

**REASONS FOR DEFAULT FOLLOW-UP OF ANTIRETROVIRAL TREATMENT AT  
THEKGANANG ARV CLINIC**

**by**

**Tebogo Johanna Mathebula**

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**SUPERVISOR:**

**PROF. C.S.L. DELPORT**

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## **ABSTRACT**

### **REASONS FOR DEFAULT FOLLOW-UP OF ANTIRETROVIRAL TREATMENT AT THEKGANANG ARV CLINIC**

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**Tebogo Johanna Mathebula**

**Supervisor: Prof C.S.L Delport**

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HIV and AIDS pandemic have been declining in South Africa. HIV and AIDS affect individuals, families, organizations and the communities at large. While the roll out of the antiretroviral treatment (ART) has brought much excitement and hope to both patients and the health practitioners, it has also brought challenges (Maskew, Macphail, Menez & Rubel, 2007:853). In order for ART to be effective patients need to adhere to antiretroviral treatment, thus adherence is a critical component of ART. Patients who discontinue treatment are at high risk of illness and death because of AIDS related diseases or developing drug resistant virus. With a better understanding of the reasons for defaulting antiretroviral treatment interventions can be designed to improve adherence to antiretroviral treatment. Thus the purpose of this study was to explore the reasons why HIV and AIDS infected patients default antiretroviral treatment because adherence to ART is of utmost important.

Within the context of qualitative and applied research the researcher utilized the collective case study design. Semi structured interviewing was used as data collection method to elicit qualitative information on the reasons why patients default ART. The main research question that was put forward to all participants was: What are your reasons for defaulting ART?

The participants in this study were patients who have default their ART during 2012. By using systematic sampling fourteen participants from Thekganang ARV Clinic in Seshego District Hospital, Limpopo province, were selected to form a sample for this study. Some conclusions based on the findings were that:

The participants were knowledgeable about the basic facts of HIV and AIDS and they had a good understanding about the importance of adherence even though they defaulted their antiretroviral treatment. The use of ART may also be challenging to individuals. The findings of this study were that not all participants in the study experienced challenges with taking ART. Those who experienced challenges

included fear of disclosing HIV status, fear of stigmatization and physical challenges due to ill health.

Regarding the reasons for defaulting ART, participants' reasons for defaulting antiretroviral treatment were similar although some of the reasons applied to only one participant. Participants' reasons for treatment default were classified into socio-economic factors, patient related, psychological related and medication related factors. Socio-economic factors included shortage of food in the household and lack of money for transport to attend clinic appointments. Patient related factors included substance abuse, lost appointment cards, participants were too busy with personal issues and relocation to another area of residence. Psychological factors that contributed to non-adherence to treatment were depression and denial. Medical related factor voiced was that participant was too confused about the drug regimen.

Most participants were satisfied with the services in Thekganang ARV clinic although some participants raised concerns about staff attitudes and long queue. The findings will assist the hospital management and the clinic staff to make informed decisions about the management of defaulters in the clinic.

The study was concluded with the relevant recommendations to the ART facilities. The recommendations included implementation of the multi-disciplinary centred approach, establishing patient education programmes and on-going support services to patients who fail to adhere to treatment.

Future research studies should determine the prevalence of drug resistant HIV patients in the ART facilities and the development of a systematic method of capturing "lost to follow up" patients who pass away within hospitals.

#### Key words

HIV

AIDS

Default

Adherence

Antiretroviral treatment

Follow-up

## **OPSOMMING**

### **REDES VIR NALATIGHEID VAN OPVOLG BESOEKE VIR ANTIRETROVIRALE BEHANDELING BY THEKGANANG ART KLINIEK**

**by**

**Tebogo Johanna Mathebula**

**Toesighouer: Prof C.S.L. Delpont**

**Departement Maatskaplike Werk en Kriminologie**

**Graad: MMW in Werknemerhulpprogramme**

Daar is 'n daling in die getalle van MIV/VIGS gevalle in Suid Afrika. Die pandemie beïnvloed individue, families, organisasies en gemeenskappe. Met die aankondiging van die sukses van Antiretrovirale (ART) behandeling was daar heelwat opgewondenheid en hoop by pasiënte en mediese praktisyns, maar dit het ook heelwat uitdagings teweeg gebring (Maskew, Macphail & Rubel, 2007:853). Vir ART om suksesvol te wees, moet pasiënte gereeld die ART behandeling ontvang. Dit vorm 'n baie kritiese komponent van die sukses van die behandeling. Pasiënte wat behandeling staak, staan 'n groot kans om met ander siektes besmet te word of te sterf. Hulle staan ook 'n groot kans om virusse te ontwikkel wat behandeling teenwerk. As die redes vir nalatigheid van opvolg besoeke vir ART beter verstaan word, kan daar gewerk word aan intervensies om dit te verbeter. Die doel van die studie was dus om navorsing te doen oor die redes waarom MIV/VIGS pasiënte nalaat om te gaan vir die lewens belangrike opvolg besoeke.

Binne die konteks van toegepaste navorsing is daar van 'n kwalitatiewe benadering gebruik gemaak. Semi gestruktureerde onderhoude is gevoer om kwalitatiewe inligting oor die redes vir nalatigheid te verkry. Die belangrikste vraag wat aan al die respondente gevra was is: "Wat is die redes waarom jy nie ART opvolg besoeke nagekom het nie?"

Die respondente was 14 pasiënte van Thekganang ART kliniek in Seshego Distrik Hospitaal, Limpopo Provinsie wat na gelaat het om hul opvolg besoeke in 2012 na te kom. Sommige van die gevolgtrekkings was:

Die pasiënte het voldoende kennis oor HIV/VIGS en hulle verstaan die belangrikheid om gereeld die antiretrovirale behandeling te ontvang, maar hulle is nalatig. Alhoewel sommige pasiënte uitdagings ervaar tydens die gebruik antiretrovirale behandeling, het die studie egter bewys dat nie alle respondente probleme ondervind tydens die behandeling nie. Die respondente wat probleme ondervind het, het die volgende redes aangevoer: hulle is bang om hulle HIV/VIGS status bekend te maak, hulle is bang vir stigmatasie en laastens vir die fisiese uitdagings van die siekte op die liggaam.

Die redes vir nalatigheid met die antiretrovirale behandeling was dieselfde, behalwe vir een respondent. Die redes is geklassifiseer in sosio-ekonomiese faktore, pasiënt verwante faktore, sielkundige faktore en medikasie verwante faktore. Sosio-ekonomiese faktore het ingesluit 'n tekort aan voedsel en geld in die huishouding en die tekort aan geld om te betaal vir vervoerkostes om by die klinieke uit te kom. Pasiënt verwante faktore was die gebruik van verbode middels, verlore afspraak kaarte en die verskoning dat hulle te besig was met persoonlike sake of dat hulle verhuis het na ander dorpe. Sielkundige faktore wat bydra tot die nalatigheid was depressie en ontkenning. Mediese faktore was dat die pasiënt nie seker was oor die medikasie nie.

Die meeste van die respondente was tevrede met die diens wat hulle by the Thekganang ART Kliniek ontvang het, maar van hulle het gekla oor die personeel se houdings en die lang rye.

Die studie is afgehandel en aanbevelings is aan die ART fasiliteite gedoen. Die aanbevelings sluit in die implementering van 'n multi dissiplinêre benadering, die ontwikkeling van opvoedkundige programme en volgehoue ondersteuningsdienste aan pasiente wat nalaat om die behandelings te ontvang.

Verdere studies kan fokus op die metodes om volgehoue behandeling te verseker, en die ontwikkeling van metodes om data te versamel van pasiënte wat gesterf het weens die “lost to follow up” konsep.

### Sleutel konsepte

HIV

AIDS

Versuim

Vasklewe

Antiretrovirale behandeling

Opvolg

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## LIST OF ACRONYMS

- ABC - Lamivudine
- AIDS - Acquired Immune Deficiency Syndrome
- ART - Antiretroviral Treatment
- ARV - Antiretroviral
- AZT - Zidovudine
- CCMTS - Comprehensive Core Management and Support
- d4T - Stavudine
- DNA - Deoxyribonucleic Acid
- EFV - Efavirenz
- ELISA - Enzyme Linked Immuno Sorbet Assay
- FTC - Emtricitabine
- HAART - Highly Active Anti Retroviral Therapy
- HCT - HIV Counselling and Testing
- HIV - Human Immunodeficiency Virus
- LPV/r - Lopinavir
- MDGs - Millennium Development Goals
- MEMS - Electronic Monitoring System
- MTCT - Mother To Child Transmission
- OIs - Opportunistic Infections
- PCR - Polymerase Chain Reaction
- PHC - Primary Health Care
- PLWHA - People Living With HIV and Aids
- RNA - Ribonucleic Acid
- SASSA - South African Social Security Agency
- STIs - Sexually Transmitted Infections
- TB - Tuberculosis
- TDF - Tenofovir
- WHO - World Health Organization
- 3TC - Lamivudine

## CHAPTER ONE

### GENERAL BACKGROUND INFORMATION ON THE RESEARCH STUDY

#### 1.1 INTRODUCTION

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) constitute a major challenge in South Africa. The Department of Health (2010c:6) indicates that in many countries in Sub-Saharan Africa, including South Africa, the HIV epidemic poses one of the greatest health and developmental challenges. Meel (2005:149) postulated that the situation in South Africa was extremely serious and that the country had in absolute numbers the largest HIV population in the world: namely, five million. This was confirmed by the United Nations Programme on HIV/AIDS (UNAIDS), quoted by Van Dyk (2008:8), who declared in 2006 that South Africa's pandemic was one of the worst in the world showing no evidence of decline.

The United Nations on HIV /AIDS Global Report (2010:28) estimated that in 2009, 5.6 million people in South Africa were living with HIV. South Africa's epidemic remains the largest in the world. However, the overall growth of the global epidemic appears to have stabilized. Even in South Africa new indications show a slowing of HIV incidents (United Nations on HIV /AIDS Global Report, 2010:28).

According to the Department of Labour (2003:70), the following factors contribute to the severity of HIV and AIDS:

- Stigmatization and discrimination of people living with HIV and AIDS resulting in lack of openness. Despite the calls that HIV should be treated like any other chronic condition, some people are still discriminating against HIV positive people.
- Disrupted family and communal life.
- High levels of sexually transmitted infections.
- Widespread myths regarding HIV and the cures.
- Social and cultural practices.

According to the United Nations on HIV/AIDS Global Report (2010:7), increasing evidence definitively demonstrates that investments in the HIV response can lead to clear reductions in discrimination and stigma, help people in accessing information and services to reduce their risk of infection, and deliver the treatment, care and support that will extend and improve the lives of people living with HIV and AIDS. Although HIV is not a curable disease, it is a manageable disease and one important investment in managing HIV and AIDS is the use of antiretroviral drugs (ARVs). Highly Active Anti- Retroviral Therapy (HAART) allows many people with HIV to live longer, have a better quality of life and experience fewer illnesses related to HIV. The *Soul City Institute for Health and Development Communication* (2008:11) maintains that antiretroviral therapy (ART) prevents HIV from multiplying, which allows the body to heal and the immune system to improve functioning. If ART works successfully, the viral load decreases and the virus should become undetectable in the blood after six months of treatment. If the virus is undetectable, it does not mean that the patient is HIV negative. It means that HIV is present in the blood, but the level is too low to measure.

According to Van Dyk (2008:31), South Africa began the roll-out of antiretroviral drugs during 2004. Currently more than 5 million people are receiving HIV treatment. In 2009 alone, 1.2 million people received HIV treatment for the first time (United Nations HIV/AIDS Global Report, 2010:7). ART is a lifelong commitment that requires patients to adhere diligently to daily medication dosing schedules and to make frequent clinic visits for care (Miller, Ketlhapile, Rybasack-Smith & Rosen, 2010:48). However, Talam, Gatongi, Rotich and Kimaiyo (2008:74) indicate that getting patients to take ART drugs every day without fail for the rest of their lives is one of the biggest challenges to overcome.

Non-adherence to ART is perceived as a potential threat to the long-term success of HIV treatment programmes. Maskew, MacPhail, Menezes and Rubel (2007:853) indicated that patients who do not return for follow-up at clinics providing comprehensive HIV and AIDS care require special attention. Daniel, Oladapo, Ogundahunsi, Fagbenro, Ogun and Odusoga (2008:221) conducted a study in Sagamu, Nigeria. The purpose of this study was to determine the rate and reason for default from ART. In the study, 100 patients who defaulted treatment for at least six

months were traced to their place of residence with the address given on the clinic chart. The findings of the study revealed that of the 100 patients who had enrolled in the ART programme during the study period, 36% of the study population defaulted treatment, 18% had died and 46% were alive and well. The study showed that about a third of the study population had defaulted treatment during the two years of follow-up. The rate of default is high considering the grave consequences of treatment that will require patients to be on second line treatment which are difficult and expensive to manage (Daniel et al., 2008:223).

Talam et al. (2008:74) conducted a cross sectional study involving 384 HIV and AIDS patients attending Moi Teaching and Eldoret Hospital in Kenya. The data collection methods used was interviewer-administered questionnaires to patients and self-administered questionnaires by key informants, such as nurses selected by purposive sampling. The findings indicated that the overall adherence levels based on timing of taking ART was low for all respondents. In this study adherence to the clinic visit was substantially high, namely 93.5%, but it is evident that patients took home the total number of prescribed doses and yet did not take them at the scheduled time. However, it was apparently not possible to establish whether the patients took the drugs later (Talam et al., 2008:77). The findings that age, sex and marital status did not significantly affect adherence was similar to other studies elsewhere.

Health care providers are often frustrated with HIV-infected patients who do not adhere to ART. Maskew et al. (2007:853) conducted a study at Themba Lethu Clinic, Hellen Joseph Hospital, Johannesburg about lost to follow-up patients exploring the reasons for non-adherence. A group of 182 patients who missed follow-up appointments at the clinic were identified. Their files were examined to identify possible contributing factors and then patients were contacted telephonically and asked about their reasons for non-attendance. The study highlighted financial difficulty as the major obstacle to obtaining treatment. Death accounted for 27% of patients lost to follow-up.

Dalal, MacPhail, Mqhayi, Wing, Fieldman, Chersich and Venter (2008:101) conducted a retrospective analysis of all adult patients receiving ART at an urban

public clinic in Johannesburg, South Africa. Patients discontinuing follow-up for at least six weeks were identified and further studied and causes for treatment default were tabulated. The findings of the study was on 1631 adult patients studied, and 267 (16.4%) discontinued follow-up during the study period. Gender, ethnicity and age were not predictive of loss to follow-up. Of those discontinuing follow-up, 173 (64.8%) were successfully traced. Death accounted for 48% for those traced.

Strict adherence to ART is required to achieve therapeutic success in HIV management. Afolabi, Ijadunola, Fatusi and Olasode (2009:6) maintain that the consequences of low adherence are serious for the individual, public health and optimal use of limited health care resources. Non-adherence in patients on ART is the strongest predictor of failure to achieve viral suppression below the level of detection.

Owing to this problem, the researcher explored the reasons why HIV and AIDS patients default on treatment at Thekganang ARV Clinic, Seshego District Hospital, Limpopo Province. Thekganang ARV Clinic serves a diverse patient population from Seshego and the surrounding extensions, namely Moletjie and Mashashane areas. The target group for the study was HIV positive adult patients receiving ART in Thekganang ARV clinic. The participants were patients who have defaulted treatment during 2012. Dr Makweya (2011) raised his concerns about the high rate of defaulters in the clinic. He indicated the need for this study in order to identify the problem areas and to develop strategies to address the problem. The researcher is of the opinion that if the reasons for patients defaulting on taking prescribed medication could be explored, value could be added to the management of HIV and AIDS patients in the clinic. The findings will assist the hospital management and the clinic staff to make informed decisions about the management of defaulters in the clinic. The study was worth undertaking in order to explore HIV and AIDS patients' perspectives on the factors that hinder their ability to attain the desired levels of adherence to ART and to improve their adherence based on the research findings. The researcher was interested in pursuing the study based on her observations that many patients in the clinic are not adhering to their treatment.

## 1.2 PROBLEM FORMULATION

The South African National AIDS Council (2007:20) indicates that professional practitioners need to enable people who have HIV and AIDS to live healthy and productive lives by ensuring that they receive full packages of treatment and care. HIV and AIDS patients need to have access to treatment, care, nutrition and support. The Foundation for Professional Development (2009:149) mentions that for the successful management of the HIV and AIDS epidemic, it is imperative that the condition be treated and accepted as a chronic disease.

Any ARV treatment facility needs to be accredited before providing ART to patients. Thekganang ARV Clinic is accredited and provides a comprehensive package of HIV and AIDS services to patients. The services include the following:

- HIV counselling and testing (HCT).
- Regular CD4 counts and viral load monitoring.
- On-going support and counselling.
- Nutritional assessment and support.
- Treatment and prophylaxis for opportunistic infections (OIs).

At Thekganang Clinic, before patients begin ART, an ART readiness assessment is carried out to determine whether the patient is in a position to adhere to the treatment. An adherence checklist is utilized to guide the counsellors on the topics that need to be emphasized during the ART readiness assessment. Patients are educated about treatment regimens, side effects and the importance of adherence. However, problems still arise after the adherence assessment because high numbers of patients do not comply. Miller et al. (2010:48) indicate that patients who discontinue treatment are at high risk of illness and death because of AIDS-related conditions.

Professional Nurse Rametsi (2011), Head of Professional Nurses at Thekganang Clinic, confirms that there is a high rate of non-adherence among HIV- and AIDS-infected patients at the clinic. In terms of the regulations from the Department of Health, the clinic staff must be in a position to account for all the patients in the clinic. Some of the patients miss scheduled appointments for particular days and turn up

days later; other patients only return when they are sick. Van Dyk (2008:105) mentions that drug resistance can develop very rapidly with missed or inadequate doses of ART medication. Missing even a few doses in a week may lead to the development of drug resistance. Drug resistance refers to the ability of the disease causing germs such as viruses to continue multiplying despite the presence of ARVs that usually kills viruses. Thus, having a drug resistant virus is a challenge because ART will not function effectively in the reduction of the HIV viral load and restoring the functioning of the immune system.

According to Thekganang ARV Clinic records, a total number of 3725 HIV-infected patients missed their appointments for the period of 2012 to 2013. The number is slightly declining due to the number of patients that are referred to their local clinics. South African National AIDS Council (2007:23) states that the Department of Health must find and remove any barriers that prevent people from going for testing, treatment and care. The researcher is of the view that with a better understanding of the reasons why patients default on treatment, interventions can be designed to improve adherence. Regarding treatment compliance, Van Dyk (2008:105) mentions that adherence of 95% or more is critical to achieve viral suppression, delay treatment failure and subsequent development of resistance. This means that in one month, the patients must not miss more than three doses. Viral suppression occurs when ART reduces the amount of virus in the body in order to improve the functioning of the immune system.

The Foundation for Professional Development (2009:158) maintains that research should be conducted to investigate the reasons for non-adherence to ART. Outcomes from such research could determine ways to improve practice and could ultimately determine best practice in adherence counselling for that specific health facility and that community.

Owing to lack of knowledge regarding reasons why HIV- and AIDS-infected patients at Thekganang ARV Clinic default on their ART, the focus of this study was on an exploration of why patients default on treatment.

## **1.3 GOAL AND OBJECTIVES OF THE RESEARCH STUDY**

### **1.3.1 Goal of the study**

The goal of the study was as follows:

To explore the reasons why HIV- and AIDS-infected patients default on antiretroviral treatment at Thekganang ARV Clinic, Seshego District Hospital, Limpopo Province.

### **1.3.2 Objectives of the study**

In order to obtain the goal of the study the following objectives were formulated:

- to theoretically conceptualise HIV and AIDS as social phenomena with specific emphasis on antiretroviral treatment;
- to explore the experiences of HIV- and AIDS-infected patients regarding the services provided at Thekganang ARV Clinic;
- to determine the HIV- and AIDS-infected patients' level of understanding about HIV and AIDS treatment adherence;
- to establish what causes HIV- and AIDS-infected patients to default on antiretroviral treatment at Thekganang ARV Clinic; and
- based on the findings of the study, draw conclusions and make recommendations to increase HIV- and AIDS-infected patients' adherence to antiretroviral treatment at Thekganang ARV Clinic, Seshego District Hospital, Limpopo Province.

## **1.4 RESEARCH QUESTION**

Bak (2004:21) states that formulating a research problem in the form of a question is fruitful for giving the writing and reading direction. The research question must relate to the problem statement and outline the specific query that the researcher is seeking to answer.

For the purpose of the study, the following research question will guide the research study: **What are the reasons for HIV- and AIDS-infected patients defaulting on follow-up antiretroviral treatment at Thekganang ARV Clinic?**

## **1.5 RESEARCH METHODOLOGY**

The research approach for this study was qualitative in nature as the researcher aimed to explore the reasons why HIV- and AIDS-infected patients default on follow-up antiretroviral treatment at Thekganang ARV Clinic. The qualitative approach enabled the researcher to understand better and gain more information about the reasons for patients not adhering to their antiretroviral treatment (Henn, Weinstein & Foard, 2006:150).

The study was applied in nature because one goal of applied research is to address immediate problems facing the professional in practice. Neuman (2006:25) emphasizes that those doing applied research conduct a study to address a specific concern or to offer solutions to a problem the organization they are affiliated with has.

In this study the researcher used the collective case study design, since a collective case study design furthers the understanding of the researcher about a social issue or the population being studied (Fouche, 2005:272). A collective case study design is one in which the interest lies in studying multiple cases in a single research study. A number of cases are selected jointly to provide insight into a phenomenon, population or condition (Ellinger, Watkins & Marsick, [sa]:5).

In this study the population was “the entire set of people” (Bless, Higson-Smith & Kagee, 2006:98), namely all the registered HIV- and AIDS-infected patients (80) who defaulted on antiretroviral treatment at Thekganang ARV Clinic, Seshego District Hospital, Limpopo Province, during 2012.

In order to “obtain the richest possible source of information to answer the research question”, a sample of 15 participants was selected by using systematic sampling (Kumar, 2005:164; Neuman, 2006:230). The first participant on a compiled list of HIV- and AIDS-infected patients who defaulted on ART during 2012 was selected randomly, after which every second participant was systematically selected until a

total sample of 15 participants was reached. The challenge, however, with the research population was that most of the participants were deceased, physical addresses or contact details were incorrect and denying to take ART at Thekganang ARV Clinic.

The researcher applied semi-structured interviewing as a data collection method, because it allowed the researcher to obtain in-depth information about reasons why HIV and AIDS patients default on antiretroviral treatment at Thekganang ARV Clinic.

In this study the researcher used an interview schedule to guide the data collection process. A qualitative interview schedule may simply involve a series of headings or may have a few carefully worded questions which are usually open-ended to allow the respondents to elaborate (Barbour, 2008:115).

Analysis of qualitative data was done by means of thematic analysis. A detailed description of the research methods used in this study will be given in chapter three of this report.

## **1.6 LIMITATIONS OF THE STUDY**

The limitations of this study are presented below:

- Although valuable data was collected, findings could not be generalised to the whole population due to the small sample of participants who were interviewed. Further studies need to be conducted.
- Another limitation was that most of the participants on the compiled list passed away or their contact details and addresses were incomplete and this delayed the study.

## **1.7 DEFINITION OF KEY CONCEPTS**

### **1.7.1 HIV**

The Department of Labour (2003:vii) simplified HIV as the “Human Immunodeficiency virus that weakens the immune system and leads to AIDS”.

HIV is a virus that attacks the human immune system. The immune system protects gems from causing infections and makes a person sick (Van Dyk, 2008:4).

The researcher defines HIV as a human virus that affects the functioning of the immune system.

### **1.7.2 AIDS**

The Department of Labour (2003:vii) defines AIDS as “a syndrome that results from infection with HIV”.

AIDS is a disease caused by a virus called HIV. The illness alters the immune system, making people much vulnerable to infections and diseases (Van Dyk, 2008:4).

The researcher defines AIDS as the complete stage of HIV where in an individual will present with the manifestations of illnesses.

### **1.7.3 Adherence**

Maskew et al. (2007:853) simply defined adherence as “correct and timely dosing of prescribed medications”.

Delamater (2006:71) summarised adherence as to “stick firmly”. HIV medication adherence means “sticking firmly to an HIV regimen taking HIV medicines every day and exactly as prescribed”.

For the purpose of this study the researcher defines adherence as taking ART in a prescribed manner without missing doses.

### **1.7.4 Default**

Miller et al. (2010:49) define default as “being more than one month late for the next scheduled consultation or medication pick up”.

Daniel et al. (2008:222) define default as “failing to collect medication for more than six consecutive months after the date of the last attendance during the course of treatment”.

The researcher defines default as a situation in which the patient does not follow the treatment plan and does not return for follow-up comprehensive services for at least three months.

### **1.7.5 Treatment**

The Department of Labour (2003:vii) defines treatment as “steps taken to care for and manage an illness”.

