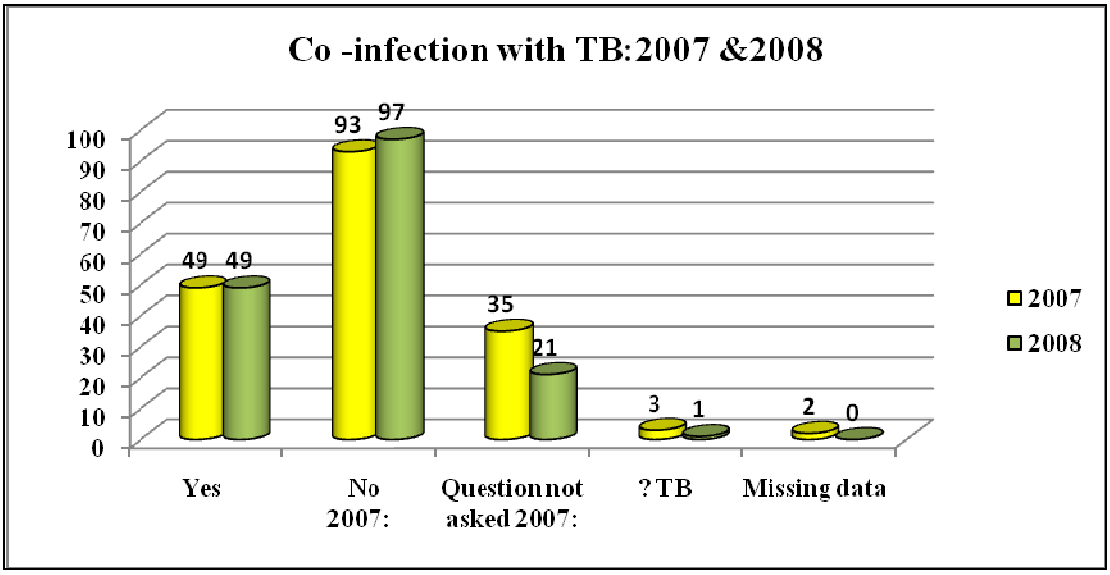


5.2.20 TB co-infection with HIV

Of the 182 patients files from 2007, 49 (27%) HIV positive patients had TB and 93 (51%) did not. However, the co-infection status for 35 patients was unknown. Three (2%) HIV positive patients were unsure and there was one that had data missing.

The situation was similar in 2008, 49 (29%) HIV positive patients were co-infected with TB, 97 (58%) patients were not and the co-infection status of 21 patients (31%) was unknown.

Graph 21: Status of co-infection with TB 2007 & 2008



5.2.21 Differentials in body weights after the initiation of ART

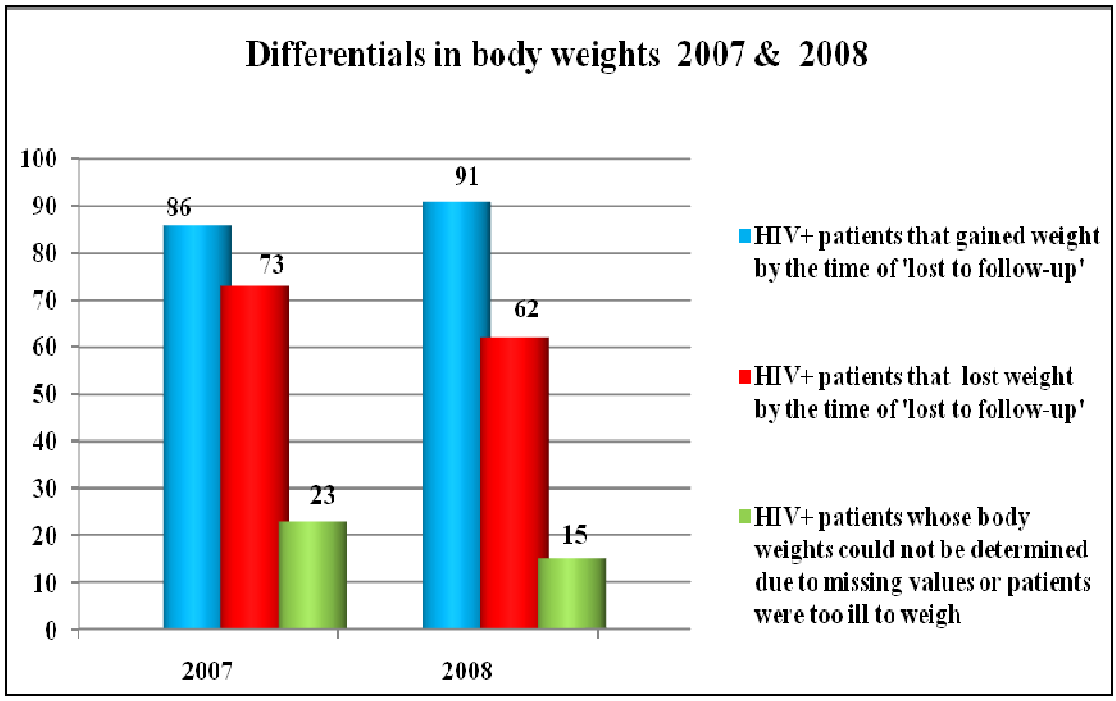
Patients are weighed at every visit to the clinic. This is part of normal clinical observation at each visit and continues after the initiation of ART. Controlled weight gain is expected after the patient has been initiated. A comparison of the weight before the ART initiation and at the time of 'lost to follow-up' revealed whether the patient gained weight as a result of the ART intervention or not.