Horny (2000:1277) defines treatment as “something that is done to cure an illness”.

For the purpose of this study, the researcher describes treatment as comprehensive services that are provided at Thekganang ARV Clinic to manage HIV and AIDS.

### **1.7.6 Antiretroviral treatment (ART)**

Medicine Net.com ([sa:1) defines ART as “treatment that suppresses or stops a retrovirus. One of the retrovirus is the human immunodeficiency virus (HIV) that causes AIDS”.

National Cancer Institute ([sa:1]) define ART as “treatment with drugs that inhibit the ability of the human immunodeficiency virus (HIV) or other types of retroviruses to multiply in the body”.

For the purpose of this study the researcher defines ART as treatment prescribed to HIV and AIDS patients in order to suppress the viral load and improve the functioning of the immune system.

## **1.8 DIVISION OF THE RESEARCH REPORT**

The contents of the research report are divided into four chapters as presented below.

### **Chapter One: General background**

The main emphasis in this chapter is on providing the rationale for the study and formulating the research problem. The chapter also focuses on the goal and objectives of the study, the research question, a brief description of the research methodology used in the study, limitations of the study, and definitions of key concepts.

### **Chapter Two: Literature study**

In this chapter the researcher undertakes a comprehensive literature study focusing on HIV and AIDS in a broader perspective, the necessity for antiretroviral drugs, and adherence. The researcher also defines the reasons for defaulting on ART from a theoretical point of view.

### **Chapter Three: Empirical study**

Chapter Three concentrates on the research methodology, as well as the empirical findings of the research study.

### **Chapter Four: Conclusions and recommendations**

The last chapter, based on the research findings, focuses on the conclusions and recommendations.

## CHAPTER TWO

### HIV AND AIDS AS A SOCIAL PHENOMENON WITH SPECIFIC FOCUS ON ANTIRETROVIRAL TREATMENT

#### 2.1 INTRODUCTION

AIDS, which is caused by HIV, is viewed as a deadly infectious disease. HIV is one of the biggest problems in the world and South Africa is experiencing an HIV and AIDS epidemic of enormous proportions. Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex and Marlink (2003:281) indicates that AIDS is the leading cause of death in Sub-Saharan Africa.

The Department of Labour (2003:65) mentions that the impact of the HIV and AIDS epidemic is significant, affecting all the spheres of life and all public and private sectors. However, the South African National AIDS Council (2007:5) emphasized the fact that HIV can be prevented but every effort must then be made to prevent the numbers growing. In this regard the Government of South Africa has a mandate to achieve the Millennium Development Goals (MDGs). The MDGs are eight international development goals with 21 measurable targets. One of the MDGs is to combat HIV and AIDS and other diseases (*Millennium Development Goals and mother and child Health*, 2010:9).

A range of co-ordinated government and civil society HIV and AIDS initiatives have strengthened national prevention and treatment care support efforts (*Millennium Development Goals and mother and child Health*, 2010:10). Currently one of the initiatives in South Africa is that all the accredited government health facilities are providing antiretroviral (ARV) services for HIV positive patients for free (Soul City Guidelines, [sa]:10). The majority of people in South Africa are aware that ARV is a treatment for HIV and that it needs to be taken for life. For the successful management of the HIV and AIDS epidemic it is imperative that the condition be treated and accepted as a chronic disease.

As the goal of the study is to explore the reasons why HIV- and AIDS-infected patients default on antiretroviral treatment, the focus of this chapter will be on

discussing the phenomenon of HIV and AIDS and the fundamental facts about HIV. The researcher will also discuss ARV treatment, the different types of regimens, and the importance of adherence to ARV treatment in the management of HIV and AIDS, as well as to explore the reasons why patients are defaulting ARV treatment. To be able to have a better understanding of HIV and AIDS as social phenomena it is imperative to describe these two concepts first.

## **2.2 DESCRIPTION OF THE CONCEPTS HIV and AIDS**

### **2.2.1 Human Immunodeficiency Virus (HIV)**

HIV is an acronym for Human Immunodeficiency Virus. *HIV management in the workplace* (2012:1) describes HIV as “the virus that causes Acquired Immune Deficiency Syndrome in human beings”. Furthermore it is stipulated that “this virus causes AIDS by weakening the body’s immune system until the body can no longer fight against common infections that healthy people’s immune system can defend against.” The Department of Labour (2003:vii) simplified HIV as the “Human Immunodeficiency virus that weakens the immune system and leads to AIDS”.

However, it is necessary to note two types of viruses that are associated with AIDS, namely HIV-1 and HIV-2 (Foundation for Professional Development, 2009:8). According to Woods (2007:14), most infections in Southern Africa are caused by HIV-1 which has many sub-types. The important subtype in Africa is subtype C. Subtype B is the most common subtype in the developed world.

Van Dyk (2008:4) indicated HIV is also known as a retrovirus because it is a reverse of other viruses. It can transform RNA into DNA and it can reproduce itself by becoming a parasite inside a living cell. The virus is unable to multiply outside a human cell. HIV can live in the body for many years and eventually causes AIDS.

### **2.2.2 Acquired Immune Deficiency Syndrome (AIDS)**

AIDS is an abbreviation for Acquired Immune Deficiency Syndrome. The Department of Labour (2003:vii) defines AIDS as “a syndrome that results from infection with HIV”. This means that AIDS is acquired, because it cannot be genetically inherited.

Van Dyk (2008:4) clearly indicates that AIDS is caused by a virus (HIV) which enters the body from outside. Immunity is the body’s natural ability to defend itself against infection and diseases. Deficiency is the weakening of the human immune system that leads to a failure to defend itself against infection, while syndrome is a collection of specific signs and symptoms that occur together.

## **2.3 EXTENT OF HIV and AIDS PANDEMIC**

HIV and AIDS has become one of the most destructive plagues in history. The deadly effects of HIV and AIDS are felt all over the world (Van Dyk, 2008:4). The HIV and AIDS pandemic may be characterized in three ways. The first is in terms of HIV infections based on the antenatal HIV prevalence. The second is in terms of the number of people who are sick with AIDS and die from AIDS-related illnesses. The last is in terms of the extent of stigma, discrimination, blame and collective denial in the country. AVERT HIV and AIDS ([sa]:1) mentions that the HIV and AIDS epidemic has become one of the greatest threats to human health and development. At the same time much has been learnt about the science of HIV and AIDS, as well as how to prevent and treat the disease. There is still no cure for HIV and AIDS, but HIV treatment has improved enormously since the mid-1990s.

### **2.3.1 HIV and AIDS pandemic worldwide**

In 2001 there were 19.7 million people living with HIV worldwide and the number of AIDS related deaths was 1.4 million (United Nations on HIV/AIDS, 2008:32). According to Motepe (2005:68) the number of people living with HIV worldwide increased from 19.7 million in 2001 to 39.4 million in 2005, while AIDS-related deaths were 3.1 million in the same year. However, it seems as if the number of people living with HIV decreased to 33.4 million in 2008 and the number of deaths

due to AIDS-related illnesses decreased to 2.0 million (United Nations on HIV/AIDS, 2009:7).

During the past decade, statistics have changed dramatically. The incidence of HIV infections fell by more than 25% from 2001 to 2011. Globally, 34 million people were living with HIV at the end of 2011. An estimated 0.8% of adults aged 15 and 49 years of age worldwide are living with HIV, although the burden of the epidemic varies between countries and regions (United Nations on HIV/AIDS, 2012:8).

### 2.3.2 HIV and AIDS pandemic in Sub-Saharan Africa

Sub-Saharan Africa remains mostly severely affected with nearly one in every 20 adults (4.9%) living with HIV and accounting for 69% of the people living with HIV worldwide. The most vulnerable group is between the ages of 15 and 24 years. Although HIV and AIDS seem to have stabilized in the rest of the world, Sub-Saharan Africa accounts for 71% of the adults and children newly infected in 2011 (United Nations on HIV/AIDS, 2012:11). Table 2.1 gives a clear summary of the HIV and AIDS epidemic in Sub-Saharan Africa for the period 2001-2011.

**Table 2.1: Summary of Sub-Saharan Africa HIV and AIDS Epidemic 2001 – 2011**

Description	2001	2008	2009	2011
Number of people living with HIV	19.7 million	22.4 million	22.5 million	20.11 million
Number of new HIV infections	2.3 million	1.9 million	1.8 million	1.5 million
Number of AIDS-related deaths	1.4 million	1.4 million	1.3 million	1.2 million

(United Nations on HIV/AIDS, 2012)

From Table 2.1 it is clear that the number of people living with HIV is increasing, but the number of new infections and AIDS-related deaths is decreasing. In 2011 there were about 1.5 million people who became newly infected and this is about 21%

lower than the 2.3 million people who were newly infected with HIV in 2001. These decreasing trends could be due to a number of factors, including the impact of HIV prevention efforts and the natural course of the HIV epidemic.

### **2.3.3 HIV and AIDS pandemic in South Africa**

The situation in South Africa is a cause for great concern. According to the United Nations on HIV/AIDS (2009:19), South Africa bears the largest burden of HIV and AIDS. UNAIDS, as quoted by Van Dyk (2008:8), declared in 2006 that South Africa's pandemic is one of the worst in the world and shows no evidence of decline. According to Schneider and Stein (2001:725) HIV was first seen in South Africa in the early 1980s, and Van Dyk (2008:27) confirms by stating that the first documented case of AIDS was recorded in South Africa in 1982. In 1990, the first series of an annual national antenatal survey in South Africa indicated that 0.8% of pregnant women tested were found to be HIV positive (Schneider & Stein, 2001:725; Van Dyk, 2008:28). By 1991, this figure had doubled to 1.5% and it became abundantly clear that South Africa was in the early stages of the rapidly growing HIV pandemic (Schneider & Stein, 2001:725). From there, HIV and AIDS were increasing.

According to the Department of Health (2011:ii) the HIV epidemic in South Africa has in the last six years shown stabilization, particularly among antenatal care for first time bookers in their current pregnancy served in public health sector clinics. Based on the statistical data of HIV prevalence in South Africa, HIV infections have been fluctuating (Independent Counselling and Advisory Services, 2009:3; Motepe, 2005:57; Visser & Mundell, 2008:66). The statistics show that HIV infections increased from 0.7% in 1990 to 30% in 2005 and decreased to 16% in 2009. Currently, the infections amongst females range between the ages of 15 and 29 years with the highest peak between 25 and 29 years. The infection rate among males ranged between 25 and 54 years with the highest peak infection between 35 and 39 years (Department of Health, 2011:ii).

According to United Nations on HIV/AIDS Global Report (2010:28) South Africa is the country with the largest number of HIV infections in the world. The epidemic varies considerably between provinces, from 15% in the Western Cape to 39% in

Kwazulu-Natal (Nicolay, 2008:1). The prevalence of HIV and AIDS in the different South African provinces during 2002, 2005 and 2010 is highlighted in Table 2.2.

**Table 2.2: South African Provincial HIV Prevalence (%)**

<b>Province</b>	<b>2002</b>	<b>2005</b>	<b>2010</b>
Kwazulu-Natal	11.7	16.5	15.8
Mpumalanga	14.1	15.2	15.4
Free State	14.9	12.6	12.6
North West	10.3	10.9	11.3
Gauteng	14.7	10.8	10.3
Eastern Cape	6.6	8.9	9.0
Limpopo	9.8	8.0	8.8
Northern Cape	8.4	5.4	5.9
Western Cape	10.7	1.9	3.8

(United Nations on HIV/ AIDS, 2012)

From Table 2.2 it can be seen that Kwazulu-Natal, Mpumalanga and the Free State had the highest HIV prevalence since 2002 up to 2010, while the Western Cape has the least. Except in Mpumalanga, North West and Eastern Cape the HIV prevalence in the other provinces seems to have stabilized while it is decreasing in other provinces. In 2002 Eastern Cape Province had the lowest HIV prevalence.

The next table presents the prevalence of HIV in the population groups for the period of 2010.

**Table 2.3: HIV prevalence by population group, 2010**

Population group	Prevalence (%)
African	13.6
White	0.3
Coloured	1.7
Indians	0.3

(United Nations on HIV /AIDS, 2012)

Table 2.3 shows that Africans are the most affected population, while the Whites and Indians are the least affected.

## **2.4 THE FUNDAMENTAL FACTS ABOUT HIV AND AIDS**

In order to understand the phenomenon of HIV, this section will explain basic facts about HIV and AIDS. The focus will be on the effect of HIV on the immune system, modes of HIV transmission, how HIV infection is diagnosed, and HIV counselling and testing.

### **2.4.1 The effect of HIV on the immune system**

The key function of the immune system is to protect the body against infections and other diseases. The CD4 lymphocytes play an important role in protecting the body against infection. The Department of Health (2010a:9) indicated that when a large proportion of these lymphocytes have been destroyed, the immune system can no longer function normally and the person becomes immune deficient. As the CD4 count drops, immunodeficiency becomes more severe. When this occurs, the person is likely to get ill with infection and other diseases such as tuberculosis and diarrhoea.

According to the Foundation for Professional Development (2009:16), opportunistic infections are infections which arise in the patient when the immune system is compromised for any reason. In HIV these infections are seen when CD4 counts are low, below 350, and mainly in the advanced stages of the disease. Opportunistic

infections affect most parts of the body including the brain, peripheral nervous system, eyes, skin, gastrointestinal system and respiratory system.

According to the Department of Health (2010b:23), tuberculosis (TB) is a co-morbid illness with HIV. Patients infected with HIV are at higher risk of developing TB compared to the general population, especially during the period immediately after initiating antiretroviral treatment. All patients with HIV should have a screening for TB. Clinicians must investigate patients for TB before starting antiretroviral treatment and to routinely screen patients on ART. Currently health facilities are providing Isoniazid (INH) as a prophylaxis to prevent TB in patients who have not been diagnosed with TB, but are HIV positive (Department of Health, 2013:15; *Soul City Institute Health and Development Communication*, 2008:62).

Van Dyk (2008:11) states that HIV is dangerous because the H1 virus does something that no other known virus has ever done. HIV directly attacks the most important defensive cells of the human system, the CD4 or T helper cells. HIV then slowly reduces the total number of healthy CD4 cells in the body and progressively weakens the ability of the human immune system to defend itself against attack from the outside. The most important question that needs to be addressed is how people acquire this virus.

#### **2.4.2 Modes of HIV Transmission**

As mentioned previously, HIV enters the body from the outside. It is of utmost importance to outline the way in which individuals can be infected with this virus. HIV is a weak virus that cannot survive outside the human body and it is mainly found in blood, semen, vaginal fluids and breast milk. Several authors (Department of Labour, 2003:66; Foundation for Professional Development, 2009:11; *HIV management in the workplace*, 2012:13; Van Dyk, 2008:34 ; Woods, 2007:14;) agree that HIV can be transmitted through the following ways:

#### 2.4.2.1 UNPROTECTED SEXUAL CONTACT (HORIZONTAL TRANSMISSION)

It is a well-known fact that HIV infection is sexually transmitted, primarily through unprotected, penetrative vaginal or anal intercourse. It is estimated that 70 to 80% of the global transmission occurs between infected persons and their partners through unprotected penetrative sexual intercourse (*HIV management in the workplace*, 2012:14). Woods (2007:14) states that bodily fluids such as vaginal and cervical secretions, semen and blood, contain a large amount of HIV.

It is noted that the presence of Sexually Transmitted Infections (STIs) increases the risk of HIV transmission. *HIV management in the workplace* (2012:14) emphasized that several factors increase the risk of infection dramatically, including the presence of a prior STI, sometimes manifested in genital sores or discharge, and having multiple sexual partners.

#### 2.4.2.2 TRANSMISSION THROUGH INFECTED BLOOD

HIV can be transmitted through blood transfusions or sharing needles or other sharp objects contaminated with HIV-infected blood. Woods (2007:14) further explains that using syringes, needles or blades which are stained with HIV-infected blood and accidental needle stick injuries put people at risk. HIV is found mainly in infected bodily fluids, especially blood. The Foundation for Professional Development (2009:11) points out that intravenous drug use accounts for up to 10% of new infections globally and this is starting to be a problem in Africa. Blood transfusions account for up to 5% of all new infections and exposure to infection through needles, needle pricks and used razor blades account for a small proportion of infections; less than 0.1%. Organ transplants from infected donors can transmit the infection as well (*HIV management in the workplace*, 2012:14).

#### 2.4.2.3 MOTHER TO CHILD TRANSMISSION (VERTICAL TRANSMISSION)

Department of Health, (2010a:9) and Page, Louw and Pakkiri (2006:51) explain that transmission of HIV from an HIV positive mother to her baby can occur in the womb during pregnancy, during child birth, and after birth during breast feeding. Mother to

child transmission accounts for up to 10% of infections especially in Africa and the incidence of mother to child transmissions in the developed world is virtually unknown (Foundation for Professional Development, 2009:11).

Most babies who acquire HIV during delivery have been exposed to maternal blood or cervical secretions that contain HIV (*HIV management in the workplace*, 2012:15). Transmission during prolonged labour can be reduced by elected caesarean section if the mother is positive and through a single dose of Nevirapine being taken (Foundation for Professional Development, 2009:12). Breast feeding also increases the risk of mother to child transmission. Mothers are always encouraged to breastfeed exclusively for six months and not to mix feed babies as mixed feeding also increases the risk of transmission. The only way to determine whether one has been infected is through an HIV test, thus the discussion below is on the diagnosis of HIV.

### **2.4.3 Diagnosis of HIV infection**

Early diagnosis of HIV is important so that any of the possible HIV-related conditions can be treated as soon as possible. The only way for people to know that they are infected with HIV is to go to a clinic or any health facility and have get tested for HIV. According to Van Dyk (2008:85) the diagnosis of HIV infection is based mainly on the testing of blood samples. The two main classes of tests are HIV antibody and the test that detects the actual virus. According to Woods (2007:17) the tests that are used to screen for an HIV infection in most public facilities are the following:

- **Rapid HIV antibody tests**

The rapid HIV antibody test is used in all public health facilities. Rapid HIV tests detect the antibodies for the virus and this test does not require specialized laboratory equipment (Department of Health, 2010a:14; *HIV management in the workplace*, 2012:26). The test is cheaper and quicker than the ELISA test (Enzyme-Linked Immuno Sorbent Assay). Van Dyk (2008:86) stressed that all positive rapid HIV test results should preferably be confirmed with a laboratory based ELISA antibody test.

- **Enzyme-Linked Immuno Sorbent Assay (ELISA) test**

This is the most commonly used test. The test tests for the presence of the antibodies to the virus (*HIV management in the workplace*, 2012:26; Van Dyk, 2008:85). The test includes drawing a blood sample which is then sent to a laboratory for testing. This test is more costly than the rapid test.

- **Polymerase Chain Reaction test (PCR)**

The PCR test tests for the presence of the virus itself and can be used from two weeks after infection with HIV (*HIV management in the workplace*, 2012:26). This test can also be used to establish the presence of the virus in infants under the age of 18 months (Department of Health, 2010a:14). The clinical stages of HIV infection can be used to guide health care providers to stage the progression of HIV since infection. Through the symptoms health care providers are able to stage the HIV infection. The clinical stages of HIV infection are presented below.

#### 2.4.3.1 THE CLINICAL STAGES OF HIV INFECTION

HIV infection is categorized into different stages, but it should be noted that the stages do not occur in a linear form. The development of HIV-related symptoms will depend on the immune system.

Department of Health, 2010a:13; *HIV management in the work place* (2012:11), *Soul City Institute Health and Development Communication* (2008:70) and Van Dyk (2008:52) categorized the HIV infection into the following clinical stages:

- **Primary infection (pre-clinical stage)**

Primary infection occurs as soon as seroconversion has taken place. Seroconversion means the point that the person's HIV status converts or changes from being HIV negative to positive (Van Dyk, 2008:52). This occurs about six weeks after infection with HIV.

- **Clinical stage 1: The asymptomatic latent stage**

The latent stage is the first clinical stage of HIV infection. During this phase the HIV-infected individual shows no symptoms. According to the Foundation for

Professional Development (2009:15) the immune system establishes a limited control over the HIV infection. Woods (2007:21) mentions some clinical symptoms of this stage, such as persistent generalized Lymphadenopathy especially in the neck, axilla and groin, but in this stage patients are usually well.

- **Clinical stage 2: The minor symptomatic stage**

According to Van Dyk (2008:54) in this second phase of infection, minor and early symptoms of HIV usually begin to manifest. The infected person can present with symptoms such as occasional fevers, shingles, skin rashes and minor mouth problems. The *Soul City Institute Health and Development Communication* (2008:7) indicate that during this stage the patient usually has a CD4 count between 350 and 500.

- **Clinical stage 3: The major symptomatic stage**

During this phase major symptoms and opportunistic diseases begin to appear as the immune system continues to deteriorate. The viral load increases and the CD4 cell count decreases. Woods (2007:21) indicated that the common features are unexplained weight loss, fever, oral candidiasis, diarrhoea, Pulmonary TB and severe bacterial infections.

- **Clinical stage 4: The severe symptomatic stage**

The Foundation for Professional Development (2009:16) indicates that the final stage of the disease can lead to untimely death unless treatment is started. During this phase the patient develops the AIDS defining conditions such as oral candidiasis, thrush in the mouth or throat, and recurrent infections such as vaginal or skin infections. Woods (2007:21) maintains that response to ART is usually good and without treatment many will die within months.

The researcher's view is that the staging of the disease is an important aspect of managing the condition once the person knows about his or her HIV positive status. Before a client can go through HIV testing, they are provided with counselling in order to prepare them for the test which will be outlined in the following section.

#### **2.4.4 HIV Counselling and Testing (HCT)**

HIV Counselling and Testing was previously referred to as Voluntary Counselling and Testing (VCT). Mnyanda (2006:15) as well as Beck, Mays, Whiteside and Zuniga (2006:67) outlined the rationale for VCT as a vital point of entry to other HIV and AIDS services, including Mother To Child Transmission (MTCT), prevention and clinical management of HIV-related illnesses, and psychosocial support. It provides benefits for those who test positive as well as those who test negative.

During HCT clients are provided with pre-test and post-test counselling. The researcher's opinion is that if pre-test and post counselling are provided accurately, the problem of clients not adhering to treatment or failing to disclose their status might be reduced to a certain extent. Clients will be empowered to understand their condition and what is happening to their bodies. The following discussion provides essential elements of pre-test and post- test counselling.

##### **2.4.4.1 PRE-TEST HIV COUNSELLING**

The Department of Health (2000a:8) defines pre-test counselling as “the counselling given to an individual before an HIV test, to make sure that the individual has sufficient information to make an informed decision about having an HIV test”. Page et al. (2006:60) indicate that pre-test counselling provides information so that the person can feel prepared for the test. Pre-test counselling reduces fear and feelings of helplessness and anger, thus helping the person being tested to cope with the result of the test. Page et al. (2006:60) and Van Dyk (2008:252) outlined the following guidelines to be used for pre-test counselling:

- **Reasons for Testing**

The counsellor needs to explore why the client needs to be tested. The client needs to be clear on why he or she is tested and what makes the client feel he or she might have been infected (Page et al., 2006:60).

- **Assessment of risks**

The Department of Labour (2003:58) postulated that this should include an assessment of personal risk of HIV infection. When assessing the risks Van Dyk (2008:253) maintains that the counsellor must assess the likelihood that the client has been exposed to HIV by considering if and how frequently she or he has been exposed to risk factors such as high-risk sexual behaviours, injecting drugs, etc.

- **Beliefs and knowledge about HIV infection and safer sex**

Schweitzer, Mizwa and Ross ([sa]:347) ascertain that increasing knowledge about HIV transmission, prevention and treatment cannot occur where the mythology about HIV and AIDS is actively contradictory. Based on this notion Page et al. (2006:61) refers to this phase as a stage of clarifying all myths and misunderstandings surrounding HIV and AIDS, because attempting to deal with HIV and AIDS while ignoring these myths will not yield the desired results. Schweitzer et al. ([sa]: 347) further declare that myths can hinder HIV prevention or treatment and health care providers must be prepared to counter them effectively.

- **Information about the test**

Clients need to be informed about the HIV test in order for them to have the knowledge about the test and the purpose of testing. According to Van Dyk (2008:254) the counsellor must ensure that the clients know what the HIV test and testing procedures entail. These include providing details about the test kit to be used.

- **The implications of an HIV test result**

Van Dyk (2008:255) indicated that the counsellor must explore with clients all the possible advantages and disadvantages of testing and explore the implications of each result, whether positive or negative.

- **Anticipate the result**

It is important for the counsellor to anticipate a negative as well as a positive HIV antibody test result and to talk about how the client will deal with the test outcome. Feelings about results should be explored (Van Dyk, 2008:256). This will assist in preparing the client for the anticipated outcome. The counsellor also needs to assess client's readiness to be tested and receive the test results. Thus identification of the

client's support network is of utmost importance at this stage whereby the counsellor must also establish if clients intend to disclose their status to loved ones

- **Information about giving results and on-going support**

The counsellor should explain to the clients when, how and by whom the test results will be given to them (Van Dyk, 2008:257). Identifying the client's support system is important so that the client is knowledgeable about the resources that are available and where he/she may seek help.

- **Informed consent**

HIV testing without informed consent is unlawful in South Africa (*HIV management in the workplace*, 2012:27). The Department of Labour (2003:58) states that the client should be given an opportunity to make a decision about taking the test. This means that the decision to be tested can be made by the client only, and informed consent must be obtained prior to testing. When the client signs consent the counsellor needs to ensure that the client understands what he or she is consenting to by ensuring that this client has been provided with the information on the nature and the form of the HIV test and the implications of such a test (Department of Labour, 2003:58). Once the client has given consent, the test will be done and the client will be seen during post- test counselling.

#### 2.4.4.2 POST-TEST COUNSELLING

Both the Department of Labour (2003:58) and the Department of Health (2000a:7) define post-test counselling as "the counselling provided when an individual receives his or her HIV test result". This simply means that during post-test counselling the client is given his/her HIV test results. The counsellor needs to ensure that the client understands the results, whether positive or negative. The Department of Labour (2003:67) states that a positive test result implies that HIV antibodies were detected and the person is infected with HIV.

A negative test result means that HIV antibodies were not detected and the person is not infected or may be infected, but is still in the window period. The window period is the time when the body is developing antibodies and occurs about 3-4 weeks after infection (Van Dyk, 2008:87). If a patient has tested positive, he or she is then

referred to a wellness clinic for CD4 cell count and antiretroviral treatment. When the person tests negative they are encouraged to repeat the test again after three weeks. Discovering an HIV positive status can be devastating to some individuals. Living with HIV can have serious psychological and social impacts on the client's life.

## **2.5 IMPACT OF HIV ON THE INDIVIDUAL**

As mentioned earlier the Department of Labour (2003:65) has acknowledged the impact HIV and AIDS have on all spheres of life. The Department of Health ([sa]:8) further emphasizes that HIV and AIDS have enormous ramifications and the negative impact can be seen in all spheres; economic, social, psychological, physical and spiritual. The impact of HIV and AIDS on the individual, household and community level is devastating. The researcher discussed briefly the psychosocial and financial impact of HIV on the individual.

### **2.5.1 Psychosocial impact of HIV on the individual**

HIV and AIDS have a negative impact on the individual, thus the impact may be distressing. Schweitzer et al. ([sa]:334) indicate that HIV and AIDS have profound psychosocial effects on the HIV-infected person, the family, the community and society as a whole. The Department of Health ([sa]:14) maintains that HIV and AIDS, unlike other terminal illnesses such as cancer, is a disease surrounded by social stigma. Mmatlwa (2001:3) mentions that people are stigmatized by perceptions surrounding HIV and AIDS and end up being silent about their status. Regarding discrimination, Peter (2011:26) ascertains that in most communities and families there is evidence of discrimination and rejection by others, including family members. The stigma attached to HIV infection further means that not only people who are infected are affected, but their families also face the possibility of social rejections (Department of Health, [sa]:16). Thus the stigma and discrimination attached to HIV and AIDS are hampering control of the disease (Meel, 2005:149).

The diagnosis and disclosure of an HIV positive result is an extremely stressful event. When living with HIV, people may face a dilemma in disclosing their HIV status to others (Van Empelen, 2005:11). People may choose not to disclose their

HIV status to their families because the HIV status may be associated with revelations of sexuality, infidelity or drug use. Disclosure of HIV status has its benefits and disadvantages that need to be carefully considered prior disclosure of HIV status. The Foundation for Professional Development (2009:31) views disclosure as an important factor for maintaining and improving adherence.

Furthermore, people living with HIV may also experience uncertainty because of the unpredictable progression of the disease, possible risk of infecting loved ones, and fear of death. They will at some point experience mixed feelings such as guilt, anger, shock and depression (Department of Health, [sa]:12).

Marital and family conflict may also occur as the partners may blame each other for the infection (Schweitzer et al., [sa]:334). These ambivalent feelings also affect significant others. Fronlich (2005:352) confirmed that HIV has a major impact on individuals and on community structures such as family. Family has traditionally been a fundamental unit of any society, but as the epidemic progresses this structure is being steadily eroded and the role of the household head in particular is undergoing radical alteration. Currently South Africa is faced with a growing number of child-headed households (Department of Labour, 2003:71; Department of Health, 2011:01). Children are forced to take on the responsibility of caring for their siblings due to the death of one or both parents. Grief is one of the most common experiences connected to HIV and AIDS (Department of Health, [sa]:16).

Regarding the pandemic, Meel (2005:149) states that HIV and AIDS cause illness, disability and death, as well as severe economic and emotional disruptions to the families. Due to these increasing levels of psychosocial stressors the HIV positive individual will become unproductive at work, continuously absenting him or herself. Loss of financial income in the household will have a devastating impact on the individual as indicated below.

## **2.5.2 Financial impact on the individual**

Schweitzer et al. ([sa]: 344) highlight that HIV and AIDS affect the economic well-being of families, businesses and societies in many ways. In South Africa the majority of people live in poor conditions, thus HIV and AIDS can contribute to the

financial burden of an individual. This is confirmed by Van Empelen (2005:10), who states that finances can be adversely affected by HIV status. The HIV-infected are concerned about their own future and also that of their households. The person living with HIV might be disturbed by what would happen if she or he becomes too ill to contribute to the household income, because illness often leads to loss of productivity and income (Van Empelen, 2005:10). Infection with HIV may also have adverse financial repercussions on the individual infected and on their families. Thus families spend money on the illnesses associated with HIV and AIDS (Department of Health, [sa]:14).

Economically productive adults leave work due to illness. Van Empelen (2005:10) acknowledge that although people infected with HIV consider returning to work, several barriers such as fear of repercussions of poor health, fear of discrimination and medication management prevent them from doing so. The introduction of ART was aimed at improving the life span and quality of life for people living with HIV so that they can be economically productive (Wasti, Teijlingen, Simkhada, Randall, Baxter, Kirkpatrick & Vijay, 2012:71). Thus the discussion below is important in order to provide a detailed account of antiretroviral treatment and different regimens that are used to manage HIV.

## **2.6 THE MANAGEMENT OF HIV THROUGH ANTIRETROVIRAL TREATMENT (ART)**

HIV is not a curable disease, but it is a manageable one. The roll out of antiretroviral drugs was delayed; South Africa began in April 2004 (Heyer & Ogubanjo, 2006:5; Van Dyk, 2008:31). The arrival of ART has given hope to millions of people living with HIV and AIDS and has turned what was once a fatal disease into a chronic, manageable disease (Heyer & Ogunbanjo, 2006:5). ART allows many people living with HIV to live longer, have a better quality of life, and experience fewer illnesses related to HIV. Taking antiretroviral treatment is a decision for life. According to Maskew et al. (2007:853) the roll out of antiretroviral treatment has brought much excitement and hope to both patients and practitioners, but it has also brought challenges and new questions.

However, Afolabi et al. (2009:1) stated that the development of antiretroviral drugs (ARV) has transformed HIV and AIDS to that of a chronic, manageable disease. Studies have reported improved quality of life for People Living With HIV and AIDS (PLWHA) on ART, reduced progression of the disease and declining mortality from the pandemic. The *Soul City Institute Health and Development Communication* (2008:12), the Department of Health (2004:2) and Van Dyk (2008:95) outlined the four primary goals of antiretroviral treatment as follows:

- Virological goal – To reduce the HIV viral load as much as possible, preferably to undetectable levels for as long as possible.
- Immunological goal – To restore or preserve immunological function so as to improve immune functioning, reduce opportunistic infections and delay the onset of AIDS.
- Therapeutic goal – To improve the quality of the HIV positive person's life.
- Epidemiological goal – To reduce HIV-related sickness and death, and to reduce the impact of HIV transmission in the community.

Antiretroviral drugs (ARVs) prevent HIV from multiplying. This allows the body to heal and the immune system to function better. If ARVs function successfully, the viral load decreases, and the virus becomes undetectable in the blood after six months of treatment (*Soul City Institute Health and Development Communication*, 2008:11). However if the virus is undetectable, it does not mean that the person is no longer infected with HIV. HIV can still be present in the blood, but the level is too low to measure (less than 400copies/mm<sup>3</sup>).

ARV therapy is very demanding, as medication needs to be taken twice daily, every day, including weekends and for life. The responsibility for successful, long-term adherence must primarily lie with the individual on therapy. The Foundation for Professional Development (2009:147) emphasized that educating and counselling patients to enable them to take their ARVs as prescribed at the right time, in the right way and in the right amount is one of the keys to the success of ARV.

### 2.6.1 Initiating and understanding ART

The success of adherence to ART depends on the intensity of treatment counselling, the education and information given to the client during the counselling sessions, and the ability of the patient to make informed choices about treatment (Foundation for Professional Development, 2009:38). People should know that ART is not a cure for HIV; the different combinations play different roles which can help to control the replication of the virus, slow down disease progression and also promote and support the restoration of the immune system. In order for this to happen the client has to understand that this means taking treatment every day on time for the rest of their lives. Dalal et al. (2008:101) emphasize that initiation of ART entails frequent clinic visit, extensive counselling, clinical and immunologic staging, and on-going monitoring.

Van Dyk (2008:100) insists that ART should be delayed until the patients are prepared to commit themselves to long-term treatment and maintaining good adherence to the therapy. In agreement, Woods (2007:46) maintains that starting ART is never an emergency; the patient must be fully prepared and they must show commitment to take their medication correctly and follow instructions. Before patients are initiated on ART, they undergo intensive treatment counselling. A treatment readiness assessment should be done over three clinic visits. The Foundation for Professional Development (2009:39) and the *Soul City Institute Health and Development Communication* (2008:21) outlined some aspects of treatment readiness assessment as follows before the patient can be initiated on ART:

- Why does the patient want to begin treatment? It is critical to ascertain why the patient needs to begin treatment. The patient needs to be assessed for treatment eligibility.
- Does the patient understand the different treatment combinations and the effect on their body? Patient needs to be educated about different treatment regimens. In order to prepare patients for ART, health workers should give patients information about how to take ART successfully (*Soul City Institute Health and Development Communication*, 2008:21).

- Discuss the patient's lifestyle and social or work environment. According to the Foundation for Professional Development (2009:39) it is helpful to understand whether the patient has a history of depression or drug abuse as this may impact on their ability to be adherent.
- Does the patient have any other medical conditions or are they currently taking any other treatment or following natural or traditional healing? The Soul City Guidelines (Isa:34) and Van Dyk (2008:102) ascertain that this is because some medications may interfere with the functioning of ART.
- What are the patient's own views on ART? By assessing this aspect the counsellor will get an opportunity to understand the patient's own perception and understanding of treatment (Foundation for Professional Development, 2009:39).
- The counsellor should explain terminology related to the HIV diagnosis and treatment. This includes discussing what CD4 count and viral count are and their impact on the disease progression.
- The counsellor should strive towards maintaining and improving adherence. The counsellor and the patient need to discuss issues relating to adherence. What adherence means, the importance of adherence and the implications for not adhering to treatment. The researcher is of the opinion that this is a necessary foundation for patients to empower them with knowledge before they are provided with ARV.

In addition to this treatment readiness assessment, the Department of Health (2004:3) recommends that the following psychosocial considerations should be taken into account before ART is initiated:

- The patient demonstrated reliability, that is to say the patient has attended three or more scheduled visits to an HIV clinic.
- The patient showed no untreated active depression, as this has been shown to impede adherence.
- The patient must have disclosed her or his HIV status to a friend, family member or a member of a support group. Disclosure of HIV positive status may influence adherence.

- The patient must have accepted his or her HIV status and needs to have insight into consequences of HIV infection and the role of ART before commencing therapy.
- Patients should be able to attend an antiretroviral centre on a regular basis.
- The patient must demonstrate willingness and readiness to take ART adherently.

Although this should not be viewed as exclusion criteria, the final decision to treat the patient will be taken by the multi-disciplinary team at the ART facility, who will initiate treatment. The patient and caregiver must be actively involved in this decision. Heyer and Ogunbanjo (2006:5) stress the importance of offering comprehensive adherence support to all patients, with additional support to patients who do not fulfil all the criteria or who have demonstrated lower adherence.

According to the Department of Health (2010a:7) the South African Antiretroviral Therapy programme, known as the Comprehensive Care Management and Support (CCMTS) programme was launched in 2003. The goals of this programme include decentralizing service delivery to Primary Health Care (PHC) level by ensuring that ART is available at all these facilities, and to retain patients on lifelong ART by preventing HIV disease progression.

The on-going high mortality from HIV and AIDS indicated that substantial changes were required to improve access to HIV care and the overall success of the programme. Improving access to ART formed an important component of South Africa's revitalized response to the HIV and AIDS epidemic. Before patients are initiated it should be assessed whether they are eligible for treatment (Department of Health, 2013:6). The criteria for eligibility for antiretroviral treatment will be briefly discussed.

### **2.6.2 Eligibility for antiretroviral treatment**

The criteria for provision of ARVs underwent changes since the roll out of ART in 2003. Stender and Jhpiego (2010:15) indicated that the World Health Organization (WHO) formally launched the 2010 antiretroviral guidelines at the AIDS 2010 XVIII

International AIDS Conference. According to these guidelines it is now recommended for adults to start ART at a CD4 count of 350 rather than 200 cells/mm<sup>3</sup>, as this has shown to reduce the risk of HIV-related illness. The Department of Health (2013:6) is also in line with those recommendations in that patients are eligible for lifelong ART if they have a CD4 count <350 cells/ mm<sup>3</sup> irrespective of HIV clinical stage, presenting with any type of TB or they are presenting with HIV stage 3 or 4 irrespective of CD4 count cells.

### **2.6.3 Antiretroviral Treatment Regimens in South Africa**

Treatment for HIV and AIDS is accomplished through numerous combinations of antiretroviral agents belonging to the following groups: nucleoside analogue reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, and protease inhibitors (Olisah, Baiyewu & Sheik, 2010:275). Two ART regimens are recommended in the South African public sector; the first line and the second line regimens. The first line regimen is divided into two sub-regimens, namely regimen 1(a) and 1(b) (Foundation for Professional Development, 2009:44; *Soul City Institute Health and Development Communication*, 2008:15; Van Dyk, 2008:100).

The *Soul City Institute Health and Development Communication* (2008:15) indicates that patients start treatment with a first line regimen. They change to the second line regimen if there are serious side effects or treatment failure. Each regimen has its criteria to determine who is eligible to use it. There are treatment regimens for adults and children, but the researcher will only briefly discuss adult regimens.

#### **2.6.3.1 SUMMARY OF ART REGIMENS FOR ADULTS AND ADOLESCENTS CURRENTLY USED IN SOUTH AFRICA**

The regimens that are used are constantly changing as new developments are made. The Foundation for Professional Development (2009:219), *Soul City Institute Health and Development Communication* (2008:73) and the Department of Health (2013:7) discussed the treatment regimens that are currently used to manage HIV

and which are divided into first line and second line regimens. The researcher will briefly discuss who is eligible for each regimen.

- **First line regimen**

This regimen consist of TDF + FTC (or 3TC) + EFV. All new patients needing treatment are eligible for this line, including pregnant women. Adolescent patients are given ABC+ 3TC+EFV.

- **Second line regimen**

This regimen is basically aimed at the management of virological failure resulting from the use of the first line regimen. The regimen consists of AZT + 3TC +LPV/r. This is for patients failing from TDF in the first line and TDF + 3TC (or FTC) and LPV/r for those patients failing on d4T.

- **Third line regimen**

Patients failing any second line regimen will be considered for this regimen; however this will be managed by an expert panel (Department of Health, 2013:7).

Patients who are given the regimens are educated prior the initiation of treatment. Patients are required to adhere to treatment so that HIV and AIDS can be managed effectively. The availability of ART has improved the quality of life for the people living with HIV and has reduced the number of opportunistic infections and deaths (Foundation for Professional Development, 2009:50). However, ART can cause drug side effects which the researcher highlighted in the following discussion.

#### **2.6.4 Side effects of and the tests to monitor the effectiveness of antiretroviral treatment**

ART can cause side effects just like almost all drugs that are used. Most people who take ART will experience side effects at some point, however there are some people who do not experience side effects at all (*Soul City Institute Health and Development communication*, 2008:33). Side effects are manageable and can be successfully

treated. Therefore it becomes the role of the counsellor to assist the patient in understanding what to expect and what to do about the side effects of ART.

The Foundation for Professional Development (2009:50), *Soul City Institute Health and Development communication* (2008:33) and Van Dyk (2008:101) agree that most drugs that are used to manage HIV will have side effects, ranging from mild to serious and more severe side effects. The mild side effects are referred to as the adjustment period and are normally seen in the first two to six weeks of treatment. Most of the side effects will disappear once the body has adjusted to the new drug (*Soul City Institute Health and Development Communication*, 2008:33).

The *Soul City Institute Health and Development Communication* (2008:33) and the Foundation for Professional Development (2009: 50) listed some of the common mild effects associated with the initial use of ART as follows:

- Headache
- Tiredness
- Nausea
- Diarrhoea
- Dizziness
- Difficulty sleeping
- Bad dreams or nightmares
- Rash
- Vomiting
- Mild confusion and muscle pains

Side effects can be difficult to live with even if they are minor. Patients need to be supported and encouraged during this period. It is important to inform patients not to stop taking any of their medication even if they have bad side effects (*Soul City Institute Health and Development Communication*, 2008:33). Patients should rather visit their health care facility as soon as possible. Once the side effects are manageable, it is necessary to conduct tests to determine the effectiveness of ART in the patients' body. This can be done through different laboratory tests. The two main tests that help the health worker monitor the effectiveness of ART are to focus

on the activity of HIV in the body and the status of the immune system. These two tests are the CD4 count test and the viral load test (*Soul City Institute Health and Development Communication*, 2008:4).

#### 2.6.4.1 CD4 COUNT TEST

*HIV management in the workplace* (2012:2) and *Soul City Institute Health and Development Communication* (2008:4) explained that a “CD4 count test measures the number of CD4 cells present in a milliliter of blood.” The results will indicate how healthy the immune system is. Woods (2007:36) indicated that a normal CD4 cell count in HIV negative healthy adults is above 500 cells/mm<sup>3</sup>. CD4 count test results are used for the following:

- A CD4 count shows you how much damage there is to the immune system.
- It shows how likely it is that a person will be infected with opportunistic infections. It is used as an indicator to determine when to start prophylaxis for opportunistic infections.
- It indicates when to start ART (*Soul City Institute Health and Development Communication*, 2008:4).

#### 2.6.4.2 VIRAL LOAD TEST

*HIV management in the workplace* (2012:2) and Woods (2007:73) define a viral load test as “a measure of the amount of HIV in the blood”. The *Soul City Institute Health and Development* (2008:4) mentions that the results will indicate how many copies of HIV there are per millilitre of blood (copies/ml). The viral load test may vary from undetectable to high levels with millions of copies. Woods (2007:73) indicates that people with an HIV infection can have a viral load ranging from less than 50 copies/ml to several million copies/ml. A viral load less than 50 copies/ml is regarded as undetectable.

According to the *Soul City Institute Health and Development Communication* (2008:4) viral load test results assist as follows:

- The viral load shows how fast HIV is likely to progress. The higher the viral load, the more rapid the disease progression and the weaker the immune system.
- It shows whether ART is effective or not, as the aim of ART is to keep the viral load as low as possible.
- If the viral load rises when a person is on ART, it shows that treatment is not working and for treatment to be effective patients need to adhere, thus discussion on the importance of treatment adherence in the management of HIV is highlighted.

### **2.6.5 ART adherence**

Maskew et al. (2007:853) simply defined adherence as “correct and timely dosing of prescribed medications”. The Foundation for Professional Development (2009:149) further defined adherence as “the extent to which a person’s behavior, taking of medication and the following of a healthy lifestyle including a healthy diet and other activities, corresponds with the agreed recommendations of the health care providers”. Adherence is one of the most crucial issues in the clinical management of HIV-infected patients receiving antiretroviral therapy. Strict adherence is required to achieve therapeutic success in HIV management. According to Glass, De Geest, Weber, Vernazza, Rickenbach, Furrer, Bernasconi, Cavassini, Hirschel, Battegay, Bucher and Swiss (2006:385) ART has led to a substantial reduction in HIV associated morbidity and mortality and HIV infection has entered the stage of chronic disease management. Adherence is imperative to guarantee the effectiveness of ART.

Olisah et al. (2010:276) maintain that adherence to ART is of critical importance, because even minor deviations from a prescribed regimen can result in viral resistance. Adherence to ART among HIV patients is the most important patient enabled factor related to virological failure and can lead to drug resistance. It is important to avoid virological failure; especially for patients who have limited resources, because the effects of treatment failure are profound (Nam, Fielding, Avalos, Dickinson, Gaolathe & Geisser, 2008:302).

Near perfect adherence to ART is required to prevent treatment failure in the individual and to prevent the spread of drug-resistant viruses. The treatment regimen should be kept as simple as possible and be tailored to suit the patient's lifestyle. Krebs, Chi, Mulenga, Morris, Cantrell, Mulenga, Levy, Sinkala and Stringer (2008:313) maintain that timely and regular clinical monitoring is a critical component in long HIV treatment.

The Foundation for Professional Development (2009:149) maintains that adherence implies the patient's willingness and ability to follow recommendations given by a health professional. Successful adherence also depends on a relationship that must be a partnership that draws on the combined abilities of the patients and the members of the health care team. Patients' adherence means taking all their medication in accordance with the manner prescribed by the doctor. According to the Foundation for Professional Development (2009:149) and Soul City Guidelines ([sa]:30) ART adherence further means commitment to:

- Practicing safe sex in order to avoid re-infections. The Soul City Guidelines ([sa]:31) further highlight that this will assist in prevention of being infected with a virus that is resistant to ART the drug resistant virus will increase the viral load in the body.
- Attending follow-up appointments as given by health care providers.
- Collecting medication from a health facility to ensure compliance to treatment.
- Maintaining a healthy diet, as this will help to fight illness. A poor diet weakens the immune system and can speed up the progress of HIV to AIDS (*The Soul City Institute Health and Development*, 2008:54)
- Maintaining a healthy lifestyle, e.g. cutting down on alcohol and smoking, and getting adequate sleep and exercise in order to have a healthy body. The Soul City Guidelines ([sa]:33) point out that alcohol can make clients forget to take ART.
- Getting support from people. This will help to reduce stress and assist clients in taking treatment correctly (Soul City Guidelines, [sa]:33).

Patients who are supported in their adherence efforts are much more likely to maintain viral loads that are undetectable. Explaining the link between viral load suppression and clinical outcome and adherence allows patients to identify obstacles

to successful adherence (Department of Health, 2010a:17). Based on this, health care professionals need methods to measure adherence to the treatment. The following methods can be used to measure treatment adherence:

- **Patient self-report**

These are basically reports that are given by patients or caregivers during the clinic visits regarding how they consume their medication (Olisah et al., 2010:276). According to Chesney (2000:171) the advantages of self-reports are that costs are low, data can be easily collected, and they can help to determine the reasons why patients are non-adherent and then develop ways to address the identified problems.

- **Pill counts**

According to Sendagala (2010:19) pill counts involve counting the number of pills that remain in the patient's bottles. Pill counts are often employed to monitor adherence and are a reliable indicator of compliance. The return of excess pills provides tangible evidence of non-adherence. The Foundation for Professional Development (2009:185) mentioned that a method like pill counts is simple, but also easy to manipulate by the patients.

- **Assays of drug level or therapeutic drug monitoring**

Olisah et al. (2010:276) mention that this includes measuring the level of drugs in the blood to determine adherence levels. Sendagala (2010:21) indicates the monitoring of drug level is a well-known therapeutic intervention considered as a direct objective measure of medication. Assays of drug level have been used in clinical trials to measure the last dose taken, but these assays are often impractical because they are expensive and unavailable in most facilities. These assays typically measure only recent doses, thus provide limited data (Chesney, 2000:172).

- **Electronic Monitoring Systems**

Electronic monitoring system (MEMS) are inserted into medication bottle caps and they contain a computer chip that records the date and time of opening and closing of the bottle (Sendagala, 2010:20). Interpretation of the data assumes that a single dose is taken each time the bottle is opened and this may also lead to inaccuracies if multiple doses are removed at once (Chesney, 2000:172).

The Foundation for Professional Development (2009:158) recommends that a number of different strategies should be used to assess the success of adherence rather than just one or two, as all the techniques have their own advantages and disadvantages.

Adherence to therapy is difficult to measure accurately. This is confirmed by the Foundation for Professional Development (2009:158) who indicates that measurement of adherence is not easy and health professionals can make subjective ratings of the success of adherence strategy. The following strategies can be used to enhance adherence:

#### *2.6.5.1 STRATEGIES TO PROMOTE ART ADHERENCE*

According to the Department of Health (2010a:18) the clinic team needs to support adherence at all points of intervention. The following recommended strategies to promote ART adherence can be employed by adherence counsellors:

- Spend time with the patients and explain the disease, the goals of therapy and the importance of adherence.
- Negotiate a treatment plan that the patient can understand and to which he or she commits.
- Arrange home visits.
- Check Missed appointments for medicine pick-ups are a powerful predictor of poor adherence and should trigger immediate questions about issues that may affect adherence and attendance.
- Reinforce the use of adherence tools, such as pill boxes or a daily dosing diary.