In 2007, 86 (47%) HIV positive patients gained weight, but 73 (40%) patients lost weight despite the ART regimen. Weight loss/gain for 23 (13%) patients could not be determined for the reason mentioned in the previous paragraph.

In 2008, 91 (54%) HIV positive patients gained weight with 62 (37%) patients losing weight despite the ART regimen. Weight loss/gain for 15 (9%) patients could not be determined for the reason mentioned in the first paragraph.

The weight gained varied from as little as 0.07kg to as much as 25kg. The weight loss also varied from as little as 0.3kg to as much as 24.9 kg.

Graph 22: Body Weight Differentials after ART 2007 & 2008

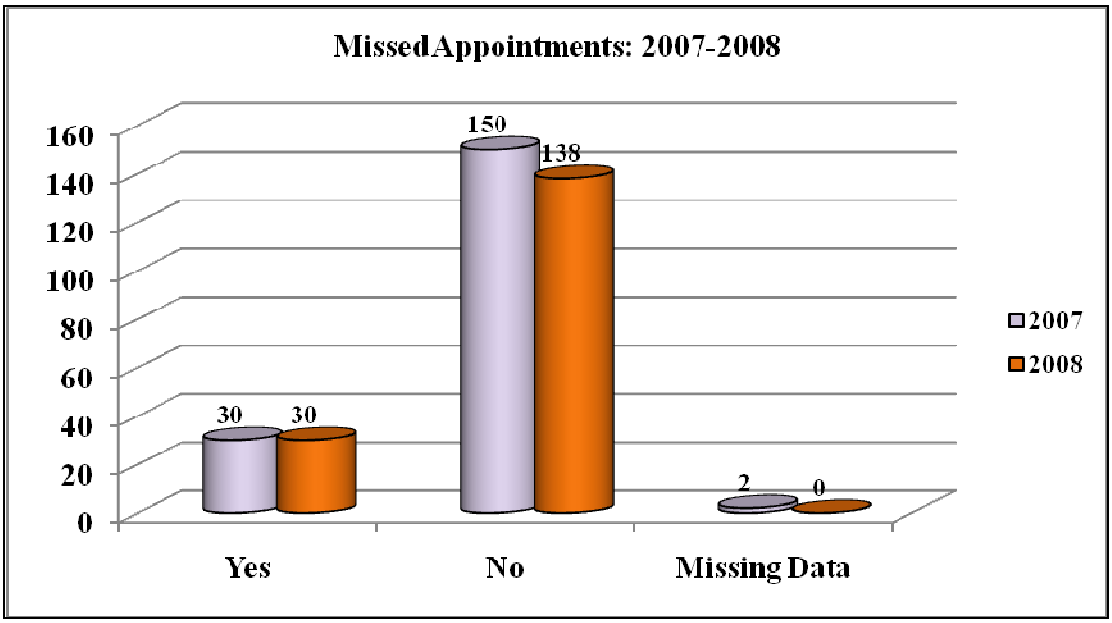


5.2.22 Missed appointments

Of the 350 files, a total of 288 (82%) patients did not miss their appointments, while 60 (17%) had miss appointments and there was only missing data for 2 (1%) patients. In this clinic there was no mechanism to trace 'lost to follow-up'. The clinic

depends solely on self-reporting by patients and relatives/communities to report deaths, relocation or illness. When patients failed to be classified through the self-reporting mechanism they were assumed to be 'lost to follow-up' even after one month.

Graph 23: Missed Appointments 2007& 2008



5.3 Conclusion

Descriptive statistics results were presented in this chapter. There were no appreciable differences in the characteristics of the 2007 and 2008 cohorts. This is probably due to the main limitation of the study in that it was largely confined to 'lost to follow-up' cases. Chapter 6 outlines the interpretation of the results.

Chapter 6

Interpretation of the Results

6.1 Introduction

The interpretations of the results are presented in this chapter. Comparisons are made with previous research work when necessary. In the course of this research an attempt was made to explain the characteristics of HIV positive patients who were 'lost to follow-up'.

6.2 Variables

6.2.1 Gender

Three-quarters of the 2007 cohort were female and just less than two-thirds of the 2008 cohort were female. These results relate to the study of Matlin & Spence (2000) that 50% of new daily infections are female; half of the 12.7 million people who have died of the disease were women. Women account for 55% of those living with the disease in Sub-Saharan Africa.

6.2.2 Age distribution

The results of the study showed that those in society who are economically viable are affected by the HIV/AIDS pandemic. Of the total number of 350 files, 260 (74%) files belonged to HIV positive people between the ages of 20-40 years who fall within the economically viable strata of society.

This finding confirms a previous study which showed that a typical HIV positive woman is usually young, of child bearing age and more economically compromised than her male counterpart (Matlin & Spence, 2000; Nicastri, et al., 2005; Edward, 2006 Solomon, et al., 2008.). More women are afflicted by HIV infection, are young and economically compromised than their male counterparts.

6.2.3 Race distribution

It was found that 95% of population of the study were African. The finding is in keeping with Census 2001, which declared Africans to comprise 73% of the South African population.

6.2.4 Relationship status

Most of the participants were single (59%). Some patients were classified single (6%), but had live-in partners.

6.2.5 Residential area

Just over a third of the research population (36%) was staying within the recommended cluster area of the clinic. The implication of this was that patients were spending a long time on the road to get to this clinic thereby incurring costs for transportation, which is a hidden cost despite the fact that the ART regimen is free. Staying far from the ART site could contribute to 'lost to follow-up'.