Van Dyk (2011:1) further suggests that in order for health care professionals to help patients adhere, it is first necessary to know the patient's stage of behaviour change, and then to identify the specific factors determining that patient's behaviour. A change of behaviour is needed to take ARVs. It is therefore necessary for health professionals to understand the basic principles underlying behaviour change. The main predictor of change is the intention to change. According to Van Dyk (2011:3) if a person has no intention or commitment to take ARVs regularly, they will not do so. It is important to talk to patients and to find out their intentions, attitudes, knowledge, beliefs, constraints and skills before trying to help them adhere to medication.

The focus of the study is on the reasons why patients are not adhering to antiretroviral treatment. The following discussion outlines what non-adherence is and explores the reasons why patients are not adhering to treatment from different perspectives.

### **2.6.6 Non-adherence to Antiretroviral Treatment.**

Non-adherence is perceived as a potential threat to the long-term success of HIV treatment. Nam et al. (2008:301) postulate that non-adherence is the most important factor known to be associated with treatment failure for HIV patients in both developed and developing countries. According to Weiser et al. (2003:281) the lack of strict adherence to ART is considered to be one of the key challenges to AIDS care worldwide. Non-adherence can lead to disease progression and death (Krebs et al., 2008:312).

Chesney (2000:172) reports that non-adherence is a common behaviour that should be expected, even with a serious disease such as an HIV infection. According to Maskew et al. (2007:853) patients who do not return for follow-up at clinics providing comprehensive HIV and AIDS care require special attention. In the literature, clients that default treatment are referred to as "lost to follow up" or "defaulters" (Brinkhof, Pujades-Rodriguez & Egger, 2009:1; Maskew, et al., 2007:853; Daniel et al., 2008:221).

Yu, Chen, Wang, Chang, Makombe, Schouten & Harries (2007:550) indicate that depending on the facility, patients are classified as "lost to follow up" if they have

missed two or more consecutive clinic appointments or have not been seen for at least two or three consecutive months. If a patient is not seen in the clinic for three consecutive months the patient is registered as a “defaulter”. Van Cutsem, Ford, Hildebrand, Goemaere, Mathee, Abrahams, Coetzee and Boulle (2011:1) indicate that “lost to follow up” is a concern for health care providers, programme planners and donors. Patients who are “lost to follow up” maybe at high risk of death and reasons for defaulting treatment need to be explored to avoid the development of drug resistance. The focus of this study is on exploring reasons for defaulting treatment, as discussed below.

#### *2.6.6.1 REASONS FOR NON-ADHERENCE TO ART*

Reasons for non-adherence to treatment are categorized into patient, psychological related, socio economic, medication and system of care factors. Several authors (Chesney, 2000:172; Dalal et al., 2008:104; Nam et al., 2008:302; Heyer & Ogubanjo, 2006:9; Krebs et al., 2008:318; Miller et al., 2010:51; Tweya, Gareta, Chagwera, Smith, Mwenyemasi, Chiputula, Boxshall Weigel, Jahn, Hosseinipour & Phiri, 2010:82; Van Cutsem et al., 2011:7; Wasti et al., 2012:73; Weiser et al., 2003:384) agree that the reasons for non-adherence are as follows:

##### **Individual or patient related factors**

Chesney (2000:174) and the Foundation for Professional Development (2009:154) both refer to patient related factors as “those factors that take into account the resources, knowledge, beliefs and expectations of the patient”. Several individual factors known to affect adherence include:

- Discontinued taking drugs.
- Substance abuse, including alcohol and drugs.
- Improved health, which results in patients stopping treatment.
- Deteriorated health.
- Internalized or external stigma.
- Non-disclosure.
- Adjustment to the disease.

- Lost identification card.
- Too sick to come to the clinic.
- Travelling away from home.
- Religious beliefs.
- Negatively influenced by others.
- Surplus of medication.
- Too busy with work or personal business.
- Problems leaving work to meet clinic appointment.
- Unsure about continuing antiretroviral therapy.
- Relocation or clinic transfer.
- Death.
- Ran out of medicine.
- Hospitalization.
- Obtaining medicine privately.
- Had not started taking drugs despite collecting them from the clinic.
- Family responsibilities.

Jin, Sklar, Oh and Li (2008:272) further mentioned that patient related factors include patient's age, ethnicity, gender, education and marital status. Several studies are conducted to determine if these factors influence adherence (Afolabi et al., 2009:6; Heyer & Ogunbanjo, 2006, 8; Jin et al., 2008: 274; Maskew, et al., 2007:854).

### **Psychological related factors**

The Foundation for Professional Development (2009:154) defines psychological factors as “thoughts, feelings, perceptions, attitudes or other cognitive or affective characteristics of an individual that influence his or her behaviour”. Psychological factors include some of the following:

- Mental health problems, such as depression and stress.
- Confusion regarding follow-up.
- Attitudes towards treatment.
- Cognitive barriers, such as lack of knowledge about the disease and its treatment.
- Loss of faith in medications.

- Forgetfulness.
- Denial of diagnosis.
- Unresolved grief reaction.

### **Medication or therapy related factors**

Therapy related factors include the following:

- Confusion about drug regimen or regimen complexity.
- Toxicity, side effects or adverse reactions.
- Large quantity of pills or heavy pill burden, and the taste of the medicine.
- Frequency of clinic visits.
- Instructions that are hard to follow.
- Requirements for drug storage.

### **System of care or health system factors**

According to FARLEX [sa] system of care refers to “a framework within which health care is provided, comprising of health care professionals, patients, resources and organizational procedures”. These factors include:

- Dissatisfaction with the clinic services.
- Negative staff attitudes.
- Administrative problems at the clinic after irregular follow-up.
- Too many patients at clinics.
- Long queues.
- High costs and unavailability of drugs.

### **Socio- economic factors**

The socio-economic factors are “the social and economic experiences and realities that help mould one’s personality attitudes and life style” (Chase, [sa]). These factors include:

- Inability to pay for transport to the clinic.
- Lack of food.
- Finances or lack of money.

## 2.7 SUMMARY

The extent or impact of HIV and AIDS is felt globally, even in South Africa. Though the pandemic has shown some evidence of decline, those who are infected and affected are faced with different challenges. There is a stigma attached to HIV and AIDS which will take a long time to overcome. The issue of stigma has been a barrier to HIV positive clients disclosing their status. We have seen how ART has transformed HIV into a manageable condition, but now the challenge that is facing clients is to ensure that they adhere to treatment so that it can be effective and prolong their life span. Strategies that promote adherence need to be implemented. Reasons for non-adherence include patient related, psychological, socio-economic, Medicine related factors and system of care factors. Reasons for non-adherence need to be continuously explored in order to retain patients on the ART programme and the reasons for non-adherence vary over time. Based on this the researcher conducted this study with an aim to explore the reasons why HIV patients default their ART. The following chapter explains the research methodology used in the study and the presentation of the empirical research findings.

## CHAPTER THREE

### RESEARCH METHODOLOGY AND EMPIRICAL RESEARCH FINDINGS

#### 3.1 INTRODUCTION

The literature clearly shows that the HIV and AIDS pandemic has evolved over the years. HIV affects individuals, their significant others and communities. Since the introduction of antiretroviral treatment, it has greatly improved the lifespan and quality of life for people living with HIV. The Foundation for Professional Development (2009:149) and Van Dyk (2008:92) agree that for the successful management of the HIV and AIDS epidemic it is imperative that the condition be treated and accepted as a chronic disease. Wasti et al. (2012:71) maintain that ART provides relief for infected individuals by reducing the likelihood of opportunistic infections rather than curing the disease. For patients to be able to have improved functioning they have to adhere to their treatment to ensure that ART functions effectively.

Obtaining the full benefit of ART is a complex individual behavioural process determined by many broader factors, including patient attributes and the health care system (Wasti et al., 2012:71). Various authors (Dahab, Charalambous, Hamilton, Fielding, Kielmann, Churchyard & Grant, 2008:2; Dalal et al., 2008:101; Glass et al., 2006:385;) ascertain that adherence to treatment is a critical component of ART management. Van Cutsem et al. (2011:1) indicated that patients lost to follow up may be at high risk of death and this is a concern both for individual clinical care and programme evaluation, as unstructured interruption of treatment can lead to the development of drug resistance. Correctly detecting and minimising lost to follow up treatment is therefore a concern for health providers, programme planners and donors. An understanding of the reasons for not returning to care is important to the design of an effective and cost effective ART programme (Brinkhof et al., 2009:5). In order to be able to intervene and assist patients who default treatment, it is important to understand why the patients are defaulting treatment. Therefore the goal of this study was the following:

**To explore the reasons why HIV and AIDS infected patients default antiretroviral treatment at Thekganang ARV Clinic in Seshego District Hospital, Limpopo Province.**

In order to obtain this goal the following objectives were formulated:

- To theoretically conceptualise HIV and AIDS as a social phenomenon with specific emphasis on antiretroviral treatment.
- To explore the experiences of HIV and AIDS infected patients regarding the services provided in Thekganang ARV Clinic.
- To determine the HIV and AIDS infected patients' level of understanding about HIV and AIDS treatment adherence.
- To establish what causes HIV and AIDS infected patients to default antiretroviral treatment at Thekganang ARV Clinic.
- Based on the findings of the study, draw conclusions and make recommendations to increase HIV and AIDS infected patients' adherence to antiretroviral treatment at Thekganang ARV Clinic in Seshego District Hospital, Limpopo Province.

Against this background, the following research question guided this study:

**What are the reasons that HIV and AIDS infected patients default follow up antiretroviral treatment at Thekganang ARV Clinic?**

## **3.2 RESEARCH METHODOLOGY**

### **3.2.1 Research approach**

For this study a qualitative research approach was used as the researcher was seeking to explore the reasons why HIV and AIDS infected patients default follow up antiretroviral treatment. The qualitative research approach was appropriate in this study due to the fact that the researcher was able to better understand and obtain information about what motivates patient behaviour (Henn et al., 2006:150) when they fail to adhere to their antiretroviral treatment.

### **3.2.2 Type of research**

In the context of this study applied research was the most applicable type of research, because the goal of applied research most often is the scientific planning of induced change in a troublesome situation (Kumar, 2005:9). It addresses immediate problems facing the professional in practice. Neuman (2006:25) emphasizes that those doing applied research conduct a study to address a specific concern or to offer solutions to a problem of their organization they are affiliated with. Considering that the researcher's focus was on a specific problem in practice, namely to explore the reasons why HIV and AIDS infected patients default antiretroviral treatment in the researcher's area of operation, applied research was the most appropriate type of research.

### **3.2.3 Research design and methods**

The collective case study design was applicable in the context of this study due to the fact that the researcher selected multiple cases (Ellinger et al.,[sa]:5) to find out from subjects why they default follow up antiretroviral treatment at Thekganang ARV Clinic. By using this design the researcher was able to enhance insight into and understanding of the phenomenon antiretroviral treatment default at Thekganang ARV Clinic.

#### **3.2.2.1 Population, sample and sampling method**

In this study the population was the 'the entire set of people' (Bless et al., 2006:98), namely all the registered HIV and AIDS infected patients who defaulted antiretroviral treatment at Thekganang ARV Clinic, Seshego District Hospital, Limpopo Province, during 2012.

As the subset of the whole population (Bless et al., 2006:100) the researcher selected a sample of 15 registered HIV and AIDS infected patients who defaulted antiretroviral treatment at Thekganang ARV Clinic, Seshego District Hospital during 2012.

The sample of 15 participants was selected by using systematic sampling (Neuman, 2006:230). In this study systematic sampling was applicable due to the fact that the

researcher obtained a list of patients who default ART from the data capturers in the clinic.

The researcher compiled a list of participants based on the following criteria:

- Participants who are 18 years of age and above.
- Participants registered at Thekganang ARV Clinic, Seshego District Hospital for ARV treatment.
- Participants who have defaulted ARV treatment during 2012.

The total number of registered HIV and AIDS infected participants was 80. The first participant on the list was selected randomly and there after every second participant was selected until a total of 15 participants was selected. At the end the researcher interviewed 14 participants, because the last participant refused to be interviewed and later passed away.

### **3.2.3.2 Data collection method**

For the purpose of this study the researcher used semi-structured interviewing to collect data from participants. Semi-structured interviews allowed the researcher to obtain more information about reasons why HIV and AIDS patients default antiretroviral treatment.

It also helped the researcher to elicit the participant's own perspectives in a flexible manner; it provided room for the interviewees to raise additional issues that are important to them; and it allowed the researcher to follow up particular interesting avenues that emerged in the interview (Barbour, 2008:295). Therefore semi-structured interviewing was an appropriate data collection method for this study.

In this study the researcher developed an interview schedule to guide the data collection process. According to Barbour (2008:115), a qualitative interview schedule involves a series of headings or may have a few carefully worded questions which are usually open-ended to allow the respondents to elaborate. However, accompanying prompts are helpful as a reminder to the researcher.

With the permission of the participants to record the interviews for data analysis purpose, a voice recorder was used to record the interviews.

### 3.2.3.3 Data analysis

De Vos (2005:333) stated that data analysis is the process of bringing order, structure and meaning to the mass of collected data. Therefore in this study the researcher, after collecting the data analysed the information using Cresswell's model of data analysis and interpretation as described by De Vos (2005:334).

The researcher arranged with the participants and scheduled appointments with them at their preferred venues. Participants were interviewed in their home language, Northern Sotho. The data was collected using a voice recorder and written notes. The recorded interviews were listened to carefully and repeatedly, transcribed into Northern Sotho text format. The researcher then translated the interview transcript to English. The researcher reread, familiarised herself with the transcripts and then analysed manually. The researcher identified themes and sub-themes according to the trends and relevance of information.

### 3.3 Trustworthiness of the research findings

In this study the researcher used semi-structured interviews to collect data from the participants who are receiving antiretroviral treatment in Thekganang ARV Clinic and have defaulted their ARV treatment. The list of participants was obtained from the data capturers in the clinic and the participants' record files were retrieved to confirm that they have indeed defaulted treatment for credibility. Interviews were conducted in the participants' home language in order to avoid misunderstandings. A digital voice recorder was used to record interviews and interviews were transcribed.

Several strategies were applied in this study to ensure the trustworthiness of the findings and these are described below:

- **Credibility:** Shenton (2004:66) mentioned that the researcher must apply tactics to help ensure honesty in informants when contributing data. In this study the researcher ensured that participants are willing to take part in the study and are free to withdraw their participation at any given point. Participants were encouraged to be open and there were no right or wrong answers to ensure that participants were honest (Shenton, 2004:67).

- **Peer debriefings:** Peer debriefing sessions are the sessions between the researcher and his or her supervisor and or professional colleagues in order to widen the vision of the investigator, as others bring to bear their experiences and perceptions (Shenton, 2004:67). These sessions assisted in reduction of biasness. In this study the researcher, after completing the analysis, met with her supervisor and senior researcher for peer debriefing. During the debriefing sessions, consistencies and differences in interpretations of the data were identified. It was also confirmed by Lietz, Langer and Furman (2006:451) that peer debriefing is important in qualitative studies as it allows the researcher to consult with a colleagues on the effects of reactivity and bias.
- **Member checking:** Regarding member checking Shenton (2004:68) states that checks relating to the accuracy of the data may take place on the spot in the course and at the end of data collection dialogues. In this study the researcher ensured that the findings of the research emerged with no biases by using member checking whereby recorded interviews were played back to the participants after the interviews. The transcribed interviews were given to the participants to ensure that it was the participants' expressions that have been transcribed and not the researcher's interpretation and perception (Lietz et al., 2006:453; Peter, 2011:55; Shenton, 2004:68).
- **Examination of previous research findings:** Shenton (2004:69) emphasises the importance of examining previous research findings to assess the degree to which the project's results are congruent with those of past studies. The researcher in this study explored different studies to relate the findings of this study to the existing body of knowledge.
- **Audit trail:** Lietz et al. (2006:449) and Shenton (2004:72) define audit trail as the process during data analysis where steps to be taken are described in order to establish rigor in qualitative research. In order to ensure the trustworthiness of the research findings in this study, the researcher laid down an audit trail by providing the participants with consent forms to sign. The consent form entailed the detailed process and procedures of the research study. The participants were given copies of the signed consent forms.

- **Reflexivity:** Shenton (2004:72) describes reflexivity as “the extent to which the researcher admits his or her own predispositions and takes steps to ensure that the research findings are the result of the experiences and ideas of the participants rather than the characteristics and preferences of the researcher himself or herself”. In this study it was important for the researcher to be aware of and to reflect on the influence of her roles as a social worker in the clinic and as a researcher. Reflexivity was further applied through constant consultations with the research supervisor for extensive dialog on the process of data analysis and interpretation.

### **3.4 ETHICAL CONSIDERATIONS**

The ethical issues applicable in this study are discussed below.

#### **3.4.1 Harm to respondents**

Regarding harm to respondents, Neuman (2006:132) postulates that social research can harm research participants in several ways: physical harm, psychological harm, legal harm and harm to a person’s career. The risk of physical harm is rare, but the participants may be exposed to emotional harm. The researcher avoided asking sensitive questions and at the end of the study the participants were given an opportunity to debrief. There was no participant that was referred to the clinical psychologist for therapy as participants did not experience psychological harm.

#### **3.4.2 Informed consent**

Kumar (2005:212) indicates that informed consent implies that participants are made adequately aware of the type of information required from them, why the information is being sought, what purpose it will be put to, how they are expected to participate in the study, and how it will directly or indirectly affect them. Participation in this research study was voluntary and the participants had the right to accept or refuse participation. Participants were given a written informed consent letter. The consent letter clearly indicated the goal and procedures of the study, including the fact that a tape recorder will be utilized to record the data and the reason for recording the interviews. The researcher ensured that the consent letter was signed only by competent and mentally fit participants.

The researcher also informed the participants that they had a right to withdraw from the research at any given time during the research process. In this study, the researcher provided the participants with an opportunity to ask questions and seek clarity throughout the process. The researcher provided a clear explanation of the purpose of the study so that participants made informed choices about participating. The researcher included the contact details of the supervisor to allow the participants to contact the supervisor if they have questions about the research.

### **3.4.3 Violation of privacy or confidentiality**

Particularly sensitive and personal information provided by participants should be protected and not made available to anyone other than the researcher (Bless et al., 2006:143). The researcher explained about confidentiality, assured the participants of confidentiality and indicated this on the consent letter.

Only the researcher had access to the data and knew which data was linked to which participant. The results of the study were presented in an anonymous manner that protected the identities of the participants, by using pseudonyms and numbers. Under no circumstances were the identities of participants made known to any other party. In order to protect the confidentiality of participants, the interviews took place at a location convenient to the participants. Protection of confidentiality included secured storage of data and the protection of the participants' identities.

### **3.4.4 Debriefing**

Debriefing entailed interviewing participants about their research experience, especially if there was a possibility that they might have been harmed by participating in the study (Babbie, 2007:67). Debriefing entailed sessions that were aimed at discovering problems or misconceptions generated by the research experience. The researcher gave the participants an opportunity to debrief at the end of the interviews and misconceptions were clarified. Debriefing was conducted by the researcher. At the end of the interview there was no participant who needed counselling despite the fact that the researcher arranged with the hospital psychologist for therapy. Participants were not harmed by participating in the study.

### **3.4.5 Actions and competence of the researcher**

Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation (Strydom, 2005:63). The researcher was knowledgeable about the field of study, namely HIV and AIDS, as she has successfully completed a short course on this topic and also has practical experience working with HIV- and AIDS-infected patients in the ARV clinic as a social worker. The researcher was also competent to conduct the study because she had successfully completed a module in research methodology. In addition, the researcher received guidance from her supervisor who was an expert in the field of study.

## **3.5 EMPIRICAL RESEARCH FINDINGS**

The information collected through semi-structured interviews from HIV and AIDS infected patients who default their ARV treatment were categorised into themes and sub-themes, interpreted and verified with literature. The findings will be presented into two sections as follows:

**Section 1:** A biographical profile of the research participants.

**Section 2:** A description of the themes and sub-themes that emerged from the process of data analysis. Each theme and sub-theme will be discussed according to a summary of findings, quotations to verify findings and an integration of literature.

### **3.5.1 Section 1: A biographical profile of the research participants**

The research participants were profiled according to the following variables: gender, age, marital status, employment status, level of education, disclosure of HIV positive status, people to whom participants disclosed their HIV status, and period of defaulting ARV treatment. Table 3.1 gives a summary of the biographical profile of the participants regarding the above-mentioned variables.

**Table 3.1: Biographical profile of the research participants**

Subject number	Age	Sex	Marital status	Highest level of education	Employment	Disclosure	Disclose to whom	Period of defaulting
1	27	M	Single	High school	Unemployed	Yes	All members	3 months
2	35	M	Single	High school	Unemployed	Yes	All members	5 months
3	43	F	Single	High school	Unemployed	No	-	5 months
4	33	F	Single	High school	Unemployed	Yes	All members	4 months
5	37	M	Single	High school	Unemployed	Yes	All members	5 months
6	42	M	Married	High school	Electrician	Yes	Wife	8 months
7	34	F	Single	High school	Domestic worker	Yes	Children	4 months
8	42	M	Single	Primary school	Motor mechanic	Yes	Girlfriend	10 months
9	46	M	Single	High school	Unemployed	Yes	Sister	6 months
10	51	F	Single	Primary school	Unemployed	No	-	4 months
11	58	M	Single	Primary school	Unemployed	Yes	Niece	5 months
12	38	M	Married	Primary school	Unemployed	Yes	Wife	10 months
13	37	F	Single	High school	Unemployed	Yes	Mother	3 months
14	28	F	Single	High school	Unemployed	Yes	Boyfriend	5 months

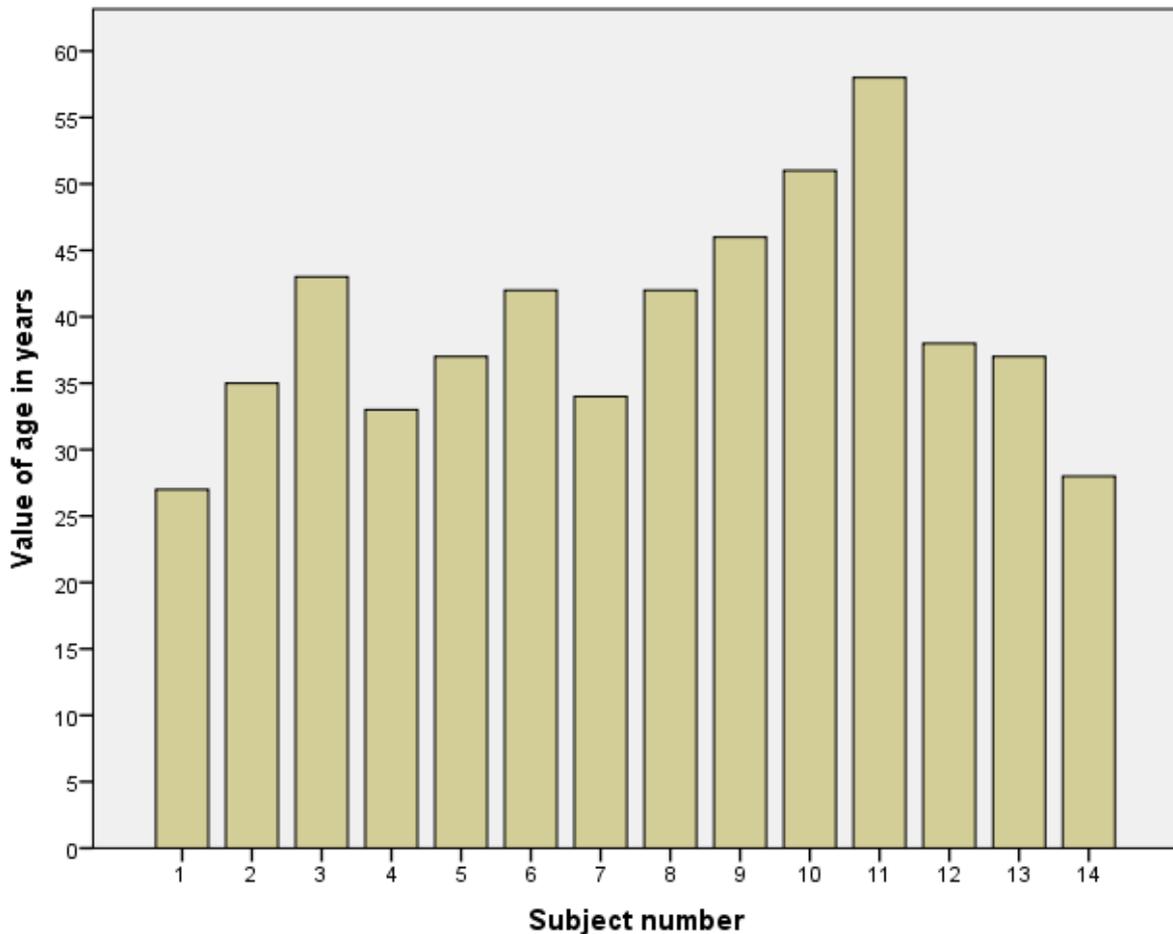
A description of each variable, as indicated in Table 3.1, is presented below.

### 3.5.1.1 *Gender*

In this study eight participants (57.1%) were male, while six participants (42.9%) were female, bringing the total to 14 participants. This is different to several studies where women make up the majority of the participants (Daniel et al., 2008:222; Miller et al., 2010:50; Olisah et al., 2010:277; Wakibi, Ng'anga' & Mbugua., 2011:8). However, the fact that men make up the majority in this study correlates with the findings of Zhou, Tanuma, Chaiwarith, Lee, Law, Kumarasamy, Phanuphak, Chen, Kiertiburanakul, Zhang, Vonthanak, Ditangco, Pujari, Choi, Merati, Yuniastuti, Li, Kamarulzaman, Nguyen, Pham and Lim (2011:3) where the majority of participants in their study were also male. The researcher is of the opinion that men are beginning to take a stance against HIV and AIDS and accessing treatment. In this study gender is not a predictor of adherence. This is confirmed by Heyer and Ogubanjo (2006:8) and Afolabi et al. (2009:4) in that evidence regarding the relationship between adherence and gender is weak and most studies are not finding any association.

### 3.5.1.2 *Age*

Figure 3.1 reflects the age distribution of the participants. The horizontal axis shows all the subjects according to their reported series number while the vertical axis shows the age of each subject in years. The ages of subjects ranged from 27 to 58 years of age. There were two subjects who were 37 and 42 years of age, respectively.



**Figure 3.1: Age distribution of the subjects**

In this study the majority of participants (42.8%) fell within the age group of 36-45 years, while 35.5% fell within the age group of 27-35 years and 27% above the age of 46 years. There were no participants between the ages of 20 and 29 years. The findings in this study correlate with the findings of several research studies on the age distribution of HIV and AIDS (Weiser et al., 2003:283; Zhou et al., 2012:5).

### 3.5.1.3 Marital Status

The findings reflect that 12 participants (85.7%) were single while only two participants (14.3%) were married. In the study there was no link established between marital status and adherence. This is in agreement with the findings of

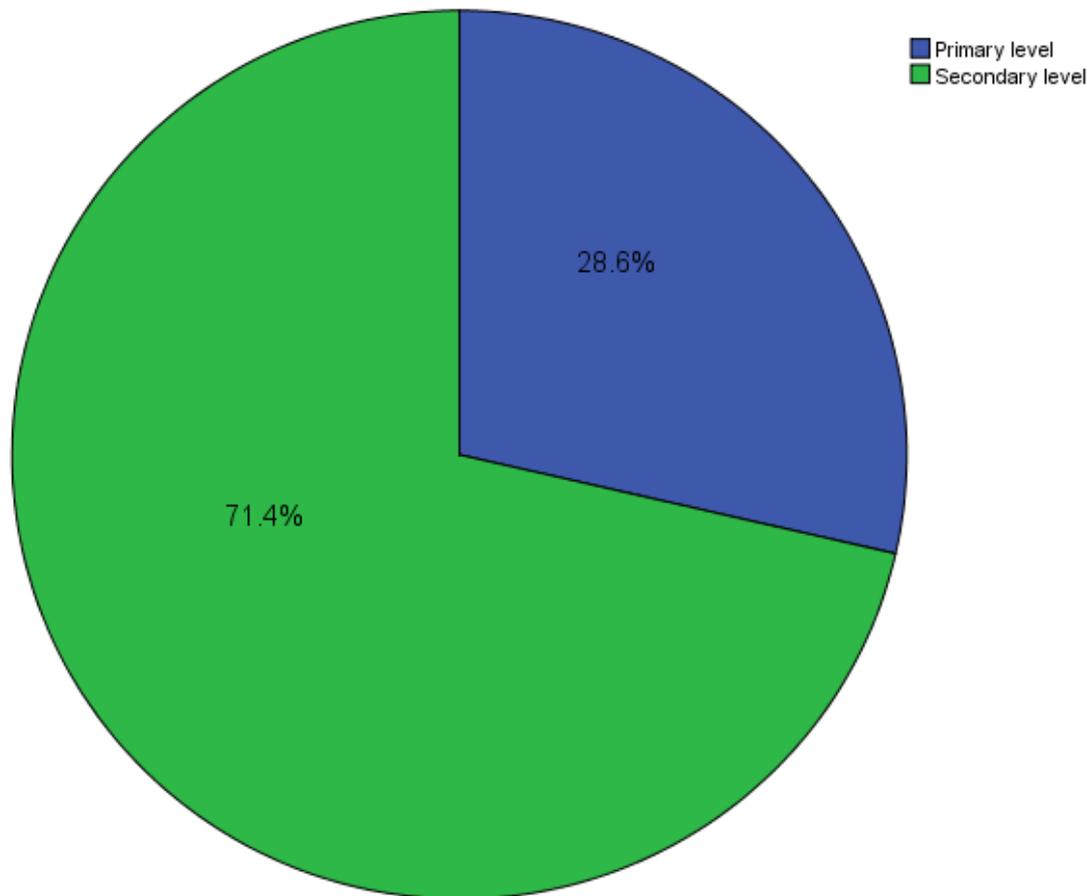
Afolabi et al. (2009:4), Talam et al. (2008:77), and Wakibi et al. (2011:5) that marital status does not predict non-adherence.

#### 3.5.1.4 *Employment Status*

In this study the findings show that 11 participants (78.6%) were unemployed. The researcher is of the view that this can also be linked to the fact that the participants are not skilled as they never completed their studies. Only three participants (21.4%) were employed as general workers. This is in agreement with of Olisah et al. (2010:277) who found that the majority of the participants were unemployed and few participants were unskilled workers. The researcher is of the opinion that the economic status of the participants is a predictor for adherence as some participants default treatment possibly due to lack of money and shortage of food in the household. Afolabi et al. (2009:4) confirms that employment status and monthly income, which are directly dependent on education status, show significant association with adherence level.

#### 3.5.1.5 *Highest level of education*

Figure 3.2 below reflects the highest level of education successfully completed by participants. Most subjects had secondary school education.



**Figure 3.2: Level of education of the subjects**

In this study 10 participants (71.4%) attended high school and four participants (28.6%) had only primary school level education. The findings are in agreement with the findings of Moratioa (2007:62), Olisah et al. (2010:277) and Wakibi et al. (2011:3). However, it is interesting to note that participants in this study never obtained any tertiary qualifications.

In the literature there are studies that conclude that the level of education is an important predictor of adherence (Maskew, et al. 2007:854; Nakiyemba, Aurugai, Kwasa & Oyabba [sa]:22). But in this study the level of education was not seen as a predictor of adherence. This is compatible with the findings of Dahab et al.

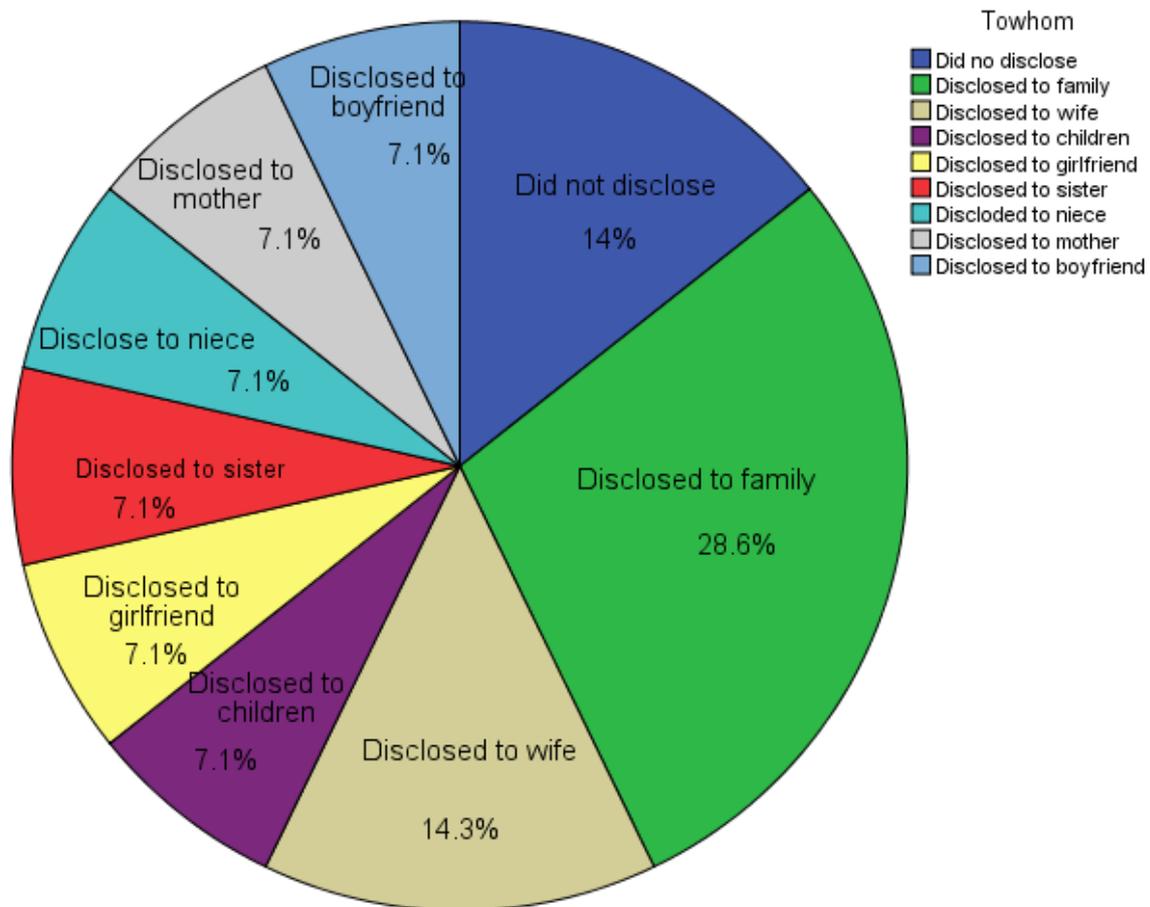
(2008:20), Heyer and Ogunbanjo (2006:8) and Talam et al. (2008:77) who found that the level of education does not significantly affected adherence.

### 3.5.1.6 *Disclosure of HIV positive status*

Van Dyk (2008:280) maintains that the disclosure of a person's HIV positive status is a personal and individual decision. In this study 12 participants (85.7%) disclosed their status, while two (14.3%) of the participants were afraid to disclose their HIV status. Non-disclosure of HIV status can be attributed to several factors such as fear of being stigmatized, rejection and discrimination from members of the family, community or health care providers (Foundation for Professional Development, 2009:31; Van Dyk, 2008:282).

### 3.5.1.7 *People to whom participants disclosed their HIV status*

Figure 3.3 reflects those people to whom participants disclosed their HIV status in their families. Most of the participants disclosed to their family members.

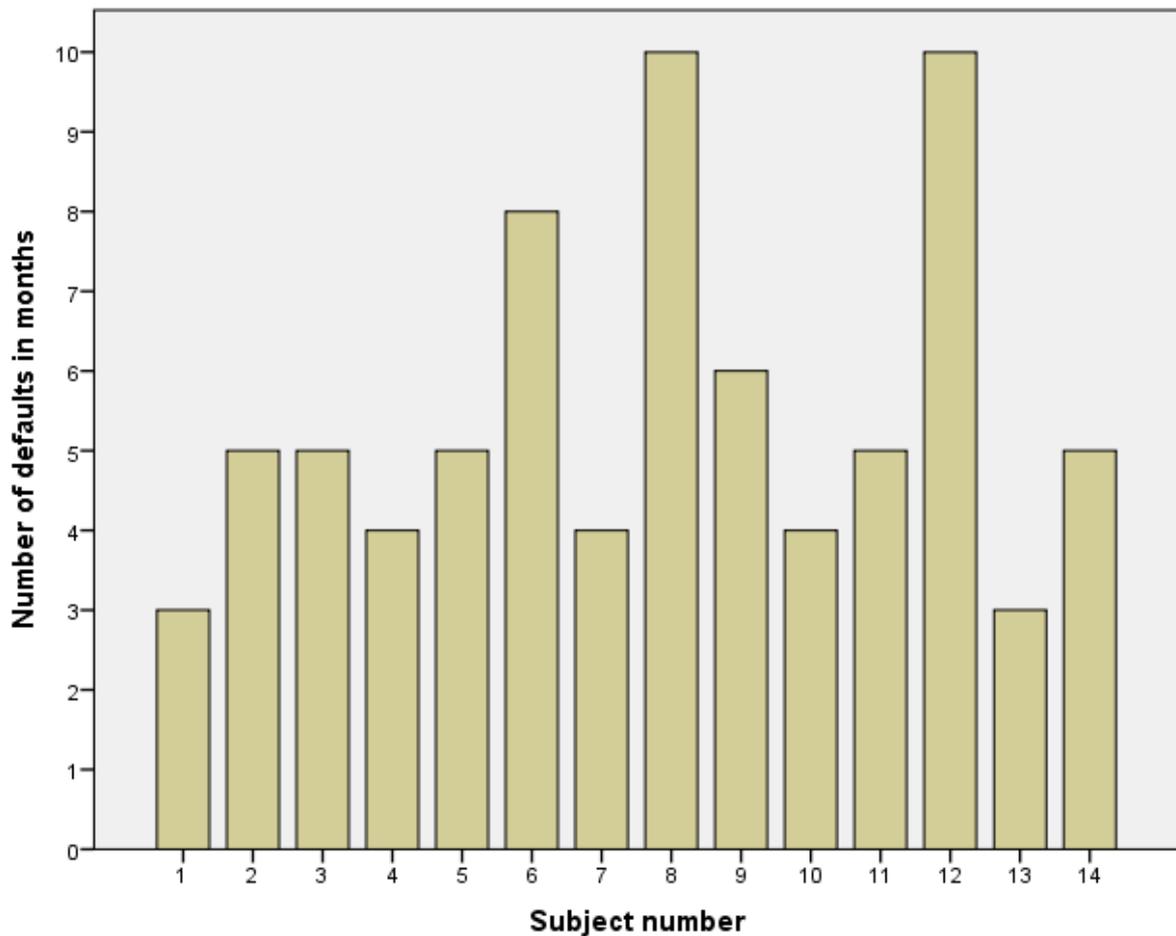


**Figure 3.3: People to whom participants' disclosure their HIV status**

It is encouraging to note that 12 participants (86%) disclosed their status, while only two (14%) did not disclose. Twenty nine percent (29%) of the participants disclosed to their family members and 14% disclosed to their wives. The other 28% of the participants disclosed their HIV status to their life partners. The researcher's view is that this is interesting as it shows that people are now caring for their partners and would like to protect them from infection or re-infection. It is also significant to observe that 7% of participants disclosed to their siblings or nieces. Only 7% of participants disclosed to their parents for support. Participants also expressed that they received care and support after disclosure. Their families encouraged them to attend their follow up treatment and they even urged them to come for retreatment after default of treatment.

### 3.5.1.8 *Period of defaulting antiretroviral treatment*

Figure 3.4 reflects the period of defaulting antiretroviral treatment. The horizontal axis shows the subject numbers while the vertical axis shows the number of default by participants in months.



**Figure 3.4: The period of defaulting antiretroviral treatment in months**

Figure 3.4 above reflects participants' period of treatment default. The majority of participants (71%) mentioned that they defaulted treatment for a period of three to five months, while 21% of participants default treatment between eight to 10 months.

### 3.5.2 Section 2: Qualitative information according to themes and sub-themes

In this section, the qualitative data findings are discussed according to themes and sub-themes. Table 3.2 below displays a summary of identified themes and sub-themes in this study.

**Table 3.2: Summary of the identified themes and sub-themes**

No	Theme	Sub-themes
1	Participants' knowledge about HIV and AIDS	1.1 Participants' understanding of HIV 1.2 Participants' description of the concept AIDS 1.3 Participants' knowledge about the basic facts of HIV and AIDS
2	Participants' experiences of HIV testing	2.1 Participants' reasons for HIV testing 2.2 Participants' feelings about their HIV positive status
3	Participants' perceptions and experiences of using antiretroviral treatment	3.1 Participants' knowledge about antiretroviral treatment regimens 3.2 Participants' experiences regarding the side effects of antiretroviral treatment 3.3 Participants' perceptions regarding antiretroviral treatment 3.4 Participants' understanding of antiretroviral treatment adherence
4	Challenges faced by participants while on antiretroviral treatment	4.1 Participants' fear of disclosing 4.2 Physical challenges experienced by participants 4.3 Participants' fear of stigmatization

5	Participants' reasons for defaulting antiretroviral treatment	5.1 Lack of money for transportation 5.2 Shortage of food in the household 5.3 Drug abuse 5.4 Problems leaving work to make clinic appointments. 5.5 Relocation 5.6 Mental health problems such as depression and stress. 5.7 Too busy with personal business 5.8 Participant had not started taking the drugs despite collecting them from the clinic 5.9 Surplus medication 5.10 Lost appointment card 5.11 Confusion about drug regimen 5.12 Child care
6	Participants' experiences of receiving treatment in Thekganang ARV Clinic	6.1 Long queues 6.2 Staff attitude

Each theme will be discussed according to the following structure:

- Theme
- Sub-theme
- Summary of findings
- Quotations to verify the findings
- Integration of literature

### 3.5.2.1 **THEME 1: PARTICIPANTS' KNOWLEDGE ABOUT HIV AND AIDS**

The majority of the participants highlighted that they have knowledge about HIV and AIDS. However, a few participants indicated that they are unable to explain HIV and AIDS. Three sub-themes were identified as follows:

- Participants' understanding of HIV
- Participants' description of the concept AIDS
- Participants' knowledge about basic facts of HIV and AIDS

#### **Sub-theme 1.1: Participants' understanding of HIV**

The majority of the participants were able to provide their own perspectives about HIV. Participants explained HIV as a virus that causes AIDS. HIV is a sexually transmitted disease and can also be acquired through contact with infected blood. When a person is diagnosed with HIV, the virus has not yet developed into AIDS. The following quotations verify that the participants had an understanding of HIV.

- “The counsellor explained that it means you start by having HIV and then if you do not take proper care of yourself it will develop to be AIDS.”
- “Mmm HIV is a virus and then that virus progresses and later will change to AIDS.”
- “HIV is a virus; if you have HIV it means your immune system is low.”
- “HIV infects the person from blood. According to me this disease is transmitted sexually.”

This finding correlates with the findings by Olowookere, Fatiregun and Adewole (2012:809) wherein the majority of participants had a good knowledge about HIV. Before patients are tested for HIV it is required by legislation that they need to be provided with HIV counselling and testing (Department of health, 2000b:5). One of the reasons for this is to increase patients' knowledge about HIV and AIDS and the test itself. However, a few participants felt that they cannot explain HIV. The participants maintain that they had no idea what HIV is and they cannot give an explanation. The following verify the participants' responses:

- “HIV I cannot really explain it to you because this disease, the way it attacked me, I was surprised myself. But I ended up sitting down, telling myself alone that it means HIV and AIDS are not the same thing, no.”
- “It is not one thing, it is one thing I cannot explain.”
- “No, I myself do not understand what those are. I do not understand what it is, whether you become swollen or you have dark marks, or what happens. I do not know; maybe today I will hear that what those are.”

In the view of the above statements it is clear that the participants had no idea about HIV as they never attempted to explain their understanding. This finding correlates with the findings of Moratioa (2007:79) that some of the participants showed a lack of knowledge about HIV. Maskew et al. (2007:854) stated that people living with HIV and AIDS who have lower literacy levels show poorer treatment adherence and more adverse health outcomes. From the literature perspective the *HIV management in the workplace* (2012:1) describes HIV as “the virus that causes acquired immunodeficiency syndrome in human beings and causes AIDS.”

### **Sub-theme 1.2: Participants’ description of the concept AIDS**

The majority of the participants were unable to explain the concept of AIDS thoroughly. Participants clearly indicated that they cannot explain AIDS. Hereunder are the direct quotations from the participants confirming that they do not have knowledge about AIDS:

- “I do not know.”
- “Ah, I am explaining both of them.”
- “Hey, they did not explain it to me, those counsellors.”
- “AIDS; I cannot really explain to you.”

From the above quotations it is evident that participants lack knowledge about AIDS. This finding was not consistent with the findings of several authors such as Asante (2013:8); Nachega, Lehman, Hlatswayo, Mothopeng, Chaisson and Karstaedt (2005:196); Olowookere et al. (2012:809) wherein majority of participants’ demonstrated excellent knowledge about AIDS.

The researcher's view is that a contributing factor to this might be the lack of continuous counselling, and thus patients end up forgetting what was emphasised during HIV counselling and testing. Moratioa (2007:11) stated that it is the duty of all health care professionals to provide the necessary information and support at a level or standard that their patients can understand. Health care professionals should regularly assess the patient's level of knowledge and information, since a lack of understanding promotes non-compliance to treatment. Knowledge about HIV and AIDS forms the basis of adherence to ART. Foundation for Professional Development (2009:3) outlined an adherence counselling checklist to be used by counsellors which includes determining patient's knowledge of HIV and AIDS as this is regarded as a barrier to adherence, along with inadequate understanding about HIV and AIDS.

Only a few participants attempted to explain AIDS from their own perspective. Participants defined AIDS as a disease that has developed to the final stages. Some direct quotations confirming that they attempted to explain their understanding of AIDS:

- "You have a virus in your body and if you keep having too much unprotected sex that is the time it will change into AIDS."
- "AIDS is a disease in a final stage; now it is visible and complete."
- "AIDS is a disease that is fully developed."

The finding was confirmed by Asante (2013:8) and Nachega et al. (2005:196) who revealed that participants had excellent knowledge about AIDS. During adherence counselling before the patient is initiated on ART, the Foundation for Professional Development (2009:203) recommends that the patient's knowledge of HIV and AIDS be assessed. Although the participants were unable to provide a complete explanation of AIDS, the majority of the participants are knowledgeable about the basic facts of HIV and AIDS and thus the discussion on sub-theme 1.3.

### **Sub-theme 1.3: Participants' knowledge about the basic facts of HIV and AIDS**

The participants know the basic facts about HIV and AIDS and this may also serve as an indication that people are becoming more knowledgeable about HIV and AIDS.

Participants know what HIV does to the body and the importance of safer sex. HIV is not a curable disease, but it can be managed through ART. HIV attacks the CD4 cells and when a person's CD4 cell count is low the viral load increases. When this happens a person will start to be sick more often. Then a blood test will be done to determine the level of the CD4 cell count and the results will be a determinant whether to start ART or not. Some quotations indicating that participants know the basic facts about HIV and AIDS namely:

- “They explained during counselling that if you have the disease, you must abstain to keep it from progressing quickly.”
- “It is a disease that is sexually transmitted; when you are infected you will not get cured.”
- “When a person starts to be sick, and you realise that this person is sick, it is HIV because HIV goes along with the CD4 cell count. It affects the number of cells in the body. If your CD4 count is less than 200, it means it is becoming AIDS. And you will start to receive antiretroviral treatment.”
- “You can live a long time with the virus, but only if you use the ARVs in the prescribed manner.”

This finding was consistent with the findings of Asante (2013:8); Nachega et al. (2005:196) that the majority of participants had knowledge about the basic facts of HIV and AIDS and the modes of transmission. Nakiyemba et al. ([sa]:24) postulated that if a person has a good level of understanding about HIV; believes that ART is effective and prolongs life; and recognises that poor adherence may result in viral resistance and treatment failure, it makes a favourable impact upon that person's ability to adhere. Van Dyk (2008:254) stated that it is important to determine exactly what the client knows about HIV infection and correct errors and myths by providing accurate information about what HIV infection and AIDS entail. For every individual to know whether they are infected or not, they must undergo an HIV test, thus the next theme is on the experience of participants when they were tested for HIV.

### 3.5.2.2 *THEME 2: PARTICIPANTS' EXPERIENCES OF HIV TESTING*

HIV positive results may be devastating for individuals. HIV counselling and testing is provided to address such devastating impacts on individuals. In this study the majority of the participants underwent counselling. However, some of the participants were too sick at the time and are now unable to recall details of what was discussed during counselling sessions. Participants know the details about the test and how the test is conducted. The experiences of the participants during HIV counselling and testing are highlighted as follows:

- “Ah, the time I came for testing – I went there one day and then they asked me if I will be fine. I told them that I would be fine and then they tested me.”
- “They took my blood. When they finished taking my blood they explained to me about the disease. After taking my blood they showed me the test kit and told me that when a person sees something like this they must know they are HIV positive.”
- “After checking me, they said the test kit has three lines. They took a certain medication and poured it on the test kit and then they told me if it reaches line number two it means I do not have AIDS. But if it reaches the end, it means I am positive.”
- “I do not remember it was long time ago”.