6.2.6 Distance of residence from ART site

The finding in this variable is directly related to the finding in the last paragraph. Primary Health Care guidelines recommend that patients attend the clinic within a five kilometre radius from their residence. In this study the finding showed that 116 (33%) of the research population lived within and up to a five kilometre radius from the ART site.

6.2.7 Level of education

More than half of the research population (54%) had secondary education and the missing data counted for about a fifth (21%) of the total research population. Therefore, the research population in this study can be regarded as averagely educated.

6.2.8 Dependants

Regardless of their HIV status, 70% of the study group, which comprised mostly of women, had dependants for whom to care. There was data missing for 17% of the research population, which meant that the number of HIV positive people with dependants could be higher.

6.2.9 Disclosure of HIV status

80% of 2007 research population and 81% of the research population had disclosed their HIV status to either family members, social support groups and/or significant others.

6.2.10 To whom has the patient disclosed his/her HIV status?

Information in the patients' files showed that 81% of the 2007 HIV positive patients disclosed their HIV status to family members, friends and/or significant others. Fewer HIV positive people (58%) disclosed in 2008.

The statements "Disclosure of HIV status" and "To whom has the patient disclosed his/her HIV status" are very crucial to social support. Research has proven that there is better compliance to ART when HIV infected people have support, either through disclosure to family members or through an association with a support group (Edwards, 2006); community support has been associated with lower death rates and better health outcomes (Zachariah, et al., 2006).

6.2.11 History of substance abuse

The finding in this research study was contrary to findings in previous research that one of the strong predictors of non-adherence to ART, which could lead to 'lost to follow-up', is alcohol (Lucas, Gebo, Chaison & Moore, 2002). Alcohol is presumed to increase risk taking and diminish personal control thereby encouraging risky behaviour,(Mbulaiteye, Ruberantwari, Nakiyingi, Carpenter, Kamali & Whitworth, 2000), but the majority of patients in this study (76%) did not abuse alcohol. Only 3% of the total population admitted to alcohol abuse.

6.2.12 Employment status

54% of the research population were unemployed as compared to 37% of the research population who were employed. Even when ART is given free, unemployed patients might have difficulty with transport and other hidden costs required by the clinic, thereby missing scheduled visitations and medication collection. This might eventually lead to 'lost to follow-up' (Hardon, et al., 2006).

6.2.13 WHO Staging

The finding in this study showed that the majority (65%) of the research population were initiated on the ARV therapy when they were already in the third or fourth WHO stages; the situation is similar for 2008 with the majority of the research population (61%) accessing ARVs at similar stages.

The South African government's policy has changed from accessing ARVs when the patient's CD4 count is 400 as compared to 2007 and 2008 when ARVs could only be offered to people with CD4 counts below 200, unless in exceptional cases. It seemed that HIV positive patients in this study were already very ill by the time they received medical attention at the clinic. There were no appreciable changes in the staging by the time of 'lost to follow-up'.

6.2.14 Type of dwelling

The information in the patients' files revealed that 75% of the research population lived in formal dwellings ranging from houses to rooms or apartments; only 13% of the research population lived in informal dwellings, which can be referred to as slums.

This finding is in contrast with what some of the early studies found, i.e. that HIV prevalence is higher in slums as compared to non-slum areas, which are generally overcrowded and noted for poor living conditions (UNAIDS, 2006; ICAD,2010).

This finding supported previous findings that the type of dwelling that an HIV positive person is staying in is not a determinant of the phenomenon of 'lost to follow-up'.

6.2.15 Patient accompanied/supported

Social support is presumed to help HIV positive people adhere to treatment thereby reducing 'lost to follow-up'. The finding of this study showed that although it was indicated in the patient files that about a third of the study popuation had support, almost 40% of the patients attended the clinic without company. When made use of appropriately, supporters help to sure that patients adhere to treatment and reduce the chances of 'lost to follow-up'.

6.2.16 Financial support

More than half of the research population supported themselves financially or were financially supported by significant others such as family or friends. Financial capability determined how regularly the HIV positive patients kept their appointments at the clinic, which were to maintain treatment in order to achieve a good health outcome.

6.2.17 ART regimen and compliance

Patient records revealed that only 9% of the research population changed the ART regime by the time they were 'lost to follow-up' and in 2008, 18% of the 168 patients' files revealed that there was a change in the ART regime. The percentage of these who changed regime is small and insignificant to attribute regime change to 'lost to follow-up'.

6.2.18 Duration of ART treatment

Three categories were used to classify duration of ART treament and thesewere, 6-12 months, 12-18 months and 18 months and above.

The finding was that 60% of the HIV positive patients were on ART for less than and up to 12 months. 13% of HIV positive patients were on treament for over 12 months and up to 18 months and only 9% were on treatment for longer than 18 months, correlating with a previous research study that the first two years on ART is critical with regards to adherence (Rosen, et al., 2007).

The results of this study painted a worse sceanrio than the findings in the research study of 13 Sub-Saharan African countires by Rosen, et al., (2008). While the finding of Rosen, et al., stipualted that 15% of the group on ART will be 'lost to follow-up' by the end of 12months, the finding of this study showed that 60% were 'lost to follow-up' and only 9 % of the study popuation were on ART treatment for 18 months and longer.

6.2.19 TB co-infection with HIV

Other studies have mentioned that infection with TB is amongst the highest HIV related opportunistic infections in South Africa (Kim & Farmer, 2006; Rosen, et al., 2007). However, the findings in this study showed that 28% of the research population was co-infected with TB, but that for 75 (21%) patients their co-infection status was unidentified.