Although literature does not clearly confirm the participants' experiences as participants mostly referred to test kits, Worthington, Jackson, Mill, Prentice, Myers, and Sommerfeldt (2010:1269) confirmed the fact that some participants could not remember what was covered during HIV testing. Goldberg (2011:1) mentioned that voluntary counselling and testing is viewed as a core intervention against the spread of HIV. Thus pre-test counselling should occur before an HIV test is undertaken and is a confidential dialogue with a suitably qualified person such as an HIV counsellor, doctor or a nurse (Department of Health, 2000b:7). Voluntary counselling and testing (VCT) is the foundation of HIV and AIDS management. The researcher's view is that if VCT is not provided effectively it will create a problem for patients, as they will not have the opportunity to address the issues that they experiencing regarding their status. According to the Department of Health (2000a:8) a positive HIV test has far

reaching implications for any individual, thus pre- and post-test counselling is required for persons undergoing HIV testing.

However, a few participants reported that they never received the pre- and post-test counselling when testing for HIV. Participants reported that they received no counselling and they never had an understanding of the test. Participants' responses indicating that they never received counselling are below:

- “To tell you the truth, at Zone 3 clinic they never sat with me when I realised that I have HIV.”
- “No there was no counselling, no counselling at the time.”
- “No, they just said many people live with it and as long as I receive treatment I will survive a million years’.
- “No, I just heard them saying ‘we are going to test you’ and I was admitted to one ward where they took me for testing and then they pricked my finger.”

Department of Health (2000b:5) and the Department of Labour (2003:58) state clearly that people need to undergo counselling before the test and after the test is conducted. The participants' experiences are not in line with the HIV and AIDS policy. The researcher's experience in the hospital is that before patients are tested they are referred to the counselling room and undergo pre- and post-test counselling. HIV counselling has undergone various transformations since its inception and currently counselling and the actual testing are provided by the lay counsellors, as they are skilled to perform this duty. Van Dyk (2008:252) and the Department of Labour (2003:58) outlined the purpose of pre-test counselling. Pre-test counselling is to give an individual all the necessary information and support to make an informed decision before undergoing HIV testing.

The researcher's opinion is that this counselling will prepare and familiarise the patient with the test before the actual test is conducted. Patients should sign informed consent forms confirming that they were provided with information regarding the HIV test. This point is emphasised by Department of Health (2000b:5) and *HIV in the Workplace* (2012:27) by stating that HIV testing without informed consent is unlawful in South Africa and people cannot be forced to have an HIV test. Although the literature does not clearly confirm the participants' experiences, some

of the participants expressed that when they were tested, they were very sick so this might have caused them not to remember anything about their counselling. The researcher is of the opinion that the problem can be managed through continuous counselling during follow up sessions with the aim of empowering patients to become more knowledgeable about HIV and AIDS. As part of pre-test counselling, patients' reasons for doing HIV testing need to be explored as this will lay the basis for counselling. Below are the participants' reasons for testing for HIV.

### **Sub-theme 2.1: Participants' reasons for HIV testing**

In this study almost all participants were tested because they were sick. Participants have experienced continuous coughing, vomiting, rashes, tiredness and feelings of weakness. Some participants visited the hospital with the purpose of getting tested for HIV, whereas other participants were advised by health care providers to get tested. The quotations below verify the participant's reasons for getting tested:

- “The reason I had myself tested: I arrived at the hospital and told them that I am sick. They asked me what was wrong and I said that I am coughing, but then the disease keeps on changing. Sometimes I am vomiting and when this sickness is cured something else will start. That is what forced me to do the test for AIDS.”
- “It is me, because I was not well physically; I became weak and tired. I had difficulty breathing.”
- “It was because I was sick. I was feeling cold and then I ended up deciding that I am going to the hospital. They asked me if I want to do the test and I told them there is no problem.”
- “The thing is, the time I came for tests I was at work and I had this silly rash. It made me dark and then it became such an issue that I went to the hospital to do a blood test.”

Only two participants went for testing because they were pregnant. The following quotations validate their reasons for getting tested:

- “I knew about my status, because I was pregnant.”
- “The time I came for blood test, I came to do a pregnancy test and then afterwards they took me to the counsellor for HIV testing.”

Page et al. (2006:60) and Van Dyk (2008:252) indicated that the patients need to be clear on why they need to be tested. The counsellor needs to explore why an individual needs to be tested. Goldberg (2011:1) maintains that the initial sessions of voluntary counselling and testing aim to assess the patient's motivation for finding out his or her sero-status. This implies that exploring the patient's reason for testing is of utmost importance. "What makes the patient feel that he or she might be infected?" (Goldberg 2011:1). Van Dyk (2008:253) mentioned that the individual's perception of their own high risk behaviour and their knowledge of HIV will assist counsellors in gaining insight into the patient's world. This will also help the counsellor to build a working relationship with the patient in order for the patient to be open during the counselling sessions. Thus Goldberg (2011:2) maintains that patients need to be given appropriate time to consider doing the test and should the patient decide to undergo the test, the pre-test counselling session will also entail a discussion about the potential outcomes of the test and the appropriate coping strategies to apply in these instances. The researcher's opinion is that patients need to make a conscious decision to find out about their status. Although the literature does not clearly confirm the participants' reasons for testing Ransom, Siler, Peters and Maurer (2005:391); Van Dyk (2008:253) outlined some of the reasons often given for wanting to get tested, other than the ones given by the participants:

- To protect others or their partners requested it.
- They feel guilty and concerned about having multiple sex partners, or they have been raped or assaulted, etc.

### **Sub-theme 2.2: Participants' feelings about their HIV positive status**

An HIV positive diagnosis may trigger different emotional reactions, as individuals react differently to situations. It might affect some positively, whereas it can affect others negatively. All the participants in this study shared their feelings when they were first diagnosed. The majority of the participants in the study expressed that they accepted their status and they never felt bad about their results. Participants were not stressed about their HIV positive diagnosis and they did not want to bother themselves about what will happen to them. Most participants seemed determined to take and continue with their antiretroviral treatment. The quotations below

substantiate the feelings of the participants after discovering that they were infected with HIV:

- “No, when it comes to my emotions if I want to tell the truth, I did not find myself scared. I do not bother myself with what is going to happen, I do not keep on telling myself that this is going to happen to me. It never pained me that much; no I never felt bad.”
- “I did not feel any pain, because my sister-in-law has the disease. I am not the only one.”
- “I just accepted it from the first time they told me for the sake of the baby, because I was pregnant. I just took it as part of life, so I never had a problem with it.”
- “I never had stress. Even when I am thinking about it I was not scared. I just told myself that this is the way things are, so I told myself that I will take treatment.”

The key responses of acceptance of HIV status as described by the participants can be associated with good or excellent adherence to ART. According to Nam et al. (2008:303) participants who had accepted their status developed a new perception of self, where they identified with being positive and accepted their new image of self with the virus. These individuals were able to develop a positive therapeutic relationship with antiretroviral treatment, meaning an ability to adhere well. Moratioa (2007:73) emphasized that acceptance behaviour and taking medication as prescribed indicates a degree of acceptance of the diagnosis.

However a few participants were affected negatively by their status. Most HIV positive people experience denial during the initial stages of their diagnosis. In this study it was evident that some participants were affected negatively by their diagnosis. Participants expressed feelings of being alone and even had suicidal tendencies, because they could not understand what was happening to them. These participants seemed depressed about their HIV status. They further expressed feeling of sadness and not believing the positive results. The following quotations prove that these participants were affected negatively by their positive status:

- “I felt bad; I thought about it too much. I even thought of committing suicide.”

- “I did not feel good; my heart was broken. That is when I started to be confused, not knowing what to do.”
- “I felt I needed to sleep, just to sleep. I did not feel anything; I just wanted to sleep. I did not understand anything, I wanted to sleep.”
- “It is just that I am negative and positive in my thoughts. I am in between; I believe and I do not believe. I do not believe that the disease is there in my body. I do not believe.”

This finding is confirmed by Moratioa (2007:70) who found that after the diagnosis the participants' emotional reactions varied from depression, anger and denial to acceptance. Some participants do not struggle to accept their condition, while others continue to experience difficulty in coming terms with the illness and its implications. Van Dyk (2008:268) agrees that most HIV positive people go through a phase of denial, because it is an important and protective defence mechanism that temporarily reduces emotional stress. Individuals experiencing adherence difficulties described aspects of denial. Those describing aspects of denial have not fully adapted their status and thus cannot develop a positive and accepting relationship with their ART. Dahab et al. (2008:3) and Moratioa (2007:70) also agree that the denial of the existence of one's own HIV positive status keeps some patients from taking treatment.

The researcher is of the view that patients should be given the time and opportunity to come to terms with their status before they can be initiated on treatment. They need to accept their status in order to be able to comply with their treatment. A participant who did not think that he was HIV infected reported discontinuing treatment because he did not feel that it was necessary to continue with treatment. This opinion is confirmed by Nam et al. (2008:304) who mention that without accepting HIV and adopting a positive therapeutic identity, the internalization of negative attitudes affect an individual's readiness to make lifestyle changes.

### 3.5.2.3 *THEME 3: PARTICIPANTS' PERCEPTIONS AND EXPERIENCES OF USING ANTIRETROVIRAL TREATMENT*

This theme is based on the experiences of participants while using antiretroviral treatment. The purpose was to establish if participants had knowledge about the treatment regimens that they were using, their experiences regarding side effects and whether participants had an understanding of the importance of adherence to treatment. Thus the following sub-themes were identified:

- Participants' knowledge about antiretroviral treatment regimens
- Participants' experiences regarding the side effects of antiretroviral treatment
- Participants' perceptions regarding antiretroviral treatment
- Participants' understanding of treatment adherence

#### **Sub-theme 3.1: Participants' knowledge about antiretroviral treatment regimens**

The majority of participants in the study do not know much about the treatment regimens that they are using. Most participants in the study reported that they do not know their treatment regimens. Participants indicated that they were educated about the treatment types, but that they would not be able to explain the types. It seems it is much easier for them to identify their medication when they see the medication containers. The quotations below verify the fact that participants had no knowledge base of the treatment that they are using:

- "I do not know their names, I mean I do not know their types."
- "Some nurses tell us their names when we come to Thekganang ARV Clinic, but I am not able to pronounce their names."
- "The medication I know, but I just know them when I see them. When it comes to names, I never took a look at the names. I never thought that one day I would be asked whether I know my treatment."
- "No those pills, they just gave me the other ones, the ones they gave me the first time and then they gave me another type the second time."

The finding correlates with the findings by South, Wringe, Kumogola, Isingo, Manyalla, Cawley, Zaba, Todd and Urassa (2013:1) that knowledge regarding

treatment was worryingly poor in HIV positive people. Maskew et al. (2007:854) and Wasti et al. (2012:76) agree that many ARV regimens are complicated and have a high pill burden. This may make compliance difficult for patients and may result in viral failure, development of drug resistance and limited future treatment options. Heyer and Ogunbanjo (2006:6) maintain that patients who have inadequate information about ART or who have difficulty understanding medication schedules and the relationship between adherence, viral load and disease progression adhere significantly poorer than patients who have an accurate understanding of the purpose of ART. The findings by Miller, Liu, Hays, Golin, Ye, Beck, Kaplan and Wenger (2003:514) revealed that poor medication knowledge eight weeks after regimen initiation was associated with a lower level of literacy.

Only four participants attempted to explain the type of medication that they are using. Participants mentioned Nevirapine as one of the drugs. Even though participants did not seem fully conversant with the treatment types, they mentioned Nevirapine, Lamivudine and Stavudine as their treatment regimens and some knew that there are three types of medicines per regimen. Some of the quotations to substantiate that they had an idea of the treatment regimen they were using are as follows:

- “I do not know them that well. The one that I know was called Nevirapine.”
- “Yes, Efavirenz, Lamivudine and Stavudine. I know these ones.”
- “I just know Zonke and Nevirapine.”
- “Yes I know them. It is Nevirapine, Lamivudine and then that other one I forgot. But there are three types.”

The finding of this study was contradictory to the findings of Miller et al. (2003:36) where on average participants in the study correctly responded to 80% of questions about medication names. The researcher is of the opinion that knowledge regarding antiretroviral treatment is a better predictor of adherence, since lack of understanding may promote non-compliance. This finding correlates with the findings of Moratioa (2007:12) that patients' understanding of their medical conditions and treatment recommendations are a strong predictor of treatment adherence. Patients need to understand what the different treatment combinations do to the body. The Foundation for Professional Development (2009:41) explains that the counsellor will have an opportunity to discuss the different treatment and scheduling options with

patients, thus they should also be shown what the drugs look like and discuss their names. A patient needs to be educated about the side effects of antiretroviral treatment.

### **Sub-theme 3.2: Participants' experiences regarding the side effects of antiretroviral treatment**

Most people who take antiretroviral treatment will experience side effects at some point, but there are some people who do not experience any side effects at all (*Soul City Institute Health and Development Communication, 2008:33*). It is important to note that any drug can have side effects and it is no different with ART. Side effects include headaches, dizziness, muscle pains, vomiting, tiredness, diarrhoea and rashes (*Foundation for Professional Development, 2009:50; Van Dyk, 2008:101*). The majority of participants in the study experienced side effects while taking their antiretroviral treatment. The quotations below support the fact that some of the participants experienced side effects:

- “It’s just that all of the pills treated me badly and they changed them. When I drank them my skin became darker, even my whole body. My hands become darker and even my nails.”
- “When I continued taking my treatment it just made me dizzy and nauseous, as if I am going to vomit.”
- “No they were making me dizzy and these things (dark spots) here on my face are because of treatment. Even my face’s skin is peeling.”
- “When I started to drink the medication I was vomiting, but then after three months I started to be fine.”
- “They (ARVs) did not treat me well; they made me react in an unusual way, because when I drink them I vomit. They gave me cramps in my feet and sometimes they made me drunk.”

The availability of ART has improved the quality of life for people living with HIV and has greatly reduced the number of opportunistic infections and deaths related to AIDS. However, ART can cause side effects for patients (*Foundation for*

Professional Development, 2009:50). Participants, as indicated, experienced side effects including dizziness, rashes, nausea, sweating and swollen legs, as confirmed in the literature. The Foundation for Professional Development (2009: 50); *Soul City Institute Health and Development Communication* (2008:33); and Van Dyk (2008:101) confirmed that patients usually experience the said side effects within weeks of initiating treatment. The researcher's opinion is that the responsibility rests with health care practitioners to educate patients about the side effects during the follow up visits. Van Dyk (2008:101) mentions that one of the important factors in the success of treatment is how well the patient tolerates antiretroviral drugs. Maskew et al. (2007:854); Heyer and Ogunbanjo. (2006:5) agree that those individuals who experienced adverse drug effects defaulted treatment. It is interesting to note that although patients experienced side effects in this study, it was not the reason they discontinued treatment. These findings are in agreement with the studies conducted by Miller et al. (2010:52), Moratioa, (2007:78) and Weiser et al. (2003: 287), who indicated that side effects associated with ART were less influential in adherence. Side effects did not pose a large barrier to adherence in this study group and participants did not discontinue their medication as a result of these side effects.

The literature suggests that not all patients who are initiated on ART will experience the side effects (*Soul City Institute Health and Development Communication*, 2008:33). This correlates with the findings of this study in that five participants never experienced any side effects, even when they started with their treatment. They highlighted that they had no ill effects from the ARVs and they never had problems with their medication. These quotations below confirm that some participants never had any side effects:

- “No I never had problems with the treatment.”
- “No, they treated me well.”
- “I never had problems with them. If I drink them when I am going to sleep, I sleep peacefully and then on my body there are no signs that these pills can give me problems.”

Only one participant never drank her treatment, despite collecting it from the hospital. Dahab et al. (2008:3) mentioned that feeling well and experiencing side effects were the main disease and treatment factors reported to influence

adherence. Feeling well after taking treatment was reported as both a barrier to and a facilitator of adherence. But usually a patient who reported severe side effects, including hallucinations, which affected his ability to work discontinued ART in the early stages of treatment. Heyer and Ogunbanjo (2006:6) maintain that adverse drug events influence willingness to take medication and are consistently associated with poorer adherence. The participants never experienced side effects, but they discontinued their treatment. However, some participants emphasized the importance of being listened to by health professionals regarding the side effects. If health professionals do not listen to the participants' complain presented during their consultations, they will default their medication. The following quotation supports this statement:

- “If they (health professionals) continue giving me the same medication and I can see that it is not treating me well, then I will stop.”

### **Sub-theme 3.3: Participants' perceptions regarding antiretroviral treatment**

Participants perceived antiretroviral treatment in different ways. The majority of participants perceived the treatment as useful and believed it enhanced their lives. Participants experienced improved appetite and they became healthy because of the treatment. The following quotations validate the participants' perceptions of taking antiretroviral treatment:

- “So when I started taking treatment I explained to the doctor that I have problems with my appetite, but since I have been taking the pills I started having an appetite and I was well and my body recovered. I became healthy.”
- “Ah, I was okay. I never had problems with the treatment. Before starting to use the medication I had a big body. Now that I am using the medicine I am fine.”
- “I do not have problems, because I realised the importance of this treatment.”
- “Ever since I started taking them I found that my body is just like it was before I was infected with this disease. I had a problem with vaginal itchiness, but when I started taking the treatment I discovered that I am better.”

Miller et al. (2010:50) and Nam et al. (2008:307) confirm that patients universally reported that they had experienced important health benefits from taking ART and

recognised that stopping ART would lead to illness. Patients desire to live longer and improve their overall health because of ART motivated adherence. Patients wish to be healthy and look well and they are committed to their families as breadwinners. The study by Wakibi et al. (2011:6) found that the respondents regarded adherence to ART as extremely important to HIV treatment and translated this knowledge into a positive belief about the necessity of antiretroviral treatment. Belief in the benefit of therapy along with the availability of free treatment is credited for improved adherence among the respondents. If patients have a good relationship with their treatment and believe that the treatment is effective they will in turn adhere to their treatment.

This study correlates with the findings of Wasti et al. (2012:76) that an individual's perceptions of ART effectiveness or visible signs that medications work are helpful to reinforce adherence, thus an individual's belief about treatment based on trust or mistrust influences adherence. Therefore the patient's belief that the antiretroviral medication is effective will improve adherence to treatment (Foundation for Professional Development, 2009:155). The researcher is of the view that although the participants perceived antiretroviral treatment as important, their actions were incongruent with their knowledge as they all defaulted treatment. However, most participants were willing to be re-initiated on treatment.

Dahab et al. (2008:2) cited that individual factors associated with poor adherence include the perception that ART has a negative effect. Only a few participants perceived the use of ARVs negatively. Participants expressed feeling good when they discontinued treatment and that their bodies no longer smelled like the medication. These are the direct quotations from the participants to validate how they perceived treatment:

- “Ever since I stopped taking treatment my body is much lighter. While I was on treatment I was asleep most of the time.”
- “I do not want them (ARV) anymore. No you always smell pills.”
- “The medication is treating me badly and that does not satisfy me.”
- “By then I had just received them (ARVs), but I had not yet started using them. When I arrived at home and I started looking at them (ARV) and I just told myself that I cannot take them.”

The decision to take ART is a decision for life. In support of the above findings Heyer and Ogunbanjo (2006:8) agree that the patient's belief system significantly influences adherence to ART, thus greater adherence is observed in patients who believe ART is effective while negative beliefs reduce adherence. The Foundation for Professional Development (2009:39) indicates that patients' own views on ART need to be assessed. This will help the counsellor to understand the patient's own perception and understanding of treatment. Whether they think it is a cure, how long they think they will have to take it and what impact they expect it to have on them, etc. A patient's understanding of treatment is imperative for treatment compliance.

### **Sub-theme 3.4: Participants' understanding of antiretroviral treatment adherence**

Adherence to antiretroviral treatment is a critical component of the successful management of HIV. The majority of the participants had an understanding of adherence to treatment and the meaning of adherence to treatment. The participants had an understanding about the importance of taking treatment on time and using protection during sex to avoid re-infection. Participants were encouraged to report their progress or challenges during follow up visits at the treatment facility. Patients are encouraged by health professionals during clinic visits not discontinue treatment without consulting their health care professionals. Adherence counselling further includes educating patients on how to take ART. The following quotations validate the participants' understanding of adherence to antiretroviral treatment:

- “The fact that I am not supposed to skip a day without taking my treatment and I am supposed to take my treatment on time.”
- “The doctor told me that I am going to start taking ARV's and when I come to hospital I should tell them how I am doing with this treatment. If they [the pills] are making me vomit I should inform them, but the main thing is that I must not stop taking my treatment.”
- “They educated me about adherence to treatment. Even when you are sick you must take your treatment. They explained how to take the medication.”

- “They taught me that if I am going to have sex we must use condoms and I should not stop taking treatment. It is my lifetime treatment.”

This finding was confirmed by Nachega et al. (2005:196) that the majority of participants had knowledge about the importance of adherence to antiretroviral treatment. Thus Glass et al. (2006:385) stated that adherence is imperative to guarantee the effectiveness of ART. It is interesting to note that in this study although most participants had knowledge about adherence, they discontinued their treatment. Weiser et al. (2003:285) confirmed that patients had excellent knowledge about HIV and AIDS, although adherence levels were inadequate. Wasti et al. (2012:76) maintain that the knowledge of the consequences of adherence and non-adherence is an important basis of trust and belief that can reinforce adherence. The success of adherence to ART depends on the intensity of treatment counselling, the education and information given to the patient during counselling sessions, and the ability of the patient to make informed choices about treatment (Foundation for Professional Development, 2009:38).

Only two participants indicated that they never received proper adherence counselling regarding treatment. These participants study divulged that they were never informed about the treatment. The following quotation confirms that the participants never received adherence counselling on initiation of ART:

- “I did not get an explanation concerning those tablets.”
- “No, they never informed me about treatment.”

Murray, Semrau , McCurley , Thea, Scott, Mwiya, Kankasa, Bass and Bolton (2009:6) confirm that barriers related to lack of accurate information about HIV and ART was a frequent theme in interviews. Participants commonly suggested that counselling about the effects of ARVs was inadequate. Wasti et al. (2012:75) indicated that two studies found that inadequate counselling or limited instruction prevented adherence. Before patients are initiated on treatment they need to undergo intensive counselling to prepare them to take treatment and identify factors that may impede adherence. In support of this view Dahab et al. (2008:2) explained that all patients underwent intensive adherence counselling aimed at preparing them to start taking ART. Counselling was also provided at all subsequent programme visits. Therefore in order to maintain and improve adherence, patients need to be

educated on the importance of adherence and the implications of non-adherence (Foundation for Professional Development, 2009:41).

#### 3.5.2.4 *THEME 4: CHALLENGES FACED BY PARTICIPANTS WHILE ON ANTIRETROVIRAL TREATMENT*

Taking antiretroviral treatment is a lifetime commitment. Only a few participants indicated that they experienced challenges when taking their treatment, thus the following sub-themes were identified:

- Participants' fear of disclosing
- Physical challenges experienced by participants
- Participants' fear of stigmatization

##### **Sub-theme 4.1: Participants' fear of disclosing**

Four participants maintain that the challenge they had with antiretroviral treatment is fear of disclosing their HIV status at work and even to their families. Participants in the study revealed that they were afraid to disclose because people talk too much and they also fear dismissal at work. The following quotations validate the participants' experience regarding their fear of disclosure:

- “Even my employers, they asked me on several occasions what type of disease I am suffering from. When I told them (employer) that I was going to take my medication they once called me to one side and asked me if I have AIDS and I said no.”
- “I started to work for those people (new employer). I never informed them that I have this type of disease, because I was afraid that if I tell them they will fire me at work.”
- “I am afraid to tell people, because people talk too much.”
- “So my understanding was that if I tell them at home, even my loved ones will start behaving strangely towards me and I will lose the people that I love. That is what made me keep quiet and keep it secret.”

Wasti et al.(2012:75) confirm that the sociocultural factors preventing adherence to ART include fear of disclosure of HIV status. This finding is compatible with the finding of Brinkhof et al. (2009:8) and Maskew et al. (2007:854) that for some patients' fear of disclosing their status, especially to employers or colleagues, led to difficulty in obtaining and using treatment correctly. Patients' feared dismissal if employers found out that they are using ARVs. Thus to prevent unwanted disclosure, participants hid their medication which in turn led to either delayed or missed doses (Brinkhof et al., 2009:8;Wasti et al., 2011:75). The literature clearly confirms the participants' experiences of fear of disclosing their HIV positive status. In support of this Foundation for Professional Development (2009:31) and Van Dyk (2008:282) agree that some reasons given by participants for not disclosing their HIV positive status include fear of rejection, isolation, stigma, discrimination, gossip, victimization from family and friends, and fear of losing their jobs. The Foundation for Professional Development (2009:31) describes disclosure of HIV positive status as the first step that is required to break down stigma.

The decision whether or not to disclose one's positive status is difficult, because disclosure or non-disclosure may have major life changing consequences. Van Dyk (2008:280) maintains that disclosure can also be accompanied by negative consequences, such as problems in relationships with sexual partners, family members, friends, community members, employers or colleagues. One participant expressed a painful experience that occurred after she informed her employer about her status. The following quotation supports the participant's experience:

- "They (employer) told me to go back home and rest; that I can return when they inform me. When I was supposed to come back for duty, they told me that they have already employed someone else. You see it is because of the issue that they did not want me back."

This participant was unable to disclose to her family and she ended up defaulting treatment. Wasti et al (2012:76) emphasized that patients who had not disclosed their HIV status, or who were unable to disclose their status to others, did not have support and were more likely to be non-adherent.

### **Sub-theme 4.2: Physical challenges experienced by participants**

Only three participants experienced physical challenges with regard to the treatment. Participants disclosed that when they were using treatment they got tired at work and others were unable to seek employment because they were physically weak. The following direct quotations validate the participants' experiences:

- “When I was still on treatment I was unable to stand, I was not able to stand for long periods. I am a domestic worker and when you stand for a long period you get tired.”
- “And the challenges that I experienced is that sometimes my body is tired, but now I think this might be because of the work I am doing. It is a heavy job.”
- “Even at school they said they want people to come and work, but when I look at myself I will not be able to work because I do not have strength.”

This is compatible with the findings of Miller et al. (2010:50) who stated that participants reported experiencing negative physical health effects although some reports were minor, such as a worsened cough. Patients who are on antiretroviral treatment experience some physical challenges which affect their functioning. ART has transformed HIV and AIDS into a chronic but manageable disease. However, Van Dyk (2008:105) confirms that antiretroviral therapy will cause irreversible changes in the patient's life and the health care professional should consider every advantage and disadvantage treatment is likely to bring before prescribing it to any patient. In the study one participant expressed that she is unable to work even if she receives job opportunities, because she is weak and she will not be in a position to perform the duties assigned to her. The other participant who worked as a domestic worker indicated that ever since she discontinued her ARVs she is fine, because when she was at work while on treatment she was unable to stand for long periods. These physical challenges had a direct impact on the lifestyle of the participants.

### **Sub-theme 4.3: Participants' fear of stigmatization**

Another challenge of being on antiretroviral treatment is the fear of stigmatization. Participants experienced negative responses from their families, colleagues, employers and communities. It was evident from participants' responses that they

are afraid to take their ARVs in front of other people, whether they are related or not. Participants in this study denoted that they are afraid to take treatment at their nearest treatment facilities as people in their neighbourhood will see them and start talking about them. The following quotations confirm the participant's direct responses that they fear to be stigmatized:

- “They (employers) told me to go back home and rest and that I will return when they want me. When I was supposed to return back for duty they told me that they have already employed someone else. You see, it is because of the issue that they didn't want me back.”
- “That is why I was afraid to take treatment at the nearest hospital, Mankweng, or even at the clinic there next to my home, because people will see me at the local clinic.”
- “I am afraid to tell people, they speak too much.”
- “When I am at work we stay at the hostels and you find that we are all staying in one place. So when I am taking my pills I am not supposed to take them in front of my colleagues. I am afraid to take them in front of them (colleagues).”

Both Van Cutsem et al. (2011:7) and Wasti et al. (2012:75) confirm that socio-cultural factors preventing adherence to ART are stigma and discrimination. In support of this view Nakiyemba et al. ([sa]:50) and Wasti et al. (2011:76) confirm that patients were embarrassed to take medication in front of others and concerned about their privacy. Owing to the fear of exclusion from society, patients skipped medication if they had to take it in front of others. Dahab et al. (2008:3) indicated that both patients and health care providers reported that fear of stigmatization reportedly caused patients to hide their ART or skip doses when in the presence of others. The issue of stigma has been a barrier to people living with AIDS in terms of getting access to available support and care services (Daniel et al., 2008:223). Wasti et al. (2012:77) agree that people living with HIV were unwilling to seek treatment at their nearest institution because of fear of stigmatization. Negative community myths and beliefs about HIV are barriers to ART adherence. Patients have to be given an opportunity to think about their living and work environment, especially whether or not the people that they work or share the house with are aware of their HIV status and if they going to have to hide their treatment (Foundation for Professional

Development, 2009:39). All these issues will impact on what is the most suitable treatment option for the client.

Murray et al. (2009:5) found that stigma in general emerged as a significant challenge to ART acceptance and adherence. This was described in many different ways, including the fear of being laughed at, the fear of being embarrassed or that others will know their status. The negative repercussions of stigma for patients included rejection by family, broken relationships and loss of employment (Weiser et al., 2003:285). The Foundation for Professional Development (2009:28) states clearly that a patient who deals more effectively with stigma and discrimination is more inclined to be adherent than those patients who have not dealt appropriately with stigma and discrimination.

In view of the above findings it is also interesting to note that although patients can be referred to their nearest treatment facilities, not all patients wish to be transferred due to the fear of stigmatization. The researcher is of the view that patients need to be assessed thoroughly and individual need to be taken into consideration because if patients are forced to go to their local treatment facilities without their willingness they will probably default treatment. In support of this statement Van Dyk (2008:92) ascertains that the management of HIV infection should be individualised so that the management can focus on the specific needs of that client. Understanding and dealing with stigma is very important in encouraging and sustaining adherence to ART, as it can impact on the quality of life for people living with HIV (Foundation for Professional Development, 2009:30).

The majority of the participants maintain that they never had challenges with their treatment. Participants denote that they never encountered problems with the treatment. The following quotations confirm the participants' responses:

- "I never had challenges; I do not want to lie."
- "I did not encounter any problems. The only ones I had was the vomiting, feeling drunk, and the cramps."
- "I never experienced any problems; the problem was with those pills that I ended up discontinuing."

It is interesting to note that these participants never had challenges with their treatment and yet they were non-adherent to their treatment. Dahab et al. (2008:2) ascertain that given that adherence is the strongest predictor of treatment success, a clearer understanding of adherence barriers in low income countries providing ART is needed. Thus exploring the reasons of treatment default is imperative.

### *3.5.2.5 THEME 5: PARTICIPANTS' REASONS FOR DEFAULTING ANTIRETROVIRAL TREATMENT*

Non-adherence to ART has become a major challenge to those who are living with HIV. The main focus of the research was on exploring the reasons patients default their antiretroviral treatment in Thekganang ARV Clinic. Due to the goal of the study the researcher presented a full picture of the reasons for treatment default although some reasons are indicated by only one participant. Based on the findings all the participants in the study default their antiretroviral treatment. The participants identified the following reasons, which will be discussed as sub-themes:

- Lack of money for transportation.
- Shortage of food in the household.
- Drug abuse.
- Problems leaving work to make clinic appointments.
- Relocation.
- Mental Health problems such as depression and stress.
- Too busy with personal business.
- Participant had not started taking the drugs despite collecting them from the clinic.
- Surplus medication.
- Lost appointment card.
- Confusion about drug regimen.
- Child care.

### **Sub-theme 5.1: Lack of money for transportation**

Although the cost for receiving treatment in government facilities is free, additional costs are incurred through travelling to the facilities and this have negative implications to participants who cannot afford it. Four participants in the study mention that the reason for defaulting treatment was because of lack of money for transportation. Participants in the study revealed that they were unable to come to the treatment facility because they could not afford transportation fees. Quotations below substantiate the participants' reason for defaulting treatment:

- “I did not have the money for transportation.”
- “No this treatment I never default just for fun. The problem was that I was unable to go and collect treatment because of transportation.”
- “The main thing that made me stop treatment was finances, so I was unable to come to the department to collect treatment.”
- “When I was supposed to come back again, it is far and I am no longer employed. It was an issue of not having money for transportation.”

In the view of the above statements it is clear that the participants failed to adhere to treatment because of financial difficulties. Several authors (Krebs et al., 2008:313; Miller et al., 2010:52; Moratioa, 2007:85; Nakiyemba et al., [sa]:39; Van Cutsem et al., 2011:7 ; Wasti et al., 2012:75) agree that patients are non-adherent because of financial difficulties. Transport costs were prominent reasons for participants failing to access their medication. Lack of money for travel seemed even worse for participants at the public facility which provides services for ARV users who are poor. In a study conducted by Nakiyemba et al. ([sa]:39) patients reported missing follow up treatment mainly due to lack of transportation to the centre. Thus financial problems affect adherence to ARV treatment.

Daniel et al. (2008: 224) also noted that many of the respondents in their study were not residing in town, thus the cost of transportation contributed to treatment default. This finding is consistent with the finding of Maskew et al. (2007:853) and Weiser et al. (2003:285) that lack of money for transportation is the biggest obstacle to obtaining treatment. Patients had to overcome great odds to adhere to treatment; they lacked adequate funds and often had to travel great distances. Lack of money for transportation was also raised as a concern by health care workers in a study by

Nakiyemba et al. ([sa]: 39) who found that travel costs for patients would affect adherence to treatment. In this study participants expressed that they defaulted treatment because they do not have money for transportation and they are staying far from the hospital. It should also be noted that the majority of the participants had no source of income in their households as they are not employed. Even though participants had the option of being referred to their local clinic, it was not a solution to all of them as some do not wish to take treatment near their homes.

### **Sub-theme 5.2: Shortage of food in the household**

Four participants in the study indicated that they default treatment because of shortage of food in the household. Participants in the study revealed that they were suffering and they cannot take treatment on empty stomachs. The following quotations are direct responses from the participants confirming that they default treatment because of shortage of food in the household:

- “The reason why I stopped taking the medication is because I was suffering; I was unable to drink my medication, because I was afraid to drink the medication as there was nothing to eat.”
- “I do not have sufficient food, so when I do not have food I do not take my medication, because I cannot take treatment on an empty stomach.”
- “Shortage of food is the main challenge.”

In the view of the above-mentioned statements it is evident that these participants were non-adherent to their treatment due to shortage of food in the household. Murray et al. (2009:10); Nakiyemba et al. ([sa]:40) and Weiser et al. (2003:284) confirm that lack of food frustrate patients' determination to take and adhere to ART, since they had nothing to eat as their appetite improved. This finding is compatible with the findings by Wasti et al. (2012:75) and Van Cutsem et al. (2011:75) that food costs are also a prominent reason for patients failing to access their medication. Most participants in this study are not employed, have no source of income in their household and do not qualify for the government disability grant. As a result lack of food interfered with their ability to comply with treatment. Murray et al. (2009:10) found that some participants indicated that the medication gives them an appetite

and they wanted to eat more often, but if there is no food in the household this posed a challenge to the patients. Food is considered vital to being able to take ART.

Moratioa (2007:85) further highlighted that the financial difficulties of patients contribute to their falling ill, which further affects the quality of their life and illness management due to inadequate nutrition. Nam et al. (2008:306) found that patients perceive ART as being powerful and strong and therefore believe that they must also be strong to withstand the potency of the drugs, thus food and the ability to eat are important in achieving adherence. Currently the South African Social Security Agency (SASSA) has a provision of social relief of distress in the form of food vouchers given to qualifying patients for a period of three months, but the challenge is that the food vouchers are sometimes not available due to budget constraints. As a result these food vouchers cannot be seen as a solution to the shortage of food. Inability to access or take food with ARVs is associated with poor adherence patterns (Nam et al., 2008:308). In view of the above statements it is evident that hungry people are inclined to stop taking ARVs, because they cannot afford to feed themselves as their body metabolism improves and the demand for food increases (Nakiyemba et al., [sa]:50).

### **Sub-theme 5.3: Drug abuse**

Only one participant out of 14 participants in the study indicated that he defaulted treatment because he was abusing substances. The following statement is a direct quotation from the participant validating that the use of substances caused him to default his treatment:

- “I ended up smoking dangerous things and using drugs. I used drugs and when I see it is time to come for my treatment, I realised that I do not have time to come.”

This is confirmed by several authors (Foundation for Professional Development, 2009:155; Van Cutsem et al., 2011:7; Van Dyk, 2008:105 ; Wasti et al., 2012:75) who found that risk factors for failure to follow up were concurrent with substance misuse, including drug abuse. Substance misuse was thus a determinant of non-adherence. Heyer and Ogunbanjo (2006:9) is in agreement with the findings that

active substance abuse is generally associated with lower adherence. Van Dyk (2008:105) maintains that patients under the influence of alcohol often do not take their medication or cannot remember if they have taken treatment. In order to address this, the Foundation for Professional Development (2009:39) maintains that it is also helpful to understand whether the patient has a history of alcohol and recreational drug use as this may impact on their ability to be adherent. Active substance abuse should be addressed before initiating ART.

#### **Sub-theme 5.4: Problems leaving work to make clinic appointments**

Out of the 14 participants only two of them cited that they default treatment because they were unable to leave their work stations to go to the hospital for collection of their treatment. Participants revealed that they were afraid to request time off from their employer to collect medication at the treatment facility. The following quotations reflect that the participants were unable to leave their work to attend clinic appointments:

- “My employer told me ‘you cannot just come and tell us that it is time for you to collect your treatment when you see that it is our busy time. When you leave your job and go then it means by the time you return here your work will be far behind’.”
- “My reason was that I found a job last year and I was afraid to tell them (employer), because they will fire me at work.”

Dalal et al. (2008:104), Weiser et al. (2003:285) and Miller et al. (2010:51) postulated that some of the reasons cited for defaulting included difficulties leaving work to make clinic appointments. This is a challenge because the clinic operates during normal working hours and they are not open during weekends. This finding is also consistent with the findings in a study by Miller et al. (2010:51) who mentioned that patients who default treatment reported that employment caused difficulties with obtaining medication as they could not take time off during the regular clinic operating hours. Fear of stigma in the workplace could also contribute to the inability to request time off to collect medication (Miller et al., 2010: 51).

### **Sub-theme 5.5: Relocation**

Only one participant cited relocation as the main reason for defaulting treatment. This participant disclosed that she returned to her home and as a result could not continue with her treatment. The following direct quotation proved that the participant defaulted treatment because of relocation from her workplace to her own family:

- “I can say it is because I returned home right. That is why I told you that at home I will lose the people that I love.”

Dalal et al. (2008:104) and Daniel et al. (2008:221) confirmed that one of the major reasons for treatment default is relocation to town of origin.

### **Sub-theme 5.6: Mental health problems such as depression and stress**

Depression and stress are some of the strongest predictors of non-adherence. In this study three participants out of 14 participants cited that they default treatment because of mental health problems such as depression and stress. Participants denoted that they were stressed. The statements below are direct quotations from the participants confirming the reasons for defaulting treatment:

- “It was because I was stressed; I was stressed and I ended up wanting to commit suicide.”
- “I had depression. I was always stressed, having a headache.”
- “So that caused, I am going to tell you the truth, it caused me to stress too much.”

The Foundation for Professional Development (2009:155) states that patient related factors that lead to non-adherence include depression. This finding is confirmed by Van Dyk (2008:269) who agrees that people with HIV and AIDS often experience depression because they feel that they have lost so much in life and that they themselves are to blame for it. Daniel et al. (2008: 223) and Wasti et al. (2012:75) also revealed that depression has been observed as a reason why patients are non-adherent to antiretroviral drug use. This finding is in agreement with the findings of Olisah et al. (2010:276) who found that patients who were not depressed were two times more likely to be adherent than those who were depressed. The consequence

is patients with HIV and AIDS that are suffering from depression may be more likely to forget to use their pills, which leads to poor medication adherence.

The participants in this study never bothered to seek professional intervention for depression. This was in agreement with the findings by Moratioa (2007:89) that although the participants could benefit from the psychological intervention, they have not received psychological counselling and it is likely that their depression may worsen their condition. In the hospital the services of the social workers and the psychologists are available which, in the researcher's opinion, the participant might have benefited from before treatment default could occur. The services of the psychologist include psychotherapy and the services of the social worker include screening and assessment, counselling and linking patients with relevant resources, such as drug rehabilitation facilities.

Olisah et al. (2010:276) indicated that depression is the most commonly observed psychiatric disorder among patients with HIV infection and thus HIV increases the risk of developing major depression through a variety of mechanisms, including direct injury to subcortical areas of the brain, chronic stress resulting from unemployment and stigmatization, worsening of social isolation, and bereavement. Research suggests that co-morbid depression in patients with HIV and AIDS maybe associated with reduced adherence to ART and furthermore with disease progression. Growing evidence suggests that adherence programs may need to include assessment and treatment of depressive symptoms or other mental health issues for those who are eligible or currently on treatment (Murray et al., 2009:6).

#### **Sub-theme 5.7: Too busy with personal business**

Only two participants out of the 14 indicated that the reason for defaulting treatment was because they had too much personal business. The first participant indicated that he went to his church and spent weeks there and later visited his parental home to discuss their family matters. Then he had to arrange with his wife to get married at home affairs. So he ended up not having time to collect his treatment. The second participant indicated that the reason for treatment default was death in his family. The participant divulged that his sister's death affected him negatively and as a

result he ended up not coming for his treatment, as he had to take care of his sister's children and mother. The statements below confirm the participants' reasons for treatment default:

- “The thing that made me not come here after a long period is family issues. So I find that when I take all these issues and put them in one place, I end up forgetting even my treatment.”
- “I stopped treatment because of problems, you see. The problem was that I lost my younger sister.”

This is confirmed by Krebs et al. (2008:312), Talam et al. (2008:77), Wasti et al. (2012:73) and Weiser et al. (2003:284) who cited that patients were too busy with personal business is one of the reasons for treatment default. This finding correlates with the findings of Wakibi et al. (2011:6) where three quarters of the respondents who gave a reason for skipping therapy stated their reason as being too busy. Wasti et al. (2012:73) cited factors impeding adherence to ART included patients being too busy with other things. Patients are having difficulties fitting treatment in with their own daily programs and this predicted non-adherence. The treatment regimen should be kept as simple as possible and be tailored to the patients' lifestyles (Heyer & Ogunbanjo, 2006:5).

The researcher's view is that busy working schedules among patients contributed to poor compliance to treatment, as patients spent most of their time at work and are unable to maintain a work/life balance and as a result they end up not having time to come to the clinic to collect their treatment. Talam et al. (2008:77) established that participants with busy working schedules adhered poorly to treatment.

#### **Sub-theme 5.8: Participant had not started taking the drugs despite collecting them from the clinic**

Only one participant mentioned that she was initiated on antiretroviral treatment and she came to the hospital during her clinic appointments to collect treatment, but she never took the treatment. The following quotation validates the participant's response that she did collect the treatment but did not start taking the drugs:

- “Yes, I received them. I never stopped coming for treatment, but no I never drank them.”

This finding is consistent with the findings of Tweya et al. (2010:82) that the most common reason for missed appointments was that patients had not started taking drugs despite collecting them. Heyer and Ogunbanjo (2006:5) outlined the South African ART guidelines where in a patient had to demonstrate an expression of willingness and readiness to take ART adherently. The researcher is of the opinion that a patient’s readiness should be thoroughly assessed before he or she can be initiated on ART. On going counselling and measures of adherence can be utilised to determine if the patient is taking treatment or not. Regarding patient readiness to treatment, the Foundation for Professional Development (2009:38) ascertained that it is important not to rush a patient into making a decision about treatment and to ensure as far as possible that the patient understands what is involved.

#### **Sub-theme 5.9: Surplus medication**

One participant indicated that the reason for defaulting treatment was because when he came for an appointment he was given a surplus of medication while he still had some at home, so he ended up not coming to the hospital and discontinuing his treatment. The following quotation verifies the participant’s response:

- “They once gave me treatment the time I came to check my blood after three months. They wrote me another prescription and I still had a surplus of medication at home. Then my appointment date passed and I told myself I will go, but I ended up not coming for treatment.”

This reason is confirmed by Krebs et al. (2008:312), who cited surplus medication as a reason for treatment default.

#### **Sub-theme 5.10: Lost appointment card**

Two participants in the study mentioned that one of the reasons for defaulting treatment is because they lost their appointment cards. Participants divulged that they misplaced their appointment cards and were afraid to come to the clinic without

cards. The statements below confirm the participants' responses regarding their reason for treatment default:

- “I lost my appointment card. When I was supposed to come and collect treatment, I looked for it but I did not find it. When you take out your file they need the card.”
- “And then, right, the other problem, *eish*, I do not know where I left my hospital card.”

Miller et al. (2010:51) and Krebs et al. (2008:313) validate that participants cited missing paperwork, including clinic cards, as a reason for missing appointments. Patients are reluctant to come to the clinic if they do not have the necessary clinic documents. This finding is consistent with the finding of Brinkhof et al. (2009:5) that administrative problems at clinics such as loss of patient cards impeded on adherence. Even though patients are not sent back from the clinic if they do not have clinic cards, patients are just reluctant to come without cards.

#### **Sub-theme 5.11: Confusion about drug regimen**

Only one participant cited confusion about drug regimen as a reason for treatment default. The participant revealed that she did not stop the medication, but she was taking them in halves as she did not know how to take the medication. The quotation below validates the participant's reason for treatment default:

- “I did not stop the medication; I was taking the medication in halves.”

Several authors (Krebs et al., 2008:313; Maskew et al., 2007:854; Wasti et al., 2012:73) agree with this finding that confusion about drug regimen and not understanding treatment are reasons for treatment default. Patients are confused about how to take the medication and as a result fail to comply with the drug regimen. The Foundation for Professional Development (2009:155) indicated therapy related factors affecting adherence to therapy for HIV and AIDS include a lack of clear instructions about how to take the medications, as well as an inability to fit medication to individual's lifestyle.

### **Sub-theme 5.12: Child care**

Only one participant in the study mentioned that she defaulted treatment because she could not leave her children, who are minors, alone at home. The following quotation verifies the participant's reason for treatment default:

- “And the children did not have a nanny and I am afraid to bother other people to ask them to babysit my children until I get back.”

Krebs et al. (2008:315) confirmed structural barriers such as child care as reasons for treatment default.

#### ***3.5.2.6 THEME: 6 PARTICIPANTS' EXPERIENCES OF RECEIVING TREATMENT IN THEKGANANG ARV CLINIC***

Participants shared their experiences about the services that they receive at Thekganang ARV Clinic. The majority of participants in the study were satisfied with the clinic services. Participants reported the services as good and that they never experienced any problems with the services. The following quotations are direct responses from the participants:

- “There are no problems. You take your file and vitals, then you consult the doctor and he will write a prescription and they will give you the next appointment date.”
- “No, I am satisfied with the clinic's services.”
- “I did not see any problems since I started drinking the pills.”
- “The staff are good and cooperative and they have passion.”

The majority of the participants were happy with the manner in which services are provided in Thekganang ARV Clinic. They did not have suggestions on how to improve the services. They expressed that staff members are friendly towards patients during the clinic visit. However, four participants raised concerns with regard to the services in the clinic. Two sub-themes emerged from this theme:

- Long queues
- Staff attitude

### **Sub-theme 6.1: Long queues**

Two participants in the study expressed concern about long queues in the clinic. They spend a long time in the clinic and some complained that they do not even have money for lunch boxes.

- “Ah the problem is that the queue is too long and is not moving.”

This finding was compatible with the findings of Dahab et al. (2008:4), Krebs et al. (2008:315) and Miller et al. (2010:51) who found that most patients interviewed felt that clinic waiting times were too long. This contributed to their dissatisfaction with clinic services and made them more likely to stop coming to the clinic to pick up their medication.

### **Sub-theme 6.2: Staff attitude**

A few participants raised concerns over staff attitudes. Participants experienced ill treatment from staff members; the manner in which staff members communicated with them was threatening and work etiquette was not adhered to. Some expressed feelings of reluctance when they are supposed to come for their appointments at the clinic. The quotations below verify the participants' direct responses:

- “At reception they are short tempered.”
- “I am reluctant to come for treatment, because they do not treat us well.”
- “Oh, one yelled at me, shouted and then told me that I am going to die. She talked to me in a harsh manner.”
- “The issue in the clinic is with doctors. You find that they are coming very late.”

Wasti et al. (2012:75) ascertain that health system factors, including the relationship with service providers, made it difficult to seek regular treatment. Several authors (Foundation for Professional Development, 2009:38; Heyer & Ogunbanjo, 2006:8; Wasti et al., 2011:77) agree that a good patient health care provider relationship is an important motivating factor for taking and adhering to complex combination drug therapies. Participants in the study complained that doctors are not giving them enough time to discuss their treatment and if they are not listened to they will default

treatment. Regarding this Wasti et al. (2012:77) emphasised that health care providers who take time for explanations encourage positive attitudes. Time spent talking to significant influencing groups would also help reinforce adherence.

### **3.6 DISCUSSION OF THE FINDINGS**

As indicated previously the aim of this study was to explore the reasons why HIV and AIDS patients on ART default the treatment. Non-compliance to ART poses challenges to the health of the people living with HIV, their significant others and communities at large, and further impedes the goals of the ART programme. The focus of the discussion hereunder is on the main findings of the study.