6.2.20 Differentials in body weights after the initiation of ART

More HIV positive people gained weight than lost weight after the commencement of ART. 51% of the research population gained weight before being 'lost to follow-up' while 39% of the research population lost weight during ART. The status of body weight could not be determined in 11% of the population either because of missing values or because the patient was too ill to be weighed. The weight that was gained varied from as little as 0.07kg to as much as 25kg, while the weight loss also varied from as little as 0.3kg to as much as 24.9 kg.

6.2.21 Missed appointments:2007-2008

Evidence in the patients' file records showed that 288 HIV positive patients did not miss appointments before they were 'lost to follow-up'. Patients are assumed to be 'lost to follow-up' even after one month.

6.3 Sub-proposition 1: Sex, Age and financial capability

Findings on **Sex, Age,** and **Age distribution** tested the proposition that:

It is likely that there are a greater number of HIV positive female patients and that they are likely to be more economically compromised than their male counterparts.

Findings of the study concurred with this proposition since it showed that 53% of the research population was women between the ages of 19-40 years. This group was two and a half times more economically compromised than their male counterparts in the same age category (21%).

6.4 Sub-proposition 2: Social support

The statement**s** "Disclosure of HIV status" and "To whom the patient has disclosed his/her HIV status" tested the proposition that**:**

HIV positive patients with social support through disclosure to members of families, spouses or support groups tend not to be 'lost to follow-up' because of the support that helps them adhere to ART treatment.

The findings in the study regarding social support are in agreement with this proposition. Previous research studies have proven that there is better compliance to ART medication and better health outcomes because of the support of significant others in the lives of HIV positive people. Patients are more likely to remain on medication due to the encouragement received from the support base thereby reducing the chance of patients being 'lost to follow-up' (Collini & Obasi, 2006; Edwards, 2006 & Zachariah, et al., 2006).

6.5 Sub-proposition 3: Change in regimen

The statement "ART Management and Compliance" tested the proposition that:

It is likely that patients who have had an adverse reaction to ART medication and/or a change in regimen will eventually stop taking the medication and be 'lost to follow-up'.

This study found out that only a small proportion (9%) of the research population changed their regimen during the course of ART treatment. The proportion of those who changed

regimen is insignificant to have an impact on ‘lost to follow-up’ since a larger number did not change regimen and were still ‘lost to follow-up’ refuting the proposition.

A previous research study attributed change of regime to adverse reaction of ART, which might lead to discontinuation (Zachariah, et al., 2006; Robbins, et al., 2007; Timothy, et al., 2008). However, this did not seem to be the case in this study due to the small number of HIV positive patients that actually changed their ART regime.

6.6 Sub- proposition 4: Type of residence and distance from ART site

The statements “Type of dwelling” and “Distance from ARV site” tested the proposition that:

It is likely that patients who live in informal residences and/or live more than five kilometres from the ARV site are more likely to be ‘lost to follow-up’ due to distance and other the socio-economic factors in the area of residence.

The finding in this study showed that the type of dwelling does not affect attendance at the clinic and therefore cannot be attributed to 'lost to follow-up’, thus refuted the first section of the proposition about informal residence.

However the second part that dealt with distance of more than five kilometres from the ARV site correlates with findings in previous studies that an unemployed HIV positive person living five or more kilometres away may find it difficult to attend clinic visitations and medicine collections due to lack of funds for transport, which could lead to ‘lost to follow-up’ (UNAIDS, 2006; ICAD, 2010).

6.7 Sub- proposition 5: Abuse of alcohol

The statement “History of substance abuse” tested the proposition that:
It is likely that patients who abuse alcohol as a coping mechanism will be ‘lost to follow-up’.

Only 3% of the research population in this study admitted to alcohol abuse refuting findings in other research that HIV positive people use alcohol as a way of dealing with stress (Mbulaiteye, et al., 2000; Arnsten, et al., 2002; Kalichman, et al., 2007) and that alcohol abuse accelerates the progression of HIV due to its adverse effect on cognitive functions, which might lead to an increase in 'lost to follow-up'. In the case of the study other factors and not alcohol could explain the reason for being 'lost to follow-up'.

6.8 Implications of the findings

Explaining the characteristics of HIV positive people who are 'lost to follow-up' is not easy to achieve because the findings showed that not all the variables tested could explain 'lost to follow-up'.

Some of the findings align with previous research work ("age", "sex", "gender", "financial capability with regards to females" and "distance of residence from ART site", "social support" and period on ART treatment before 'lost to follow-up').

Literature on "HIV and alcohol" is vast and all researchers seem to agree that a lot of HIV positive people abuse alcohol as a way of managing stress. The opposite was found in this study. Only 6% of the research population confirmed that they abuse alcohol. Another variable that made an impact is the statement on the "Type of dwelling". Previous studies of this phenomenon indicated that compliance is a challenge for HIV positive people living in informal housing (slums), however, the opposite was found in this study. Most of the HIV positive people in this study lived in formal residences.

Other variables that produced different results contrary to the expected were in areas such as "Change in ART regimen", "level of education", and general "financial capability".

The findings of the study concurred with two of the sub-propositions:

It is likely that there are a greater number of HIV positive female patients and that they are likely to be more economically compromised than their male counterparts.
; and

HIV positive patients with social support through disclosure to members of families, spouses or support groups tend not to be 'lost to follow-up' because of the support that helps them adhere to ART treatment.

The finding also partially agrees with a third one:

It is likely that patients who live in informal residences and/or live more than five kilometres from the ARV site are more likely to be 'lost to follow-up' due to distance and other the socio-economic factors in the area of residence.

Because while it was true that a five kilometre distance from the ART site to the patient's residence could be a contributing factor to 'lost to follow-up' "type of dwelling" is not associated with 'lost to follow-up'.

However, the findings of the study refuted two of the propositions:

It is likely that patients who abuse alcohol as a coping mechanism will be 'lost to follow-up'.

HIV positive patients with social support through disclosure to members of families, spouses or support groups tend not to be 'lost to follow-up' because of the support that helps them adhere to ART treatment.

The two main objectives of the study were:

- To determine the demographic profile and socio-economic profiles such as age, sex, race, marital status, residential area, educational levels and employment status of patients that are 'lost to follow-up'; and
- To identify how far into the treatment period HIV infected people default on ART treatment.

Both objectives of this study were met. The finding in this study could not answer the section of the research questions that enquired:

- *What causes HIV positive people to be 'lost to follow-up' during the course of ART regimens given the fact that the treatment is available and obtainable free of charge in public health facilities*?

There was an attempt in the findings of the study to answer the second and third sections:

- *Will knowing the characteristics of HIV positive patients and putting measures in place be sufficient to mitigate against the phenomenon of 'lost to follow-up'? Are socio-economic factors determinants of 'lost to follow-up' in HIV positive people?*

6.9 Conclusion

The results in the preceding chapter were interpreted in this chapter. Findings indicated that some variables could explain 'lost to follow-up', but most could not. Explanation on the characteristics of HIV positive people was not easy to achieve due to changes in the dynamics. The conclusion and suggestions for further research is presented in the next chapter.

Chapter 7

Conclusion and suggestions for further research

7.1 Introduction

This chapter concludes the research survey. Explanations, significance and implication of the findings in the light of the purpose for which the research was undertaken will be stated. Suggestions for further research that may appear in the light of the findings will be offered. Findings regarding 'lost to follow-up' in a different setting will be mentioned with recommendations.

7.2 Comparison with other studies

The study of Rosen, et al (2007) revealed that Africa has only managed to retain 60% of its patients on ART at the end of a two-year period, with 'lost to follow-up' being the main reason of the attrition followed by death. However, it was mentioned that better patient tracing procedures, better understanding of 'lost to follow-up' and early initiation of ART are required for better retention on ART.

I concur with the idea that benchmarking should be done at the centre/facilities that manage to keep a larger percentage of the patients on treatment and copy this as good practise in facilities such as ours (Rosen, et al., 2007; Dala,l et al., 2008).

Setting up of standards and policies will help management to assess the quality of services provided at the clinic. Peer review visitations to other well performing HIV/AIDS clinics will help in standardising procedures in the clinics and make the management constantly aware of quality services, especially good clinical record keeping. As more patients come to the clinic there has to be a more effective and efficient tracking system to follow up on 'lost to follow-up'.

Information in the patients' files showed that many patients (60%) that participated in the study were unemployed. The counsellors should be provided with dedicated telephone lines for follow-ups on patients in order to be in constant communication at all times.

Home visits are expected by the social workers but there is no transportation to perform this duty. Where it is too expensive to have a dedicated vehicle for the clinic, the hospital must provide transportation for the social workers in order to effectively conduct home visits.

7.3 Limitation of the study

The analysis had several limitations:

- The data was retrieved from a clinic where the educational competence of the counsellors clerking the patient and writing down patient's details was substandard, and varied.
- Voluntary relocation of patients to other facilities could not be determined because of poor tracing methods, although patients classified as 'lost to follow-up' might be receiving treatment somewhere else.
- A face-to-face data collecting system might have produced a clearer picture because confusing statements could have been clarified and thereby reduced the quantity of missing values.
- The most significant limitation is the fact that there was no control group. Having a control group could have added further insight into why patients were 'lost to follow-up'. It also would have been easier to compare the similarities in the characteristics of both the control group and the research subjects in order to arrive at more conclusive results.

7.4 Recommendations

The hospital does not have a proper patient tracking mechanism in place. Essential resources, vehicles and staff are not enough and social workers need transport in order to follow-up on patients or undertake visitations.

Findings of this research found that characteristics of HIV positive patients who are 'lost to follow-up' do not have any socio-economic boundaries and this should be kept in mind when looking for solutions. Intervention must be socially and culturally acceptable within the norms of the target population and must cater for the differences in educational/literacy levels of patients. Side effects of medication should be monitored.

At every visitation, confirmation of contact details should be updated.
Human resource challenges should be addressed and preferably good quality staff should be employed. Information gathering is as good as the person who captures it.

The relationship between government and NGOs should be reviewed and streamlined to include Service Level Agreements (SLAs) with institutions over and above the Memorandum of Understanding (MoU) with the national Department of Health for better control by the hosting institutions. Uniform information should be gathered from all patients at all times, and in-house service workshops could solve this problem.

In addition, providing ARV at more clinics and at regulated and agreed standards will go a long way to stop patients travelling long distances to the clinics for medication. Also, the provision of a multiple supply of medication e.g. three months for stable patients will go a long way in reducing monthly transportation costs and minimising financial burdens.

The research questions:
"*What causes HIV positive people to be 'lost to follow-up' during the course of ART regimens given the fact that the treatment is available and obtainable free of charge in public health facilities*? *Will knowing the characteristics of HIV positive patients and putting measures in place be sufficient to mitigate against the phenomenon of 'lost to follow-up'? Are socio-economic factors determinants of 'lost to follow-up' in HIV positive people?"* were only answered in part.