#### **3.6.1 Participants' knowledge about HIV and AIDS**

The majority of the participants had a good understanding of HIV. Participants clearly explained HIV as the virus that causes AIDS. It was evident from the findings that participants had information about HIV and the fact that one is infected with the virus first and later the virus will progress to be AIDS. When that occurs, the person becomes sick and it means his or her immune system is weak.

It was evident from the participants' responses that they were unable to give a description of the concept AIDS. This correlated with several findings such as those of Jin et al. (2008:277) who confirmed that patients' knowledge about their disease is not always sufficient.

All the participants had basic knowledge about HIV and AIDS. Participants demonstrated knowledge that HIV is not a curable disease, but that it can be managed by antiretroviral treatment. They clearly voiced that in order to prevent the infection of HIV people need to practice safe sex or total abstinence. When one becomes sick is because the CD4 cell count is low and this serves as an indicator to start ART.

### **3.6.2 Participants' experiences of HIV testing**

Most participants received pre- and post-test HIV counselling, as required by legislation. However, a few participants indicated that they never received counselling. According to these participants there was no counselling and it was never clearly explained to them that they are infected with HIV or what the test entails. This study further revealed that some participants were too sick when they tested and thus unable to provide details of what was covered during counselling sessions.

The reasons for testing for HIV should be clearly explored in order to prepare the patients for testing. In this study the participants' reason for testing for HIV was because of ill health. Participants clearly expressed that they suffered from recurrent illnesses such as coughing, vomiting, skin rashes and feelings of weaknesses and tiredness. Although literature does not confirm the participants' reasons for testing, Van Dyk (2008:253) mentions some reasons for testing for HIV.

Participants in this study expressed feeling good about their HIV positive status. Participants clearly voiced their views in that they accepted their status and they never experienced their status as a stressful event. This finding correlates with the findings of Moratioa (2007:89) in that participants expressed the importance of acceptance of HIV status as part of a healthy approach towards healing. However several authors such as Department of Health ([sa]:11) and Van Dyk (2008:267) indicated that HIV positive people experience fears, stress, anger, guilt, anxiety and denial about their HIV positive status.

### **3.6.3 Participants' perceptions and experiences of using antiretroviral treatment**

The findings of this study discovered that the majority of participants in the study showed a lack of knowledge about ART. Participants did not have knowledge about their treatment regimens. These findings are consistent with the findings of Heyer and Ogunbanjo (2006:6) and Jin et al. (2008:277) who state that participants lack knowledge about treatment.

Participants experienced side effects while on antiretroviral treatment, but this was not a predictor for adherence and even those who never experienced side effects ended up defaulting. This study finding also showed that not all participants initiated on ART will experience side effects and this was in agreement with *Soul City Institute Health and Development (2008:33)*.

The use of antiretroviral treatment is perceived in different ways. In this study it was revealed that participants' emphasized the importance of taking treatment and disclosed that after taking treatment their health improved. This finding correlates with the findings by Nakiyemba et al. ([sa]:24) that a patient's beliefs about their illness and the effectiveness of medication are predictive of adherence.

Only a few participants in the study had a good understanding of antiretroviral treatment and the importance of taking treatment on time. The study showed that participants had a knowledge base of adherence to antiretroviral treatment. However, despite having the knowledge about treatment adherence and the consequences of non-adherence, participants discontinued their ART.

#### **3.6.4 Challenges faced by participants while on antiretroviral treatment**

Taking antiretroviral treatment poses challenges to patients. In this study it was discovered that challenges faced by participants include fear of disclosing their HIV status and stigmatization, as well as physical challenges experienced by participants. Although the majority of participants disclosed their HIV positive status, it was clear from the findings that some of the participants were afraid to disclose their status and this further prevented them from obtaining support from their families.

Regarding physical challenges, a few participants reported feeling tired whilst they are at work and others were unable to seek employment due to ill health. The last challenge of being on ART was fear of stigmatization. The findings of this study revealed that participants were afraid to take treatment at their nearest treatment facilities due to fear of stigmatization. It was evident from the participants' views that they were afraid to go to the nearest treatment facilities, because people from their neighbourhood will recognised them. This findings are compatible with the findings of

Van Cutsem et al. (2011:7) and Wasti et al. (2012:75), affirming that fear of stigmatization impedes adherence to ART.

It is necessary to note that from the findings most participants never experienced challenges while taking their treatment and yet they default their treatment. Thus the aim of the study was to explore the reasons why patients default their antiretroviral treatment.

### **3.6.5 Participants' reasons for defaulting antiretroviral treatment**

Based on the research findings the reasons for participants' treatment default includes socio-economic, patient related, psychological and medication factors. The main findings are highlighted below.

#### **3.6.5.1 SOCIO-ECONOMIC FACTORS**

From the findings of this study participants clearly voiced that they default treatment because of lack of money for transportation. Several authors (Krebs et al., 2008:313; Miller et al., 2010:52; Moratioa, 2007:85; Nakiyemba et al., [sa]:39; Van Cutsem et al., 2011:7 ; Wasti et al., 2012:75) confirmed that lack of money for transportation is a predictor for non-adherence to ART.

The other reason for default divulged by participants was shortage of food in the household. This made it difficult for participants to adhere to treatment as they cannot consume their ARVs on empty stomachs.

#### **3.6.5.2 PATIENT RELATED FACTORS**

Patient related factors were evidently stated as a reason for treatment default. Some participants clearly voiced that they default treatment because they were too busy with personal issues. Another reason was that there was nobody at home to take care of the children whilst the mother came for her clinic appointment. Other reasons for defaulting treatment included relocation, substance abuse due to the social pressures of life, and lost appointment cards. Participants who had lost their appointment cards were too scared to come for the follow up visits and others discontinued their follow up visits because they had a surplus of medication. These

findings were congruent with the findings of Jin et al.(2008:274); Krebs et al. (2008:313) and Miller et al. (2010:51)

### 3.6.5.3 *PSYCHOLOGICAL RELATED FACTORS*

The findings of this study revealed that most participants default treatment due to psychological problems, including mental health care problems such as depression and denial. One participant collected treatment from the clinic, but never drank the medication as she felt she was not ready and could not take the medication. This was consistent with the findings of Foundation for Professional Development (2009:155) and Tweya et al. (2010:82).

### 3.6.5.4 *MEDICATION OR THERAPY RELATED FACTORS*

This study clearly revealed that the reasons for treatment default include medication related factors. Participant reason for defaulting treatment was that she was confused about how to take her treatment .This was in agreement with several authors (Jin et al., 2008:274; Krebs et al., 2008:313; Maskew et al., 2007:854).

## **3.6.6 Participants' experiences of receiving treatment in Thekganang ARV Clinic**

The findings of this study demonstrated that the majority of participants were satisfied with the services in Thekganang ARV Clinic. Participants expressed feeling good about the services and the clinic staff members are good and cooperative. However it is critical to note that some participants were dissatisfied with the services in Thekganang ARV Clinic. Some participants raised concerns about staff attitude and long queues in the clinic. This was in agreement with several authors (Dahab et al., 2008:4; Miller et al., 2010:51; Wasti et al., 2012:75).

## **3.7 SUMMARY**

The goal of this study was to explore the reasons for defaulting antiretroviral treatment. From the qualitative data collected participants were knowledgeable about HIV and AIDS and the importance of adherence to treatment. However, some

participants had not yet accepted their HIV status. From the data collected most participants disclosed their status to their loved ones even though some still had challenges regarding disclosure and issues surrounding stigma. The reasons that compelled participants to default treatment included, among others, lack of money for transport, shortage of food, drug abuse, surplus medication and loss of appointment cards.

The next chapter presents the overview of the goal and objectives of the study and how these objectives have been achieved. Based on the findings, the conclusions are set out and recommendations are formulated with regard to the reasons for defaulting treatment. These recommendations can be used as guidelines in developing strategies for dealing with patients treatment default.

## CHAPTER FOUR

### CONCLUSIONS AND RECOMMENDATIONS

#### 4.1. INTRODUCTION

HIV and AIDS is a public health problem in the country that affects all the spheres of life. South Africa's response to HIV and AIDS has evolved over the last few years. Being diagnosed with HIV can be distressing and challenging to individuals. A person living with HIV needs to develop strategies to cope with the daily challenges of HIV and AIDS. Government has committed to providing ART to patients in the public sector. The availability of ART has transformed the management of HIV and has given hope to millions of people living with HIV. In order for ART to be effective, patients need to adhere to their treatment and this has emerged as a challenge to many patients as ART requires a life-long commitment (Miller et al., 2010:48). There is no doubt that most patients are unable to adhere to treatment. Adherence is necessary to ensure the effectiveness of ART.

Patients who default treatment are at risk of illness and death because of AIDS related illness and poor adherence increases the development of drug resistant HIV (Dalal et al., 2008:101; Miller et al., 2010:48). An understanding of the reasons for treatment default is of critical importance in order to enhance the effectiveness of ART. It is therefore critical for treatment facilities to develop programmes to enhance adherence as poor adherence to ART is the most known factor associated with treatment failure.

In order to understand HIV infected patients' reasons for treatment default, the goal of this study was: **to explore the reasons why HIV and AIDS infected patients default antiretroviral treatment at Thekganang ARV Clinic in Seshego District Hospital, Limpopo Province.**

In order to achieve the goal of the study the following objectives were formulated:

- To theoretically conceptualise HIV and AIDS as a social phenomenon with specific emphasis on antiretroviral treatment.

- To explore the experiences of HIV and AIDS infected patients regarding the services provided in Thekganang ARV Clinic.
- To determine the HIV and AIDS infected patients' level of understanding about HIV and AIDS adherence.
- To establish what causes HIV and AIDS infected patients to default antiretroviral treatment at Thekganang ARV Clinic.
- Based on the findings of the study, draw conclusions and make recommendations to increase HIV and AIDS infected patients' adherence to antiretroviral treatment at Thekganang ARV Clinic in Seshego District Hospital, Limpopo Province.

Against this background, the following research question guided this study:

**What are the reasons that HIV and AIDS infected patients default follow up antiretroviral treatment at Thekganang ARV Clinic?**

In this final chapter, based on the findings, the researcher will present conclusions as well as recommendations concerning the reasons for defaulting ART and also future research.

## **4.2. CONCLUSIONS**

Based on the empirical findings the following conclusions with regard to information collected can be made and linked with the objectives of the study:

- **Participants' level of understanding of HIV**  
The majority of participants had an understanding of HIV. Participants were able to describe HIV, the modes of transmission of HIV, and the effect of HIV on the immune system.
- **Participants' description of AIDS**  
Although the majority of participants had an understanding of HIV, most of them were unable to present their understanding about AIDS. They ascribe their lack of understanding to the counsellors in the sense that this was never explained to them.

- **Participants' knowledge about the basic facts of HIV and AIDS**

The majority of participants knew the basic facts about HIV and AIDS. Participants were able to explain the methods of preventing HIV infection. Participants clearly explained that HIV attacks the CD4 cells and if the CD4 cell count is less than 200 then it means the virus has developed into AIDS. This adequate knowledge can be attributed to the fact that there is continuous education about HIV and AIDS in the media and the myths surrounding HIV are slowly lessening. However, despite this adequate knowledge regarding HIV and AIDS and the use of ART, participants ended up discontinuing their ARVs.

- **Participants' experiences of HIV counselling and testing**

It was evident that the majority of the participants received pre-and post-test HIV counselling when they were initially tested. However, participants were mostly referring to an explanation of the test kit and the interpretation of the test results. A few participants never received counselling. Participants attributed this to lack of counselling services, while others were too sick to understand what was covered during the pre- and post-test HIV counselling. This can be linked to the fact that some participants were having difficulties accepting their results.

- **Participants' reasons for testing for HIV and feelings about HIV positive status**

With regard to the reasons for testing for HIV, it was evident that most participants tested for HIV due to ill health and only a few participants tested because they were pregnant. Participants were concerned about recurrent illnesses and as a result they decided to undergo HIV testing. Participants in this study expressed positive feelings regarding their HIV positive status. They accepted their status and expressed feeling good about their results. Even though it was evident from the findings that participants accepted their status, they failed to adhere to their treatment.

- **Participants' knowledge about ART regimens**

Adherence to medication is essential to ensuring successful treatment. The empirical findings confirmed that the majority of participants had no knowledge of their treatment regimens. Lack of knowledge about treatment regimens can be attributed to lack of continuous adherence counselling and

the poor literacy level of participants, as participants constantly indicated that they could not pronounce drug names.

- **Participants' experiences regarding side effects**

It was clear from the findings that most participants experienced side effects when they were initiated on treatment. However, this was never a cause for them to discontinue treatment. In this study both participants who experienced side effects and those who did not experience side effects defaulted treatment. Thus, it can be concluded that treatment side effects was not a reason for non-adherence to ART.

- **Participants' perception regarding ART**

The study further revealed that participants perceived treatment positively and were willing to be re-initiated on treatment, although a few participants perceived treatment negatively. Patient's knowledge and beliefs about HIV and ART can influence adherence.

- **Participants' understanding regarding ART adherence**

In this study it was clearly revealed that participants had an understanding of adherence to treatment and the meaning of adherence to treatment. This can be closely associated with the fact that participants received adherence counselling and thus they had adequate understanding of the importance of adherence, such as taking treatment on time and the importance of practising safer sex to avoid the risks of re-infections. Although participants' level of understanding about adherence to treatment was satisfactory, participants still discontinued their treatment.

- **Participants' challenges of being on ART**

Although being on ART has shown to improve the quality of life of individuals living with HIV, it was proven that being on ART has a number of challenges. From the findings of this study it was evident that participants experienced the following challenges: fear of disclosing, physical challenges, and fear of stigmatization. However, in this study not all participants had challenges with treatment.

- **Participants' fear of disclosure of HIV positive status**

From the findings of the study most participants disclosed their status to their families even though they ended up defaulting their treatment. The findings of this study revealed that only a few participants were afraid to disclose their

status to their families and their employers. Participants were afraid that their employers would dismiss them or that their family would reject them. Participants' fear of disclosure may be linked to the fact that HIV and AIDS is a stigmatized disease.

- **Physical challenges experienced by participants**

In this study participants' experienced physical challenges. Participants experienced body weakness, which affected their ability to be productive and return to the world of work.

- **Participants' fear of stigmatization**

Stigma has emerged as a reason for treatment default. This challenge led to individuals not accessing treatment at their nearest treatment facilities. Some participants were afraid to take their ARV's in front of other people, such as family members and colleagues.

- **Factors impeding participants' adherence to treatment**

Based on the research findings, factors impeding adherence to treatment were identified as patient related, psychological related, socio-economic and health system factors.

- **Socio-economic factors**

In this study it was evident that participants' reason for treatment default was lack of money for transportation. Participants were unemployed and could not afford transport cost to the treatment facility. Participants also default treatment because of shortage of food in their household. This can be linked to poor socio-economic conditions, as they had no sources of income in the households.

- **Psychological related factors**

Participants default treatment due to mental health care problems, such as depression. Even though participants had depression they never seek professional help for their problems. One participant collected treatment from the clinic, but never drank the treatment because she was not ready for treatment.

- **Patient related factors**

The findings of this study showed that the majority of participants in this study default treatment due to patient related factors. Patient related factors included relocation, loss of appointment cards, surplus medication, child care,

substance abuse and problems leaving work to be able to attend clinic appointments. It was evident from the findings that some participants were given treatment, but that they had difficulties fitting the treatment into their lives as participants indicated that they were too busy with personal business and as a result ended up defaulting treatment.

- **Medication or therapy related factors**

The findings of this study revealed that one participant's reason for treatment default was because of confusion about drug regimen. This can be attributed to a lack of understanding by the participant and the fact that there is no continuous counselling during follow up visit.

- **Participants' experiences of receiving treatment in Thekganang ARV Clinic**

It was evident from the findings of this study that the majority of participants were satisfied with the clinic services. Only a few participants were dissatisfied with the clinic services. Some participants clearly raised concerns about long queues and staff attitude. With regard to the long queues participants complained that the waiting time spent in the clinic was too long and this affected them when they visited Thekganang ARV Clinic to collect their treatment. A few participants complained that staff members in the clinic shout at them and they do not get adequate time to talk to staff members.

## **4.3 RECOMMENDATIONS**

Based on the empirical findings, the following recommendations can be made:

### **4.3.1 Recommendations with regard to participants' HIV and AIDS knowledge**

Although it was evident from the empirical findings that the majority of participants had knowledge about HIV and AIDS, a few participants showed gaps in their treatment knowledge base. A person diagnosed with HIV might have limited knowledge regarding the condition. In this study it was clear that not all participants are knowledgeable about HIV and AIDS and adherence to treatment. Significant

gaps in patient knowledge may contribute to non-adherence. In order to maximize the benefit of ART patients should be educated on the need of adhering to treatment schedules and taking treatment correctly. Health care workers need thus to intensify health education which can be addresses by means of the following:

- Gaps in patients' knowledge can be addressed by continuous education and the availability of promotional material to empower patients about HIV and AIDS, ART and other related topics such as nutrition management, cancer, management of stress, TB, dealing with HIV and AIDS stigma, and disclosure of HIV positive status.
- Health talks in the clinic during patients' visits and through the local radio stations by health professionals in the clinic and hospital is recommended.

These education strategies will benefit patients on ART and those who are not on treatment yet. Patients' knowledge about the condition and medicine can influence adherence. The more knowledge patients have, the better informed and equipped they will be to make informed decisions.

#### **4.3.2 Recommendations with regard to implementing a multi-disciplinary patient centred approach**

- From the empirical findings it is evident that participants experienced psycho-social stressors that might be effectively addressed by a multi-disciplinary team available in most hospitals. A multi-disciplinary team should include a psychologist, a social worker, nurses, medical doctors, counsellors, pharmacists and dieticians.
- Health professionals should acknowledge that every patient is unique and needs to be attended to as an individual in order to be able to develop an individual treatment plan. The necessity of patient involvement in the treatment plan should also be encouraged. The treatment plan should focus on aspects such as type of treatment regimen, time of taking treatment (this should be guided by the patient's life style), number of pills to be taken, dosage intervals, dietary restrictions, reminder strategies of taking treatment, support system, treatment side effects and duration of the treatment.

- Participants faced challenges such as fear of disclosure, unresolved grief and depression. These challenges can be addressed by team members such as social workers and psychologists. Patient specific counselling may lead to better knowledge and in turn promote adherence.
- It is also recommended that all newly diagnosed patients need to be assessed by a multi-disciplinary team to address any underlying problems before they can be initiated on ART.

#### **4.3.3 Recommendations with regard to therapeutic patient education programmes**

Given the complex factors associated with non-adherence to treatment, a single strategy will not be effective when intervening. Therefore the following comprehensive strategy to address non-adherence is recommended:

- Each clinic and hospital should establish a support group to provide support to patients who fail on treatment. The support group for non-adherent patients should assist patients in sharing experiences, developing new coping strategies and having access to reliable information.

#### **4.3.4 Recommendations with regard to participants' reasons for treatment default**

With regard to factors impeding treatment in this study the following recommendations are made:

##### **○ Socio-economic factors**

The study divulged that the majority of participants default treatment due to socio-economic conditions. With regard to lack of money for transportation, patients need to be continuously encouraged to take treatment at their nearest treatment facilities by dealing effectively with stigma.

This should also include mobilisation of the community to participate and fully understand the benefit of ART and the importance of adherence to treatment. This may also assist in influencing the patients' ability to take treatment in their communities.

Regarding shortage of food in the households the following is recommended: Patients need to be encouraged to be self-reliant by establishing projects such as gardening in their households to alleviate poverty and encourage them to seek employment. This should be facilitated by the social workers in Thekganang ARV Clinic in partnership with the community development section in the Department of Social Development.

- **Psychological related factors**

This study has shown that most of the participants default treatment due to psychological related factors such as depression, denial, unresolved grief and substance abuse. These factors can be effectively addressed by in-house therapists, such as a psychologist or social worker.

The services of the psychologist should include providing psychotherapy and family therapy. The social worker in the clinic should conduct assessments and screening of patients, individual counselling, health education, and home visits to the family to assess home circumstances and to provide support to the family. The social worker should also assist in placing patients in a rehabilitation centre if needed as well as providing after care and reintegration services to such a patient and his or her family.

- **Patient related factors**

Patient related factors include child care, being too busy with personal business, surplus medication and relocation.

Patients need to be encouraged to fit their treatment plans into their lifestyle and the necessity of maintaining work-life balance should be explained to them. Treatment readiness should be done comprehensively to identify patients who are not ready to start ART. Continuous monitoring will also assist in addressing the issue of patients collecting treatment but not drinking their pills, as well as patients who have a surplus of medication.

- **Medication or therapy related factors**

This study further discovered that one participant was non-adherent to treatment because she was confused about how to take her medication. This can be successfully addressed through on-going individual counselling and education on the use of medication.

#### **4.3.5 Recommendations with regard to an on-going support services to patients**

If a patient fails to adhere to treatment, the patient needs to attend intensive counselling before the treatment regimen is changed to ensure that adherence is improved. On-going support counselling is an essential intervention to be used in order to be able to identify and address the challenges that the patient presents during consultations.

Treatment counselling should involve basic procedures to establish a relationship of trust and understanding, and to exchange information. This should also be utilised with those patients who adhere to treatment to promote continued adherence. From the findings of the study some participants did not recall what was covered during HCT. On-Going support counselling will assist to remind them of the information they received during HCT.

Patients who are having difficulty with issues surrounding stigma can also benefit from the on-going support, so that they will be able to access treatment at their nearest treatment facilities. Dealing with stigma can have an impact on the patient's ability to adhere to ART.

Patients having difficulties understanding their treatment regimens and the importance of adherence will benefit from on-going support services.

#### **4.3.6 Recommendation with regard to patient–health care provider relationship**

In this study, the study revealed that there was a general positive attitude towards relationship between participants and the health care provider. This is demonstrated by the high number of participants who indicated that the health care providers were friendly. However there were a few participants who were not satisfied with the attitudes of some health care providers.

A good patient-health worker relationship was seen as a motivating factor for adhering to treatment. Patients' adherence to treatment can be improved by enhancing the relationship and communication between patients and health care providers. It is thus recommended that more attention should be given to the enhancement of good patient-health care provider relationships.

#### **4.3.7 Recommendation with regard to future research**

Further research needs to be conducted and the following recommendations are made for future researchers:

- A qualitative analysis to get an in-depth analysis on the family involvement in the antiretroviral treatment and care for HIV positive patients.
- A quantitative study on the prevalence of drug resistant patients in the clinic.
- A research study to develop a systematic method of capturing “lost to follow up” patients who pass away within the hospital.
- Follow up exploratory studies on reasons for treatment default for non compliance to antiretroviral treatment as reasons for non adherence will vary over time.
- A research study to determine the effectiveness of down referral system.

#### **4.4 ACHIEVEMENT OF THE GOAL AND THE OBJECTIVES OF THE STUDY**

Table 4.1 focuses on how the goal and objectives of the study were achieved.

**Table 4.1 Summary of the achievement of objectives**

Nr	Objectives	Objectives achieved
1	To theoretically conceptualise HIV and AIDS as a social phenomenon with specific emphasis on antiretroviral treatment.	This objective was achieved as per discussion presented in Chapter Two.
2	To explore the experiences of HIV and AIDS infected patients regarding the services provided in Thekganang ARV Clinic.	This objective was achieved through the discussion in Chapter Three based on the qualitative empirical findings on the experiences of participants in Thekganang ARV Clinic.
3	To determine the HIV and AIDS infected patients' level of understanding about HIV and AIDS adherence.	The objective was successfully attained in Chapter Three through the discussion on the participants' knowledge base of HIV and AIDS.
4	To establish what causes HIV and AIDS infected patients to default antiretroviral treatment.	The objective was achieved through the discussion in Chapter Three based on the empirical findings on why HIV positive patients are non-adherent to ART.
5	To draw conclusions and make recommendations based on the findings to improve HIV and AIDS infected patients' adherence to antiretroviral treatment.	The objective was achieved through the discussion on conclusions and recommendations in Chapter Four.

The goals and the objectives of the study were achieved as presented in this chapter.

## 4.5 SUMMARY

The aim of this study was to explore the reasons why HIV positive patients default their treatment. The experiences and challenges of living with this condition were discussed. It has been noted that participants in the study default treatment due to individual, psychological, socio-economic and therapy related factors. This study revealed that HIV positive individuals face different challenges. These challenges include, but are not limited to, stigmatisation, physical challenges and fear of disclosing HIV status. The challenges impeded on the participants' adherence.

Although most participants had knowledge about the importance of adherence, have demonstrated acceptance of their positive status and even disclosed their status to their significant others, they were still non-adherent to treatment. The factors affecting adherence have to be taken into consideration in order to promote adherence to ART. The study has been concluded by making recommendations based on the empirical findings to enhance adherence to ART as well as and recommendations for future research.

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## Annexure A: Informed consent form

## Annexure B: Editorial letter

## Annexure C: Semi-structured interview schedule

## Annexure D: Letter of ethical clearance

## Annexure E: Letter of approval from Department of Health Limpopo Province