The variables showed that the two strongest possible causes for 'lost to follow-up' were unemployment and the distance of residence from the ART clinic site. We were not able to adequately answer the above research question in this particular study.

What are the reasons why some patients were 'lost to follow-up' when others in the same circumstances were not? This question approached from a different angle may best be answered through further research. Perhaps following up the 'lost to follow-up' cases through a Proper Patient Tracking System and having face-to-face interaction with those who are 'lost to follow-up' could enrich the findings.

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Appendix 1: World Health Organisation Adults and AIDS Staging System
Source: 2005 HIV and AIDS policy guidelines- Department of Health

Stage 1
1. Asymptomatic
2. Persistent generalized lymphadenopathy
3. Acute retroviral infection (sero-conversion illness) and /or performances Scale 1: asymptomatic, normal activity.

Stage 11
4. Unintentional weight loss <10% of body weight
5. Minor mucocutaneous (e.g. seborrhea, prurigo, fungal nail infections, oral ulcer, angular cheilitis)
6. Herpes zoster within the last five years
7. Recurrent upper respiratory tract infection (e.g. bacterial sinusits, URTI), and/or performance Scale2: symptomatic, normal activity.

Stage111
8. Unintentional weight loss> 10% of body weight
9. Chronic Diarrhoea>one month
10. Prolonged fever> one month
11. Oral candidacies
12. Oral hairy leukoplakia
13. Pulmonary TB within the last year(PTB)
14. Several bacterial infection (pneumonia, pyomyositis)
15. Vulvovaginal candidiasis>one month /poor response to therapy and /or performance Scale 3: bedridden< 50% of the day during the last month.

Stage 1V
16. HIV wasting (8+9 or 10)
17. *Pneumocystis carinii* pneumonia (PCP)
18. CNS toxoplosmosis (Toxo)
19. Cryptosporidiosis plus diarrhea>one month
20. Isosporiasis plus diarrhea
21. Cryptococcosis-non pulmonary
22. Cytomegalovirus infection other than the liver, spleen, or Lymph node (CMV)
23. Herpes simplex infection; visceral or > one month mucocutaneous (HSV)
24. Progressive multifocal leucoencephalopathy (PML)
25. Disseminated mycosis (i.e. histoplasmosis, coccidiomycosis)
26. Candida oesophageal/tracheal/pulmonary
27. Atypical mycobacteriosis disseminated (MOTT)
28. Non-typhoidal Salmonella septicaemia
29. Extra-pulmonary tuberculosis(ETB)
30. Lymphoma
31. Kaposi's sarcoma(KS)
32. HIV encephalopathy (ADC)
33. Invasive cervical carcinoma and/or performance Scale 4: bedridden>50% of the day during the last month.

APPENDIX 2: The Counselling Schedule currently used at the ART Clinic of TDH for Treatment Failure and Defaulters – October 2008

DR. Referring: …… Date:
……
(DR. PLEASE COMPLETE SECTION 2)

REASON…….

1**. IDENTIFICATION**					
PATIENT NAME:					
ADDRESS:					
PHONE NR:					
2**. TREATMENT FAILURE (Completed by Medical Dr/Professional nurse)**					
DATE INITIATED:					
ARV MEDICATION (REGIMEN)			1	2	3
2.1 VIROLOGICAL FAILURE			YES	NO	
VIRAL LOAD HISTORY					
DATE	VALUE	DATE	VALUE	DATE	VALUE
2.2. IMMUNOLOGICAL FAILURE		YES		NO	
CD4 COUNT HISTORY					
DATE	VALUE	DATE	VALUE	DATE	
EXPLAIN NEW/RECURRENCE OF OLD SYMPTOMS					
3. LOW ADHERENCE(COUNSELLORS)					
MISSED DOSES/DAYS		YES		NO	
LATE DOSES		YES		NO	
STOPPED ART		YES		NO	
4. REASON FOR LOW ADHERENCE					
4.1.PSHYCHOLOGICAL					
STRESS/DEPRESSION		YES		NO	
NOT MOTIVATED		YES		NO	
BILL BURDEN		YES		NO	
FORGETTING		YES		NO	
4.2. SOCIAL					
DEATH IN FAMILY		YES		NO	
RELATIONSHIP PROBLEMS		YES		NO	
PERSONAL PROBLEM		YES		NO	
STIGMA		YES		NO	

ALCOHOL	YES	NO
FINANCE/MONEY	YES	NO

TRANSPORT PROBLEMS	YES	NO
EMPLOYMENT	YES	NO
KEPT APPOINTMENTS	YES	NO
LOST FILLS	YES	NO
ABSTAIN	YES	NO
FAITHFUL	YES	NO
CONDOMIZE	YES	NO
4.3 BIOLOGICAL		
SIDE EFFECTS	YES	NO
HOSPITALIZED	YES	NO
PREVIOUSLY ART EXPOSRE-PMTCT	YES	NO
IF PREGNANT PLEASE ANSWER		
PLANNED THE PREG	YES	NO
DISCLOSED TO SEXUAL PARTNER	YES	NO
CONDOMIZED	YES	NO
MARRIED/STABLE RELAT	YES	NO
DO YOU CONSIDER ABORTION	YES	NO
4.4.ART STOPPED	**YES**	**NO**
4.4.1. STOPPED BY DR	**YES**	**NO**
SIDE EFFECTS	YES	NO
TOXICITY	YES	NO
NO SUPPRESSION OF VIRUS	YES	NO
CONTRAINDICATION	YES	NO
OTHER REASONS		
4.4.2 STOPPED SELF	**YES**	**NO**
SIDE EFFECTS	YES	NO
FELT BETTER	YES	NO
MONEY/GRANT STOPPED	YES	NO
CLINIC FRUSTRATION	YES	NO
PILL FATIGUE	YES	NO
FAMILY PROBLEMS	YES	NO
CHURCH	YES	NO
EMPLOYER	YES	NO

OTHER MEDICATION USED	**YES**		**NO**
TB	YES	NO	
EPILEPSY	YES	NO	
TRADITIONAL MEDICNE	YES	NO	
HERBS	YES	NO	
OTHER SPECIFY	YES	NO	
5. CHECK ADHERENCE ISSUES			
KNOWLEDGE	GOOD	MODERATE	INSUFFICIENT

ABOUT HIV/AIDS/ARV			
MOTIVATION	GOOD	MODERATE	INSUFFICIENT
COPING SKILLS	GOOD	MODERATE	INSUFFICIENT
PERSONALITY	GOOD	MODERATE	INSUFFICIENT
COMMUNICATION	GOOD	MODERATE	INSUFFICIENT
FINANCIAL SITUATION	GOOD	MODERATE	INSUFFICIENT
FOOD SECURE	GOOD	MODERATE	INSUFFICIENT
6. INFORMATION REGARDING ARV (Tick if explained to patient)			
REGIMEN 1A:	YES	NO	
3TC (Lamivudine)	MORN/EVEN	SAME TIME EVERYDAY	NONE SERIOUS
D4T (Stavudine)	MORN/EVEN	SAME TIME EVERY DAY	NAUSEA: DIARRHOEA
EFV(Efavirenz/Stocrin)	EVENING	BEFORE BEDTIME	DROWSY: NIGHTMARES
REGIMEN 1B:	YES	NO	
3TC (Lamivudine)	MORN/EVEN	SAME TIME EVERYDAY	NONE SERIOUS
D4T (Stavudine)	MORN/EVEN	SAME TIME EVERY DAY	NAUSEA: DIARRHOEA
Nevirapine	MORN/EVEN	½ TAB FOR 2 WEEKS	RASH,MOUTH SORES; JAUNDICE,VOMITING
Regimen 2:	YES	NO	
	DOSE	DETAILS	SIDE-EFFECTS
AZT (zidovidine)	MORN/EVEN1	AFTER MEAL	HEADACHE
DDI(diagnosing)	MORNING	EMPTY STOMACH:2 HOURS BEFORE OTHER 2	GASTRIC IRRITATION
KALETRA	MORN/EVEN3	AFTER MEALS	DIARRHOEA
6.1 DISCUSS PROBLEMS WITH DRUGS			
PILL BURDEN	YES	NO	
MEALS AND PILLS DIET RESTRICTIONS	YES	NO	
FRIDGE,STORAGE AND PILLS	YES	NO	
EXERCISE	YES	NO	
ALCOHOL	YES	NO	
OTHER MEDICATION	YES	NO	
7. ADHERENCE STRATEGIES(how to remember)			
MEDICINE CONTAINERS	YES	NO	
BUDDY (WHO)	YES	NO	
CELL PHONE /ALARM	YES	NO	

DIARY CHART	YES	NO	SUPPLY THE DIARY CHART
8. SUMMARY			
9. RECOMMENDATION:			
SIGNED Counsellor			
10. FINAL RECOMMENDATION SOCIAL WORKER			

…… ……

Signed: Social Worker Date

APPENDIX 3: Sheet of the variables for the review of the records of HIV positive individuals who defaulted on ART at Tshwane District Hospital (Revised Data Collecting Tool for the Research Study)

1. IDENTIFICATION						
RESEARCH IDENTIFICATION:						
RESIDENTIAL AREA:						
GENDER	MALE:			FEMALE:		
AGE						
RACE	AFRICAN	WHITE	COLOURED	INDIAN	OTHERS	
RELATIONSHIP STATUS	MARRIED	MARRIED BUT LIVING WITH BOYFRIEND/GIRLFRIEND	SINGLE	SINGLE BUT STAYING WITH A PARTNER	COHABITING	WIDOWED BUT LIVING WITH BOYFREND/GIRLFRIEND
WIDOWED	SEPARATED	SEPARATED BUT LIVING WITH A PARTNER	QUESTION NOT ASKED	SEPARATED FORM PARTNER	PARTNER	
LEVEL OF EDUCATION	NO EDUCATION	PRIMARY	SECONDARY	TERTIARY	NOT SPECIFIED	
ANY DEPENDANT		YES	NO	NOT STATED		
DISCLOSURE OF HIV STATUS		YES	NO			
DISCLOSURE OF HIV STATUS TO:	FAMILY MEMBER	SUPPORT GROUP	FRIENDS/BUDDY	OTHERS		
	NOT YET DISCLOSED	QUESTION NOT ASKED	NOT STATED	BOYFRIEND/GIRLFRIEND/SPOUSE		
THERE IS HISTORY OF ABUSE	ABUSE	SMOKING	DRINKING	SMOKING & DRINKING	SNUFF & SMOKING	
	QUESTION NOT ASKED	NO ABUSE	MODERATE			
2. EMPLOYMENT HISTORY						
UNEMPLOYED	EMPLOYED/	SELF EMPLOYED	QUESTION NOT ASKED	PRISONER		
SOCIAL DISABILITY GRANT	STUDENT	PIECE JOB				
3.TREATMENT HISTORY						
3.1MEDICAL HISTORY /CLINICAL FEATURES ON 1ST VISIT TO CLINIC						
3.2 WHO STAGING ON 1ST VISIT						
3.3 MEDICAL HISTORY /CLINICAL FEATURES ON LAST VISIT TO CLINIC						
3.4 WHO STAGING ON LAST VISIT						
3.5 START WEIGHT(BODY WEIGHT AT F1RST VISIT						
3.6 START WEIGHT(BODY WEIGHT AT LAST VISIT						
3.7 LIVING CONDITION						
4. RESIDENTIAL AREA						
5. TYPE OF DWELLLING	**HOUSE**	**HOME**	**FLAT**	**ROOM**	**SHACK**	
SHELTER/HOPSICE	**QUESTION NOT ASKED**	**NOT STATED**	**STAYING ON THE STREET**	**NOWHERE TO STAY**	**PRISON**	
6.. MEDICATION HISTORY						
6.1 COMPLIANCE WITH ART MANAGEMENT IS BY	CELL PHONE	PILL BOXES	CLOCKWATCH	SELF	BUDDY	
	PILL DIARY	CELLPHONE/CLOCKWATCH	NOT AVAILABLE	CAREGIVERS	QUESTION NOT ASKED	
PATIENT WAS ACCOMPANIED/SUPPORTED BY:	FAMILY MEMBER(S)	OTHERS	CAME ALONE	FRIENDS/ OTHERS	BOYFRIEND/GILFRIEND/SPOUSE	

DRUG STORAGE: DOES THE PATIENT HAVE ACCESS TO A FRIDGE TO STORE MEDICATION?	(1)YES	(2)NO	(3) QUESTION NOT ASKED	ORIGINAL FILE LOST			
WHO IS SUPPORTING PATIENT FINANCIALLY :	(1)SELF	(2)FAMILY MEMBER	(3)SOCIAL GRANT	(4) OTHERS	(5) BOYFRIEND/GIRLFRIEND/SPOUSE	(6) QUESTION NOT ASKED	(7) NO-ONE
REASONS FOR REFERRAL							
DATE OF COMMENCEMENT OF ART AT TSHWANE DISTRICT HOSPITAL							
BASE LINE CD 4 COUNT							
BASE LINE VIRAL LOAD		**BASELINE LOG VALUE**					
TYPE OF REGIMEN		**NO OF MONTHS ON ART TREATMENT**					
ADHERENCE SUPPORTER	SIBBLING (1)	PARTNER/LOVER/ SPOUSE (2)	FRIENDS(3)	OTHERS (4)	NO-ONE (5)	QUESTION NOT ASKED(6)	
	FAMILY MEMBER(7)	NO SUPPORT(8)	CARE GIVER(9)	NOT AVAILABLE (10)			
DATE OF FIRST VISIT TO THE CLINIC							
DRUG AT INITIATION	(1)d4T/3TC/efavirenz	(2)D4t/3TC/NVP	(3)AZT/ddl/ritonavir	(4)d4T/NVP/Efv	(5) 3TC/NVP/AZT	(6)AZT/D4T/Efv	
	(7)Efv/NVP/AZT	(8)itonaivir/NVP/Efv	(9)d4T/3TC/AZT	(10) Not available	(11)3TC/Zerit /viramune	(12)3TC,4DT&Kaletra (13) AZT	
DRUG ON THE LAST VISIT	(1) d4T/3TC/efavirenz	(2)D4t/3TC/NVP	(3)AZT/ddlritonavir	(4)d4T/NVP/Efv	(5) 3TC/NVP/AZT	(6)AZT/D4T/Efv	
(7)Efv/NVP/AZT	(8) Ritonaivir/NVP/Efv	(9)3TC/d4T/AZT	(10)3TC,4Dt &Kaletra	(11)AZT	(12)3TC/AZT /efv	(13) NOT AVAILABLE	
PATIENT'S RESPONSE TO TB INCIDENCE		(1) YES	(2) NO	(3)QUESTION NOT ASKED	(4)? TB		
DATE LAST SEEN AT THE CLINIC							
MISSED APPOINTMENT		YES	NO				

Appendix 4: World Health Organisation Adults and AIDS Staging System

SERVICE POINT INFORMATION

Province---------- District/Metro Council----------
Facility Name---------- Facility File Number----------Visit date:----------

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PATIENT INFORMATION
Name---------- Surname----------Date of birth:

Id no: sex: ☐☐ Adult(≥15yrs) ☐ Child (≥15yrs)) ☐

Citizenship----------
Postal Address: Physical Address
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Tel No:----------

If child, details of the next of kin ☐☐ Parent ☐ Guardian
Name:----------
Surname---------- Tel no:----------

EDUCATION

Not yet schooling	☐	Preschool	☐
No education	☐	Grade 0-5	☐
Grade 6-7	☐	Grade 8-1	☐

POPULATION GROUP

African	☐	Coloured	☐
White	☐	Indian	☐
Other	☐		

MARITAL STATUS (*patient or primary caregiver*) EMPLOYMENT (*patient or primary caregiver*)

Single	☐	Married	☐	Employed	☐
Separated	☐	Divorced	☐	Unemployed	☐
Widowed	☐	Cohabiting	☐	Self-employed	☐

IS PATIENT THE PRIMARY CAREGIVER RECEIVING ANY OF THE FOLLOWWING SOCIAL ASSISTANCE/GRANTS

Pension *Yes* ☐ *No* ☐ Child Support *Yes* ☐ *No* ☐
Disability grant Yes ☐ *No* ☐ Other (specify ----------

DATA CAPTURE

Name and surname of data capturer---------- Capture date----------